Ambasáid na hÉireann
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THE NATIONAL FORUM OF PLHA NETWORKS IN UGANDA
THE UGANDA HIV/AIDS PARTNERSHIP
NAFOPHANU

THE PEOPLE LIVING WITH HIV STIGMA INDEX

UGANDA

COUNTRY ASSESSMENT REPORT

September 2019

PACK
Prevention of HIV & AIDS in the Communities Of Karamoja

SHARING THE CHALLENGE
UGANDA AIDS COMMISSION

UGANDA

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THE PEOPLE LIVING WITH HIV STIGMA INDEX

September 2019

Uganda

Prepared by

The National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU)
Plot 213, Sentema Road, Mengo
P.O. Box 70233 Kampala
Tel: +256 200 944448, +256 701 444448
Email: info@nafophanu.org
Website: www.nafophanu.org

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

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EXECUTING/ROLL OUT TEAMS

Technical Working Group (TWG) members

Dr. Stephen Watiti	NAFOPHANU Board Chairperson/Chairperson of TWG
Ms. Proscovia Namakula	WONETHA
Ms. Ruth Ninsiima	Friends of Canon Gideon Foundation (FOCAGIFO)
Mr. Kuraish Mubiru	Uganda Young Positives (UYP)
Mr. Richard Serunkuuma	Positive Men's Union (POMU)
Mr. Gabriel Amori	Uganda Network of Religious Leaders Living with or personally affected by AIDS (UNERELA+)
Mr. Stanley Nsubuga	Uganda Network of Young People Living with HIV/AIDS (UNYPA)
Dr. Elvis Basudde	Vision Group
Ms. Jane Mwirumubi	Family Rescue Initiative
Ms. Milly Katana	Advocate
Ms. Dorothy Namutamba	International Community of Women Living with HIV East Africa (ICWEA)

National Steering Committee (NSC) Members

Dr. Zepher Karyabakabo	- Uganda AIDS Commission/Chairperson of NSC
Dr. Peter Mudiope	- Ministry of Health (MOH)
Mr. Jotham Mubangizi	- UNAIDS
Ms. Jackie Katana	- Embassy of Ireland
Ms. Lillian Mworeko	- International Community of Women Living with HIV East Africa (ICWEA)
Ms. Daphine Katusiime	- Young Person
Mr. Charles Serwanja	- Inter Religious Council of Uganda (IRCU)
Ms. Sylvia Nakasi	- Uganda Network of AIDS Services (UNASO)
Mr. Robert Munyenya	- Ministry of Gender, Labour & Social Development (MGLSD)
Ms. Molly Kate Rwankore	- The AIDS Service Organisation (TASO),
Mr. Louis Javuru	- Uganda National Academy of Sciences (UNAS)
Ms. Joanita Kawalya Muganga	- Private Sector/Arts
Mr. Denis Bwanika	- US President's Emergency Plan for AIDS Relief (PEPFAR)
Mr. Simon Sigirenda	- Centers for Disease Control (CDC)
Ms. Susan Ajok	- Straight Talk Foundation/PACK Grant Management Unit
Dr. Stephen Watiti	- Representative of TWG

Peer Reviewers: 1. Prof. Fredrick Kayanja 2. Prof. Harriet Mayanja-Kizza 3. Prof. Livingstone S. Luboobi 4. Prof. Charles Rwabukwali 5. Prof. Peter Mugyenyi

Consultant: Mr Richard Batamwita of Sciences Research Consortia (SRC),

NAFOPHANU staff

Ms. Stella Kentutsi	- Executive Director/Principle Investigator
Ms. Victoria Kiwanuka	- Programme Officer Advocacy
Ms. Proscovia Nanyanzi. Luzige	- Programme Manager
Ms. Winnie Ikilai	- Programme Development Officer
Mr. Steven Sentongo	- Accountant
Mr. Geoffrey Twine	- Finance Administration Manager

LIST OF ACRONYMS

ART	Anti Retroviral Therapy
CBO	Community Based Organization
CSOs	Civil Society Organizations
FSW	Female Sex Worker
GNP+	Global Network of People living with HIV
HCT	HIV Counseling and Testing
HIV	Human Immuno-deficiency Virus
HTS	HIV Testing Services
ICF	International Classification of Functioning
ICW	International Community of Women living with HIV
IPPF	International Planned Parenthood Federation
IRB	Institutional Review Board
KPs	Key Populations
LGBTQI	Lesbian Gay Bisexual Transgender Queer Intersex
MOH	Ministry of Health
MSM	Men who have Sex with Men
MUREC	Mildmay Uganda Research Ethics Committee
NAFOPHANU	National Forum of People living with HIV/AIDS Networks in Uganda
ODK	Open Data Kit
PACK	Prevention of HIV/AIDS in Communities of Karamoja
PI	Principal Investigator
PLHIV	People Living with HIV
PWUID	People Who Use or Inject Drugs
SRHR	Sexual & Reproductive Health Rights
TG	Transgender
TWG	Technical Working Group
UAC	Uganda AIDS Commission
UNAIDS	Joint United Nations Program on HIV/AIDS.
UNSCT	Uganda National Council for Science and Technology
UPDF	Uganda People’s Defence Forces
UPHIA	Uganda Population HIV Impact Assessment

Uganda

FOREWORD

Thirty seven years into the fight against HIV&AIDS, Uganda has made significant progress in the control and management of the epidemic. These achievements have been as a result of implementing a range of behavioral, biomedical and structural interventions guided by the multi-sectoral approach that Uganda AIDS Commission is proud to coordinate through the partnership mechanism. The partnership mechanism brings together various stakeholders comprising of state and non-state partners that comprise of line ministries, decentralized response, Parliament, CSOs, People Living with HIV (PLHIV), AIDS Development Partners, Academia, Cultural leaders, faith based organizations, media and the Private sector. Although over three decades have passed from the onset of the pandemic, stigma, and discrimination against people living with HIV and those populations at increased risk of HIV transmission still exists.

To achieve the numerous milestones, the country is guided by the policy framework with policies, laws and guidelines in place. For instance, the National Strategic Plan (NSP) 2015/2016-2019/2020 provides for specific interventions and actions in line with the four thematic areas of HIV prevention, care and treatment, social support and systems strengthening. Under social support, Uganda aims at reducing vulnerability to HIV&AIDS and mitigating the impact on PLHIV and other vulnerable groups. This is being done by scaling up efforts to eliminate stigma and discrimination and such efforts must consider both internal and external stigma experiences related to HIV and also other stigma intersections of either belonging to certain categories of people or nature of work.

According to Uganda Population based HIV Impact Assessment Survey (UPHIA) 2016-2017, overall prevalence of HIV infection is at 6.2% for adults with 7.6% for women and 4.7% for men while AIDS related deaths have reduced from 45,000 in 2011 to 28,000 in 2018. Currently, there are 1.3 million people living with HIV and of these about 1.2 million are accessing Anti-Retroviral Therapy (ART). These successes notwithstanding, there still exists varying levels of stigma and discrimination against people living with HIV and populations at increased risk of contracting and/or transmitting HIV. This presents a major barrier to effective management and control of the HIV and AIDS epidemic.

The PLHIV Stigma Index Survey fits in the national policy guidelines of conducting research into the epidemic and promoting research information sharing to ensure evidence based interventions. Being the second national PLHIV Stigma Index in Uganda, building on the first one conducted in 2013, it becomes a benchmark for a more responsive stigma reduction strategy. It is important to note that since 2013, the external stigma levels have reduced and so our efforts should be geared towards addressing internal stigma by targeting individual feelings as depicted by variables of internal stigma in various proportions.

I congratulate NAFOPHANU upon this great work of rolling out the second national PLHIV Stigma Index Survey. The findings will guide our stigma reduction work within the framework of the Presidential Fast Track Initiative to ending AIDS as a public health threat by 2030.

Dr. Nelson Musoba
Director General, Uganda AIDS Commission

ACKNOWLEDGMENTS

The roll out of the second National PLHIV Stigma Index in Uganda was made possible with financial and technical support from the Embassy of Ireland through the Prevention of HIV&AIDS in Communities of Karamoja (PACK) Project. NAFOPHANU is very grateful for this indispensible support.

As per the principles of meaningful and broader inclusion, the PLHIV Stigma Index was highly consultative. We thank the Technical Working Group (TWG) members led by Dr. Stephen Watiti and members that included Proscovia Namakula, Ruth Ninsiima, Kuraish Mubiru, Richard Serunkuuma, Gabriel Amori, Stanley Nsubuga, Dr. Elvis Basudde, Jane Mwirumubi, Milly Katana and Dorothy Namutamba.

The implementation of the PLHIV Stigma Index had the National Steering Committee (NSC) providing overall oversight role. The team was chaired by Dr. Zepher Karyabakabo and the members included Dr. Peter Mudiope, Mr. Jotham Mubangizi, Ms. Jackie Katana, Ms. Lillian Mworeko, Ms. Daphine Katusiime, Mr. Charles Serwanja, Ms. Sylvia Nakasi, Mr. Robert Munyenya, Ms. Molly Kate Rwankore, Mr. Louis Javuru, Ms. Joanita Kawalya Muganga, Mr. Denis Bwanika and Mr. Simon Sigirenda, Ms. Susan Ajok and Dr. Stephen Watiti. 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, Ms. Victoria Kiwanuka, Ms. Proscovia Nanyanzi. Luzige, Ms. Winnie Ikilai, Steven Sentongo and Geoffrey Twine who tirelessly worked with the auxiliary Survey Consulting team from the Sciences Research Consortia (SRC) led by Richard Batamwita 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.

Appreciation also goes to Research, Academia, Science and and professionals Self Coordinating Entity (RASP SCE) through its secretariat of Uganda National Academy of Science (UNAS) team of experts that peer reviewed the report: 1. Prof. Fredrick Kayanja 2. Prof. Harriet Mayanja-Kizza 3. Prof. Livingstone S. Luboobi 4. Prof. Charles Rwabukwali 5. Prof. Peter Mugyenyi being coordinated by Mr. Louis Javuru.

NAFOPHANU would like to acknowledge the invaluable role executed honorably 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 not have been successful. The staff of health facilities were exit interviews were held are greatly appreciated.

Together for a positive difference!

Stella Kentutsi
Executive Director, NAFOPHANU

DEFINITION OF KEY TERMS IN THE CONTEXT OF HIV STIGMA

Discrimination: Discrimination is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. It also refers to 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 characterized by rejection, isolation, denial and discrediting, consisting of action or omission that is directed towards individuals. Discrimination follows stigma.

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 (PLHIV) 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.

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: A process of devaluation' of people either living or associated with HIV. 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.

Resilience: The ability to cope with a crisis or to return to pre-crisis status quickly.

Viral load: A measure of the number of viral particles present in an organism or environment, especially the number of HIV viruses in the bloodstream.

Key Populations: Populations that are most at risk of acquiring or transmitting HIV regardless of the legal and policy environment.

Men who have Sex with Men (MSM): Males who have sex with males, regardless of whether or not they also have sex with women or have a personal or social gay or bisexual identity.

Transgender: People whose gender identity and expression does not conform to the norms and expectations traditionally associated with their sex at birth

Gay: Same-sex sexual attraction, same-sex sexual behavior and same-sex cultural identity.

Lesbian: Woman attracted to other women. She may or may not be having sex with women.

Homosexual: People who have sex with and/or sexual attraction to people of the same sex.

People Who Use or Inject Drugs: People who smoke, chew, sniff, drink and inject drugs orally or directly into the body through a vein, muscle or under the skin with a needle or syringe through illicit methods of drug use.

EXECUTIVE SUMMARY

For close to the 37 years, HIV has been one of Uganda's highest burden infectious diseases causing both mortality and morbidity in varying proportions. By 2016, Uganda had an HIV prevalence of 6.2% among adults aged between 15-49; an estimated 1.3 million adults and 96,000 children living with HIV (UNAIDS report 2016, UPHIA 2016-2017). The government of Uganda continues to work with several donors, collaborating institutions and civil society organizations to provide lifelong treatment. Out of the 1.3 million PLHIV, 1.1 million are accessing ART. Despite the great success of enrolment of many PLHIV on treatment, stigma and discrimination remain a structural barrier to HIV prevention efforts.

As part of the national effort to address stigma and discrimination, NAFOPHANU has continued to rally several Government ministries, Civil Society Organizations (CSO), Community-Based Organizations (CBO) and funding agencies like UNAIDS, Embassy of Ireland and Population Council to lead country-wide efforts to reduce HIV related stigma through several social behavioral interventions including, knowledge sharing, capacity building, advocacy at policy level and research about HIV related stigma. The execution of the serialized PLHIV stigma index studies to determine forms and trends in HIV stigma and inform programming is another key strategy which NAFOPHANU has spearheaded over the last seven years. The strategies targeted; policy reforms, advocacy for improved HIV related services, capacity building, stigma reduction interventions and mobilization of beneficiaries and stakeholders to practice and/or promote positive living.

In 2019, with support from the Embassy of Ireland through the Prevention of HIV&AIDS in Communities of Karamoja (PACK) Project, NAFOPHANU implemented the 2019 People Living with HIV Stigma Index survey reaching 1398 People Living with HIV (PLHIV) in 9 regions of Uganda covering 21 districts. The Stigma Index (SI) is a quantitative survey in which PLHIV are both the interviewers and the respondents. These experiences are for the last 12 months.

KEY FINDINGS

Background characteristics

A total of 1398 respondents, 874 (62.47%) females and 524(37.46%) males participated in the second national PLHIV Stigma Index survey. Out of this total, 56(4%), were still in school at the time of the survey, majority had primary level education 553 (39.53%), 360 (25.73%) were unemployed, 931(66.55%) were in an intimate relationship. Of those in intimate relationships, 591(63.48%) reported that their partners were HIV positive, 211 (22.66%) in discordance and 129 (13.86%) were not sure of the partner's status. Among all participants, 758 (54.18%) belonged to a PLHIV network and 423 (20.36%) belonged to a KP category (sex workers, PWUID, gay, transgender and MSM).

Knowledge of client HIV status by others

The proportions of PLHIV who reported about specific categories of people who knew the client's HIV status was high but varied by group. The highest proportions were family members at 1129 (80.77%), followed by friends 1064(76.13%), children 906 (64.83%) and sexual partners at 898 (64.26%). The least reported proportions were those of co-workers 375 (26.88%) and employers 308 (22.09%).

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Disclosure challenges

Five hundred and nine (509) representing 36.38% respondents reported that it was difficult to disclose HIV status to other people as 448 (3202%) revealed that they hide their HIV status from others. It was noted that husbands were more likely to know the status of their wives/partners than the wives and also 68.88% of the women had disclosed more to their children than to other family members.

Experiences of external forms HIV stigma

External forms of HIV stigma such as exclusion from social gatherings, physical and verbal harassment or being gossiped about have comparatively reduced much more than the internal forms. The most persistent form of external stigma was awareness of both family members and non-family members who made discriminatory remarks or gossip about the PLHIV at 34%. All other forms of exclusion generally reduced to from 4.5% to 1.3% when compared with the 2013 PLHIV Stigma Index survey.

Experiences of internal forms HIV stigma

Similarly, internal forms of HIV stigma had reduced but in smaller proportions compared to the external. Between 2013 and 2019, the proportion of PLHIV who self-reported on the construct of feeling guilty of being a PLHIV reduced from 50% in 2013 to approximately 24% in 2019, with no major gender difference. Owing to internal forms of HIV stigma, 255 (18.23%) mentioned they felt worthless because of living with HIV.

Reactions to negative experiences of HIV stigma

Participants agreed to having experienced HIV related stigma situations over the last 12 months. One hundred and eleven (111) representing 7.93% chose not to attend social gatherings, 61(4.36%) chose not to seek social support, 84(6%) chose not apply for job(s), 95(6.79%) decided to isolate self from family but the majority 284 (20.30% decided not have sex. This was more reported among females 208(23.80%) than males 76(14.50%). Depending on the type of partner the PLHIV had, not having sex was taken as a positive living option.

Coping mechanism with HIV related stigma (resilience)

The coping mechanisms to HIV internal stigma have over time increased since 2013 when the first national PLHIV Stigma Index was conducted. On a scale that measured resilience ranging from -10, through zero to 10 where negative is the worst and positive is the most preferred (a better resilience), 50% of the PLHIV had a resilience score of 4, meaning that despite HIV+ status, the level of resilience is equally high and could cope with stress and sero status. Coping with HIV internal stigma varied between regions, with the highest resilience in Karamoja and Bugisu regions while the lowest was in Teso.

Access to HIV care and treatment services

HIV testing is a gateway to HIV care and treatment. Findings reveal that testing for HIV was voluntary (personal choice) at 86.1%. The main reason for taking the test was because of falling sick at 33.5% but others felt were at risk at 27.3%. Most PLHIV (62.2%) took less than 6 months to enroll for treatment after the test but others delayed due to fear of others learning about their status (1032 - 74%) and because they were generally not ready to deal with HIV infection at (378 - 27.02%).

Stigma Index

There was increased uptake of ART with some gaps in adherence. Whereas almost all sampled PLHIV 1365 (99.71%) were taking ART by the time of the survey in January 2019, fears about someone learning of the person's status led 284 (20%) to miss a dose of their ART. More males (21.41%) compared to females (9.68%), reported missing doses of ART.

Access to viral load was high though rates of viral load suppression were still below the recommended UNAIDS 90-90-90 targets with the current national average at 88%. According to the PLHIV Stigma Index survey, 980(70.17%) reported viral load suppression in the last 12 months.

Experiences of mental health related conditions

Approximately 540 (39%) respondents reported forms of feeling nervous, anxious or on the edge over the last 2 weeks before the survey. About 538 (39%) reported not being able to stop or control worrying, 432 (31%) had little interest or pleasure in doing things and 453 (33%) reported feelings of depression or hopelessness. Overall, 301 (39.71%) had not received any type of support such as counseling for the mental health conditions experienced.

Human rights and effecting changes

The human rights abuses and violations were minimal and had generally reduced compared to the 2013 survey. Cases of forced testing or disclosure had been experienced by few 16 PLHIV representing 1.14% during the past one year before the PLHIV survey or even beyond. Among the negative experiences that stood out was the denial of residence in another country based on one's HIV status which was reported by 57 (4.8%) respondents.

The empowerment (self-efficacy) of PLHIV in line with human rights violation and abuse has also increased, for instance, out of the 186 PLHIV who reported experiencing abuse or human rights violations, 35 (18.82%) tried to do something about the matter either in form of complaints, contacting a lawyer, a government official or politician, a community based Organization to deal with the matter or speaking publicly about the matter

Stigma and Discrimination Experienced for Reasons Other than HIV Status

Within the KP category, that is People Who Use or Inject Drugs (PWUID), Sex Workers (SW), Lesbians, Gay, Transgender (TG), Men who have Sex with Men (MSM), non- HIV related stigma and discrimination was almost six times more than the HIV related stigma compared to the general population. Discriminatory remarks or gossip about the PLHIV were the commonest non-HIV stigma discriminatory experiences within among all the groups e.g. transgender at 33.65%, MSM at 24.24%, gay homosexual at 16.67%, gay lesbian at 39.39%, sex workers at 28.78 and PWUID at 28.92%. This data confirms the concept of double stigma- that KP face both sex/work-oriented stigma in addition to HIV related stigma and implies the need to deal with both. The opportunity to reach this group is quite huge given the proportion of those who belong to a support group is high which provides an easy entry point for reaching the targeted KP.

