

Nigeria People Living with HIV (PLHIV)

Stigma Index Survey 2.0 Report



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By: Network of People Living with HIV/AIDS in Nigeria (NEPWHAN)



Acronyms

AIDS	Acquired Immuno-deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
ASWHAN	Association of Women Living with HIV and AIDS in Nigeria
CBO	Community Based Organization
CD4	Cluster of differentiation 4
CSO	Civil Society Organization
DSD	Differentiated Service Delivery
FCT	Federal Capital Territory
FHI	Family Health International
FMOH	Federal Ministry of Health
FSW	Female Sex Workers
GF	Global Fund
GNP+	Global Network of People living with HIV
GoN	Government of Nigeria
GPLHIV	General Population Living with HIV
HCW	Health Care Workers
HIV	Human Immuno-deficiency Virus
HTS	HIV Testing Services
ICW	International Community of Women Living with HIV
IP	Implementing Partner
KII	Key Informant Interviews
KP	Key Population
KPLHIV	Key Population Living with HIV
KPSE	Key Population Size Estimate
LACA	LGA AIDS Control Agency
LGA	Local Government Authority
LGBT	Lesbian, Gay, Bisexual, and Transgender



M&E	Monitoring and Evaluation
MSM	Men who have sex with Men
NACA	National Agency for Control of AIDS
NAIIS	Nigeria HIV/AIDS Indicator and Impact Survey
NGO	Non-Governmental Organizations
NEPWHAN	Network of People Living with HIV/AIDS in Nigeria
OSS	One Stop Shops
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
PWID	Persons Who Inject Drugs
PWUD	People Who Use Drugs
SACA	State AIDS Control Agency
SSMPA	Same-Sex Marriage Prohibition Act
SFH	Society for Family Health
SMOH	State Ministry of Health
STDs	Sexually Transmitted Diseases
TBA	Traditional Birth Attendants
TB/HIV	Tuberculosis and HIV coinfection
TG	Transgender
UNAIDS	The Joint United Nations Programme on HIV/AIDS
WSW	Women who have Sex with Women



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Implementation of the Nigeria People Living with HIV Stigma Index 2.0 Survey was led by the Network of People living with HIV/AIDS in Nigeria (NEWHAN) and the KP Secretariat, who were both Principal Investigators for the survey; with the Global Network of People Living with HIV(GNP+) serving as the overall technical lead (Technical Service Organization-International).

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Executive Summary

Stigma and discrimination have profound implications for HIV prevention, treatment, care, and support services. It impacts an individual's capacity to acknowledge and manage their own HIV infection, affecting their physical and psychological well-being and quality of life. In Nigeria, with the highest population of persons living with HIV (PLHIV) in West Africa, stigma and discrimination have remained a major challenge. Recent studies that explored and reported on these issues faced by PLHIV in Nigeria, showed prevalent instances of abuse on PLHIV and key population. Since the last Nigeria Stigma Index Survey in 2014, a combination of factors, including shifts in the HIV epidemic, growth in available evidence on HIV related stigma and discrimination, and changes in the global response to HIV, especially with the introduction of the test and start treatment strategy, support the need to update the Stigma Index Survey in Nigeria. The primary objective of the Nigeria Stigma Index Study 2.0 is to document experiences of stigma and discrimination among PLHIV in Nigeria.

This was a cross-sectional study that utilized a mixed-methods approach, involving quantitative and qualitative methods, in determining the extent, forms, and experiences of stigma among PLHIV in Nigeria, and the strategies to address them. The quantitative study involved the use of the structured and standardized Stigma Index Survey 2.0 tool to interview 1,240 PLHIV from among the General and Key Population groups in the 16 States + the Federal Capital Territory (FCT). The qualitative study employed the use of a semi-structured Focus Group Discussion (FGD) guide to elicit experiences of stigma among 120 PLHIV in three selected States. The quantitative survey respondent breakdown was as follows: general population living with HIV- 941; female sex workers (FSW)- 161; gay men and men who have sex with men (MSM)- 81; and people who use drugs (PWUD)- 57. In terms of current gender identity, the study included females 763; males- 418; transgender 9; non-binary 3; and those who preferred not to state their gender 15.

80% of the respondents reported that other people were aware of their status. One in every four of these respondents revealed that their status was disclosed without their consent. Experience of stigma and discrimination due to HIV status within the last 12 months was reported as 22% across all respondents. One in every four respondents reported that they were either pressured or that it was not their choice to get tested. Nearly one in every five respondents delayed starting treatment for more than one month after being diagnosed with HIV. There were minimal proportions of respondents reporting stigma from health facility staff due to HIV. Health workers revealing respondents' HIV status to other people without their consent was the most reported stigma issue. This was reported by 7% of the respondents. Over 80% of respondents were sure that their hospital records were kept confidential.

Regarding rights abuse, 10.9% of the respondents reported experiencing abuse of their rights. However, among those whose rights were abused, only about one in four persons acted. Among those who did not act, 40.8% reported that the reason for not acting was because they were unaware of where and how to seek redress. Also, 5% of those who did not act felt that nothing will come out of their action, while an additional 12% reported that they feared that acting might result in status disclosure.

In terms of stigma experienced for reasons other than HIV, bisexuals, and respondents with a different gender identity from their gender at birth reported blackmail as the most form of abuse experienced. For sex workers and gay/homosexual/MSM, the most reported abuse was verbal harassment. Lesbian and women who have sex with women reported physical harassment as the most frequent form of abuse. PWIDs, on the other hand, reported the most occurring stigma as family members making discriminatory remarks or gossiping about them.



Trends in stigma and discrimination over the last three waves (2011, 2014 and 2021) have shown improvements across key indicators. There has been a steady decline in reported internalized stigma, denial of access to healthcare services and reports of mandatory/forced HIV tests and medical procedures. Despite some of these gains, there are still widespread challenges, such as verbal abuses and disclosure of PLHIV status to others without their consent. Furthermore, stigma and discrimination for reasons other than HIV status, such as gender identity, sexual identity, sex workers and drug use, have emerged as a growing challenge. Therefore, Nigeria has an obligation to address stigma and discrimination issues that affect PLHIV human rights and health outcomes. Removing barriers in access to HIV and non-HIV health information and services, as well as implementing laws and regulations that aim to support and promote better health outcomes, are actions that must be taken seriously by stakeholders.

Following the results from the survey, some key recommendations are made for consideration and implementation:

- First, there is need to create greater awareness and sensitization on critical issues of stigma and discrimination as it affects PLHIV.
- In addition, concerted efforts should be made to implement laws and policies that seek to protect the rights of PLHIV and Key population.
- Key population should be educated on their rights and ways of seeking redress when their human rights are violated. Mechanisms and guidelines should be put in place to facilitate better reporting, documentation and redress of stigma and related abuses of PLHIV and Key population.
- PLHIV must be educated on their rights, especially about their sexual and reproductive rights.
- Continuous training and retraining of health care facility workers on interpersonal communication, and on delivery of “stigma-free” HIV and non-HIV services to PLHIV.
- National HIV programs and implementing partners should embed strategies to address stigma issues in their program designs.



Introduction

HIV related stigma and discrimination refers to irrational or negative attitudes, behaviors, and judgments towards people living with or at risk of HIV.¹ Stigma and discrimination remain one of the biggest barriers preventing people living with HIV from accessing healthcare. These have profound implications for HIV prevention, treatment, care, and support. It impacts on individuals' capacity to acknowledge and manage their own HIV infection, affecting their physical and psychological well-being and quality of life². In responding to stigma and discrimination in Nigeria, the country enacted the HIV/AIDS Anti-Discrimination Act 2014, and further developed a stigma reduction strategy.

