THE NATIONAL FORUM OF PWHA NETWORKS IN UGANDA
THE UGANDA HIV/AIDS PARTENERSHIP

THE PEOPLE LIVING WITH HIV STIGMA INDEX

UGANDA

August 2013

UNAIDS

SHARING THE CHALLENGE
UGANDA AIDS COMMISSION

Stigma Index

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

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

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
AIS	AIDS Indicator Survey
ART	Anti-Retroviral Therapy
CSO	Civil Society Organisation
GCOWAU	Global Coalition of Women Against AIDS in Uganda
GIPA	Greater Involvement of People Living with HIV
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV
IDUs	Injecting Drug Users
JUPSA	Joint UN Programme of Support on AIDS
IPPF	International Planned Parenthood Federation
LGBTI	Lesbian, Gay, Bi-sexual, Trans-gender and Intersex
MOH	Ministry of Health
MUREC	Mildmay Uganda Research Ethical Committee
MSM	Men who have Sex with Men
NAFOPHANU	National Forum of People Living with HIV/AIDS Networks in Uganda
NAPWA SA	The National Association of People living with HIV and AIDS in South Africa
NEP+	Network of Networks of HIV Positives in Ethiopia
NEPHAK	National Empowerment Network of People Living with HIV and AIDS in Kenya
NEPWHAN	Network of People Living with HIV in Nigeria
NGO	Non Government Organization
NSAs	Network Support Agents
NSC	National Steering Committee
TWG	Technical Working Group
OIs	Opportunistic Infections
PLHIV	People Living with HIV
POMU	Positive Men's Union
POPTU	Post Primary Teachers Union
PWD	People with Disabilities
RAS	Research Academia and Science
RDS	Respondent Driven Sampling
SALT	Support on AIDS and Life through Telephone Helpline
SCE	Self Coordinating Entity
SRC	Sciences Research Consortia
UAC	Uganda AIDS Commission
UHRN	Uganda Harm Reduction Network
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNAS	Uganda National Academy of Science
UNERELA+	Uganda Network of Religious Leaders Living with or Personally Affected by HIV
UNYPA	Uganda network of Young Persons Living with HIV
UPDF	Uganda Peoples Defense Forces
UYP	Uganda Young Positives
VCT	Voluntary Counseling and Testing

Definition of key terms in the context of stigma

Discrimination: Discrimination is the treating of someone in a different prejudicial manner, often on the basis of their belonging, or being perceived to belong to a particular group. It is the unfair, unfavourable and unjust treatment based on prejudice regarding race, colour, sex, perceived HIV status or diseases which is characterised by rejection, isolation, denial and discrediting. Discrimination consists of action or omission that is directed towards individuals who are stigmatized.

Index: In this context, index refers to a collection of information (data) organized in a way which allows us to reach overall conclusions about particular issues and to measure differences in stigma and or how a situation has changed overtime among different populations. The People Living with HIV Stigma Index, for example, will give a measure of how much HIV related stigma and discrimination there is at a certain point in time, in a certain community. This point of reference, we believe will make possible for the same survey of individuals in the same community in the future to get a sense of whether HIV related stigma and discrimination is increasing or decreasing in the community.

PLHIV Stigma Index: The People Living with HIV Stigma Index is not only a survey but a programmatic based initiative that has been developed and implemented by, with and for PLHIV. The PLHIV index is based on key statements that relate to issues of HIV. These statements constitute the items which are measure to generate an index. Most of the items cluster around experiences of stigma and discrimination, testing, disclosure, having children among others.

Stigma: A mark of disgrace or discredit, a distinguished mark or characteristic to label someone as inferior because of an attribute they have. Also refers to unfavourable attitudes, beliefs directed towards someone or something usually culturally constructed. Stigma is often accompanied by discrimination.

HIV related Stigma: Real or perceived negative feeling to a person or group of persons (in this case PLHIV) by virtue of HIV positive status. A person is ignored, socially excluded and treated differently from others because of their HIV status.

Network of People Living with HIV: Is a group, association or an affiliation of HIV positive individuals who unite for a common purpose.

Legal redress: Setting right a wrong done to someone and possibly compensating them resulting from this wrong. Legal redress implies doing this through the courts of law, a human rights commission or any other similar and or legally acceptable forum. It may involve having a lawyer or an advocate represent a person who was wronged and using the law to urge that the wrong be addressed amicably.

Sexual and Reproductive Health Services (SRHS): Sexual and reproductive health services are health care and counselling services that contribute to sexual and reproductive health and wellbeing, through preventing and solving sexual and reproductive health problems. They include; information about sexual and reproductive health issues, access to safe, effective, affordable and acceptable methods of family planning, care for pregnancy and childbirth, care and counselling related to sexually transmitted infections, including HIV, and services to prevent and solve sexual and reproductive health problems.

Smart Phones: In our context, referred to hand held phones, with application features that enable reprogramming to host the electronic questionnaire, permit instant data collection, submission to a secured server in real time. It also serves as a quality control devise as GPS points and consistency in question lay out with conditional validation rules.

Foreword

Thirty one years since the first AIDS case was reported in Rakai District, HIV and AIDS continue to impact negatively on the well being and productivity of individuals. Currently, approximately 1,390,000 people are living with HIV and Uganda has lodged important progress in scaling up evidence-informed response to the epidemic, for instance, the roll out of Option B+ and the number of PLHIV enrolled on ART has increased from 372,785 in 2012 to 566,460 in 2013. With the prevalence rate rising from 6.4% in 2005 to 7.3% in 2011, a lot more needs to be done to reduce new infections.

The Government of Uganda has instituted a policy framework to guide the national response. For instance, the National Strategic Plan 2011/12-2014-15, National Prevention Strategy 2011-2015, National HIV and AIDS Policy 2011 and other specific HIV and AIDS related policies are in place. Despite these efforts, stigma and discrimination remain a hindrance factor to accessibility and utilization of the available HIVandAIDS services and the achievement of the national aspiration of getting to Zero Discrimination as stipulated in the National HIV Prevention Strategy as *'A Uganda where new HIV infections are rare, and where everyone, regardless of age, gender, ethnicity or socioeconomic status has uninterrupted access to high quality and effective HIV prevention services free from stigma and discrimination'.*

Evidence is needed on the dynamics of the epidemic whether on behavioral, structural or + bio-medical interventions. The PLHIV Stigma Index Survey conducted in late 2012 and early 2013 thus fits in the national policy guidelines of conducting research into the epidemic and the response, and promote research information sharing to ensure evidence based interventions. Being the first ever PLHIV Stigma Index in Uganda, we pledge to conduct subsequent surveys to measure levels of stigma among PLHIV, with the findings in this report as a baseline. Stigma and discrimination reduction is among the minimum package for HIV intervention and increasing meaningful involvement of PLHIV in prevention endeavours has to remain the basis for partner engagement towards stigma reduction.

I applaud NAFOPHANU for coordinating this survey as it is vital in provision of strategic information that will guide planning and decision making in the national HIV&AIDS response and also evaluation of effectiveness of programmes being undertaken in stigma reduction.

I therefore wish to take this opportunity to call upon all Ugandans and stakeholders in the response to engage in a comprehensive campaign to reduce stigma in all health and social gatherings but also use this report as a point of reference. It is a unique opportunity for all of us to embrace quality service delivery in a stigma free environment.

Dr. David Kihumuro Apuuli
DIRECTOR GENERAL, UGANDA AIDS COMMISSION

Acknowledgements

The implementation of the PLHIV Stigma Index in Uganda was made possible with financial and technical support from the Joint UN Programme of Support on AIDS in Uganda (JUPSA) through UNAIDS. NAFOPHANU and other partners at large greatly applaud this indispensible support.

As per the principles of meaning and broader inclusion, the PLHIV Stigma Index was highly consultative. A Technical Working Group (TWG) led by Dr. Stephen Watiti spearheaded most of the technical insights and country specific program experiences in addition to roll out guidance. Members included Proscovia Namakula (POPTU), Anne Peace Baguma (SALT), Flavia Kyomukama (GCOWAU), William Mulindwa (POMU), Gabriel Amori (UNERELA+), Paddy Masembe (UNYPA) and Sam Ocen (UYP). This contribution is highly appreciated.

The implementation of the PLHIV Stigma Index had the National Steering Committee (NSC) providing overall oversight role. Technical input from the TWG was synthesized by the NSC and contributed programmatically to contextualize the PLHIV Stigma Index into the existing country HIV/AIDS programs and frameworks. The team was chaired by Ms. Lillian Mworeko, Regional Coordinator of International Community of Women Living with HIV-East Africa (ICW EA) and the members included Dr. Betty Kasanka (Ministry of Health), Joyce Kadowe (Uganda AIDS Commission) Dr. Henry Tabifor (UNAIDS), Ms. Mary Oduka-Ochan (Irish Aid) representing AIDS Development Partners, Jackline Kemigisha representing Young Persons, Florence Aliba Ediu of Inter Religious Council of Uganda (IRCU) representing Faith Based Organisations, Bharam Namanya of Uganda Network of AIDS Services (UNASO) representing AIDS Service Organisations,Teddy Chimulwa of The AIDS Support Organisation (TASO) representing service providers and Joseph Atiku of Reproductive Health Uganda. Dora Kiconco Musinguzi of UGANET supported the team with legal expertise. NAFOPHANU warmly appreciates this commitment and input from all of you.

Further recognition is the contribution of the NAFOPHANU secretariat staff led by Ms. Stella Kentutsi and Margaret Happy who tirelessly worked with the auxiliary Survey Consulting team from the Sciences Research Consortia (SRC) led by Richard Batamwita, Philip Kasibante and Bernard Baitwababo, to execute core study activities. We are grateful to the wide-ranging experience in research and program components that they shared in the execution of PLHIV Stigma Index in Uganda.

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Thanks to National Empowerment Network of People Living with HIV/AIDS in Kenya(NEPHAK) for all the support during the learning visit that heralded the surveyin Uganda

Lastly, NAFOPHANU would like to acknowledge the invaluable role executed honourably by the PLHIV who collected the data, coordinated the data teams in selected districts and respondents who provided very useful information and without whom, the survey would have been in vain.

Stella Kentutsi
Executive Director, NAFOPHANU

Executive Summary

UNAIDS defines HIV-related stigma and discrimination as "a process of devaluation' of people either living or associated with HIV and AIDS; Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status"[1]. The Uganda National HIV Prevention Strategy (2011-2015)[2] identifies stigma as a key driver of the epidemic and under the outcome of strengthened sustainable enabling environment, efforts should mitigate underlying factors that drive HIV epidemic targets to eliminate stigma and discrimination by 2015"

Several reports (3 4 5) have consistently documented that HIV related stigma is highly prevalent. No matter the form in which stigma is measured, its effects are largely negative and grossly affect the quality of life of People Living with HIV (PLHIV).[6] Most commonly, it restrains prevention, treatment care and support interventions. The reports have explicitly indicated that stigma is poorly understood and therefore not well measured because of its complexity

The PLHIV Stigma Index presents such an opportunity to permit comparison of levels of stigma despite the diversity of settings and populations. According to PLHIV Stigma Index User guide[7] "People living with HIV often face stigma and discrimination. Many do not know what their rights are and how they can help to change things for the better. The PLHIV Stigma Index is not only a Survey but a project that has been developed and implemented by, with and for PLHIV. In Uganda, this is the first stigma index (Base year) and will serve as a baseline for subsequent related surveys so as to monitor trends HIV related stigma in follow up years.

The main aim of collecting this information and presenting it in the form of an index is to broaden understanding of the extent and forms of stigma and discrimination faced by PLHIV in different countries. Within Uganda, a deeper understanding of the current stigma levels, forms and trends could help NAFOPHANU together with other country programs to design interventions that will address the problems and promote PLHIV rights in specific contexts. Broadly, the information collected will serve as an evidence-base and tool for critical advocacy activities to promote the rights of PLHIV and effect positive change. Among the immediate outcome(s) is an empowered process of PLHIV for greater and meaningful involvement in HIV prevention, care, and treatment and advocacy activities. The long term outcome is to reduce stigma and discrimination. Specifically, the information will help to inform the development and implementation of national policies that protect the rights of PLHIV as well as shape the design of programmatic interventions so that they consider the issue of HIV-related stigma and discrimination within their content/context. The study adopted a blend of approaches that included documentary review, learning visit to Kenya, a standard cross-sectional survey and documentation of a few case studies. A standard structured cross-sectional survey design provided by Global Network of People Living with HIV (GNP+), International Community of Women Living with HIV (ICW), International Planned Parenthood Federation (IPPF)

1.UNAIDS: UNAIDS Fact sheet on Stigma and Discrimination, 2003

2.The Uganda National HIV AIDS prevention Strategy, 2011-2015

3.Macquarrie K, and Nyblade L. (2006) Can we measure HIV/AIDS stigma and discrimination; Current knowledge about quantifying stigma in developing countries ICRW, Policy Project

4.Sean. DY, Zdenek H. (2010) HIV-related stigma, social norms and HIV testing in Soweto and Vulindlela, South Africa, J.cquar Defic Syndr

5.Parker R, Aggleton P, Attawell K, Puerwitz J, Brown L. (2002)HIV/AIDS related stigma and discrimination: A conceptual Framework and agenda for action, Horizon Program

6.Mahaja AP, Sayles JN, Patel VA, Remien RH, Ortiz D, et al (2008) Stigma in HIV/AIDS Epidemic: A review of the literature and recommendations for the way forward. AIDS 22:S67-S79

7.The People Living with HIV Stigma Index User Guide, developed by GNP+, ICW, IPPF and UNAIDS

and UNAIDS was adopted for this Survey. Specific methodological steps were derived from the accompanying PLHIV Stigma Index User Guide.

An innovative data collection method - shared filling process (side-by-side interviewing), with flexibility for probing and prompting by either the interviewer or interviewee was implemented. The approach was participatory to allow eliciting of sensitive information. A sample of 1110 PLHIV was determined to be statistically adequate to represent the PLHIV in Uganda. The calculation adopted was based on the current number of PLHIV (1.2 million persons in Uganda). Different regions in Uganda were represented and this was on the basis of the eight regions in Uganda as per NAFOPHANU clustered regions. Data collection was conducted in December 2012 and January 2013 by experienced and trained PLHIV.

Though stigma is still prevalent, its manifestation and continuum has changed from widespread social exclusion as it was before antiretroviral therapy. Owing to initiation of ART[8] clients experience change in physical health functioning which predicts a positive longitudinal change on measures such as internal stigma. The commonest forms of stigma and discrimination are gossip 60% (666) followed by verbal harassment, insults and or threats 37% (411). The Uganda findings are consistent with findings from other African countries that have recently rolled out the PLHIV Stigma Index. ([9] [10] [11] [12]) Proportions for exclusion in different settings range between 2 to 5%.

Social exclusion: Social exclusion is still prevalent at different levels, for instance exclusion at social gathering was reported at 16% (177), at religious functions; 7% (77) and at family activities; 10% (111) in the last 12 months. The 68% (126), n= 185 of those who reported exclusion said it was due to HIV status. Gossiping was the most prevalent form of stigma with 60% (666), n=1110 of the PLHIV perceiving being gossiped about at least once within the last 12 months.

Internal stigma and fears: Internal stigma is quite high in the sampled population. Many PLHIV had low self esteem and blamed themselves for being affected by HIV. For instance, blame as an aspect of internal stigma was experienced by similar proportions of 50% (205) vs 50% (203), n=408. In the last 12 months, the main decision made by PLHIV was not to have children, more female 56% (326) than males 44% (261), n=587 preferred not to have children.

Access to work: Twenty three percent (255), n=1110 of the PLHIV reported losing jobs or incomes within the past year preceding the survey. About 8% (89) of the respondents reported that they had encountered refusal to work in the previous 12 months. Discrimination by either co-worker or employer was cited by 24% (267).

Poverty among PLHIV: The income levels are generally low, 60% (666) earned less than USD 100, one fifth (222) reported that they earned between USD100 to USD300; and about 18% (200) reported earning more than USD300 on a monthly basis. (1 USD=2600 Ug SHS). With regard to having food, majority 71% (789) of the respondents reported lacking sufficient food between one and seven days. These findings portray a very challenging situation that would require tangible support from multiple players.

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[8] Wagner GJ, Ghosh-Dastidar B, Garnett J, Kityo C, Mugyenyi P. (2012) Impact of HIV Antiretroviral Therapy on Depression and Mental Health among Clients Living with HIV in Uganda. Psychosom Med

[9] Network of Networks of HIV Positives in Ethiopia (NEP+ 2011) Ethiopia PLHIV Stigma Index

[10] National Empowerment Network of People Living with HIV and AIDS in Kenya (NEPHAK,2011) Kenya PLHIV Stigma Index Assessment

[11] Network of People Living with HIV in Nigeria (NEPWHAN, 2011) Nigeria PLHIV Stigma Index Assessment

[12] The National Association of People Living with HIV and AIDS in South Africa (NAPWA SA, 2012), South-Africa PLHIV Stigma Report

Testing and diagnosis: The commonest 35% (385) reason for undertaking an HIV test was ascribed to illness or the death of husband/wife or partner. However, a slightly lower number (32% (363) revealed that they just wanted to know their status. Other reasons included referral due suspected HIV-related symptoms (13% (144)), pregnancy (10% (105), and referral due to a sexually transmitted infection 7% (75). A small proportion, 2% (20) tested because of employment demands.

Disclosure and confidentiality: The majority of the respondents 81% (899) had disclosed their HIV status to health care worker, PLHIV colleagues 77% (855), social workers 72% (800), and their partners 61% (678). It was revealed that 4% (45) of PLHIV had their HIV status disclosed to the husband/wife by someone else without their consent. Similarly, 7% (78) mentioned that a health care professional had ever told other people about the PLHIV status without their consent.