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Key recommendations

The various stakeholders in the multi sectoral response need to undertake an effective response to the HIV epidemic by tackling the root causes of stigma and ensuring that services are inclusive and accessible. This can be done by empowering People living with HIV to understand their rights and act on violations, address fears and change attitudes, include KPs in healthcare programming, protect PLHIV from discrimination laws and have stigma and discrimination reduction as a goal in national strategies.

1. BACKGROUND

In Uganda, the HIV prevalence has over the recent past shown varying peaks at 6.4% in 2004 according to the Sero-Behavioral Survey of 2004, a slight rise to a 7.3% in 2011 as was shown by the AIDS Indicator Survey and a slight drop to 6.2% within the age group of 15- 49 years according to UPHIA (2016-2017) report. Over these years, the variation in the HIV prevalence was attributed to specific factors and notably, the roll out of the nation-wide care and treatment programs integrated in Anti Retroviral Therapy (ART) and Prevention of Mother to Child Transmission (PMTCT) programs. These have significantly contributed to the reduction in new infections; death rates among those already infected leading to prevalence plateauing at 6%.

Similarly, the last two years of 2017 and 2018, have shown more positive gains in the HIV care and treatment programs. Specific changes have included further adoption of Test and Treat policy guidelines, innovations and emphasis on Viral load monitoring, enhanced HIV prevention programs such as elimination of Mother to Child Transmission (eMTCT), safe male circumcision, targeting of key and priority populations, improved HIV Testing Services (HTS), Differentiated Service Delivery (DSD) and innovations such Assisted Partner Notification (APN), quick and more localized testing tools such the oral quick tests and capacity building initiatives. The country's vision is to reduce HIV infections to Zero by 2020 as per the National HIV and AIDS Strategic Plan (NSP) 2015/16-2019/2020.

For close to 20 years, one of the outstanding factors documented to have negatively affected HIV decline and progress towards zero infections in Uganda and elsewhere is the HIV related stigma and discrimination. Owing to the impact of HIV stigma and discrimination, Uganda joined other countries and organizations such as Global Network of People living with HIV (GNP)+, International Community of Women living with HIV (ICW), International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on AIDS (UNAIDS) to progressively gather data, monitor and document the magnitude, forms and trends in HIV stigma to inform changes in HIV related laws, policies and programs to improve the lives of PLHIV.

THE 2019 PLHIV STIGMA INDEX

The tool was developed by the Global Network of PLHIV (GNP+), UNAIDS, ICW and IPPF in 2008 (stigmaindex.org) and updated in 2017. In Uganda, the first national PLHIV Stigma Index survey was conducted in 2013, at a time when the National ART program was in commencement phases. Between 2014 and 2017, regional-level and audience specific PLHIV stigma studies were conducted including the baseline and end line survey in Central and South Western Uganda in 2014 and 2015 respectively, Stigma Index survey among LGBTI conducted by Uganda Network of Religious leaders Living with of personally affected by HIV (UNERELA) in 2015, stigma index among sex workers by Women's Organisation Network for Human Rights Advocacy (WONETHA) in 2016-2017, the YPLHIV Stigma Index survey in the Eastern region districts of Iganga, Jinja and Bugiri in 2017 and the Karamoja regional PLHIV Stigma Index survey in 2017.

The PLHIV Stigma Index is a quantitative survey in which people living with HIV are both the interviewers and the respondents. The PLHIV stigma Index is entirely not only a study but also an evidence-based process of empowering the PLHIV in several countries to live meaningful lives. The empowerment process involves the PLHIV taking central roles in data collection, analysis, dissemination of data and using the data for lobbying, policy reforms, health services delivery improvements, knowledge generation and creation of comprehensive knowledge about the human rights of PLHIV. The starting efforts of PLHIV stigma index focused on overcoming HIV related stigma by firstly quantifying and documenting its magnitude in several settings.

Before 2017, the PLHIV stigma index county assessment used a standard PLHIV stigma questionnaire which was developed in 2008. In 2016, documentation by GNP+ showed that from 2008, over 100,000 PLHIV had been interviewed in over 90 countries. However, changes in the HIV epidemic, including the recent adoption of Test and Treat guidelines and Viral Load testing prompted an iterative process to update the Stigma Index, a project that was led by Population Council's Project Supporting Operational AIDS Research (SOAR) and the stigma index partners, in consultation with a range of stakeholders in various countries. The updated Stigma Index – the Stigma Index 2.0 – was tested in Cameroon, Senegal and Uganda in 2017 and has been available from GNP+ since the end of 2017.

Therefore, the 2019 second national PLHIV Stigma Index survey in Uganda explored additional components of community-based programming and biomedical and behavioral interventions. These included viral load, Pre Exposure Prophylaxis (PrEP) and Test and Treat. It also explored stigma among key populations, mental health, resilience and coping mechanisms despite HIV stigma. The 2019 Uganda Country assessment adopted and used the 2017 Questionnaire and PLHIV sampling procedure to collect and analyze the data.

1.2 STUDY GOALS AND OBJECTIVES

The overall goal of conducting the PLHIV stigma index survey was to estimate the prevalence of HIV related stigma and discrimination among the PLHIV with an aim to develop evidence-based responsive strategies.

1.2.1 Specific study objectives

I. Estimate the prevalence of HIV related stigma[1] based on selected known domains of:
    a. Internal stigma (individual feelings that often lead to negative actions)
    b. External stigma that manifests through community and family structures, workplaces and institutions.

II. Determine the impact of HIV related stigma on:
    a. Disclosure
    b. Treatment and care services for the PLHIV
    c. Missed opportunities arising from fears of HIV related stigma
    d. Rights-based violations

III. Describe the action taken (resilience) by PLHIV to mitigate impact of HIV stigma.

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[1] HIV related stigma covers experienced or perceived HIV stigma

IV. Describe how different groups are affected by HIV related stigma especially the key populations (sex workers, men who have sex with men, people who use/inject drugs, lesbians, gay, bisexual, transgender, intersex).

V. Analyze trends in the HIV related stigma using comparatively related data at two-time points 2013 versus 2019.

2. 0 METHODS

2.1 STUDY DESIGN

The PLHIV Stigma Index survey adopted a one-group post only cross-sectional design. The design was based on PLHIV empowerment principles and therefore conceptualized as a project. The PLHIV stigma Index used largely quantitative research methods for data collection and analysis. The qualitative component picked on stories/scenarios of PLHIV lived experiences. The GNP+ approved protocol also allows for comparison with sub studies and sub analysis of specific issues to guide advocacy, policy reforms, service delivery and promotion of dignity for the PLHIV. This design was non-experimental and only comparative in nature to determine trends.

2.1.1 Study setting

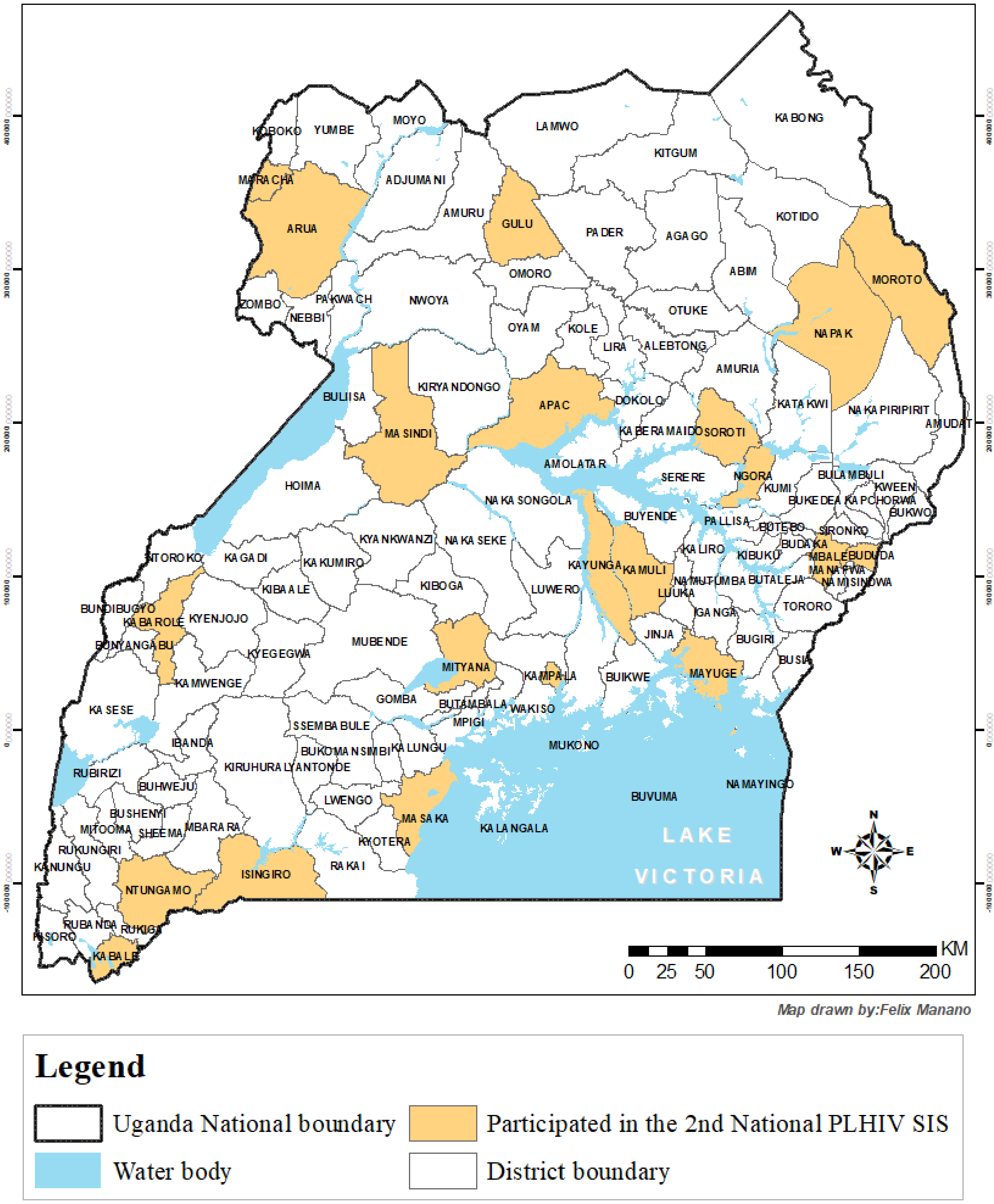
The study was conducted in 9 regions, 21 districts and among groups of PLHIV in armed forces, the prison community as well as People With Disabilities. For the key populations, places such as brothels, bars, night clubs, street-based venues and sites for People Who Use or Inject Drugs (PWUID) were identified and visited. One major defining feature for the selection of the districts was harmonization with specific districts where the first PLHIV Stigma Index survey was implemented in 2013. This was solely to enable determination of trends in HIV related stigma within those districts and institutions.

Table 1 : Study regions, districts and language used

Sub Region	Districts	Language
North	Gulu,Apac	Luo
South West	Ntungamo, Isingiro, Kabale	Runyankore/Rukiga
Elgon Region	Mbale, Bududa	Lumasaba
East Central	Kamuli, Mayuge	Lusoga
West Nile	Arua, Maracha	Lugbara
Karamoja	Moroto, Napak	Ngakarimajong
Central	Kampala, Mityana, Kayunga, Masaka	Luganda/English
East (Teso)	Soroti Ngora	Ateso
Western	Kabarole, Masindi	Runyoro/Rutoro

Figure 1: Map showing the sampled districts

Note: Newly approved districts not reflected on the map



2.2. TARGET POPULATION

The study targeted PLHIV who had lived with HIV for at least 6 months and above.

2.2.1. Inclusion criteria

Table 2: Inclusion and exclusion criteria for eligibility to participate in the survey

Inclusion	
i.	Registered in the district PLHIV network of the sampled district
ii.	Found at venue and confirmed to be receiving ART or HTS from the facility
iii.	Registered as part of the community-based agencies for key populations or sampled through snowballing from KPs)
iv.	**Self-report having exchanged sex (for money or goods at least once in the last month (Female sex workers)**
v.	**Self-report having bought sex from a female (at least once in the last one month for Males)**
vi.	**Speaks (languages of study area)**
vii.	**Must have lived in the community for a minimum of 3 months**
viii.	**Able and willing to provide consent for interviews**

Exclusion	
i.	**Obviously under the influence of alcohol or other substances**
ii.	**Not registered in any of the networks, community based KP networks,**
iii.	**Not attending a designated health facility in the selected district**
iv.	**Not of age 18 years and above**
v.	**Had any other condition that, in the opinion of the Investigator or designee, would preclude provision of voluntary informed consent, make participation in the survey unsafe, complicate interpretation of survey outcome data, or otherwise interfere with achieving the survey objectives.**
vi.	**Unable and unwilling to provide consent for interviews**

2.2.2. Sample Size

Approximately 1,400 PLHIV respondents were calculated as the minimum representative sample size. The 1,400 was broken down proportionately into other smaller sub groups including; the general population, People with Disabilities (PWDs), uniformed men (UPDF), PWUID, sex workers, transgender, men who have sex with men (MSM), religious leaders and the prison community (Uganda Prisons Services inmates and officers).

Approximately 1,400 PLHIV respondents were calculated as the minimum representative sample size. The main assumption made during the calculation of the sample size was the number of PLHIV in Uganda by end of 2017 which was approximately 1.3 million (UPHIA, 2016/2017). Based on the infinity sample population formula as reflected in Morgan Table sample size calculation, any number beyond 800 respondents was determined as adequate to permit generations based on simple random sampling procedures.

Sample size determination:

$$S = \frac{X^2NP(1-P)}{d^2(N-1) + X^2P(1-P)}$$

$$S = \frac{3.841 \ x \ 1{,}300{,}000 \ x \ 0.17(1-0.17)}{(0.5)^2(1{,}300{,}000-1) + 3.841 \ x \ 0.17(1-0.17)}$$

$$= \frac{3.841*1300000*0.17*(1-0.17)}{0.02\text{^}2*(1300000-1)+3.841*0.17*(1-0.17)}$$

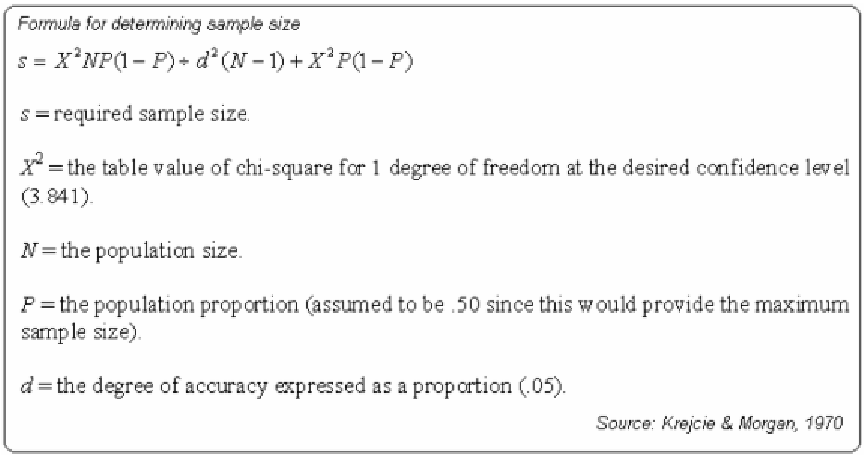
S = 1354

This figure is adjusted to address sub populations to 14000 respondents but not non response. Responses have been at 97% in most surveys.

$$n' = \left[\frac{n}{1+\frac{n}{N}}\right]$$

From current literature:

N= approximately 1.300.000 Persons based on UPHIA result of 2017
P is approximated at17% for 8 variables calculated to represent the proportion with internal HIV stigma
d = 2%.



Formula for determining sample size

$s = X^2NP(1-P) \div d^2(N-1) + X^2P(1-P)$

s = required sample size.

X^2 = the table value of chi-square for 1 degree of freedom at the desired confidence level (3.841).

N = the population size.

P = the population proportion (assumed to be .50 since this would provide the maximum sample size).

d = the degree of accuracy expressed as a proportion (.05).

Source: Krejcie & Morgan, 1970

However, given the diversity of the PLHIV and key populations, heterogeneity of the districts, rural and urban, uniformed forces and the varying ages and periods of living with HIV, a minimum sample of 1400 was presumed more accurate to cater for these variations. It was equally feasible to reach the target sample because of the existing registration networks and the working relationship between NAFOPHANU, the districts and the community-based agencies for KPs.

2.2.3. Sampling Frame and Sampling Plan

The primary sampling frame was the list of registered PLHIV within the district PLHIV forums. This served as sample frame for the group categorized as "general". During the process of developing the sampling frame, lists from the districts were shared with NAFOPHANU secretariat. The second sampling frame was a list of potential clients registered with community-based key population agencies. These were sampled by snowball mainly from Kampala and its surrounding areas. The last sampling frame was a random list of clients receiving ART services from a designated ART clinic in the sampled district through exit interviews.

2.2.4. Participant recruitment

i) Within the districts:

For all sampled districts, the district PLHIV District Forum Coordinator worked closely with the data collection sampling team to list specific individuals that had been randomly selected from the sampling frame for the district. This list included proportionally representative eligible numbers of male and female respondents. A list of names was shared with the Coordinator to mobilize the participants for consent and subsequent interviews at a secure venue of preference.

ii) Selection at health facilities:

Clients attending ART services at either Non-Government health institutions (Private not for profit) and/or Government health institutions were sampled through exit interviews.

iii) Selection at CBO for KPs

The CBOs dealing with KPs in the districts of Kampala, Wakiso and Mukono shared lists of registered members. Out of these lists, eligible potential respondents were met at places of convenience selected with the help of the CBO member who was in position to identify the eligible participant. After identifying the eligible participant, snowball sampling methods were used to assess recruit and interview the other eligible members. Additionally, some KPs were found at specific sites such as Most At-Risk Population Initiative (MARPI) clinic at Mulago National Referral Hospital.

2.3. DATA COLLECTION AND MANAGEMENT PLAN

Preparation for data collection included a week-long training of selected data collection teams at NAFOPHANU Secretariat in Kampala. To ensure quality and PLHIV survey standards, the data teams were trained in PLHIV stigma index survey methods, interviewing skills using hand-held Tablets or phones and research ethics. During the training, a field-based pre-test was conducted an in two urban areas; Banda in communities of Kireka C and the Knowledge Room in Kinawataka and the surrounding areas, all located in in Nakawa Division, Kampala district. Following the pre-test, required modifications were incorporated in the tools.

