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STIGMA INDEX SURVEY AMONG PEOPLE LIVING WITH AND AFFECTED BY HIV IN CENTRAL AND SOUTH-WESTERN UGANDA

ENDLINE REPORT

DECEMBER 2015

NAFOPHANU

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ACRONYMS AND ABBREVIATIONS

AIDS:	Acquired Immune Deficiency Syndrome
ART:	Anti-Retroviral Therapy
CAFOD:	Catholic Agency for Overseas Development
EID:	Early Infant Diagnosis
FGD:	Focus Group Discussion
GNP+:	Global Network of People Living with HIV
HCT:	HIV Counseling and Testing
HIV:	Human Immuno-deficiency Virus
ICW:	International Community of Women Living with HIV
IDUs:	Injecting Drug Users
IPPF:	International Planned Parenthood Federation
KII:	Key Informant Interview
IPPF:	International Planned Parenthood Federation
KM:	Kitovu Mobile
LGBTI:	Lesbians Gay Bi-sexual Transgender and Intersexual
M&E:	Monitoring and Evaluation
MSM:	Men who have Sex with Men
MUREC	Mildmay Uganda, Research Ethics Committee
NAFOPHANU:	National Forum of People Living with HIV & AIDS Networks in Uganda
NHC:	St Francis Hospital Nsambya Home Care Department
NSP:	National Strategic Plan
OR:	Odds Ratio
PEPFAR:	President’s Emergency Plan for AIDS Relief in Africa
PLHIV:	People Living with HIV
PMTCT:	Prevention of Mother-to-Child Transmission
PwD:	Persons with Disabilities
SAS:	Statistical Analysis System
SPSS:	Statistical Package for Social Scientists
SRI:	Stigma Reduction Initiative
TOR:	Terms of Reference
TWC:	Technical Working Committee
UAC	Uganda Aids Commission
UN:	United Nations
UNAIDS	United National Joint Program on AIDS
UNCST:	Uganda National Council for Science and Technology
X^2:	Chi Square

ACKNOWLEDGEMENT

We the implementers of the stigma reduction project in Uganda, owe deep gratitude to CAFOD who worked diligently to develop funding proposals and approached BET 365. It is this critical technical and financial support which made the current stigma reduction project a success. We acknowledge and appreciate the coordination efforts of CAFOD Kenya team led by Ms. Mabel Kagonya Ogola and Ms. Catherine Ogola.

Alongside, CAFOD, we also appreciate the three institutions in Uganda; Kitovu Mobile (KM), St Francis Hospital Nsambya Home Care Department (NHC) and the National Forum of People Living with HIV Networks in Uganda (NAFOPHANU), whose efforts are indispensable and geared towards positive transformation and improvement of the quality of lives of People Living with or affected by HIV. We particularly want to acknowledge the three partner institution representatives; Kitovu mobile staff led by; Robina Ssentongo, Godfrey Nsamba, Evelyn Auma, Immaculate Tayebwa; NHC staff led by Dr. Maria Nanyonga Musoke, Dr. Charles Namisi, Eleanor Nakimuli Lutakome, Resty Ingabire and Dan Kalibala, as well as NAFOPHANU representatives led by; Stella Kentutsi, Cissy Namuzimbi, Proscovia Nanyanzi, Geoffrey Twine, Richard Batamwita and Sumayiah Namuwaya. They did not only create a concrete foundation upon which HIV stigma reduction project is premised but also jointly, conducted the baseline study, executed specific interventions and have finally conducted the end-line survey.

Appreciation also goes to heads of the health facilities (Nsambya Hospital and Kitovu Mobile) both at the main facilities, outreaches and within communities for their generosity that permitted the study team to hold interviews in the facility setting and their additional role in mobilizing the eligible participants. Similarly, the success of this activity, depended a lot on the supervisors and research assistants. Their collective experiences in building client relations and thereafter collecting sensitive information was indeed rewarding and greatly contributed to quality data at several intervals.

Lastly, the project implementing institutions; KM, NHC and NAFOPHANU appreciate the invaluable role of all respondents in their respective categories who shared experiences and thoughts on a range of sensitive topics. Without this exceptional voluntary participation, this End line survey would have not been successfully executed. We thank you.

Stella Kentutsi	Robina Sentongo	Dr. Maria Nannyonga
Executive Director	Executive Director	Coordinator
NAFOPHANU	KM	NHC

Executive Summary

To prove the contribution of HIV stigma reduction project to overall reduction of HIV related stigma in Central and south Western Uganda, two surveys, were conducted. A baseline survey in November 2014, followed by a series of stigma reduction interventions and an end-line survey in December 2015. The two studies were preceded by PLHIV Stigma Index study of 2012/2013 (PLHIV-SI). The three studies are guided by the Global Network of People Living with HIV (GNP+), International Community of Women Living with HIV (ICW), International Planned Parenthood Federation (IPPF) and UNAIDS tools and methodology of executing HIV stigma studies in form of an Index.

The Stigma baseline study of 2014, was ground-breaking since it was an action based study intended to bench mark project indicators in addition to informing the design of project activities intended to reduce HIV stigma specifically in Central and South Western Uganda. The end-line survey was then executed to determine the changes that the project could have directly contributed to HIV stigma reduction.

The main purpose of the two surveys was two- fold; to measure and document HIV stigma and discrimination experiences and use this evidence to formulate and implement faith context interventions (evidence –responsive strategies) to reduce HIV stigma by a magnitude of 20% in a period of one year.

Methodology

Both the baseline and end-line surveys adopted a prospective cohort design. The baseline used mixed methods approach using quantitative and qualitative approaches. The end-line survey identified the same respondents who had been interviewed during the baseline. The procedure for identification was use of health facility records. During the execution of the projects, progressive monitoring was done. The quantitative component adopted slightly modified PLHIV stigma index questionnaire, with few questions added compared to the original GNP+ index, while the qualitative questionnaire was derived from the quantitative findings that required further qualitative insights. Therefore, the quantitative component was conducted and analyzed first to inform the qualitative. The time of execution of the end-line survey was approximately two months.

Quantitative Analysis sequentially followed the eight sections of stigma questionnaire using a series of descriptive statistics and measures of associations. Before generating cross tabulations, the dependent variables of interest (Internal stigma) and independent background variables were listed. Both the dependent and independent variables were analyzed and compared with scales provided within stigma questionnaire. Since these scales were categorical, statistical tests using Pearson chi-square tests were run.

Main gap in the literature

Recent systematic reviews and project-based special studies concluded, that stigma reduction interventions were seldom and where they existed, little had been done to evaluate and document their effectiveness in addressing HIV stigma so as to form a basis for evidence based strategies. The literature available indicates that stigma reduction has been tackled through interventions based on; expansion of Anti-retroviral programs, involvement of PLHIV as adjunct care givers, media campaigns and communication for social change. The most successful interventions point to interventions at the health facility where a series of action plans are implemented by management of health facility using participatory approach that involves staff and the PLHIV. Literature on the faith context and how it relates to HIV stigma and faith context intervention is less documented. In Uganda, Canon, Gideon Byamugisha, has written theological booklets about HIV in general and religion. His focus on HIV stigma is rather based on personal lived experiences but not large scale studies. This fundamentally justified this study.

Main findings

During the end-line, a total of 1,981 respondents were reached. Of these, 540 (27%) were male, 1,440 (63%) were female and one transgender respondent. The number of respondents is less by 27 (2%) from the baseline participants calculated sample of approximately 2,000. At baseline, total of 2,018 respondents participated in the survey. Out of 2,018, 638 (32%) were male 1,380 (68%) female and one trans-gender. The loss-to follow up of 5%, was amongst the males (from 32% to 27%). Similar to the baseline, the number of respondents who were living with HIV was 1,816 (90%) and those affected were 202(10%).

Most, importantly, both internal and external stigma reduced during the intervention period by a big margin. Internal stigma reduced to 35% from 53.7%. The original project intention was to reduce HIV stigma by 20%. Out of the 8 components that measure internal stigma, self-blame was mentioned by a relatively high proportion (19.7%) within the group which had internal stigma.

Similarly, almost all components that measure external stigma equally reduced: For instance, gossip reduced to 30.6% from 47.7%, verbal insult reduced to 17% from 30.5%, and physical threats reduced to 6.8% from 14%.

There is difference in the reduction levels of stigma by gender. HIV stigma reduced more amongst the females than the males. By end-line, the proportion of females who reported stigma was 33% from 59% at baseline, while that of males reduced from 41% to 39%.

There are a number of tailored interventions that were put in place following the baseline study. The outstanding intervention was the use of faith leaders to reach out the masses in different settings and channels with messages and interpersonal communication geared toward creating self-esteem for the Person Living with HIV. This was intended to reduce internal components of stigma. Other interventions included training of PLHIV in advocacy skills in line with overcoming HIV stigma. The details of the interventions were provided in a Stigma Reduction Intervention Protocol.

Summary of main findings per thematic area

Experiences of external stigma (Stigma from other people)

Between the baseline and end-line survey, most of the components that measure external stigma reduced. For instance, the number of respondents who self-reported gossip reduced from 1,003 (47.7%) to 606 (30.59%), verbal insult, from 616 (30.5%), to 339 (17.11%) and physical threats from 284 (14.1%) to 135 (6.81%). Comparing the three surveys, 2013, 2014, and 2015, external forms of HIV related stigma are on down word trend. The noted difference is that between 2014, and 2015, a sharp decrease is observed. During the same period, the rates of HIV stigma reduction was more observed within the females.

Exclusion experiences at institutional level work, education and health services)

Generally, experience of exclusion at institutional level is very low for instance, the proportions that reported such experiences ranged between 0.6% to 4%. At end-line, the comparatively high exclusion at work places reported at baseline reduced from 7% to 4% by end-line. This component measured those who had been refused employment or a work opportunity. Both at endline and baseline, the outstanding reasons for exclusion were related to having HIV.

Experiences of internal stigma (feelings and fears about self-due to HIV status)

Within all the categories of respondents, HIV stigma reduced between the end-line and baseline surveys. Internal stigma reduced by 33%. Generally, respondents who were not fearful of HIV related stigma increased between the baseline and end-line from 1,309 (64.9%) to 1,524 (76.9%).

The following feelings and fears were reported; blame self (30%), feels ashamed (19.6%), blames others (18%), have low self-esteem (13.9%), feels guilty (12.7%), feels sinful (8.8%).

Respondent's reactions to various forms of stigma

Following the actual experiences or anticipated forms of either external or internal stigma, respondents usually develop a reaction formation, i.e. they decide to do certain actions. Generally, the negative, poor health behaviors have reduced between the baseline and end-line surveys. For instance, the proportion of those, who made a decision to avoid social gathering reduced from 9.4% at baseline to 5.4% at end-line. The proportion that decided not to have more children from 576 (41.1 %) to 604(30%), not to have sex reduced from 387(28%) to 308(15%) not to get married from 363 (26.3%) to 290 (14.6%) and not isolated self from family and friends from 75(5.4%) to 48(2.4%)

Respondent knowledge and practices regarding HIV & AIDS Rights, law and policies

Across the two surveys, there was varying awareness and knowledge levels of respondents about HIV UN declaration on HIV, laws and policies which were reported to be above average. Similar to the baseline, the proportion of females who had ever heard of the declaration of Commitment on HIV&AIDS were more 1,067 (76%), compared to 333(24%) males at end-line. At baseline the females were 1,004 (72%), whereas the males were 376 (59 %). During the end line, more than 63% of the male were not aware, had not read the policies or even discussed them.