Treatment: At the time of the survey, 88 % (976) of the respondents were on antiretroviral therapy (ART) and that could be the reason for rating their health condition in the range of fair to excellent. Most 95% (1054) mentioned that they had access to treatment whenever they needed it. Similarly, 66% (733) of PLHIV had constructive discussion with a health care professional(s) on issues such as one's sexual and reproductive health, sexual relationship(s), emotional well-being and drug use. Male respondents reported a higher proportion than the female respondents in holding constructive discussion with health professionals on these subjects.

Rights, laws and policies: The proportion of respondents who had heard of the national HIV/AIDS Policy which provides guidelines on the rights of PLHIV was less than half (41% (433). Overall respondents 87% (961) reported having not experienced discriminatory practices in the last 12 months, save 6 % (66) that reported having been forced to submit to a medical or health procedure including HIV testing.

Effecting change: Among PLHIV who reported experiencing violation of their rights, only 25% (61), n=254, attempted to take a legal action against those who violated them. A slightly higher proportion, 48% (122) have confronted, challenged or educated someone who was stigmatizing and/or discriminating.

Having children: Almost all PLHIV reported to have child/children (90%,) male and (96%) female n=1110, of these children, 24% (261) of them were reported HIV positive. Out of the 261 positive children, 148 were biological children and 14% (20) were for other PLHIV. Sixty seven percent (742) PLHIV reported to have received counseling about reproductive options after being diagnosed HIV-positive. Thirty three percent (365) reported that they have been advised by health care professionals not to have children after being diagnosed as HIV-positive. Eleven percent (121) reported to have been forced by health workers to undergo sterilization because of their HIV positive status.

Follow up Post-Interview; Nineteen percent needed referral for specific support; slightly more females 20% (111) Vs 17% (95) needed referral than males. It was noted that 19% (211) needed legal support. About 50% (555) needed other types of support; other forms of support included; nutrition, counseling and general financial support. The steps which most interviewers undertook to help those who needed help included giving sufficient information about referral (62%), promise to give further information (9%) and the rest indicated that further follow up was required.

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Recommendations

The recommendations are made in light of the changing face of stigma in the Ugandan context, the low levels of knowledge about human rights that relate to HIV, PLHIV's inabilities to effect changes, and the countless challenges faced, including lack of access to adequate food and generally poverty. Below are specific recommendations for the major players (NAFOPHANU, Civil Society Organizations (CSO) and Uganda AIDS Commission. Many of the recommendations are derived from the findings but also from literature reviewed.

NAFOPHANU

Owing to the current and anticipated roles of NAFOPHANU as a key player that brings together PLHIV networks in Uganda, the following recommendations which are derived from the key findings are proposed.

- Widely disseminate the findings of the PLHIV Stigma Index firstly to Uganda AIDS Commission and other Government of Uganda Ministries, Departments and Agencies, Civil Society Organisations, UN agencies, AIDS Development Partners, PLHIV networks and the general public including the academia and press.
- Utilise the current PLHIV networks to advocate for the rights of PLHIV and empower them to assert their rights. Because of the network set up, it is relatively easy to empower members with specific knowledge and skills in advocacy and knowledge about their rights as PLHIV
- Advocate and conduct sub group studies of stigma for; religious leaders, key populations, Women and Young Positives. HIV related stigma was relatively more complex in these sub groupings. Also plan to conduct a similar exercise in 2 to 3year's time.

Civil Society Organisations

The CSO has made a huge contribution in broad aspects of addressing HIV stigma in Uganda. The following recommendations are focused on such contribution and their anticipated roles with respect to HIV stigma reduction intervention in Uganda. The recommendations reflect both the key findings as well as literature reviewed.

- Provide updated accurate information about HIV disease patterns, infection trends, treatment options and reproductive health matters that are related to HIV.
- Increase access to MARPS friendly services including religious leaders, as unique and complex stigma was depicted in these sub groups

Uganda AIDS Commission (Government of Uganda)

As per its policy mandate, the Uganda AIDS Commission is charged with coordinating multi-sectoral policy issues and activities from both public and private sectors. With this in mind, the following Policy Level recommendation is made.

- The government's efforts in measuring trends in comprehensive knowledge about HIV, accepting attitudes towards those living with HIV, Personal knowledge and discrimination, attitudes towards negotiating safer sex relation is quite commendable. It is recommended that such indicator surveys continue to be implemented to monitor trends in broad domains of stigma reduction.
- Rejuvinate AIDS competence programme
- Develop Anti-stigma policy

1.0 Introduction

This report presents the results of PLHIV Stigma Index in Uganda as conducted by the National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU). The results will provide a baseline for Uganda and will be utilized as evidence that can be used as an advocacy tool for effecting changes in the national HIV and AIDS response more especially on stigma and discrimination reduction and will further be used as benchmark for subsequent studies. The PLHIV Stigma Index has been conducted in other countries using a standard questionnaire and methodology, the survey is led by PLHIV in the respective countries.

NAFOPHANU was established in May 2003 with a country wide mandate as an umbrella organization for People Living with HIV&AIDS to provide systematic and all inclusive coordination structure for PLHIV networks, associations and support groups in order to play advocacy, policy and decision making roles in the HIV and AIDS partnership. NAFOPHANU envisions a population of people living with HIV able to live a quality and sustainable life 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.

With support from UNAIDS Uganda Country Office, NAFOPHANU rolled out the PLHIV Stigma Index Survey in Uganda. The survey was to support an evidence base and tool for critical advocacy for activities to promote and protect the rights of PLHIV, and reduce stigma and discrimination. This initiative also backs the UNAIDS Vision of "Zero New Infections, Zero Stigma and Discrimination and Zero AIDS Related Deaths". The Agency was also engaged in literature review of specific reports of countries that recently rolled out the PLHIV Stigma Index in the region such as Kenya, Swaziland, Malawi, South Africa, Nigeria, Ethiopia and other relevant documents.

1.2 Background on HIV-related stigma and discrimination in Uganda

According to Universal Declaration of Human Rights[13] Article 2, provides for non discriminatory practices. 'Everyone is entitled to all the rights and freedoms set forth in this Declaration", without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

From the early days of the epidemic, HIV stigma and discrimination and gender inequalities were identified as obstacles to effective response to HIV[14]. Until today, stigma and discrimination threatens the possibility of achieving an AIDS Free Generation by 2015 as stipulated in the National Strategic Plan 2011/12-2014-15 and UNGASS Declaration 2011. Reducing stigma and discrimination could go a long way in contributing to an AIDS free generation. The AIDS Free Generation can only be achieved by stakeholders working together to attain the goal of universal access to HIV prevention, treatment care and support. This was reinforced by the World AIDS Day 2012 Declaration which states, among its key principles, 'Ending stigma and discrimination against People Living with HIV and key populations'[15]. UNAIDS defines HIV-related stigma and discrimination as "a process of devaluation' of people either living or associated with HIV and AIDS; discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status" [16]

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[13] http://www.un.org/en/documents/udhr/index.shtml (Accessed 18 March 2013)

[14] Piot P, (2006) How to reduce the stigma of AIDS: Key note address, Symposium at the XVI International AIDS Conference, Toronto

[15] World AIDS Day Declaration, PEPFAR Blueprint 2012

[16] UNAIDS: UNAIDS fact sheet on stigma and discrimination, 2003

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Availability of Antiretroviral Therapy (ART) has made an important breakthrough in the management of HIV and AIDS[17]. This has to a large extent influenced the way communities perceive HIV stigma and discrimination. However, this treatment requires very high levels of adherence to medications which can be achieved through a stigma free environment to foster benefits of improved quality of life to the individuals and to public health as a whole.

World over, HIV stigma and discrimination are recognized as barriers to achievement of universal access to quality healthcare services to those who need these services. HIV stigma and discrimination is manifested by keeping those who need HIV services away from these services by perceived or actual HIV Status (stigma and or discrimination).[18] . This is manifested in health care, family, community and work place settings.

1.3 Uganda situation

In Uganda, prevalence of HIV has ranged between 6-7%[19] in the general population for the past 10 years. However, recent reports have indicated that the epidemic upsurged[20] . 'The prevalence rates i.e. proportion of Ugandans, age 15-49, who are infected has risen and now stands at 7.3% (and even higher in women at 8.3%), and up from 6.4% in the 2004-05 survey. To crown it all, the estimated number of new infections has been rising steadily: from 124,000 in 2009; 128,000 in 2010; to now 130,000 in 2011'[21] . Currently, there is renewed effort to curb new infections by aligning intervention to the drivers of epidemic. The National target is to have a 30% reduction in the new infections by 2015. The National HIV/AIDS Strategic Plan 2011/12-2014/15(NSP) vision addresses stigma and discrimination components as;

"A Uganda where new HIV infections are rare, and where everyone, regardless of age, gender, ethnicity or socio-economic status has uninterrupted access to high quality and effective HIV prevention services free from stigma and discrimination ".[22]

In Uganda, HIV has been known over the past three decades, However, the Uganda AIDS Indicator Survey 2011 suggests that stigma and discrimination is still a force to reckon with. To note are some positive aspects for instance from the AIS, a population-based survey, 93% of men and 92 % of women were willing to care for a family member with HIV. However on the downsize, 21.6 % of men and 16.8 % of women felt PLHIV should be ashamed of themselves, while 22 % of men and 18.3 % of women agreed that those with HIV should be blamed for bringing the disease to community[23] . Similarly, about 32% revealed that if a family member got AIDS, they would not necessary want it to be a secret, meaning they would either disclose or would wish this person discloses. A study conducted among HIV-infected men and women who were clients of The AIDS Support Organization (TASO) to determine the social predictors of disclosure as well as to explore and describe the process, experiences and outcomes related to disclosure revealed[24] that disclosure of HIV serostatus to sexual partners supports risk reduction and facilitates access to prevention and care services for People Living with HIV/AIDS.

17.Siegfriend, Uthman and Rutherfort (2010) Optimal Time for Initiation of Antiretroviral Therapy in Asymptomatic HIV-Infected , Treatment-Naïve Adults (Review). Cochrane Database of Systematic Reviews, 2010, Issue 3 No.CD008272. DOI:10.1002

18. Surlis S, Hyde A (2001): HIV-positive patients' experiences of stigma during Hospitalization. Journal of the Association of Nurses in AIDS Care,12(6), 68-77

19. Uganda Sero Behavioral Survey 2005

20. Uganda AIDS Indicator Survey 2011

21. Vinand Nantulya 'Our HIV/AIDS Epidemic: What each one of us must do?' 2012

22. Uganda National HIV AIDS Prevention Strategy 2011-2015

23. Uganda AIDS Indicator survey, 2011

24. King R, Katuntu D, Lifshay J, Packel L, Batamwita R; Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda.

1.4 Effects of stigma

The fear of stigma and discrimination affects the uptake of HIV services. Multiple studies in Sub-Saharan Africa provide evidence that people have experienced stigma and discrimination as a result of receiving an HIV positive test result thus influencing the uptake of these and similar services[25] . This has played a negative role in the uptake of HIV services. Several studies have documented that women are more prone to stigma and discrimination than men, but men too have been found to suffer this unjust treatment especially in healthcare settings.[26] However, because of gender inequality, women often are more affected and fear to disclose for fear of violence from male partners. For instance, with the era of elimination of Mother to Child HIV Transmission (eMTCT), pregnant women must as part of antenatal services take an HIV test which comes with benefits as well as consequences for sero-positive status[27] . Women were found to experience both perceived stigma and discrimination as a result of utilizing PMTCT services.[28]

The Mode of Transmission Study[29] observes that Human rights, Stigma and discrimination are among contextual risk factors that drive the HIV and AIDS epidemic. Double stigma has been faced by some minority groups in society as a result of sexual orientation and sex-related work. The groups affected are very high-risk populations - including sex workers and men who have sex with men (MSM) which hinders the fight against HIV.

Involvement of PLHIV has increasingly been sounded as one of the ways to reduce stigma and discrimination within different settings[30] . It has also been noted that it is important to involve communities[31] at different levels to understand the dimensions of HIV stigma and discrimination and include them in the fight against the vice.

1.5 Survey justification

The findings of the PLHIV Stigma Index survey are meant to;

1. Enhance multi sectoral response to HIV and AIDS based on the results of PLHIV Stigma Index to feed into the UNAIDS vision of ***"Zero New Infections, Zero Stigma and Discrimination and Zero AIDS Related Deaths".***

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[25] S C Kalichman, L C Simbayi; HIV testing attitudes, AIDS stigma, and voluntary HIV counseling and testing in a black township in Cape Town, South Africa; Sex Transm Infect 2003;79:442–447

[26] Simbayi, L. C. et al.; Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. Social Science & Medicine, Vol 64(9), May 2007, 1823-1831.

[27] Eide M; Social Consequences of HIV-Positive Women's Participation in Prevention of Mother-to-Child Transmission programmes; Patient Education and Counseling; Volume 60, Issue 2 , Pages 146-151, February 2006

[28] Nyblade L and Field M.L 2000. ―Women, Communities and the prevention of mother-to-child transmission of HIV: Issues and findings from community research in Botswana and Zambia, ICRW Report-in-Brief. Washington: International Center for Research on Women.

[29] Uganda AIDS Commission; Uganda HIV Modes Of Transmission and Prevention Response Analysis (2009)

[30] Madan, Y. et al. 2006. ―Active involvement of PLAs to design and develop mass media campaign to address stigma and discrimination related to HIV and AIDS, PSI Zimbabwe; poster presented at PEPFAR Annual Meeting, Durban, South Africa.

[31] Chen, J. et al. 2005. ―Community environment and HIV/AIDS-related stigma,―AIDS Education and Prevention 17(1): 1–11.

2. Provide various stakeholders with a better and deeper understanding of the current stigma levels, forms and trends that is needed to design interventions that will address the stigma and discrimination, promote and protect the rights of PLHIV.
3. Serve as an evidence-base tool for critical advocacy intervention to promote the rights of PLHIV and reducing stigma and discrimination.

1.6 Objectives of the Survey

1.6.1 The main objective

The main objective of Index survey was to document stigma and discrimination related to HIV and AIDS and provide evidence that can be used as an advocacy tool for effecting changes in the national HIV and AIDS response.

1.6.2 Specific objectives

1. To find out the experiences of PLHIV regarding stigma and discrimination in Uganda
2. To provide evidence for the review/development and implementation of national policies and legal frameworks that protect the rights of PLHIV
3. To compare trends, forms, and levels of stigma and discrimination in Uganda and other countries that have carried out PLHIV Stigma Index survey.
4. To provide evidence for programmatic interventions to effect changes

2. Methodology

2.1 Introduction

This survey adopted a phased approach that included document review, learning visit to Kenya, a comprehensive cross section survey and documentation of selected case studies.

2.2 Survey Design

This was a cross sectional survey that used mainly quantitative methods. The standard methodology developed by ICW, IPPF, GNP+ and UNAIDS was adopted. The questionnaire was translated into 8 local languages (Luganda, Lusoga, Ateso, Lumasaba, Luo, Lugbara, Runyoro/Rutoro and Runyankore/Rukiga). The broader conceptual issues covered background characteristics, experiences of stigma and discrimination and experiences of HIV testing, disclosure, treatment and having children.

2.3 Scope of the survey

Geographically, the survey was conducted among PLHIV in the eight NAFOPHANU clustered regions of Uganda[32] . 18 districts were purposively selected and they included Arua, Maracha, Lira, Ngora, Soroti, Bududa, Mbale, Mayuge, Kamuli, Masaka, Kayunga, Mityana, Ntungamo, Isingiro, Kabarole, Masindi, Wakiso and Greater Kampala. Other institutions considered included the Uganda Peoples Defence Forces and Uganda Prisons. In terms of time scope, retrospective experiences were limitted to the last one year before the survey. The past one year is indicative of current situation, stigma experiences related to current stigma continuum. The conceptual scope covered the lived experiences of PLHIV on aspects of stigma and discrimination in broader domains of access to care and treatment services, employment, reproductive rights and effecting change.

2.4 Target population:

The target respondents for this survey were PLHIV drawn from rural and urban settings. All respondents were 18 years and above and were either members of a network of PLHIV or non members but with a link to an established registered network within Uganda. The respondents included women and men, young persons representing the general population. Key Populations (Uniformed Personnel, Long Distance Truck Drivers, Sex Workers, Injecting Drug Users (IDUs), Men who have Sex with Men (MSM), sex workers, fishing community, refugees and Lesbian Gay Bisexual Transgender and Intersexual (LGBTI)[33] . Other specific cohorts of the religious leaders, teachers and Persons with Disabilities (PWD) were also included in the survey.

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[32] NAFOPHANU clustered 8 regions for coordination purposes; West Nile, Northern, Central I, Central II, Western, South Western, Eastern, and North Eastern

[33] MSM/LGBTI categories are part of key populations

A total of 1110 interviews were pre-determined from a quantitative calculation based on the reported number of PLHIV of about 1.2 million Ugandans (UNAIDS 2011 Report) using the formula below;

$$n = \frac{N}{1 + \left[(N * (e)\ 2) * 100/rr\right]}$$

$$n = \frac{1,200,000}{1 + (1,200,000 * (0.03)2\ ) * \left[100/99\right]}$$

Where, n = estimated sample size
N= Finite population size
e = level of precision

rr=Response rate

The following assumptions were taken into consideration during the size estimation

1. The population of PLHIV in Uganda estimated at 1.2 Million. This formed the finite population (N=1200000 PLHIV) upon which the registered members were obtained.

2. The permissible error (level of precision (e) allowed was set to be 3% of the key indicator variable (stigma prevalence among PLHIV)

3. The non-response rate was negligible given that the members were registered and would most likely be willing to participation. Additionally, their leaders participated in mobilizing them during the survey.