2.3.1 Questionnaire

A modified PLHIV stigma index questionnaire was used. This questionnaire was adapted from the PLHIV standard questionnaire which was developed in 2008 by GNP+, ICW, IPPF and UNAIDS. The 2017 PLHIV standard questionnaire was designed to capture lived experiences of PLHIV and how these experiences have shaped actions or affected the PLHIV levels of resilience and coping mechanism. This 2017 questionnaire and sampling methodologies was pilot tested in Uganda, Senegal and Cameron and high levels of consistency were confirmed. The questionnaire was programmed into a data collection platform using the Open Data Kit (ODK). The ODK was programmed with skip logic to control for entry level errors. Other forms of data quality checks and ethical considerations were enforced during data collection by supervisors. Data collection was side-by-side by trained interviewers using hand-held data collection devices (smart phones). With available internet connectivity, all data was sent daily over to a central mobile data collection platform at Sciences Research Consortia (SRC) after verification by supervisor attached to each data collection team of four. To have consistence, data collection was done in local language appropriate to the study district and where possible, by same-sex PLHIV interviewers.

2.4. DATA ANALYSIS PLAN

The 2017 PLHIV standard questionnaire contains eight thematic analytical areas; Demographics, HIV status disclosure, Experiences of PLHIV stigma due to HIV, Interactions with health workers, Human rights and effecting changes and specific experiences of stigma and modules of HIV among KPs. All these thematic areas have sub sections, and scales in the sub sections of mental health to aid analysis. To allow for comparison, disaggregation by gender was done for most variables and some sections for regions. All data entry was done in STATA 12 by Stata Corp LP, Texas USA.

2.5. STUDY MONITORING

Overall responsibility:

The Principal Investigator (PI) who also doubled as the Executive Director (ED) of NAFOPHANU bore the overall investigative role responsibility for all the study in addition to providing key roles such as identifying collaborating districts (PLHIV networks), institutions that provided to members of the TWG, National Steering Committee (NSC) and or identification of contractors for specific services.

2.6. ETHICAL CONSIDERATIONS

The PLHIV stigma index is part of serialized studies done by NAFOPHANU in Uganda. All the previous studies were reviewed and approved at Mildmay Uganda Research Ethics Committee (MUREC). Given this IRB knowledge about the study, NAFOPHANU submitted this survey protocol to MUREC for ethics review. MUREC subsequently reviewed and approved for registration at UNSCT. UNSCT equally approved and registered this study as SS3013.

2.7. SCOPE

The Geographical scope: The PLHIV Stigma Index survey was a country-wide assessment conducted in 9 regions; within 21 districts and 9 language segments to reflect the social cultural factors.

Time Scope: The main emphasis was on PLHIV stigma experiences of the last year. The last one year is symbolic of recent experiences. In some instances, however, PLHIV experiences that happened long ago- beyond the last 12 months before the survey were explored. Questions on Mental health explored last two weeks

Content Scope: The content HIV stigma experiences be it internal or external in the era of social behavioral and biomedical interventions in Uganda.

3. 0 RESULTS

3.1. STRUCTURE OF THE RESULTS

This report largely covers the five specific objectives. However, content for the five specific objectives is aligned and further broken down into 8 thematic areas written out as sub sections chronologically from 3.2 to 3.9. Sequentially, section 3.2 is about; socio-demographic characteristics, 3.3 details the disclosure experiences, Section 3.4, explores experiences of stigma and discrimination, section 3.5 is about internalized stigma and resilience, section 3.6 focuses on interactions with health workers, section 3.7 is about human rights experiences and effecting changes and 3.9 explores experiences of HIV stigma and discrimination not related to HIV among KPs. In most cases, findings are disaggregated by sex of the respondents to observe differences. Comparison of the 2013 and 2019 results is also presented at back of the report.

3.2. SOCIO-DEMOGRAPHIC BACKGROUND CHARACTERISTICS

This section presents aggregated socio-demographic characteristics of the respondents reached during the PLHIV stigma index survey. A total of 1398 respondents, 874(62.47%), females and 524 (37.46%) males participated in the PLHIV stigma index survey. Although the highest proportion is skewed to the females, most PLHIV studies have depicted similar proportions of male/female- that is females are usually slightly more than the males. Owing to this skewness, the disaggregation compares proportions within columns. The following were the proportions reached in the various categories:

Table3: Category of respondents

No	Category	Female	Male	Total
1	General Population	547	295	842
2	Persons With Disabilities (PWD)	19	11	30
3	Uganda People's Defense Forces (UPDF)	19	11	30
4	People Who Use & Inject Drugs (PWUID)	42	41	83
5	Sex Workers (SW)	166	39	205
6	Gay/ Lesbian	15	18	33
7	Gay/Homosexual		18	18
8	Transgender (TG)	14	37	51
9	Men who have Sex with Men (MSM)		33	33
10	Religious Leaders	10	13	23
11	Prison Community	32	18	50
	Total	**867**	**531**	**1398**

Table 4: Background characteristics of the sampled respondents by sex

Background information	Responses	Female n (%)	Male n (%)	Total n (%)
Sex at birth		874 (62.47)	524 (37.46)	1,398 (100)
Currently in school	Yes	20(2.29)	36(6.87)	56(4.00)
Currently in an intimate relationship	Yes	519(59.38)	411(41)	931(51)
HIV status of partner (s)	Yes, my partner(s) is also HIV-positive	304(58.57)	286(69.59)	591(63.48)
	No, my partner(s) is not HIV-positive	116(22.35)	95(23.11)	211(22.66)
	Unsure about the HIV status of my partner(s)	99(19.08)	30(7.30)	129(13.86)
Member of a network of PLHIV	Yes	465(53.20)	292(55.73)	758(54.18)
Highest level of formal education you have completed	No formal education	298(34.10)	111(21.18)	409(29.24)
	Primary/elementary/ local equivalent	349(39.93)	204(38.93)	553(39.53)
	Secondary/ high school/local equivalent	180(20.59)	158(30.15)	339(24.23)
	Trade/vocational school	17(1.95)	19(3.63)	36(2.57)
	University/tertiary education	30(3.43)	32(6.11)	62(4.43)

Table 4 shows 931 (51%) were in an intimate relationship with more females 519 (59.38%) vs males at 411 (41%). The data also shows that 591 (63.48%) have partners who are living with HIV, 211 (22.66%) were in discordant relationship while but 129 (13.86%) were unsure of the status of their partners. The membership to a PLHIV network is slightly over half with 758 (54.18%). Most respondents had low levels of education, about 409 (29.24%) with 298 (34.1%) female and 111 (21.18%) male had no formal education, 583(39.53%) had primary/elementary education with almost similar proportions of females and males at 39.93% vs 38.93% respectively while those at secondary level were 339 at 24.23% (20.59 female and 30.15% male). Data revealed that the average number of years PLHIV had known their status was 9 years.

The fact that some people do not know the HIV status of their sexual partners increases risk of transmission to those who are negative, but also can lead to gender based violence in case the other partner finds out through other means. In terms of HIV programing, the data on the unknown HIV status of sexual partners justifies the need for continued sensitization and awareness on testing among partners to reach the 13% who reported being unsure of partners' HIV status. This could be done through focused counselling to permit HIV status disclosure adoption of recent interventions like Assisted Partner Notification to complement the already existing voluntary HIV testing and care services and mandatory ones.

It is also important to note that majority of the respondents had no and/or low levels of education that only 62 (4.43%) had completed university/tertiary education. This could be due to either high levels of stigma or they have adequate information. This calls for specific targeting of PLHIV who are highly qualified and may be feeling more stigmatized since they do not belong to any network hence missing out on the psychosocial support and sense of belonging that peers enjoy together that has been instrumental in minimising stigma.

3.2.1. Economic profile of sampled respondents

The two question domains that were administered to explore the economic profiles of the respondents were employment status and ability to meet basic needs. The employment status variable measures current employment in specific categories. The basic needs domain specifically assessed an individual's ability to purchase or access food (three meals a day, shelter, clothing and other basic amenities).

Table 5: Economic profile of sampled respondents by sex

Category of people	Responses	Female n (%)	Male n (%)	Total n (%)
Employment status	In full-time work (as an employee)	62(7.09)	67(12.79)	131(9.29)
	In part-time work (as an employee)	76(8.70)	55(10.50)	131(9.36)
	Working full-time, but not as an employee (self-employed or business owner)	256(29.29)	157(29.96)	413(29.52)
	Doing casual or part-time work (self-employed or paid work for others)	240(27.46)	125(23.85)	365(26.09)
	Unemployed	240(27.46)	120(22.90)	360(25.73)
Unable to meet basic needs in last 12 months	Never	159(18.19)	134(25.57)	295(21.02)
	Some of the time	615(70.37)	334(63.74)	949(67.83)
	Most of the time	100(11.44)	56(10.69)	156(11.15)

Table 5 shows that generally high proportion of PLHIV had gainful employment (26.09%), but the unemployment rates were equally high with 360 (25.73%) of the respondents. There was a slight difference in self-employment between men and women (29.96%M vs 29.29F) thus implying that, behavioral economics could be initiated through the PLHIV forums/networks within the district to encourage, guide and promote self-employment as it seems to offer more opportunities and quite easy to penetrate. This also shows that the survey missed on the critical cadre of PLHIV who are employed and efforts should be geared towards getting these people into networks.

Concerning basic needs, this considers ability to look after family with at least 3 meals a day, school requirements, medical care, home use items among others. More women than men reported inability to meet some of the basic needs at 100 (11.44%) female vs 56 (10.69%) male. This could be interpreted in gender dynamics as men are often considered to be the bread-winners and failing on this responsibility could explain the high proportion. Meeting basic needs is highly associated with employment rates to ensure ability to meet basic needs and access to productive resources. With the reducing rates of HIV stigma, it is highly likely that more PLHIV will join economically productive ventures but this needs to be promoted systematically.

Table 6: Current or past membership in select population categories by sex

Category of people	Responses to the categories	Female n (%)	Male n 12.79 (%)	Total n (%)
Refugee or asylum seeker	Yes	35(4.00)	28(5.34)	63(4.50)
	No	837(95.77)	495(94.47)	1,333(0.21)
	referred not to answer	2(0.23)	1(0.19)	3(0.21)
Migrant worker	Yes	52(5.95)	33(6.30)	85(6.08)
	No	818(93.59)	491(93.70)	1,311(93.64)
	Preferred not to answer	4(0.46)	0(0.00)	4(0.29)
Internally displaced person	Yes	52(5.95)	27(5.15)	79(5.65)
	No	818(93.59)	495(94.47)	1,315(93.92)
	Preferred not to answer	4 0.46)	2(0.38)	6(0.43)
Incarcerated/in prison	Yes	44(5.03)	40(7.63)	84(6.00)
	No	826(94.51)	482(91.98)	1,309(93.57)
	Preferred not to answer	4(0.46)	2(0.38)	6(0.43)

Note: Responses to the category of belonging to racial/ethnic/religious group and indigenous/aboriginal group was presumed to have outliers and non consistent data.

In Table 6, there was evidence that some respondents in proportion ranging from 4.5% to about 6% are or have ever been part of specific categories of populations namely refugee/asylum seeker, migrant worker, internally displaced person or in prison. Overall, this data implies the need for programs that are tailored to meet the needs of these diverse groups of populations. Therefore, HIV care and treatment needs assessment should be designed to cater for both the general and special categories.

3.3. HIV STATUS DISCLOSURE

This section explores two main aspects of HIV related stigma; knowing the respondent's HIV status and circumstances through which they got to know about the status.

3.3.1 Knowledge of HIV status by others

A listing of ten categories of individuals was provided from which the respondents selected from. Respondents were subsequently asked if those categories of people who knew the respondent's HIV status, had consent from the respondent to disclose the client's HIV status

Table 7: People or groups of people who knew the PLHIV status by sex

Category of people	Responses categories	Female n (%)	Male n (%)	Total n (%)	2013 (%)
Husband/wife/partner(s)	Yes	483(55.26)	415(79.20)	898(64.26)	63.9
Respondents children	Yes	602(68.88)	304(58.02)	906(64.83)	60.5
Other family members	Yes	714(81.69)	415(79.20)	1129(80.77)	67.6
Friends	Yes	663(75.86)	401(76.53)	1064(76.13)	48.8
Neighbors	Yes	538(61.56)	302(57.63)	840(60.11)	48.8
Employer (s)	Yes	175(20.02)	133(25.38)	308(22.09)	21.6
Co-workers	Yes	222(25.40)	153(29.20)	375(26.88)	32.5
Your teachers/ administrators	Yes	15(1.72)	31(5.92)	46(3.36)	9
Your class mates	Yes	14(1.60)	22(4.20)	36(2.64)	
Community leaders (politicians or religious	Yes	420(48.05)	236(45.04)	656(46.96)	34

Note 1: proportion/figures for response categories no, NA, prefer not to answer are not reflected in Table 6. So, the columns may not add up to 100%

Note 2: The data for 2013 is where the PLHIV disclosed to the above categories themselves. The highest disclosure then was to health care workers at 81.2%, other PLHIV at 77.5% and social workers/counselors at 73.2%. Least disclosed to was employer at 21.6% and teacher/administrator at 9%

In Table 7, there are at least four categories with high proportions of people or groups of people whose HIV status was known by amongst these groups, including; other family members, 1130 (80.77%), friends 1065(76.13%), husband/wife/partner, 899(64.26%) and the respondent's children 907(64.83%). The lowest proportion reported to being knowing the PLHIV status was among class mates, 37(2.64%), among teachers and administrator, 47(3.36%) and employers 309(22.09%). Note that the proportion of males who knew the status of their wives/partners was high 79.2% vs 55.26%. In contrast, a high proportion of women 602(68.88%) reported more children and other family members at 714 (81.69%) to know their PLHIV status. In this data, females could have disclosed to children and family members in anticipation of positive social support while the men did not perceive it as such. Empowerment programs that promote disclosure are still very relevant in the Ugandan context and need to be reinforced.

Beatrice (64) from Ntungamo, "I have lived with HIV for 30 years now and what has helped me most is support from my children. They even helped me to disclose to their dad. But I have never told my employer for fear of losing my job"

3.3.2 Disclosure circumstances

To explore the circumstances through which disclosure for the PLHIV happened ethically or otherwise, a follow up question of whether disclosure was done with PLHIV consent was asked to those who had confirmed other people or groups of people knew their status (Table 8)

Table 8: Respondents whose HIV status was ever disclosed without the PLHIV consent by sex.

Category of people	Responses categories	Female n (%)	Male n (%)	Total n (%)	2013 (%)
Husband/wife/partner(s)	Yes	125(25.88)	102(24.58)	227(25.25)	4
Respondents children	Yes	146(24.25)	81(26.64)	227(25.03)	4.1
Other family members	Yes	197(27.59)	112(26.99)	309(27.35)	6.7
Friends	Yes	182 (27.45)	99 (24.69)	281(26.38)	20.8
Neighbors	Yes	163(30.30)	82(27.15)	245(29.13)	20.8
Employer (s)	Yes	33(18.86)	25(18.80)	58(18.77)	3.7
Co-workers	Yes	49 (22.07)	29(18.95)	78(20.74)	6.8
Your teachers	Yes	3(20)	7(22.58)	10(21.28)	3.9
You class mates	Yes	4(28.57)	5(22.73)	9(24.32)	
Community leaders (politicians or religious	Yes	115(27.38)	76(32.20)	191(29.07)	12.5

Proportion/figures for response categories of no, N/A, prefer not to answer are not reflected in Table 7. So, the columns may not add to 100%

Table 8 shows that over 1 in 4 PLHIV mentioned that their status was disclosed without their consent. This cuts across females and males almost with equal proportion for the groups of people. The non-consented disclosure was more to the neighbors 245(29.13%), community or religious leaders 191(29.07%), followed by family members 309(27.35%) and friends 281(26.38%). Compared to 2013, disclosure of HIV status without consent was largely due to friends and neighbours at 20.8%.

Jacob (32) from Napak, "I was home relaxing and my wife came back very furious on why I had kept my status a secret. I was still buying time to tell her since I did not have the courage on my own. She broke down and revealed to me that our neighbor had told her since we pick ARVs from the same health centre. Fortunately she did not leave but it took us time to stabilize our relationship."

In ethical HIV programming principles, disclosure should be a voluntary process and consenting should be promoted as it provides an opportunity for an evaluation of risks, a self-appraisal of the individual and an adhoc follow up actions following disclosure. Further research is recommended to explore why the proportions ranging between 18% and 29% revealed that their disclosure was non consensual.

3.3.3 Experiences of HIV status disclosure

Many times, PLHIV experience specific forms of treatment or psycho social challenges during or after positive HIV status disclosure. This result portrays these experiences for the PLHIV who disclosed and if they found the experience yielding either positive or negative outcome or nothing changed.

Table 9: Experiences of HIV status disclosure by sex

General views	Reponses categories	Female n (%)	Male n (%)	Total n (%)
Disclosing your HIV status to people you are close to (e.g., partner, family, close friends) has been a positive experience.	Agree	673(77)	416(79.39)	1089(77.84)
	Somehow agree	74(8.47)	57(10.88)	132(9.44)
	Disagree	110(12.59)	40(7.63)	150(10.72)
People you are close to were supportive when they first learned about your HIV status.	Agree	600(68.65)	361(68.89)	962(68.76)
	Somehow agree	103(11.78)	73(13.93)	176(12.58)
	Disagree	150(17.16)	77(14.69)	227(16.23)
Disclosing your HIV status to people you don't know very well has been a positive experience	Agree	387(44.28)	246(46.95)	633(45.25)
	Somehow agree	167(19.11)	107(20.42)	275(19.66)
	Disagree	274(31.35)	149(28.44)	423(30.24)
People you don't know very well were supportive when they first learned about your HIV status.	Agree	310(35.47)	224(42.75)	535(38.24)
	Somehow agree	185(21.17)	118(22.52)	303(21.66)
	Disagree	320(36.61)	151(28.82)	471(33.67)
Disclosing your HIV status has become easier over time	Agree	602(68.88)	356(67.94)	959(68.55)
	Somehow agree	111(12.70)	86(16.41)	197(14.08)
	Disagree	141(16.13)	70(13.36)	211(15.08)

According to Table 9, disclosure to people with whom the PLHIV had close ties was a positive experience reported in close to over three-quarters for both men and females 1089(77.84%). Similarly, over two-thirds that disclosed to people they were close to received support from them the first time they learnt of their HIV status. To a small extent, disclosure to people not so close had positive results comparatively lower to those they were close to at 633 (45.25%). The data also indicated that HIV status disclosure had been an easier process over time with 602

(68.88%) women and 356 (67.94%). Generally, disclosure experiences were positive to majority who disclosed, and became easy over time. This enabling environment should be leveraged to encourage more opportunities for the PLHIV to disclose HIV status voluntarily which is a key step towards HIV positive living and averting new infections.

Joshua (37) from Mityana, "After exclusion from a village yam growing project in 2013, I decided to re-examine the pros and cons of disclosing my HIV status. In the process I have had to painfully forego some opportunities. It all started after spending long hours at the ART clinic. and when I tried to explain myself to the Project Manager, he (the Project Manager) turned a deaf ear and I was sacked."