Background

The People Living with HIV Stigma Index was first launched in 2008 to measure the stigma and discrimination experiences of PLHIV globally. It was developed as a joint initiative of several organizations, including The Global Network of People living with HIV (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF), and the Joint United Nations Programme on HIV/AIDS (UNAIDS)³. The 1st and 2nd Stigma Index Surveys were carried out in 2011 and 2014, respectively, led by the Network of People Living with HIV/AIDS in Nigeria (NEPWHAN). Ten years after the global launch of the Stigma Index Survey, it was updated and strengthened to Stigma Index 2.0. This revision was informed by a combination of factors, including a focus on specific populations to better understand how different groups of people living with HIV are affected by stigma and discrimination; a new questionnaire that is streamlined and easier to use; and to provide a global standardized methodology, to allow comparison among countries and over time.

In support of the effort to address stigma and discrimination among PLHIV in Nigeria, and with funding support from the Global Fund, through Family Health International (FHI 360), the Nigeria Stigma Index Survey 2.0 was implemented. The study was led by NEPWHAN and the KP Secretariat, in collaboration with other stakeholders in the national response, with technical support from GNP+. The survey findings will be used to inform HIV programming priorities, as the global and national HIV responses enter new phases of strategic planning and resource prioritization. The findings will also serve as a strong tool for advocacy to relevant agencies and organs of Government in dealing with stigma-related issues.

Country Context

The population of Nigeria, as estimated in 2020, is more than 200 million, making it the most populous country in Africa.⁴ The country also has one of the highest number of people living with HIV globally. HIV/AIDS contributes to the burden of disease, and poses a major public health threat for the country.⁵ The 2018 Nigeria HIV/AIDS Indicator and Impact Survey (NAIIS) report estimates that the prevalence of HIV

¹ HIV.gov. (2020) Standing Up to Stigma. What is Stigma. Available at: <https://www.hiv.gov/hiv-basics/overview/making-a-difference/standing-up-to-stigma>

² UNAIDS. People Living with HIV Stigma Index. Available at: https://www.unaids.org/sites/default/files/media_asset/20110829_PLHIVStigmaIndex_en_0.pdf

³ Global Network of People Living with HIV. People Living with HIV Stigma Index. Available at: <https://gnpplus.net/project/people-living-with-hiv-stigma-index/>

⁴ Trading Economics. Available at: <https://tradingeconomics.com/nigeria/population>

⁵ National Agency for the Control of AIDS (NACA). (n.d.). Revised National Hiv and AIDS Strategic Framework 2019-2021.



in Nigeria is 1.4% with about 1,900,000 Nigerians, aged 15-64 living with HIV.⁶ Nigeria has the second largest HIV epidemic in sub-Saharan Africa, and one of the highest rates of new infection. Nigeria has continued to direct efforts towards ensuring PLHIV achieve viral suppression, to minimize the risk of HIV transmission and achieve HIV epidemic control. In this regard, in 2020, 86% of PLHIV in Nigeria were receiving antiretroviral therapy.⁷

Stigma and discrimination have remained a major challenge in Nigeria. During the 2011 Stigma Index Survey in Nigeria, data was collected from 706 PLHIV in 12 States. One in five respondents reported they were denied access to healthcare services because of their HIV status. 63% of respondents reported that they felt ashamed because of their HIV status, with one in five reporting feeling suicidal. 18.8% of respondents reported they were forced to submit results of a medical or health procedure, while 12% were forced to submit to HIV test, making this the most violated rights. Additionally, 15% of respondents reported that they were tested for HIV without their knowledge. One in five respondents reported breaches in confidentiality of their HIV status by health care professionals. In relation to treatment, 13.5% of respondents reported not having access to ART, even though most respondents were recruited from HIV clinic venues.⁸

In 2014, a total of 4,241 PLHIV were interviewed for the Nigeria Stigma Index Survey. 45 (1.1%) respondents claimed that they were denied access to healthcare services due to their HIV status. In addition, many respondents (89.8%; 3,808 PLHIV) were denied family planning services. 39.2% (n=1663) of respondents reported feeling ashamed because of their HIV status, and 7.1% reported feeling suicidal. 8.6% of respondents reported they were pressured to take a HIV test. Likewise, 8.6% of respondents reported that they were tested for HIV without their knowledge. Less than one quarter of the respondents were aware of the National law, policy or set guidelines on HIV/AIDs, while less than half had any knowledge of the declaration of commitment from the Government.⁹

The Same-Sex Marriage Prohibition Bill (SSMPA) was signed into law in Nigeria in 2013. In addition to prohibiting marriage between persons of the same sex, the SSMPA effectively criminalizes lesbian, gay, bisexual, and transgender (LGBT) persons based on sexual orientation and gender identity.¹⁰ Punishments under the SSMPA are severe and range from 10 to 14 years in prison. Since signing SSMPA into law, there has been increase in LGBT human rights abuses in Nigeria, including physical and sexual violence, aggression, arbitrary arrests, extortions, and persecutions.¹¹ Studies have also shown that

Following the signing of SSMPA into law, there has been increases in LGBT human rights abuses including physical and sexual violence, aggression, arbitrary arrests, extortions, and persecutions. This has further exacerbated the situation of members of these subgroups.

⁶ Nigeria HIV/AIDS Indicator and Impact Survey, 2019

<https://www.naiis.ng/resource/factsheet/NAIIS%20PA%20NATIONAL%20FACTSHEET%20FINAL.pdf>

⁷ UNAIDS Country Factsheet, Nigeria, 2020. Available at:

<https://www.unaids.org/en/regionscountries/countries/nigeria>

⁸ HIV Leadership through Accountability Programme: GNP+, NEPWHAN (2011). PLHIV Stigma Index Nigeria Country Assessment. Amsterdam: GNP+.

⁹ Report of National Stigma Index Survey Among People Living with HIV/AIDS in Nigeria.

¹⁰ Human Rights Watch (2016) Tell me where I can be Safe. The impact of Same Sex Marriage (Prohibition) Act. Available at: <https://www.hrw.org/report/2016/10/20/tell-me-where-i-can-be-safe/impact-nigerias-same-sex-marriage-prohibition-act>

¹¹ Human Dignity Trust (2021) Nigeria. Available at: <https://www.humandignitytrust.org/country-profile/nigeria/>



female sex workers and persons who inject drugs have also faced similar human rights abuses, following police crackdown.^{12 13} These have negatively affected their livelihoods and general well-being. On the positive side, the HIV/AIDS Anti-Discrimination Act signed into law in 2014, made it illegal to discriminate against people based on their HIV status. It prohibits any employer, individual or organization from mandating anyone to take a HIV test as a precondition for employment or access to services. This was aimed at creating a more supportive environment, allowing people living with HIV to carry on their lives as normally as possible.¹⁴

Since the last Stigma Index Study in 2014, a combination of factors, including shifts in the HIV epidemic, growth in available evidence on HIV related stigma, and changes in the global response to HIV, especially with the introduction of the test and start treatment strategy, support the need to update the current Stigma Index Survey in Nigeria. More so, data from this index survey has provided measurement parameters and a strong tool for advocacy to relevant agencies and organs of Government in dealing with stigma related issues. NEPWHAN, as a network, has used findings from Stigma Index studies to guide programmes, advocacy, and frameworks of dialogue for religious leaders to address stigma and discrimination related issues. The global changes in the HIV/AIDS trajectory and the platform created by the GNP+, including the adoption of the new global HIV strategy, the political declaration that focus on ending inequalities, and the country's determination to end AIDS by 2030, provided the need to conduct the PLHIV stigma index survey 2.0

Objectives

The primary objective of the Nigeria Stigma Index Study is to document experiences of stigma and discrimination among PLHIV in Nigeria.