2.6 Sampling process

Determination of district samples: The number of registered PLHIV within the district was the basis for the calculation of the proportion which a particular district contributed to the overall total of 1110. A deliberate decision was made to have equal representation of females and males. From the sampling frame provided, names of females and males were separated and written out on separate sheets in Excel 2003. Thereafter, a computer program was used to randomly sample the female/male quota as per the availed list. The names of those persons which corresponded to the number generated by computer were then marked off and determined as the eligible respondent for the survey within that district. This was done for all the 18 districts and Greater Kampala. In instances where the pre-determined respondents could not be located, interviewers were required to make call backs to ensure that the particular respondent is reached. Upon total failure to locate the respondent, communication was made to the data manager who then re-run the random number program to identify the next eligible respondent. This was done to avoid interviewers replacing respondents and adhere to the pre-determined sampling.

2.7 Data collection

2.7.1 Data collection tools

The international survey methodology of the PLHIV Stigma Index questionnaire[34] was adopted with minor modification to suit the country context. Data was collected using Smart Phone Data Collection Technology. Data was collected in December 2012 and January 2013. All interviewers and team supervisors were provided with a field manual for reference throughout the field exercise.

2.7.2 Field team composition

As per guidance from standard methodology, all interviewers were PLHIV both male and female with varying education backgrounds and professions. The rationale behind using this specific team is reflected in the quote from a South African as *"being interviewed by another person living with HIV does make a difference - as you feel they really would understand more about how you feel about things related to being HIV positive"*

2.7.3 Training of data collection and supervision

Data teams had a 3-day tailored training in data collection and management prior to the survey.

The management of the survey had a five tier structure; from national level to field teams at the bottom. The research team comprised, principle liaison person, who communicated directly with NAFOPHANU, data management teams, Quality control supervisors and PLHIV who collected and mobilised in the field.

2.8 Learning experience from Kenya

Before the roll out phase, representatives from NAFOPHANU secretariat and Board, a UNAIDS official and the consulting team went to a learning visit in Kenya. The main purpose of this visit was to learn from the Kenyan team the methodological and implementation aspects of the PLHIV Stigma Index which they had completed the previous year. Three Agencies were visited; National Empowerment Network of People Living with HIV and AIDS in Kenya (NEPHAK), the National AIDS Control Council Kenya (NACC) and Her Story Centre. The visit to Kenya informed methodological and implementation aspect of the survey in Uganda and provided detailed experiences of how to roll out PLHIV Stigma Index which the Uganda team adopted. Firstly, the five tier implementation structure was a significant component and the Ugandan team adopted it. During the same visit, key stigma program commendable aspects were noted including; the team learnt that in Kenya an HIV Tribunal exists and a Key Populations Desk in NACC were set up. Additionally, sub studies with sex workers and religious persons had been embarked on following results and recommendations from the Kenyan Stigma Index. National guideline for HIV/STI program for sex workers have been fully implemented with commendable results.

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[34] . www.stigmaindex.org downloaded May 2012

2.9 Study management and implementation arrangements

At the national level, a National Steering Committee (NSC) was formed and charged with an oversight role for Stigma Index in Uganda. Below NSC was the Technical Working Group (TWG) whose membership comprised of only networks of PLHIV drawn from difference network organanisations within Uganda. The TWG roles were to provide technical guidance, working closely with consulting team. Several meetings focusing on the technical issues were discussed and consensus reached by this team before, during and after study execution. Below the TWG were a team of NAFOPHANU secretariat core staff and a team of study consultants. The NAFOPHANU staff and the consulting team's main role was to execute all the survey processes such as; registering the study with relevant ethical bodies, overseeing data collection through the team of PLHIV, data management and writing the technical report as well as reporting. During the reporting, phases, a team of academicians were asked to peer review the written drafts, before a verification of the findings by the several other stakeholders including the data collectors themselves.

The following are the team members at each implementation tier. At the National level, NAFOPHANU constituted a 10 and 8-member TWG and NSC respectively. The survey had 10 field teams comprised of 2-5 members each. The lead consulting team was comprised of 6 technical persons.

A pre-test was conducted in neighbouring townships of Nansana, Nabweru and Kazo in Wakiso District to inform final preparation of the survey implementation.

2.10 Data analysis

Data from Smart phones[35] was stored on a secured server and later transformed into SPSS V.15 for subsequent analysis. After thorough logical cleaning, analysis was implemented starting with explorations of all variables using descriptive procedures. This was followed by generation of cross tabulations. Following the User Guide and mindful of the objectives to be answered, advanced analysis techniques were not executed for this report. It is however observed further specific analysis using the same data could be derived for specific sections.

Data was weighted based on gender to normalize the sample (0.78 for females 1.39 for males) weighting factors respectively. This systematically leveled off any anticipated gender imbalances (over estimation due to representation) for the general population. However, both the weighted and un weighted data did not significantly differ. It was also deemed necessary to separately consider the respondents that self reported themselves as transgender[36] (14 persons) and their responses are considered separately.

Validation and review process was conducted by the NAFOPHANU secretariat in conjunction with UNAIDS TWG, NSC, UAC and UNAS respectively.

2.11 Ethical Considerations

2.11.1 Survey approval

The PLHIV Stigma Index Survey in Uganda obtained ethical approval from Mildmay Uganda Research and Ethical Committee (MUREC). Mildmay is a centre engaged in HIV, care, treatment and training of health workers in HIV/AIDS services and research. The Survey was also registered with the Uganda National Council for Sciences and Technology as per the laws governing research in Uganda (Registration Number SS3013)

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[35] Smart Phones: In our context, referred phones, with application futures that enable reprogramming to host the electronic questionnaire, permit instant data collection, submission to a secured server real time. It also served as quality control devise as GPS points and consistency in question lay out with conditional validation rules.

[36] Transgender is an umbrella term that includes transsexuals and transvestites. A transsexual is someone who may be born biologically male, yet has a female gender identity or be born a female and yet define themselves as a man. A transvestite is a man who likes to wear female clothes and adopt traditionally female characteristics

2.11.2 Participants' consent

Before commencement of any interview, interviewers were required to read the information sheet to the respondents. This was followed by reading the consent form and seeking voluntary consent. Interviewees were informed of their freedom of only using initials if they so wished on the consent signatory section. A copy of the information sheet was given to the respondent.

2.11.3 Confidentiality

During and after data collection, participants' information remained confidential. Secondly, interviewers did not have chance to look at the data after it was sent through Smart Phones to the secured server. During training and pretesting, interviewers were cautioned on the need to have maximum respect for interviewees and to uphold values of confidentiality given the sensitivity of the information. For all who had access to data, ethically and legally binding confidentiality forms were signed before data collection.

2.11.4 Compensation

Owing to transport challenges that were anticipated to be incurred by the interviewees as way to have privacy in some locations, the survey managers agreed to have standard fee of Uganda shillings three thousand (3000) per participant interviewed. 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.

2.11.5 Follow up Post-Interview

Interviewers were asked to note issues that need referral and on-going support for more empowerment and linkages to services and other PLHIV networks.

3. Results

3.1 Report structure

Following on from the executive summary, introduction and methodology, this report follows the content of the questionnaire and is divided into 3 sections.

Section 1: Background characteristics about the respondent and his/her household.

Section 2: Experiences of HIV-related stigma and discrimination; forms of stigma; the protection of the rights of PLHIV through law, policy and/or practice.

Section 3: Experience of testing, disclosure, treatment and having children.

Finally, recommendations and conclusions are presented

The naming convention of tables uses a prefix of the section

Uganda

Section 1: Background characteristics of respondents

This section presents the background characteristics of the respondents. A total of 1110 respondents participated in the survey. The total number which participated was exactly the predetermined sample size. Table 1.1 presents the socio-demographic characteristics of respondents.

Table 1.1 Background characteristic of the sampled respondents by gender

Background characteristic	Male Number	Percent	Female Number	Percent	Total Number	Total Percent
Category						
Youth	51	4.6	65	5.8	116	10.5
Sex workers	11	1	30	2.7	41	3.7
Civil servants	82	7.4	89	8.0	171	15.4
General population	292	26.2	321	28.8	613	55.2
PWDs	15	1.3	13	1.2	28	2.5
Truck drivers	13	1.2	0	0.0	13	1.2
Fishing community	4	0.4	5	0.4	9	0.8
Armed forces	40	3.6	13	1.1	53	4.8
LGBTIs	7	0.6	2	0.2	9	0.8
Religious leaders	21	1.9	14	1.2	35	3.1
IDUs	20	1.8	2	0.2	22	2.0
Total					***1110***	***100***
Age						
18-19 years	17	1.5	17	1.5	34	3.1
20-24 years	23	2.1	42	3.8	65	5.9
25-29 years	35	3.2	57	5.1	92	8.3
30-39 years	139	12.5	193	17.4	332	29.9
40-49 years	207	18.6	165	14.9	372	33.5
50+ years	134	12.1	81	7.3	215	19.4
Total					***1110***	***100***
Marital status						
Married /cohabiting living together	354	31.9	184	16.6	538	48.5
Married /cohabiting but temporarily not living together	53	4.8	54	4.9	107	9.6
In relationship but not living together	33	3	48	4.3	81	7.3
Single	52	4.7	53	4.8	105	9.5
Divorced/separated	29	2.6	61	5.5	90	8.1
Widow/widower	32	2.9	156	14.1	188	17.
Total					***1109***	***100***
Type of employment						
In full-time employment (as an employee)	99	8.9	47	4.2	146	13.2
In part-time employment (as an employee	49	4.4	47	4.2	96	8.7
Working full-time not as an employee (self employed)	181	16.3	118	10.6	299	27
Doing casual or part-time work (self-employed)	166	15	197	17.7	363	32.7
Unemployed and not working at all	60	5.4	145	13.1	205	18.5
Total					***1109***[37]	***100***

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[37] In some cases, totals may not add up to 1110, this means that one or more respondents never provided a response to that particular question.

3.1: Sub categories of the target population

Majority of the respondents 55% (613) belong to a general population that comprise of peasants, business owners and self employed persons. The civil servants accounts for about 15% (171) of the total respondent and they are almost equally distributed between males and females. The youth account for 11% (116) with females more than males 6% (65) vs 4.5% (51). In this sample, the most at risk groups such as sex workers 4% (41), LGBTI 1% (9), and IDU 2% (22), Armed Forces 5% (53) were also represented in varying proportions.

3.2 Age categories

Majority of the respondents were in the age category of (40-49 years). Adults aged 50 and above years accounted for close to 20% (215). Marital status among the sample also varied. The married/cohabiting category was the largest 49% (538) but also a large proportion 25% (278), n=1110 were either divorced or separated or widowed.

3.3 Employment status of respondents

High levels of unemployment 18% (205), n=1110 were revealed among the respondents. Majority, 33% (363) were self employed in part time casual employment. Only 13% (146) were in full time employment. According to the Uganda Bureau of Statistics, the percentage of individuals in the general population in paid employment is 21%, this percentage is slightly higher than this sampled population of Stigma Index survey. Those who are self employed are 79 % which is also quite high compared to PLHIV sample of 33%. Overall unemployment in the general population stands at 3.6%.[38]

3.4 Length of time respondents have lived with HIV

The respondents were asked about the duration they have been living with HIV. The time duration refers to time since the respondents knew their status. It may/may not reflect time since infection.

Duration	Male Number	Percent	Female Number	Percent	Total Number	Percent
0-1 year	49	4.4	48	4.3	97	8.8
1-4 years	139	12.5	161	14.5	300	27.1
5-9 years	202	18.2	188	17	390	35.2
10-14 years	112	10	94	8.5	206	18.6
15+ years	52	4.7	63	5.7	115	10.4
Total	**554**	**49.8**	**554**	**50**	**1108**	**100**

As shown in Table 1.2, majority 35% (390) had lived with HIV between 5-9 years. According to the results, 10% (115) reported to have lived with HIV for over 15 years. This implies that with positive living, most PLHIV are living longer.

3.5 Marital relationships

The questionnaire included questions on the duration, the respondents have been involved with their partners in relationships. This was partly to establish how many PLHIV were in relationships.

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[38] Uganda Bureau of Statistics, statistical abstract, 2012

Table1.3 Duration respondents have been involved with their partner in relationship

Duration of involvement with partner in relationship	***Number***	***Percent***
0-1 year	309	27.8
1-4 years	211	19
5-9 years	209	18.9
10-14 years	151	13.6
15+ years	230	20.7
Total	***1110***	***100.0***

According to the responses, most of the respondents 28% (309) were newly (0-1 year) involved with their partners in relationship. Almost the same proportion 34% (381) had been involved for over ten years. By implication, a 28%(309) magnitude of very recent sexual relations requires continued prevention with positive messages to be provided to these couples.

3.6 Sexual activity in the last 12 months

The survey included questions on current sexual activity of the PLHIV

Table1.4 Sexually active by gender

Sexually active in last 12 months	***Male***	***Female***	***Total***
Yes	441(79.5%)	334(60.2%)	775(69.8%)
No	114(20.5%)	221(39.8%)	335(30.2%)
Total	***555(50%)***	***555(50%)***	***1110(100%)***

According to the results shown in Table 1.4, 70% (775) of the respondents were sexually active in the preceding 12 months. The percentage of men who were sexually active in the 12 months preceding the survey was 80% (441) where as the female was 60% (334) of the total female respondents.

3.7 Belonging to most at risk sub groups

It is known that HIV infection varies within sub groups whereby some individuals are more vulnerable than others in the same population. Therefore associating with or belonging to these groups could add to the stigma and discrimination that PLHIV experience. In this Survey, one of the questions elicited responses whether; respondents currently belong or have in the past belonged to specific population subgroups.

Category	***Number of cases***	***Percent of cases***
Men who have sex with men	19	1.7
Gay or lesbian	17	1.5
Transgender	23	2.1
Sex worker	51	4.6
Injecting drug user	36	3.2
Refugee or asylum seeker	10	0.9
Internally displaced person	25	2.3
Migrant worker	22	2.0
Prisoner (in mates)	54	4.9
Don't belong to any of these categories	853	76.8
Total	***1110***	***100***

According to the results in table 1.5, 77% (853) of the PLHIV said they did not belong to any of the population subgroups, and 8% (87) were in the high most at risk categories such as sex workers and injecting drug users, all combined. Those who revealed, that they were men having sex with men, lesbians or gay and transgender accounted for 5% (59).

3.8 Level of education

Table1.6 Distribution of respondents by level of education

Level of education	Male	Female	Total
No formal education	8.0	8.7	16.8
Primary school	27.1	21.8	48.9
Secondary school	18.6	8.4	26.9
Technical college/university	5.7	1.7	7.4
Total percent	***59.4***	***40.6***	***100***
Number of cases			***1110***

Level of education is one of the important indicators of self awareness and may influence other social and social cultural values including life situations. The result shown in table 1.6, majority, 49% (543) of the respondents' level of education was primary school 24% (266), male vs 26% (288) female). Those who had no formal education at all, accounted for, 17% (188). Those with technical college/university education were only 7% (71 males vs 17 females). Generally at high levels, males are more educated than females which could explain the differences in gender-based assertiveness. In addition, the 7% of the persons with high levels of education does not imply that people at that level do not live with HIV; it is only because they rarely join networks of PLHIV and therefore could not be reached by the survey.

3.9 Location of PLHIV Households

The survey asked about location of household of the respondents as this could have a link with levels and forms of stigma. The distributions show that majority of the respondent were coming from small towns 54% (600) followed by rural areas 40% (442) and the rest were from large towns.

3.10 Average monthly income

Poverty, among other factors, is one of the key issues affecting the lives of PLHIV. Thus, the respondents were asked about their levels of income on a monthly basis

Table1.7 Distribution of respondents by average monthly income of their households

Monthly income (UGX)	Number	Percent
1- 50,000	301	27.1
50,001-100,000	131	11.8
100,001-150,000	68	6.1
150,001-200,000	62	5.6
200,001-300,000	99	8.9
300,001-400,000	80	7.2
400,001-500,000	63	5.7
500,001-600,000	49	4.4
600,001-700,000	8	0.7
700,001-800,000	25	2.3
800,001-900,000	9	0.8
900,001-1,000,000	19	1.7
Above 1,000,000	113	10.2
None	83	7.5
Total	***1110***	***100.0***

Table 1.7 results indicate that many 72% (804) PLHIV on a monthly basis, earn five hundred thousand shillings (500000) and below on average. A small percentage 11% (113) earn above one million Uganda shillings. It was also reported that a section 7.5% (83) revealed that they do not earn at all[39] . High incidence of poverty relates to many variables and obscures many components of the PLHIV in that care and treatment seeking can in most cases be attained if the affected person has income. This is because costs such as transport to health facilities for drug refill, purchase of recommended medicines that may not be readily available at the clinics, food requirements and other social needs require that a client must have some dependable income sources.

[39] Some 8.7% indicated that they do not earn at all, given our context, they may not be earning regular incomes but could have some form of livelihood given most people in rural and small towns are farmers. So interpretation of this component should bear that in mind.

3.11 Access to food on daily basis

Another indicator for assessing level of poverty is number of days of missed meals. Respondents were asked about the number of days within the month preceding the survey when any member of their household had no access to adequate food.

Table 1.8 Number of days in the last one month when members of their household did not have enough food

Number of days	Number	Percent
1-7 days	323	70.7
8-15 days	75	16.4
16-21 days	38	8.3
22-30 days	21	4.6
Total	**457**	**100**

In table 1.8, majority 71% (789), n=1110) of the respondents reported lacking enough food between one and seven days. Enough food refers to how many days has any member of household not had sufficient food to eat. Overall 41%,(455) of the respondents in this survey reported situation where they didnot have sufficient food.

Nutritional components play a vital role in the treatment and adherence processes. These findings portray a very challenging situation that would require tangible support from multiple players. Social support and networking forms the starting point towards any positive behavioral or health outcomes. If the basic human needs of PLHIV such as companionship and having a sense of belonging as well as economic status would improve either directly or indirectly, chances are high that they would have access to food through the networks. Even then, lack of adequate food is reflected in a person's appearance and a person who looks sickly and is known to be living with HIV is likely to attract public stigma.

