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PACK
Prevention of HIV & AIDS in the Communities Of Karamoja

THE PEOPLE LIVING WITH HIV STIGMA INDEX

KARAMOJA BASELINE SURVEY REPORT
MAY 2017

Alliance of Mayors and Municipal Leaders on HIV/AIDS in Africa

NAFOPHANU

Straight Talk Foundation

The AIDS Support Organisation
TASO
Living Positively with HIV

ACRONYMS

AMICAALL:	Alliance of Mayors and Municipal Leaders Against HIV/AIDS
CSO:	Civil Society Organizations
IRB:	Institutional Review Board
MUREC:	Mildmay Uganda Research and Ethics Committee
NAFOPHANU:	National Forum of People Living with HHIV/AIDS Networks in Uganda
PACK:	Prevention of HIV/AIDS in Communities of Karamoja
GNP+:	Global Network of People Living with HIV
ICW:	International Community of Women Living with HIV/AIDS (ICW)
ODK:	Open Data Kit
PLHIV:	People Living with HIV
PMTCT:	Prevention of Mother to Child Transmission
SRHS:	Sexual Reproductive Health Services
SIK:	HIV Stigma Index in Karamoja
STF:	Straight Talk Foundation
TASO:	The AIDS Support Organization
TWG:	Technical Working Group
UNAS:	Uganda National Academy of Sciences
UNASO:	Uganda Network of AIDS Service Organizations
SRC:	Sciences Research Consortia

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The PLHIV Stigma baseline survey in Karamoja region is part of the Prevention of HIV/AIDS in Communities of Karamoja region (PACK) Project 2016/17-2020/21. The project is intended to contribute to reduction of new HIV infections amongst adolescents and young people (10-24 years) in Karamoja region.

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EXECUTIVE SUMMARY

Introduction

The PLHIV Stigma baseline survey in Karamoja (SIK), is part of the serialized Stigma Index surveys conducted in Uganda since 2013. The surveys use the standard stigma index methodology. The SIK overriding purpose was the need for baseline data to support measurement of changes for the planned five-year project titled Prevention of HIV/AIDS in Communities of Karamoja region (PACK) with an aim to reduce new HIV infections amongst adolescents and young people
(10-24 years) in the Karamoja sub-region for the project period 2016-2021.

Definitions

HIV-related stigma is defined as 'A process of devaluation' of people either living or associated with HIV &AIDS'

Discrimination that follows stigma is defined as 'Unfair and unjust treatment of an individual based on his or her real or perceived HIV status'

Stigma Index is 'A measurement of how much stigma prevails following trends, forms and lived experiences of PLHIV'

Study participants background

The study reached out to 977 respondents with a gender representation of 299 (31%) males and 678 (69%) female in the districts of Moroto, Nakapiripirit, Napak, Amudat, Abim, Kotido and Kaabong. Of the 977, 932 (95.39%) self-reported not to belong to any special categorization. The proportion of the target respondent in the age category of 15-25 years was 117 (12%), and those of 25 to 29 years were 158 (16.17%) of the responded identified.

Key findings

The magnitude of HIV stigma in Karamoja was generally high. Overall, data based on the seven components of external HIV stigma shows that 32% respondents have experienced external HIV stigma in the last 12 months preceding the survey. External HIV stigma is defined as a form of HIV related stigma that crops and is executed by other persons other than the PLHIV him/herself. Examples of external HIV stigma components include exclusion, gossip, verbal threats, physical harassment and assault. The computation of 32% was based on 2193 responses to the proxy measures of HIV external stigma listed above.

Regarding internal HIV stigma, the data indicated a proportion of 29% with internal stigma overall. Internal HIV stigma represents internal feelings of stigmatization of the PLHIV because of their HIV positive status. The computation for 29% is based on 1714 responses to the seven proxy components of internal stigma that include: feelings of shame, blame self and other, feeling of low self-esteem, feeling of being punished and suicidal tendencies in the last 12 months preceding the study. The findings indicate one additional key fact that HIV related stigma was highest among the young people 25 to 29 years of age.

Access to SRHS and ART services (Key finding from qualitative study component)

There are specific motivations to seeking sexual and reproductive health services and ART, but the most outstanding was availability of a Special Corner within the health facilities where young persons living with HIV are served. This has reduced the fear previously held by many to seek services.

Despite the positive revelations above, the relatively young categories still fear to access SRHS especially those still in school. They cited limitations such as: lack of knowledge about condoms, fear to be seen by others while picking condoms, gossip from other people when they pick condoms.

On the side of barriers, availability of food and nutrition supplies were the most challenging aspect for the people that inferred with ART adherence.

"The drugs are very strong, after taking them, sometimes you feel dizzy. Secondly some of us they kept changing the drugs we were on but these drugs have side effects e.g. I used not to wear glasses but I am so my sight has been affected." Out of school 15-19 year old PLHIV participant in FGD- Mororo.

HIV stigma and social cultural restrictions have reduced on general level but, those remaining are still a deterrent to the PLHIV in some institutions. Some of the challenges mentioned relate to drug complication and side effects.

Summary of quantitative data by specific disaggregation

HIV stigma by Age

**The computation for HIV stigma by different levels of disaggregation is based on responses to any of the seven proxy measures of external stigma and not all the seven combined. So, the percentages are slightly higher.*

With respect to external forms of stigma, there was a slight difference in age categories. For instance, HIV stigma was 75% for the age category of 15 to 24 years combined, but varied between the category, (70%) for 15-19 years and (77%) for 20 to 24 years. The age category where HIV stigma was reported highest was age 25- 29 years (84%). After this age, the HIV stigma reduced to 71% among the 50+ years.

HIV stigma by District

There are specific variations by district in terms of HIV stigma prevalence. Napak had the highest prevalence of stigma with 97% respondents reporting external forms of HIV stigma. The three districts of Kaabong, Nakapiripirit and Amudat had almost similar proportions of approximately 89%. The districts with slightly lower proportions were: Kotido (53%), followed by Moroto and Abim at about 80%.

HIV stigma by education

HIV related external stigma reduced by education, the higher the education level, the better. For instance, of those who had no formal education or stopped in primary 602 (80%) had HIV stigma, where as those who had secondary education 142(70%) had HIV stigma, but those who had technical college or university, 17(57%) had HIV external stigma.

These general findings have implication on targeting interventions for HIV stigma reduction in the context of Karamoja. In other words, although HIV stigma is generally high in the Karamoja region, it varies by key parameters such as age, education and district. So, any interventions should tag along these specific data components and variations.

External stigma (Prevalence of exclusion)

Specific forms of exclusion as per the standard HIV stigma index categories are prevalent. For instance, in all the districts combined, exclusion from social gatherings was at 9%, while exclusion from religious and family level activities was at 4%. Most respondents between 75% and 82% attributed the exclusion to living with HIV.

External stigma HIV stigma experiences

Unlike exclusion which was comparatively lower, other standard PLHIV stigma index categories in the domain of external stigma were very high. For instance, about 67% have experienced gossip, 62% verbal insult/harassment, 23% physical harassment and 30% physical assault in the past 12 months.

External stigma (Discriminatory experiences)

Key aspects of discrimination within family and at household level are high in the region. For example: psychological pressure or manipulation by husband/wife or partner under the pretext of HIV, sexual rejection, discrimination by other PLHIV, and discrimination of household members where the PLHIV lives was reported by 880 (90%) respondents.

Internal stigma and fears

The HIV stigma experiences in the category of internal stigma and fears were equally high. For instance, the proportion of cases that felt ashamed were 630 (65%), those who felt guilty were 474 (49%), those who experienced low self-esteem were 225 (23%), blamed themselves were 212(22%), felt suicidal were 159(16%). There are differences in the proportions by gender for instance females who feel suicidal are remarkably far higher than males, 11(3.5%) males compared to 148(22.3%) females. Only two categories blame others, 41(4%), and the "I feel I should be punished" 14(1.4%) were reported in lower proportions. In interpretation of these proportions, the percentage of cases is beyond 100% for items scales that measure internal stigma because of possible multiple response options.

Perceived reasons for HIV stigma and discrimination

The most cited reasons by 439 (45%) of the respondents regarding stigma and discrimination were two; peoples' fear of getting HIV from the PLHIV 448(45%) and lack of knowledge about HIV transmission mechanisms 441(45%). About 8% indicated that having HIV is considered shameful whereas 19% are not sure of the possible reasons for HIV stigma.

> *"At one of the community based children support homes, where scholastic psychosocial support materials (food, clothing and scholastic material) is provided, but we know that the beneficiaries are children living with HIV. Some would-be beneficiaries don't go to this center because of anticipated shame of vising this center"* FGD of Moroto Town, 15- 19 years children.

Access to work and employment opportunities:

Aspects of institutional level HIV stigma issues identified included; 45(13%) men and 165(25%) of women who were forced to change places of residence. Of the 13% who reported to have been forced to change place of residence 32(82%) attributed it to HIV positive status among the men, compared to 64 (39%) females. Out of the 20 men and 40 women whose job description changed or were refused promotion, 17 (85%) men and 32 (80%) female, attributed it to having an HIV positive status.

Individual reactions/coping with HIV stigma

The most outstanding reactions was a decision not to have children reported by 307(31%) followed by not attending social gatherings, 270 (28%) and not to have sex 246 (25%). However, the major issue of concern is that comparatively high proportion of men 51(16%) versus 51 (8%) women reported that they avoided going to a hospital when they needed to. Not seeking health services has direct implication on deterioration

Knowledge of laws, rights and policies related to HIV

Quite a high proportion 693 (71%) had heard of the Declaration of Commitment on HIV/AIDS which protects the rights of PLHIV and the National HIV Policy, but the proportion of men 237(76%) were more aware compared to female 456 (68.6%). The point of concern is that fewer respondents, 345 (35%), reported to have ever discussed the content of the declaration.

Effecting changes

Data demonstrated evidence of effecting changes, whereby 170 (54%) men vs 310 (47%) females, confronted, challenged or educated someone who was stigmatizing. Overall, 331(33.8%) have tried to solve an issue of stigma and discrimination. It is worth noting that over 801(82%) indicated having rendered support to another PLHIV to overcome negative HIV situations, strengthening the argument for peer support interventions in stigma reduction.

Testing and diagnosis experiences

Voluntary decisions to undertake HIV test are on the increase. For instance, the major reason reported by 378(39%) respondents was the desire or willingness to know one's HIV status. Similarly, pregnancy is another predominant reason mentioned by 202(20%). However, during the HIV testing, only 74% received both pre-post testing counselling services, presenting some missed opportunities for the 26% who would have benefited from posttest counseling services.

Disclosure and confidentiality

It is common practice for the PLHIV to disclose to more than one category of individuals, in this study, the category most disclosed to by 694(71%), were the health care workers followed by husband/wife/partner 656(67.14%). The issue of concern of much concern is that high proportion 104 (10.6%) reported that their health care workers have not been disclosed to. In addition, 252(26%) proportion of the respondents have not disclosed to their employers. These findings confirm the fear surrounding aspects of disclosure to employers for fear of job loss. The fear to disclose to health care workers needs to be explored because it has direct influence on treatment options provided by the health workers and a possible loss of opportunity for healthcare support system.

Having children and access to reproductive health services

Most respondents 799(81.8%) revealed that they have children. Most of these children were their biological children. Though majority of female respondents 461 (69.3%) had received PMTCT services, some females 58(5.9%) did not know that such treatment and services existed. Another proportion, 127 (13%) mentioned that they were not HIV positive at the time of the pregnancy. This could be interpreted to mean two possibilities, either they acquired HIV after delivery or were not aware of their HIV status during pregnancy and delivery time.

CHAPTER ONE: INTRODUCTION

1.1 The report and PACK project in summary

The report presents a synthesis of results from the People Living with HIV (PLHIV) Stigma Index baseline survey in Karamoja. The survey aligns broadly to the PLHIV stigma index survey goals but specifically the Prevention of HIV/AIDS in Communities of Karamoja (PACK) project that runs from 2016 to 2020. The PACK project aims at empowering communities to address social cultural barriers including violation of human rights, and access to justice to HIV&AIDS prevention, care and treatment and social support. The survey was part of the PACK project with the main objective of finding out experiences of HIV stigma and discrimination in Karamoja. The survey results will ultimately provide evidence for differentiated policies for advocacy on HIV stigma and to support the development of effective strategies to overcome stigma and discrimination faced in the context of Karamoja region.

The empowerment processes

The PLHIV stigma index standard programmatic requirements consider any HIV related stigma survey as empowerment process of the PLHIV (Federation, 2008). To adhere to this requirement, all the research assistants were PLHIV. Secondly, other technical consultations relating to the study execution processes were made with PLHIV networks or their representatives at various levels.

Similarly, during the project implementation, NAFOPHANU will oversee advocacy, coordination and capacity building for PLHIV networks in the Karamoja region to address HIV stigma and discrimination as a key barrier to utilization of services. Other key Civil Society Organizations (CSO) will collaborate to implement activities related to advocacy and demand generation for improved HIV&AIDS services in Karamoja.

Methods and study implementation

The SIK utilized a cross-sectional design in combination with key participatory processes. Owing to the survey approach, the thrust of the data is quantitative. Quantitative data was collected using electronic SMART phone devices. Data analysis followed sequentially the key sections of stigma questionnaire, 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. The uniqueness of this study is the analytical focus on specific HIV related stigma issues related to adolescents and young people based on the recommendation of the Technical Working Group (TWG). The near final draft of the study was peer reviewed by the Uganda National Academy of Sciences.

Participants' demographics

The study reached out to 977 respondents with a gender representation of 299 (31%) males and 678 (69%) female in the districts of Moroto, Nakapiripirit, Napak, Amudat, Abim, Kotido and Kaabong. Of the 977, 932 (95.39%) self-reported not to belong to any special categorization. The proportion of the target respondent in the age category of 15-25 years was 117 (12%), and those of 25 to 29 years were 158 (16.17%) of the responded identified. Most respondents, 333(34.08%), were in the age category of 30 to 39 years. By marital status, most 522(53.43%) were married/cohabiting with the husband/wife living in the same house. About 410(41.97%) were employed in casual employment. The education levels were low, with many respondents 366 (37.5%) who reported having no formal education and almost an equal number 399 (38.7%), who completed only primary education.

The qualitative study component targeted only adolescents and young people in the age categories of 15-24 years. Some of them were in school while others were out of school in the three districts of Moroto, Napak and Nakapiriprit. The study team acknowledges the challenges of reaching the young people during the sampling process. Despite this limitation, the proportions reached are sufficient to provide substantial evidence for learning and subsequent programing of interventions.

This study essentially presents findings sequenced as per three main sections of PLHIV stigma index questionnaire including; respondents background characteristics, experiences of stigma and discrimination and experiences of testing diagnosis, disclosure, treatment and having children. Besides the main three sections, a fourth is added to show a comparison of results of the PLHIV stigma index in Karamoja with other PLHIV surveys such as the 2012/2013 stigma index, the 2014/2015 stigma reduction project implemented in the 7 districts of Central and South-Western Uganda and recent PLHIV stigma index among young people in the districts of Iganga, Mayuge and Jinja.