Revelations of effecting changes

Integral to the discussion of an empowered PLHIV is the issue of effective changes. Typically, an empowered PLHIV is expected to have the skills and a character to protect and or influence situations of HIV stigma. The proportion of those who effected changes (confronted, challenged or educated someone who experienced and or/ discrimination from other people) decreased from 794 (39%) to 658(33%). More females reported to have effected changes at end line 440(66.7%) females versus 218(33%) compared to the males 525(38%), females and 269(42%) at the baseline. The probable reason why men participation is less could explained by their availability during the training which the project used to intervene on issues of empowerment.

Recommendations

i. The project recognized the key role of the faith leaders in inspiring the communities to overcome HIV stigma. It is therefore recommended that close collaboration with the faith leaders and communities be maintained. The faith community have an edge in mobilizing the communities for positive changes to reduce HIV stigma in the project districts and elsewhere.

ii. Refresher trainings and reflective sessions on the tasks expected of the faith leaders need to be conducted. Where possible, faith leaders at different levels need to be supported to draw action plan for continuity of HIV stigma reduction interventions as a priority.

iii. Where possible and if resources allow, the number of faith leaders should be increased to create a ripple effect within several districts. This will however, require mobilizing, training and agreeing on the tasks to execute by the faith leaders.

iv. Partners (NHC and KM) are asked to continue mobilizing resources for a comprehensive stigma reduction campaign targeting multiple players. This will increase the results gained in the last one year of the project.

v. NAFOPHANU as a key player that brings together PLHIV networks in Uganda, is asked to widely disseminate the findings of the SRI interventions to Uganda AIDS Commission, line ministries, Civil Society and UN agencies, AIDS Development Partners, PLHIV networks, the general public, the academia and press. This will help to integrate faith contextual interventions in on-going stigma reduction interventions in Uganda.

vi. HIV Program with a focus on HIV stigma reduction should place PLHIV at the center of SRI through training, expanding expert clients' roles at health facilities and in communities

vii. The Uganda AIDS Commission is specifically asked to continue embracing faith leaders and to further provide strategic level guidance on how to promote and increase the participation of faith leaders in HIV stigma reduction country wide

CHAPTER 1: INTRODUCTION

1.1 The report in summary (Background)

The report presents comprehensive results from a baseline study conducted as part of the HIV Stigma Reduction Initiative (SRI). With intent to provide the project context, specific information in introductory section is provided to highlight the project background (see section 1.3 for a brief on the project). The baseline was conducted jointly by three Institutions, namely: Kitovu Mobile (KM), St Francis Hospital Nsambya Home Care Department (NHC) and the National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) in Central and South Western Uganda.

The end-line study followed the same methodology as the baseline. The two studies were part of the stigma reduction initiative to determine the changes after an intervention of stigma reduction using the faith leaders. This baseline survey provided the baseline situation upon which HIV stigma reduction interventions were based. This is in addition to providing the bench mark upon which progress on specific activities and results would be measured. Whereas the end-line provided comparative data to assess the changes that might have occurred during the project period. The stigma reduction project generally compliments the National HIV & AIDS response as it addresses stigma and discrimination, a key challenge to the National HIV response which has been reported in several national documents such as the National Strategic Plan 2016-2020, the National HIV Prevention Strategy 2011-2015.

In 2013, a similar study was conducted by NAFOPHANU among People Living with HIV in registered district-based networks including Central and South-Western Uganda. Therefore, this baseline adopted similar methodology and tools as developed by GNP+. The current HIV stigma reduction project intends to; measure HIV stigma, implement stigma reduction interventions and evaluate outcomes.

1.2 Uganda’s context

As a response to recent trends in HIV epidemic in Uganda, the Ministry of Health in Uganda has adopted several HIV care and treatment strategies and policies, including; the National HIV Counseling and Testing (HCT) scale-up, the Test and Treat policy for less than 15-year-old, the PMTCT Option B+ for all HIV positive pregnant women and Early Infant Diagnosis (EID) for the newborns Born with HIV positive mothers. These strategies and policies imply that more PLHIV will be identified and will need both care and treatment. This is confounded by a rapidly growing population (at a rate of 3.4 % per year), a rising incidence of HIV in the general population, with an estimated 135,000 new HIV infections a year. Therefore, the national burden of HIV will continue to rise with an increase in demand for care and a further increase in the unmet need for care and treatment.

Although access to ART in Uganda has increased over time, with a lot of effort from Presidents Emergency Plan for AIDS Relief in Africa (PEPFAR) and other organisations in the provision of HIV & AIDS care and treatment services, the country still lags behind the universal access target of 80% by 2015 as articulated in the National

Strategic Plan [NSP] 2010/11 – 2015/16. Approximately only 60% of eligible clients are actually accessing ART services.

Among the current obstacles to care and treatment, is HIV-related stigma as documented in several reports. Stigma and discrimination devalue PLHIV. The Uganda National HIV Prevention strategy (2011-2015) identifies stigma as a key driver of the epidemic and indicates that all efforts should be made to eliminate stigma and discrimination by 2015. With the anticipated rise in numbers of PLHIV, there will probably be a corresponding rise in numbers of stigmatized persons with HIV, which will further drive the HIV epidemic higher. This makes interventions related to HIV stigma reduction a pillar in the national response.

It is also important to note that manifestations of HIV-related stigma and discrimination hase changed over the last 20 years, due to massive sensitization programs, direct involvement of PLHIV in HIV advocacy campaigns to reduce stigma and existence and access to anti-retroviral therapy. In 2013, Internal stigma was reported to be 50% from a population of PLHIV in registered HIV networks in Uganda. Internalized stigma is now more pronounced than other forms of HIV-related stigma. Results from the 2013, Uganda PLHIV stigma index, recognized this phenomenon and made a specific recommendation to tackle internalized stigma thorough empowerment of the PLHIV. It is assumed that once PLHIV are empowered to overcome situations of internal stigma, other forms of stigma are unlikely to occur.

1.3 Faith context and stigma reduction strategies

The Faith setting in Uganda is known to offer various services including: health, education, livelihoods, welfare and humanitarian responses, youth work, broadcasting and media, and a variety of catechetical initiatives. It also includes the worship and social environments provided by the local faith community. This initiative mobilizes faith leaders to develop effective strategies to tackle stigma experienced both in the broader and faith-linked contexts. The implementing institutions provided appropriate training to the faith leaders and systematically supported them to develop responsive stigma reduction strategies to address findings from the baseline survey. Strategies were adjusted to accommodate additional considerations from the interim survey. Periodic learning and exchange meetings within and between participating partners informed further development and refinement of the project:

This choice of faith based leaders is supported in current literature and particularly in regard to empowering the PLHIV. They play critical roles in the fight against stigma. (Williams 2011, Warren Parker et al, 2005, Kiwanuka, 2012).

The project was specifically intended to promote HIV prevention and treatment services by including evidence-based stigma reduction in HIV programmes in Uganda. This project hoped to strengthen Government led initiatives on expanding prevention, and treatment services.

The project broad activities directly aimed at measuring and documenting HIV-related stigma and discrimination experiences among PLHIV and those affected by HIV, implement evidence-responsive strategies with the aim of reducing HIV-related stigma and discrimination in the population and to increase the voices of PLHIV to influence partners at all levels for relevant policy implementation to reduce stigma. The project targeted to reach a total population of 73,152 beneficiaries, comprising of 5,401 men, and 15,214 women directly, while 52,537 would indirectly benefit from the interventions. To reach the beneficiaries, the project planned to mobilize faith leaders to develop effective strategies to tackle stigma experiences both in broader and faith-linked contexts as agents of change.

1.4 Funding and implementing partners

The Catholic Agency for Overseas Development (CAFOD) is the official overseas development agency of the Catholic Church in England and Wales. Established in 1962, CAFOD has more than fifty years of experience in sustainable development and emergency response, and more than thirty years of experience in HIV and AIDS response. CAFOD was supporting a one & half year stigma reduction intervention in catchment areas reached by KM and NHC of Uganda. The SRI was funded by Bet360 through CAFOD.

This project was implemented by two health services provider institutions; Kitovu Mobile (KM): KM reaches out to clients in the areas of Masaka, Lwengo, Kalungu, Rakai and Sembabule districts. Approximately 3,000 individuals reached by KM are on ART,while over 8,000 clients are on ART at Nsambya Home Care (NHC) services, Kampala, Wakiso and Mukono districts.

NAFOPHANU which serves as the technical partner on the project was established in May 2003 with a country wide mandate as an umbrella organisation for People Living with HIV&AIDS to provide systematic and all inclusive coordination structure for PLHIV networks, associations and support groups. NAFOPHANU envisions a population of PLHIV able to live a quality and productive life in a sustainable manner while the mission is to position and coordinate the efforts of PLHIV networks in order to contribute significantly to the national HIV&AIDS response. Membership encompasses networks of PLHIV at national and district levels. Other partnership in the project include; the Uganda AIDS Commission, religious institutions and PLHIV networks.

1.5 Project Results (Outcomes)

There are three intended results (outcomes) for the stigma reduction project.

i. Measured and documented HIV Stigma and discrimination experiences

ii. Reduced HIV stigma and discrimination through evidence-responsive strategies. (20% reduction from the current 50%)

iii. Increased voices of PLHIV to influence partners at all levels for relevant policy implementation that reduce stigma.

The details of the activities are in the main project document.

1.6 Purpose of the baseline survey

In order to achieve result area 1: A baseline survey was conducted to establish current indicator levels within specific domains of HIV stigma among PLHIV and those affected. (This provided the baseline situation before intervention). This baseline was used to refine targets, track and measure performance towards the attainment of the HIV evidence-based stigma reduction project. The end-line is therefore a follow up to see the changes that could have happened in the targeted communities and districts.

1.7 Specific Baseline survey objectives

i. To measure and document HIV Stigma and discrimination related experiences in Central and South West of Uganda
ii. To describe the stigma and discrimination as perceived by PLHIV within a faith-based context
iii. To document and share evidence to support advocacy on key HIV policy issues in resource-poor settings

1.8 Scope:

Geographical scope: The catchment areas of NHC and KM targeting specific beneficiaries. The catchment areas included areas where both Kitovu Mobile and Nsambya Home Care. For Kitovu, the study covered; Masaka, Kalungu and Sembabule; for NHC, the baseline covered Kampala, Wakiso and Mukono.

Time scope: Experiences of stigma were measured based on the last one year (2014-2015 before the interviews.

Content scope: The content focused on lived and anticipated experiences of stigma as a person living with or affected with HIV. Other key areas covered included; knowledge about rights, laws and policies, experiences of testing/diagnosis disclosure and confidentiality. The last section specifically inquired about the challenges and problems that the faith community faces as regards their responses to stigma and discrimination.

CHAPTER 2: METHODOLOGY AND APPROACH

2.1 Study design

The end-line and initial baseline surveys adopted a cohort design, and defined progressive data collection aspects, that added a longitudinal component, integrated at specific intervals. Within this cohort design, mixed methods of data collection were used at baseline were repeated and end line. During the first phase, a desk review to guide sample size determination and inclusion of major content topics was done. This was followed by a cross-section survey were individual interviews with PLHIV and affected persons were conducted. This phase was mainly quantitative, only few individuals who had reported extreme experiences of HIV stigma and discrimination were interviewed as case studies.

Based on this phased approach, further information was collected during round talks. At the time of developing specific HIV stigma reduction interventions, the study design allowed for collection of further qualitative information from key informants and other high level personalities and agencies that deal with HIV and AIDS. These qualitative methods included Focus Group Discussion (FGDs), key informant interviews and round talks. The final information was generated with the hope of generating information needed for intervention design and policy advocacy issues.