Secondary objectives:

- a) To document modes of stigma and discrimination manifestations among PLHIV.
- b) To identify factors associated with experiences of stigma and discrimination against PLHIV.
- c) To measure the level of HIV-related stigma and discrimination experienced by PLHIV.
- d) To measure changes in experiences of stigma and discrimination over time.
- e) To identify strategies, and make recommendations on how to deal with HIV-related stigma in Nigeria.

¹² Salihu, H.A. and Fawole, O.A (2020) Police Crackdowns, Human Rights Abuses, and Sex Work Industry in Nigeria: Evidence From an Empirical Investigation. *International Criminal Justice Review*. 31(1), page(s): 40-58

Available at: <https://doi.org/10.1177/1057567720907135>

¹³ Molobe, I. D. (2019). Human rights abuses experienced by people who use drugs. A Nigeria-focused review. *International Journal of Medical and Surgical Sciences*, 6(4), 133-135. Available at:

<https://doi.org/10.32457/ijmss.2019.039>

¹⁴ UNAIDS (2015) Nigeria passes law to stop discrimination related to HIV. Available at:

https://www.unaids.org/en/resources/presscentre/featurestories/2015/february/20150211_nigeria_law#:~:text=i nto%20law%20th



Methodology

Study Design

The study adopted a mixed-method cross-sectional design that employed quantitative and qualitative methods in determining the extent, forms, and experiences of stigma among PLHIVs in Nigeria, and the strategies to address them. The quantitative study involved the use of the structured and standardized Stigma Index Survey 2.0 tool to interview PLHIV from among the General and Key Population groups in the 16 States + FCT. Therefore, the FCT plus 16 out of 36 states were selected as the study states. The qualitative study employed the use of a semi-structured Focus Group Discussion (FGD) guide to elicit experiences of stigma in FGDs among the different PLHIV survey participant groups in three selected States. The FGD States were selected based on high burden of HIV, and a cultural mix from the Northern, Southern and Central regions of the country. In addition, formative Key Informant Interviews were conducted to determine the specific sites for recruiting study participants.

Study Setting

16 States, plus the Federal Capital Territory (FCT), were selected for this study, as shown in the map below:

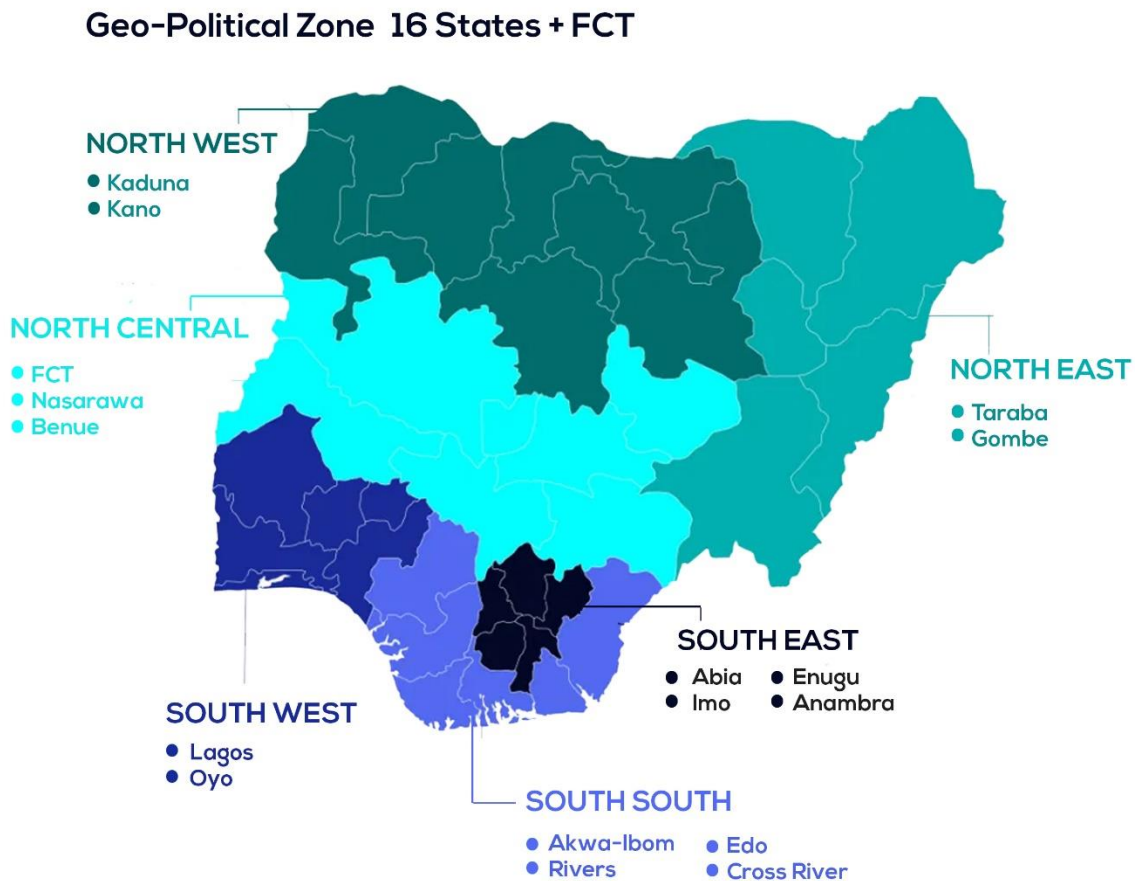


Table A: Selected Study States by Region

S/N	Geo-political zone	16+1 States
1	South-East	Abia, Imo , Enugu, Anambra
2	South-South	Akwa-Ibom , Rivers, Edo, Cross River
3	South-West	Lagos , Oyo
4	North-Central	FCT, Nasarawa, Benue
5	North-East	Taraba, Gombe
6	North West	Kaduna , Kano

The States were selected based on the following criteria:

- Burden of HIV in the general population. (HIV Prevalence from the 2018 National AIDS Indicator and Impact Survey (NAIIS)).
- States classified as high burden KP States and surveyed in the most recent KP size estimate.
- The need for geographical spread (all 6 geopolitical zones (administrative divisions of Nigeria) were represented).
- The need to analyse trends. A substantial number of States from the previous Stigma Index Survey were included. Thus, 6 States highlighted above were repeated.

Sampling

The study population was drawn from persons living with HIV, including women, men, young persons and KP (MSM, FSW, PWID and Transgender people). Twenty five percent (25%) of the overall sample size was allocated to KPLHIV.

Inclusion criteria:

- Aged 18 years or older.
- Self-reported as living with HIV, and aware of their status for at least 12 months.
- Provided informed consent to participate in the study.
- Mentally sound and capable of providing consent to participate.
- Understands the predominant Nigerian Languages (English or Pidgin English)

The sampling frame consist of all people living with HIV, including the Key Populations Living with HIV (KPLHIV: FSW, MSM, PWUD, Transgender). GNP+ recommended guidelines to countries on determining sample sizes, based on the fear or avoidance of seeking health care because of anticipated stigma.



Therefore, the study used data from the last Nigeria Stigma Index survey, which illustrated that 34.6% and 11.9% of PLHIV who participated in the survey avoided seeking care at a clinic or hospital respectively, due to anticipated stigma related to their HIV status. Average of these two numbers (24%) was used to calculate the sample size. Sample size was further adjusted for non-response at 10%.

$$n_0 = z^2 * p * (1-p) / d^2$$

Where:

$z = 1.96$ (z statistic for a confidence level at 95%)

$p =$ Anticipated % reporting avoidance of a healthcare facility

$d =$ Degree of precision

The final sample size was calculated as $N = 1235$. The study sample size was allocated across the 16 + 1 study States based on the estimated number of PLHIV living in each State.