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40 The 457 figures shows the total number of respondent who reported not to have enough food

Section 2: Experience of stigma and discrimination

2.1 Stigma and discrimination at family and community level

Several constructs have been used in the survey to measure the level of HIV stigma at family and community levels. The key constructs include; exclusion from social gatherings, religious activities, family activities and incidents of physical and verbal harassment/assaults that respondents experienced within the year preceding the survey.

Based on the responses given, those who had experienced the specified stigma forms were further asked about the reasons why they encountered various incidents. This was done in order to distinguish between stigma associated with HIV/AIDS and stigma related to other factors. These results are entirely based on the respondents' perceptions of the causes of stigma and discrimination.

Exclusion relates to reduction of daily social interactions, exclusion from family and community events, shunning or turning away by the public and even a breakdown in relationships. Exclusion was reported by respondents as seen from table 2.1

Table2.1 Percentage of respondents who reported stigmatization and discrimination at family and community level by the frequency in the previous 12 months

Experience in the last 12 months	*Never*	*Once*	*A few times*	*Often*	*Total respondents*
Exclusion from social gatherings	83.9	3.9	8.3	3.8	1110
Exclusion from religious activities	92.9	3.5	2.6	0.9	1110
Exclusion from family activities	90.5	2.6	4.9	2.1	1110
Aware of being gossiped about	39.5	7.5	26.3	26.6	1110
Verbally insulted, harassed and/or threatened	64.1	11.8	16	8.1	1110
Physically harassed	85.4	6.2	6.7	1.6	1000
Physically assaulted	89.7	4.9	4.2	1.2	1110

From table 2.1, 16% (177) of the respondents said that they had faced exclusion from social gatherings or activities at least once in the last 12 months prior to the survey and (68% (126),n=185). of the reason given by those who were excluded said it was related to HIV stigma. Four percent, n=185 reported that such events occurred once, (8% (15), n=185) reported 'a few times' and (4% (7), n=185) 'often'. Owing to the devastating effects of exclusion, the affected person may stop attending such events in the future or selectively which ones to attend, when and where to do so. Because exclusions bring about shame to the individual, the pain that the person feels may lead to internal stigma causing fear and blame while others may feel worthless and suicidal.

Case in point below;

Louis, 38 years, lives in Ngora district. He was diagnosed with HIV when he had gone for SMC and thus had not prepared for the news he received about being HIV positive. He rushed home, told his wife, expecting to receive support from her. Instead, she packed her things and left. Her parents, however, refused her to stay home that she had to go back to her husband and children. On return, she went for a HIV test that turned negative. From then, she stopped caring for him and it is only his children that have to give him food amidst protests from their mother. She has told friends and family the husband's status which makes it hard for him now to associate with community members. He blames himself and has considered suicide a number of times. He is hanging in there, expecting a miracle to happen to change his wife's attitude, "I trust God is looking upon me and the suffering Iam going through to send me a miracle that will reunite me with my wife despite my status."

Uganda

Exclusion from religious activities or places of worship was reported by 7% (77) of the PLHIV. Among these, respondents who said they had experienced this exclusion a few times in the previous 12 months were about 3% (3), n=77) while 2% (3), n=77) said often. Those who reported exclusion from religious activities or places of worship due to HIV related reasons accounted for 58% (45), n=77 of those excluded. The findings above could imply places of worship depict low levels awareness of HIV infection, care and support and are a fertile ground for stigma. Some PLHIV may loose trust in the places of worship and either change or stop attending spiritual gatherings yet spiritual care is one of the key care components.

Regarding the question on how often they had been excluded from family activities (eating together, sleeping in the same rooms, cooking) in the last 12 months, 10% (111) reported facing exclusion at least once in the previous 12 months. Of those that encountered exclusion, three quarters 75% (83), n=111) associated it with their HIV status. At family level, stigma may occur through isolation of PLHIV, by separation of sleeping rooms, eating utensils, clothes, not eating together and confining the HIV positive family member to home so that he/she is not seen by people in the neighborhood which increases both internal and external stigma. This is exemplified by Magarita's story

Magarita lives in Bulawoili TC, a suburb of Kamuli District. She lost her husband in 1999 due to AID and left her with five children aged 2 to 14years. She currently lives in a two roomed house with her mum who discriminates against her because of her HIV positive status and suffering from an advanced stage of Tuberculosis "My family liked me before I fell sick but now they are discriminating me to the extent of ringing a bell in the morning for me to pass, having cleared the way so that I do not infect them with HIV. I have even reached even to the extent of committing sucide as I have no one to come and support me"

In most societies, the family is the most trusted and supportive institution towards a PLHIV. If stigma of whatever form happens at this level, it will slowly degenerate into lack of respect for each other. A communication breakdown among family members may arise as the PLHIV may stop expressing their needs. Such occurrences could lead to internalized stigma. It also implies that people still lack information about HIV infection in general despite the massive awareness campaigns that have been conducted in the country previously. Above all, people are not aware of the impact of what seems to be small actions towards PLHIV for instance separation of utensils or clothes from those used by the PLHIV.

Gossiping was the most prevalent form of stigma in Uganda. According to the survey results, 60% (666) of the PLHIV are aware of being gossiped about at least once within the last 12 months prior to the survey. Gossip leads to other forms of stigma like blame and finger pointing and questioning of individual behavior. This also means that disclosure will be done selectively or not done at all. People will not be free to seek and uptake treatment. Social exclusion increases and misconceptions could continue due to gossip.

PLHIV experience other forms of stigma other than exclusion and being gossiped about such as being verbally insulted, harassed and/or threatened. For instance from the survey results, 36% (399) of the respondents had been verbally insulted, harassed and/or threatened at least once in the previous 12 months. Forty eight percent (191), n=399) exclusively attributed such an act to their HIV status while additional 30% (119), n=399) said the cause was both HIV status and other reasons. This is shown in Eddie's case where the Father still insists should be taken to police and killed.

Eddie 18 years, lives in Migadde Wakiso District. He lost his mum when he was 2years old and was brought to live with the grand mother who was with 5 other orphans. The father did not want anything to do with the innocent boy. "I used to fall sick but my grandmother only kept giving me herbs" says Eddie.His father never cared at all. One day, a community volunteer known as expert client, working with Baylor Uganda came to their home, gave the grand mum HIV testing information that was to be done in homes. The grand mother accepted and Eddie tested HIV positive. He was taken to Baylor with help from the Community Volunteer for treatment and was started on ARVs. He is doing well emotionally and physically but his father continues to request that the boy is taken to police to be killed. At the moment he stays with the Community Volunteer and has aspirations like any other boy; "I would like to be a Counsellor so that i help others in need."

Regarding physical harassment, 15% (165) said they were physically harassed at least once in the last 12 months and 23% (38), n=165 of them attributed it their HIV status and other reasons. On the other the hand, 33% said such an act was exclusively attributed to their HIV status.

Harassment especially when it happens at household level is often what is seen as domestic violence but many individuals suffer this quietly due to traditional norms for example answering back an adult or husband is talking is regarded as bad manners and luck of respect. What happens at home is not supposed to be shared or told to other people so that way people suffer silently and fail to seek support from other organizations. Stigma manifests in different forms at different levels as reported by the respondents in the

Figure 1: Percentage of respondents who reportedly encountered various forms of stigma at family and community levels by the perceived reasons for stigmatization in the last 12 months.

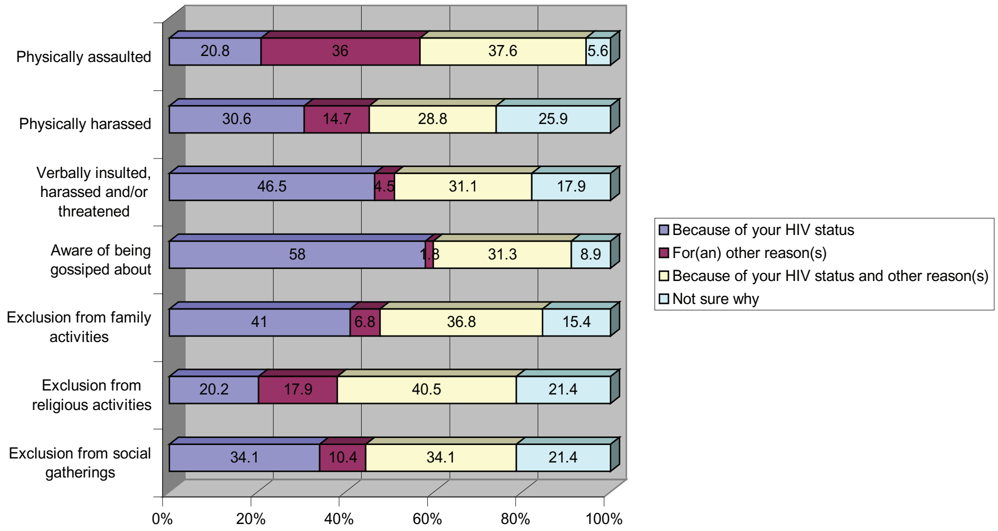
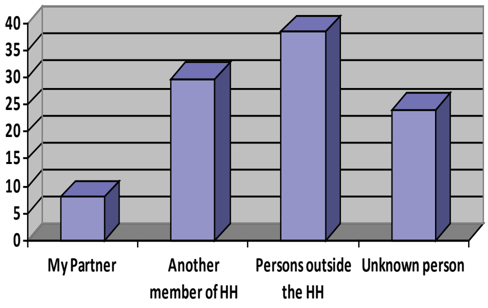


Figure 2 Percentage of respondents who have been physically assaulted by specific categories of individuals in the last 12 months



In figure 2, one respondent in every three was assaulted by another member of the household and 38% (42), n=111of the physically assaulted

were assaulted by persons outside the household but known to them. Of those assaulted, 21% (23) n=111 attributed it to their HIV status. Assault of the PLHIV could potentially reflect high levels of enacted stigma expressed by community members and gender based violence.

A number of respondents felt there were other reasons why they felt they were stigmatized or discriminated against other than their HIV status as recorded in table 2.1.1 below:

Table 2.1.1 Other reasons why respondents felt they were stigmatized

Social category	***Frequency***	***Percent***
Sexual orientation (men who have sex with men, gay or lesbian ,transgender)	7	13.5
Sex worker	16	30.8
Injecting drug user	13	25
Refugee or asylum seeker	2	3.8
Internally displaced person	2	3.8
Migrant worker	2	3.8
None of the above-it was because of an(other) reason(s)	6	11.5

Table 2.1.1 depicts other reasons why the respondents felt they were stigmatized or discriminated against other than their HIV status. It only reflects those who said other reasons other than HIV status. This would thus call for specialized intervention regarding service delivery for the key population.

Table 2.1.2 Percentage of respondents who reported various forms of stigma in last 12 months

Experience in the last 12 months	***Never***	***Once***	***A few times***	***Often***
Psychological pressure or manipulation by my Husband/wife or partner in which my HIV-positive status was used against me	81.6	7.4	7.1	3.9
Experienced sexual rejection as a result of my HIV Positive status	78.5	5.3	12	4.2
Discriminated against by other people living with HIV	87.3	3.2	7.7	1.7
My wife/husband or partner, or any members of my household experienced discrimination as a result of my HIV-positive status	81.2	5.9	8.5	4.4
Have been denied family planning services because of my HIV status	13.4	64.4	22.3	0
Have been denied sexual and reproductive health services because of my HIV status	12.8	87.2		

Nearly one in five of the PLHIV revealed that they had been subjected to psychological pressure or manipulation by their husband/wife or partner, taking advantage of their HIV status, at least once in the previous 12 months before the survey. Out these, 7% of the PLHIV, experienced it once while another 7% reported it happening a few times. This was mostly experienced more by men than women.

PLHIV who said they had experienced sexual rejection at least once in the last 12 months before the survey were 21%. Of those who experienced rejection more than a half said they experienced it a few times in the last 12 months before survey. Sexual rejection is a leading factor in domestic violence, including non provision of basic needs, marital rape, poor negotiation skills for condom use and extra marital sexual relationships that could lead to new infections and family breakdown. Similarly psychological pressure leads to mis-trust and concealment of secrets. The fact that PLHIV need a lot of social support, aspects of sexual rejection are detrimental to the quality of lives of PLHIV.

Another form of discrimination is stigmatizing/discriminatory behavior inflicted upon PLHIV by other PLHIV. In this Survey, this was reported by 14%(No) of the respondents who had experienced it at least

once in the previous 12 months before the survey. This could be attributed to the fact that PLHIV are involved in service delivery so know their peers and a lot about their social life but also lack quality training and mentoring in HIV care and support, for instance, most of the training for peer supporters range from one to five days of training and limited mentoring and supervision due to lack of adequate resources.

Discrimination on the basis of being a PLHIV may extend to other household or family members. As seen from table, 2.1.2 of PLHIV reported that their wives/husbands or partners or other members of their family/household had experienced discrimination at least once in the previous 12 months before survey as a consequence of their HIV status.

The respondents were asked what their perception was of some forms of HIV related stigma and/or discrimination in the last 12 months and to give reasons for being discriminated against.

Table 2.1.3 Percentage of respondents by reason for experiencing some form of HIV-related stigma and /or discrimination in the last 12 months by gender

Why do you think that you have experienced some form of HIV-related stigma and/or discrimination in the last 12 months	*Male*		*Female*		*Total*	
	Number	*Percent*	*Number*	*Percent*	*Number*	*Percent*
People are afraid of getting infected with HIV from me	183	16.5	205	18.5	388	35
People don't understand how HIV is transmitted and are afraid	104	9.4	73	6.6	177	16
People think that having HIV is shameful and they should not be associated with me	150	13.5	136	12.3	286	25.8
Religious beliefs or "moral" judgments	23	2.1	17	1.5	40	3.6
People disapprove of my lifestyle or behavior	22	2.1	19	1.8	41	3.9
I look sick with symptoms associated with HIV	40	3.6	38	3.4	78	7
I don't know/I am not sure of the reason(s)	203	19.2	178	16.8	381	36.0

As shown in table 2.1.3, 35% of PLHIV associated the stigma/discrimination inflicted upon them to fear of transmission of the virus. More than one quarter of the PLHIV believed that the reason for their stigmatization /discrimination was due to people thinking that having HIV is shameful and therefore should not be associated with them. Religious beliefs or "moral" judgments were mentioned by 3%. In secondly literature, the 2011, AIDS Indicator survey revealed that 20% of the respondents in the general population believed that PLHIV should be ashamed and blamed for bring HIV in the community.

The notion of associating HIV/AIDS with shame has many discussions, but affects females more than males. For instance, a widow will be blamed for getting into a new relationship while a widower is expected to get another wife sooner so they get a companion or someone to help with the family care and younger wives are usually blamed for bringing infection to the family. Children born to mothers whom societies know are HIV positive risk enacted stigma many times as society often assumes that the children might have also gotten infected.

2.2: Access to work, health and education services

People, irrespective of HIV sero status, are entitled to work, health and education services.

The respondents were therefore asked to respond to questions regarding stigma and discrimination at work, health and educational settings.

Table 2.2.1 Distribution of respondents by frequency of various forms of discrimination related to work and education services in past 12 months

Experience in the last 12 months	*Never*		*Once*		*A few times*		*Often*		*Number of cases*
	Male	*Female*	*Male*	*Female*	*Male*	*Female*	*Male*	*Female*	
Lost job or source of income	288 43.4	229 34.5	47 7.1	26 3.9	32 4.8	23 3.5	7 1.1	12 1.8	664
Change of job description/ been refused promotion due to my HIV status	445 40.1	374 33.7	23 2.1	16 1.4	18 1.5	16 1.4	9 0.8	4 0.4	904
Have been dismissed, suspended or prevented from attending education institution due to HIV status	427 48.6	390 44.4	13 1.6	11 1.3	14 1.7	11 1.3	8 1.0	5 0.6	879
Have been denied health services, including dental care, due to my HIV status	519 47.5	525 48	11 1	6 5	15 1.4	10 .9	3 .3	4 .4	1093

As shown in table 2.2.1, 23% (255) of the PLHIV reported losing jobs or incomes within the past year preceding the survey and 27% (68), n=255 of these attributed it HIV status. Among those that reported losing their jobs or incomes, more than a half 58% (148), n=255 were men. The respondents were asked if they were refused employment or work opportunity in the same period because of their HIV status, 8% (89), n=1110 had encountered refusal in the previous 12 months. About 8% (7), n=89) of the PLHIV revealed that they had been subjected to such discriminatory practices due to their HIV status at least once in the previous 12 months before the survey. More than a quarter 26% (288), n=1110 of those whose job descriptions were changed attributed it to a combination of factors including poor health. This would call for countrywide education and sensitization on positive living and productivity of individuals irrespective of status.

Table 2.2.2 Reasons for encountering various forms of discrimination related to work and education services in past 12 months

Reason for discrimination	***Gender***				***Total***	
	Male Number	***Percent***	***Female Number***	***Percent***	***Number***	***Percent***
Because of my HIV status	28	19.7	14	9.3	42	28
For(an) other reason(s) Both because of my HIV status and	36	24	25	16.7	61	40.7
other reason(s)	20	13.3	13	8.7	33	22
Not sure why	3	2	11	7.3	14	9.3

From the table 2.2.2, 29% (321) attributed their being discriminated in relation to work and education services to their HIV status. Almost 40% (444) attributed it to other reasons not related to HIV status and 10% (111) were not sure of why they were discriminated.