Quantitative data was collected using the modified, standard PLHIV Stigma Index variables. Very few variables to suit selected performance indicators were added to the standard stigma index tool. The qualitative tool for case studies was developed by the social worker team to generate desired qualitative information. The end-line survey which is part of the stigma reduction project will use same methods and study design.

2.2 Target population

The end-line survey targeted respondents who had participated in the baseline survey since most of these respondents had equally directly benefited from the interventions through the project implementation year. The target respondents for this survey were PLHIV and those affected by HIV from both rural and urban settings. All respondents were 18 years and above and were either members receiving HIV care, treatment and other services from or care takers (affected persons) of person receiving the mentioned services from KM and NHC. The respondents included women, men and young person’s representing the general population. The study also targeted the key Populations (Uniformed Personnel, Truck Drivers, Sex Workers, Injecting Drug Users (IDUs), Men who have Sex with Men (MSM), Persons with disabilities (PWD) fishing community, refugees and Lesbians, Gay Bisexual Transgender and Intersexual (LGBTI).

2.3 Sample size estimation

The baseline pre-determined a sample of 2,000 respondents including the infected and affected. Both KM and NHC contributed equal proportions 50% of the respondents. For the quantitative component 80% of the respondents were registered clients of the two implementing partners (Kitovu Mobile and St Francis Hospital

Nsambya Home Care). Whereas 20% were treatment supporters registered with the two implementing partners. The 80% proportion was minimum proportion for inclusion and is a requirement set by the GNP+.

Sample size formula

Key assumptions that were considered in determining the sample size

a. The sample size calculation was based on NAFOPHANU study with 50% internal stigma,
b. A reduction of stigma in 18 months period of 20% (Horizon Mombasa Kenya)
c. Study power of 80, non-respondent rate 10%, lost to follow up of 10% in 11 months and design effect for variation in study sites/urban/rural issues.
d. The a cohort study design with a component of follow up with a major component of descriptive and outcome analysis
e. The primary outcome variables are categorical/ proportional
f. The sample size is consistent with the primary objective of the study: Baseline proportional values
g. The response rate was likely to be high at 90%, and lower loss to follow up of 10%: Evidence from NHC about retention in care.
h. The sample size was based on primary beneficiaries; indirect beneficiaries are more to do with impact of interventions at community level.
i. From literature, the prevalence of internal stigma was 50% amongst PLHIV. This formed the basis for our sample size determination

2.4 Sampling methodology

Before the baseline study, the two Organisations (KM and NHC), agreed to contribute equal numbers of respondents in order to obtain the 2,000 sample. To determine specific samples, at either KM or NHC, proportion at the various levels were used to choose the final respondents. The screening variables, that determined proportions included; sex, age, district, HIV status and members in Key population categories. From the total population of 2,000, required, approximately 1,700 (85%) were PLHIV and 300(15% were in the category of affected (treatment supporters). Several techniques were used to identify eligible respondents including key populations. The end-line was therefore supposed to trace the same baseline respondents to measure the changes.

The standard stigma index questionnaire, required specific categories of population to be included in the stigma studies. Therefore, the study team used the 2012/13 PLHIV Stigma Index to pre-determine the proportion of key population to include in the study.

2.5 Selection of respondents (pre-selection)

The two implementing partners had list of registered clients in their databases. A listing of updated clients was requested by the research sampling team prior to field activity. A set of screening information was agreed to enable sampling of eligible members. An example of screening information was ART status, residence, occupation, length on ART, age, sex, marital status. Given this screening information, the data management team categorized eligible respondents and proportionately determined the numbers.

The end-line study, participants were those, who had previously participated in the baseline. The program team of NHC and KM kept listed of the participants at baseline. It is these persons that were followed and re-interviewed. During business, a computer program was used to randomly select client numbers of eligible respondents by respondent category. All listed client numbers were given to the project coordinators to mobilize the respondents systematically and schedule ad-hoc appointments, preferably during refill dates where possible and for those whose appointment dates was within the study interview period and were necessary were invited and compensated for transport.

2.6 Measurement

The measurements were based on validated scales of Stigma Index standard methodology developed by ICW, IPPF, GNP+ and UNAIDS. The scales were applied on the following study section: 1) experiences of stigma and discrimination and their causes, 2) access to work, health and education services, 3) internal stigma, 4) rights, laws and policies, 5) effecting change, 6) HIV testing and diagnosis, 7) disclosure and confidentiality, 8) treatment, 9) having children and 10) problems and challenges.

2.7 Study tools

The survey adopted the PLHIV stigma index tools that were developed by UNAIDS, ICW, IPPF and the GNP+. Precisely the tool measures and detects changing trends in relation to stigma and discrimination experienced by PLHIV. Additional components of the tool address the niche perspective of faith. Very few adjustments were made to the standard stigma index tool to address the local context.

Following tools refinement, the tools were translated into one local language - Luganda which is the most commonly used language in the study districts. Almost all the target respondents were conversant with Luganda.

2.8 Data collection

2.8.2 Quantitative and Qualitative primary data collection

Before data collection, a pre-test was conducted. Quantitative data from all eligible respondents was collected electronically. A hand held phone HUAWEI Ascent P7 series was configured to the final electronic stigma index questionnaire. This technology was quite familiar with most research assistants and no specialised training was required. Data capture was instant as well as submission to secured server. Data collection involved conducting side-by-side interviews with the eligible survey respondents. All completed and reviewed entries were submitted to a central server. The qualitative data from the cases identified was collected manually on hard copies.

Data was collected by a team of competent interviewers many of them being PLHIV. Selection to participate in the study data collection was competitive and merit-based as adverts were run on notice boards of the NHC and

KM and on social media. Selection of potential candidates was done and formal interviews were conducted with the best being selected. They were then trained for 4 days and one day was used to pre-test the tool. This ensured mastery of the English and Luganda translated questionnaire and all the study procedures. In total 60 interviewers were trained but only 50 were finally recruited to collect data. On average data collection lasted 14 days for each institution.

The data collection teams were supervised by a dedicated team of supervisors. Every 4 interviewers were allocated a supervisor, who worked closely with the team all through the day in the field. Another level of supervision and quality control was done by rolling quality controller besides the project coordinators who mobilized the respondents. Additionally senior project team members routinely visited the data collection sites as part of their oversight roles to ensure maximum quality of data collection. Generally, there were more female respondents and therefore, more females were recruited and retained for female interviewers. As part of the quality assurance plan, all data was collected on phones and no data was submitted before team supervisor looked at the completed form.

2.9 Data management, processing analysis

2.9.1 Quantitative

All quantitative data was retrieved from the central server through a process called merging. The merged data was cleaned for any logical consistence. This stage was followed by generation of descriptive tables depending on the variable types. A series of descriptive statistics with specific disaggregation were run. During cross tabulations, crude odds rations (O.R) were generated. For comparison purposes, the chi square test (χ^2) and the Fisher's exact test were used for categorical variables. Multivariate logistic regression model was developed to examine factors independently associated with respondents who had internal stigma. Demographic variables that showed an association at the $p = 0.05$ level were incorporated in the final model. All analyses were conducted using SPSS Version 15

2.9.2 Qualitative data

During baseline, qualitative data was collected along relatively structured themes. This made it easy to manage it in MS-Word. The responses were typed along the thematic areas. During initial coding of the data, key supporting quotation were noted and later retrieved to back strong arguments in the write-up. The analysis approach was mainly inductive. However, during the end-line, a technical decision was made not to collect qualitative data immediately after the quantitative. Another small qualitative study will be done, in a few months after the end-line. Additionally, during the project implementation, pieces of qualitative data were collected to inform key decision about the intervention. This data is reflected in the routine monitoring data for the project.

2.9.3 Defining the depending variables (internal stigma)

To arrive at meaningful conclusions and guide the process of intervention design, the original data sets were sub categorized in several formats to generate cross-tabulations and statistical values. The dependent variable for internal stigma were determined. For every respondent who responded yes to any answer option among the eight item scale that measures internal stigma was considered as having stigma. Stigma was later categorized in lower and higher stigma level sub scales (Any one which picked 4 items out of the 8, was categorized as low, where as those who picked more than 5, were categorized as high. The scales were later sub categorized into lower, moderate high and very high. i.e. any respondent who chose two options off the 8 items scales was categorized as lower, those who picked 4 (moderate), 6 (High), all the 8 (Very high). This process was done, with consent of representatives of senior project team members. At final analysis, the defined stigma (dependent) was assessed against other relevant background variables to determine the associations.

During analysis of quantitative variables, it ensured that statistical decisions were based on counts within categories (females. males but within categories). This consideration of percentage counts within categories was made because the females (1,440 were more than the males 540).

2.10 Survey Limitations

It was generally challenging to identify and reach out to the key population categories. This has affected the pre-determined sample size for the specific categories of key populations. (details in section 7)

2.11 Ethical approval

Owing to the fact that this survey is in a series of Stigma index survey, the principal investigator applied for an amendment and continuation application of the original stigma survey. This was done and ethical approval was granted by the Mildmay Uganda Research and Ethical Committee (MUREC). Mildmay is a center engaged in HIV, care, treatment and training of health workers in HIV & AIDS services and research. During the study all ethical practices were adhered too including verbal and written consent before any study proceedings. The guidance from GNP+ recommends use of initials on the consent forms to maximum private information and not to reveal the details of participant. Even those who wish not to have their initial but consent are considered, this considered as verbal consent.

2.12 Compensation

Owing to transport challenges that were anticipated to be incurred by the interviewees as way to have privacy locations, the survey managers agreed to have standard fee of Uganda shillings five thousand (5,000/= an Equivalent to 1.5 US Dollars) per participant interviewed with the catchment of KM and (10,000/= Equivalent to 3 US Dollars) for participants within the catchment of NHC. This is slightly above 1 Us dollar. The purpose was purely to cover transport compensations. A provision for compensation is provided for in the PLHIV Stigma Index User Guide.

2.13 Study management and implementation arrangements

At the Agency level, a Technical Working Committee (TWC) whose membership comprised of representatives from the three institutions (KM, NHC and NAFOPHANU) was formed. The TWC roles were providing technical guidance, working closely with project managers and field teams. The TWC also provided over sight functions. Members of the TWC partly participated in the training of research assistants. Several meetings focusing on the technical issues were conducted and consensus reached.

Below the TWC, NAFOPHANU secretariat core staff whose main role was, to execute all the survey processes such as; registering the study with relevant ethical bodies, training data collectors and supervisors, overseeing data collection through the team of PLHIV and affected, data management and writing the technical report as well as reporting. During the reporting phases, the NAFOPHANU team consulted regularly with the project team leaders of NHC and KM, social workers attached to the project and other senior experts at the three institutions.

2.14 Summary of HIV Stigma interventions implemented

The SRI project intervention was developed in separate document called the Stigma Intervention protocol. The main component of stigma reduction focused on reducing internal forms of stigma. The approach to the stigma reduction was the use of faith leaders as agents of change in their respective communities. The use of faith leaders had been applied in Kenya, Zambia and Ethiopia in HIV stigma related project. Following the refinement of the stigma reduction protocol for Uganda, over 60 faith leaders were trained as agents of change. The trainings lasting 4 days were conducted and repeated at least twice with the same faith leaders. They were later assigned tasks to embark on sensitizing communities and their followers at any time of their convenience in the regions of their jurisdiction.

To ensure that the faith leaders executed the task agreed upon, the team of social workers and M&E attached to the project participated technical in technical reviews and regular monitoring and supervision to ensure that the agreed upon task were executed.