Table B: Sample Size versus Target Achieved by States delineated by PLHIV and KPLHIV Groups

State	PLHIV (NAIIS 2018 Spectrum)	Proportion (%)	Final Study Sample Size	Sample Delineation by KP and Non KP		Target Acheived	Proportion of Target Achieved
				GPLHIV (75%)	KPLHIV (25%)		
Abia	51976	4.2	52	39	13	52	100.0%
Akwa Ibom	175886	14.1	175	131	44	170	97.1%
Anambra	78855	6.3	78	59	20	78	100.0%
Benue	160046	12.9	159	119	40	163	102.5%
Cross River	39769	3.2	40	30	10	41	102.5%
Edo	39434	3.2	39	29	10	39	100.0%
Enugu	50990	4.1	51	38	13	51	100.0%
FCT	41462	3.3	41	31	10	41	100.0%
Gombe	17390	1.4	17	13	4	17	100.0%
Imo	49774	4.0	49	37	12	49	100.0%
Kaduna	49818	4.0	49	37	12	50	100.0%

Kano	47587	3.8	47	35	12	47	100.0%
Lagos	116924	9.4	116	87	29	116	100.0%
Nasarawa	55986	4.5	56	42	14	57	101.8%
Oyo	46490	3.7	46	38	13	46	100.0%
Rivers	173303	13.9	172	129	43	176	102.3%
Taraba	47428	3.8	47	39	13	47	100.0%
Total	1243118	100.0	1235	934	311	1240	100.4%

Within each State, the sample size was further allocated to ensure that the study adequately captured experiences of intersectional stigma by sufficiently recruiting participants from each key population.

Recruitment of Participants

Two strategies were used to recruit participants. These were:

- Venue-Based sampling (also referred to as “Time Location Sampling”) and
- Limited Chain Referral.

This two-tiered strategy was designed to capture the diverse and intersectional experiences of stigma more adequately across all population groups, and to ensure the inclusion of PLHIV across the care continuum. 79.3% of respondents were recruited using the venue-based sampling, while 20.7% were recruited using the limited chain referral. Prior to participants’ recruitment, formative key informant interviews (KII) were conducted to determine and validate the sites for recruiting study participants.

Key Informant Interviews

The study was conducted in all 16 + 1 States to systematically identify, validate, and map venues accessed by PLHIV in each State. A qualitative key informant interview tool was used to identify locations where people living with HIV access healthcare services. The interviews were conducted with stakeholders in the various States who are conversant with HIV programs in their respective States. Stakeholders reached include community leaders, NEPWHAN State Coordinators, KP State coordinators, Support Group leaders, health care workers, etc. This activity helped generate a list of venues, including health facilities, Support Groups, Community Based Organizations (CBOs), and One Stop Shops (OSSs). This was further reviewed by the research team to ensure that a good geographical spread was achieved in each State. Field teams, with the support of the research team used the approved list and a sampling worksheet to create workplans for reaching different venues.

Venue-based sampling

983 (79.27%) study participants (KPLHIV and non KPLHIV) were recruited using this approach. To ensure the inclusion of PLHIV who may not access traditional outpatient treatment facilities due to experiences of



stigma, venues where participants were recruited from was extended to private clinics, One Stop Shops (OSSs), PLHIV/KP Support Groups, and CBOs who offer specialized care to the community PLHIV/KP groups. Community based venues that provide services to hard-to-reach key populations were intentionally targeted.

Venue criteria for participants' recruitment:

- Venue should be a public, private healthcare center providing services to PLHIV, ranging from HIV antiretroviral treatment, STI testing and treatment or other sexual/reproductive health services, needle exchange, condom provision, or other services related to HIV, or community-based venues for those less connected to treatment.
- Venue where management was willing to assist in the recruitment of their patients to participate in the Stigma Index 2.0 Survey
- The venue with a patient population of at least 10 PLHIV across a four-hour block.

Limited Chain Referral

The limited chain referral approach was used to recruit hidden PLHIV who avoid visiting HCFs and accessing services. Those who completed the survey from the venue-based recruitment and those identified from community consultations were given three to six tracked project business cards, and asked to distribute the cards to potential participants. The business cards listed the study office and contact phone number, but did not include the eligibility criteria or the focus of the study. Potential participants who contacted the study staff were screened to check eligibility. Eligible potential participants were then introduced to the study and asked if they would like to participate. Appointments were scheduled for physical meetings with eligible participants who agreed to participate. Informed consents were obtained from the potential participants, after which the interviews were conducted.

Focus Group Discussion (FGDs) Component

FGDs were conducted in Akwa Ibom, Benue, and Taraba States. FGDs were conducted based on PLHIV typology to encourage free exchange of information. There were separate groups of FGDs for the PLHIV and KP groups. 5 FGDs were conducted in each State, with 8 persons in each session. A total of 120 PLHIV participated in the FGDs. NEPWHAN/KP Coordinator and State Supervisor moderated the FGD sessions. FGD participants comprised mostly of persons fluent in English and Pidgin English. Participants were required to provide informed consent, and were assigned pseudo names to protect their identity. Demographic information was collected from all the participants. All interviews took place in quiet/private spaces and were audio-recorded. Each interview lasted about 60 to 90 minutes. Audio-taped interviews were transcribed verbatim in English.

Table C: FGD Breakdown by State and Typology

Typology	Benue	Akwa Ibom	Taraba	Total
Adolescents and Young People	1	1	1	3
GP Living with HIV	1	1	1	3
FSW (can be inclusive of PWID)	1	1	1	3
MSM (can be inclusive of PWID)	1	1	1	3
Women Living with HIV	1	1	1	3
Total	5	5	5	15

Preliminary Processes

Document Review

The research team carried out a targeted review of scientific documents including study protocol, technical reports, presentations at technical meetings, working papers and briefings, and existing research instruments, as well as the qualitative and quantitative questionnaires. These reviewed documents provided the basis for structuring the research process and identifying areas of gaps and items that required revision.

Review Meetings

Several review meetings were held with members of the study's Technical Committee and Steering Committee. A Technical Committee meeting was held in Abuja for review of the study protocol and data collection tools on the 20th and 22nd April 2021. Attendees at the meeting were drawn from NEPWHAN, NACA, KP Secretariat, UNAIDS, SFH, NASCP, and members of the research team (National Consultant, Data Manager and Administrative Assistant). The Nigeria Stigma Index Survey Protocol, the quantitative questionnaire for PLHIV and the qualitative key informant tool were reviewed during the meeting. The study questionnaires were pretested on the 21st of April 2021 in in the FCT (Kubwa and Karu). The tools were administered on 20 persons living with HIV. Among these were 15 non-KP and 5 KP. A total of 14 males and 6 females were interviewed. Observations from the pretesting were aggregated and presented to members of the Technical Committee for discussions on 22nd April.

On 27th April, the research team presented the study protocol to the Steering Committee. The Steering Committee consisted of 13 high level stakeholders from NACA, SFH, NEPWHAN, ASWHAN, KP Secretariat, UNAIDS, CCM, PEPFAR, FMOH (NASCP), NHRC, and Law Enforcement Agents/Police. The meeting which held at the main conference hall of the National Agency for the Control of AIDS (NACA) Abuja, was chaired by the DG NACA, Dr Gambo Aliyu. The Protocol was well received by the Steering Committee. Feedback was provided to the research team on areas that require revision in the Protocol. These included expanding details on sampling methods, inclusion of COVID-19 adaptations, and description of the data analysis process. These revisions were made, and the Protocol was re-submitted on the 4th of May 2021. Approval of the Steering Committee to proceed with the survey was received on the 5th of May 2021.