1.2 Background

The recent trends of HIV prevalence in Karamoja sub region, as part of North Eastern region are of concern, for instance it is reported that the prevalence rose from 3.5% in 2006 to 5.3% in 2011(Uganda AIDS Indicator Survey). Subsequently this region has received targeted support to improve the Sexual Reproductive Health (SRH) and HIV intereventions. For instance the region, received funding worth ($5m for 2016/2017) for expanded advocacy from KOICA through UNFPA. Additionally, Irish Aid also approved up to $20m for comprehensive SRH and HIV programming for adolescents and young people in the Karamoja region for 2016-2020 through JUPSA and CSOs. Despite these combined interventions, informal PLHIV engagement reveals a growing evidence of HIV related stigma manifesting at various levels. The key response has been a few HIV support groups that are emerging in response to the HIV stigma and discrimination. Suffice to note that in almost all the national level assessments, HIV related stigma is associated with barriers to access HIV care and treatment and social support (National Priority Action Plan, 2015).

1.3 Survey context

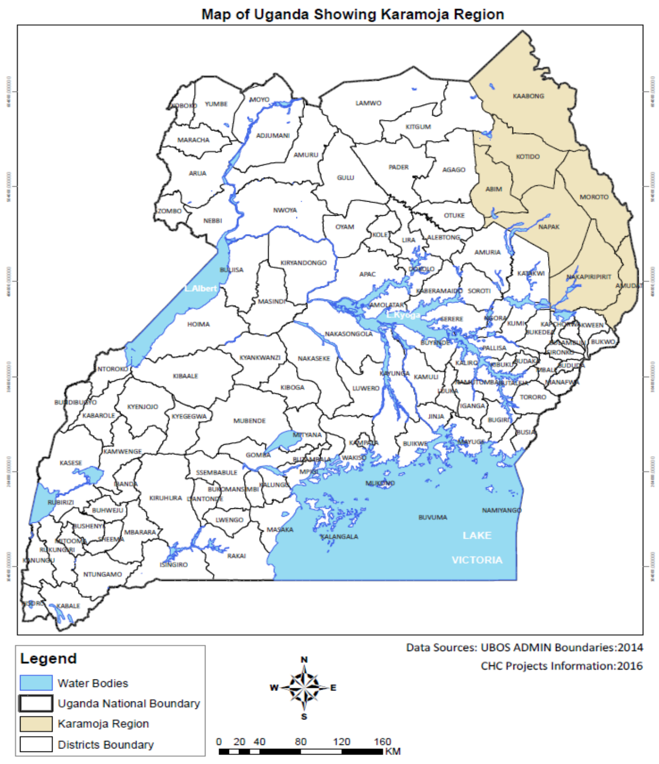


Figure 1: Map of Uganda showing Karamoja Region

The HIV&AIDS prevalence in Karamoja region is increasing despite the various interventions implemented aimed at addressing this challenge. The current HIV prevalence for the North Eastern Region of Uganda stands at 5.3% UAIS, 2014/15) up from 3.5% (Uganda AIDS Commission) an indication double spiral in a span of five years.

The region is also reported to have the highest syphilis prevalence of 3.3% among women and 1.7% among men 15- 49 years. The national average is 1.8% (UAIS, 2011). A recent study by USAID/CHC in 2015, the percent with comprehensive knowledge about the ways to avoid and acquire HIV among 15- 49 years individuals was 17.4% in Moroto and 24.7% in Kaabong. Previously, among the youth 15-24 years in Karamoja, comprehensive knowledge about HIV&AIDS was 17% and increased 32% for women and 33% to 45% men between 2004/2005 and 2011 (UAIS, 2011). The percentage of women and men aged 15-49 who know that HIV can be transmitted from mother to child by breastfeeding and that the risk of mother to child transmission (MTCT) of HIV can be reduced by mother taking special drugs during pregnancy is 68% for women and 62% for men leaving out one in three women and two in five men who do not have this knowledge. The UNICEF(UNICEF, 2014), Adolescent Girls Vulnerability index shows that in Uganda, the most challenging region in which to be an adolescent girl is Karamoja where over half of adolescent girls between 10 and 19 years (54%) are vulnerable at all three levels (Individual, household and community).

1.4 The PACK project goal

The goal of the project is to contribute to reduction of new HIV infections amongst adolescents and young people (10-24 years) in Karamoja Region. The project will be implemented over five-year period 2016-2021. The project targets adolescent and young people, owing to the increasing HIV and Sexual Reproductive Health challenges within this community.

1.5 The PACK project objective

To empower communities to address social cultural barriers including violation of human rights and access to justice to HIV &AIDS prevention, care and treatment and social support by 2021.

1.5.1 Specific Objectives of the PLHIV baseline stigma index survey

i. To find out the experiences of PLHIV regarding stigma and discrimination in Karamoja

ii. To provide evidence for the review/development and implementation of regional and national policies and legal frameworks that protect the rights of PLHIV

iii. To provide evidence for programmatic interventions to effect changes

iv. To propose recommendations aimed at addressing stigma in the region to ensure increased access to HIV and Sexual Reproductive health services (SRHR) in the region.

1.6 Geographical scope

The baseline was conducted in the seven districts of Karamoja: Moroto, Nakapiriprit, Napak, Amudat, Abim, Kotido and Kaabong (see region in Figure1). The PACK project target population is adolescents aged 10- 19 years and young people of 20- 24 years old.

Funding and Implementing partners

Irish Aid is supporting a Consortium of Civil Society Organizations (CSO-C) consisting of Alliance of Mayors and Municipal Leaders on HIV/AIDS in Africa (AMICAALL), National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU), Straight Talk Foundation (STF) and The AIDS Support Organization (TASO). The CSO consortium will implement a high impact five year program of prevention of HIV and AIDS from the Communities of Karamoja 2016/2017 to 2020/2021, in Karamoja Region. The survey was a preliminary activity to support measurement of changes of the PACK project regarding stigma index reduction interventions.

CHAPTER TWO

APPROACH AND METHODOLOGY

2.1 General Approach

The approach was generally consultative and involved discussions with the CSO consortia members and different stakeholders; women, men, boys, girls, NAFOPHANU district coordinators, health facility representatives, and sub-county officials. A combination of participatory methods of data collection was used. However, the thrust of this data was quantitative. In addition, the methodological approaches for any HIV related stigma study recommends an empowerment process of the PLHIV. This empowerment process was adhered to in all engagements during the preparatory stages and through execution of entire PLHIV baseline stigma index survey processes.

2.1.1 Consultations with the consortia members and stakeholders

Before commencement of data collection, NAFOPHANU held preliminary consultative meetings with Technical Working Group (TWG) to ensure mutual understanding about the survey processes, key deliverables and tasks for members, a road map for study implementation, technical details in the methodology and ethical approval from Mildmay Uganda Ethics and Research Committee (MUREC). All the above study related decisions were agreed upon. The TWG also participated in reviewing the first and second draft reports. During the first draft, the TWG made recommendation to collect more precise explanatory data using qualitative approaches and to delve more into HIV stigma among the young people. So, the sample for the qualitative study targets only the young people 15 to 24 years.

2.2 Study Design

Given this background, the study used a cross-sectional design to collect data at a single point in time. Based on this design, quantitative methods were used to collect and analyse data per the standard stigma index survey. Within this design, specific activities were undertaken at three major phases: Preparatory phase, data collection phase and analysis and reporting phases.

2.3 Standard PLHIV Stigma Index questionnaire and key definitions

The study adopted the 2013 PLHIV Stigma Index questionnaire, which was adopted from the one developed in 2008 by Global Network of People Living with HIV (GNP)+, International Community Women Living with HIV (ICW), Joint United Nations Program on HIV (UNAIDS) and International Planned Parenthood Federation (IPPF):
At operational level, key definitions adopted were internal and external forms of stigma, and these have formed the basis for analysis of other variables. Using internal forms of HIV stigma, the study made four distinct categories of HIV stigma levels: 1) Very high

stigma, 2) High stigma, 3) Moderate, 4) Low.

Definitions:

- Very high: A respondent who mentions having experienced 6 or more components of HIV internal stigma
- High: A respondent who mentions having experienced 5 components of HIV internal stigma
- Moderate: A respondent who mentions having experienced between 3 and 4 components of HIV internal stigma
- Low: A respondent who mentions having experienced between 1 and 2 components of HIV internal stigma.

2.4 Target population and sample size

The target population was PLHIV, 18 years and above. The data available of PLHIV in Karamoja was 9073 PLHIV. Out of this sample, 976 respondents were determined as most sufficient sample to represent the seven districts for quantitative methodology. The sample size formula used was adopted from (Israel) Based on this sample, a precision of 3% and confidence interval of 5% was used. The sample for qualitative data was based on districts where the level of HIV stigma was considered highest after analysis of preliminary quantitative data. These districts were Napak, Nakapiripirit and Moroto. Though the levels of HIV stigma were relatively low in Moroto, it was considered for the qualitative study to represent the urban areas.

2.5 Quantitative samples

As per the study objective, a representative quantitative sample was needed to yield estimates. A precision of 3% instead of the usual 5% used in the previous PLHIV stigma index was therefore recommended. The second reason for use of precision of 3% was diversity of Karamoja region with sparse population and seven distinct tribal groups such as Pokot, Lebuthur, Nkarimajongo and Jie. These factors increase the level of heterogeneity and thus require a huge sample size. Within this target audience, a study population was derived using a 97% confidence level. According to the Mogan table for sample estimates, a population of 8361 persons can be represented by a sample of 976 persons at a precision of 3%.

Table 1: Approximate Number of PLHIV in Karamoja region by July 2016

District	Children 15	Adults	Total
Moroto	135	1644	1779
Nakapiripirit	55	963	1018
Napak	39	732	771
Amudat	45	842	887
Abim	96	1383	1479
Kotido	215	1872	2087
Kaabong	95	925	1020
Total	712	8361	9041

Source: Districts PLHIV forums aggregated data of registered members.

Based on the population figures of PLHIV in Table 2, appropriate proportionately representative samples per districts are calculated (see Table 2).

Table 2: Sample respondents determined per district by gender

District	Adults	Total percentage	Absolute numbers	No of females	No of males
Moroto	1644	0.197	192	130	62
Nakapiripirit	963	0.115	112	76	36
Napak	732	0.088	85	58	27
Amudat	842	0.101	98	67	31
Abim	1383	0.165	161	110	52
Kotido	1872	0.224	219	149	70
Kaabong	925	0.111	108	73	35
Total	8361	1.000	976	664	312
Total (N)	976	NA	976	664	312

Total sample is 976 individuals

By district, the study purposively conducted FGDs from three districts:

- Mororo: 15-19 years old in school, 15-19 years out of school, 20-24-year males and females out of school
- Nakapiripit: 15-19 years old in school, 15-19 years out of school, 20-24 years males only,
- Napak: 15-19 years old out of school, 20-24 years old out of school females only.

2.6 Sampling frame enlisted the respondents

A stratified multi-stage probability sampling approach was used to select study sub counties. Below is a four stage multi-stage selection process that was used.

Stage 1	District selection: All the seven districts of Karamoja were pre-determined
Stage 2	Classification of the selected sub-counties into rural and urban sub-counties (At this stage, these formed two strata): Though most of Karamoja is rural, the data teams ensured urban representation during the sampling.
Stage 3	Probability Proportion to Size (PPS) approach was used to determine the number females/males within the age group targeted. This was factored into the calculation of sample allocation.
Stage 4	The sampling frame was obtained from the registered membership network per district to determine those to sample. The round-between function in Microsoft Excel was used in Excel to generate random numbers. It is these numbers which were used to select corresponding respondents.

2.7 Reaching sampled respondents for interviews

The research team worked with field mobilizers under the leadership of the NAFOPHANU field team to reach respondents in the sampled villages following the generated PLHIV district sample. This had names of randomly sampled respondents. Depending on the mobilization and consensus with the respondents, interviews were conducted in safe places to maximize confidentiality. Qualitative participants were purposively sampled and mobilized per district.

2.8 Data collection Instruments

Translation of the English PLHIV stigma index questionnaire was undertaken for main dialects (Lebthur, Pokot, Ngakarimojong and Jie). To increase acceptance and community participation, translation services were handled by Karamoja speaking persons based in the respective districts. The translation process involved back-to-back translations. The translation process also benefited from research assistant training feedback on the most acceptable translation per language.

2.9 Ethical considerations

This PLHIV baseline stigma survey was approved by Mildmay Uganda Research Ethics committee (MUREC) and registered with the Uganda National Council for Science and Technology (UNSCT). Given the sensitivity of executing the PLHIV stigma index and the ethical requirement, the research team enforced all the required ethical standards at all stages starting with preparatory phase, during training of research assistants, and during data collection and analysis. The research team were told to seek consent, keeping all data gathered confidentially only to be used for purposes of the study. Consent before recording and taking photos even during training was sought. Normally, in conducting the PLHIV stigma Index, part of the empowering process includes working with PLHIV as data collectors and key actors in the study process. All data collectors were PLHIV with competence in data collection and both local Language and English reading and speaking. During recruitment of data collection team, the ratio of ¾ of females to male was observed. This is because, from NAFOPHANU's experience of implementing stigma index studies, usually females are more than males by about 25%. Based on this lesson, data collection team have to be match in number by recruiting more female interviewers.

2.9.1 Seeking local area approval

Appropriate authorization and approvals to implement the study at the selected villages was obtained at all levels of community and particularly from the administrative area for all the sampled areas.

2.10 Data collection (quantitative and qualitative)

The first phase of data collection focused on quantitative. Within the sampled villages, research teams used the unique identifiers to reach eligible clients for interviews. Most times, a local guide or mobilizer located the eligible respondent. Upon locating the respondent and agreement on venue for the interview, appropriate permission including consent were executed. Research teams were reminded to keep all the information with utmost confidence during the interview and post data collection period. The use of Smart phones for data collection increased confidentiality as all submitted data was only accessed by the investigators and data managers.

After the first phase of quantitative data collection, the qualitative data was collected in three districts using Focus Group Discussions (FGDs) with adolescents and young people. Data collection was done by a modulator and note taker and overseen by a research manager. A total of 8 FGDs were collected with varying team participants who ranged between 5 to 8 per FGD.

Table 3: Focus Group Discussion selection criteria per district

Districts	Age15-19 Males/ females In school	Age15-19 Females/ Males Out of school	Age20-24 Males/ Females Out of school
Moroto	1	1	1
Napak	0	1	1
Nakapiripirit	1	1	1

Each FGD composed of 5males and 5 females from each age group. These were selected by the help of the mobilizer from each district who was familiar with the adolescents in the community.

2.11 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 is 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. The electronic platform on the Smart phone has an ODK Collect installed to enable collection and secure transmission of data. Configuration of the ODK Aggregate was made to receive data sets for this project. The use of mobile technology for data collection improves data quality by reducing human errors. A validation program was in built in the electronic forms to systematically reduce entry errors in the field. Proper data formats, were automatically enforced with Skip patterns. The data collection interface was programmed allow the display of relevant questions based on data entered to previous questions.