Additionally, over 500 PLHIV were trained twice in advocacy skills to generally gain self-confidence and prepare them to avoid for issues at structural barriers that contribute to HIV stigma. (the trainings lasted two days each). The training was practical and based on key issues affecting the PLHIV and particularly access to care and treatment services.

Generally, the results gained over the last one year during the implementation of the SRI are attributed to these interventions. (A separate document that provides details of the full implementation guidelines is available at either NHC or KM).

CHAPTER THERE: RESULTS

The results are presented according to the eight sections within the standard HIV stigma reduction questionnaire. Every section is introduced to provide a fair understanding of content issues within the section. The report uses tables to summarize the information in a condensed reader friendly format. Key results from the baseline are referred to compare the changes that potentially occurred after the interventions that were implemented.

SECTION 1: BACKGROUND CHARACTERISTICS OF RESPONDENTS

3.1.0: BACKGROUND CHARACTERISTICS OF RESPONDENTS

This section presents the background characteristics of the respondents. During the end-line, a total of 1,981 respondents were reached. Of these, 540 (27%) were male and 1,440 (63%) were female. The number of respondents is less by 38 (2%) from the participants at the baseline. At baseline, total of 2,018 respondents participated in the survey. Out of 2,018, 638 (32%) were male and the rest 1,380 were females. The loss-to follow up of 5%, is more amongst the males (from 32% to 27%).

The proportion of females reflected in this study is similar to many other studies in Africa conducted on HIV stigma studies that have found almost three times the females. (Holzemer, 2007), Zimbabwe National Network of PLHIV, 2014, Uganda Stigma Index Survey, 2013 and NEPHAK (2011).

Table 1: Background characteristic of the sampled respondents by sex

Background characteristics	Male		Female		Transgender		Total	
	n	%	n	%	n	%	n	%
Refugee or asylum seeker	4	26.67	11	73.33	0	0.00	15	0.8
Internally displaced person	15	36.59	26	63.41	0	0.00	41	2.1
Migrant worker	111	65.29	59	34.71	0	0.00	170	8.6
Injecting drug user	1	16.67	5	83.33	0	0.00	6	0.3
sex worker	0	0	26	100.00	0	0.00	26	1.3
Gay or lesbian	0	0	0	0.00	0	0.00	0	0.0
Transgender	0	0	1	100.00	0	0.00	1	0.1
Prisoner	40	58.82	28	41.18	0	0.00	68	3.4
General population	352	21.26	1,304	78.74	0	0.00	1,656	83.5
Total	523		1,460				1,983	
Age								
Youth aged 15–19 years	26	44.83	32	55.17	0	0.00	58	2.93
Adult aged 20–24 years	31	30.39	70	68.63	1	0.98	102	5.15
Adult aged 25–29 years	44	23.53	143	76.47	0	0.00	187	9.44
Adult aged 30–39 years	127	21.67	459	78.33	0	0.00	586	29.58
Adult aged 40–49 years	167	29.30	403	70.70	0	0.00	570	28.77
Adult aged 50+ years	145	30.33	333	69.67	0	0.00	478	24.13
Total	540	27.26	1,440	72.69	1	<1	1,981	100
Marital status								

Background characteristics	**Males**		**Female**		**Transgender**		**Total**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Married/cohabiting and husband/wife/partner is currently living in household	313	57.96	472	32.78	0	0.00	785	39.63
Married or cohabiting but husband/wife/partner is temporarily living/working away from the household	11	2.04	60	4.17	1	100	72	3.63
In a relationship but not living together	24	4.44	147	10.21	0	0.00	171	8.63
Single	111	20.56	236	16.39	0	0.00	347	17.52
Divorced/separated	54	10.00	189	13.13	0	0.00	243	12.27
Widow/widower	27	5.00	336	23.33	0	0.00	363	18.32
	540	100	1,440	100	1	100	1,981	100
Type of employment								
In full time employment (as an employee)	126	23.33	159	11.04	0	0	285	14.39
In part-time employment (as an employee)	43	7.96	43	2.99	0	0	86	4.34
Working full time but not as an employee	53	9.81%	109	7.57	0	0	162	8.18
Doing casual	83	15.37	128	8.89	0	0	211	10.65
self employed	199	36.85	785	54.51	1	100	985	49.72
Unemployed and not working at all	36	6.67	216	15.	0	0	252	12.72
	540	100	1,440	100	1	100	1,981	100

Source: Stigma Reduction end-line index 2015/2016.

The first section on categorization of respondents, the number exceeded the total sampled because of a few cases that reported to belong to more than one category. For instance, one could report to belong to sex worker as well as migrant worker or others. This was a multiple response category.

3.1.1 Sub categories of the Target Population

As shown in table 1, majority1,656 (83.5%) of the respondents belong to the general population. This is followed by migrant workers 170 (8.6%), prisoners 68 (3.4%), internally displaced persons 41 (2.1%) and sex workers 26 (1.3%). Between the baseline and end line, there are variations in some categories, for example at baseline, the proportion of sex workers was (49; 2.3%), and that of general population was 1,681 (79.8%). As presented in 3.1.0, out of the 2,018 respondents at baseline, only 1,981 were traced successfully and interviewed for end-line.

3.1.2 Age categories

There are very minor variations between the baseline and end line proportions with respect to age categories. This is because the same population was reached during both surveys. However, the age group 30 and above represented three quarters of the study population 1,634 (82.5%) with the majority being between 30—39 years, 586 (29.58%) while 570 (28.77%) belonged to the 40—49 years' age group, and 478 (24.13%) were 50+ above. Considering age groups from 15 to 29, the proportions of males and females are almost similar with 101 (18.70%) and 347 (17.01%) (24.1%).

3.1.3 Marital categories

Table 1, also shows the proportions of the marital status which was almost equally distributed amongst the married and non-married respondents: 1,028 (51.89%) were married or staying with a person considered to be a wife/ husband and 953 (48.11%) were not married (single, divorced, widow/widower). Although there are no major variations between the end line and baseline survey, there were several differences between the males and females. For instance, there are more females in relations but not living together 147 (10%), Vs 24 (5%) males, more separated divorced females, 189 (13%, VS 59 (10%) males, and more widowed females 336 (23%), VS 27 (5%) males. It is also important to note that the proportion of females who are in relationship and living with the partners reduced from 13% at baseline to 10% by end line.

3.1.4 Employment status and forms

According to Table 1, a big population reported to be employed 1,729 (87.28%). Among the employed population, the majority 985 (49.72%) were self-employed (self-employment includes those involved in farming): there were fewer self-employed males 199 (36.85%) compared to the 785 (54.51%) females. However, in the category of un employed and not working at all, there are fewer males 34 (7%) compared to females 216 (15%). The proportions for end-line and baseline are almost the same. The main noticeable difference is that by end-line the proportion of males in fulltime employment as employees, 126(23%) increased from 119(18%) while that of females decreased from 189 (13%) to 159 (11%).

3.1.5 Level of education

Education influences many other variables with regard to health and social economic issues including self-awareness and discovery. In this study, education attainment was broadly categorized into four categories. (No formal education, primary education, secondary school, technical college/university)

Table 2: Level of education attainment of respondents by sex

Level of education	Male		Female		Transgender		Total	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
No formal education	247	45.74	691	47.99	0	0	938	47.35
Primary school	147	27.22	412	28.61	0	0	559	28.22
Secondary school	89	16.48	237	16.46	0	0	326	16.46
Technical college/university /seminary	57	10.56	100	6.94	1	100	158	7.98
Total	540	100	1,440	100	1	100	1,981	100%

Source: Stigma Reduction end-line index 2015/2016.

According to table 2, results indicate almost half the respondents, 1,043 (52.65%) had some form of formal education. A slightly higher proportion,(47.99%) of females compared to 45.74% males had not attained formal education. Generally, 559 (28.22%) reported to have attained primary education, but still with slight differences in proportions of females (28.61%) compared to males (27.22%). Generally, the proportion of males with formal education 54% is slightly high than the females 52%. This is similar to attainment of technical/university education where the proportion of males 57 (10.56%), is slightly higher than the females 100 (6.9%).

3.1.6 Household average income

Household income is yet another key variable which has often been reported in many public health studies and therefore equally important in this stigma reduction. This variable referred to income accruing from all member of the household who were earning or getting some cash returns or remittances. The results were computed for a monthly average.

Table 3: Distribution of respondents' average households monthly income

Monthly Income (UGX)	n	%	n	%
	End line		Baseline	
1-50,000	345	17.42	166	8.2
50,001-100,000	340	17.16	74	3.7
100,001-150,000	205	10.35	101	5
150,001-200,000	204	10.30	40	2
200,001-300,000	311	15.70	125	6.2
300,001-400,000	138	6.97	106	5.3
400,001-500,000	116	5.86	82	4.1
500,001-600,000	62	3.13	108	5.4
600,001-700,000	43	2.17	14	0.7
700,001-800,000	30	1.51	72	3.6
800,001-900,000	26	1.31	30	1.5
900,001-1,000,000	45	2.27	61	3
Above 1,000,000	108	5.45	996	49.4
No income at all	8	0.40	43	2.1
Total	1,981	100.00	2,018	100

Source: Stigma Reduction index surveys: 2014/2015 (baseline) and 2015/2016 End-line

In Table 3, results compare the baseline and end-line reported average monthly incomes. During baseline, there were some gaps in collecting sufficient information about this variable. But, at the end-line, more attention was paid to it. So the variation seen could be due to an improvement in the data collection standard specific to this variable. By end-line, the 311 (15%) of households had an average monthly income of 200,000 to 300,000. Generally, 70% of the households have average income below 300,000 Uganda shillings.

3.1.7 Access to three meals a day

Access to three meals a day was a proxy indicator to indirectly measure poverty and nutritional aspects at household level. Anyone who reported to have had access to three meals a day (breakfast, lunch and dinner) was assumed to have enough food. This was computed in days within a month the household did not have enough food and reported as such:

Table 4: Number of days in the last one month when a member of their household did not have enough food

Number of days	n	%	n	%
	End line		Baseline	
1-7 days	380	19.18	329	16.3
8-15 days	109	5.50	188	9.3
16-21 days	34	1.72	53	2.6
22-30 days	415	20.95	417	20.7
Had enough food	1,038	52.40	1,031	52.4
Total	1,981	100.00	2,018	100

Source: Stigma Reduction index surveys: 2015/2016 End-line

Table 4 shows that majority 1,038 (52.40%) of the respondents reported having enough food in the last one month that preceded the end-line survey. Nonetheless, a relatively big number (20.59%) reported to have lacked food between 22-30 days within a month. The proportion of people that were reported to have enough food could be because the study population has rural areas where those with energy and access to land usually participate in farming activities to obtain food. There are minor variations between baseline and end line results. However, these are only confirmatory that the respondents reached have limitations in access to food.

3.1.8 Length of time respondent have been living with or affected by HIV

The period a respondent has lived with HIV is assumed to have an association with stigmatization levels. The time duration refers to time since the respondents knew their status. It may not reflect time since infection. Equally the stigma levels among the affected could vary with time since the person they take care or are associated with was diagnosed with HIV.