Training of Interviewers

A National Training of Trainers (NTOT) for the Stigma Index Survey 2.0 was held at in Nasarawa State from 5th to 7th May 2021. The training was organized to build capacities of trainers to facilitate regional stepdown training for Data Collectors, State Supervisors and State actors across the different regions. Regional trainings were conducted from 17th to 19th May 2021. The regional trainings were held simultaneously in 5 locations, namely FCT, Imo, Akwa Ibom, Kano and Oyo States. All 44 Data Collectors, 17 State Supervisors and all the State actors (NEPWHAN and KP State Coordinators and SACA M&E Officers) participated in the trainings. The regional trainings helped prepare all the participants for carrying out the survey.





Ibadan Regional Step-down training for Data Collectors and Supervisors



Akwa-Ibom Regional Stepdown training for Data collectors and Supervisors

The trainings helped to build the capacities of the participants, and ensured that participants had a good knowledge of the PLHIV Stigma Index Survey, understood the study approach and became familiar with all survey tools on the REDCap platform. Additionally, participants were trained on steps in conducting interviews, and provided with counselling tips and security protocol. The training sessions involved practice exercises, presentations, group work and discussions. Participants' knowledge gain was assessed through pre and post-tests. At the end of the trainings, the research team confirmed that all participants improved their knowledge and met the minimum requirement to be part of the study. 30 male and 14 female Data Collectors participated in the study.



National Coordinator of NEPWHAN (Abdulkadir Ibrahim) addressing participants at the National Training of Trainers in Nasarawa State.

Minimum Requirement for Selection of Data Collectors

- A PLHIV and / or KPLHIV.
- Understood the predominant Nigerian Languages (English or Pidgin English).
- Experienced in electronic research data collection with REDCap or any other software.
- Ability to use an android tablet.
- Resident in the implementation State
- Disclosed HIV status and is living positively.
- Completed all training sessions.



Data Collection

Data collection commenced on 31st May in 13 out of the 17 States. The 4 South-Eastern States of Anambra, Enugu, Imo, and Abia did not start data collection till the 7th of June 2021, due to security unrest and the stay-at-home order issued in the South-East by IPOB. Data collection lasted 10 days in each State. Hence, data collection was concluded on 11th June in 13 States, and 18th June in the 4 South Eastern States.

Data was collected using REDCap electronic data capturing software. At the end of each day of data collection, data was reviewed by Supervisors before being uploaded to the server. All State Supervisors provided interim reports on the survey's progress, including quotas achieved by typology. The research team provided constant support to State Supervisors and Data Collectors throughout the data collection phase. The research team monitored the quality of the work. This was done by reviewing the data from the server's backend. Support was provided to field teams via in-person supervision, as well as by phone, and e-mail. Study States were assigned a team of Data Collectors proportional to the number of PLHIV respondents allocated to each State. The State Supervisors provided direct monitoring of the process.

Ethics

Ethical approval for the Study was obtained from the National Health Research Ethics Committee (NHREC) Nigeria prior to the commencement of the survey.

Results

Socio-demographics

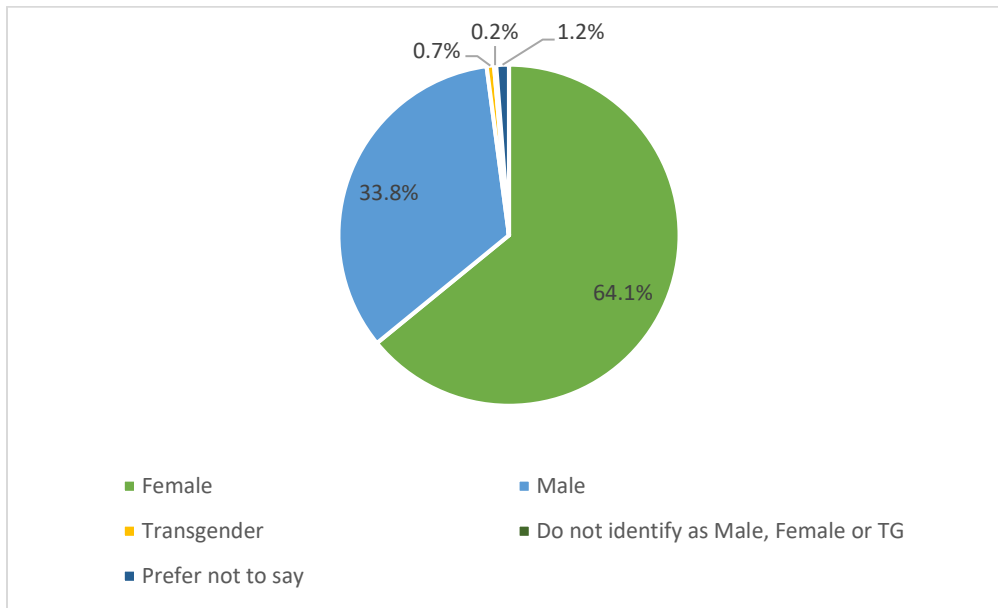
1,240 PLHIV participated in the PLHIV Stigma Index Survey. 802 (64.7%) were females, while 438 (35.3%) were males. Of this population, 161 (13.0%) were female sex workers, 81 (6.5%) were men who have sex with men, while 4.6% were people who use drugs. Enrolment achievement by region showed 427 (34.4%) of the sample size population was from the South-South region of the country, as shown in Table (1) below. Most of the participants - 412 (33.2%) were aged 35 – 44, and majority of this number were females, while over two-third of both female and male participants (75.5% and 71.8%) indicated that they were involved in an intimate/sexual relationship. Participants' current gender identity is categorized in figure (1) below:

Table 1: Enrolment Achievement by Typology and Region, Age & Support Group membership

Characteristics	Male (n=438)	Female (n=802)	N=1240
Enrollment by Typology			
PLHIV (non-KP)	33.3%	66.8%	75.9%
FSW	0.0%	13.0%	13.0%
MSM	6.5%	0.0%	6.5%
PWUDs	68.4%	31.6%	4.6%
Enrollment by Region			
North-East	42.2%	57.8%	5.2%
South-East	29.1%	70.9%	18.6%
South-West	36.4%	63.6%	13.1%
South-South	36.8%	63.2%	34.4%
North-West	52.1%	47.9%	7.9%
North-Central	29.7%	70.3%	20.9%
Age			
18 - 24	11.4%	5.9%	7.8%
25 - 34	34.7%	27.9%	30.3%
35 - 44	17.4%	41.9%	33.2%
45 - 54	23.1%	20.8%	21.6%
≥55	13.5%	3.5%	7.0%
Gender	64.7%	35.3%	100%
Intimate/Sexual Relationship			
Yes	75.5%	71.8%	73.1%
No	24.5%	28.9%	26.9%