For the qualitative data, the voice recorder tool was used to capture participant's voices. This data was later retrieved from the Smart phones into password protected computers for subsequent analysis. Analysis of qualitative data was done through extensive review of the scripts to identify details of key experiences related to HIV and seeking of SRH with communities and at health care facilities. Several of the stimulating quotes were noted, interpreted and attached to text segments to amplify meaning and context for the quantitative data

2.12 Data collection teams: Recruitment, Training and Deployment

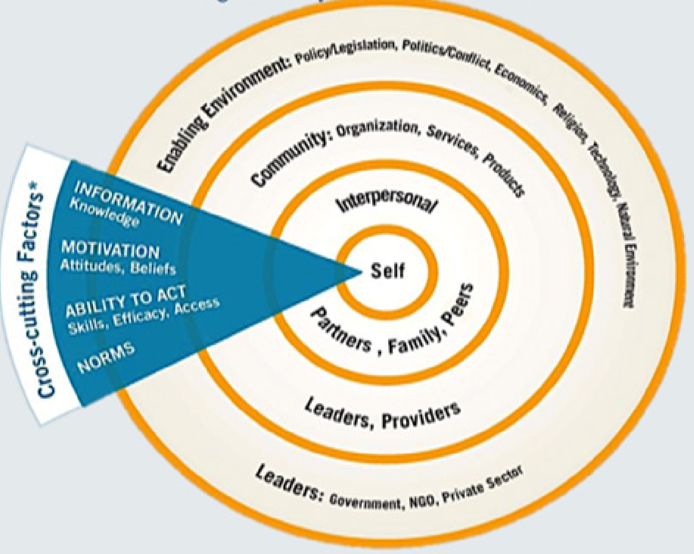
NAFOPHANU embraces the gender principles, as such, during the survey, there was a balance of males and female research assistants and investigators. Research assistants (RAs) recruited were competent in using English and the local language for data collection. Data collection training was conducted by NAFOPHANU technical teams and the consultant in Moroto District. During the training, data collected received ethics training in addition to the questionnaire administration technics and content issues.

2.13 Quality control

Deployment into the field had four team formations with four research assistants (RAs) and one supervisor. For purposes of quality control, supervision staff were very competent persons with team building and leadership skills, phone technology and ability to work with PLHIV in a non- judgement way. Before submission of data, the supervisor verified the entries daily. Finally before final report preparation, the TWG and UNAS and SRC reviewers provided technical oversite.

2.14 Data Analysis Plan -Quantitative

Fig 1. Analytical Framework



The developers of the index are yet to provide a detailed analysis plan. However, going by experience, where analysis is done at three levels (Univariate, bivariate and multivariate). This has worked perfectly in the past. However, the new thinking in Social Behavioral Change project is to contextualize issues based on the Socio-ecological model, (McKee N et al. 2000. See adopted analytical framework) as the guiding (Figure 1). The frame work targets the individual (self) but is cognizant of the influencing factors beyond the individual in adoption of positive behaviors. In adopting, McKee model, interpretation of data was analyzed using these perspective of information/ knowledge, experiences, motivation, ability to act, gender, and norms as they relate nine sub section of the PLHIV stigma index survey.

As per guidance from UNAIDS Country Office, the proxy measures of HIV stigma were combined into composite variables to aggregate the magnitude of HIV stigma based on either external or internal stigma. This permitted computations for the overall stigma totals. Additionally, stigma was either grouped into levels; low, moderate, high and very high. The study adopted use of descriptive statistical tests. This was intended to ease reading and understanding of the prevalence of HIV stigma.

2.15 Study limitations

Identifying Data collection teams: The standards for conducting HIV stigma index recommend an empowerment process. As such data collection is undertaken by PLHIV. This was rather challenging to identify, train and maintain language competent PLHIV with the minimum level of education from the sampled districts. Although the identified data collection team was given extensive training and supervision support through the data collection phases, hence fulfilling the empowerment aspect, a more competent team with language abilities, SMART phone use skills and relatively high education levels would have been preferred given the length of standard Questionnaire and procedural requirements.

Tracking of eligible sampled respondent:

As per the protocol, sampling was to be made from the registered network members or members linked to the network of PLHIV in the districts. However, the registered network membership lists were in some cases made per the ART facility registration. Since some members used different names while at the health facility and within the communities, it was quite hard to trace some sampled respondents especially for districts like Abim and Amudat. This was in addition to long distances travelled tracing eligible respondents who in some cases could have migrated to other distant places.

Limitation of sample frame by districts:

Some lists were incomplete to cover the required sample. In some cases, the sampled names, respondent resided in far places outside of the districts and this made replacement of such respondents inevitable. The districts coordinators found it so difficult to reconcile the lists per specifications in the protocol leading data collection delays as the lists for 4 districts were compiled much later. This made the execution of the study particularly data collection register delays. These delays have eventually affected other study execution processes.

Limitation in identifying Adolescent and young people:

It was quite hard to identify the project target respondent of adolescent and young people. In terms of proportion, few were registered with the networks making it hard to reach and sample them. It was therefore decided that some qualitative data will be collected and analyszed to bridge this gap.

Questionnaire related limitations: The standard HIV stigma Questionnaire has limitations in some questions that relate to domains of HIV treatment. For examples questions that ask about PMTCT, ART, having children and related experiences have been overtaken by recent developments in HIV treatment, care practices. Additionally, questions that ask sufficient food and household income, number of people living a household needed to have been tailored more to the context of the Karamoja regions.

2.16 Study strength

Regarding executing HIV stigma index as per the international standards, the study exhibited the empowerment process that is highly regarded. The PLHIV were at the center of executing almost all study processes; during planning, coordination, active leadership during training, data collection and mobilization of stakeholders.

Despite the limitation highlighted above, the study sample was achieved in all the pre-determined districts, covering a cross section all eligible adult respondents, by gender and self-defining categories such as migrant worker, sex worker, injecting drug users and general population.

This study also paid specific attention to the issues of adolescents and young people in the age bracket of 15 to 24 years and next category of 25-29. This is unique feature especially for adolescent who are experiencing sexual related desires and with no concrete interventions that target them consistently.

During the planning, execution, data analysis and synthesis of the results, the situation of Karamoja is quite peculiar making this regional based study a beneficial one in terms of constituting specific stigma interventions that will help to address HIV stigma and promote the wellbeing of the PLHIV at large.

CHAPTER THREE

RESULTS

3.1 Report structure:

The PLHIV stigma index conventional way of presenting results follows the three major sections reflected in the 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. The report uses disaggregated tables and selected figures to condense key descriptive results. For explanatory insights, participant's narratives and quotes are imbedded in appropriate sections. After presentation of the major findings, additional sections such as conclusions, study limitations, study strength and recommendation follow. To have detailed level of stigma, key tables are appended with specific disaggregation.

3.2 Box 1: Karamoja Ethnology

1. Karamoja region is composed of seven sparsely populated districts including: Kotido, Kabong, Moroto, Abim, Amudat, Nakapiripirit and Napak.
2. On average the population density (number of people living per square kilometer) ranges between 26KM2 to 42Km2, far below other districts like Mbale district which have 1026/Km2
3. Within Karamoja, the district with the highest population (197200 persons) is Kotido
4. On average the proportion of females is slightly higher than the males in every district, at 53% Females, 46% males.
5. The predominant economic activity has been nomadic pastoralism for generations and generations leading to several food shortages that required AID support from Government of Uganda and donor for close to 30 years.
6. The education levels are generally low compared to other regions within the country
7. Since the beginning of 2011, the communities have embraced domestic farming enterprises on small scale and high potential to live in permanent households.
8. Most Karamojong have polygamous families but officially accepted through payment of bride price
9. Most times, adorn markings on their forehead and around the face and use animal skin for wearing traditionally

This section presents the background characteristics of the respondents. A total of 977 respondents participated in the survey. The total minimum pre-determined sample was 976 Out of 977, 299 (31%) were males and 678(69%) females. The proportion of females reflected in this survey is like the three-previous PLHIV stigma index surveys in Uganda that reached out the adult PLHIV. The adult population of males in all these studies range between 31% to 33%. The following tables 1 to 7 show descriptive results with a key interpretation of the implication of the data.

Table 4: Background characteristics of the sampled respondents by gender

Category	Male n (%)	Female n (%)	Total n (%)
Men who have sex with men	5(0.51%)	0(0.00%)	5(0.51%)
Gay or lesbian	3(0.31%)	1(0.10%)	4(0.41%)
Transgender	1(0.10%)	1(0.10%)	2(0.20%)
Sex workers	2(0.20%)	8(0.82%)	10(1.02%)
Injecting drug users	0(0.00%)	0(0.00%)	0(0.00%)
Refugee or asylum seekers	0(0.00%)	5(0.51%)	5(0.51%)
Internally displaced persons	3(0.31%)	4(0.41%)	7(0.72%)
Member of an indigenous group	1(0.10%)	7(0.72%)	8(0.82%)
Migrant worker	1(0.10%)	11(1.13%)	12(1.23%)
Prisoner	3(0.31%)	8(0.82%)	11(1.13%)
General population (Does not belong to any specific categories)	299(96%)	633(95.8%)	932(95.2%)

Multiple responses were allowed/possible. For example, one can be gay, but also a refugee. Note: Gay are different from MSM. Because one could be gay but does not practice sex with men but MSM have sex with fellow men.

As shown in Table 4, majority of respondents, 932 (95.2%), belonged to the general population. This means any interpretation of the findings may not to any extent be affected by the special categories that the person belongs or has belonged to in the past given the mining activities in the region(Mines, 2013). It was expected several men would migrate to this area as workers but this was not evidenced. The proportions shown in Table 5 could mean that Karamoja region population has maintained their social and cultural fabric. Any intervention targeting this community should put into consideration this evidence of a strong social fabric.

Table 5: Respondent Age Categories by Gender

Age Range	Male n (%)	Female n (%)	Total n (%)
15 to 19 years	9(2.9%)	18(2.7%)	27(2.76%)
20 to 24 years	24(7.7%)	66(9.9%)	90(9.22%)
25 to 29 years	37(11.9%)	121(18.2%)	158(16.17%)
30 to 39 years	102(32.7%)	231(34.7%)	333(34.08%)
40 to 49 year	90(28.8%)	143(21%)	233(23.85%)
50 and above	50(16%)	86(12.9%)	136(13.92%)
Total	312(100%)	665(100%)	977(100.00%)

Note: The age categories of 10-24 which the PACK focuses were quite hard to identify during the survey because their registration in district networks of PLHIV was still low compared to the adults.

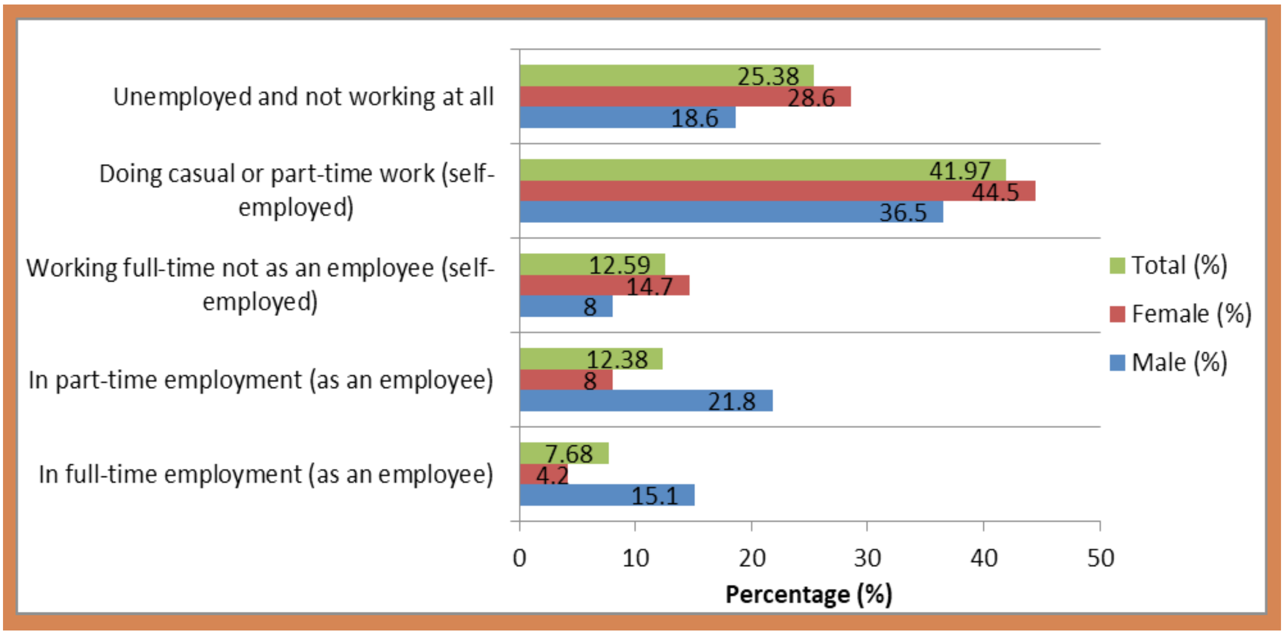
The predominant age categories were 30 to 39 years 333 (34%), and 40 to 49 years, 233 (23.9%). These age proportions per age category are like other HIV survey conducted recently in Uganda. A key observation of this data is the relatively high proportion of females compared to males in the low age categories from 20 to 24 upto to 25 to 29 years. Within the age categories of 40 to 49 and those above 50 years, the proportion of females is comparatively small. In data, more proportions of females at lower age groups compared to men were PLHIV. Though the reason for this phenomenon cannot be confirmed, the social and cultural factors that expose females to vulnerable situations could offer an explanation that point to females acquiring HIV at relatively early ages. The implication of this result potentially implies that PACK project should to a big extent pay attention to gender related dynamics that have been revealed in others studies. Some of the documented gender issues include labor intensive activities left to women and all decision are made by the men yet the bread winner is the female leading to several cases of polygamy (FACT Project, 2016):

Table 6: Respondents Marital Status by Gender

Marital Status	Male n (%)	Female n (%)	Total n (%)
Married or cohabiting and husband/wife/ partner is currently living in household	222(71.2%)	300(45.1%)	522(53.43%)
Married or cohabiting but husband wife/ partner is temporarily living/working away from the household	27(8.7%)	56(8.4%)	83(9.1%)
Single	25(8%)	95(14.3%)	120(12.28%)
Divorced/separated	19(6.1%)	56(8.4%)	75(7.68%)
Widow/widower	19(6.1%)	158(23.8%)	177(18.12%)
Total	312(100%)	665(100%)	977(100.00%)

In Table 6 above, findings revealed that majority of the respondents 522(53.4%) were married and their partner was staying in the household. The proportions show differences regarding marital status of men and women. More men 222 (71%) compared to 300 (45.1%), were married, and more females were divorced 158 (23.8%) compared males 19 (6.%). Though divorce and gender relations was not explored directly in this study, evidence from other studies (Uganda PLHIV country assessment 2013), indicate that self-blame as a form of internal stigma affects the females and they end leaving their marital relationships. Additionally, the proportion of those widowed show a high proportion of females, meaning either the males remarry after death of partner or more men pass way for failure to seek treatment.

Figure 2: Respondents Employment Status by Gender



Except for 248 (25%) respondents who were not employed in any of the listed forms of employment, majority 729 (75%) self-reported to be employed. Within the category of casual or part time work, more females 296 (44.5%) compared to 114 (36.5%) males were employed. The category of full time has more males 47 (15%) compared to 28 (4.2%) females. These results imply that institutional level HIV stigma is likely to be low in this kind of setting as few PLHIV are in formal institutions, but self-stigma is more likely to be prevalent. Interventions that directly target self-stigma would be more preferred in this setting.