Huzairu (40) from Masindi, "We were in a discordant relationship when my wife started mistreating me. I asked a few friends to mediate and she has since changed her attitude towards me. We are now at peace"

Flavvy (22) a university student, "I had feared to disclose my status to fellow students thinking they would stigmatise me. When I did, I was overwhelmed by the support I received that my CD4 went high and I virally suppressed because one of the students became my treatment buddy. Her daily reminders made me adhere to my medication."

Konte (45) a truck driver, "Ever since I disclosed by status to fellow truck drivers, they have not been supportive and have also informed the Truck Drivers' Association who have even recommended that my routes be reduced for fear that I will die very soon."

3.4. EXPERIENCES OF STIGMA AND DISCRIMINATION

The section quantifies the HIV-related stigma the respondents may have experienced because of living with HIV. The variables and questions explored and presented in Table 9 mainly cover external forms of HIV stigma. The time reference compares the last 12 months before the survey and experiences past the last 12 months of the survey. The last 12 months symbolizes a more recent experience, where the period before the last 12 months depicts experiences of long ago.

Table 10: Experiences of exclusion and gossip because of HIV positive status by sex

Exclusion and awareness of gossip	Response categories (yes only)	Female n (%)	Male n (%)	Total n (%)
Social gatherings or activities (e.g., weddings, funerals, parties, clubs) because of your HIV status?	Yes, within the last 12 months	42(4.81)	18(3.44)	60(4.29)
	Yes, not within last 12 months	59 (6.75)	18 (3.44)	77(5.50)
Religious activities or places of worship because of your HIV status	Yes, with the last 12 months	12(1.37)	5(0.95)	17(1.22)
	Yes, not within last 12 months	14(1.60)	6(1.15)	20(1.43)
Exclusion from family activities	Yes, with the last 12 months	37(4.23)	13(2.48)	50(3.57)
	Yes, not within last 12 months	48(5.49)	16(3.05)	64(4.57)
Been aware of family members making discriminatory remarks or gossiping about you	Yes, with the last 12 months	156(17.85)	90(17.18)	246(17.58)
	Yes, not within last 12 months	174(19.91)	69(13.17)	243(17.37)
Aware of other people (other than family members) making discriminatory remarks or gossiping about you	Yes, with the last 12 months	237(27.12)	130(24.81)	367(26.23)
	Yes, not within last 12 months	200(22.88)	84(16.03)	284(20.30)

Note: To avoid clutter, responses for no, and NA are not reflected in the Table 10

According to Table 10, exclusion experiences of discrimination due to HIV status were minimal at social gatherings at 60 (4.29%). However, awareness of family members who made discriminatory remarks or gossip was reported by 246(17.58%), while that of non-family members was by 367(26.23%). This was more reported by females 27.12% vs 24.81%% males during the last 12 months. There was minimal exclusion at places of worship with 17 (1.22%) and at family level with 50 (3.57%). Whereas exclusion experiences have drastically reduced, this data could be interpreted at two levels; firstly, exclusion reduction that imply social norm change (collective code of conduct) to devoid exclusion experiences reduced partly because of no differences in physical appearance between the PLHIV and others in the community. The second interpretation relates to perceived norm (the result of individuals interpreting and perceiving values, norms of those around them). Positive desirable behaviors of no discrimination or verbal remarks could be addressed through focused communication campaigns.

David (48) from Moroto, "During the Local Council I campaigns in 2018, a fellow candidate discouraged the electorate from voting me into office alleging that they should not waste time electing me since I was to die of AIDS soon."

Sofia (26) from Kabale, 'In 2018, my aunt warned her children against playing with mine so that they do not get infected with HIV. My children were hurt by this exclusion. We are no longer on good terms'.

Joseph (33) from Maracha, 'I was not allowed to work after disclosing my HIV status. My colleagues and supervisors feared that I might infect them with HIV or even fall sick and die on the job'.

Jane (47) from Masaka, "I am always discriminated by my family members because of my HIV status and loss of sight. Even my request to join a local church choir was turned down because of my disability. So I am facing double stigma and discrimination."

Table 11: Experiences of harassment, refusals and discrimination because of HIV positive status by sex

Experiences of verbal harassment, refusals and discrimination	Response categories (yes only)	Female n (%)	Male n (%)	Total n (%)
Someone ever verbally harassed you (e.g., yelled, scolded, or was otherwise verbally abusive	Yes, within the last 12 months	210(24.03)	106(20.23)	316(22.59)
	Yes, not within last 12 months	149(17.05)	66(12.60)	215(15.37)
Someone ever blackmailed	Yes, within the last 12 months	116(13.27)	59(11.26)	175(12.51)
	Yes, not within last 12 months	97(11.10)	43(8.21)	140(10.01)
Someone ever physically harassed or hurt you (e.g., pushed, hit, or was otherwise physically abusive)	Yes, with the last 12 months	90(10.30)	33(6.30)	123(8.79)
	Yes, not within last 12 months	54(6.18)	20(382)	74(5.29)
Refused employment or lost a source of income	Yes, with the last 12 months	71(8.12)	40(7.63)	111(7.93)
	Yes, not within last 12 months	59(6.75)	28(5.34)	87(6.22)
Job description or the nature of your job ever changed, or have you ever been denied a promotion	Yes, with the last 12 months	36((4.12)	16(3.05)	52(3.72)
	Yes, not within last 12 months	28(3.20)	19(3.63)	47(3.36)
Your wife/husband or partner(s) ever experienced discrimination	Yes, with the last 12 months	74(8.47)	53(10.11)	127(9.08)
	Yes, not within last 12 months	53(6.06)	37(7.06)	90(6.43)

Note: Proportion/figures for response categories of no, NA, are not reflected in Table 11 so the columns do not add to 100%

From Table 11, verbal harassment is the commonest with one in five people, including yelling, scolding that was reported by 316 (22.59%) respondents. The proportion of females 24.03% was slightly higher than the males 20.23%. Similarly, blackmail was reported by 175 (12.51%), physical harassment by 123 (8.79) while husbands/wives/partners of PLHIV experienced discrimination with 127 respondents representing 9.08%. This data implies a need for further equitable empowerment programs to reduce gender gaps in addressing HIV stigma and discrimination but also work towards eradication of the noted external experiences.

At institutional level, some respondents 111(7.93%) reported refusal of employment or loss of income, while 52(3.72%) reported changes in job descriptions or nature and denial of promotion over the last 12 months before PLHIV survey. The above shows more challenges reported among the females compared to the males in almost all forms of stigma discrimination components. This data has direct implication on interventions for that they should not be gender blind both at individual and institutional level.

Compared to the 2013 PLHIV Stigma Index survey, awareness of discriminatory remarks at family level and other people was reported by 390 (58%). Similarly all the components used to measure external stigma reduced in proportions reporting such experiences between 2013 and 2019. This reduction could be associated with several factors including the national roll out of ART and efficacy of the ART to health for majority.

Georgia (44) from Kayunga, 'As a VHT, I was recruited for a national immunization campaign to mobilise families with children under 5 years. To my shock and on orders of a health inspector, I was dismissed without pay. Although I had done well on day one, it was alleged that I was incompetent. I was told that all this was done because of my HIV+ status."

Ambrose (52), religious leader from Kamuli, "I was denied presiding over a confirmation ceremony for children in my parish. This was due to fear that I was not a role model since as the custodian of morals had embarrassed the church for being HIV+."

3.5. INTERNALIZED STIGMA (THE WAY PLHIV FELT ABOUT THEMSELVES) AND RESILIENCE

The section presents experiences of internal HIV stigma and the levels of resilience despite the HIV stigma. The specific information explored was whether the PLHIV ability to meet his/her needs or cope over the past 12 months had been positively affected, not affected, or negatively affected because of the HIV status. Resilience is about remaining the same or better despite a negative experience. See Table 12.

Table 12: Effects of PLHIV on ability to cope over the last 12 months by sex

Effect on select categories on the PLHIV	Has been positively affected by my HIV status n (%)		Has not been affected by my HIV status n (%)		Has been negatively affected by my HIV status n (%)	
	Female	Male	Female	Male	Female	Male
Self-confidence	322(36.84)	211(40.27)	455(52.06)	256(48.85)	91(10.41)	51(9.73)
Self-respect	354(40.50)	216(41.22)	483(55.26)	278(53.05)	33(3.78)	25(4.77)
Ability to respect others	360(41.19)	217(41.41)	485(55.49)	291(55.53)	21(2.40)	13(2.48)
Ability to cope with stress	300(34.32)	189(36.07)	453(51.83)	272(51.91)	107(12.24)	53(10.11)
Ability to have close and secure relationships with others	316(36.16)	207(39.50)	457(52.29)	277(52.86)	82(9.38)	34(6.49)
Ability to find love	225(25.74)	160(30.53)	417(47.71)	261(49.81)	164(18.76)	78(14.89)
Desire to have children	147(16.82)	118(22.52)	397(45.42)	248(47.33)	197(22.54)	104(19.85)
Achievement of my personal or professional goals	224(25.63)	156(29.77)	471(53.89)	277(52.86)	106(12.13)	68(12.98)
Ability to contribute to my community	279(31.92)	189(36.07)	494(56.52)	282(53.82)	68(7.78)	40(7.63)
Ability to practice a religion/faith as I want to	321(36.73)	207(39.50)	503(57.55)	283(54.01)	28(3.20)	23(4.39)

In Table 12, with the exception of 417(47.71%) for females and 261(49.81%) males respondents who mentioned ability to find love was affected, other 10 factors were slightly above average, meaning they remained resilient. On the negative side, some respondents' desire to have children was affected (197(22.54%) females and 104(19.85) males).

Resilience (PLHIV ability to cope with HIV stigma)

Operationally defined, resilience was a score used to the determine the level of coping given a range of 10 factors as listed in Table 12, from self confidence to ability to practice a religion. All these factors are asked to a PLHIV and an average score is calculated based on either positive effect, negative effect or no effect at all. The range of resilience score can go up to negative (-10) can be zero (0), which implies no change or effect) or could be up to positive (+10) which means that despite HIV, ability to cope and subsequently positive living among PLHIV is very high.

The overall calculated resilience was 1.85%, above the zero. Meaning despite, HIV, the PLHIV have coped positively on average.

Table 13: Resilience score by study region

Regions	n	Mean	SD
Kampala	318	1.457872	7.664907
Busoga	114	-.4563492	5.567858
Bugisu	116	6.249521	5.567858
Karamoja	91	7.387014	3.665187
Teso	93	-7.051545	4.299993
Buganda	207	5.270071	5.880633
Bunyoro	106	1.118187	9.130566
West Nile	70	-1.676757	7.540776
South West	104	-2.226496	8.828081
North central	114	2.072125	7.525955

From the Table above, the highest level of resilience was in Karamoja region at 7.3, followed by Bugisu at 6.2 and Buganda at 5.2. The worst scores of resilience were observed in Teso at 7.05 and South West at 2.2. There is therefore need to understand the variance in coping mechanism, the factors behind the statistics and replication of best practices.

Note: Geographically, Kampala is part of Buganda region, but for study purposes, it was singled out given that most KPs were drawn from this region including UPDF, prison community, sex workers, men who have sex with men, transgender, lesbians and people who use/inject drugs among others.

Table 14: Categorized scores

Resilience categories	n(%)	Cumulative %
-10 to -6	401(28.75%)	28.75%
-5.9 to-1	147(10.54%)	39.28%
0	45(3.23%)	42.51%
1 to 5.9	142(10.18%)	52.69%
6 to 10	660(47.31%)	100%

Isaac (25) from Bududa, "I have failed to maintain a stable relationship because of my 'unusual' openness. I usually share WhatsApp pictures while taking my ARVs. I have so far separated with two partners and I do not mind, I will wait until I get the one who will accept my being open about my HIV+ status. I know that out of my openness and resilience, I have and continue to help many young people."

Derrick (48) a soldier, "As a senior army officer, I am not able to participate in community work within the barracks because I fear that if I do, the juniors will find out and gossip about my HIV status."

3.6. ACTIONS BY PLHIV IN THE PAST 12 MONTHS AS A RESULT OF INTERNALIZED STIGMA

There are often several ways of action adopted by persons who experience internal HIV stigma. Many of them avoid or make decisions to engage or participate in social activities. A set of seven common actions was presented and respondents marked off the type of reaction or actions that they adopted over the last 12 months because of living with HIV.

Table 15: Reactions/action ever done by PLHIV because of HIV status In the last 12 months by sex

Specific experiences	Response categories	Female n (%)	Male n (%)	Total n (%)
Chosen not to attend social gatherings	Yes	67(7.67)	44(8.40)	111(7.93)
	No	801(91.65)	477(91.03)	1278(91.40)
Chosen not to seek health care	Yes	17(1.95)	5(0.95)	22(1.57)
	No	853(97.60)	517(98.66)	1370(98)
Chosen not to apply for job(s)	Yes	60(6.86)	24(4.58)	84(6)
	No	731(83.64)	471(89.89)	1203(85.90)
Chosen not to seek social support	Yes	40(4.58)	21(4.01)	61(4.36)
	No	826(94.51)	497(94.85)	1324(94.60)
Isolated myself from family and/or friends	Yes	49(5.61)	46(8.78)	95(6.79)
	No	816(93.36)	476(90.84)	1292(92.40)
I decided to not have sex	Yes	208(23.80)	76(14.50)	284(20.30)
	No	607(69.45)	427(81.49)	1035(73.98)

Note: Multiple response options possible; percentages may exceed 100%.

Table 15 shows that the commonest decision was not to have sex. This was more reported among females 208(23.80%) than in males 76(14.50%). Depending on the type of partner the PLHIV has, not having sex could be a positive living option to avoid re/co-infection.

Most of the reactions were not negative during the 2019 PLHIV survey compared to the 2013. In 2013, the proportion of individuals who reported negative actions were comparatively high. For instance, those who decided not to seek health care were 4% in 2013, vs 1.5% in 2019. Those individuals who exhibited negative reaction in the 2019 data including the few that chose not attend social gatherings (7.93%), apply for a job (6%) or seek health care (1.57%) would need to be supported during the follow-on interventions through continued promotion of care and treatment services and specific efforts that build PLHIV resilience.

Doddy (30) from Mayuge, "When I tested HIV+ five years ago, I decided to abstain from sex till I get a fellow PLHIV to marry. It also took me time to have a suppressed viral load so I feared getting new infections."

To explore specific internal PLHIV stigma, the survey integrated specific question domains in form of statements that required the respondents to state if they agreed or disagreed. (Table 15).

Table 16: Proportion that agreed/disagreed with a set of statements about their HIV status and disclosure issues.

Specific experiences	2019				2013		
	Response categories	Female n (%)	Male n (%)	Total n (%)	Female	Male	Total
It is difficult to tell people about my HIV infection	Disagree	557(63.73)	328(62.60)	885(63.33)			
	Agree	314(35.93)	195(37.21)	509(36.38)			
Being HIV positive makes me feel dirty	Disagree	755(86.38)	467(89.12)	1222(87.40)			
	Agree	117(13.39)	55(10.50)	172(12.29)			
I feel guilty that I am HIV positive	Disagree	650(74.37)	399(76.15)	1049(75.05)			
	Agree	221(25.29)	119(22.71)	340(24.30)	158(49.4)	162(50.6)	320 (50)
I am ashamed that I am HIV positive	Disagree	675(77.23)	424(80.92)	1099(78.60)			
	Agree	197(22.54)	100(19.08)	297(21.23)	174 (51.2)	166 (48.8)	340 (50)
I sometimes feel worthless because I am HIV positive	Disagree	694(79.41)	433(82.63)	1127(80.60)			
	Agree	169(19.34)	86(16.41)	255(18.23)	184 (62.8)	209 (71.3)	393(68)
I hide my HIV status from others	Disagree	593(67.85)	356(67.94)	950(67.90)			
	Agree	281(32.15)	167(31.87)	448(32.02)			

Note: 2013 tool has feelings of low self esteem which can be equated to feeling worthless in the 2019 tool

Data in Table 16, shows that 509(36.38%) respondents agreed that is difficult to tell people about their HIV status, 172(12.29%), agreed that HIV positive status makes them feel dirty, 297(21.23%), feel ashamed that they are HIV positive, 340(24.30%) sometimes felt worthless because of living with HIV. Overall, 448(32.02%) respondents revealed that they hide their HIV status from others. In this data, most components show similar proportion between both sexes. Based on the statements in Table 14, the categories that agreed were quite many per statement, meaning that overcoming internal forms of HIV stigma is still a needed intervention. The interventions could use theory driven approaches that guide behavioral change at individual and interpersonal levels.

Ricardo (35) from Kamuli, "I feel guilty that I am HIV+ that I find it difficult to disclose my status."

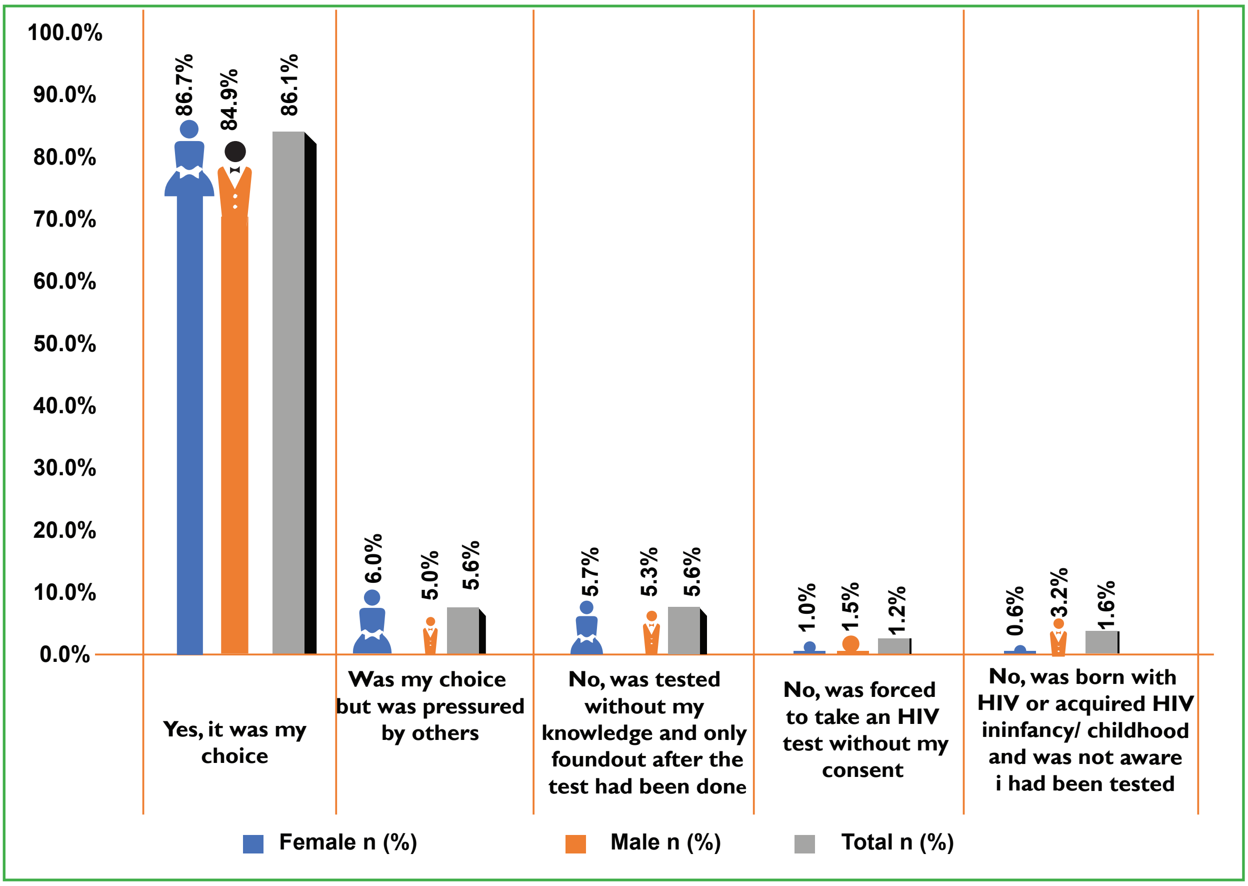
3.7. INTERACTIONS WITH HEALTH CARE SERVICES

This section contains four main sub sections including; HIV testing, care and treatment experiences, the PLHIV general health status at the time of PLHIV survey and the service delivery experiences while seeking care either at a regular health facility or elsewhere and sexual and reproductive health services. Like in other sections, the data is disaggregated, except for variables which are applicable to females only in reproductive health sub section.