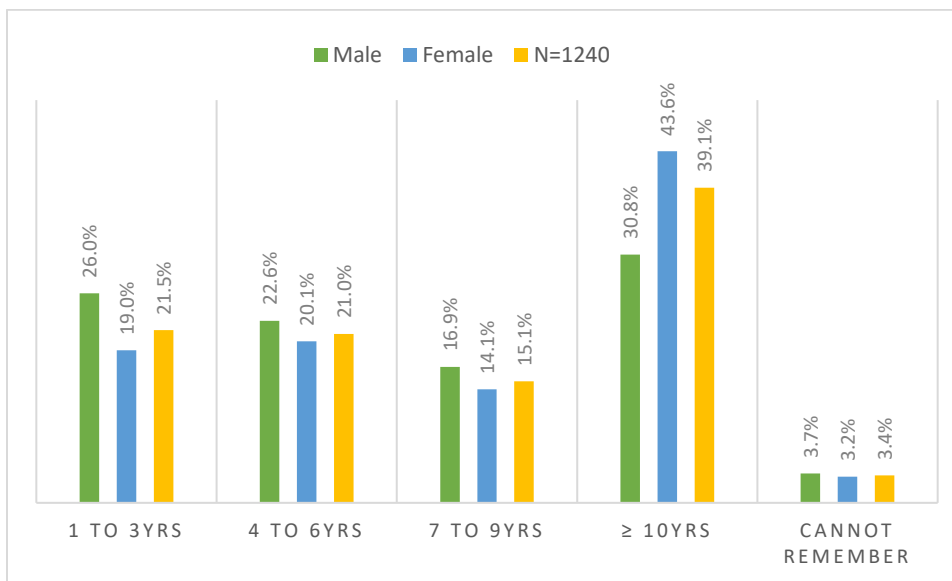


Figure (1): Participants current gender identity



On HIV status awareness, 350 (43.6%) female participants and 135 (30.8%) male participants reported that they have been aware of their status for 10 years and above. Figure (2) below, represents a breakdown of participants' proportions by duration of HIV status awareness.

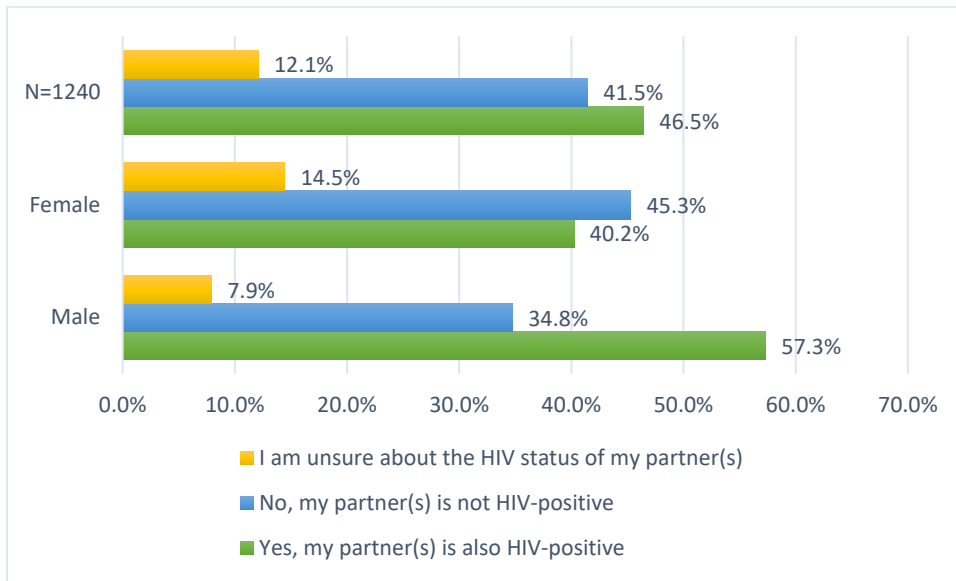
Figure 2: Duration of HIV status awareness



Out of the number that reported they were involved in intimate/sexual relationships, 419 (46.5%) reported that their partner were also HIV-positive, while 109 (12.1%) participants were unsure about the status of their partners.

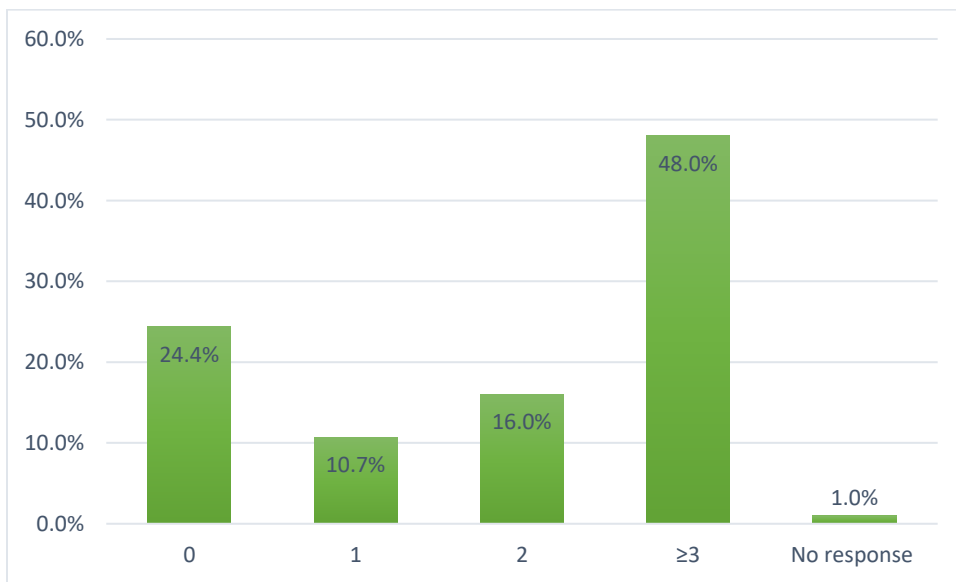


Figure 2b: Partner's HIV Status



Regarding number of children living in household that the participants take care of, 595 (48.0%) participants reported having at least 3 children living in the same household, while 302 (24.4%) participants reported having no children in their home for which they were responsible for.

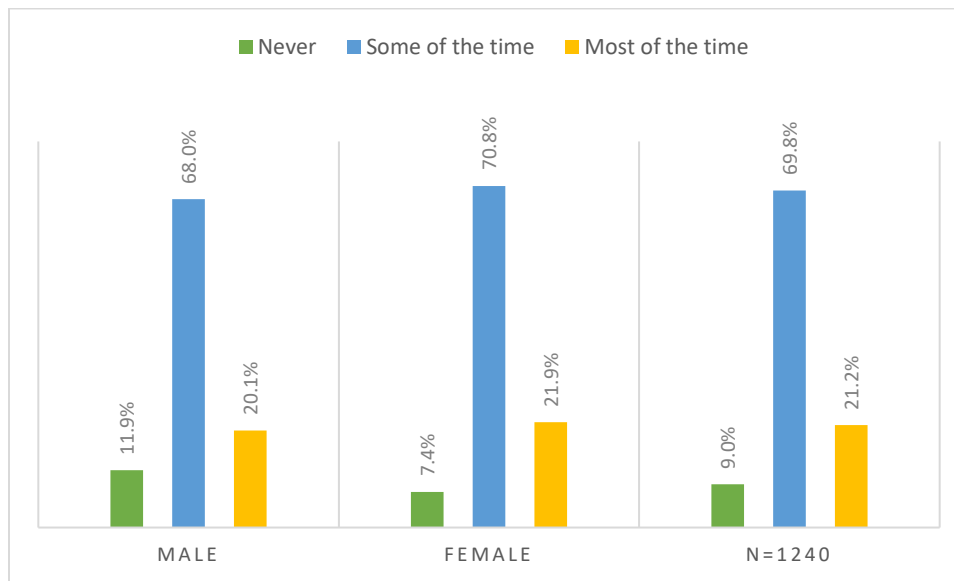
Figure 3: Participants number of children in household



More so, the study also considered participants' ability to meet their basic needs. 111 (9.0%) participants reported they were always able to meet their basic needs in the last 12 months, 865 (69.8%) participants were unable to meet their basic needs sometimes, and 263 (21.2%) participants were unable to meet their basic needs most of the time.