Table 7: Length of time respondents have lived with HIV from time of diagnosis by gender

Period	Male n(%)	Female n(%)	Total n(%)
0 to 4 years	109(34.9%)	300(30.71%)	409(41.86%)
5 to 9 years	106(34%)	192(19.65%)	298(30.50%)
10 to 14 years	61(19.6%)	116(11.87%)	177(18.12%)
15 years and above	36(11.5%)	57(5.83%)	93(9.52%)
Total	312(100%)	665(100%)	977(100.00%)

Length of living with HIV was self-reported by client from time of diagnosis and not determined in the laboratory

Table 7 shows that majority had lived with HIV between 0 and 4 years, 409 (41.86%). The proportion of PLHIV reduces with the number of years an individual has lived with HIV. H however, a marked drop was observed among the female category from 0 to 4 300 (30.71%), to 5 to 9 years, at 192 (19.65%) years. The data also indicates a possibility of more recent HIV infections as per the high proportion that reported having lived with HIV for less than 4 years.

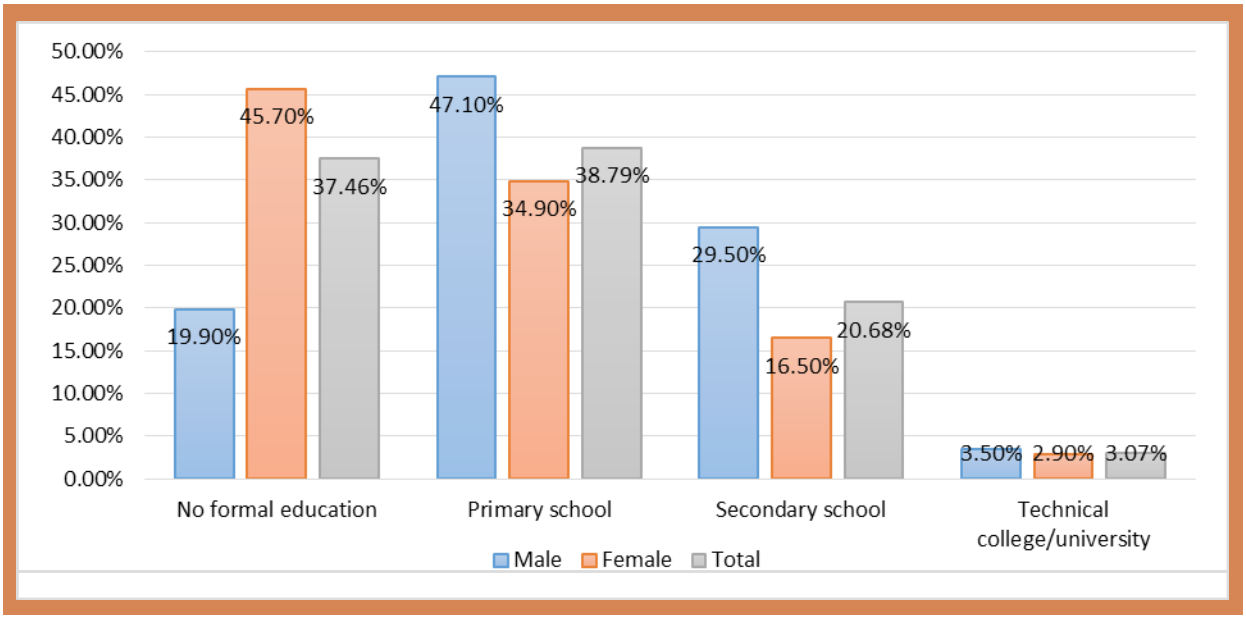
Table 8: Duration the respondents have been involved with partner in relationship

Period	Male	Female	Total
0 to 4 years	123(39.4%)	255(38.3%)	378(38.69%)
5 to 9 years	85(27.2%)	174(26.2%)	259(26.51%)
10 to 14 years	45(14.4%)	90(13.5%)	135(13.82%)
15 years and above	59(18.9%)	146(22%)	205(20.98%)
Total	312(100%)	665(68.07%)	977(100.00)

In Table 8 above, findings show that 378 (38.69%) of respondents had been in a sexual relationship with their partners for a period lasting between 0 and 4 years, followed by those between 5 to 9 years, 259 (26.51%). Those who have been in relationship for 15 years and above were 205 (21%). There are no observable differences in the proportions by gender.

Data not in table indicates that about 491(50.1%) were sexually active, but more males 229 (73%), vs 262 (39%) females were sexually active. This finding is partial proof that the PLHIV could live near normal productive lives in addition to active participation in social responsibilities as sexual relationships.

Figure 3: Distribution of respondents by level of education



Per Figure 3: many respondents, 366 (37.5%), reported no formal education. Similarly, 379 (38.79%) only attained primary level education. Generally, men had attained more formal education than females in all the categories of primary, secondary and technical. For quite some time, education attainment for the entire region of Karamoja has been a challenge.

Though most government programs such as Universal Primary Education, Alternative Basic Education and other literacy program exist, evidence from show about 51% of individuals between 6 to 24 years had never attended school and the overall literacy rates was 26% and 21 for females ((UBOS), 2018) This effect is therefore not different for the PLHIV. These results have implication on addressing HIV stigma directly, because literacy level negatively affect drug adherence, treatment supporter's availability and information sharing.

Table 9: Distribution of respondents by average monthly income of their households

Income	Frequency	Percent
1- 50,000	476	48.72
50,001- 100,000	191	19.55
100,001- 150,000	76	7.78
150,001- 200,000	57	5.83
200,001- 300,000	70	7.16
300,001- 400,000	47	4.81
400,001- 500,000	32	3.28
500,001- 600,000	7	0.72
600,001- 700,000	6	0.61
700,001- 800,000	4	0.41
800,001- 900,000	1	0.10
900,001- 1,000,000	4	0.41
Above 1,000,000	2	0.20
None	4	0.41
Total	977	100

The poverty levels are generally high among the sampled respondents with the majority reporting a range of 1 to 50000 shilling per month for the entire household. Household income is calculated as an average for all working people in household. From the table, above, the median income is between 50001 and 100000 per month. Poverty has several implications with respect to accessing social and health services for entire population. This poverty situation can be more challenging for the PLHIV as they have several health-related needs such as accessing care and treatment services from often distant health facilities and food requirements which is scarce. There is therefore an apparent need for NAFOPHANU to promote HIV related stigma intervention as well playing an advocacy role with other CSO to acquire resources that will be used to support those in need of resources to enable them access care services and food.

Figure 4: Proportion of respondents reporting number of days in the last one month when members of their household did not have enough food

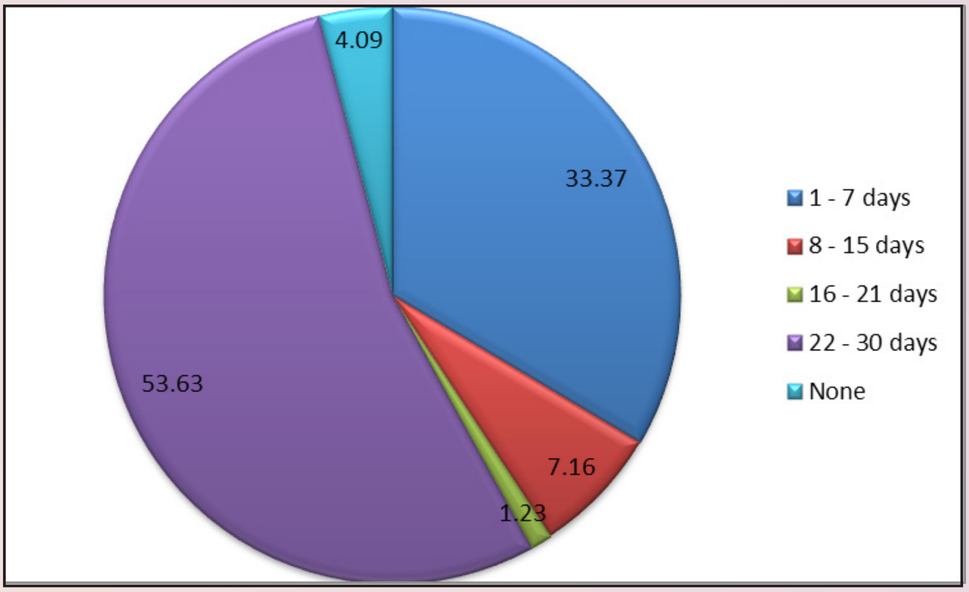


Figure 4 above illustrates that only 40 (4.1%) had enough food as per the working definition. The results show a general food crisis where many respondents, 524 (53.6%) household members, went for between 22-30 days without enough food. Enough food is defined as having 3 meals a day (breakfast, lunch and supper). Lack of food has direct negative impact on ART adherence levels and nutrition status of the PLHIV. Interventions that are targeting reduction of HIV stigma in this region should consider household food supplementary support to promote general health for the PLHIV.

SECTION 2:

EXPERIENCES OF STIGMA AND DISCRIMINATION

3.2. HIV Stigma at family and community level

This section presents findings of the first continuum of HIV stigma (external stigma). This type of HIV stigma is categorized as external stigma as it emanates from other people outside of the individual. The core 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 reactions to experiences by PLHIV who are reported to have stigmatized or discriminated the respondents.

Table 10: Percentage of respondents who reported stigmatization and discrimination at community level by the frequency in the previous 12 months

Reported experiences (proxy measures)	Never	Once	A few times	Often	Total
Excluded from social gatherings or activities (e.g. weddings, funerals, parties, and clubs)	889(90.99)	37(3.79)	26(2.66)	25(2.56)	977(100)
Excluded from religious activities or places of worship	936(95.80)	19(1.94)	13(1.33)	9(0.92)	977(100)
Excluded from family activities (e.g. cooking, eating)	923(94.47)	26(2.66)	19(1.94)	9(0.92)	977(100)
Been aware of being gossiped about	329(33.67)	59(6.04)	200(20.47)	389(39.82)	977(100)
Been verbally insulted, harassed and/or threatened	379(38.79)	78(7.98)	188(19.24)	332(33.98)	977(100)
Physically harassed and/or threatened	759(77.69)	97(9.93)	65(6.65)	56(5.73)	977(100)
Physically assaulted	685(70.11)	74(7.57)	93(9.52)	125(12.79)	977(100)

The overall percentage of external stigma is 32%. this proportion is based on a computation that generated a total count of 2193 responses out of the expected 6839. The 2193 (32%) responses were related experiences of external HIV stigma in the past 12 months. In Table 9, there are variations in the specific components of external stigma. For instance, the proportion of PLHIV who reported that they have never been excluded from social gathering activities were quite many, 889(90.9%), similar proportions were reported for exclusion from religious activities or places of worship, 936(95.80%), and exclusion from family activities were 923(94.47%). On the contrary, experiences of being gossiped about in the last 12 months were reported by high proportion 648(66%), similarly experiences of verbal insult were reported by 598 (61%).

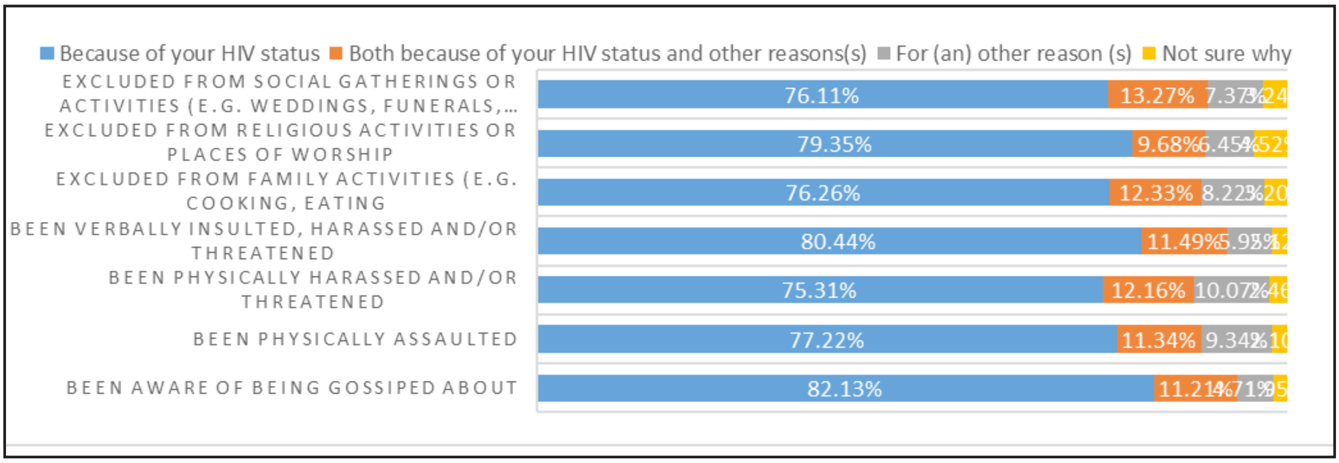
Like the quantitative data, the qualitative narratives equally showed gossip as prevalent.

"I used to move with my friends but when they discovered I was HIV positive I stopped because they kept gossiping about me" FGD participant, Namalu, out school, 15- 19 years]

These findings point to the need to revitalize components of sensitization that should be implemented through use of multi channel approaches. There should be sensitization through mass media (TV, Radio and Posters), and through interpersonal communication channels such as community shows where stigma experience are talked about and their implications, small group discussions and dialogue sessions where myths about HIV are demystified. This kind of targeted sensitization is hoped to increase awareness and promote desirable behaviors in addition to promoting positive living and generally bring the HIV stigma to minimal levels.

Figure 5, lists several reasons why the individual was excluded.

Figure 5: Percentage of respondents who reportedly encountered various forms of stigma at family and community levels by the perceived reasons for stigmatization in the last 12 months



According to Figure 5, most of the exclusion experiences by the PLHIV in the last one year was directly attributed the HIV status of the client. The proportions of those who attributed the exclusion to HIV status was 75% and above. This data confirms that the PLHIV's strong beliefs that the HIV stigma and discrimination experiences were more related to living with HIV. Based on this evidence, interventions that address specific aspects of HIV related stigma are justified for the region.

As part of the standard HIV stigma questions, a possible link between the category of belonging or having belonged to a group had been assumed to be a source of double HIV stigma. Such categories of belonging included sexual orientation (Men who have sex with men, gay), sex workers, injecting drug users, refugee or asylum seeker, internally displaced persons, migrant workers and prisoners. In this data most respondents 932 (95.2%), did not belong to any special grouping so HIV stigma associated with belonging to any these groups was highly unlikely.

3.3 Experiences of Physical assault in the last 12 months

Out of those who reported to have experienced physical assault in the last 12 months, a follow up question was asked about the person who had assaulted them. Out of the approximately 292 persons who reported physical assault, 6% mentioned their husband/wife/partner, 6.8% mentioned another member of the household, and the majority 15% said persons outside the household who were known to them. It is a known fact that the PLHIV require a supportive environment and this was the basis of requirement for treatment supporter in most care and treatment programs. Therefore, aspects of physical assault need to be addressed to promote positive leaving. The most feasible approach is the use of PLHIV as champions to reinforce messages that promote living in harmony all household members. NAFOPHANU and CSOs should detail talking points for VHTs and selected champions (PLHIV) to identify and visit such homestead to dialogue on support issues and address possible misunderstandings.

3.4 HIV related discrimination at family and community levels

As noted, early HIV stigma is a continuum, and the literature makes a distinction between HIV stigma and discrimination. Discrimination is the worst manifestation of HIV stigma in the continuum of HIV stigma. The section below explores actual experiences of discrimination in the last 12 months (Table 10). The data in Table 10, links HIV positive status to how this status could have been used as sources/cause for discrimination or manipulation for the PLHIV.