Table 5: Length of time respondents have lived with or affected by HIV

Duration	Male		Female		Transgender		Total	
	n	%	n	%	n	%	n	%
0–1 year	50	9.26	106	7.36	0	0	156	7.87
1–4 years	151	27.96	279	19.38	0	0	430	21.71
5–9 years	176	32.59	460	31.94	1	100	637	32.16
10–14 years	93	17.22	353	24.51	0	0	446	22.51
15+ years	69	12.78	229	15.90	0	0	298	15.04
Don’t know	1	0.19	13	0.90	0	0	14	0.71
Total	540	100	1,440	100	1	100	1,981	100

Source: Stigma Reduction index surveys: 2015/2016 End-line

In Table 5 findings show that majority 637 (32.16%) of the study population reported to have lived with HIV from 5- to 9 years. Within this major category, there were slightly equal proportions of males (32.59%) and females (31.94%). Overall, a big proportion 86.77% reported to have lived or been affected by HIV from 5 years and above. Those who reported 0-1 year were quite few at 156 (7.87%) but almost similar with the baseline value. For those who have lived with or affected by HIV for 15+ years, the female proportion is higher than that of the males; 12.78% and 15.9% respectively. There is a big variation amongst those who have lived or affected by HIV between 1—4 years; the proportion of males (27.96%) is higher than females 19.38%.

3.1.9 Sexual activity amongst the study population

Owing to instances of HIV stigma, many social and welfare aspects of life are reported to be negatively affected. Where most people avoid sex as reaction to the negative forms of stigma as reported 2013 PLHIV index in Uganda. In this end-line survey, questions around current sexual activity were explored as reported in table 1. 6. The past 12 months are considered to indicate current situation.

Table 6: Sexually active by gender in the last 12 months

Response	**Male**		**Female**		**Total**			**Chi-square test of statistical Chi-square test of statistical significance**	
	No	**%**	**No**	**%**	**No**	**No**	**%**	**Value**	**Sig**
Sexually active	417	77.22	803	55.76	1	1,220	61.64	77.098	<0.001
Not sexually active	123	22.78	637	44.24	0	760	38.36		
Total	540	100.00	1,440	100.00	1	1,980	100.00		

Source: Stigma Reduction index surveys: 2015/2016 End-line

In Table 6, majority 1,221 (61.64%) of the respondents reported to be sexually active with variations in proportions; 417 (77.22%) males and 803 (55.76%).Generally, males were more sexually active than females P=<0.001 in the last one year since project initiation. The proportion of males who were sexually active by end-line increased by approximately 5% (from 73% to 77%).

At baseline, 1,239 (61%) of the respondents were sexually active. Among the males, 467(73%) and 772 (56%) females reported to be sexually active, P=<0.001 in the last one year preceding the survey. Both the end-line and baseline indicate that the males were more sexually active.

SECTION 2: EXPERIENCE OF STIGMA AND DISCRIMINATION FROM OTHER PEOPLE

3.2.1 Experiences of exclusion due to stigma and discrimination in the last 12 months

Table 7: Experiences of exclusion due to stigma and discrimination the last 12 months

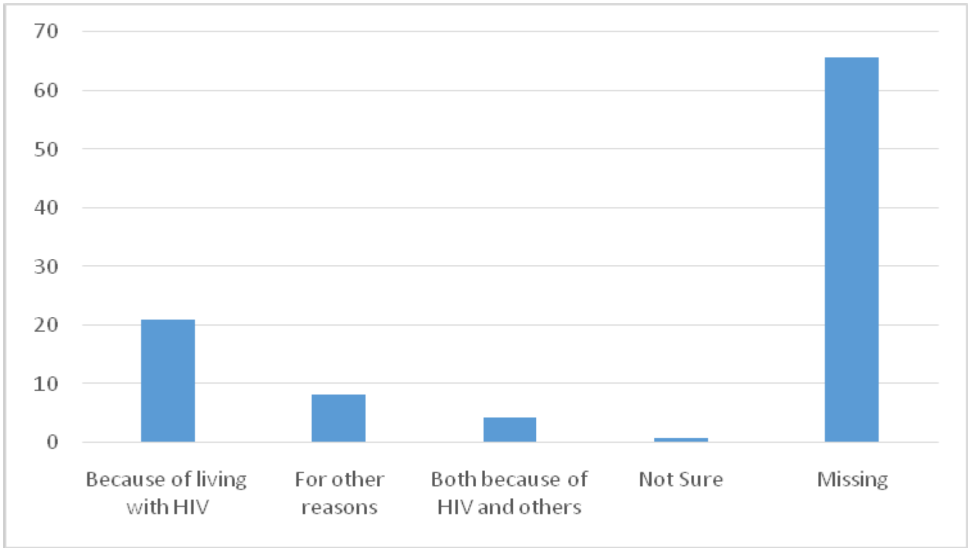
Experience in the last 12 months	***Never***		***Once***		***A few times***		***Often***	
	No	%	No	%	No	%	No	%
Exclusion from Social gatherings or activities	1,923	97.07	13	0.66	22	1.11	23	1.16
Exclusion from Family activities	1,940	97.93	9	0.45	19	0.96	13	0.66
Exclusion from Religious activities or places of worship	1,965	99.19	6	0.30	2	0.10	8	0.40
Being gossiped about?	1,375	69.41	96	4.85	209	10.55	301	15.19
Being verbally insulted, harassed and/or threatened?	1,642	82.89	92	4.64	121	6.11	126	6.36
Being physically threatened?	1,846	93.19	40	2.02	48	2.42	47	2.37
Being physically assaulted?	1,931	97.48	31	1.56	11	0.56	8	0.40

Source: Stigma Reduction index surveys: 2015/2016 End-line

From Table 7 the most prevalent form of external stigma was gossip 606 (30.59%) followed by verbal insult,339 (17.11%), physical threats, 135 (6.81%).This data shows a remarkable reduction in external stigma compared to the baseline values; which showed that showed gossip at 1,003 (47.7%) verbal insult

3.2.2 Self-reported reasons for enacted HIV stigma

Figure 1: Self-reported reasons for enacted HIV Stigma among PLHIV



From figure 1, for those respondents that reported HIV stigma, approximately 20% mentioned that the reasons for exclusion and discrimination was because of living with HIV. Comparing with the baseline, this proportion has reduced from 67% to 20%. This difference of 47% is more attributed to the interventions executed during the SRI of 2014/2015 in the selected districts of Central and South West Uganda.

SECTION 3: ACCESS TO WORK HEALTH AND EDUCATION SERVICES AND FREQUENCY OF OCCURRENCE

3.3.1 Access to work health and education services and frequency of occurrence

This section specifically presents institutional level discrimination, where persons living with or affected by HIV are subjected to. The section highlights aspects of; job loss, suspension, forced change of location or job, including non-promotion due to HIV and denial of either health or educational services. The section also draws a link between discrimination and faith or religious connotations.

Table 8: Access to work, health and education services and frequency of occurrence

Response	*Never (%)*	*Once (%)*	*A few times (%)*	*Often(%)*
Forced to change your residence or unable to rent accommodation	97.48	1.41	0.86	0.25
Lost a job or another source of income	93.06	2.81	2.25	1.88
Refused employment or a work opportunity	95.86	2.37	1.21	0.56
Job description or your work changed, or refused promotion	98.38	0.91	0.50	0.20
Experience of work-related discrimination linked to faith community	99.39	0.45	0.10	0.05
Dismissed, suspended or prevented from attending an educational institution	99.04	0.61	0.15	0.20
Child/children been dismissed, suspended or prevented from attending an educational institution	99.14	0.45	0.30	0.10
Denied health services, including dental care	99.34	0.40	0.10	0.15
Denied sexual and reproductive health services	99.55	0.20	0.15	0.10

Source: Stigma Reduction index surveys: 2015/2016 End-line

In Table 8 about 4.14% of the respondents reported to have been refused employment or work opportunities. Also, 2.52% reported to have been forced to change their residence or unable to rent accommodation. Although discrimination still exists, there has been a significant reduction in these aspects of external stigma. Between the end-line and baseline, respondents who were forced to change their residence or unable to rent dropped from 7% to 2.52% as well as those who were refused employment from the same to 4.14%.

SECTION 4: HIV INTERNAL STIGMA

This section presents information about the way respondents affected and infected feel about themselves because they are living with or affected by HIV. Additionally, the section presents data about the reactions that the PLHIV or affected persons have manifested owing to this situation of internal stigma. The definition of internal stigma adopted for this study is: the degree to which PLHIV/affected endorse the negative feelings associated with HIV and apply those feeling to themselves. Usually internalization of the blame, shame, fear, guilt, hopelessness associated with HIV experiences leads to negative consequences in form of the decision they make or the reactions that follow.

3.4.1 : Experiences of internal stigma

In the HIV stigma reduction initiative, internal stigma was measured using an 8 item validated scale. Several sub categories are presented in this section to synthesize stigma and guide intervention development to reduce internal stigma.

Table 9: Experiences of internal stigma in the last 12 by sex, with significant statistical value

	Male		Female		Total		Chi-square test of statistical significance (d=1)	
	n	**%**	**n**	**%**	**n**	**%**	**Value**	**Sig**
I feel ashamed	53	9.81	147	10.21	200	10.10	0.179	0.91
I feel guilty	42	7.78	97	6.74	139	7.02	0.729	0.69
I blame myself	82	15.19	310	21.53	392	19.79	10.20	0.01
I blame others	27	5.00	158	10.97	185	9.34	16.64	0.01
I have low self-esteem	47	8.70	131	9.10	178	8.99	0.17	0.92
I feel I should be punished	3	0.56	38	2.64	41	2.07	8.43	0.01
I feel suicidal	6	1.11	32	2.22	38	1.92	2.59	0.27
I feel sinful	14	2.59	58	4.03	72	3.63	2.34	0.31
None of the above	387	71.67	948	65.83	1,335	67.39	6.56	0.034

Source: Stigma Reduction index surveys: 2015/2016 End-line

Total column indicates only respondents who responded to the items across. For example, 200 in 6th column, row 2 is out of 1,981 (total population sample.). The basis of comparison of differences between females and male is on actual responses within categories by both.

There were differences observed within the scales specific to gender. For example females (10.97%) who blame others is twice (5.00%) that of males. Likewise, the proportion of females who feel suicidal is twice the males; 2.22% females Vs 1.11% males. With the exception of feeling sinful and should be punished, the rest of the items that measure internal stigma revealed statistically significant differences between males and females. Although, there has been a reduction in internal stigma, all the differences have reportedly affected females more than males.

Table 10: Experiences of internal stigma in the last 12 comparing baseline and endline after an intervention

	End-line		Baseline		% reduction between endline and baseline
	n	%	n	%	
I feel ashamed	200	10.10	396	19.6	9.50
I feel guilty	139	7.02	256	12.7	5.68
I blame myself	392	19.79	605	30	10.21
I blame others	185	9.34	364	18	8.66
I have low self-esteem	178	8.99	280	13.9	4.91
I feel I should be punished	41	2.07	80	4	1.93
I feel suicidal	38	1.92	95	4.7	2.78
I feel sinful	72	3.63	178	8.8	5.17
None of the above	1,335	67.39	942	47	20.39

Across all the 8 component of internal stigma, there are significant reported reductions in internal stigma. Given that the baseline and end-line targeted the same individuals, who had received the intervention, the results are highly attributed to the intervention implemented by KM and NHC.