3.7.1. HIV Testing decisions and experiences

Over the years, Uganda has been promoting voluntary HIV testing care and treatment services and in some cases, provider-initiated services. In Figure 2, questions were asked retrospective to ascertain the key factors that relate to the PLHIV prior reasons for testing and the testing circumstances the first time.

Figure 2: The choice to undertake an HIV test by the PLHIV



From Figure 2, self-initiated testing was common and similar across gender at 1212 (86.7%) and 1187 (84%) respectively. A few PLHIV were pressured by others or were tested without their knowledge 78(5.6%). Compared to 2013 study, 968 (87.2%) testing was by choice, 68 (6.1%) testing was by choice but pressured, testing by force was by 29 (2.6%) while those who were tested without their knowledge were 45 (4.1%).

This data confirms that most individuals continue to test for HIV voluntarily.This could be attributed to national level programs that often recommend voluntary testing and counseling as a first choice. Since voluntary testing yield more benefits as a key entry point for prevention, care and treatment services for those who test positive, efforts to sustain VCT should sustained.

Victor (24) from Mbale, "I went for a job interview and had to undergo a medical test. They told me later that they could not hire me because they found me HIV+ yet wasnot told that was part of the package. That is how I discovered my status"

Eva (29) Kabarole, "It was my personal choice to test as I prepared for marriage."

The PLHIV were also asked to mention the main reason for undertaking the HIV test (Table 17).

Table 17: Main reason for taking an HIV test by sex

Main reason for HIV testing	Female n (%)	Male n (%)	Total n (%)	2013 (%)
A provider recommended it, or as part of other health care (e.g., antenatal, medical male circumcision, STI testing/treatment, PrEP)	125(15.43)	37(7.87)	162(12.65)	
I believed I was at risk for HIV	222(27.41)	128(27.23)	350(27.39)	
I felt sick and I/my family thought it might be HIV related	267(32.96)	163(34.68)	430(33.57)	385 (34.7)
As part of or because of a community-based program	32(3.95)	29(6.17)	61(4.76)	
It was a requirement (e.g., for employment, visa/citizenship, incarceration, marriage)	6(0.74)	2(0.43)	8(0.62)	20(1.8)
I just wanted to know	107(13.21)	94(20)	201(15.69)	363(32.1)
Other reason	51(6.30)	17(3.62)	68(5.31)	33(3.1)

Note: the 2018 tool did not capture all variables and so comparison with 2013 has that limitation

According to Table 17, the most common reasons for taking an HIV test were feeling sick or a belief in being at risk for HIV with 430 (33.57) and almost in similar proportions for both men and women (34.68% vs 32.96%) respectively. Provider-initiated testing is higher in females compared with males (15.43% vs 7.87%). This difference could be attributed to Ante Natal Care (ANC) service attendance where expectant mothers are required to undergo HIV testing. These approaches relate to the value of combination prevention approaches; starting with awareness creation about the HIV risk, provision of an enabling environment for testing and actual service delivery. Most of these programs already exist and they only require sustaining over the years.

Faith (31) from Kabale, "As a young widow, when I persistently fell sick with HIV related symptoms, I was advised to take an HIV test."

Nelson (45) from Ntungamo, "I tested because I felt I was at risk since my former girlfriend died of AIDS related symptoms."

Mary (37) from Ngora, "If it was not for my third pregnancy where it was mandatory to test for HIV at our Health Centre IV, I would not have known my HIV status that early."

3.7.1.1 The time lag between thinking about the need and actual testing

Most times, HIV Testing Services (HTS) services promote awareness and recommend regular testing to find out the HIV status of individuals. However, there is always delay by some people from the time they consider testing to when they actually get tested. Figure 3; explores the time lag.

Figure 3: Time lag between contemplating to take an HIV test and actual testing

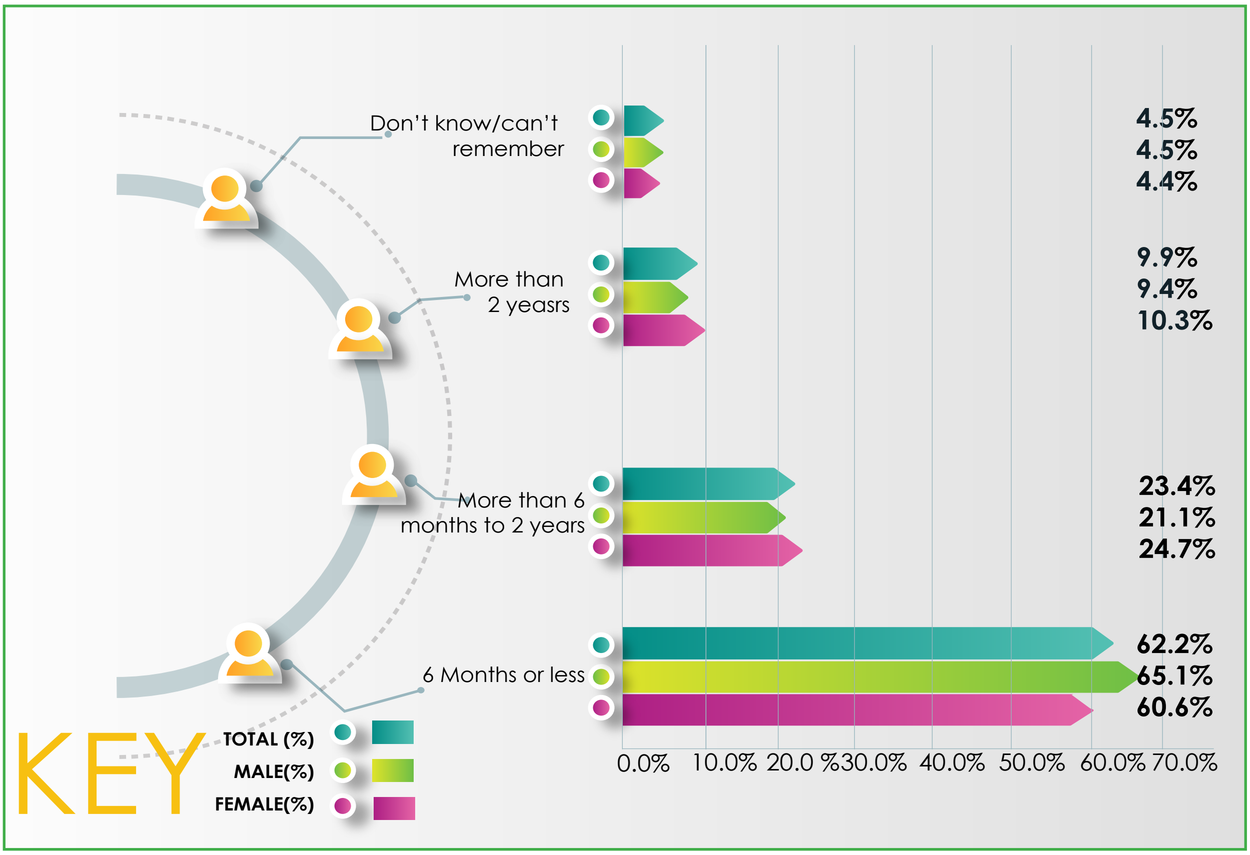


Figure 3 shows two-thirds of respondents 870 (62.2%) took up to six months to initially test for HIV, almost in equal proportions for both men and women at 65.1% and 60.0% respectively. The delays are most times due to a phase called pre-contemplation to undertake the test either because of a presumed past risk. The communication about early HIV testing needs to be sustained to draw more people into early testing given it benefits especially when the country rolled out the Test and Treat programme.

Lucy (65) from Kampala, "These days life is easy as one can access HIV testing from the easiest point of care. I wonder why people delay to take an HIV test when conditions are now better. During the early

90s, one had to go to AIDS Information Centre at Baumann House and it took a good time before getting results. So, we really contemplated for long before going for the test. Even then, AIDS was a death sentence without readily available ARVs, so we feared so much. What eventually prompted me to go sooner were the alarming AIDS deaths occurring on a daily basis."

3.7.1.2 Testing delays by PLHIV

To contextualize the delay, the respondents were asked whether fears about how other people such as friends, family or employers would respond if the respondent tested positive made them hesitate to undertake the HIV test. A large proportion 480(37.54%) held fears of others finding out the respondent's HIV status. The fears did not differ so much between females and males; 312(38.52%) females vs 168(35.74%) males. HIV related stigma reduction interventions should not only target the PLHIV but the significant others (friends, communities) as these are often the source of external stigma leading to delayed testing benefits that would occur for the individual(s) at risk.

Besides the fears that prevented some respondents from seeking HTS on time, Table 17 explores specific factors that could have caused the respondent's delay, hesitate or prevented him/her from seeking timely HIV care and treatment services.

Table 18: Reasons for hesitation or delay to seek care or treatment for HIV by sex

Factors related to hesitation to take up ART	Responses categories	Female n (%)	Male n (%)	Total n (%)
I was worried that my partner, family or friends would find out my status	Yes	252(28.83)	159(30.34)	412(29.44)
	No	622(71.17)	365(69.66)	987(70.55)
I was worried other people (not family or friends) would find out my status	Yes	644(73.68)	388(74.05)	1032(73.83)
	No	230(26.32)	136(25.95)	366(26.16)
I was not ready to deal with my HIV infection	Yes	259(29.63)	119(22.71)	378(27.02)
	No	615(70.37)	405(77.29)	1020(72.98)
I was afraid health workers (doctors, nurses, staff) would treat me badly or disclose my status without my consent	Yes	34(3.89)	34(6.87)	70(5)
	No	840(96.11)	488(93.13)	1328(95)
I had a bad experience with a health worker previously	Yes	19(2.17)	7(1.34)	26(1.86)
	No	855(97.83)	517(98.66)	1372(98.13)

Table 18 shows that 1032 (73.8%) respondents; both men and women delayed to seek for care due to the worry of non-family members or friends finding out about their status. Similarly, some respondents were generally not ready to deal with the HIV infection at individual level.

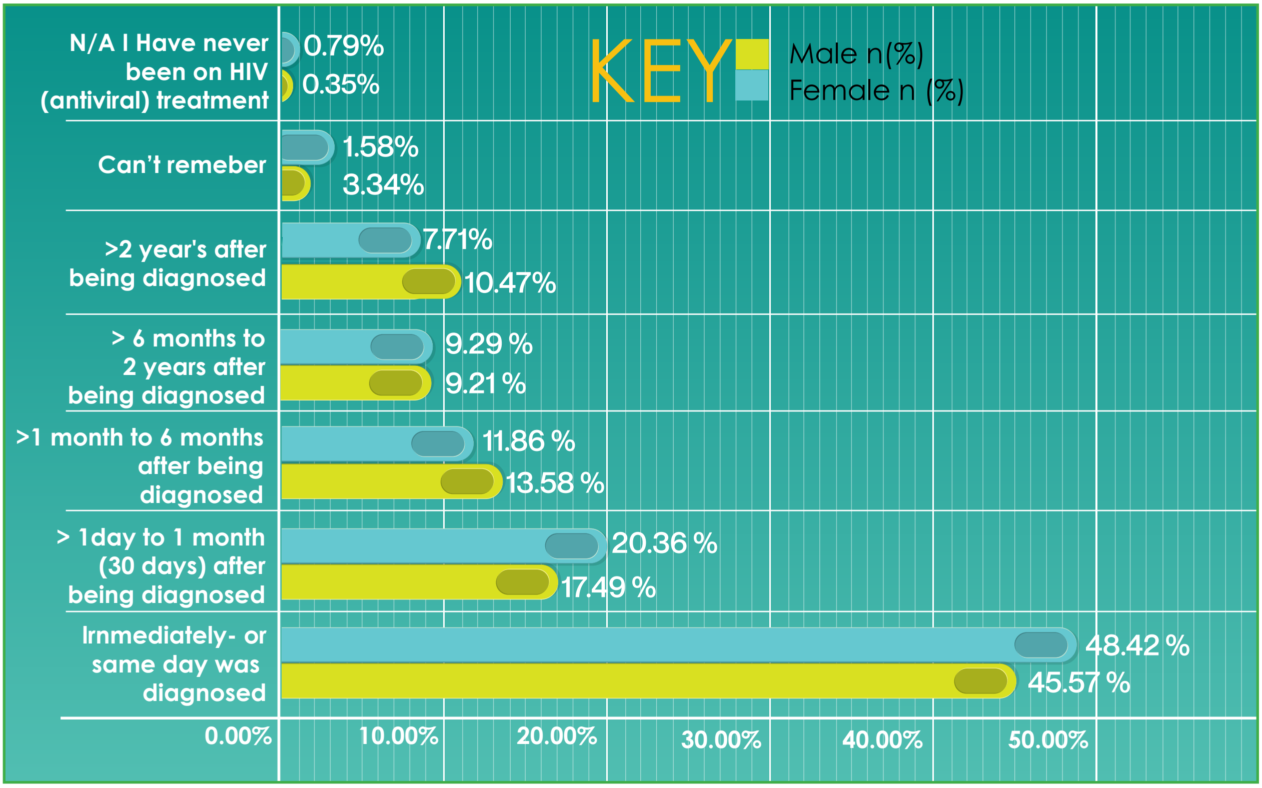
The data in Tables 18 shades more light on the need to deal with barriers in terms of fears that often lead to delays in seeking HTS. These barriers are usually at individual level, interpersonal (family and friends) but more at community level. This implies that those who have not sought HIV testing would be having similar anticipations and challenges, therefore, HIV related stigma reduction interventions should not only target the PLHIV but the significant others (friends, communities) as these are often the source of external stigma leading to delayed testing benefits that would occur for the individual at risk.

Jeff (42) from Isingiro, "Even before I took the HIV test, my family had already labeled me an AIDS patient that would die very soon. So, after the test, I did not want to take medication, all I wanted was to die. But my counselor supported me that I started ARVs after 8 months."

3.7.1.3 Time lag between testing and starting ART by PLHIV

The time lag between diagnosis with HIV and initiation on antiretroviral treatment was also explored.

Figure 4: Period between HIV diagnosis and starting on ART



According to Figure 4, nearly a-half 641(46.58%) of respondents interviewed reported they were initiated on ART immediately or on the same day the diagnosis was made. These two time periods (immediately initiated, > 1 day to a month) point to compliance with WHO recommendations for Test and Treat programs.

Most of those who were initiated on ART, 1247(91.15%) reported that it was their choice to start taking antiretroviral treatment and not necessarily due to pressure or force by others. Those who reported that having taken a decision to delay after treatment was available were 62 (4.53%). The finding re-echoes the value of providing information for people to decide voluntarily.

Uganda

Bella (27) from Kabarole, "After testing HIV+, it took me almost a year to enroll for ART as I was worried my family and friends would find out and subsequently tell my husband. It was the onset of AIDS symptoms that I was forced to start ARVs."

3.7.2 Taking Antiretroviral Treatment (ART)

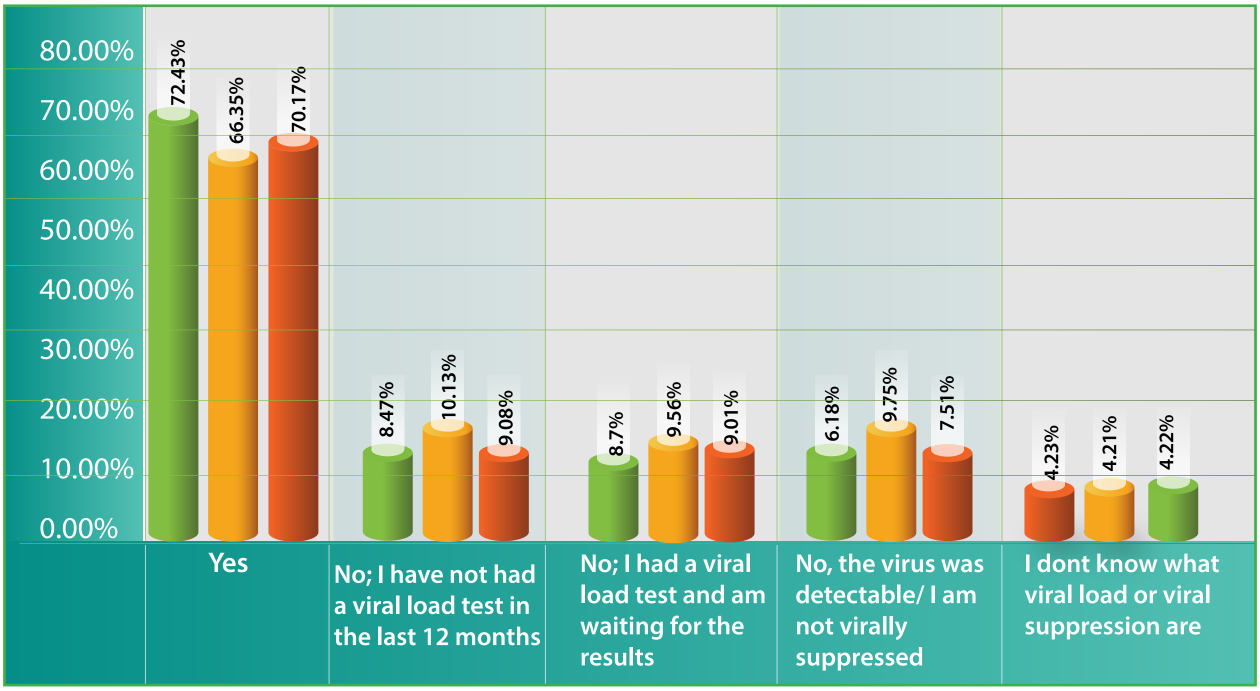
Almost all respondents 1365 (99.71%) were taking ART by the time of the PLHIV stigma index survey in January 2019. The only major concern is that in the past 12 months, fears about someone learning of the respondent's status led 284(20.31%) to miss a dose of their ART. More than 21.41% males compared to 19.68% females, reported to have missed a dose of their treatment in the past 12 months because of the fear that someone would learn about their HIV status.