Grace, 28 years, was a healthy and beautiful woman, with a job in one of the CBOs in Lira district. She was recently diagnosed with HIV and because her CD4 was high, she was put on Septrin. She and her boyfriend decided to have a baby and she is now 8 months pregnant. Because of pregnancy, her CD4 count lowered and had to be initiated on ARVs to protect her and the baby. But, she had started showing AIDS related symptoms. Her colleagues at work, including close friends, kept away from her when she needed them most. Life became unbearable when her immediate supervisor told her point blank that she cannot sit close to him because he could be infected by HIV. Grace considered quitting her job despite the fact that she needs her salary to access treatment and also prepare for the baby's arrival. She has enlisted the support of a counselor who has encouraged her to accept her condition, including stigma at work, that she has regained her strength, continues to go to work and with eMTCT services, is very hopeful will deliver a HIV negative baby.

2.3: Internal stigma and fears

Internal stigma is where one has negative feelings based on their HIV positive status. Respondents' perception of internal stigma was examined and the responses recorded.

Table 2.3.1 Perception and fears respondents had about themselves as a result of their HIV positive status by gender

Experience in the last 12 months	*Gender Male Number*	*Percent*	*Female Number*	*Percent*	*Number of cases*
I feel ashamed	166	48.8	174	51.2	340
I feel guilty	162	50.6	158	49.4	320
I blame myself	205	50.2	203	49.8	408
I blame others	122	43.6	158	56.4	280
I have low self esteem	209	71.3	184	62.8	293
I feel I should be punished	38	52.8	34	47.2	72
I feel suicidal	51	58.0	45	51.1	88
Total					***1801***

NB: Multiple response question

Table 2.3.1 presents the proportion of PLHIV who revealed that they have feelings as a consequence of owing to their HIV positive and these feelings are broadly categorized into internal stigma. They include shame, guilt, low self esteem, blaming one or others, suicidal, and seeking punishment. The percentages may not necessarily add to 100% of the responses since they were multiple and one respondent could mention more than one category. In this table, we observe that 88 persons feel suicidal. This calls for continous counselling to avoid the blame game and consquently reduce internal Stigma.

"I have never felt as ashamed as I did when they told me I was HIV+. I wondered how people would react when they got to know. I had many sleepless nights knowing that people would laugh at me." says Patrick from Bududa District

Table 2.3.2 Respondents' decision not to engage in some activities because of their HIV status in the last 12 months by gender

Decision taken in the last 12 months in connection with HIV-positive status	*Gender Male Number*	*Percent*	*Female Number*	*Percent*	*Number of case*
I have chosen not to attend social gathering(s)	55	50.5	54	49.5	109
I have isolated myself from my family and/or friends	48	47	54	53	102
I took the decision to stop working	46	62.5	27	37.5	73
I decided not to apply for a job/work or for a promotion	41	61	26	39	67
I withdrew from education/training or did not take up an opportunity for education/training	26	52	24	48	50
I decided not to get married	116	37	197	63	313
I decided not to have sex	119	37.5	198	62.5	317
I decided not to have (more) children	261	44.5	326	55.5	587
I avoided going to a local clinic when I needed to	55	54.5	46	45.5	101
I avoided going to a hospital when I needed to	31	66	16	34	47
Total					***1766***

NB: Multiple response question

Internal stigma can lead to abandoning life goals and aspirations. During the survey the respondents were asked if they have foregone various family and social activities, health services, opportunities related to career and education, among others in the last 12 months before the survey in connection to their HIV-positive status. Majority 53% (588) of the respondents decided not to have (more) children while 29% (321) decided not to have sex and 28% (310) decided not to get married respectively. About 10% (111) decided to isolate themselves from family and/or friends. Isolation implies internal stigma and has potential to negatively affect the PLHIV quality of life in many aspects.

"How would I get married with my HIV status? I had the pill burden, the guilt and did not know much about condom use. It was thus ok with me to remain single." Says Matilda from Maracha District.

Table 2.3.3 Percentage of respondents that were fearful that various forms of stigma would happen to them in the last 12 months by gender

Type of fear in the last 12 months	*Gender Male Number*	*Percent*	*Female Number*	*Percent*	*Number of cases*
Being gossiped about	257	51	248	49	505
Being verbally insulted, harassed and/or threatened	147	47	168	53	315
Being physically harassed and/or threatened	89	59	62	41	151
Being physically assaulted	70	56.0	55	44.0	125
Someone would not want to be sexually intimate with me	181	56.0	142	44.0	323
Total					***1419***

The table 2.3.3 above shows respondents' fears of various forms happening to them and these include gossiping, verbal insults, harassment and threats, physical harassment and threats, physical assault. In total 505 PLHIV feared that they would be gossiped about and this was equally feared by both females(248) and (257) males. Similarly a big number (323) feared that someone would not want to be sexually intimate with them more than 56% of these were men. This could mean that many persons will not disclose their HIV status or will not adhere to treatment or take their spouses and children for treatment when need arises.

2.4: Rights, laws and policies

Rights, laws and policies are critical in understanding HIV and AIDS related stigma and discrimination. At international level, Uganda has ratified several international human rights treaties, conventions and declarations that the state is supposed to promote, protect and fulfill rights of PLHIV. The Uganda Constitution in 1995 is the cardinal law that provides for the bill of rights, it provides for non discrimination and equality of all persons. Laws made by the parliament of Uganda are supposed to be in line with the constitutional provisions.

Uganda has both constructive laws (rights enhancing laws) and laws that contain provisions that promote rights of PLHIV. For example the Employment Act 2006 strengthens provisions of anti discrimination of all workers despite Health status; the Domestic Violence Act 2010 provides protection to all family members against violence to include assault and psychological torture. However Laws such as the Marriage Act, The Divorce Act, the Succession Act, the Penal Code contain some old/archaic provisions of the law hinder rights of inheritance and ownership of property for example and whose impact on HIVAIDS is very gross and also fuel stigma and discrimination.

By the time of the this survey , Parliament was considering the HIV Prevention and Control Bill, an HIV specific legislation that has both rights enhancing provisions and depriving propositions .

It contained provisions that promote non discrimination on the ground of HIV or perceived status. On the other hand provisions will likely fuel discrimination like forced disclosure of test results, mandatory testing, Criminalization of HIV transmission that all have a negative impact towards PLHIV.

Respondents were asked about the knowledge and understanding of the international and national documents as in Table 2.4.1

Table 2.4.1 Respondents who have heard of the UN Declaration of Commitment on HIV/AIDS and National

HIV/AIDS Policy	Male Number	Percent	Female Number	Percent	Total cases	Total percent
Have heard of the declaration of Commitment on HIV/AIDS which protects the rights of people living with HIV	276	26.1	226	21.3	1059	47.4
Have ever read or discussed the content of this Declaration	111	22.2	102	20.4	501	42.6
Have heard of the national HIV/AIDS policy which protect(s) the rights of people living with HIV in this country	241	22.8	193	18.2	1058	41
Have ever read or discussed the content of this policy	96	22.1	86	19.8	182	41.8

From the information given above, 47% (502) of the respondents had heard of the UN Declaration of Commitment on HIV/AIDS and of these, 43% (215) had ever read or discussed the content of this declaration. Similarly almost 41% (433) of the respondents had heard of the National HIV/AIDS Policy which protects the rights of PLHIV in the country and 42% (181) of these had ever read or discussed the content of this policy. This means people are aware but not knowledgeable about international and national policies and laws that promote and protect rights of PLHIV.

As per the number above, few PLHIV are aware and knowledgeable of the existence and content of both UN Declaration on HIV and national HIV instruments and policies, It means the majority lack information that empowers them to seek protection or promote their rights. Therefore, care must be taken in interpretation of this particular finding as the question asked of the respondent restricted itself to UN Declaration of Commitment to HIV and National HIV Policy as the proxy indicators of knowledge levels on rights. If the question, had inquired about the Ugandan Constitution and the Laws, chances are high that a large majority of the PLHIV would have expressed high level of knowledge. Despite the limitation, national level sensitization campaigns on policies and laws should be embarked on.

Since stigma and discrimination is a human rights violation, respondents were asked about experiences regarding discriminatory practices like forced medical procedure, denied health insurance, segregation among others due to their status.

Table 2.4.2 PLHIV who reported that they experienced discriminatory practices due to their HIV status

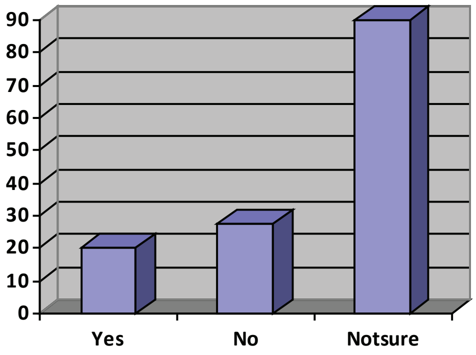
Discriminatory practices in the last 12 months	*Male Number*	*Percent*	*Female Number*	*Percent*	*Total cases*	*Total percent*
I was forced to submit to a medical or health procedure (including HIV testing)	40	3.6	26	2.3	1110	6
I was denied health insurance or life insurance because of my HIV status	25	2.2	13	1.1	1110	4.3
I was arrested or taken to court on a charge related to my HIV status	13	1.2	6	0.5	1110	1.6
I had to disclose my HIV status in order to enter another country	18	1.6	9	0.8	1110	2.4
I had to disclose my HIV status to apply for residence or nationality	13	1.1	4	0.4	1110	1.5
I was detained, quarantined, isolated or segregated	9	0.8	6	0.5	1110	1.4
None of these things happened to me	467	42	494	44.5	1110	86.6

Table 2.4.2 shows that, 6% (66) reported being forced to submit to a medical or health procedure because of their HIV status. The percentage of respondents that reported experiencing none of the discriminatory practices is 87% (961). Basing on the nature of respondents for the survey, targeted respondents did not relate to most categories captured in the question. Responses in table 2.4.2 are complimentary to results in prior section discussed under stigma where, PLHIV face HIV AIDS associated discrimination at family, community and at workplace. Below is the experience of Gregory in Mayuge

I went to pick my appointment letter only to be told that I had to undergo a medical examination. I already knew my sero status which I told the Human Resource Officer. She could not believe me and therefore had to do the examination which confirmed to them my HIV + status That marked the end of getting the job as they could not recruit me even though had passed the interview."

Regarding abuse of rights, Figure 3 presents number of PLHIV whose rights were violated in the last 12 months.

Figure 3. Percentage of respondents whose rights have been abused in the last 12 months



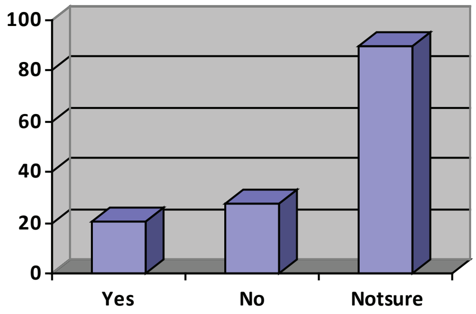
As per figure 3, 23% (255), reveal that their rights have been abused in the last 12 months before the survey. This is in relation to assault, abuse, exclusion, forced to submit to medical tests and other forms of discriminatory practices. However, 11% (111) n= 1110, respondents were not sure of the violation of their rights. This could imply a knowledge gap on aspect of human rights of PLHIV. This confirms the findings in table 2.4.1, which indicates that about 53 % respondents were not aware of important documents that stipulate their human rights such as the UN Declarations.

Respondents who reported experiencing violation of their rights were further asked if they had taken any legal action to redress the violation.

Figure 4: Percentage of respondents who experienced violation of rights and attempted to get legal redress

As shown in Figure 4, almost three persons in every four whose rights were violated did not attempt to take any legal action (n=254). This could imply two most probable issues; most people whose rights are abused never go for legal redress either due to lack of knowledge about the legal procedures or the environment is not supportive to pursue the legal action in a given setting.

A number of respondents had attempted to get legal redress and the process had begun.

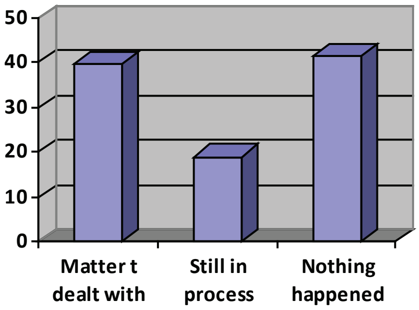


According to the results, 86% (53) n=63 of those who had attempted to get legal redress reported that the process had begun in the last 12 months before the survey. Some PLHIV are quite aware of their rights and legal procedures.

Having attempted legal redress, respondents were requested to respond on how far the matter had been dealt with. as Ziporah narrated her ordeal;

Ziporah is a widow in Isingiro District with six children. She lost her husband to AIDS in 2008. He left her a piece of land to cater for the family's welfare. The in-laws expected her to die soon after her husband to take over the property. When they realized she was instead getting better, stronger and productive, one of her brother-in-law opened up a case against her that the land left to the family by her husband actually belongs to him. The Local Council 1 (LCI) ruled in her favour which annoyed the in-law that he took the case to LCII court which also ruled against him. He then took the case to LCIII, where after bribing the officials, the case was ruled in his favour. Ziporah is fighting hard and producing all evidence to overturn the ruling. She is running out of finances to sustain moving to and from the sub-county, which is quite a distance from her home. She remains assertive and is currently seeking free legal aid to ensure she reclaims what belongs to her and her children.

Figure 5: Percentage of respondents who attempted to get legal redress and how the process was



From Fig 5 above, 40% (25) of those who had attempted to get legal redress reported that their matters had been dealt with and a slightly higher number of the respondents said that the relevant bodies took no measure to redress the reported incidents. The matter was reported to be still undergoing legal process in about 20% (16), n=63.

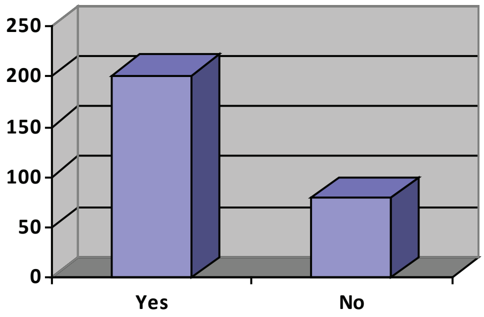
While other PLHIV had opted to get legal redress to avoid violations, others had not and Table 2.4.4 explains why.

Table 2.4.3 Percentage of respondents who did not attempt to get legal redress by reason for not doing so.

Reason (n=196)	*Number*	*Percent*
Insufficient financial resources to take action	38	19.4
Process of addressing the problem appeared too bureaucratic	19	9.7
Felt intimidated or scared to take action	25	12.8
Advised against taking action by someone else	17	8.7
No/little confidence that the outcome would be successful	33	16.8
None of the above	64	32.7
Total	***196***	***100***

Various reasons were given by respondents for refraining from seeking legal protection when their rights are violated. The reasons varied from insufficient financial resources to personal attributes. As seen in the table 2.4.3, 19% (38), n=196 attributed not to take legal redress due to insufficient financial resources. Almost the same number 17% (33) attributed it to lack of confidence in the legal system and felt that the outcome may not be successful. Sixty four percent had other reasons. However, it could also mean that since the laws and Judicial systems that promote PLHIV Rights are known by few, then taking legal action becomes a challenge. Respondents who experienced violation of their rights were asked if they have attempted to bring their cases to the attention of government officials.

Figure 6: Percentage of respondents who attempted to get government officials for action against the abuse they have experienced.



As seen from Figure 6, only one in five respondents took their cases to government officials for action against the violation of their rights. According to the responses given, 87% of those who brought their cases to government officials did it within the last 12 months. This could imply that either PLHIV have no confidence in government officials, or ignorant of the role the officials can play or were not supported when they tried. From all the observations, regarding, Laws and policies, PLHIV do not use both judicial system and administrative offices. They suffer silently and they need to be empowered, to seek justice and as many indicate the financial challenges Legal aid requires.

2.5: Effecting change

There are a number of cases where PLHIV 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. PLHIV were asked if they have challenged or educated anyone who was stigmatizing them in the last 12 months preceding the survey.

Table 2.5.1 Percentage of respondents who confronted, challenged or educated someone who was stigmatizing in the last 12 months and who know organizations and groups that can help with stigma and discrimination.

	Male Number	Percent	Number	Female Percent	Total cases	Total percent
Have confronted, challenged or educated someone who was stigmatizing and/or discriminating against you	296	26.8	267	24.1	1106	50.9
Know of any organizations or groups that you can go to for help if you experience stigma or discrimination	348	31.4	323	29.1	1110	60.5
Total						

As seen in Table 2.5.1, half 51% (563) n=1106 of the respondents said that they stood their ground in front of a stigmatizing person/s. This could be attributed to advocacy skills imparted to the PLHIV though there is still room for improvement.

Also as counseling services contribute significantly in relieving PLHIV from psychosocial stress and enhancing their wellbeing, respondents were asked if they knew where they could get counseling services. From the information given in Table 2.5, 61% (671) n=1110 of the respondents knew organizations or groups where they can go to for help if they experienced stigma or discrimination.

Table 2.5.2 Type of organizations rendering support to reduce stigma mentioned by respondents

Type of Organizations / groups known by the PLHIV	*Male*	*Female*	*Percent of case (n=671)*
People living with HIV support group	36.1	34.9	71
Network of people living with HIV	25.2	23.3	48.5
Local non-government organization	17	15.7	32.7
Faith-based organization	10	7.6	14.6
A legal practice	2.4	2.1	4.5
A human rights organization	5.8	4.8	10.6
National non-governmental organization	10.	7.3	17.3
National AIDS Council (UAC)	2.7	2.9	5.6
International non-governmental organization	2.4	2.1	4.5
UN organization	1.2	0.7	1.9
Other	0.4	0.4	0.8

Those who said knew where psychosocial services are provided were also asked about the type of organizations that provide such services. From the results in Table 2.5.2 most of the respondents 71% 476), n=671 identified the PLHIV support group (Associations), 48% (322), n=671 identified the Network of PLHIV and 33% (221), n=671 identified a local NGO. Apart from these three types, very few respondents spoke of getting support from other types of organizations including from legal practice, human rights organization, National AIDS Council, UN organizations and any other. More publicity is thus needed on how PLHIV can access services beyond support groups and networks.