Table 11: Percentage of respondents who reported various forms of discrimination in last 12 months

Responses	Never	A few times	Often	Once	Total
Psychological pressure or manipulation by my Husband/ wife or partner in which my HIV-positive status was used against me	70(7.16)	732(74.92)	95(9.72)	80(8.19)	977(100)
Experienced sexual rejection because of my HIV Positive status	44(4.50)	844(86.39)	54(5.53)	35(3.58)	977(100)
Discriminated against by other people living with HIV	36(3.68)	858(87.82)	47(4.81)	36(3.68)	977(100)
My wife/husband or partner, or any members of my household experienced discrimination because of my HIV-positive status	66(6.76)	717(73.39)	79(8.09)	115(11.77)	977(100)

According to Table 11, the proportions reporting discrimination are generally high. The case in point is that only; 70 (7.16%) never reported psychological pressure or manipulation by husband/wife or partner under the guise of HIV positive status. Equally so, is a proportion of 95% that reported discriminatory experiences related to sex rejection and a high proportion over 90% who mentioned that their wives/husband/ or any member of household were discriminated as a result of the respondent's positive HIV status with reference to last 12 months. There are quite a number of implications based on these self reported revelations. However, the most important intervention to promote is comprehensive knowledge about issues of HIV stigma particularly the benefits that accrue if HIV stigma or discrimination is reduced. Such benefits include positive living where PLHIV can live productive lives, aspect of HIV preventions that occur if the PLHIV is supported to seek care and treatment as less domestic violence at homesteads.

3.5 Perceived reasons for discrimination

In almost all the sub-sections above, the HIV related stigma and discrimination was reflected as high. Certainly, there could be several and varying reasons for such high level of HIV stigma and discrimination, table 12, lists the pre-categorized reasons.

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

Response	Total
People are afraid of getting infected with HIV from me	448(45.85%)
People don't understand how HIV is transmitted and are afraid	441(45.14%)
People think that having HIV is shameful and they should not be associated with me	87(8.90%)
Religious beliefs or "moral" judgments	15(1.54%)
People disapprove of my lifestyle or behavior	21(2.15%)
I look sick with symptoms associated with HIV	58(5.94%)
I don't know/I am not sure of the reason(s)	188(19.24%)

Multiple response options possible/ allowed ***

Per table 12, there are mainly two outstanding reasons associated with HIV stigma experiences. The reasons were: peoples' fear of getting infected with HIV from the PLHIV which was mentioned by 448(45.8%). The second reason reported by 441(45.14%) was people's understanding of how HIV is transmitted is low hence the heightened fears. This data implies that knowledge levels are quite low in matters relating to HIV, causes, management and care services. During the PACK project implementation, aspects of continued awareness raising on the causes and transmission of HIV should be prioritized.

"I had these challenges' while at school. Some of my bedmates would ask why Iwas swallowing the medicines daily, as a result of that I kept on isolating myself while swallowing the drugs to avoid questioning." [Out of school 15-19 year old PLHIV participant in FGD- Mororo]

"In Karamoja we drink fresh blood but when you are HIV positive they do not allow you to drink it yet it's the main food in the villages" [In school, 15-19 old PLHIV participant in FGD- Moroto]

"They segregate you and they don't share bed (animal skin) with you who is infected. [Out school, 15-19 old PLHIV participant in FGD- Moroto]

3.6 Access to work, health and education services

The sub-section presents findings linked with institutional level discrimination faced by PLHIV. It highlights aspects of; changes in job location because of job loss, suspension and non-promotion due to HIV and AIDS, denial of either health or educational services that ordinarily happen because of someone's HIV positive status.

"At health facilities, HIV stigma and discrimination is not there because there is a corner, we just go and pick our drugs without fear" [20-24 years old, out of school FGD participant, Namalu]

Table 13: Distribution of respondents by frequency of various forms of discrimination related to work and education services in past 12 months

Response		Never	Once	A few times	Often	Total who responded
Forced to change place of residence or been unable to rent accommodation	Male	271(86.9%)	23(7.4%)	13(4.2%)	5(1.6%)	312
	Female	500(75%)	96(14.4%)	46(6.9%)	23(3.5%)	665
Lost a job or another source of income	Male	111(35.6%)	3(1%)	0(0.00%)	1(0%)	115
	Female	73(11%)	4(0.6%)	2(0%)	2(0%)	81
Job description or the nature of your work changed/ refusal of promotion	Male	292(93.6%)	13(4.2%)	6(1.9%)	1(0.3%)	312
	Female	621(93.4%)	19(2.9%)	12(1.8%)	13(2%)	665

multiple response question

From table 13, the findings indicate varying proportions between men and women about experiences of institutional level HIV stigma. For instance, about 41(13%) men, vs 163 (25%) women were forced to change place of residence or unable to rent accommodation. Similarly, about 64% male's vs 89% females reported to have lost a job or another source of income.

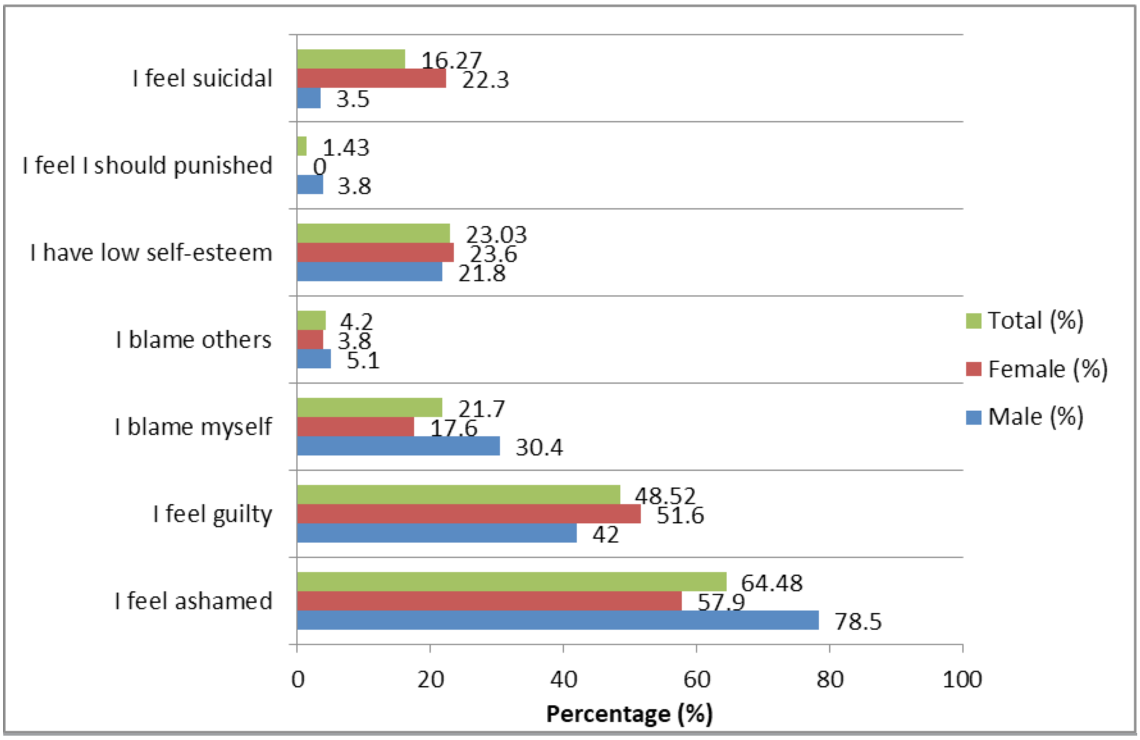
Of the 41 (13%) who reported to have been forced to change place of residence or become unable to rent accommodation, 34 (82%) attributed it to HIV positive status among the men, compared to 64 (39%) females. Out of the 20 men and 40 women whose job description changed or were refused promotion, 17 (85%) men vs 32 (80%) attributed it to having an HIV positive status. These findings generally demonstrate the severity of HIV stigma on other human rights defining factors such as access to employment, nature of employment and treatment while at work. The Global Network of People living with HIV noted that HIV interacts with employment at individual, community and national levels. As such individuals may be unable to continue work for health or discrimination practices, at community the burden of taking care of the PLHIV increases, and at national level, the lost workforce and cost of health care. Therefore, reinforcement of measures that deter discriminatory practices should be enhanced by all partners.

3.7 Internal stigma

This sub section presents findings about the way respondents feel about themselves because they are living with HIV. The follow up sub section, presents findings about the reactions emerge as a result of internal stigma. The operation definition of internal stigma adopted for this survey is the degree to which PLHIV endorse the negative feelings associated with living with HIV and apply those feelings to him/herself. Usually internalization of feelings, often results into negative consequences in form of the decision they make or the reactions that follow.

In the survey, internal stigma was measured based on a seven item HIV stigma scale.

Figure 6: Percentage distribution of perception and fears respondents had about themselves as a result of their HIV positive status by gender



****Multiple response option responses****

The total may exceed the sample size because this was a multiple response question to establish the perception and fears that respondents have about them as result of their HIV+ status.

Proxy measure calculation based on data in Figure 6 indicate that the level of internal HIV stigma is 29%. This proportion is derived from a total count of 1714 responses for the seven proxy measures above. Regarding the specific measures in table 17, majority 630(65%) felt ashamed, followed by 474 (48.5%) who felt guilty, and 225 (23%) who had low self-esteem. Similarly, males who felt guilty were 131(42%) males compared to 343(51%) females. But the proportion of males that felt ashamed and blamed self is comparatively high than the females. There are differences in the proportions by gender for instance females who feel suicidal are remarkable far higher than males 3.5% male compared to 22.3% females. This data means that internal forms of HIV are quite prevalent and interventions that address HIV at individual level need to be promoted in combination with others. The literature indicates that once self-stigma is overcome, other forms of stigma are likely to subside as well.

“I had a lot of thoughts I even wanted to commit suicide” [Namulu - out of school FGD participant]

3.7.1 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.

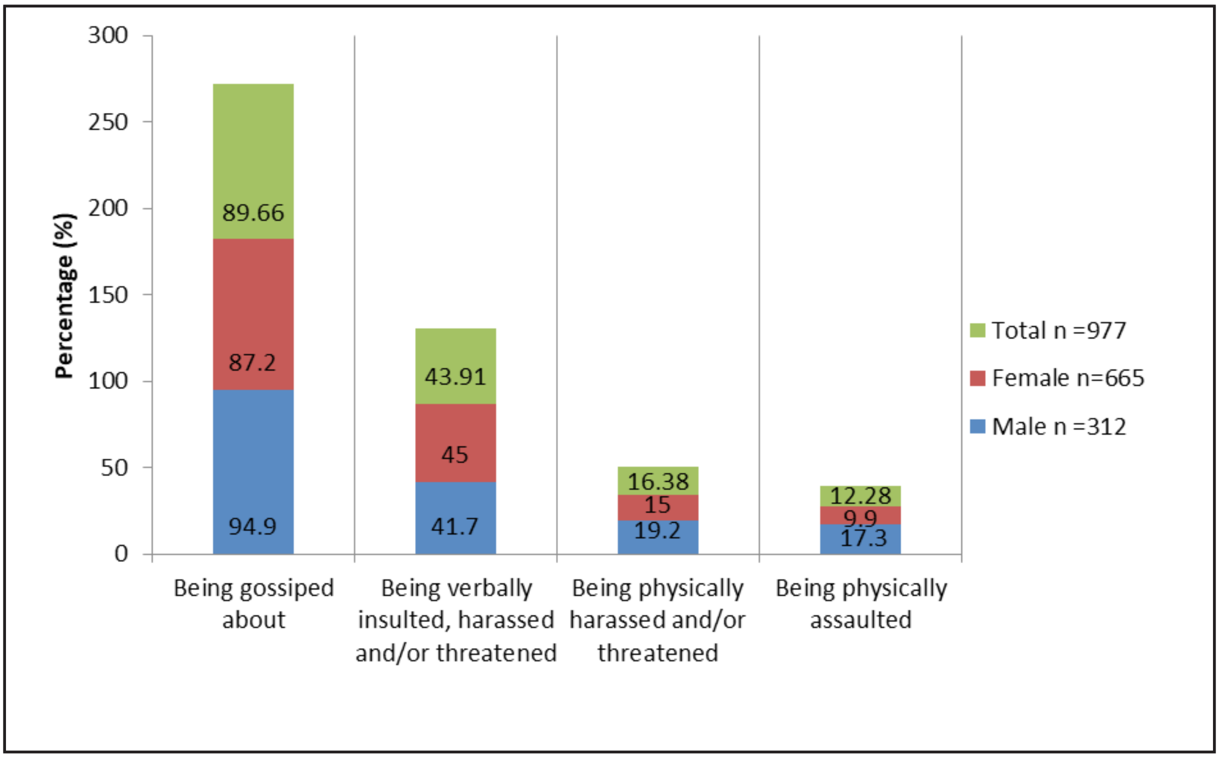
Table 14: Percentage distribution of respondents' decision not to engage in some activities because of their HIV status in the last 12 months by gender

Responses	Male n= 312	Female n=665	Total n =977
I have chosen not to attend social gathering(s)	114(36.5%)	156(23.5%)	270(27.64%)
I have isolated myself from my family and/or friends	25(8%)	139(20.9%)	164(16.79%)
I took the decision to stop working	16(5.1%)	16(2.4%)	32(3.28%)
I decided not to apply for a job/work or for a promotion	16(5.1%)	27(4.1%)	43(4.40%)
I withdrew from education/training or did not take up an opportunity for education/training	54(17.3%)	8(1.2%)	62(6.35%)
I decided not to get married	52(16.7%)	122(18.3%)	174(17.81%)
I decided not to have sex	27(8.7%)	219(32.9%)	246(25.18%)
I decided not to have (more) children	36(11.5%)	271(40.8%)	307(31.42%)
I avoided going to a local clinic when I needed to	9(2.9%)	21(3.2%)	30(3.07%)
I avoided going to a hospital when I needed to	51(16.3%)	51(7.7%)	102(10.44%)

Table 14, shows various decisions reported by the respondents, but those that stood out include decision not to have (more) children 307 (31.4%), followed by not attending social gatherings 270 (27.6%), and not to have sex 246 (25.18). Although all these reactions or decision have implications on social wellbeing of the PLHIV, the major issue of concern is that comparatively high proportion of men 51 (16%) vs 51 (7.7%) women who reported that they avoided going to a hospital when they needed to. This data shows several negative reactions to experiences of stigma that need to be addressed. These reactions have triggered off other reactions but of much concern is avoiding to go to hospital even when someone needed to. Awareness campaigns should promote the PLHIV rights over the seven categories above and how these rights can be embraced through positive living.

3.7.2 Internal HIV stigma and fears

Figure 7: Percentage of respondents that were fearful that various forms of stigma would happen to them in the last 12 months by gender



In Figure 7, findings revealed that majority of respondents, 876 (89.6%) feared to be gossiped about, 429 (43.91%) feared to be verbally insulted, harassed or threatened, and 160 (16.38%) feared to be physically harassed or threatened. Except for fear of being physical assaulted, other forms of fear did not reveal any significant differences between the men and women. This finding reveal that some of the documented HIV related stigma is hypothetical (It has not actually happened), but is only anticipated. This form of HIV stigma ordinarily follows under the internalized stigma which has several consequences firstly to the individuals as it obscures them from pursuing personal and health development goals. The use of faith community during the one year HIV Stigma reduction project in Central Uganda in 2015 was beneficial in addressing self-stigma. A reduction of over 20% internalized stigma was registered in one period. Interventions that work through faith context should be embraced.