Deus (19) from Masaka, "As a young person living with HIV, I take my medicines religiously knowing that is the only way to live positively. It is cumbersome but I look at the big picture of having a family and setting up a business. It is unfortunate some of my peers miss dozes because of fear to be seen at the ART clinic."

3.7.3. ART and Viral Load Monitoring

Since 2014, the Government of Uganda through the Ministry of Health and with support from AIDS Development Partners have implemented viral load testing programs, initially in urban settings but eventually reaching several parts of the country. The aim is to ensure that all PLHIV on treatment have an undetectable viral load which is hoped to subsequently lead to zero transmission of the HIV virus. Figure 4 shows the proportion of respondents who reported viral load suppression and other related factors.

Figure 4: Results of viral load monitoring over the last 12 months



The data in Figure 4, shows that 980(70.17%) of PLHIV reported viral load suppression in the last 12 months. However, the data presents several gaps in HIV programming and opportunities for interventions. For instance, there are several PLHIV who had not done a viral load test, others were still waiting for results, others were simply not aware of viral load or viral load suppression and some had unsuppressed viral load. These gaps require tailored interventions. Further disaggregation of data by district would enable identification of districts where the gaps are more prevalent and would inform further rollout of the viral load services.

Tawfiq (23) from Kayunga, "I am hearing about viral load suppression for the first time. What does it mean and how can I access the service?

Grace (44) from Arua, "At Arua Regional Referral Hospital, we were educated about viral load testing and why we must have undetectable viral load if we are to have optimal treatment outcomes. I am glad my colleagues and I have suppressed viral load."

3.7.4 General Health Status

Besides the HIV status and care treatment experiences, respondents' general health issues were also explored. Overall most respondents reported a good health status 981(70.89%), 365(26.11%) reported a fair health status and only 42(3%) reported a poor one at the time of the PLHIV stigma index survey. This could be attributed to majority being on ART and the various ongoing adherence programmes for positive living.

3.7.4.1 Diagnosis of selected infections/diseases by sex in last 12 months

The PLHIV stigma index survey also asked about other infections related to HIV such TB, Hepatitis, STD and mental health conditions. Sexually transmitted infections were the most reported 194(13.87%) to have been diagnosed among the respondents followed by TB (113(8.08%). Among those diagnosed, 250 (44.17%) reported to be taking medication or treatment for the diagnosed conditions, whereas 256 (45.23%) were not. Most of the treatment programs in Uganda focus on TB and HIV for the PLHIV and to a less extent focus on sexually transmitted infections. Integrating sexual reproductive health (SRH) as part of the service package has beneficial effects. The data also presents missed opportunities for reaching those who were not undergoing treatment.

3.7.4.2 Mental health related conditions

Experiences of mental health conditions were limited to the last two weeks before survey. The quantification was based on how often (once, twice, several times, or most of the time) the respondent felt the condition and how it presented (Table 18).

Table 19: Frequency of occurrence of mental health related conditions over the past two weeks by sex

Mental health conditions	Never		Once		Several times		Most of the time	
	Female	Male	Female	Male	Female	Male	Female	Male
Feeling nervous, anxious or on edge	516(59.04)	341(65.20)	270(30.89)	136(26)	71(8.12)	35(6.69)	17(1.95)	11(2.10)
Not being able to stop or control worrying	491(56.18)	368(70.36)	276(31.58)	115(21.99)	79(9.04)	33(6.31)	28(3.20)	7(1.34)
Little interest or pleasure in doing things	588(67.28)	377(72.08)	207(23.68)	108(20.65)	66(7.55)	34(6.50)	13(1.49)	4(0.76)
Feeling down, depressed, or hopeless	574(65.68)	370(70.75)	215(24.60)	115(21.99)	70(8.01)	32(6.12)	15(1.72)	6(1.15)

According to Table 19, more men compared to women reported that they have never experienced anxiety and depression. Approximately 540 (39%) reported forms of feeling nervous, anxious or on the edge over the last 2 weeks before the survey. About 538 (39%) reported not being able to stop or control worrying, 432 (31%) reported having little interest or pleasure in doing things, 453 (33%) reported feelings of depression or hopelessness. Questions that explored support given to those who had suffered mental related conditions in of those who experienced any of this mental health related condition, only 301 (39.71%) had received any type of supports such as counselling or other types. Almost a quarter of the respondents agreed to having most of the defined mental health condition in Table 18, yet most programs have not been focusing on mental health conditions.

Yoweri (35) from Mityana, "There are moments when I feel hopeless and have little pleasure in doing anything. There are always many questions going on in my head including why I have to be HIV+. But then I pick myself up as life has to continue."

3.7.5. Service Delivery Experiences

The service delivery issues explored included access to health services for HIV related care and treatment; satisfaction with the available services at the health facilities where they seek care, government or public health facilities where most care was sought 1054(75.45%) by both females and males. This calls for further system strengthening interventions for government of Uganda facilities. In these facilities, respondents reported varying experiences over the last 12 months while seeking HIV- specific health care from the health facility staff (Table 21)

3.7.5.1 External HIV stigma experienced for non-HIV related health needs.

These experiences were explored with a reference period of the past 12 months, when PLHIV sought care for non-HIV related health needs. The questions inquired the attitudes of the health workers towards PLHIV.

Table 20: Experiences while seeking HIV specific care from health workers by sex

Experiences of HIV stigma	Response categories	Female n (%)	Male n (%)	Total n (%)
Denial of health services because of your HIV status	Yes	7(0.80)	5(0.95)	12(0.86)
Being advised not to have sex because of your HIV status	Yes	74(8.47)	48(9.16)	122(8.72)
Being talked badly about or gossiped about because of your HIV status	Yes	51(5.84)	26(4.96)	77(5.50)
Verbal abuse (yelling, scolding, or name calling or being otherwise verbally abusive	Yes	50(5.72)	22(4.20)	72(5.15)
Physical abuse (pushing, hitting, or being otherwise physically abusive)	Yes	8(0.92)	6(1.15)	14(1)
Avoidance of physical contact with you/taking extra precautions (such as wearing double gloves)	Yes	19(2.17)	14(2.67)	33(2.36)
Telling other people about your HIV status without your consent	Yes	32(3.66)	24(4.58)	56(4.)

Table 20 shows that most of the reported experiences faced while seeking HIV specific care from health workers were mainly positive. The major negative experience revealed was telling other people about the respondent HIV status without the PLHIV consent 56(4%) and cases of gossip 77(5.5%). Additionally, 122(8.72%) reported to having been advised not to have sex because of HIV status. Whereas health care stigma is low, efforts should be geared towards zero stigma by building the capacity of health workers to make them AIDS competent. A stigma free environment makes it easier for PLHIV to access care and treatment.

Erias from Gulu, "I have been a subject of gossip at the health centre. Every time I go for my hypertensive drugs, I am referred to as the AIDS 'sick' man even when I am healthy and productive".

3.7.6. Experiences while seeking non- HIV related care needs

These experiences were explored with a reference period of the past 12 months, when PLHIV sought care for non-HIV related health needs. The question inquired the attitudes of the health workers towards PLHIV.

Table 21: Experiences of HIV related stigma while seeking Non-HIV related needs / care from health workers by sex

Experiences of HIV stigma	Response categories	Female n (%)	Male n (%)	Total n (%)
Denied of health services	Yes	11(1.26)	4(0.76)	1.07)
Advised not to have sex	Yes	3(0.34)	2(0.38)	5(0.36)
Talked badly about or gossiped about	Yes	29(3.32)	23(4.39)	52(3.72)
Verbal abuse (yelling, scolding, or name calling or being otherwise verbally abusive	Yes	28(3.20)	21(401)	49(3.50)
Physical abuse (pushing, hitting, or being otherwise physically abusive)	Yes	20(2.29)	10(1.91)	30(2.14)
Avoidance of physical contact with you/taking extra precautions (such as wearing double gloves)	Yes	4(0.46)	3(0.57)	7(0.50)
Told other people about your HIV status without your consent	Yes	13(1.49)	11(2.10)	24(1.72)

Many of the respondents 540 (61.78 %,) indicated that they had disclosed their HIV status, while they sought care outside the HIV clinic for general (non-HIV related) health care services. Despite the disclosure of their status by the PLHIV during non-HIV specific related health needs, HIV related stigma experiences were comparatively fewer (Table 21)

Izidoro (31) from Apac, "I went to a health centre with a dental ailment. When I disclosed my status to the dentist, he got so scared that to pull out my tooth, he put on three gloves."

3.7.7. Medical records

This sub section explores the confidence and trust which the PLHIV have for the health workers. It is generally assumed that a high trust in the medical records will contribute to an increase in openness by the PLHIV and uptake of health services. Secondly, confidentiality with information or records is proxy for non-verbal harassment or gossip by health workers towards PLHIV.

About four in five PLHIV accounting for 85.3% had confidence that their medical records were kept confidential. Going forward, an assurance of confidentiality clause and practice by health workers is critical in promoting trust among the PLHIV.

3.7.8. Actions by health workers toward PLHIV in last 12 months

During the 2013 PLHIV stigma index survey and other surveys that followed, PLHIV were asked about stigma and discrimination and the kind of advice health workers gave for those who were sexually active. In the 2019 PLHIV stigma index survey, a deliberate effort was made to include specific questions that explore HIV related stigma and discrimination at the health facilities by the individual health worker.

Table 22: Reported actions taken by health workers solely because of the clients PLHIV status

Specific actions	Response categories	Female n (%)	Male n (%)	Total n (%)
Advised you not to mother/father a child	No	685(78.38)	428(81.84)	1113(79.60)
	Yes	111(12.70)	41(7.84)	152(10.87)
	Prefer not to answer	64(7.32)	35(6.69)	99(7.08)
Pressured or incentivized you to get sterilized (a surgical procedure to prevent you from having children; for example, a vasectomy or tubal ligation)	No	788(90.16)	460(87.95)	1248(89.30)
	Yes	14(1.60)	4(0.76)	18(1.29)
	Prefer not to answer	60(6.86)	37(7.07)	97(6.94)
Sterilized you without your knowledge or consent	No	783(89.59)	434(82.98)	1217(87.10)
	Yes	12(1.37)	4(0.76)	16(1.14)
	Prefer not to answer	66(7.55)	55(10.52)	121(8.66)
Denied you contraception/family planning services	No	775(88.67)	410(78.39)	1185(84.70)
	Yes	13(1.49)	4(0.76)	17(1.22)
	Prefer not to answer	67(7.67)	73(13.96)	140(10.01)
Told you that in order to get your HIV (antiretroviral) treatment you had to use contraception, or a specific method of contraception	No	762(87.19)	412(78.78)	1174(84.05)
	Yes	27(3.09)	5(0.96)	32(2.29)
	Prefer not to answer	67(7.67)	64(12.24)	131(9.37)

From Table 22, close to one in ten of the PLHIV reported that health workers advised them not to have children. However, some respondents preferred not to answer and there was no reason for preferring not to answer. One possibility for fearing to answer rests in fear about given negative feedback on the health care workers that could result in denial of services during regular care.

The challenge has often been distinguishing between medical advice as opposed to stigmatizing situations.

Rebecca (42) from Gulu, "With onset of eMTCT, I went to a gynaecologist to have another baby. It is from there that I discovered that I was sterilised without my knowledge. When I inquired from the health workers, they said it was in my favour not to have more children since I was HIV+ and already had children."

Leilah (38) from Arua, 'In 2009, I was pregnant and HIV positive. The health workers at the ART clinic were unhappy with me for considering pregnancy in my situation (HIV positive)."

Table 23: Reported actions by health workers done to women solely because of the HIV status

Actions by health workers	Response categories	Female n (%)
Advised you to terminate a pregnancy	No	775(88.67)
	Yes	12(1.37)
	Prefer not to answer	65(7.44)
Pressured you to use a specific type of contraceptive method rather than counseling you on a range of available options	No	766(87.64)
	Yes	20(2.29)
	Prefer not to answer	63(7.21)
Pressured you to use a particular method of giving birth/delivery option	No	752(86.04)
	Yes	26(2.97)
	Prefer not to answer	74(8.47)
Pressured you to use a particular infant feeding practice	No	739(84.55)
	Yes	30(3.43)
	Prefer not to answer	80(9.15)
Pressured you to take antiretroviral treatment during pregnancy to reduce the chance of HIV transmission rather than counseling you.	No	747(85.47)
	Yes	31(3.55)
	Prefer not to answer	73(8.35)

Note: Multiple answer question

Table 23 shows that the proportions of those who responded no and those who preferred not to answer are comparatively higher than those who said yes for all the listed actions. Whereas the no response could be a true reflection of what transpired, the option of preferring not to answer needs to be investigated qualitatively as it might be due to fear for denial of services anticipated if clients reported the health workers. Besides, though the numbers that said yes to the question is low, no one should have her rights violated, even if considered in the best of the PLHIV. The decision should be jointly agreed to.

Margaret (35) from Isingiro, "Instead of counselling and giving me options for family planning, the nurses shouted at me to stop giving birth since I was HIV+ with four children."

3.8. HUMAN RIGHTS AND EFFECTING CHANGE

The section relates to human rights' violations and abuses experienced by PLHIV. It also covers issues of awareness of PLHIV rights and knowledge of existing laws. The section also quantifies proportion of respondents who have effected changes or stood up for their rights and how they have been successful in effecting positive changes. The reference period for all the factors listed out is either before 12 months or during the last 12 months before the PLHIV stigma index survey.

3.8.1 Experiences of human rights abuses

To explore and quantify human rights abuses regarding HIV positive status, a set of eleven negative attributes were listed upon which respondents were required to relate to and mention if those abuses happened at two time points; in the last 12 months or beyond the last 12 before the PLHIV stigma survey as shown in Table 24.

Table 24: Experiences of forced testing or disclosure to access social-economic benefits or waivers.

Experiences of specific abuses of rights to	No	Yes, but NOT within the last 12 months	Yes, within the last 12 months	Prefer not to answer or N/A
Obtain a visa or to apply for residency/ citizenship in a country	1314(95.94)	32(2.29)	10 (0.72)	15 (1.07)
Apply for a job or get a pension plan	1306(93.42)	31(2.22)	15(1.07)	46(3.29)
Attend an educational institution or get a scholarship	1305(93.35)	19(1.36)	5(0.36)	69(4.94)
Get health care	1343(96.07)	36(2.58)	7(0.50)	12(0.86)
Get medical insurance	1349(96.49)	24(1.72)	3(0.21)	22(1.57)
I was arrested or taken to court on a charge related to my HIV status	1367(97.78)	14(1)	9(0.64)	8(0.57)
I was denied a visa or permission to enter another country because of my HIV status	1369(97.93)	15(1.07)	3(0.21)	11(0.79)
I was denied residency or permission to stay in another country because of my HIV status	1275(91.20)	38(2.72)	19(1.36)	66(4.72)
I was forced to disclose my HIV status publicly or my status was publicly disclosed without my consent	1303(93.20)	16(1.14)	16(1.14)	63(4.51)
I was forced to have sex when I did not want to. "Forced" means physically forced or coerced.	1351(96.64)	25(1.79)	8(0.57)	14(1)

Results in Table 24, illustrate cases of forced testing or disclosure of HIV status that were experienced by 95 respondents during the past one year before the PLHIV survey or even beyond. The proportions of negative experiences are fewer in the last one year compared to the period beyond past 12 months.Among the negative experiences that stood out was the denial of residence in another country because of a positive HIV status reported by 57 (4.8%).

Out of the 186 respondents who reported experiencing abuse or human rights violations, 35 (18.82%) mentioned that they had tried to do something about the matter either in form of complaints, contacting a lawyer, a government official or politician, a Community Based Organization to deal with the matter or speaking publicly about the matter.

Out of the 35 who have attempted to deal with the abuses or violations, (42.86%) reported that matters had been dealt with, 3 (8.57%) said the matter was in the process of being dealt with, and 17(48.57%) said nothing happened or the matter was not dealt with.

Belinda (28) Inmate, 'I was working with a certain school in Kampala, and got in an intimate affair with a colleague. After sometime, we got misunderstandings and he reported to police that I was trying to infect him with HIV. The matter was presented in courts of law and I was sentenced to five years in prison on charges of attempting to transmit HIV. My family does not know where I am and would like to request NAFOPHANU to help me get in touch with them'.

Godfrey (45) Inmate, 'I was arrested over charges of attempting to transmit HIV, taken to a hospital where I was tested and found to be HIV positive and the complainant was HIV negative. The case was taken before the judge who then ruled in the favor of the HIV negative lady. I was sentenced to eight years in prison for attempting to transmit HIV. All this was done to me after getting some misunderstandings with my neighbor over a piece of land'.

The two incarcerated stories mean that the HIV Prevention and Control Act (2014) has been effected to imprison PLHIV, even when their issues were not HIV related. Therefore, the judicial system and processes need to be cognizant of the environment in which people who are openly living leave to avoid black mail and unnecessary criminalization.

3.8.1.1 Reasons for not attempting to seek redress for negative experiences

One of the key outcomes of PLHIV empowerment is the capacity of the PLHIV to respond to challenges of rights abuse. Therefore, all PLHIV who mentioned experiencing any abuses in the past 12 months before the survey were asked if they tried doing anything about the abuse in form; either filing a complaint, contacting a lawyer a government official or politician, Community Based Organisation or PLHIV, speaking out publicly, etc. The PLHIV who reported not have attempted to use any mechanisms above to seek redress for the issues were further asked the main reason for not attempting (Table 25).

Table 25:The main reason for not trying to address the rights abuses by sex

	Female n (%)	Male n (%)	Total n (%)
Did not know where to go/how to act	51(5.84)	31(5.92)	82(5.86)
Insufficient financial resources to act	13(1.49)	10(1.91)	23(1.640
Process of addressing the problem appeared too complicated	15(1.72)	10(1.91)	25(1.79)
Felt intimidated or scared to act	13(1.49)	3(0.57)	16(1.14)
Was worried acting might lead people to learn about my HIV status	10(1.14)	0	10(0.71)
Advised against acting by someone else	2(0.23)	2(0.38)	4(0.29)
No/little confidence that the outcome would be successful	10(1.14)	3(0.57)	13(0.93)
Lack of evidence for the abuse	8(0.92)	2(0.38)	10(0.71)

The main reason 82(5.86%) that stood out was not knowing where to go or how to act. Raising awareness and sensitization about human rights abuses and guidance on how to pursue such matters is still an issue of concern that needs to be addressed by CSOs and other relevant bodies or institutions.