As much the respondents were able to identify the support organization, an analysis of service utilization in facilities that provide psychosocial counseling for stigma related issues was made and the responses made below,

Table 2.5.3 Percentage of respondents who sought help from organizations and other specific support in the last 12 months by sex

Have you sought help from any of the above organizations or groups to resolve an issue of stigma or discrimination?	***Male***	***Female***	***Total***
Yes	28	26.4	54.4
No	23.9	21.7	45.6
Number of cases			***669***
Have you ever tried to solve an issue of stigma and discrimination either on your own or with the assistance of others?			
Yes	29.5	30.2	59.7
No	20.5	19.8	40.3
Number of cases			***1110***
In the last 12 months, have you supported other people living with HIV?			
Yes	38.8	37.7	76.5
No	11.2	12.3	23.5
Number of cases			***1110***
What types of support did you provide?			
Emotional support (e.g. counseling, sharing personal stories and experiences)	43.8	43.2	87
Physical support (e.g. providing money or food, doing an errand for them)	17.6	16	33.6
Referral to other services	21.4	20.4	41.8
Number of cases			***850***

Looking at service utilization in facilities that provide psychosocial counseling for stigma related issues, 55% (367) n=669 of the respondents reported to have ever used them. Sixty percent (666), n=1110 of the respondents reported to have ever tried to solve them on their own and it is also reported in equal measures of male and female respondents. Most 87% (740) n=850 of the respondents said they offered emotional support (e.g. counseling, sharing personal stories and experiences) and 34% (289), n=850 offered physical support (e.g. providing money or food, doing an errand for them). Forty one percent (348), n=850 of the respondents said they made referral to other services. Therefore, PLHIV are at the fore front of providing psychosocial support and it is mainly within the networks. The networks need to have their capacity built to provide quality psychosocial support to their peers and community at large. An individual can have control over what is taking place around their lives if they have the capacity to influence decisions affecting their lives. Respondents were asked about their capacity to influence decisions and responses recorded below

Table 2.5.4: Percentage of respondents who felt that they could influence and those who recommended other to organizatio addressing stigma by sex

Do you feel that you have the power to influence decisions in any of the following aspects	*Male*	*Female*	*Total*
Legal/rights matters affecting people living with HIV	17.4	13.2	30.6
Local government policies affecting people living with HIV	12.1	9	21.1
Local projects intended to benefit people living with HIV	16.5	10.4	26.9
Uganda government policies affecting people living with HIV	4.3	2.6	6.9
National programs/projects intended to benefit people living with HIV	6.5	3.7	10.2
International agreements/treaties	1.5	0.8	2.3
None of these things	17.8	25.9	43.7

NB: Multiple response question

When asked about their feelings towards influencing decisions that affect their life and wellbeing, 31 % felt that they have the power to influence legal/rights affecting PLHIV and 27% said they felt they have power to influence local projects intended to benefit PLHIV.

Respondents were asked to suggest possible areas of interventions to address stigma. There are a number of organizations of people living with HIV working against stigma and discrimination. If one of them asked you, "What is the most important thing we should be doing as an organization to address stigma and discrimination?" what would you recommend?

Table 2.5.5 Percentage of respondents who suggested what organizations should be doing to address stigma and discrimination

	Male	*Female*	*Total*
Advocating for the rights of all people living with HIV	12.2	11.6	23.8
Providing support to people living with HIV through emotional, physical and referral support	14.3	17	31.3
Advocating for the rights and/or providing support to particularly marginalized groups (men who have sex with men, injecting drug users, sex workers)	2.5	1.6	4.1
Educating people living with HIV about living with HIV (including treatment literacy)	11.5	9.5	21
Raising the awareness and knowledge of the public about AIDS	9.4	10.5	19.9

About a third (31%) suggested providing support to PLHIV by providing emotional, physical and referral support while almost a quarter suggested advocating for the rights of all people living with HIV. Raising the awareness and knowledge of the public about AIDS as another area of intervention was suggested by 21 %. Provision of emotional, physical and referral support for the PLHIV plays a big role in promoting the well being of an individual and therefore raising their self esteem which helps in dealing with internal stigma.

Section 3: Experience of testing, disclosure, treatment and having children

3.1: Testing and diagnosis

Testing is very important because it plays crucial roles in diagnosis and 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.

Table 3.1.1 Reasons for testing HIV status

Reasons	***Number***	***Percent***
Employment	20	1.8
Pregnancy	105	9.8
To prepare for a marriage/sexual relationship	41	3.7
Referred by a clinic for sexually transmitted infections	75	6.8
Referred due to suspected HIV-related symptoms (e.g. tuberculosis)	144	13
Husband/wife/partner/family member tested positive	79	7.1
Illness or the death of husband/wife/partner/family member	385	34.7
I just wanted to know	363	32.7
Other	33	3.1
Total		***1245***

NB: Multiple response question

The most common reason 35% (385) cited for testing for HIV was illness or death of husband/wife/partner/family member. Although this aspect may not directly show the prevailing stigma, it could mean that HIV testing is still a dreaded phenomenon. Other reasons like employment, preparing for marriage/sexual relationship were not cited much. This implies the need to raise awareness of the importance of HIV testing before marriage or initiation of sexual relationship as opposed to testing when sick or after losing a partner. The reluctance to taking an HIV test and waiting for symptoms/indicators of HIV like illness or sickness/death of a partner delays treatment thus down plays the role of treatment as prevention. Increasing people's awareness, while advocating for the rights of PLHIV can go a long way to reduce stigma and discrimination.

Respondents were asked about the main decision maker while they were taking the HIV test and the responses presented below

Table 3.1.2 Decision making for testing HIV status

How was the decision made	***Number***	***Percent***
I took the decision myself to be tested (i.e. it was voluntary)	968	87.2
I took the decision to be tested, but it was under pressure from others	68	6.1
I was made to take an HIV test (coercion)	29	2.6
I was tested without my knowledge – I only found out after the test had been done	45	4.1
Total		***1110***

From table 3.1.2, 87% (968) of the respondents said that it was their own decision and those who said were coerced accounted for 3% (29). Those who were pressurized to be tested were 6% (68) while those who were tested without their knowledge and only found out after the test had been done were 4% (45). Though a small percentage, all tested must have consented as a respect to PLHIV rights.

Counseling is one of the most important components in HIV testing process and it is usually given before and after the test. Counseling also provides an opportunity to share information with clients promote measures to reduce the risk of HIV infection and transmission.

Table 3.1.3 Counseling services during HIV testing

How was the dicision made	***Number***	***Percent***
I received both pre- and post-HIV test counseling	937	84.5
I only received pre-test HIV counseling	37	3.3
I only received post-test HIV counseling	75	6.8
I did not receive any counseling when I had an HIV test	60	5.4
Total		***1109***

***1 respondent had no response**

In view of the above, respondents were asked whether or not they received counseling services when they were tested for HIV. From the results, 3% (37), n=1109 of the respondents received only pre-test counseling and the proportion of those who did not receive any counseling were 5% (60) and this indicates that there need to further strengthen counseling services. The biggest proportion 85% (937) received both pre and post test counseling.

3.2: Disclosure and confidentiality

Disclosure is a very important tool in breaking through with stigma. However, it has to be done consciously and care should be taken to who, when and where to disclose.

Respondents volunteered information about their HIV status to different people especially to those who are close to them like their partners, family members, other PLHIV, health care workers, social workers/counselors. The responses are as per table below

Table 3.2.1 Percentage distribution of how different groups of people first got to know about respondent's HIV status

Category of people	***I told them***	***Someone else told them, with my consent***	***Someone else told them, without my consent***	***They don't know my HIV status***	***Not applicable***
Your husband/wife/partner	63.9	6.8	4.0	4.5	20.9
Other adult family members	67.6	5	6.7	11.2	9.5
Children in your family	60.5	4.5	4.1	19.2	11.6
Your friends/neighbors	48.8	3.7	20.8	21.7	5.1
Other people living with HIV	77.5	4.7	6.5	6.8	4.5
People whom you work with (your co-workers)	32.5	3.4	6.8	17.7	39.6
Your employer(s)/boss(es)	21.6	2.6	3.7	13.2	58.8
Your clients	19.7	1.4	3.8	23.6	51.5
Injecting drug partners	7.2	1.8	2.1	6.3	82.5
Religious leaders	36	3.4	6.9	38	15.6
Community leaders	34	3.6	12.5	36.7	13
Health care workers	81.2	5.7	4.6	3.9	4.1
Social workers/counselors	73.2	6.5	5.2	9.7	5.4
Teachers	9	2.9	3.9	19.4	64.9
Government officials	12	3	3.2	44.8	37.1
The media	4.4	1.3	2.9	37.2	54.2

From table 3.2 ,most respondents volunteered to give information about their HIV status to different people especially their partners, family members, other PLHIV, health care workers and social workers/counselors. However, majority 81% (899) felt comfortable disclosing to health care worker than any other persons. Since most people seem to be confident disclosing to the health workers, it is important for the health workers to undertake the highest degree of confidentiality of their clients' status. Disclosure is a personal responsibility and optional. Therefore nobody should be coerced to disclose.

Rights violations are witnessed in the percentages of disclosure without consent and for those who have not yet disclosed, a support mechanism needs to be put in place for PLHIV to benefit from disclosure.

Table 3.2.2 Percentage of respondents that reported pressure to disclose their HIV status and their perception about confidentiality

How often did you feel pressure from other individuals living with HIV or from groups/networks of people living with HIV to disclose your HIV status?	***Number***	***Percent***
Often	65	5.9
A few times	102	9.2
Once	44	4
Never	897	81
How often did you feel pressure from other individuals not living with HIV		
Often	65	5.9
A few times	114	10.3
Once	48	4.3
Never	882	79.5
Has a health care professional (for example, a doctor, nurse, counselor, laboratory technician) ever told other people about your HIV status without your consent?		
Yes	77	7
No	755	68.3
Not sure	274	24.8
How confidential do you think the medical records relating to your HIV status are?		
I am sure that my medical records will be kept completely confidential	830	75.0
I don't know if my medical records are confidential	237	21.4
It is clear to me that my medical records are not being kept confidential	40	3.6

As shown in Table 3.2.2, well over three quarters 81% (897), n=1110 of PLHIV did not encounter any pressure to disclose their HIV status to other individuals living with HIV or from groups / networks of people living with HIV or other individuals not living with HIV 80% (888). This could be attributed to anticipated social network support from fellow PLHIV that is stigma free.

Seven percent (77) of the PLHIV reported that they found that their HIV status was disclosed to other people by health care professionals (doctor, nurse, counselor, laboratory technician) without their consent. A quarter 25% (274) of the respondents reported that they were not sure whether health care providers maintained their HIV status confidential or not. Three quarters 75% (830) of the PLHIV were sure that their medical records related to their HIV status were completely confidential. Health care providers need to take extra caution when it comes to disclosing clients' status to avoid heightening stigma.

The news of positive results is always devastating and for one to cope, there is need for support from the members around the PLHIV. The support given influences the coping, the treatment adherence and dealing with stigma. The table below indicates the support received by respondents.

Table 3.2.3 Percentage of respondents who reported various reactions of people when they first knew about their HIV status

Category of people	*Very Discriminatory*	*Discriminatory*	*No different*	*Supportive*	*Very supportive*
Your husband/wife/partner	8.1	8.8	13.5	38.7	31
Other adult family members	4.9	5.2	15.7	57	17.2
Children in your family	1.5	1.3	15	59.2	22.9
Your friends/neighbors	4.2	11	26.9	50.5	7.4
Other people living with HIV	1.1	1.1	11	63.1	23.7
People whom you work with (your co-workers)	3.4	5.6	24.1	56.4	10.6
Your employer(s)/boss(es)	7.4	5.2	22.7	55.2	9.6
Your clients	2.8	2.8	31.2	53.1	10.1
Injecting drug partners	5.1	5.1	17.2	66.2	6.6
Religious leaders	1.3	0.8	23.9	58.7	15.4
Community leaders	2.2	3.4	34.9	52.1	7.4
Health care workers	1.6	0.9	6.6	64.9	25.9
Social workers /counselors	1.3	1.1	10.2	63.3	24
Teachers	2.8	7.1	28	51.6	10.6
Government officials	2.4	3.4	38.1	50.3	5.8
The media	4.9	10.4	36.1	37.7	10.9

NB: Multiple response question and percent of cases represent the category irrespective of number of respondents

The categories that were identified by relatively large proportions (more than 50%) of respondents as being supportive include: other adult family members, children in the family, friends and neighbors, other PLHIV, co-workers, employers, clients, injecting drug partners, religious leaders, community leaders, health care workers, social workers/counselors and government officials. The largest proportion of respondents identified injecting drug partners as the most supportive with 66% (130) n=197, followed by the health care workers with 65% (683), n=1052

3.3: Treatment

In order to understand their perception about their health status, the respondents were asked to rate their current health condition as ‘excellent’, ‘very good’, ‘good’, ‘fair’ and ‘poor’

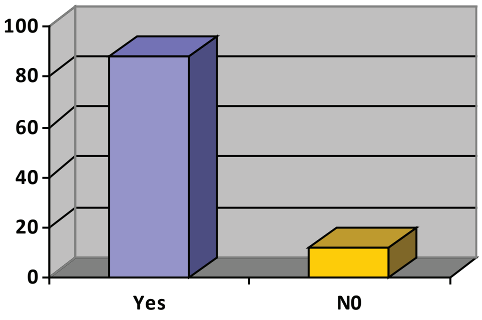
Table 3.3.1 Distribution of the respondents by self-perceived health status by sex

Self perceived health status at the time of the survey	***Gender***	
	Male	***Female***
Excellent	15.6	13.7
Very good	25.7	20.8
Good	37.8	44
Fair	17.4	17.5
Poor	3.6	4
Total	100	100
Number of cases	553	554

As shown in Table 3.3.1, more than half of the respondents perceived their health status as ‘excellent’ or ‘very good’ or ‘good’. Respondents that rated their health status as poor accounted for only 4%. This means that 96% (1062), n=1107 of the PLHIV perceived their health in the range of fair to excellent. This could be attributed to positive living campaigns that have been ongoing.

The survey further explored PLHIV taking ART.

Figure 7: Percentage of respondents currently taking ART



As shown in Figure 7, 88% (976) of the respondents were on ART and that may be the reason for their rating their health condition in the range of fair to excellent as shown in Table 3.3. Comparing with the general population ART estimates, 88% proportion is quite high, but could be attributed to the role PLHIV networks play in supporting their members with knowledge and skills to overcome stigma and subsequently seek care and treatment services. Due to the changing eligibility criteria for receiving ART, from CD4 250 to 350, for adults and treatment for all children below two years which translated to 540094 persons needing ART for CD4 of 350 but only 290971 accessed treatment in 2011, the report indicates that about 62% of adults who are in need of ART access it. Treatment as prevention needs to be taken into consideration urgently.

Of importance to note is that the survey targeted PLHIV in their networks and thus a number of PLHIV who are not yet members could be missing on ART access.

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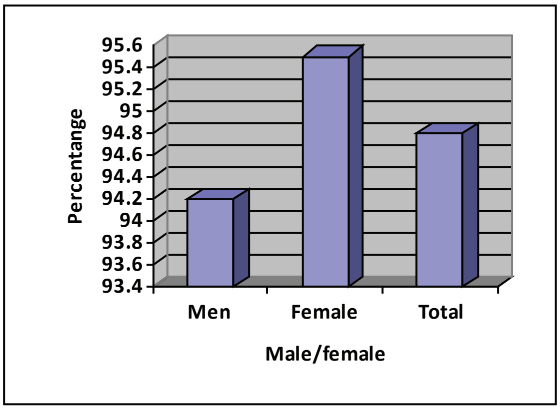
41. Global AIDS Response Progress report, Uganda AIDS Commission, April, 2012

Figure 8: Proportion of respondents on perceived access to ART by sex



Respondents were asked about their perceived access to ART treatment and as shown in Figure 8 above. Ninety five percent (1054), n=1110 of the respondents perceived that they had access to treatment whenever they needed it. 3% of the respondents did not think that they had access to ART while 2% percent did not know if it is accessible.

Table 3.3.2 Proportion of respondents by perceived reasons for not having access to ART by

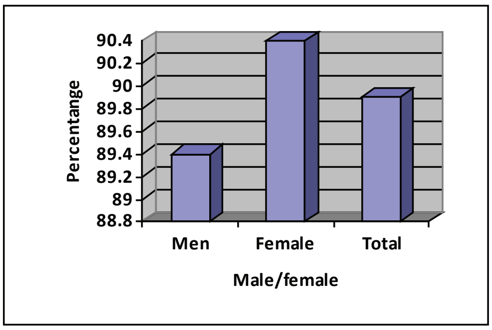
Why don't you have access	*Gender*		*Total*
	Male	*Female*	*n=32*
Because it's bad/side effects	5.3	15.4	9.4
It's expensive/can't afford it	21.1	15.4	18.8
I don't take them/take septrine /not sick	36.8	15.4	28.1
Stock out	26.3	38.5	31.3
Reluctant	5.0	.0	3.1
I don't know why	5.0	15.4	9.4

From the results in Table 3.3.2, more than a quarter (9), n=32 of the PLHIV who said do not have access to ART treatment; said they do not take them or they take septrin or felt they are not sick. This was reported by more than a third of the male respondents that do not have access to ART while more than a third of the female respondents reported stock out. Fifty nine percent of the respondents that reported not having access to ART treatment are male which could be attributed to low male involvement.

According to the results, 84% (976) of the respondents were taking medication to prevent or to treat OIs at the time of the survey. This implies that relatively a big number of PLHIV are receiving treatment, therefore support environment that are devoid of stigma and discrimination need to be promoted to continuously support those on treatment and work with them to share accurate information and their lived experiences of fighting and preventing stigma.