Figure 4: Participants' ability to meet basic needs



In relation to educational status, 48 (3.9%) of the participants had no formal education, while 1,191 (96.1%) had some formal education. The greatest proportion of participants came from those with secondary/high school as their highest level of education (45.3%). Regarding work status, over two-third of the participants 955 (70%) were employed, 19 (1.5%) were retired, and 266 (21.5%) were unemployed. Table 2 below provides a sub-category breakdown of participants' highest level of education and work status.

Table 2: Participants highest level of Education and Work status

Characteristics	Male (n=438)	Female (n=802)	N=1240
Highest level of formal Education			
No formal education	3.4%	4.1%	3.9%
Primary/elementary/local equivalent	9.4%	12.2%	11.2%
Secondary/high school/local equivalent	40.5%	47.9%	45.3%
Trade/vocational school	3.7%	3%	3.3%
University/tertiary education	43%	32.7%	36.3%
Current work status			
In full-time work (as an employee)	18.3%	15.7%	16.6%
In part-time work (as an employee)	19.4%	23.1%	21.7%
Self-employed or business owner	20.6%	17.8%	18.8%
Self-employed or paid work for others)	16.4%	21.7%	19.8%
Retired/on pension	3.9%	0.3%	1.5%
Unemployed	21.5%	21.5%	21.5%

All 1,240 respondents were asked if they were members of different minority groups. 443 (35.8%) reported that they belonged to a racial, ethnic, or religious minority group. 358 (28.9%) participants were members of indigenous/aboriginal groups. 58 (4.7%) participants were living with disability. 25 (2.0%) participants were refugees or asylum seekers. 24 (1.9%) participants were migrant workers. 22 (1.8%) participants were



internally displaced persons, and 10 (0.8%) participants preferred not to say. 7 (0.6%) respondents reported they were incarcerated/in prison.

Table 3: Participants' Membership of Marginalized Group

Characteristics	Yes	No	Prefer not to say
Member of a racial, ethnic, or religious minority	35.8%	63.0%	1.2%
Member of an indigenous/aboriginal group	28.9%	70.0%	1.1%
Living with disability	4.7%	94.6%	0.7%
Refugee or asylum seeker	2.0%	97.0%	0.7%
Migrant worker	1.9%	96.6%	1.5%
Internally displaced person	1.8%	97.4%	0.8%
Incarcerated/in prison	0.6%	98.8%	0.7%

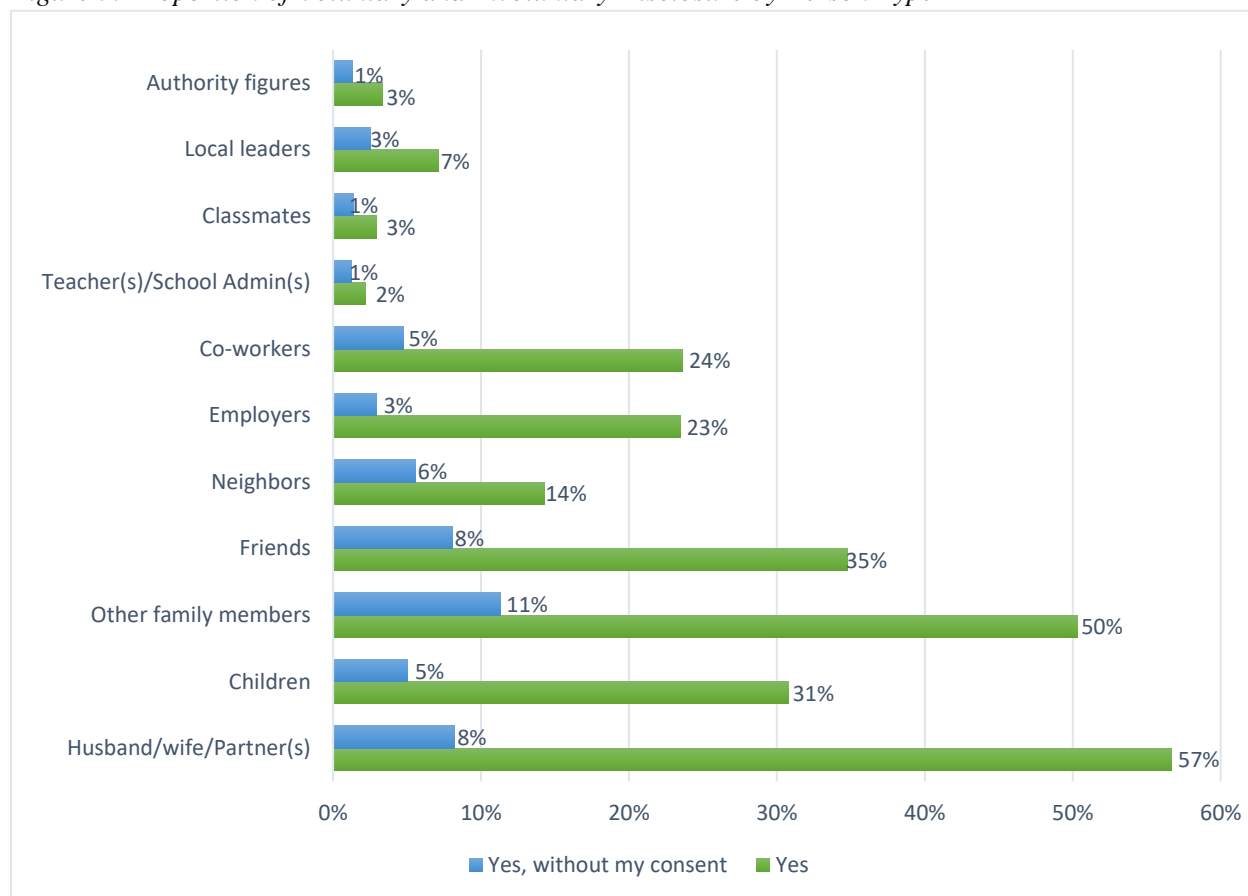
Disclosure

Figure 6 highlights the types of people who know about participants' HIV status whether voluntary and involuntary. Of the 997 (80.5%) participants who reported that they have disclosed their HIV status, 242 (19.5%) reported that their status was disclosed without their consent. About 140 (11.3%) participants reported that their status was disclosed to other family members without their consent. Other high proportion of involuntary status disclosure occurred among friends (8.1%), neighbors (5.6%) and co-workers (4.8%).

Over 25% of both female sex workers (FSWs) and men who have sex with men (MSM) experienced HIV status disclosure without their consent.