3.4.2 Respondent's decision not to engage in some activities because of their HIV status in the last 12 months by gender

With the various negative consequences related to HIV stigma, those infected and affected suffer and end up avoiding specific places or participation in specific activities as reflected in Table 9 below

Table 11: Decision not to engage in social and health activities because of HIV status in last 12 months

	Male		Female		Total		Chi square test	
	No	%	No	%	No	%	Value	Sig
I have chosen not to attend social gathering(s)	42	7.78	66	4.58	108	5.45	7.83	0.010
I have chosen not to attend religious events/services	6	1.11	23	1.60	29	1.46	0.66	0.720
I have isolated myself from my family and/or friends	13	2.41	35	2.43	48	2.42	0.026	0.980
I took the decision to stop working	11	2.04	11	0.76	22	1.11	5.80	0.055
I decided not to apply for a job/work or for a promotion	9	1.67	14	0.97	23	1.16	1.66	0.440
I withdrew from education/training or did not take up an opportunity for education/training	9	1.67	4	0.28	13	0.66	11.63	0.003
I decided not to get married	48	8.89	242	16.81	290	14.64	19.87	4.850
I decided not to have sex	48	8.89	260	18.06	308	15.55	25.32	3.180
I decided not to have (more) children	171	31.67	433	30.07	604	30.49	0.912	0.630
I avoided going to a local clinic when I needed to	24	4.44	129	8.96	153	7.72	23.030	9.980
I avoided going to a hospital when I needed to	6	1.11	8	0.56	14	0.71	132.750	1.490
I have stopped taking medication that I know I need	4	0.74	1	0.07	5	0.25	7.030	0.030
None	292	54.07	818	56.81	1,110	56.03	2.460	0.300

Source: Stigma Reduction index surveys: 2015/2016 End-line

These responses are multiple response, so they do not add up to 100% considering all the categories. In Table11, several decisions were revealed but the most prominent ones, included; not having more children 604(30.49%), followed by not having sex 308(15.55%), not getting married 290(14.64%) and not attending social gatherings 108(5.45%). This implies that PLHIV find it hard to have children if HIV positive. Following the stigma reduction intervention almost all negative reactions reduced as per the results at end-line compared with baseline. At baseline, the proportions were, not having more children 809(40.1%), followed by not to have sex 488(24.2%), not to get married 428(21.2%) and not to attend social gatherings 200(9.9%).

Table 12: Decision not to engage in social and health activities because of HIV status in last 12 months comparing end line and baseline

	End line		**Baseline**		**Total**
	n	**%**	**n**	**%**	**% Reduction**
I have chosen not to attend social gathering(s)	108	5.45	130	9.4	3.95
I have chosen not to attend religious events/services	29	1.46	28	2.0	0.54
I have isolated myself from my family and/or friends	48	2.42	75	5.4	2.98
I took the decision to stop working	22	1.11	14	1.0	0.11
I decided not to apply for a job/work or for a promotion	23	1.16	19	1.4	0.24
I withdrew from education/training or did not take up an opportunity for education/training	13	0.66	14	1.0	0.34
I decided not to get married	290	14.64	363	26.3	11.66
I decided not to have sex	308	15.55	387	28	12.45
I decided not to have (more) children	604	30.49	576	41.7	11.21
I avoided going to a local clinic when I needed to	153	7.72	119	8.6	0.88
I avoided going to a hospital when I needed to	14	0.71	15	1.1	0.39
I have stopped taking medication that I know I need	5	0.25	4	0.3	0.05
None	1,110	56.03	540	39.1	-16.93

From table 12 above, there are quite a number of visible differences in term of reaction by the respondents' self-reported decisions between the end-line and baseline. For instance, at baseline, 9.4% reported making a decision to avoid social gathering, but end-line, this proportion reduced to 5.4%. those who reported self isolation self from family and/or friends equally reduced from 5.4% to 2.4%.

3.4.3 Hypothetical stigma (Fearfulness)

In view of HIV stigma, some percentage of respondents were fearful that various forms of stigma would happen to them through implementation. Views varied by gender as illustrated below.

Table 13: Respondents that were fearful that some forms of stigma would happen to them

	Male		Female		Total		Chi-square test of statistical significance	
	n	**%**	**n**	**%**	**n**	**%**	**Value**	**Sig**
Being verbally insulted, harassed and/or threatened	140	25.93	301	20.90	441	22.26	6.013	0.050
Being physically threatened	37	6.85	117	8.13	155	7.82	12.67	0.002
Being physically assaulted	19	3.52	75	5.21	95	4.80	22.32	1.400
Not fearful	393	72.78	1,131	78.54	1,524	76.93	10.69	0.010

From table 13, most respondents 441 (22.26%) reported fear that some form of verbal insults, harassment or threat would happen to them. These included males (25.39%) than females (20.90%). Other proportions of anticipated stigma or discrimination experiences were mentioned more by females as per table 3.2. In comparison to the baseline findings, a big number 665 (33%) was fearful of some form of verbal insult, harassment. Generally, respondents who were not fearful of HIV related stigma increased between the baseline and endline from 1,309 (64.9%) to 1,524 (76.9%).

3.4.4 Further analysis of internal stigma components

This sub section is geared towards more analysis and presentation of results to understand the problems of internal stigma and any association with background variables such as sex, education level, employment, age, rural urban and others.

Table 14: Prevalence of stigma by sex

Sex	Prevalence of HIV stigma			Chi-square test of statistical significance (d=1)	
	HIV Stigma reported	No HIV stigma reported	Total	Value	Sig
Male	214(39.63%)	326(60.37%)	540(100)	8.530	0.014
Female	481(33.40%)	959(66.60%)	1,440(100)		
Transgender	1(100)	0(0)	1(100)	N/a	N/a
Overall total	696(35.13%)	1,285(64.87%)	1,981(100)	N/a	N/a

From table 14, study findings reveal that the overall level of stigma is 696 (35.13%) in the study population. Among all the females interviewed, the proportion that reported internal HIV related stigma was 481 (33.4%) and males were 214 (39.63%). In comparison with the baseline, stigma reduction was more experienced within the females (from 59% at baseline to 33% at end-line). The reduction among the males was minimal from 41% to 39%. The changes within the females could be attributed to their participation in trainings and other interventions where the faith leaders reached the female easily as opposed to the males. Generally, literature about health seeking reveals that females are better at seeking health services as opposed to men.

Table 15: Levels of stigma by age

	End line		Baseline	
	HIV Stigma	Total	HIV Stigma	Total
Youth Aged 15-19 Years	22(37.93%)	58(100)	40(54.8%)	73(100%)
Adult aged 20-24 years	41(40.20%)	102(100)	49(53.8%)	91(100%)
Adult aged 25-29 years	67(35.83%)	187(100)	105(57.1%)	184(100%)
Adult aged 30-39 years	232(39.59%)	586(100)	382(61.1%)	625(100%)
Adult aged 40-49 years	195(34.21%)	570(100)	289(50.7%)	570(100%)
Adult aged 50+ years	139(29.08%)	478(100)	218(46.%)	474(100%)
Total	696(35.13%)	1,981(100)	1,084(53.7%)	2,018(100%)

Table 15 indicates the variations in the levels of stigma among the various age categories. Largely, HIV stigma was reported more within age category 30-39 years, 232 (39.59%). From this table, it can be seen that stigma increases with age until the age category of 30-39 and then steadily drops.

Between the baseline and end-line, the most affected age group is 30-39, but with significant reduction after the interventions. Further intervention of stigma reduction should prioritize the most affected group (30-39 years). The reduction in HIV stigma in this group was 382 (61.1%) at baseline to 232(39.59%) at end-line.

From table 15, there are variations in the levels of stigma within the different age categories. Generally, HIV stigma is reported more within the category of 30-39 years, 382 (61.1%). From this table, it can be observed that stigma increases with age until the age of 30-39 and then it starts dropping steadily

Table 16: Prevalence of stigma categories (low and high stigma) by sex

	High Stigma	Moderate Stigma	Low Stigma	Total
Male	5(0.93%)	28(5.19%)	507(93.89%)	540(100)
Female	44(3.06%)	74(5.14%)	1,322(91.81%)	1,440(100)
Transgender	0(0)	0(0)	1(100)	1(100)
Total	49(2.47%)	102(5.15%)	1,830(92.38%)	1,981(100)

As shown in Table 16 findings revealed that HIV stigma levels were still higher among females as seen in the "High Stigma" column. HIV stigma reduced by a slight margin; from 60(4.3%) to 44(3.06%). By implication, there has been an improvement that can be attributed to the stigma reduction interventions.

Table 17: Prevalence of levels of HIV stigma by age considering three levels

Range	High Stigma	Moderate Stigma	Low Stigma	Total
Youth Aged 15-19 Years	0(0)	3(5.17%)	55(94.83%)	58(100)
Adult aged 20-24 years	3(2.94%)	11(10.78%)	88(86.27%)	102(100)
Adult aged 25-29 years	11(5.88%)	17(9.09%)	159(85.03%)	187(100)
Adult aged 30-39 years	18(3.07%)	39(6.66%)	529(90.27%)	586(100)
Adult aged 40-49 years	12(2.11%)	24(4.21%)	534(93.68%)	570(100)
Adult aged 50+	5(1.05%)	8(1.67%)	465(97.28%)	478(100)

In Table 17, results show variations in consideration of two age categories, 25 to 29years at 5.88% compared to adults aged 30 to 39 years (3.07%) of HIV stigma within the high categories. This provides evidence that the stigma reduction interventions had a bearing on the lessening stigma as compared to the baseline findings (7% for both 20 to 24 and 25 to 29 years).

Table 18: Prevalence of stigma by categories of respondents (Infected and affected)

Categories of persons	End-line			Baseline		
	HIV stigma Present	HIV stigma Not present	Total (%)	HIV stigma Present	HIV stigma Not present	Total
PLHIV	637 (35.59%)	1153 (64.41%)	1790 (100)	1029 (56.7%)	787 (43.3%)	1,816 (100)
Persons affected by HIV	59 (30.89%)	132 (69.11%)	191 (100)	55 (27.2%)	147 (72.8%)	202 (100%)
Overall total	696 (35.13%)	1,285 (64.87%)	1,981 (100)	1,084 (53.7%)	934 (46.3%)	2,018

In Table 18, a difference between stigma levels was reported among infected and affected persons. The level of HIV stigma reported by the PLHIV is comparatively high 637(35.59%) as opposed to those affected 59(30.89%). This difference was not statistically significant P =0.196. There is a clear indication that the stigma reduction interventions worked as reflected with the reduction of baseline stigma levels from 1,029 (56.7%) to 637(35.6%)among the PLHIV. On the contrary, the HIV stigma levels among the affected slighted increased by 2% between the baseline and endline. The reason could be related to non-exposure to the stigma reduction interventions during the project period.

Table 19: Prevalence of stigma by categories of respondents by marital status

Marital status	End-line		Baseline		% difference between end-line and baseline
	HIV Stigma	**Total**	**HIV Stigma**	**Total**	
Married/cohabiting and husband/wife is currently is living in household	279(35.54%)	785(100)	63(66%)	96(100%)	30.5%
Married or cohabiting but husband/wife/partner is temporarily living/working away	24(33.33%)	72(100)	148(57.4%)	258(100%)	24.1%
In a relationship but not living together	67(39.18%)	171(100)	128(55.2%)	232(100%)	16.0%
Single	112(32.28%)	347(100)	71(46.4%)	153(100%)	14.1%
Divorced/separated	90(37.04%)	243(100)	137(46%)	298(100%)	9.0%
Widow/widower	124(34.16%)	363(100)	536(54.7%)	979(100%)	20.5%
Total	696(35.13%)	1,981(100)	1,084(53.7%)	2,018(100%)	18.6%

Findings from Table 19 Indicate that HIV stigma at end-line was highest among those in relationship but not living together 67(39.18%), followed by married/cohabiting 279(35.5%) and married or cohabiting but husband/wife is temporarily living working away 24(33.33%). it is also noted that between the end-line and baseline, the biggest change (30.5%) was among the married, cohabiting and husband is currently living in the household. This finding relates clearly to the increasingly high HIV prevalence among the married people, according to the National behavior-sero surveys, Uganda AIDS Indicator Survey and the Modes of Transmission study.