OI commonly manifests in the lives of PLHIV and therefore need to be attended to. However, some PLHIV do not access OI as presented below;

Figure 9: Proportion of respondents by perceived access to medication to OI



PLHIV were asked about their perceived access to medication to prevent or to treat OIs and as shown in Figure 9, 90% (999) of the respondents perceived that they had access medication to prevent or to treat OIs whenever they needed it. The number of PLHIV who self reported to have access to medication is quite high compared to the general population. This high percentage could be attributed to the PLHIV network support in terms of information and support to overcome stigma and peer to peer encouragement to seek treatment and live positively. This also underscores the need to enhance the capacity of registered networks.

Table 3.3.2 Proportion of respondents by perceived reasons for not having access to medication to OI by sex

Why don't you have access	Gender Male	Female	Total n=85
Because it's bad/side effects	5.8	7.9	6.7
It's expensive/can't afford it	46.2	47.4	46.7
I don't take them /not sick	1.9	5.3	3.3
Stock out	30.8	26.3	28.9
Reluctant	7.7	.0	4.4
I don't know why	3.3	5.6	8.9

From the results in Table 3.3.2 above, 47% (40), n=85 of the PLHIV who said don't have access to medication to prevent or to treat OIs, said it is expensive/or cannot afford it. More than half 58% (49) of the respondents that reported not having access to medication to prevent or to treat OIs are male. The issue of stock outs greatly affects adherence to treatment and consequently positive living.

Having constructive discussion with health professionals on a range of issues like positive living, sexual and reproductive health, treatment options for improved quality of life of PLHIV is critical, the table below depicts these results.

Table 3.3.3 Percentage of respondents who were on treatment and have had constructive discussions with health care professionals by gender

	Gender Male	Female	Total
Had a constructive discussion with a health care professional(s) on the subject of your HIV-related treatment options in last 12 months	74.2	73.2	73.7
Had a constructive discussion with a health care professional(s) on other subjects such as your sexual and reproductive health, sexual relationship(s), emotional well-being, drug use, etc	65.2	63.6	64.4

From the table 3.3.3, almost three quarters of the respondents (74% (822)) said that they had had constructive discussions with a health care professional(s) on the subject of their HIV-related treatment options in the last 12 months prior to the survey. The proportion of PLHIV that had constructive discussion with a health care professional(s) on other subjects such as sexual and reproductive health, sexual relationship(s), emotional well-being, drug use among others in the last 12 months was 64% (716) for both males and females. Male respondents (65% (363) Vs 64% (353)) reported having constructive discussion with health professionals on other subjects compared to female respondents.

3.4 Having Children

In almost all societies, the desire to have children is a welcome phenomena, however, it used to be perceived as a risky aspect for PLHIV. A Survey published in 2006 (Nakayiwa, and other) , revealed that only, 18% of sampled population (1092) living with and attending the TASO clinics in Eastern Uganda expressed the desire to have children. The desire for children was quite low partly because of the confusing messages at the time and males were four more times likely to desire children than females. Therefore, sexual and reproductive health communication remains critical in promoting safe sex practices as well as respecting the human rights of PLHIV which will help them lead positive lives. However, in some contexts, health professionals may not properly implement these services and may even misinform the PLHIV and violate their reproductive rights (Table 3.4.2)

Table 3.4.1 Percentage of respondents with their respective responses on having children by gender

Do you have a child /children?	Gender Male	Female	Total
Yes (biological)	62	70	66
Yes (both biological and non biological)	26	22.3	24.2
Yes (Adopted)	2.3	2.7	2.5
Do not have children	9.4	4.7	7

From Table 3.4.1 above, 90% of male and 95% female respondents reported having a child/children. Of all those who had children, 25% reported that these children were HIV positive (both biological and none biological). Fourteen Percent (n=148) reported out of the 25% were their biological children. PLHIV need advice on how and when it would be more appropriate to get children. This is in the interest of protecting the unborn baby, preserve the mothers' healthy and generally for the family to be prepared to for a new baby in the family.

Table 3.4.2 Percentage of PLHIV with experiences related to reproductive health/rights by gender

Reproductive health /rights related experience	Yes		No		Don'tknow		Number of cases
	Male	Female	Male	Female	Male	Female	
Since being diagnosed as HIV-positive, have you ever received counseling about your reproductive options	63	72	24.8	20	0	0	1108
Has a health care professional ever advised you not to have a child since you were diagnosed as HIV-positive	28	38	61	52	0	0	1106
Has a health care professional ever coerced you into being sterilized since you were diagnosed as HIV-positive	8	12	81	77	0	0	1107
Is your ability to obtain antiretroviral treatment conditional on the use of certain forms of contraception	10	17	64	61	6	11	1107

As shown in Table 3.4.2, more than two thirds 67% (742) of the PLHIV reported to have received counseling about reproductive options after being diagnosed as HIV-positive. Fourteen percent (154) of the respondents also revealed that their ART treatment was provided conditional to the use of certain forms of contraception. Eight percent (88) did not know whether their ability to obtain antiretroviral treatment was conditional on the use of certain forms of contraception. Female respondents were asked if any health professional tried to impose his/her belief/view with respect to termination of pregnancy (abortion), method of giving birth and infant feeding practices. The percentage of female respondents who reported experiencing such incidents were 12% (64), 26% (145) and 25% (138) respectively. This mainly implies that rights of PLHIV have been violated, however, small the percent is compared to total sample. With inadequate information, some women still do not know that they have a right to have children even when they are living with HIV, as science has proved they can have HIV free babies under eMTCT. They only need guidance on how to get HIV free children.

The Prevention of HIV transmission from Mother to Child (PMTCT) program is important in the fight against HIV. Respondents were asked if they have ever been given ART treatment to prevent mother to child transmission of HIV during pregnancy.

Table 3.4.3 Percentage of female respondents who reported on their experience of PMTCT

Have ever been given antiretroviral treatment to PMTCT	*Number*	*Percent*
Yes-I have received such treatment	216	39.6
No-I did not know that such treatment existed	97	17.8
No-I was refused such treatment	5	0.9
No-I did not have access to such treatment	66	12.1
No-I was not HIV positive when pregnant	161	29.5

From the table 3.4.3, 39% (216) said yes, 30% (161) said they were not HIV positive during pregnancy. Despite the relentless effort to scale up and provide eMTCT services throughout the country, 18% (97) expressed no knowledge of the existence of such treatment this implies that there is need for sensitization and mobilisation of mothers for eMTCT services.

Nakayiwa S, Abang B, Packel I, Lifshay J, Purcell DW, King R, et al: Children and pregnancy risk behavior among HIV-Infected men and women in Uganda. AIDS Behavior, 2006

3.5: Problems and challenges

This sub section presents the main problems and challenges related to experiences of testing, diagnosis, disclosure/confidentiality, antiretroviral treatment and having children among the PLHIV.

Table 3.5.1 Problems and challenges in relation to experience of testing and diagnosis with HIV

Experience of Testing and Diagnosis	*N= 1110* *Number of cases*	*Percent cases*	*Overall percent*
Fear of stigma/discrimination/internal/external	170	22.1	15.3
Long distance/transport	24	3.1	2.2
General body weakness/ I am ever sick	13	1.7	1.2
Fear of results/testing positive/needs courage/lot of pressure/fear of death	394	51.2	35.5
Lack of treatment/drug stock outs	15	1.9	1.4
Lack of confidentiality	12	1.6	1.1
Lack of test kits/equipment	25	3.2	2.3
Disclosure	13	1.7	1.2
Unqualified staff/rude	18	2.3	1.6
Its expensive	8	1.0	0.7
Rejecting results/self denial	17	2.2	1.5
Fear of giving birth to HIV positive child	1	0.1	0.1
Fear of discordance situation resulting	13	1.7	1.2
Few health personnel/under staffing leading to delays	14	1.8	1.3
Poverty	7	0.9	0.6
Low male involvement	2	0.3	0.2
No results given	1	0.1	0.1
Fear of losing marriage /marriage problem occurring	3	0.4	0.3
Total	***770***	***100***	***69.4***

(The responses have multiple responses and any interpretation of the table should take this in consideration)

With regard to disclosure and diagnosis with HIV positive status, table 3.5.1, illustrates that, most challenging aspect was fear of being HIV positive 51% (394) followed by, fear of stigma and discrimination, 22% (170).These two aspect are related in a way provides an insight to apparent levels of HIV associated stigma.

Table 3.5.2 Problems and challenges in relation to experience of Disclosure and confidentiality

Experience of Disclosure and confidentiality	*N= 1110 Number of cases*	*Percent cases*	*Overall percent*
Lack/limited support/care/information	31	3.6	2.8
Loss of friends/not getting partners	6	0.7	0.5
Fear of stigma/discrimination/feel ashamed/ denial/abused/laughed at/rejection	652	75.3	58.7
General body weakness	8	0.9	0.7
Transmitting disease/spreading HIV	25	2.9	2.3
Lack of treatment/drug stock outs	7	0.8	0.6
Don't want to disclose/personal/not ready	29	3.3	2.6
Lack of/can't guarantee confidentiality	51	5.9	4.6
Fear	25	2.9	2.3
Loss of jobs/job opportunities	4	0.5	0.4
Fear of losing marriage/partner/marriage problem occurring/domestic violence	17	2.0	1.5
You get stressed and die so fast/fear of death	11	1.3	1.
Total	***866***	***100***	***78.***

(The responses have multiple responses and any interpretation of the table should take this in consideration)

Similar to the results in previous table, the problems and challenges with regard to disclosure and confidentiality also strongly point to fear of stigma broadly 73% (652)the key pointers in this broad domain as seen in table 3.5.2 include; fear of stigma, discrimination, feeling a shamed, denial, abuse and rejection.

Table 3.5.3 Problems and challenges in relation to experience antiretroviral treatment

Experience with antiretroviral treatment	*N= 1110 Number of cases*	*Percent cases*	*Overall percent*
Lack of drugs/drug stock outs/access/treatment	94	12.5	8.5
Adherence issues/taking drugs for life/every day/drug resistance/forget to take drugs/tiresome	174	23.0	15.7
Fear of stigma/discrimination/internal/external	8	1.1	0.7
Long distance/high transport cost	38	5.0	3.4
General body weakness	8	1.1	0.7
Drug side effects	233	30.9	21.0
Changing of regimens/changing to second line	9	1.2	0.8
Lack of test kits/equipment	2	0.3	0.2
Death	34	4.5	3.1
Personal/refused to answer	8	1.1	0.7
Fear of giving birth to HIV positive child	2	0.3	0.2
Few health personnel/under staffing leading to delays	1	0.1	0.1
Don't have enough food/lack of nutritional support	135	17.9	12.2
Prevention	9	1.2	0.8
Total	***755***	***100***	***68***

(The responses have multiple responses and any interpretation of the table should take this in consideration)

The problematic aspects relating to experiences of antiretroviral therapy, revealed four major issues including; reported drugs side effects 31% (233) drug adherence issues, 23% (174) lack of enough food/lack of nutritional support, 18% (135) and drug stock outs, 13% (94). These challenges point to the holistic requirements of providing an HIV service. For instance aspect such as drug adherence, drug effects, lack of food need more a multisectoral approaches. As mentioned, adherence issues would require, mainly counseling, drug side effects, would require medical attention, food issues require, directly food support as well as economic livelihood intervention, where as drug stock out relate to health system issues. All these must be addressed systematically for a proper HIV/AIDS care and treatment service provision.

Table 3.5.4 Problems and challenges in relation to experience with having children as PLHIV

Experience with having children	***N= 1110 Number of cases***	***Percent cases***	***Overall percent***
Fear of giving birth to HIV positive child	377	45.9	34
Adherence issues/taking drugs for life/ every day/drug resistance/forget to take drugs/tiresome	3	0.4	0.3
Fear of stigma/discrimination/internal/external	15	1.8	1.4
General body weakness/die in labour/ death/reduce immunity	236	28.7	21.3
Lack of treatment/inadequate PMTCT access	1	0.1	0.1
Fear of dying and leaving children without support/care	22	2.7	2.0
To follow medical rules/PMTCT guidelines	8	1	0.7
Its expensive/costly/poverty	154	18.7	13.9
Inadequate knowledge/information in PMTCT	5	0.6	0.5
Discordance situation	1	0.1	0.1
Total	822	100	74.1

(The responses have multiple responses and any interpretation of the table should take this in consideration)

Experiences of having children, as PLHIV, has often, been reported in several reports. National programs such as PMTCT, provide technical support to families that would wish to have children even when they the parent/parent are PLHIV. In 3.5.4, fear of giving birth to HIV positive child is the most, 46% (377) among other issue in this domain. This aspect is followed by, reported general body weakness/death in labour, 29% (236), and aspect of poverty, 19% (154).

4.0 Comparison of selected stigma constructs with other African Counties.

In recent years, particularly from 2011 to 2012, several African countries have implemented the PLHIV Stigma Index in their settings. One of the major objectives of PLHIV Stigma Index Survey in Uganda was to measure as well as compare stigma across settings. Below are tables and diagrams that depict different aspects of stigma comparing Uganda with African countries. A few variables were considered regarding both internal and external stigma.

Table 4.1: Experiences of HIV specific forms of stigma

Country	*Experience of HIV Internal Stigma*		
	Gossip (%)	*Low esteem (%)*	*Loss of job/income (%)*
Ethiopia	69	53	76
Kenya	61	46	40
Nigeria	54	53	26
South Africa	45	18	3.4
Uganda	60	33	22

From table 4.9.1, it is observed that across all the countries, gossip was the highest form of stigma, and most depicted in Ethiopia. In terms of experiencing job loss, still Ethiopia has the highest magnitude of all the countries compared. Also results for Uganda in relation to other countries, it is second lowest after South Africa in terms of job losses.

Figure 10: Knowledge of laws and rights of PLHIV, comparing different countries

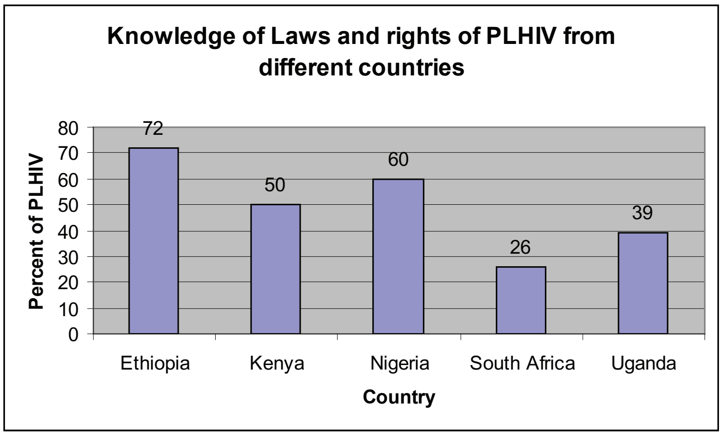
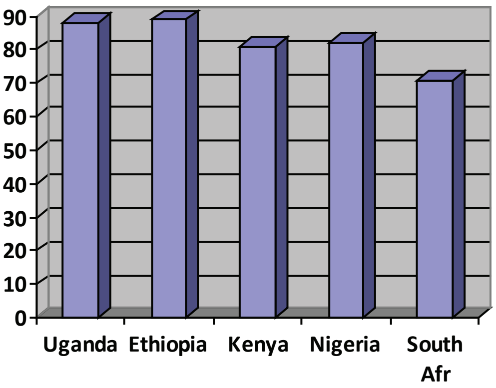


Figure 10: Knowledge of laws and rights of PLHIV, comparing different countries

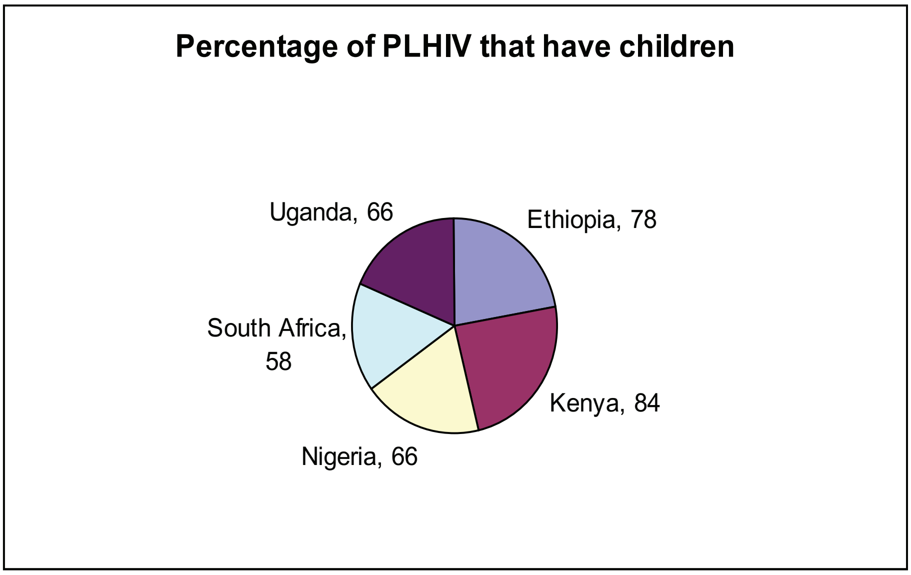
Of the compared African countries, Ethiopia has highest percent (72%) regarding knowledge of laws promoting and protecting rights of PLHIV. Uganda stands at 39% with South Africa standing lowest with 26%. This calls for country wide sensitization on laws and rights of PLHIV. Another comparison was on number of PLHIV accessing ART in the five countries



The general presentation is that most PLHIV in the selected African countries are actually accessing treatment with Ethiopia at 89%, Uganda 88%, Nigeria 82%, Kenya 81% and South Africa at 71%. What is not captured, however, is number of PLHIV on waiting list in the respective countries.

Regarding having children, a comparison was made to that effect.