3.8.2. Knowledge of laws that protect the rights of PLHIV

About half 678 (48.50%) of the respondents, were aware of laws in Uganda that are geared towards protecting the rights of PLHIV, whereas 150 (10.73%) said there are no such laws, and 570 (40.77%) did not know if such laws exist. Regardless of knowledge levels about laws that protect the PLHIV against abuses and violations, all respondents were asked to mention some of the actions they had undertaking from a list of positive actions (Table 25)

3.8.3 Actions by PLHIV to effect positive changes

The PLHIV empowerment process enhances the PLHIV capacity to effect changes. Specific changes are expected owing to increased awareness of the rights abuses, knowledge of laws that protect the rights of PLHIV. A set of seven applicable tools or methods for effecting changes were asked the PLHIV if they had used them either during the last 12 months before the survey or beyond before the PLHIV stigma index. (Table 26).

Table 26: Stigma and discrimination experiences for reasons orther than HIV for the transgender category.

	No		Yes, but NOT within the last 12 months		Yes, within the last 12 months	
	Female	Male	Female	Male	Female	Male
Challenged or educated someone who was engaging in stigma or discrimination against you	407(46.57)	237(45.32)	249(28.49)	161(30.78)	218(24.94)	125(23.90)
Challenged or educated someone who was engaging in stigma or discrimination against other people living with HIV	365(41.76)	219(41.87)	263(30.09)	166(31.74)	246(28.15)	138(26.39)
Provided emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination	**347(39.70)**	**195(37.28)**	**279(31.92)**	**177(33.84)**	**248(28.38)**	**151(28.87)**
Participated in an organization or educational campaign working to address stigma and discrimination against people living with HIV	**516(59.04)**	**278(53.15)**	**192(21.97)**	**142(27.15)**	**166(18.99)**	**103(19.69)**
Encouraged a community leader to take action about issues of stigma and discrimination against people living with HIV	**567(64.87)**	**307(58.70)**	**163(18.65)**	**117(22.37)**	**144(16.48)**	**99(18.93)**

Stigma Index

	No		Yes, but NOT within the last 12 months		Yes, within the last 12 months	
	Female	Male	Female	Male	Female	Male
Encouraged a government leader or a politician to take action about issues of stigma and discrimination against people living with HIV	656(75.06)	359(68.64)	117(13.39)	97(18.55)	101(11.56)	67(12.81)
Spoke to the media about issues of stigma and discrimination against people living with HIV	763(87.30)	431(82.41)	64(7.32)	54(10.33)	47(5.38)	38(7.27)

According to Table 26, over half of the respondents had taken positive actions. However, the proportion that reported providing emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination was slightly lower than half 248(28. 38%) female Vs 151(28.87%) male in the last 12 months before the survey.

Muhammud (50) from Kampala, "I was jailed under mysterious circumstances and despite my pleas, was denied access to my HIV medication. When I came out, I used this as a cause for a struggle against the 'misbehaving' prison wardens. Things have now changed as HIV positive inmates are now escorted to the ART clinic."

Denise (22) from Masindi, "There is this health worker who used to shout at us when we would come for refill and link up with peers in our youth friendly corner. She would tell us we were going to die anyway and so should not be that happy. We all told that her attitude was taking some of us backwards and if any of us died, she would be responsible. She then changed her attitude and we have since enjoyed our peace in the youth friendly corner."

PWD (30) from Masaka, "As a PWD living with HIV, I joined my colleagues and engaged a health worker who had been abusing fellow PWDs when they came for refills. She always expected us to move faster, did not care about the blind nor called a sign language expert to interpret for the deaf. Our engagement yielded fruits and now we are given priority when we visit the facility and this has greatly enabled us to adhere to our medication."

3.9 STIGMA AND DISCRIMINATION EXPERIENCED FOR REASONS OTHER THAN HIV STATUS

Previous PLHIV stigma index surveys introduced the concept of double stigma with an attribution that the categories named as key population face because of belonging to some groups as well a second form of stigma associated with living with HIV. In 2017, the concept of intersectionality was promoted by Population Council. This entire section deals with the stigma associated with belonging to known groups or behaving in ways that the individual does that are more closely related to key population categories and not HIV positive status. Aspects of intersectionality are also hinted on or implied in the interpretation of results.

The key population groups whose data is reflected include; Transgender, Men who have Sex with Men, Gay/ Lesbian & Homosexual, Sex Workers and People Who Use or Inject Drugs. Data for women who have sex with women (WSW) and bisexual was not included owing to the small number of respondents who were reached during the survey, 14 for WSW and 18 for bisexual category. All KPs were asked a question of whether other people including (those in their category, family or friends others in the community) knew their sexual orientation or belonging to KP category.

3.9.1 Transgender

Gender identity, membership into network organization and non-HIV-related stigma

The term transgender was operationally defined to mean people who were assigned a sex category on their original birth certificate that does not match their current gender identity or preference. While 51 respondents for the Transgender category were reached, 2 preferred not to answer to any questions and only 49 responded.

Out of a total of 51 persons that were categorized as transgender, 42 (82%) reported that other transgender persons, 20 (39%) family members or friends of the transgender persons and 17 (33%) other community members knew the sex orientation of the transgender persons.

Out of the 51 transgender, 28 (57.14%) said they belong to a network or support group of transgender persons. The non- HIV related stigma and discrimination experiences by the transgender are summarized in Table 27.

Table 27: Stigma and discrimination experiences for reasons other than HIV for the transgender category

Specific experiences of exclusion, gossip and others	No	Yes, within past 12 month,	Yes, but not in past 12 months	Preferred not to answer
Ever felt excluded from family activities	33(67.35)	9(18.370	5(10.20)	2(4.08)
Ever felt that family members have made discriminatory remarks or gossiped about you	25(51.020	16(32.65)	5(10.20)	3(6.12)
Ever felt afraid to seek health services	43(87.76)	2(4.08)	2(4.08)	2(4.08)
Ever avoided seeking health services because you worried someone may learn of your gender identity	39(79.59)	6(12.24)	2(4.08)	2(4.0)
Someone ever verbally harassed you because of your gender identity	27(55.10)	14(28.57)	6(12.24)	2(4.08)
Someone ever blackmailed you because of your gender identity	31(63.27)	14(28.57)	2(4.08)	2(4.08)
Someone ever physically harassed or hurt you because of your gender identity?	33(67.35)	13(26.53)	1(2.04)	2(4.08)

According to Table 27, feelings about family members that made discriminatory remarks or gossiped about the PLHIV were the commonest the non-HIV stigma discriminatory experiences within the transgender group. In comparison to HIV related stigma in Table 10 where 3.57% in Table reported exclusion experiences in the past 12 months experiences, Table 28 reveals high rates at 18.37% and shows that non-HIV stigma is approximately six times more than the HIV stigma.

Maco (29) Transgender, "My family disowned because I transgendered. They do not care if I am HIV positive but continue to make discriminatory remarks over my orientation. My big brother threatened to beat me up if I showed up in our father's compound."

This data confirms the double stigma that KPs face; both sex-oriented stigma as well as HIV related stigma and implies the need to deal with non- HIV related stigma for this group as a priority. The opportunity to reach these groups is quite high as the proportion of those who belong to a support group is high. Therefore, interventions targeting the transgender would target the groups with relevant information and support.

3.9.2 Men who have sex with men (MSM)

Gender identity, membership into network organization and non-HIV-related stigma

Commonly, men who have sex with men are termed as MSM. This group was reached through registered members within MSM based on snowball sampling technique. Out of the 33 respondents who were categorized as MSM, only 4 confirmed that they had ever had sex with another man and 16 preferred not to answer. Out of a total of 33 MSM, 31 (100%) reported that other MSM were aware of their gender identity, 12 (39%) family members or friends of the MSM and 10 (32%) other community members knew the gender identity of the MSM. Out of the 33, 24 (77%) MSM reported to belong to a network or support organization of MSM.

Table 28: Stigma and discrimination experiences for reasons other than HIV for the MSM category

Specific experiences of exclusion, gossip and others	No n (%)	Yes, within past 12-month, n (%)	Yes, but not in past 12 months n (%)	Preferred not to answer n (%)
Ever felt excluded from family activities	25(75.76)	5(15.15)	2(6.06)	1(3.03)
Ever felt that family members have made discriminatory remarks about or gossiped about you	22(66.67)	8(24.24)	2(6.06)	1(3.03)
Ever felt afraid to seek health services because you worried someone may learn you are an MSM	26(78.79)	3(9.09)	3(9.09)	1(3.03)
Ever avoided seeking health services because you were worried someone may learn you are an MSM	27(81.82)	3(9.09)	2(6.06)	1(3.03)
Someone ever verbally harassed you because you are an MSM	24(72.73)	6(18.18)	2(6.06)	1(3.03)
Has someone ever blackmailed you because you are an MSM/have sex with men?	23(69.70)	7(21.21)	2(6.06)	1(3.03)
Someone ever physically harassed or hurt you because you are an MSM	25(75.76)	4(12.12)	3(9.09)	1(3.03)

Table 28 shows that over one in five MSM have reported that family members made discriminatory remarks or gossiped about the PLHIV as non-HIV stigma discriminatory experiences MSM.

Like the transgender category, Table 27 shows, the non-HIV stigma and discrimination experiences within the MSM group is generally high compared to HIV related stigma. For instance, about 20.21% reported exclusion from family activities. The non-HIV stigma is approximately seven times more than the HIV stigma. The trend is similar for other components compared all through.

Harry (33) MSM, "As an MSM, my biggest challenge is not being HIV+ but my family members and friends who insult and condemn me at any given opportunity. I have been ridiculed for my being an MSM."

This implies that programming should target stigma outside HIV if the PLHIV who are MSM are to receive comprehensive care, social support and sense of belonging despite the orientation. Fortunately, most MSM belong to a network which would make it easy to use the buddy system.

3.9.3 Gay /homosexuals

Gender identity, membership into network organization and non-HIV related stigma

Commonly, gays/homosexuals are people who ascribe to gay/homosexual activities; they may or may not necessarily have sex with men. In this sample, only 18 individuals were categorized as belonging to the gay/homosexual category. Of the 18 respondent who self-identified as gay, 9 (50%) belong to a network or support group for gays.

Table 29: Stigma and discrimination experiences for reasons other than HIV for the Gay category

Specific experiences of exclusion, gossip and others	No n (%)	Yes, within past 12-month, n (%)	Yes, but not in past 12 months n (%)
Ever felt excluded from family activities	14(77.78)	2(11.11)	2(11.11)
Ever felt that family members have made discriminatory remarks about or gossiped about you	11(61.11)	3(16.67)	4(22.22)
Ever felt afraid to seek health services because you worried someone may learn you are gay	14(77.78)	1(5.56)	3(16.67)
Ever avoided seeking health services because you worried someone may learn you are gay	15(83.33)	1(5.56)	2(11.11)
Someone ever verbally harassed you because you are gay	12(66.67)	3(16.67)	2(11.11)
Has someone ever blackmailed you because you are an MSM/have sex with men?	15(83.33)	2(11.11)	1(5.56)
Someone ever physically harassed or hurt you because you are an gay	16(88.89)	1(5.56)	1(5.56)

The data in Table 29 is depictive of the trends discussed in the two categories of transgender and MSM. The only limitation is the number reached was quite small and hard to mark quantitative generations. Despite low number, there are all indications that PLHIV who are gay/homosexuals require support to survive all forms of discrimination against them at various levels.

3.9.4 Gay/lesbian

Gender identity, membership into network organization and non-HIV related stigma

Commonly, gays/lesbians are people who ascribe to gay/lesbian activities; they may or may not necessarily have sex with females. In this sample, only 33 individuals were categorized as belonging to the gay/lesbian category. Of the 33 gay/lesbian, 32 (97%) reported that other gay/lesbian, 11(33%) family members and 8(24%) other people in the community knew the gender identity of the respondent. Data also shows that 19(57.58%) of the gay/lesbian belong to network or support group for gay/lesbian.

Table 30: Stigma and discrimination experiences for reasons other than HIV for the Gay Lesbian category

Specific experiences of exclusion, gossip and others	No n (%)	Yes, within past 12-month, n (%)	Yes, but not in past 12 months n (%)
Ever felt excluded from family activities	21(63.64)	9(27.27)	2(6.06)
Ever felt that family members have made discriminatory remarks about or gossiped about you	17(51.52)	13(39.39)	2(6.06)
Ever felt afraid to seek health services because you worried someone may learn you are gay/lesbian	27(81.82)	4(12.12)	2(6.06)
Ever avoided seeking health services because you worried someone may learn you are gay/lesbian	26(78.79)	4(12.12)	3(9.09)
someone ever verbally harassed you because you are gay/lesbian	20(60.61)	11(33.33)	2(6.06)
Has someone ever blackmailed you because you are gay/lesbian	23(69.70)	7(21.21)	3(9.09)
Someone ever physically harassed or hurt you because you are gay/lesbian	24(72.73)	6(18.18)	3(9.09)

The proportions that reported specific forms of non- HIV related stigma in the category of gay/lesbians is slightly higher in comparison with the MSM, transgender and gay/homosexuals.

Jenny (36), Gay/Lesbian, "I found myself attracted to fellow women and I find no problem with it. However, my family does not want to hear of it or respect it as my personal choice. They have abused me and even threatened to put my picture in the newspapers to ashame me."

Approaches that have been proposed to reach the categories above with interventions will equally be feasible for this category. Working with and through their trusted networks will minimize stigma since peer to peer support will be provided.

3.9.5 Sex workers

Gender identity, membership into network Organization and non-HIV related stigma

Among the key population groups, sex workers are the most known group in Uganda's context and as such their proportionate sample was comparatively high in the 2019 PLHIV stigma index survey. Out of the 1398 respondents, 205 (14.66%) confirmed that they have ever had sex in exchange for money or goods, 1045 (74.75% said no and 148(10.59%) preferred not to answer. At the time of the PLHIV stigma index survey, 158 (77.07%), self-identified as sex workers.

Out of a total of 205 individuals who were categorized as sex workers, 171 (83%) reported that other sex workers or peers in sex work community, 68 (33%) family members or friends of the sex worker and 68 (33%) other community members knew that the respondent engages in sex work. Out of the 205 sex workers, 75 (36.59%) reported to belong to a network or support organization of sex workers. Table 30 shows proportions of non- HIV related stigma and discrimination experiences for the Sex Workers category.

Table 31: Stigma and discrimination experiences for reasons other than HIV for the SW category.

Specific experiences of exclusion, gossip and others	No n (%)	Yes, within past 12-month, n (%)	Yes, but not in past 12 months n (%)	Preferred not to answer
Ever felt excluded from family activities	162(79.02)	28(13.66)	11(5.37)	4(1.95)
Ever felt that family members have made discriminatory remarks about or gossiped about you	129(62.93)	59(28.78)	12(5.85)	5(2.44)
Ever felt afraid to seek health services because you worried someone may learn you are sex worker	175(85.37)	22(10.73)	5(2.44)	3(1.46)
Ever avoided seeking health services because you worried someone may learn you are sex worker	178(86.83)	19(9.27)	5(2.44)	3(1.46)
someone ever verbally harassed you because you are sex worker	138(67.32)	54(26.34)	10(4.88)	3(1.46)
Has someone ever blackmailed you because you are sex worker	152(74.15)	45(21.95)	3(1.46)	5(2.44)
Someone ever physically harassed or hurt you because you are sex worker	154(75.12)	45(21.95)	3(1.46)	3(1.46)

Like other data in key population categories, the statistics for the sex work group are equally of concern. For instance, the list proportion was 19(9.27) for those who reported having ever avoided seeking health services because they worried that someone may learn they were sex workers. Other proportions range between 10.73% (ever felt afraid to seek health services because you worried someone may learn you are sex worker) and 28.78% (ever felt that family members have made discriminatory remarks about or gossiped about you). Given the relatively huge numbers of sex workers, this data indicates that several of the sex workers miss out on health services primarily because of non-HIV related stigma.

Jonata (32) sex worker, "I started sex work at 22 years and found out was HIV+ when I was 28 years. I have been physically harassed not because of my HIV status but because I am a sex worker. There are functions I cannot attend because I will be a point of gossip."

3.9.6 People Who Use or Inject Drugs

Gender identity, membership into network Organization and non-HIV related stigma

In this sample 83(5.94%) reported to have ever injected drugs and 1223 (87.48%) said no. At the time of the survey, 71(85.54%) of those who had ever injected drugs self-identified as PWUID, 11 (13.25%) said no, and one respondent preferred not to answer. Of the 83 PWUID, 77(93%) reported that other PWUID; 44(53%) family members and 37(45%) other people in the community know the identity of the respondent. Data also shows that 30(36.14%) of the PWUID belong to network or support group for PWUIDs. Table 31 illustrates the non- HIV stigma and discrimination experiences for the PWUID category.

Table 32: Stigma and discrimination experiences for reasons other than HIV for the PWUID category

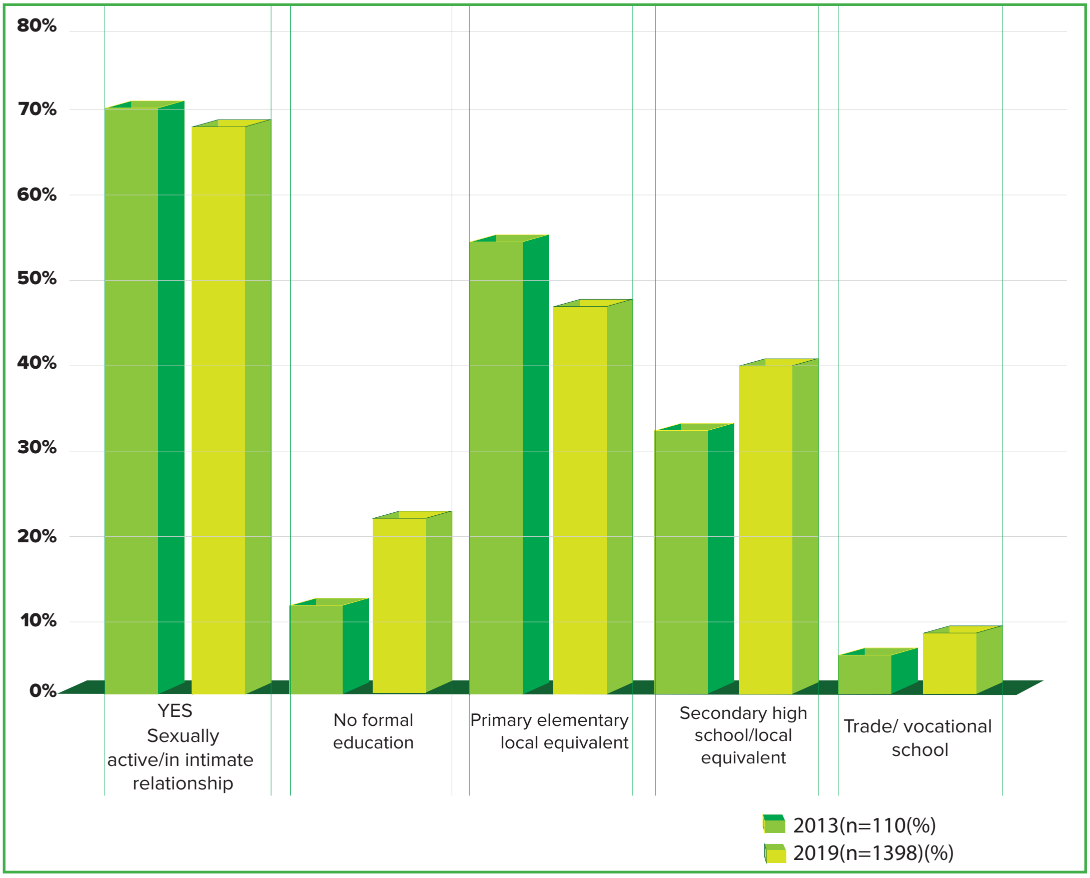
Specific experiences of exclusion, gossip and others	No n (%)	Yes, within past 12-month, n (%)	Yes, but not in past 12 months n (%)
Ever felt excluded from family activities	26(63.41)	8(19.51)	7(17.07)
Ever felt that family members have made discriminatory remarks about or gossiped about you	47(56.63)	24(28.92)	11(13.25)
Ever felt afraid to seek health services because you worried someone may learn you are a PWUID	66(79.52)	12(14.46)	5(6.02)
ever avoided seeking health services because you worried someone may learn you are an PWUID	67(80.72)	12(14.46)	4(4.82)
someone ever verbally harassed you because you are sex worker	63(75.90)	15(18.07)	5(6.02)
Has someone ever blackmailed you because you are an PWUID	71(85.54)	8(9.64)	4(4.82)
Someone ever physically harassed or hurt you because you are an PWUID	66(79.52)	10(12.05)	7 (8.430

Similar to other key population groups, feelings of family members making discriminatory remarks gossip were the commonest for the PWUID (42.12%). There is similarity of non- HIV stigma for this category, like others. This group might present more challenges to reach with interventions as their membership to support groups for PWUID is quite low. Approaches to reach them may be tailored differently to address this inherent stigma and discrimination.