SECTION 5: RIGHTS, LAWS AND POLICIES

This section presents findings related to knowledge about law policies and the application of the knowledge to seek the PLHIV rights.

5.1.1 Background to the Rights, Laws and Polices

The protection issues and promotion of human rights, warranted the creation and adoption of specific international and national declarations which Uganda is a member state having ratified several of this declarations. From the perspective of the Ugandan laws, the 1995 Constitution, is the cardinal law that protects the rights of all persons, without discrimination of any kind.

Some of the laws that manifest commitment of the government to deter discrimination include;

The Employment Act 2006 that strengthens provisions of anti-discrimination of all workers despite Health status; the Domestic Violence Act 2010 that provides for protection to all family members against violence to include assault and psychological torture.

The recent HIV Prevention and Control Act, was assented to in July 2014 with provisions that were contested by several civil society agencies. For instance, the Act contains clauses that suggest forced disclosure by clinicians to partners of the person identified to have HIV and criminalizes deliberate and attempted transmission. At the same time, the Act advocates for the nondiscriminatory grounds owing to HIV in all settings. In line with the current stigma index, similar questions that sought experiences of PLHIV and those affected with regard to laws, rights, and polices were explored at length. In this section, the results will present any changes that might have occurred in the period of one year from baseline to end-line.

Table 20: Respondents knowledge and understanding of the international and national documents by location

Response	Urban		Rural	
	n	**%**	**n**	**%**
Ever heard of the Declaration of Commitment on HIV&AIDS	674	48.11	727	51.89
Ever read or discussed the content	319	39.33	492	60.67
Ever heard of your country's national policy and law	611	47.70	670	52.30
Ever read or discussed the content	237	37.26	399	62.74

Table 20 shows that a big proportion (70.72%) of respondents have ever heard of the Declarations of Commitment of HIV. 1,281(64.66%) reported that they had ever heard of the country’s national policy and law almost similar with the baseline figure, 64%. Conversely, there are variations and differences between the rural and urban. Those that had ever heard declarations of commitment of HIV 51.89% vs 48.11%.Likewise, those who had ever heard of their country’s national policy and law were 52.3% Vs 47.7%.Equally, those in rural areas reported to have read and discussed the content 62.74% vs 37.26% respectively. Conclusively, the interventions have led to a remarkable increment in the knowledge and understanding of the international and national document by location.

Table 21: Respondents knowledge and understanding of the international and national documents by sex

	Male		Female		Transgender	
	Yes	**%**	**Yes**	**%**	**Yes**	**%**
Ever heard of the Declaration of Commitment on HIV&AIDS	333	23.77	1,067	76.16	1	0.07
Ever read or discussed the content	195	24.04	615	75.83	1	0.12
Ever heard of your country's national policy and law	334	26.07	946	73.85	1	0.08
Ever read or discussed the content	173	27.20	462	72.64	1	0.16

According to Table 21, more female respondents 76.16%, reported to have ever heard of the declaration of commitment of HIV and AIDS followed by those who had ever read or discussed the content 75.83% and 73.85% who had ever heard of their country's national policy and law. On the other, majority (26.07%) of males had ever heard of their country's national policy and law. The project interventions geared towards promoting rights and protecting violation of rights for both PLHIV and general public enabled bridging of the knowledge gap among beneficiaries. These results imply though knowledge is critical in advocacy issues, but the major limitation is simplifying the international declarations to simple messages which many targeted audiences can understand and apply given their relationship.

SECTION 6: EFFECTING CHANGE

Effecting change is about situations where the PLHIV have made commendable efforts to change misconceptions, confronted negative practices and educated people on various aspects since GIPA declaration. In order to change the perceptions towards HIV/AIDS, PLHIV have courageously challenged and confronted negative incidents. Table 22, asks the PLHIV if they have had experiences related to effecting changes, in the area of HIV stigma.

3.6.1. Experiences of effecting change

Table 22: Effecting changes and knowledge of support organisation by sex

Response	Male		Female		Total	
	NO	**%**	**No**	**%**	**No**	**%**
In the last 12 months, have you confronted, challenged or educated someone who was stigmatizing and/or discriminating against you?	218	33.08	440	66.77	658	33.2
Do you know of any organisations or groups that you can go to for help if you experience stigma or discrimination	216	26.73	592	73.27	808	40.8

From table 22 it is observed that 440 (66.77% females) and 218 (33.08% males) indicated that they had ever confronted, challenged or educated someone who experienced or discriminated from other people. Nonetheless, some gender differences manifest on this although there is a slight margin. Also, it was revealed that knowledge about any organisations or groups that could provide help during instances with the affected/infected person experience stigma remained low 808 (40.8%). This could have happened because interventions did not put emphasis on this component of effecting changes but over coming self-stigma. As far as knowledge is concerned, there is still need to bridge the differences between the males and females which would otherwise guide the interventions in terms of information provision to specific groups.

Table 23: Knowledge of the type of organisation rendering support to reduce HIV stigma mentioned by respondent

Responses	Male		Female		Transgender		Total	
	No	%	No	%	No	%	No	%
People living with/affected by HIV support group	144	26.23	405	73.77	0	0.00	549	27.7
Network of people living with/affected by HIV	103	37.59	171	62.41	0	0.00	274	13.8
Local non-governmental organisation	19	19.00	81	81.00	0	0.00	100	5.0
Faith-based organisation	50	45.45	60	54.55	0	0.00	110	5.6
Faith leaders or other faith representatives	5	41.67	7	58.33	0	0.00	12	0.6
A legal practice	1	5.26	18	94.74	0	0.00	19	1.0
A human rights organisation	11	36.67	19	63.33	0	0.00	30	1.5
National non-governmental organisation	16	50.00	16	50.00	0	0.00	32	1.6
National AIDS council or committee	4	40.00	6	60.00	0	0.00	10	0.5
International non-governmental organisation	1	20.00	4	80.00	0	0.00	5	0.3
UN organisation	1	25.00	3	75.00	0	0.00	4	0.2
Other Organisations	2	9.09	20	90.91	0	0.00	22	1.1

Table 23 indicates that majority 549 (27.7%) reported that there exist support groups within the PLHIV close networks. Whilst it was revealed that knowledge about existence of other agencies and organisations that can support the PLHIV is still low. A total of 274 (13.8%) reported the Network of people living with/affected by HIV as existing. By implication, the PLHIV failure to know or relate to human rights organisation, legal practice, and NGOs, limits their ability to seek justices or advocate for their rights. Going forward, more sensitization about the availability of human rights agencies is needed. This can be done PLHIV secretariat through the district PLHIV networks.

Table 24: Experiences of seeking support from the organisations/type of support by sex

Response	Male		Female		Transgender		Total	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Have you sought help from any of the above organisations or groups to resolve an issue of stigma or discrimination?	24	35.82	43	64.18	0	0.00	67	3.4
In the last 12 months, have you supported other people living with/affected by HIV?	440	30.30	1,011	69.63	1	0.07	1452	73.4
Type of supported the individual provided								
Emotional support (e.g. counseling, sharing personal stories & experiences)	299	30.51	680	69.39	1	0.10	980	49.5
Physical support (e.g. providing money or food, doing an errand for them)	295	33.48	586	66.52	0	0.00	881	44.5
Referral to other services	213	33.49	422	66.35	1	0.16	636	32.1

Although table 24Shows that the proportion of respondents seeking support from the mentioned organisation has remained low 67 (3.4%), it has been reported by majority 1,452 (73.4%) who have supported others to seek support. Ultimately, this has partly confirmed the contribution of PLHIV if they are well empowered to actively support others. In general, support offered ranges from emotional support (980, 49.5%) to physical support (881, 44.5%), and then referral to other services (636, 32.1%). Social support has been a fundamental component in the stigma reduction project with considerations of working with PLHIV to streamline support as a form of stigma reduction intervention.

SECTION 7: TESTING / DIAGNOSIS

HIV testing and counseling (HCT) has remained critical to any successful management of HIV. Specifically plays crucial roles in diagnosis. Most HIV programmes observe that HCT, provides benefits to an individual, the family and the community in terms of preventing transmission, initiating timely treatment and enhancing care and support which collectively contribute to improving the health situation of PLHIV and reduction of incidents of new infections. Both the end-line and baseline collected information about HCT (table 25).

3.7.1 Experiences of HIV Testing and diagnosis

Table 25: Proportion of respondents who have not tested for HIV

3	Male		Female		Transgender		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Yes	527	97.6	1,428	99.2	1	0.05	1,956	98.7
No	13	2.4	12	0.8	0	0.00	25	1.3
Total	540	100	1,440	100	1	0.05	1,981	100.00

Table 25 shows that about 1.3% of the respondents have not tested. On the assumption that all PLHIV tested, this population can be attributed to only the affected. Among those who have not tested, 13 (2.4%), males have not tested compared to 12(0.8%) females. Respondents were also asked to share their experiences with regard to counseling. Generally, most of them 1,703 (84.4%) reported to have received pre and post HIV test counseling, 177 (8.8%), received post-test counseling, while only 41(2%) report to have received only pretesting. Counselling. Table 26 present reasons for testing. The reasons are sometimes multiple and the percentages may exceed 100%

Table 26: Reasons for HIV testing by sex

Testing reasons	Male		Female		Transgender		Total	
	No	%	No	%	No	%	No	%
Employment	4	19.05	17	80.95	0	0.00	21	1.1
Pregnancy	2	1.01	197	98.99	0	0.00	199	10.0
To prepare for a marriage/sexual relationship	14	56.00	11	44.00	0	0.00	25	1.3
Referred by a clinic for sexually transmitted infections	34	47.22	38	52.78	0	0.00	72	3.6
Referred due to suspected HIV-related symptoms (e.g. tuberculosis)	90	31.14	199	68.86	0	0.00	289	14.6
Husband/wife/partner/family member tested positive	25	17.48	118	82.52	0	0.00	143	7.2
Illness or the death of husband/wife/partner/family member	126	21.50	460	78.50	0	0.00	586	29.6
I just wanted to know	273	39.45	418	60.40	1	0.14	692	34.9
Other	58	40.28	86	59.72	0	0.00	144	7.3

Multiple responses

As indicated in table 26, 586(29.6%) of the respondents reported illnesses or the death husband/wife/partner or family members as the reason for having undertaken an HIV test. Likewise, 692(34.9%) of the respondents merely wanted to know their status. The proportion of those who wanted to know their status is similar to the 2013 PLHIV stigma index in Uganda. The implication is that sensitization about the benefits is testing should be intensified.

SECTION 8: DISCLOSURE AND CONFIDENTIALITY

One of the most complex phases in accepting HIV status of any individual is the fear for disclosure. On the other hand, disclosure is a very important tool in breaking through with stigma. PLHIV who outspoken still mentioned that though disclosure has benefits, it has to be done consciously and care should about how, to whom when and where to disclose. Like the PLHIV stigma index of 2013, the baseline of 2014, this end-line asked similar questions about experiences of disclosure. (Table 27).