3.8 Rights, Laws and Policies

For over a decade now, Uganda promulgated constructive laws (laws that enhance rights of individuals). At an international scene, Uganda has been a signatory to most of the conventions that promote rights of individuals. The Uganda Constitution of 1995 is the cardinal law that protects the rights of all persons, without discrimination of any kind. Many of the provisions of the constitution are reflected in other bylaws and Acts to enforce these laws. 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 and the

HIV Prevention Control Act 2014 that prohibits Stigma and discrimination at all levels. These laws are equally referenced in clauses of the National HIV and AIDS Policy. In line with the current stigma index, similar questions that sought experiences of PLHIV about laws, rights, and polices were explored at length.

3.8.1 Knowledge on UN declarations, National HIV Policy and Experiences of discussions of the content

Awareness is often the first step before knowledge. In table 14, the findings relate to both awareness (heard of) and knowledge (aspects of discussion). Generally, awareness of the UN declaration and National HIV Policy was high but knowledge was low.

Table 15: Percentage of respondents who have heard of the UN Declaration of Commitment on HIV/AIDS and National HIV/AIDS Policy

Responses	Male	Female	Total
Heard of the Declaration of Commitment on HIV/AIDS which protects the rights of people living with HIV	237(76%)	456(68.6%)	693(70.93%)
Ever read or discussed the content of this Declaration	115(37.2%)	230(34.6%)	345(35.31%)
Heard of the national HIV/AIDS policy which protect(s) the rights of PLHIV	224(71.8%)	459(69%)	683(69.91%)
Ever read or discussed the content of this policy	91(29.2%)	240(36.1%)	331(33.88%)

The findings indicate a generally high proportion 693 (70.9%) had heard of the Declaration of Commitment on HIV and AIDS which protects the rights of PLHIV. There are narrow gaps in the proportion of men 237(76. %) Vs 456 (68.6%) who said they had heard. It should be noted that those who have ever discussed the content of the declaration above are less by twice 345 (35%). At the national level, almost the same proportion 683 (69.9%) reported to have heard of the National HIV/AIDS Policy. Almost an equal proportion of males and females have heard about the National HIV Policy. Despite this high proportions which have heard of the international declaration and national policies, the proportion that have discussed are below 35% for both the declaration and the policy. During the implementation of the PACK project, mechanisms that will help the target community to be motivated to read or trigger discussions on these laws should be thought of and specific interventions developed. Such intervention would empower the PLHIV to seek redress during instances of violations of their rights.

3.8.2 Experiences of discrimination in the last 12 months

The experiences presented in Table 15, relate to violations of any kind that happened to a PLHIV as a direct result his or her HIV status. These experiences are limited to a time scope of one year before the survey. This period connotes a recent experience but also avoids recall bias (forgetting actual experiences that happened before).

Table 16: Percentage of PLHIV who reported that they experienced discriminatory practices due to their HIV status

Responses	Male n=312	Female n=665	Total n=977
I was forced to submit to a medical or health procedure (including HIV testing)	29(9.3%)	48(7.2%)	77(7.88%)
I was denied health insurance or life insurance because of my HIV status	23(7.4%)	27(4.1%)	50(5.12%)
I was arrested or taken to court on a charge related to my HIV status	8(2.6%)	8(1.2%)	16(1.64%)
I had to disclose my HIV status in order to enter another country	13(4.2%)	5(0.8%)	18(1.84%)
I had to disclose my HIV status to apply for residence or nationality	6(1.9%)	11(1.7%)	17(1.74%)
I was detained, quarantined, isolated or segregated	5(1.6%)	15(2.3%)	20(2.05%)
None of these things happened to me	234(75%)	567(85.3%)	801(81.99%)

*** multiple response options allowed or possible*

According to Table 16, generally the proportion of cases that report that none of the listed forms of discriminatory practices happened to them in last 12 months is high 801 (81.9%), with more cases of females 567 (85.3%) vs 134 (75%) males reporting. These results show that more males experienced more discriminatory practices, more specifically on the items of forced disclosure. The proportion of males who self-reported that they had to disclose their HIV status before entering another country are 4.2% vs 0.8% females. Other specific examples where males experienced discrimination more than the females is denial of health insurance 23 (74%) males vs 27(4.1%) females. These cases also imply the mobility of men as opposed to females hence facing such practices comparatively at a high rate.

> *"What prevents you is fear and when you are a girl and you are pregnant and a boy dumps you, you cannot attend antenatal because they want both of you. When you don't have a man, they don't attend to you". [15-19 year old, FGD participant, Namalu]*

3.8.3 Abuse of Rights and getting legal redress

The interest of this section was to reveal experiences of whether the PLHIV felt that their rights had been abused in the last twelve months before the survey. Secondly those who reported to have experienced abuse, the legal related actions they embarked on. The findings indicate that about 273 (28%) mentioned that their rights had been abused. This could be largely attributed to the context of Karamoja- a region that was for some time ravaged by cattle rustling activities and other forms of insurgencies with less control on the rule of law, hence favoring situations of possible abuse of rights in the general community including those of PLHIV.

Among the 273 (28%) who reported abuse related to HIV positive status, approximately 131 (48%) mentioned that they attempted or instituted actions in form of or legal redress in response to the abuse experienced within a period of 12 months. The proportion of those who had attempted to seek legal redress in this study is probably high, because of the context of Karamoja where human rights agencies have over time sensitized communities on seeking legal and other formal procedures for solving rights abuses.

Similarly, the majority (66.67%) who attempted to get legal redress reported that their matter(s) had been dealt. The context Karamoja is quite versatile with legal and support services to redress abuses given the presence of NGOs whose focus is such. In addition, many those who reported abuse in the last 12 months but never though legal redress indicated their greatest barrier was insufficient financial resources to take action.

3.9 Effecting Changes

This sub-section relates to how the PLHIV manage to support themselves and others in overcoming situations where their rights are violated because of their HIV status. The actions (confronting, sensitizing and others) undertaken by the individual are explored. The section also explores the client's awareness and close relation with support agencies in the reach.

3.9.1 Confronting/Educating someone

The percentage of respondents who confronted, challenged or educated someone who was stigmatizing in the last 12 months and who knew organizations and groups that could help with stigma and discrimination revealed similar proportion of about 50%. However, key difference is seen between men and women. Generally, a high proportion of males 170 (54%) vs 310 (47%) confronted, challenged or educated someone who was stigmatizing. Additionally, more men 204 (65%) vs 297 (45%) knew of any organizations or groups could seek assistance if they experience stigma and discrimination. Table 16 lists possible agencies that provide support services related to HIV stigma and discrimination prevention, control or reduction.

Table 17: Type of organizations rendering support to reduce stigma known by respondents

Response	Total n =977
People living with HIV support group	346(35.41%)
Network of people living with HIV	315(32.24%)
Local non-government organization	105(10.75%)
Faith-based organization	36(3.68%)
A human rights organization	36(3.68%)
National non-governmental organization	17(1.74%)
National AIDS Council or Committee	17(1.74%)
International non-governmental organization	4(0.41%)
UN organization	3(0.31%)
Other	37(3.79%)

As seen in table 17, the most known agencies are the local ones such as; PLHIV support groups mentioned by 346 (35.4%), Network of PLHIV mentioned by 315(32%) and local non-government Organization. Data not in table indicates that among 501 respondents who knew about the organizations, a high proportion 335(67%) had sought help from such agencies. The data also indicates that more females 214 (72%) vs 121(59%) males having sought the services in the last 12 months before the survey. The planned PACK work should therefore maximize working with these local agencies for effective and efficient project gains.

3.9.2 Experiences of solving Stigma at Individual Level

The PLHIV survey also explored proportions of PLHIV who have ever tried to solve an issue of stigma and discrimination either individually or with assistance of others. The findings revealed that few 331 (33.8%), with differences in proportions between men 112 (38%) vs 213 (32%) females had tried. However, in terms of PLHIV supporting another PLHIV, there proportions go up generally, 803 (82%) said that they had helped another PLHIV to overcome negative HIV situations. On the contrary a slightly high proportion of females 803 (84%) vs 247 (79%) males have supported others to solve HIV related stigma issues. The data shows that approximately 711 (72.7%) provided emotional support such as counselling, sharing personal experiences and stories. More females 76%, vs 66% men provided this type of support. Similar to emotional support, a high proportion of females 41%, compared 31% provided physical support (money, food, or doing an errand.), but support related to referral to other services was reported by a high proportion of men, 22% vs 15% females. These findings imply that working with both males and females as change agents while noting their differences and supporting them along will be beneficial to the program.

3.9.3 Individual perceptions of ability to influence decisions.

These findings are based on respondents' feelings of their power/ability to influence the decisions in spheres that are devoid of ridicule and promote the wellbeing of PLHIV in their communities.

Table 18: Persons who felt could influence HIV related policy level matters to address stigma by gender

Components to influence	Males n=312	Females n=665	Total n=977
Local government policies affecting people living with HIV	190(60.9%)	378(56.8%)	568(58.14%)
Local projects intended to benefit PLHIV	76(24.4%)	249(37.4%)	325(33.27%)
Uganda government policies affecting PLHIV	52(16.7%)	22(3.35%)	74(7.57%)
National programs/projects intended to benefit PLHIV	41(13.1%)	24(3.6%)	65(6.65%)
International agreements/treaties	12(3.8%)	4(0.61%)	16(1.64%)
None of these things	27(8.7%)	71(10.7%)	98(10.03%)

Findings in Table 18 show that majority of the respondents 568 (58%), 190 (60.9), males compared to 378 (56.8%) females believed that they have the power to influence local government policies affecting PLHIV. The second component that some respondents believed could influence are the local projects intended to benefit the PLHIV. Within this category more females 37% vs 24% males mentioned power to influence policies. This finding implies that since the PLHIV have a belief that they can influence the policies, then working with them to gain comprehensive knowledge about issues of HIV stigma and discrimination will form a very good platform for them to advocate for their rights. It is highly possible if the current PLHIV networks are strengthened through mentorship and provided with resources including tools, HIV stigma situation and reproductive health services as per the project plan the situation of PLHIV regarding stigma will be improved in this region.

3.9.4 Addressing HIV stigma and discrimination: Suggestions to Organizations

Given the lived experiences of PLHIV in general, HIV programing and as part of the greater involvement of PLHIV, questions relating to the role which organizations of PLHIV (PLHIV networks) should be doing were explored. Respondents were specifically to mention the most important role the PLHIV networks and organization should be rendering with respect to addressing HIV related stigma.

Table 19: Respondents suggestion about what organization should be doing in respect to HIV stigma services

Suggested services	Male n=312	Female n=665	Total n=977
Advocating for the rights of all PLHIV	205(65.7%)	329(49.5%)	534(54.65%)
Providing support to PLHIV by providing emotional, physical and referral support	142(45.5%)	247(37.1%)	389(39.81%)
Advocating for the rights and/or providing support to particularly marginalized groups (men who have sex with men, injecting drug users, sex workers and migrant workers	33(10.6%)	71(10.7%)	104(10.65%)
Educating PLHIV about living with HIV (including treatment literacy)	30(9.6%)	174(26.2%)	204(20.88%)
Raising the awareness and knowledge of the public about HIV&AIDS	100(32%)	134(20.2%)	234(23.96%)

As per the ranking of the most important issues that organizations should be doing as indicated in Table 19, advocacy 534 (54%), was ranked highest, followed by provision of emotional support 389 (39%), subsequently, raising awareness 234 (23%) and education 204(20.8%). The finding shows close consensus between males and females on most of the most important actions that organization should be executing. In this context, advocacy stood out highest and since advocacy is an encompassing concept, the current CSOs in this consortium should aim to develop, implement and monitor the advocacy strategy specific to Karamoja. Advocacy should form a big part of the PACK project since some of the issues such as inadequate food, long distances to health facilities, poverty rights abuses, should be confronted at a high level.

SECTION 3:

EXPERIENCES OF TESTING, DIAGNOSIS, DISCLOSURE, TREATMENT AND HAVING CHILDREN

This is the third main section as reflected in stigma index tool. The section presents experiences related to HIV testing and diagnosis of an HIV positive results, followed by disclosure experiences the PLHIV underwent during the first, he/she disclosed or other got to know about his/her HIV positive status. Other sub-sections explore treatment and experiences of having children as a PLHIV.

3.10: Testing and diagnosis experiences

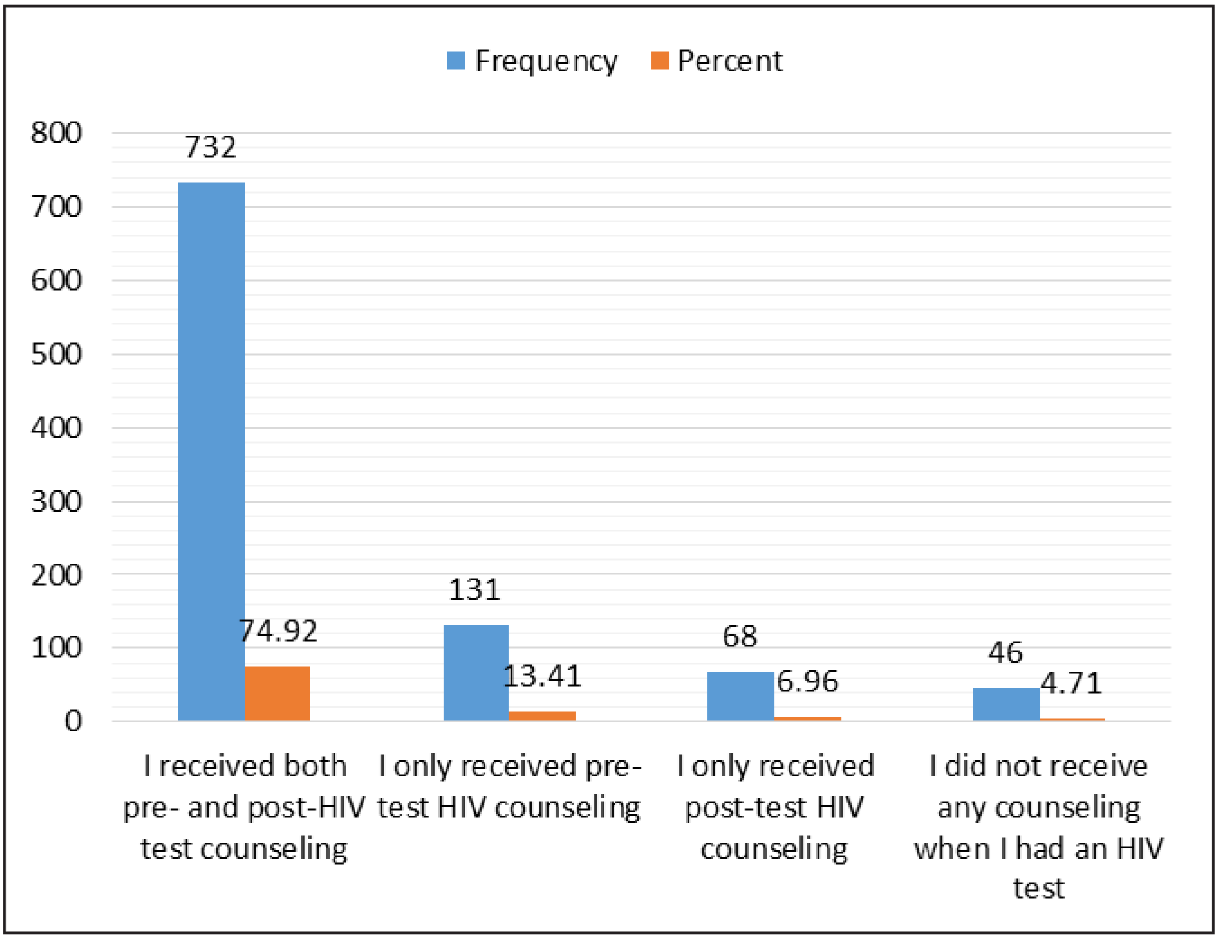
Almost all HIV treatment procedures recommend HIV testing before any treatment, care and support services at health facilities. However, deciding to undertake an HIV test on voluntary basis has remained a challenge to most of the people who may not be knowing their status. There are certainly varying reasons that determine undertaking the HIV test (table 19). In this survey, its assumed that whoever participated in the study must have underwent an HIV test at one time previously. So, the experiences explored here refers to the time when the clients experienced such events.