Fobbie (29) PWUID, "I am a drug user and what I have experienced most are discriminatory remarks not because I am HIV+ but because I am a PWUD. Sometimes I keep quiet but other times I retort back to make people keep quiet about it."

4.0 KEY COMPARISONS BETWEEN THE 2013 AND 2019 PLHIV STIGMA INDEX SURVEY KEY FINDINGS

Figure 6: Background characteristics of the respondent comparing the 2013 and 2019 PLHIV stigma index



Comparatively, there are fewer cases of participants who reported being in intimate sexual relationships in 2019 compared to 2013 PLHIV survey.

Table 32: Economic profile of sampled respondents comparing 2013 and 2019 PLHIV stigma index

Category of people	Responses	**2013 (n=1110 (%)**	**2019 (n=1398) (%)**
Employment status	In full-time work (as an employee)	146(13)	131(9.29)
	In part-time work (as an employee)	96(9)	131(9.36)
	Working full-time, but not as an employee (self-employed or business owner)	299(27)	413(29.52)
	Doing casual or part-time work (self-employed or paid work for others)	363(33)	365(26.09)
	Unemployed	205(18)	360(25.73)

Stigma Index

Table 33 shows that there are more cases of unemployment reported in 2019 PLHIV stigma survey among the clients compared with the 2013.

Figure 7: Experiences of HIV stigma and discrimination in the last 12 months before survey comparing 2013 and 2019 PLHIV stigma index

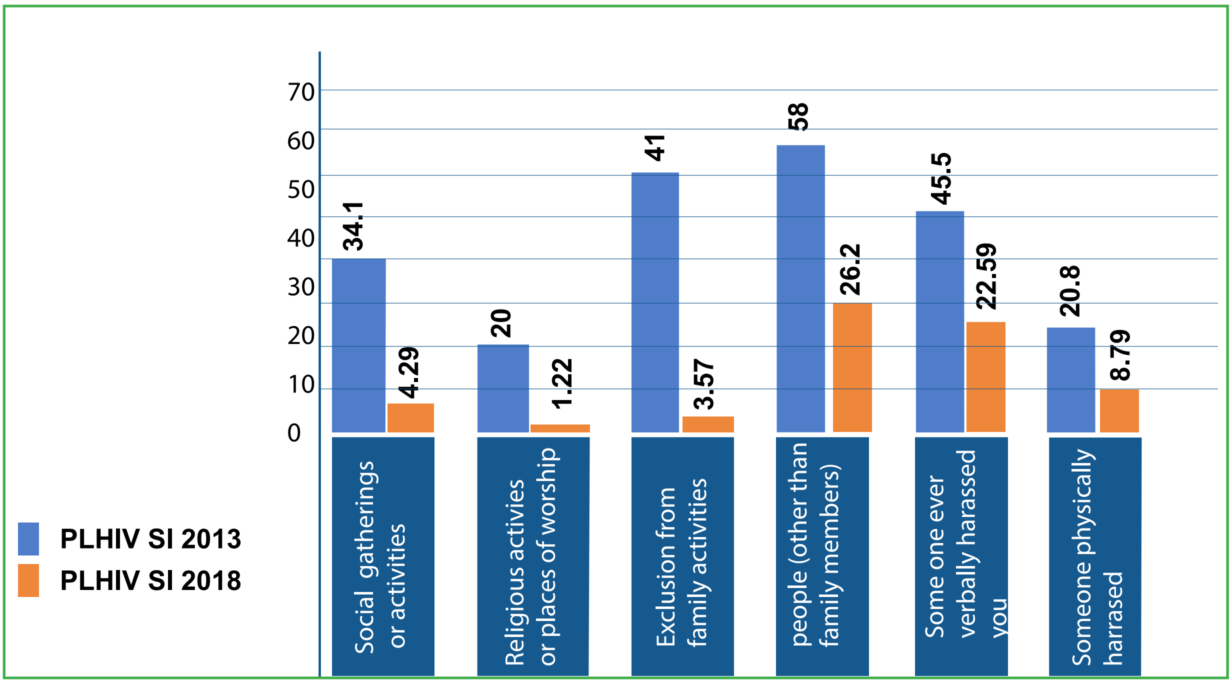
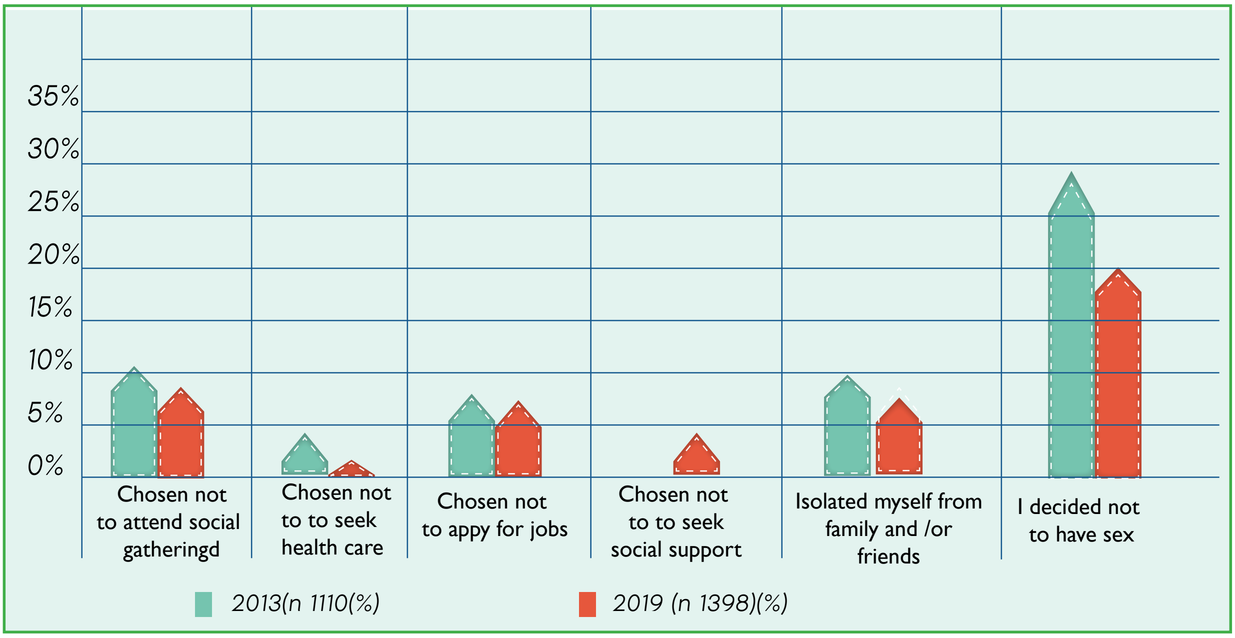


Figure 8: Reactions/action ever done by PLHIV because of HIV status in the last 12 months by sex survey comparing 2013 and 2019 PLHIV stigma index



5.0 CONCLUSION

HIV related stigma has to some extent reduced considerably in both external and internal components that were measured to determine stigma levels. For instance, in one of the constructs that measured internal HIV stigma (I feel guilty that am HIV positive) the proportion who said yes to feelings of guilty reduced from 50% in 2013 to approximately 24% in 2019, with no major gender difference.

About internal stigma, some PLHIV still mention that it is difficult to tell other people about their HIV status, some feel ashamed of their HIV positive status while others feel worthless and hide their status from others.

Despite the key challenges within internal HIV stigma that have persisted, the levels of resilience (coping with HIV negative effects) is high. On a scale that measures resilience ranging from -10, through zero to 10) where negative is the worst and positive is the most preferred (a better resilience), 50% of the PLHIV had a resilience score of 4, meaning despite HIV, the level of resilience is equally high. In terms of regions, resilience varies and is highest in Karamoja and Bugisu regions and less in Teso.

Comparatively external forms of HIV stigma were reported less compared to the internal ones. The most persistent form of external stigma was awareness of family members and non-family members who made discriminatory remarks or gossip of non-family members about the PLHIV. Other components such as exclusion from social gathering, family activities, religious gathering, that measure external stigma had generally reduced to a minimal of 1.3 to about 4.5%. Reduction is external stigma are projected to positively affect internal stigma if consistent intervention geared towards reducing HIV are sustained.

HIV status disclosure rates are high, in that particularly family members, 1130(80.77%), friends 1065(76.13%), husband/wife/partner, 899(64.26%) and the respondent's children 907(64.83%). Husbands were more likely to know the status of their wives/partners than the women, and also women had disclosed more to their children and other family members

Almost all respondents 1365 (99.71%) were taking ART by the time of the PLHIV stigma index survey in January 2019, rating their health as good. The only major concern is that in the past 12 months, fears about someone learning about the PLHIV HIV positive status led 284(20.31%) to miss a dose of their ART. More than 21.41% males compared to 19.68% females, reported missing their ART in the past 12 months because of the fear that someone would learn about their HIV status.

The rates of viral load suppression are still below the recommended national targets of 90%, only 980(70.17%) reported to have been told they have undetectable viral load or are virally suppressed in the last 12 months.

The human rights abuses and violations were also minimal and are generally reducing as very few cases of forced testing or disclosure had been experienced by PLHIV during the past one year before the PLHIV survey or even beyond. Among the negative experiences that stood out was the denial of residence in another country because of a positive HIV status reported by 57 (4.8%). Out of the 186 respondents who reported experiencing abuse or human rights violations, 35 (18.82%) mentioned that they had tried to do something about the matter either in form of complaints, contacting a lawyer, a government official or politician, a Community Based Organization to deal with the matter or speaking publicly about the matter. Besides, the cases raised such as forced sterilization for both men and women, though few, should be non-existent.

Within the KP categories, non- HIV related stigma and discrimination is almost six times higher than the HIV related stigma. Discriminatory remarks or gossip about the PLHIV were the commonest non-HIV stigma discriminatory experiences within and among all the groups. This data confirms that concept of double stigma that KP face both sex-oriented stigma in addition to HIV related stigma and implies the need to deal with such inter-sectionality. The opportunity to reach these groups is quite huge as the proportion of those who belong to a support group is high, therefore interventions should target the groups with relevant information and support

6.0 RECOMMENDATIONS

Basing on the key outcomes observed about the PLHIV stigma index at country level between the 2013 and 2019, the following are presented as actionable recommendations for future programs to ensure success in leading to desired changes. These recommendations are specific to agencies or institutions depending on the role they play in the national HIV response.

NAFOPHANU

i. Widely disseminate the findings to all relevant stakeholders to enable the country and specific institutions embark on interventions that will address stigma and discrimination.
ii. Develop a framework with clear indicators to monitor outcomes as a result of stigma reduction interventions
iii. Empower PLHIV forums to reach out to their peers and promote positive living. The buddy model should be adopted as part of peer to peer psycho-social support as it has been proven to reduce stigma.
iv. Build capacity of PLHIV to advocate for their rights, implement initiatives that reduce stigma among their peers, effective coordination to make their structures functional and mobilise resources to support stigma reduction interventions.
v. Recruit more PLHIV into networks as out of 1398 respondents, only 54.18% belonged to networks. The networks play a big role where peers support each other and so non members should be brought on board. In the same vein, highly educated and well off PLHIV should be targeted as could be experiencing stigma and yet did not participate in the survey.
vi. Integrate core areas in programming such as issues around mental health, key populations, economic empowerment, SRHR,
vii. Revitalize the implementation of specific advocacy campaigns in close collaboration with national and regional entities as well as service delivery institutions.
viii. Follow up on dissemination of the National Anti-stigma Policy to support PLHIV, for instance, criminalization of HIV transmission has taken root and yet the law should not be counterproductive but enabling.
ix. Partner with CBOs, CSOs, implementing partners to support PLHIV efforts in addressing stigma and discrimination and mitigating their impact.
x. Conduct specific PLHIV stigma index studies, be it cohort or regional based, to provide more specific data. e.g. among in school adolescents.

Civil Society Organizations (CSOs)

Besides, NAFOPHANU, there are other CSOs whose mandate and vision have a bearing on stigma reduction related interventions country-wide. They should;

a) Continue to support key processes in the national response with a focus on HIV and HIV stigma reduction interventions.
b) Support health facilities to reduce waiting period for PLHIV that seek care and treatment services through effective engagement and support to expert clients and roll out of Differentiated Service Delivery models.

c) Advocate for continued improvements in service delivery especially for programs targeting lifelong treatment services and various categories of population

d) Consolidate advocacy for repealing laws that criminalize PLHIV.

Uganda AIDS Commission (UAC)

i. Utilize the PLHIV data and recent trends in HIV stigma to guide the development of national level interventions and policies that address stigma and discrimination at the country level and in specific institutions including work places.

ii. Adopt and use the current PLHIV stigma data to monitor national level improvements in quality of service and access to care and treatment services for PLHIV since there is a close link between quality services and reduction in HIV stigma and treatment outcomes.

iii. Ensure a forum for compilation and dissemination of research findings

iv. Resumption of the Partnership Fund to support coordination efforts of the Self Coordinating Entities (SCEs) that would among others enable strengthening of PLHIV structures to reach their peers for all forms of support that reduce stigma.

v. Dissemination of the national Anti HIV Stigma and Discrimination Policy. This has specific policy statements, strategies and implementation framework for execution of the stigma reduction campaign at all levels.

vi. As part of ending AIDS as a public health threat by 2030, UAC should adopt stigma reduction as part of the Presidential Fast Track Initiative.

The Ministry of Health (MOH)

a. Ensure universal access to interventions that support PLHIV to access care and treatment services in a stigma free environment.

b. Guide implementing partners in charge of health communication to design and implement HIV stigma reduction specific communication materials and integrate them in current national communication plan for health.

c. Strengthen efforts that ensure that all ART sites include a strong counseling component in their delivery of services for PLHIV.

d. Expedite operationalization of the AIDS Trust Fund that is expected to support implementation of HIV care and treatment programmes and addressing stigma as a barrier to HIV prevention efforts.

Ministry of Gender, Labour and Social Development (MGLSD)

i. Oversee implementation of policies related to employment and work place in regard to HIV. Findings reveal that employers and co-workers were least disclosed to and some PLHIV have lost their jobs due to being HIV+

ii. Work with relevant institutions such as cultural and religious leaders to address issues that make stigma a persistent barrier to HIV prevention efforts. Men engagement should be core of this programming

The Academia and Research institutions

The researchers and universities play a major role in shaping new understanding through theories and models. Given the complexity of HIV related stigma, the following recommendations are suggested for the academia and research institutions:

- Research and advise such as on stigma and its related intersections, school settings and role of HIV status disclosure. At the moment, some experts are suggesting disclosure should be tagged to benefits. These complex scenarios should be routed by the academia before national programs can operationalize them.
- Coordinate the researchers to have findings widely known and PLHIV should be informed of outcomes out of researches involving them.

AIDS Development Partners (ADPs)

- Need to have a specific PLHIV network grant to support stigma reduction interventions and coordination efforts as part of complementing biomedical and behavioral approaches in Uganda.
- Adopt and use the current evidence to provide necessary funding for further implementation of HIV care and treatment programs.
- Fund biometric interventions to improve clients monitoring through the cascade of care and treatment. Biometric systems are expensive but play a great role in tracking clients and avoiding losing them during care or transition to other health from the regular ones. With peers at hand, follow up will be easy.

7. STUDY LIMITATIONS:

Two main study limitations were observed: the categorization of groups and the loss of variables between the first 2013 and 2019 PLHIV surveys.

The conceptualization of the background profile of respondents on domains which asks respondent to indicate if they currently belong or have ever belong to groups categorized as; racial, ethnic or religious minority was had to elicit consistently. The constructs of racial, ethnicity or religious minority requires separation.

The changes in the PLHIV standard questionnaire from 2008 to the 2017, led to non-administration of many questions within the standard sections of internal and external stigma. For instance, out of the eight variables that were used to quantify stigma in 2013, only one was contained in the 2017 tool. This has made explicit comparison difficult.

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e) Uganda Population based HIV Impact Assessment Survey (UPHIA) 2016-2017

Internal stigma manifestations across selected African countries from 2009-2016

Variable %	Ethiopia	Kenya	Uganda	South Africa	Eswatini	Zambia	Zimbabwe	Malawi		Ivory Coast	Mozambique	Tanzania
								‘12	‘16			
Ashamed	46	43	50	29	13	45	22	13	14	33	35	29
Guilty	44	44	50	28	13.2	44	19	29	25	30	33	15
Blame self	53	49	50	31	13	40	16	20	26	26	60	31
Blame others	26	27	50	19	15.5	29	20	14	10	10	36	13
Low self esteem	52	45	67	22	12.5	34	19	10	14	14	36	44
Should be punished	28	8	50	11	2.5	10	4	15	7	7	6.1	5.4
Feeling Suicidal	19	15	55	11	3.5	12	7	3.2	8.7	8.7	10	6.4

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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The National Forum of People Living with HIV Networks in Uganda
(NAFOPHANU)
Plot 213, Sentema Road, Mengo
P.O. Box 70233 Kampala
Tel: +256 200944448
+256 701 444448

Email: info@nafophanu.org
Website: www.nafophanu.org

Prevention of HIV&AIDS in Communities of Karamoja(PACK) Partners