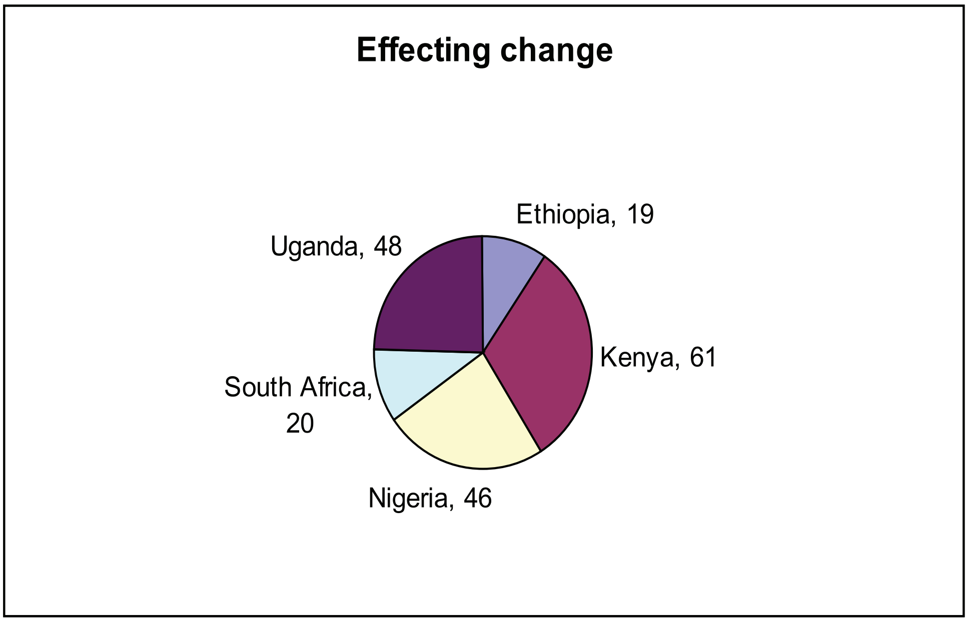
Figure 12: PLHIV that have children



From Figure 12 above, Kenya has a high percent of PLHIV having children at 84% and Uganda stands at 66% together with Nigeria. This calls for universal access and utilization of eMTCT services for an HIV free generation in Africa.

Since rights violations are reported in all countries, it is important to determine level of PLHIV able to effect a change for promotion and protection of PLHIV rights

Figure 13: Effecting Change



All compared countries, save for Kenya, fall below 50% of PLHIV who can effect change with Ethiopia lowest at 19% followed by South Africa at 20%, Nigeria at 46% and Uganda at 48%. There ought to be a deliberate policy to empower PLHIV to effect change and minimize rights violation in various countries.

5.0 Conclusion

5.1 Introduction:

This section is categorised into the 3 main components assessed in this survey including 1. Experiences of stigma, 2 knowledge about laws, policies and, 3 experiences of effecting positive changes to redress stigma and discrimination related events. Given the nature of the report format, some of the aspects that should have been essential in the conclusion section as per standard reports structure, have been highlighted in the executive summary section of this report. The structure of the section contains two parts; key issues and summary.

5.2 Key issues

Aspects of exclusion: Exclusion of PLHIV in the communities, family and religious centers is still evident. Though comparatively less, with reference to the period before ART scale up. The highest exclusion was reported at social gathering, (16%), family level (10%) and religious centers (7%). Of those 185 individuals who reported exclusion, 68% (65) said it was because of being a PLHIV.

Forms of stigma: The main stigma practices occur in form of gossip (60%), verbal insults and or threat (37%). Of those who experienced gossip, 58% report that it was because of their HIV Status, while those who were insulted or threatened, 47% report that it was due to their HIV positive status.

Stigma at family level: Approximately 20%, of PLHIV revealed that they had been subjected to psychological pressure or manipulation by their husband/wife or partner, taking advantage of their HIV status, at least once in the previous 12 months before the survey. This is s a manifestation of stigma at the family level. Thirty three percent, of those who reported that it was by another member of the household and 38% of the physically assaulted was by persons outside the household but known to them. Of those assaulted, 21% attributed it to their HIV status.

Reasons for stigma: Knowledge gaps about the transmission of HIV have persisted in the communities and in away lead to stigma. The most reported reason (35%) about the possible causes of stigma/discrimination inflicted upon PLHIV is fear of transmission of the virus. More than one quarter of the PLHIV believed that the reason for their stigmatization /discrimination was due to people thinking that having HIV is shameful and therefore should not be associated with them.

Aspects of internal stigma and fears: Regarding internal stigma, the most outstanding aspect was that of blaming self 408 (37%), followed by feeling of shame 340(31%) and feelings of guilt 320 (29%). The gender distribution for most of these aspects was equal, no major noticeable variations.

Expressed impact of internal stigma; Majority (53%) of the respondents decided not to have more children, (29 %) decided not to have sex, 28% decided not to get married respectively. About 10% decided to isolate themselves from family and/or friends and other (9%) have avoided going to local clinic when sick.

Aspects of Access to work, education and health: Issues of discrimination at institutional level are still prevalent. A substantial percentage, 27% of the 147 (23%) PLHIV who reported losing jobs or incomes within the past year preceding the survey attributed it to being HIV positive status. Additionally 62 (8%) been dismissed, suspended or prevented from attending education institution due to HIV status. Whereas 50 (5%) were denied health services including dental care.

Rights, laws and policies; Knowledge about laws and policies was quite limited, only 40% PLHIV are aware and knowledgeable of the existence and content of both UN declaration on HIV and nation HIV instruments and policies. It means the majority lack information that empowers them to seek protection or promote their rights. In the 12 months before the survey, 6 % reported being forced to submit to a medical or health procedure because of their HIV status. In general 87% revealed that they didn't experience discriminatory practices during period of reference.

Effecting changes; A limited number of PLHIV have effected positive changes. Of the 23% (254) who reported that their rights had been abused in the last 12 months, only 25% mentioned that they had attempted to take legal redress. According to the results, 63 (86%) of those who had attempted to get legal redress reported that the process had begun in the last 12 months before the survey (n=63). However, on a positive note, 563 (51%) of the 1106 PLHIV reported to have confronted, challenged or educated someone who was stigmatizing and/or discriminating against them.

Testing and diagnosis; HIV test is still a dreaded practice and at the time the PLHIV tested, many non- HIV voluntary practices were experienced. The most common reason (35%) cited for an HIV test was illness or death of husband/wife/partner/family member. The reluctance to take an HIV test, and waiting for symptoms of HIV, like illness or sickness/death of a partner, delays, treatment. Early treatment has been shown as preventive strategy. Some proportion reported that they were tested without their knowledge 45(4%), others were forced 29 (3%), and to others 68 (6%) it was simply pressure from others.

Disclosure and confidentiality: Disclosure to significant others such as husbands/wives/ partners health worker was reported by about over 70%, the outstanding majority, (81%) revealed to health workers. Some PLHIV have not told their HIV status to household members (11%) and to children in the family (19%). On a negative note, 7% revealed that their status had been disclosed to others by the medical persons without their consent.

ART Treatment; PLHIV networks have a significant role in ART treatment. Majority (88%) of the respondents were on ART and that may be the reason for their rating their health condition in the range of fair to excellent. Comparing with the general population ART estimates in Uganda, 88% is such a high proportion. However, recognizing, factors around network support in terms of knowledge, skills and above all the potential to have overcoming stigma plays a big role in ART treatment.

Having children: Almost all, PLHIV stay, with children, of the 90% of male and 95% female respondents who had children, 25% reported that these children were HIV positive (both biological and none biological). One hundred forty eight were biological children of the PLHIV.

Challenges of PLHIV: The challenges of being PLHIV are many and require a holistic approach.

The most challenging aspect was with regard to HIV test was fear of being HIV positive 51% (394) followed by, fear of stigma and discrimination, 22% (170). The problematic aspects relating to experiences of antiretroviral therapy, revealed four major issues including; reported drugs side effects 31% (233) drug adherence issues, 23% (174)lack of enough food/lack of nutritional support, 18% (135) and drug stock outs, 13% (94) .All these aspect require a holistic approach.

5.3 Summary

It has been observed that HIV and AIDS have become generalised and mature in Uganda, with this realisation, the continuum of stigma has moved from wide spread social exclusion to specific forms of stigma mainly -gossip. Though one approach is not recommended to overcome this hybrid stigma, stigma reduction interventions built in on-going HIV programs such as eMTCT, where human rights issues as well as personal responsibility issues of positive living are highly recommended. Subsequently Interventions that focus on addressing internalised stigma are more suited to our context in that, once the PLHIV is empowered to over come situations of internal stigma then other forms of stigma are unlikely to occur.

Of paramount importance is the need to empower PL HIV so that they have knowledge and information about their rights, services, stigma and discrimination and that they can stand up and challenge any forms of stigma and discrimination, inform and lead to change in policies, laws and legal frameworks that cause stigma and discrimination and demand that implementation of programmes are within the Human Rights Framework (HRF).

6.0 Methodological Limitations

i. Performing analysis and comparing the proportions to large sample of other sub populations was quite a challenge. This was mainly because the sub category populations were few in number compared to others. Improvement in selection of sub groups and specific sub studies could address this methodological challenge.

ii. The People living with Stigma index only focused on lived experiences of PLHIV as the main source of data. Better evidence of stigma issues would have also from persons in the same community who self report themselves as negative. In an attempt to minimize this limitation, this survey has made key reference to the Uganda AIDS Indicator Survey 2011 (AIS) in the background section. The AIS provides some insights about stigma related attitudes from the general public.

iii. Some interviews with religious leaders were on phones and no direct interaction, it is quite hard to ascertain quality in such case, but these were also few and did not affect the results much. Subsequent stigma index survey needs to include qualitative designs, but also plan to adopt telephone interviews appropriately.

iv. The design of the survey focused more on adults, 18 years and above. This was based on the assumption that adults would easily consent, and more importantly would be in position to talk about HIV AIDS stigma and discrimination exhaustively. However, all consultative meeting with stakeholders emphasized the need to include a children (12-17 years preferably).

v. Questions on income were not easy to quantify given that many persons were not working. Subsequent study would need to given national program a lee way to quantify income levels.

vi. The proportion of registered number of PLHIV in the district was the primary basis for the determination of the sample picked from each selected districts. The methodological challenge that arises due to this is over and under representation, simply because their district registration is more complete. An M&E department at NAFOPHANU and a more strengthened structure for registration of members should be ensured.

vii. The guidance by the user guide and international questionnaire on the possible categories of respondents to include in the survey generates and yield aspects of heterogeneity. This makes uniform sampling a challenge, and comparison with multiple sub group is rendered almost impossible

viii. In terms of reporting, the international guide, follows a format which does not related easily with the survey objectives. A standard report format where each objective is written about would be preferred.

ix. Given the aspects of lived experienced, a blend of qualitative methods that focus on phenomenology (person lived experiences and life trajectories) will be very suitable as an annexed study design.

7. The PLHIV Survey strength:

Despite the above limitations, this is the first PLHIV Stigma Index in Uganda and has provided a better understanding of the levels and forms HIV AIDS stigma at family, community and institutions level. It has also provided a baseline upon which future surveys will bench mark. Additionally the standard tools have helped to compare data with other neighboring countries on aspects of HIV AIDS associated stigma.

8.0 Recommendations

The recommendations are made in light of the changing face of stigma in the Ugandan context, the high levels of unemployment among PLHIV, the low levels of knowledge on HIV related human rights among PLHIV, PLHIV inability to effect change, and the countless challenges including poverty and lack of access to food. Below are specific recommendations for the major stakeholders (NAFOPHANU, Civil Society Organization (CSO), and Uganda AIDS Commission). Most of the recommendations are derived from the findings in the survey and few from literature reviews.

NAFOPHANU:

i. Owing to the current and anticipated roles of NAFOPHANU as a key player that brings together PLHIV networks in Uganda, the following recommendations are proposed:

ii. Widely disseminate the findings of the PLHIV Stigma Index first 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.

iii. Develop an M&E framework with key performance indicators to monitor outcomes as a result of Stigma reduction interventions by PLHIV at National level, but also share tools with PLHIV networks to document and report cases of Stigma and Discrimination in their respective districts.

iv. Utilise the current PLHIV networks to advocate for the rights of PLHIV and empower them to assert their rights. Because of the network set up, it is relatively easy to empower members with specific knowledge and skills in advocacy with knowledge about their rights as PLHIV.

v. Mobilize resources to conduct a sub study on stigma among children below the age of eighteen to explore issues that were not looked at in the adult population study.

vi. 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.

vii. Advocate for and conduct sub group studies of stigma for; religious leaders, Sex Workers, IDUs, Women, Young Positives, LGBTI and other cohorts. HIV related stigma was relatively more complex in these sub groupings.

viii. Promote the core elements of PLHIV positive living at several levels using the district fora.

ix. Provide technical assistance to PLHIV networks so that they can plan and control their districts

x. Scale up the Social Support mechanism of PLHIV in their organized networks as this facilitates voluntary disclosure, access to treatment, confidentiality, adherence and group advocacy and lobbying.

xi. In light of internal stigma and fears, a programme in life skills training for PLHIV should be instituted. This will strengthen PLHIV esteem, reduce internal stigma and their role as Agents of Change shall be enhanced.

xii. Promote the core elements of PLHIV positive living at several levels using the PLHIV networks.

xiii. Mobilise resources for a comprehensive stigma reduction campaign targeting multiple players.

Civil Society

The CSO has made a huge contribution in broad aspects of addressing HIV stigma in Uganda. The following recommendations are focused on such contribution and their anticipated roles with respect to HIV stigma reduction intervention in Uganda. The recommendations reflect both the key findings as well as literature reviewed.

a. Develop public-private partnerships for as both NGOs, and community based to bridge some of the human resource gaps in stigma reduction initiatives

b. Provide technical support for intensified monitoring of the violation of rights, changing continuum of stigma and building monitoring capacity for all players

c. Encourage and support the meaningful participation of PLHIV in national matters that concern them (National laws, economic programs, and policies)

d. Provide relevant and accurate information on HIV disease patterns, infection trends, treatment options and reproductive health matters that relate to HIV related stigma with harmonized messaging

e. Support health facilities in the development of all encompassing treatment procedures, support them in issues of access to treatment

f. Advocate for provision of infrastructure, human resource and Support health facilities in the development of all encompassing treatment procedures, in a stigma free environment, including the attitude of health workers.

g. Advocate for the scheduled implementation of subsequent stigma index country assessments

h. Conduct AIDS Competence trainings for multiple stakeholders.

i. Advocacy for increased access to MARPS friendly services including religious leaders as unique and complex stigma was depicted in these sub groups

Uganda

Uganda AIDS Commission

As per policy mandate, the Uganda AIDS Commission is charged with coordinating multi-sectoral policy issues and activities from both public and private sectors. With this in mind, the following Policy Level recommendations derived both from key findings and from literature reviewed are suggested.

- Institutionalise the PLHIV Stigma Index assessment, promote and implement it nationally
- Provide policy level guidance on how to promote and increase access to MARPS friendly services.
- Rejuvenate and implement AIDS Competence programmes targeting the entire population.
- Embark on anti stigma policy that addresses stigma experienced in homes communities and other institutions such as schools, hospitals and workplaces
- Institutionalise the PLHIV Stigma Index assessment, promote and implement it nationally
- Provide policy level guidance on how to promote and increase access to MARPS friendly services.
- Work place policy implementation
- Provide policy level guidance on how to promote and increase access to MARPS friendly services. This could be done through production of guidelines for MARPS service, creating demand for such services, and improving documentation to inform service provision for MARPS
- The government efforts in measuring trends in comprehensive knowledge about HIV, accepting attitudes towards those living with HIV, Personal knowledge and discrimination, attitudes towards negotiating safer sex relation is quite commendable. It is recommended that such indicator surveys continue to be implemented to monitor trends in broad domains for stigma reduction.
- Advocate for provision of infrastructure, adequate human resource and logistics 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.
- Promote ethical practices (observe patient's rights to confidentiality) among the health professionals as indicated in the report that many healthcare providers disclose private information without client's consent.
- Uphold the integration of stigma and discrimination reduction initiatives into national programs such as eMTCT, HCT, ART, HBC and Prevention with Positives
- Adopt the people living HIV stigma index baseline survey results and prepare to conduct subsequent surveys in the future.
- Promote ethical practices (observance of patients rights to confidentiality) among the health professionals as many were reported to disclose private information without consent of the clients
- Allocate specific special studies that focus on sub groups where HIV related stigma is more pervasive
- Fund media campaigns that will promote positive health dignity, and HIV prevention country wide, encourage safe mode (Safer practice- condom use, faithfulness, safe transfusions, needles, groves and basic care package), use available medication, adopt VCT and empower PLHIV.
- Develop sustainability strategies and plans for continued participation of National government to challenge stigma and discrimination
- Focus the national HIV/AIDS strategies to monitor national programs components that relate to stigma reduction
- Mobilize resources for projects that are directly focusing on helping stigma reduction in specific populations

Government of Uganda (Central Government)

- According to the findings and literature reviewed, most stigma emerges from low levels of HIV infection modes, it is thus recommended that the government of Uganda continues to implement education campaigns through the media about comprehensive knowledge of HIV to dispel misconceptions

Stigma Index

- The government efforts in measuring trends in comprehensive knowledge about HIV, accepting attitudes towards those living with HIV, Personal knowledge and discrimination, attitudes towards negotiating safer sex relation is quite commendable. It is recommended that such indicator surveys continue to be implemented to monitor trends in broad domains of stigma reduction
- The government of Uganda should also uphold non discriminatory laws that have a potential to inculcate stigma and discrimination

Promote professionalism that will to combat stigma among health workers and so that they can have more contact with patients.

As Edwin Cameron observes, '...if we do not appreciate the nature of stigma, none of our interventions can begin to be successful. AIDS is probably the most stigmatised disease'

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Stigma Index

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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