Table 20: Reasons for testing HIV status

Response	Frequency	Percent
Employment	18	1.84
Pregnancy	202	20.68
To prepare for a marriage/sexual relationship	35	3.58
Referred by a clinic for sexually transmitted infections	56	5.73
Referred due to suspected HIV-related symptoms (e.g. tuberculosis)	166	16.99
Husband/wife/partner/family member tested positive	52	5.32
Illness or the death of husband/wife/partner/family member	59	6.04
I just wanted to know	378	38.69
Other	11	1.13
Total	977	100

As per Table 20, the major reason reported is a willingness to know 378(39%) their HIV status. Similarly, pregnancy 202(20%) is another predominant reason why the PLHIV tested. The data also shows that most respondents 883 (90%) decision to undertake the HIV test was made by themselves without coercions. These findings and particularly the willingness to test voluntarily could be attributed to efforts by existing HIV programs that have reached out communities in Karamoja with testing services. Therefore, NAFOPHANU and her partners should seize this opportunity to ease entry and implement the Planned PACK project working closely with other implementing partners.

Figure 8: Services received during HIV testing



Similar to other studies, the number which received pre and post test counselling is high 732 (74%), but still below the recommended 100%. The PACK project should be concerned of 46(4.7%) who never received any counselling either before or after the testing. This should form part of the advocacy components to avail enough staff to offer the needed services, or to sensitize the clients about the value of post test counselling.

The two captions below highlight both motivations and barriers for the clients to seek treatment derived from the qualitative data: see outline below

- Good counseling services at the facilities
- Designated ART corner where drugs are dispensed. This reduces fear
- Friendly health workers who encourage clients to take drugs
- Extra care and follow during times when clients miss appointments
- Nearness of the ART facility
- Availability of food and family support
- Availability of clean water at the facilities
- Positive changes in social cultural beliefs: Before females did not even have

Whereas the barriers to accessing SRHS and ART

- Fear/stigma: This was exhibited by isolation experienced from communities, labeling and eventual fear to get services
- Lack of confidence
- Lack of cash for use at the available private health facility or to purchase food recommended in combination with the drugs
- Negative attitudes by men towards FP leading to domestic violence
- Myths that FP leads to infertility
- Gossip" You could be taking your drugs well, but if they laugh at you, abandon" young FGD participant

"The drugs are very strong, after taking them, sometimes you feel dizzy. Secondly some of us they kept changing the drugs we were on but these drugs have side effects e .g. I used not to wear glasses but I am using my sight has been affected." Out of school 15-19 year old PLHIV participant in FGD- Mororo.

"Some people fear to access these services like us because we are still young and not having sex. [In school, 15-19 old PLHIV participant in FGD- Moroto]

"Fear to ask for the condoms from the doctors or nurses because they are afraid of what they will think" [In school, 15-19 old PLHIV participant in FGD- Moroto]

3.11: Disclosure and confidentiality

This sub section presents experiences related to disclosure of HIV. The focus is how other people first learnt of the HIV status of the PLHIV. The sub section explores the reasons different people developed after knowing the person's HIV positive status. In addition, information on the process of disclosure is discussed.

Literature on HIV disclosure portray disclosure as an empowering process but also a very challenging step in management of HIV (Uganda PLHIV Stigma Index, 2013 and GNP+ Manual for HIV Conducting HIV stigma Index, 2008).

Table 21: Percentage distribution of how different groups of people first got to know about respondent's HIV status

Category of people	I told them	Someone else told them with my consent	Someone else told them without my consent	They don't know my HIV status	N/A	Total
Your husband/ wife/partner	656(67.14)	54(5.53)	73(7.47)	48(4.91)	146(14.94)	977(100)
Other adult family members	623(63.77)	50(5.12)	147(15.05)	77(7.88)	80(8.19)	977(100)
Children in your family	581(59.47)	33(3.38)	106(10.85)	164(16.79)	93(9.52)	977(100)
Your friends/ neighbors	430(44.01)	52(5.32)	190(19.45)	226(23.13)	79(8.09)	977(100)
Other people living with HIV	629(64.38)	50(5.12)	148(15.15)	57(5.83)	93(9.52)	977(100)
People who you work with (your co-workers)	352(36.03)	43(4.40)	118(12.08)	281(28.76)	183(18.73)	977(100)
Your employer(s)/ boss(es)	314(32.14)	35(3.58)	84(8.60)	292(29.89)	252(25.79)	977(100)
Your clients	484(49.54)	35(3.58)	115(11.77)	228(23.34)	115(11.77)	977(100)
Injecting drug partners	267(27.33)	9(0.92)	45(4.61)	125(12.79)	531(54.35)	977(100)
Religious leaders	307(31.42)	38(3.89)	58(5.94)	405(41.45)	169(17.30)	977(100)
Community leaders	274(28.05)	33(3.38)	85(8.70)	434(44.42)	151(15.46)	977(100)
Health care workers	694(71.03)	18(1.84)	109(11.16)	52(5.32)	104(10.64)	977(100)
Social workers/ counselors	354(36.23)	31(3.17)	89(9.11)	366(37.46)	137(14.02)	977(100)
Teachers	249(25.49)	38(3.89)	57(5.83)	417(42.68)	216(22.11)	977(100)
Government officials	196(20.06)	39(3.99)	63(6.45)	473(48.41)	206(21.08)	977(100)
The media	134(13.72)	40(4.09)	71(7.27)	450(46.06)	282(28.86)	977(100)

Note: *Your clients, in this meant if you are an employer or you are doing business and you have clients or people that buy from you.*

Per Table 21, it is evident that various categories of people got to learn of respondent status the first time through the respondent him/herself. Like other surveys, the category most disclosed to were the health care workers 694(71%), followed by husband/wife/partner 656(67.14%).

The issue of concern is that quite a high proportion of the respondent's employers 292(29%) have not be disclosed to. During the PACK project implementation, attention should be paid to the reasons and interventions for non-disclosure to healthcare workers, given the finding of a high proportion 104 (10.6%) who revealed that their health care workers have not been disclosed to.

These findings confirm the fear surrounding aspects of disclosure to employers and healthcare workers. The fear surrounding disclosure to employers is often associated with negative consequences such as denial of promotion, ridicule, denial of opportunities for further education and other work-related discrimination. However, the fear to disclose to health care workers has not been rare in previous PLHIV studies. Research is needed why a generally large proportion of clients have not disclosed to their health workers.

Table 22: Percentage of respondents that reported pressure to disclose their HIV status and their perception about confidentiality

Frequency of pressure to disclose	Frequency	Percent	Valid Percent
Frequency of pressure from other PLHIV or from groups/networks of PLHIV to disclose your HIV status			
Often	130	13.31	13.31
A few times	91	9.31	9.31
Once	54	5.53	5.53
Never	702	71.85	71.85
Total	977	100	100
Frequency of pressure from others individuals not living with HIV to disclose clients HIV status			
Often	155	15.86	15.86
A few times	120	12.28	12.28
Once	64	6.55	6.55
Never	638	65.30	65.30
Total	977	100	100
Health care professional telling other people about clients HIV status without consent			
Yes	140	14.33	14.33
No	592	60.59	60.59
Not Sure	245	25.08	25.08
Total	977	100	100
Confidentiality about medical records relating to clients HIV status			
I am sure that my medical records will be kept completely confidential	608	62.23	62.23
I don't know if my medical records are confidential	257	26.31	26.31
It is clear to me that my medical records are not being kept confidential	112	11.46	11.46
Total	977	100	100

Table 22 illustrates that 275(28%) of the respondents felt pressure from other PLHIV networks of PLHIV to disclose their HIV status. Also, 339 (34.69%) of the respondents revealed that they felt pressure from other people not living with HIV. Quite a high proportion, 140 (14%) revealed that health care workers told the respondent HIV status without the respondent consent. These findings implied two major programmatic aspects. Programs and interventions for HIV related stigma need to target the PLHIV themselves as a starting point. This will help to created awareness and the motivation for them to desist from stigmatizing others. Supported disclosure is a key element but the trust of the healthcare workers should be promoted especially with confidential records and information. This means HIV stigma reduction interventions should also target healthcare workers as a priority group.

3.11.1 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 for the first time are bound to react differently.

Table 23: Percentage of respondents who reported various reactions of people when they first knew about their HIV status

Parties	Very discriminatory	Discriminatory	No different	Supportive	Very supportive	Not applicable	Total
Your husband/wife/partner	73(7.47)	59(6.04)	161(16.48)	377(38.59)	142(14.53)	165(16.89)	977(100)
Other adult family members	37(3.79)	27(2.76)	151(15.46)	528(54.04)	128(13.10)	106(10.85)	977(100)
Children in your family	20(2.05)	14(1.43)	135(13.82)	500(51.18)	198(20.27)	110(11.26)	977(100)
Your friends/neighbors	42(4.30)	60(6.14)	170(17.40)	424(43.40)	135(13.82)	146(14.94)	977(100)
Other people living with HIV	7(0.72)	8(0.82)	128(13.10)	490(50.15)	231(23.64)	113(11.57)	977(100)
Your co-workers	5(0.51)	15(1.54)	217(22.21)	358(36.64)	105(10.75)	277(28.35)	977(100)
Your employer(s)/boss(es)	8(0.82)	4(0.41)	252(25.79)	319(32.65)	84(8.60)	310(31.73)	977(100)
Your clients	9(0.92)	20(2.05)	144(14.74)	462(47.29)	139(14.23)	203(20.78)	977(100)
Injecting drugs partners	6(0.61)	5(0.51)	94(9.62)	210(21.49)	63(6.45)	599(61.31)	977(100)
Religious leaders	4(0.41)	1(0.10)	212(21.70)	395(40.43)	115(11.77)	250(25.59)	977(100)
Community leaders	5(0.51)	7(0.72)	243(24.87)	329(33.67)	64(6.55)	329(33.67)	977(100)
Health workers	17(1.74)	4(0.41)	81(8.29)	301(30.81)	516(52.81)	58(5.94)	977(100)
Social workers/counselors	5(0.51)	7(0.72)	217(22.21)	328(33.57)	153(15.66)	267(27.33)	977(100)
Teachers	3(0.31)	9(0.92)	236(24.16)	280(28.66)	75(7.68)	374(38.28)	977(100)
Government officials	4(0.41)	9(0.92)	258(26.41)	264(27.02)	69(7.06)	373(38.18)	977(100)
The media	10(1.02)	22(2.25)	212(21.70)	212(21.70)	57(5.83)	464(47.49)	977(100)

The evidence presented in Table 23 confirms that the benefits of disclosure are much more compared to non-disclosure. Looking at most of the components in Table 24, the proportions that reacted by supporting the respondent far outweigh proportions that were not supportive at all. Overall, health care worker is reported to have supported most 301 (30%) supported and 516(52%) very supportive. The immediate implication of this data is that the PLHIV should accept the benefits of disclosure and then NAFOPHANU and her partners should devise means of making the disclosure process simple to all.

3.12: Treatment

The PLHIV stigma index is an empowering process, but the ultimate goal is to enable the PLHIV 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. In addition, treatment access experiences are linked to reproductive health services most of the time. This sub section presents the respondent's general health and support from health workers based on a categorization ranging from excellent to poor.

> *"Sometimes when we go to the health facility, they change our drugs we develop side effect like reddening of the eyes, skin rash and body aches."* [15-19 year old, in school, FGD participant, Moroto].

Table 24: Percent distribution of the respondents by self-perceived health status at the time of survey by sex.

Perceived status of health	Male n=312	Female n =665	Total n=977
Excellent	50(16%)	175(26.3%)	225(23.03%)
Very good	86(27%)	168(25.3%)	254(26.00%)
Good	103(33%)	118(17.7%)	221(22.62%)
Fair	71(22%)	184(27.7%)	255(26.10%)
Poor	2(0.6%)	20(3%)	22(2.25%)
Total	312	665	977(100%)

Table 24 generally portray that the respondent reached perceive their health status to range between fair 255(26%) to excellent 225(23%). This could be attributed to care and treatment services that have expanded up to rural and even hard to reach places. More females 175(26%) vs 50 (15%) regarded their health as excellent.

At the time of the survey almost all respondents, 98%, reported to be taking ART and the majority 869 (89.05%) confirming that they have access to ART. Overall 839(85%) and both men and women report to have had a constructive discussion with a health care professional(s) about HIV-related treatment options. Similarly, a high proportion of men and women 746(76.35%) reported to have held discussions with healthcare workers on subjects such as reproductive health. See barrier in the quote below,

> *"The doctors of here behave as if they do no't want to work but when you go to Amalele, they attend to you very fast but you have to go with money since its private"* ***(who said?)***

Table 25: Percentage of respondents who were on treatment and have had constructive discussions with health care professionals by gender

Discussion	Male	Female	Total
Had a constructive discussion with a health care professional(s) on the subject of your HIV-related treatment options?	274(87.8%)	565(85%)	839(85.88%)
Had a constructive discussion with a health care professional(s) on other subjects; respondent's sexual and reproductive health, sexual relationship(s), emotional well-being, drug use, etc?	239(76.6%)	507(76.2%)	746(76.35%)

3.13 Having Children

In the early years of the HIV epidemic and specifically before the discovery of drugs and roll out of PMTCT and later eMTCT, having children was generally scorned by many people including health workers. Given the recent trends in care and treatment, such fears are on down trend since children born of HIV positive mothers have high chances of survival if their care during pregnancy is clinically sufficient. Even those born with HIV have higher chances of living near normal life if their treatment regime is properly handled. Most respondents 799(81.8%), 246 (79%) vs 553 (83%) revealed that they have children. Most of these children were their biological children.

3.13.1 Experiences related to ART and PMTCT

All female respondents were asked if they have ever been given Anti- Retroviral treatment to prevent mother to child transmission of HIV during pregnancy.

Table 26: Percentage of female respondents who reported receiving ART and PMTCT services.