Table 27: Percentage distribution of how different groups of people first got to know about respondent's HIV status

Response	I told them	Someone else told them, WITH my consent	Someone else told them, WITHOUT my consent	They don't know my test result	Not applicable
Your husband/wife/ partner	1,052(53.1)	57(2.9)	30(1.5)	168(8.5)	674(34.0)
Other adult family members	1,449(73.1)	38(1.9)	44(2.2)	228(11.5)	222(11.2)
Children in your family	1,117(56.4)	24(1.2)	17(0.9)	537(27.1)	286(14.4)
Your friends/neighbors	1,066(53.8)	26(1.3)	147(7.4)	620(31.3)	122(6.2)
Other people living with HIV	1,295(65.4)	43(2.2)	89(4.5)	414(20.9)	140(7.1)
Your co-workers	422(21.3)	18(0.9)	38(1.9)	647(32.7)	856(43.2)
Your employer(s)/boss(es)	237(12.0)	9(0.5)	14(0.7)	503(25.4)	1,218(61.5)
Your clients	211(10.7)	15(0.8)	37(1.9)	1,035(52.2)	683(34.5)
Injecting drug partners	23(1.2)	0(0.0)	3(0.2)	617(31.1)	1,338(67.5)
Religious leaders	453(22.9)	12(0.6)	30(1.5)	1,222(61.7)	264(13.3)
Community leaders	455(23.0)	30(1.5)	57(2.9)	1,178(59.5)	261(13.2)
Health care workers	1,729(87.3)	9(0.5)	18(0.9)	95(4.8)	130(6.6)
Social workers/counselors	1,495(75.5)	11(0.6)	26(1.3)	148(7.5)	301(15.2)
Teachers	221(11.2)	2(0.1)	13(0.7)	980(49.5)	765(38.6)
Government officials	72(3.6)	1(0.1)	6(0.3)	1,268(64.0)	634(32.0)
The media	23(1.2)	0(0.0)	7(0.4)	1,215(61.3)	736(37.2)

The table above shows that over a half of the respondents reported to have told their spouses and other people voluntarily. The Majority 87.3%, told health workers, followed by social workers 75.5%, other adult family members, 73.1%, PLHIV, 65.4%, children in the family, 56.4%, neighbors/friends, 53.8% and spouses,53.1%. Column of this table could also be interpreted to suggest "*I told them* "to mean (I disclosed to them) and the rest of the column mean the client did not disclose to them (not applicable excluded). By implication, supported disclosure at the family level particularly between the partners and other family members including children has been a critical intervention which has been re-activated probably worked.

Table 28: Disclosure experiences of persons who disclosed

Frequency of pressure from others to disclose the fact that you are living with or affected by HIV?			
		n	%
Never		1,803	91.01
Once		65	3.28
A few times		79	3.99
Often		34	1.72
Source of Pressure			
Other individuals living with HIV or from groups/ networks of people living with HIV	Yes	42	2.12
Other individuals not known to be living with HIV (e.g. family members, work colleagues, neighbors)	Yes	125	6.31
Other individuals in their professional capacity (e.g. doctors, other health care workers, counselors, social workers, non-governmental organisation employees, faith leaders)	Yes	32	1.62
Disclosure of your HIV status or the fact that you are affected by HIV an empowering experience?			
Yes		1,674	84.50
No		236	11.91
Not applicable		71	3.58

In table 28, the percentage of the respondents who reported not to have received pressure from others to disclose their HIV increased from 86.8% to 91%during end line survey status or those affected by HIV, whereas those that received pressure were 9%. Those that reported to receive pressure, majority revealed that they received such pressure from individuals not known to be living with HIV such as family members, work colleagues, and/or neighbors. Majority 1,674(84.5%) who disclosed found disclosure to be an empowering experience. In comparison with the baseline, disclosure as promoted by professional health counselors has helped overcome HIV related stigma.

Table 29: Percentage of respondents who reported various reactions of people when they first knew about their HIV status

Response	Very discriminatory n(%)	Discriminatory n(%)	No different n(%)	Supportive n(%)	Very supportive n(%)	Not applicable n(%)
Your husband/wife/ partner	53(2.7)	63(3.2)	156(7.9)	427(21.6)	452(22.8)	830(41.9)
Other adult family members	14(.7)	37(1.9)	179(9.0)	725(36.6)	648(32.7)	378(19.1)
Children in your family	1(.1)	4(.2)	134(6.8)	561(28.3)	539(27.2)	742(37.5)
Your friends/neighbors	16(.8)	81(4.1)	380(19.2)	684(34.5)	211(10.7)	609(30.7)
Other people living with HIV	1(.1)	8(.4)	424(21.4)	792(40.0)	277(14.0)	479(24.2)
Your co-workers	3(.2)	38(1.9)	194(9.8)	298(15.0)	50(2.5)	1,398(70.6)
Your employer(s)/boss(es)	5(.3)	21(1.1)	112(5.7)	158(8.0)	66(3.3)	1,619(81.7)
Your clients	5(.3)	36(1.8)	226(11.4)	169(8.5)	13(.7)	1,532(77.3)
Injecting drug partners		2(.1)	25(1.3)	6(.3)	2(.1)	1,946(98.2)
Religious leaders	1(.1)	13(.7)	168(8.5)	368(18.6)	150(7.6)	1,281(64.7)
Your local faith community	2(.1)	9(.5)	316(16.0)	345(17.4)	62(3.1)	1,247(62.9)
Social workers/counsellors	2(.1)	1(.1)	88(4.4)	714(36.0)	728(36.7)	448(22.6)
Health care workers	3(.2)	3(.2)	32(1.6)	758(38.3)	987(49.8)	198(10.0)
Community leaders	2(.1)	23(1.2)	284(14.3)	310(15.6)	72(3.6)	1,290(65.1)
Teachers		12(.6)	130(6.6)	175(8.8)	23(1.2)	1,641(82.8)
Government officials	2(.1)	14(.7)	97(4.9)	108(5.5)	12(.6)	1,748(88.2)
The media	1(.1)	2(.1)	43(2.2)	114(5.8)	1(.1)	1,820(91.9)

The categories that were identified by relatively large proportions (more than 50%) of respondents as being supportive and very supportive Health care workers (88.1%), social workers (72.7%) other adult family members(69.3%), children in the family (55.5%), and other people living with HIV (54.0%). Conclusively, more respondents have reported support from health care workers. Categories of respondents who were supportive initially were targeted as change agents in the project intervention to reduce HIV related stigma unlike the friends and neighbors who did not constitute the 50% mark at project completion.

9 CONCLUSIONS

9.1 THE CONTINUUM OF HIV STIGMA AND GENDER ISSUES

The 2013, PLHIV Stigma index made recommendations to prioritise interventions that focus on internalised stigma. These were deemed more suitable to changing context of HIV Stigma in a generalized and mature HIV epidemic. The wide social exclusion witnessed just before discovery and use of ART reduced over time. Based on this recommendation, HIV care and treatment institutions particularly NHC, KM and NAFOPHANU implemented a project on stigma focusing more on internalized stigma using mainly faith leaders as change agents at different level in a one-year project.

A big positive change in most forms of internal stigma was observed in most of the components that measure internal HIV stigma, namely; feeling ashamed, feeling guilty, blaming self, or others, having low self-esteem and others) has been witnessed following the interventions that NHC, KM and NAFOPHANU implemented over the last one year in selected districts in Central and South Western Uganda. Generally empowering the PLHIV is so critical to achieving betters results of reducing HIV stigma. The results imply that HIV stigma can significantly be reduced with focused interventions.

During the stigma reduction intervention, most of the positive changes in reduction of HIV stigma were observed among the females. The reasons could be due to full participation of the females in the subsequent interventions that the program implemented. At baseline, the stigma levels of males were slightly lower than those of females. By end-line, the stigma levels of females were far less compared to that of males. This suggests that further interventions need to integrate gender aspects in the interventions particularly reaching out the males.

9.2 STUDY STRENGTH

The most outstanding strengths the study design. The study adopted an observation cohort component. Before the interventions were implemented, a baseline was conducted among the target population. After one year of intervention, an end-line was conducted among the same population. Attribution is possible because there are positive changes to the intervention linked to the implemented interventions by the project. Similarly, the study reached out sub populations within Urban and rural areas. The study also builds on the first two studies; the PLHIV study of 2013, the baseline in 2014. All these studies have used similar tools and approaches to measure and document HIV stigma.

1.0 Recommendations

The study recommendations are cognizant of the role play by the faith leaders in the project area and the original project design. Therefore, the recommendations are tailored accordingly to the stakeholder’s roles, level of effort in the current project and engagement.

a. As originally noted, the faith setting provides unrivalled opportunity to reach out most segments of the society at different levels. It is therefore recommended that close collaboration with the faith community be maintained. The faith community have an edge in mobilizing the communities for further positive changes to reduce stigma in former project districts as well in others across the country.
b. To maintain the close collaboration commenced during the SRI between faith leaders and the implementing partners, refresher trainings and reflective sessions on the tasks expected of the faith leaders need to conduct. Where possible, faith leaders at different levels need to be supported to drawn action plan for continuity of stigma reduction interventions as a priority.
c. Resource are critical at operational level. Therefore, partners are asked to continue mobilizing resources for a comprehensive stigma reduction campaign targeting multiple players. This will increase the results gained in the last one year of the project.
d. Where possible and if resources allow, the number of faith leaders should be increased to create a ripple effect within several districts. This will however, require mobilizing, training and agreeing on the tasks to execute by the faith leaders.
e. NAFOPHANU as a key player that brings together PLHIV networks in Uganda, is asked to widely disseminate the findings of the successfully SRI interventions to Uganda AIDS Commission, the Government of Uganda, Civil Society and UN agencies, AIDS Development Partners, PLHIV networks and the general public including the academia and press. This will help to integrate faith contextual intervention in on-going stigma reduction interventions in Uganda. The successful interventions also give key players that HIV stigma can successfully be reduced using interventions in faith context.
f. The partners should intensify capacity building initiatives that promote income generating activities of the vulnerable PLHIV households. This is because majority of the PLHIV are experiencing widespread poverty.
g. It is recommended that Civil Society Organisation support health facilities in the development of all-encompassing treatment procedures, support them in issues of access to treatment, drugs and supplies as well as advocate for provision of infrastructure. Reductions in structural barriers will provide a plat form for an HIV stigma free environment, including the attitude of health workers.
h. Civil Society Organisations should advocate for scheduled implementation of subsequent stigma index country assessments
i. It is recommended that the current findings about HIV stigma is sufficient for use in the development of National Anti-Stigma Policy. Therefore, partners need to advocate with Uganda AIDS Commission on this important aspect.
j. The MOH and UAC should ensure the provision of infrastructure, adequate human resource and logistics coordination to enhance service provision to permit treatment, care and support activities in both clinical and community settings to sustain treatment programs for clients on ART.

k. The Uganda AIDS Commission is specifically asked to continue embracing faith leaders and to further provide strategic level guidance on how to promote and increase the participate faith leaders in HIV stigma reduce country wide

l. Mobilize resources for projects that are directly focusing on helping stigma reduction in specific populations while prioritizing internal stigma specific approaches.

m. We also recommend that the leadership of the Catholic Church, Anglican Church and the Islamic faith in Uganda consider including the highlighted specific activities intended to reduce HIV stigma in their HIV & AIDS training package for their faith leaders to enable them reach a wider community as change agents in reducing HIV & AIDS stigma among their faithful.

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Disclaimer:

The People Living with HIV Stigma Index is designed as an evidence-gathering and advocacy tool led by and for people living with HIV to raise awareness of stigma and discrimination as experienced by people living with HIV (PLHIV). To that end, the methodology is designed to capture respondents' perceptions and experiences of stigma and discrimination, external as well as internalised. As research respondents those participating in the research have a right to anonymity and to confidentiality regarding their responses. Survey questions are limited to this focus and the methodology does not include follow-up questions to re-confirm respondents' perceptions or to take action to respond to individual instances of stigma and discrimination documented. As a result, while the data present information and evidence on perceived and experienced stigma, the survey is not intended to be used as a fact-finding tool or a source of allegations of individual instances of wrong-doing.

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