Response	Frequency(n)	Percent(%)
Yes-I have received such treatment	461	47.2
No-I did not know that such treatment existed	58	5.9
No-I was refused such treatment	6	0.6
No-I did not have access to such treatment	13	1.3
No-I was not HIV positive when pregnant	127	13
Sub total	665	68.1
Missing	312	31.9
Grand Total	977	100

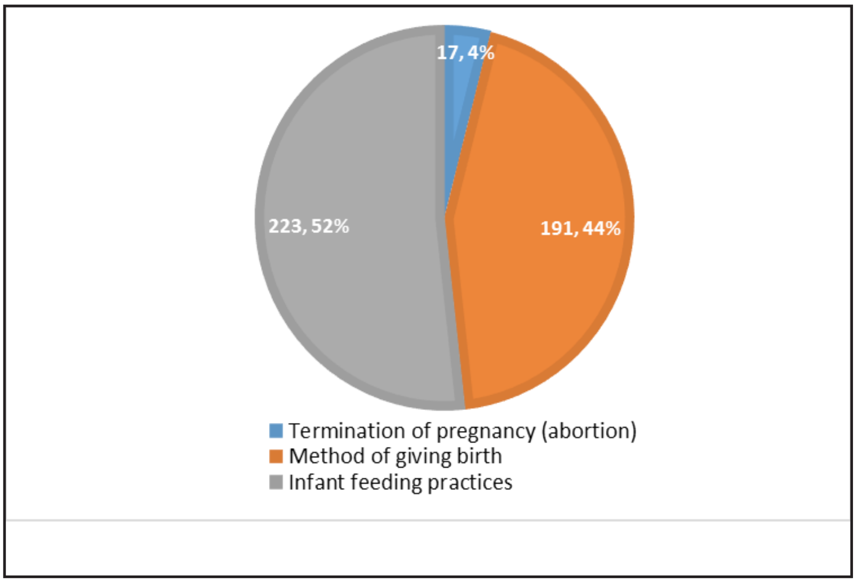
Note: Multiple response possible/allowed and cumulative totals not added.

As per findings in Table 26, majority 461 (69.3%) female respondent had received PMTCT services. Some females 58(5.9%) did not know that such treatment existed. Another proportion, 127 (13%) mentioned were not HIV positive at the time of the pregnancy. These data suggest that programs such PACK should have a sensitization component that integrates prevention services that are already nationally approved. These should be used a channel for communicating such services to improve care and treatment experiences. The success of the care and treatment programs will ultimately help to reduce HIV stigma as the PLHIV become healthy and more productive.

3.13.2 Experiences related to reproductive health rights during pregnancy

Given the sensitivity of giving birth while HIV Positive and particularly the negative attitude which both the health work force fraternity and communities had towards the female PLHIV, this section explores if there have been significant positive changes experienced by females in this regard. The question posed was if in the last 12 months, the respondents had been coerced by a health care professional in relation termination of pregnancy, method of giving birth, or infant feeding practices because of HIV status

Figure 9: Coercion by health workers on reproductive health matters;



The results in Figure 9 indicate that coercion by health workers is evident as reflected in the percentages of female respondents. Though it may not necessary be the wish of healthcare workers to enforce some medical standards especially with treatment guidelines, the issues of coercion are better explored with level of knowledge of the clients. As the PACK project commences, an increase in awareness of some reproductive health matters would certainly reduce the felt levels of coercion from health workers. What the clients might think of as coercion may actually be proven medical recommendations that they out to abide.

Table 27: Percentage of PLHIV with experiences related to reproductive health/rights by gender

Subject	Gender	Yes	No	Not applicable	Don't know
Since being diagnosed as HIV-positive, have you ever received counseling about your reproductive options?	Male	189(19.34%)	105(10.75%)	18(1.84%)	0(00%)
	Female	525(53.74%)	93(9.52%)	47(4.81%)	0(00%)
Has a health care professional ever advised you not to have a child since you were diagnosed as HIV-positive?	Male	118(12.08%)	189(19.34%)	5(0.51%)	0(00%)
	Female	192(19.65%)	438(44.83%)	35(3.58%)	0(00%)
Has a health care professional ever coerced you into being sterilized since you were diagnosed as HIV-positive?	Male	110(11.26%)	201(20.57%)	1(0.10%)	0(00%)
	Female	98(10.03%)	493(50.46%)	74(7.57%)	0(00%)
Is your ability to obtain antiretroviral treatment conditional on the use of certain forms of contraception?	Male	118(12.08%)	163(16.68%)	27(2.76%)	4(0.41%)
	Female	282(28.86%)	302(30.91%)	21(2.15%)	60(6.14%)

Table 27 above shows that more than half of the respondents, 714(73.08%), reported to have received counselling services about reproductive options after their HIV diagnosis with higher female proportions 525(53.74%) compared to male 189 (19.3%). Similarly, 310(30.91% were advised not to have children by health care professionals. The 98(10.03%) who reported coercion into sterilization, all said it was because of their HIV+ status. Also, about 400 (30.96%) reported their ability to obtain ART was conditional to certain forms of contraception. The data reveals a lot of complex issues between the health care workers and PLHIV with regard to appropriate care and components of discrimination during care seeking. This could be happening because both sides may not properly understand each other and the mistrust continues. Strategies to sensitize both the clients and health care workers need to be deployed. The starting point could be healthcare workers to fully understand the social and other care needs besides the medical services that is often given priority over other needs.

4. CONCLUSION

The magnitude of HIV stigma is generally high. From this data, aspects of internal HIV stigma such as feeling ashamed, feeling guilty, self-blame, loss of self-esteem and suicidal thoughts were reported in high proportion, implying that HIV related stigma was high in this region. In addition, external stigma that includes components such as gossip about the PLHIV, verbal insults, physical harassment and thereats were equally high. Among the external forms of HIV stigma, exclusion from activities at family level and religious activities was low but exclusion from social gathering was quite high. This evidence is collaborated by so many cases of respondents who attributed the HIV stigma of living with HIV. There are differences in the proportions by gender for instance females who feel suicidal are remarkably far higher than males.

Generally, these high levels of HIV stigma could be attributed to lower levels of sensitization, resulting into fear of getting HIV from the PLHIV and lack of knowledge about HIV transmission. Interventions related to sensitization on the causes of HIV and cascade of transmission is critical in the context of Karamoja. Both internal and external forms of HIV stigma would potentially reduce if interventions are specific to what the study has revealed in high proportions.

5: RECOMMENDATIONS

Given that PACK project is in the commencement phase, two types of recommendation have been made, these include the project specific recommendations to strengthen implementation mechanisms and broad ones that could be implemented later.
Specific recommendations:

i. Adopt a life stage approach: The data has shown that adolescent and young people have high levels of HIV stigma. The first thing is for the project to adopt the life stage approach to addressing health behaviors among these two age categories. At this stage of life, the young adults often make several life transitions that often expose them to health risks. It is therefore recommended that PACK project should adopt both healthy behavioral communication strategies and ensure health services availability at the health facilities. They healthy communication should specifically enable the young people to: adopt behaviors and seek services that help them to reduce risk exposure to HIV, (condom use, partner reduction, ART adherence) and unintended pregnancy. All young people who are PLHIV need to be helped to enroll in care, adhere to ART and belong to YPLHIV networks for psychosocial support.

ii. Promote comprehensive correct knowledge: The PACK project should promote comprehensive correct knowledge of HIV and pregnancy behaviors. Adolescent and young people live in a world of peer pressure where information is often given by friends and sometimes this information is never complete for them to make appropriate decisions on behaviors. The project should use Interpersonal communication channels to ensure that the young adults acquire and demonstrate comprehensive correct knowledge in a range of health issues particularly on HIV&AIDS, condom use, contraception, food and nutrition, safe male circumcision, plus where to obtain services

iii. Need for a specific communication strategy: There should be sensitization through mass media (TV, Radio and Posters), and through interpersonal communication channels such as community shows where stigma experience and implications are discussed. Small group discussions where myths about HIV are demystified are also needed. Within these discussions, small doable actions should be emphasized and followed up by the monitoring team. This kind of targeted sensitization should bring the HIV stigma to minimal levels and practically enable the target population access HIV and reproductive health services. To operationalise this recommendation, NAFOPHANU needs to work with her partners to develop a communication campaign to promote desirable behaviors among this target group.

iv. Train project staff in simple straight forward communication that target improvements in awareness and knowledge of HIV stigma. Given the relatively low completion rates of education, use of oral methods to pass information to general population and gatherings, would be preferred. Guided radio talk shows in the local languages should equally be used to invoke discussions then experts can address the myths over radio.

v. Encourage PLHIV active participation in implementing the program: It is generally noted that the levels of education for most of the PLHIV who were sampled was low. This justifies the need for equal participation of every one including those who are less privileged with education. This is should be fast tracked because the majority who are not educated belong to this category so, any plans to create a ripple effect for the desired behavior should consider working with them.

vi. NAFOPHANU and CSOs should detail talking points for VHTs and selected champions/ expert clients (PLHIV) to identify and visit targeted homesteads to dialogue on support issues and address possible misunderstandings that relate to HIV stigma and promote use of Health facilities, reduction of HIV, unintended pregnancies and other behaviors.

vii. The CSO in this consortium should aim to develop, implement and monitor the advocacy strategy. Advocacy should form a big part of the PACK project since some of the issues such as inadequate food, long distances to health facilities, poverty, rights abuses, should be confronted at a regional level and requires participation of several actors.

viii. In the commencement phases, PACK project should aim to increase awareness of some reproductive health matters that are quite unclear to the clients and breed mistrust between health workers and PLHIV. The channels of communication should be varied but each should reinforce to have a large effect among the target audiences. Besides, health workers need to be AIDS competent through one to one/group sessions.

ix. There is need for integration of prevention services that are already nationally approved. During the PACK project, stigma reduction communication and support services should be linked with care and support services improve care and treatment experiences. The success of the care and treatment programs will ultimately help to reduce HIV stigma as the PLHIV become healthy and more productive.

Broad recommendations

i. The National programs need to develop and sustain strategies for HIV disclosure. Through the National Stigma Policy, aspects of disclosure should be well articulated and promoted given the broader benefits of disclosure and study observation of high levels of non-disclosure. NAFOPHANU and other implementing partners need to dialogue on process and make policy recommendations for disclosure

ii. Research is needed why a generally large proportion of clients have not disclosed to their healthcare workers in the Karamoja region.

iii. Research is needed to identify myths about drinking of animal blood by PLHIV in the Karamoja region and how it has become lethal leading to death of the clients. This specific research should form a basis for clinical based study to specifically identify the causative agents within the fresh blood.

Recommendation drawn by the participants during the Karamoja data interpretation meeting

1. Activate and strengthen the PLHIV network in Napak district. The none existence of networks in this new district could be the reason why the HIV stigma in this district was comparatively higher than the rest

2. Measures to address stigma especially in schools should be put in place. These could range from awareness raising to punitive measures for the school staff or any offender within the school setting.

3. Scale up interventions to address the social cultural aspects like consuming of raw animal blood and waste through increased sensitization on the dangers of the practice.

4. Include adolescent corners at health facilities to cater for YPLHIV so that they can feel free to disclose and therefore access services & reduce stigma.

5. Include disaggregation of respondents who suffer stigma due to change in drug regimens.

Annexes

Annex1: Levels of External stigma categorized into low and high by age

	High	Low	None	Total
Youth aged 15-19 years	3	16	8	27
Adult aged 20-24 years	13	56	21	90
Adult aged 25-29 years	31	102	25	158
Adult aged 30-39 years	76	194	63	333
Adult aged 30-39 years	28	145	60	233
Adult aged 50+ years	25	72	39	136
Total	176	585	216	977

The calculation for stigma levels are based on the explanation in subsection 2.3.A
Annex 1: Proportion with high HIV stigma overall was 18%, and low HIV stigma was 60%.

Annex 2: Levels of External stigma by categorized into (Very high, High, low, moderate by age

	High	Low	Moderate	None	Very High	Total
Youth aged 15-19 years	0	13	5	8	1	27
Adult aged 20-24 years	2	45	22	21	0	90
Adult aged 25-29 years	6	83	44	25	0	158
Adult aged 30-39 years	18	143	108	63	1	333
Adult aged 30-39 years	5	107	61	60	0	233
Adult aged 50+ years	4	40	52	39	1	136
Total	35	431	292	216	3	977

The proportion with high HIV stigma was 4%, low were 44%, and moderate was 30%.

Annex 3: Level of External HIV stigma categorized into (High, low) by Districts

	High	Low	None	Total
ABIM	56	94	36	186
AMUDAT	16	65	17	98
KAABONG	17	73	18	108
KOTIDO	8	123	88	219
MOROTO	40	114	38	192
NAKAPIRIPIRIT	6	66	17	89
NAPAK	33	50	2	85
Total	176	585	216	977

Annex 4: External HIV stigma levels by District

	High	Low	Moderate	None	Very High	Total
ABIM	8	22	120	36	0	186
	5	51	24	17	1	98
KAABONG	3	61	26	18	0	108
KOTIDO	3	107	21	88	0	219
MOROTO	8	97	48	38	1	192
NAKAPIRIPIRIT	3	58	11	17	0	89
NAPAK	5	35	42	2	1	85
Total	35	431	292	216	3	977

Annex 5: External HIV stigma by Education

	High	Low	None	Total
No formal education	69	224	73	366
Primary school	78	231	70	379
Secondary school	27	115	60	202
Technical college/university	2	15	13	30
Total	176	585	216	977

Annex 6: External HIV stigma levels by Education

	High	Low	Moderate	None	Very High	Total
No formal education	14	172	106	73	1	366
Primary school	11	158	140	70	0	379
Secondary school	10	95	35	60	2	202
Technical college/ university	0	6	11	13	0	30
Total	35	431	292	216	3	977

Quotations from young people

There is heightened adherence to ART drugs no matter the schedules and other interference for the young people. See excerpts from different FGD participants;

- "Sometimes when I am not working I meet with my friend we go to the football pitch and this does not interfere with my treatment plans"

- "I do all the house chores but they do not interfere with my taking of the drugs because I know if I miss, this will lead to my loss of life, so I have to consider that first"

- "I do all the house chores in time and then at my free time, I go visiting my friends. That does not interfere with my treatment because that's what I first think of."

- "I always spend time with my family, my children and my wives (3 wives). I visit my wives and the other part of the family the grannies, aunties and look for money and this never interferes with my treatment because I know how to keep time and appointments."

- "Nothing interferes with my taking of drugs; I have to be an example to my brothers"

- "This can only happen may be when you're not feeling well that morning and you do not do the house work but still you have to take the drugs" Nakapiripit Young people [15-19, in school, FGD participants]:
- "I always get my treatment from Moroto regional referral hospital; have come to find that the health workers are very hospitable and caring sometimes they even follow up with a call. They remind you. They give you advice on how to live positively and how to adhere to drugs"

Excepts that evidence barriers to access health and social services

- "At times you can go there and meet a different counselor whom you are not used to. This may hinder me from opening up like I do with the previous one"

- "Family planning makes a woman grow fat, so women will fear losing their husbands. Even my religion (Islam) does not allow a woman to use family planning"

- "My community it does not allow someone who is HIV positive to marry, they say you will keep on increasing the number of people who are sick"

- "I don't know the culture but they do not allow a woman to eat fouls when pregnant, so in case you are HIV positive you miss out on that".

- "In my culture when the people in the village learn that you are HIV positive, they avoid associating with you, they don't allow you to go back to the village and tell you to remain in town where you got the sickness from".

- " I cannot swallow these drugs without food as the drugs are strong"

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