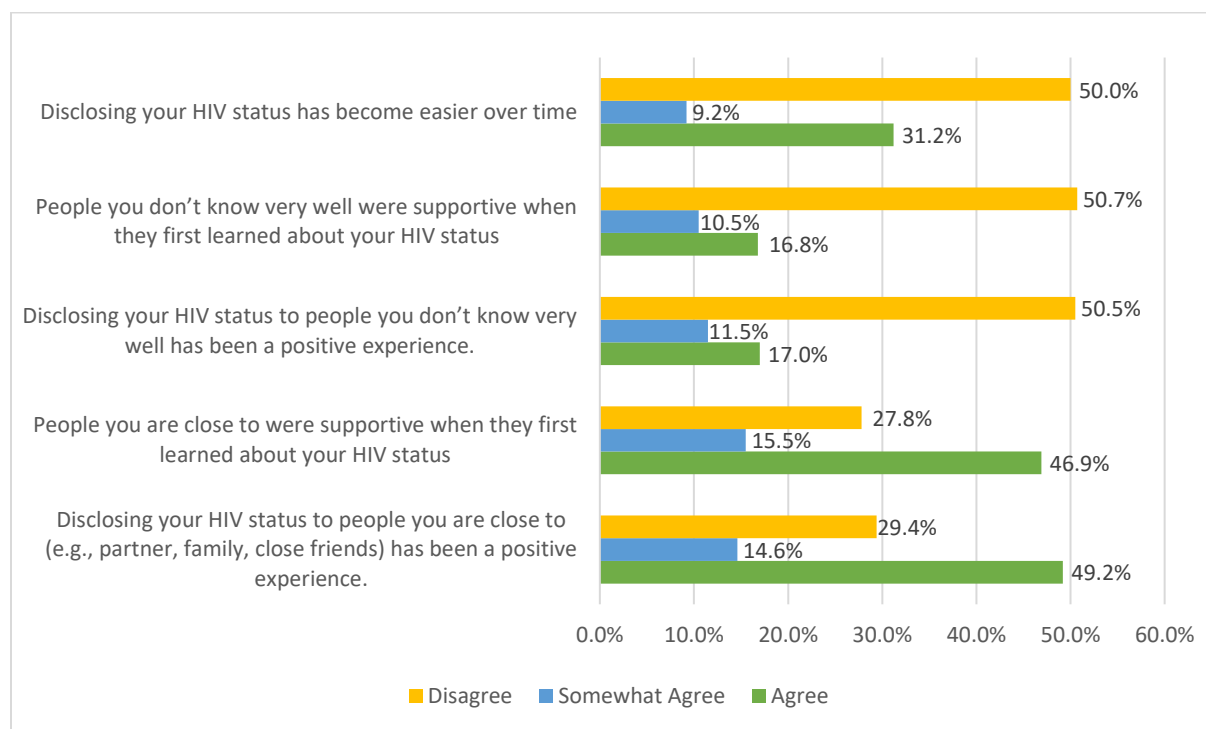
Figure 5: Proportion of Voluntary and Involuntary Disclosure by Person Type



When asked about their experiences when disclosing their HIV status to people they were close to, 610 (49.2%) participants said it has been a positive experience, 181 (14.6%) somewhat agreed with them and 364 (29.4%) participants disagreed that it has been a positive experience. 581 (46.9%) respondents said they got support from people they were close to on learning their status, 192 (15.5%) somewhat agreed with them, and 345 (27.8%) participants disagreed that the people were supportive. 211 (17%) agreed that disclosing their HIV status to people they did not know very well had been a positive experience, 142 (11.5%) somewhat agreed, and 626 (50.5%) disagreed. 208 (16.8%) participants agreed that people they did not know very well were supportive when they first learnt about their HIV status, 130 (10.5%) somewhat agreed, and 273 (22%) participants disagreed. 386 (31.2%) participants agreed that disclosing their HIV status had become easier over time, 114 (9.2%) somewhat agreed, and 619 (50%) disagreed that disclosing their HIV status had become easier over time.



Figure 6: Participants Experience Disclosing HIV Status



Experience of Stigma and Discrimination

When analyzing the burden of stigma and discrimination faced by PLHIV due to their HIV status, it was observed that 24.7% of the female participants have experienced one form of stigma and discrimination within the last 12 months, while 22.6% indicated yes to ever experiencing one form of stigma and discrimination. Among key populations, majority of PWUDs (26.3%) have experienced one form of stigma and discrimination within the last 12 months, as shown in table (6) below. The stigma and discrimination issues considered included exclusion from social gatherings, religious or family activities; discriminatory remarks or gossiping; verbal or physical harassment; blackmail; denial of job or income because of their HIV status.

All PLHIV age bands reported experiencing some form of stigma and discrimination. Adults aged between 35-44 (24.5%) experienced some form of stigma and discrimination within the last 12 months, while the younger adults, aged 18-24 (21.7%) reported experiencing some form of stigma and discrimination within the last 12 months.

Table 4: Proportion of Respondents who have experienced Stigma and Discrimination due to HIV status by Typology, Age Group and Region

Characteristics	Yes, within 12 months	Yes, not within 12 months
Typology		
PLHIV (non-KP)	20.3%	23.3%



PWUDs	26.3%	26.3%
MSM	30.9%	19.8%
FSW	24.2%	25.5%
Gender		
Male	20.5%	20.3%
Female	24.7%	22.6%
Age		
18 - 24	21.7%	8.3%
25 - 34	23.7%	22.3%
35 - 44	24.5%	26.2%
45 - 54	16.0%	25.0%
≥55	19.5%	23.0%
Region		
North-East	37.5%	26.6%
North-West	14.4%	8.3%
North-Central	33.3%	47.5%
South-East	20.4%	20.9%
South-South	15.3%	9.4%
South-West	21.0%	30.9%

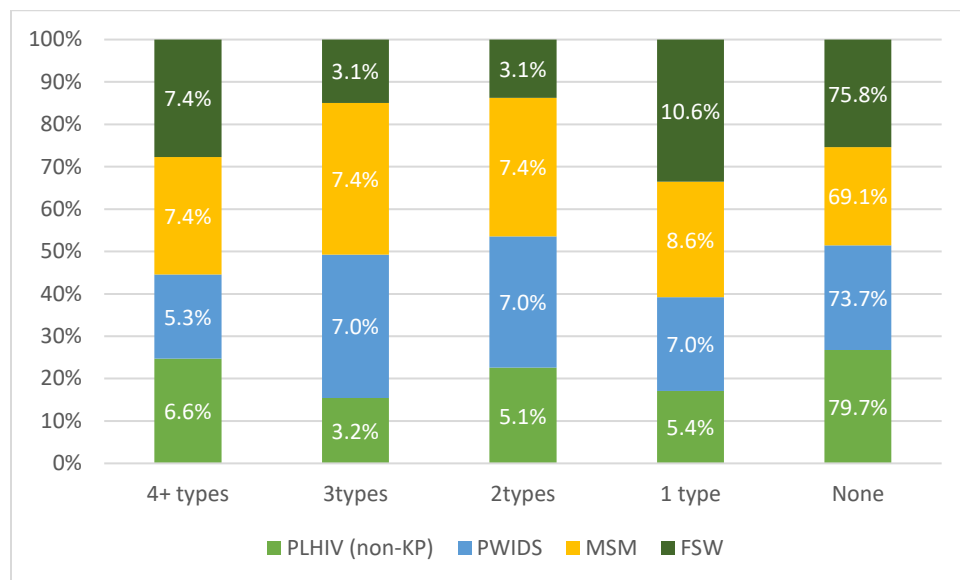
When looking at how PLHIV experience stigma and discrimination due to their HIV status, it differs by other intersectional identities. As shown in Figure 7, people who have ever sold sex reported experiencing proportionately more forms of discrimination within the past 12 months, due to their HIV status when compared with people not in any of the key populations. The same holds true for transgender and nonbinary people, MSM, and FSW, though to a somewhat lesser extent than for people who have ever sold sex.

PWIDs and MSM (26% and 31% respectively) experienced HIV-related stigma and discrimination in the last 12 months in greater proportions in comparison to other groups.

Looking at how PLHIV experienced stigma and discrimination due to HIV status within the last 12 months, it differs across typology as shown in table (11) below. MSM and FSW at 7.4% each, reported experiencing more forms of discrimination within the past 12 months due to their HIV status when compared with PLHIV (non-KP). The same observation holds for PWUDs, although to a somewhat lesser extent than MSM and FSW.



Figure 7: Number of forms of Stigma and Discrimination Experienced within the last 12 months across different groups/typology.



Many participants reported that the most occurring type of stigma and discrimination they faced were use of words, either by gossips, discriminatory remarks, verbal abuse, blackmail, etc. These were the top categories for types of stigma and discrimination respondents faced.

North-East and North Central reported experiencing the greatest proportion of stigma and discrimination within the last 12 months.

Verbal abuse, discriminatory remarks, and gossiping were reported as the most reoccurring type of stigma and discrimination experienced by PLHIV.

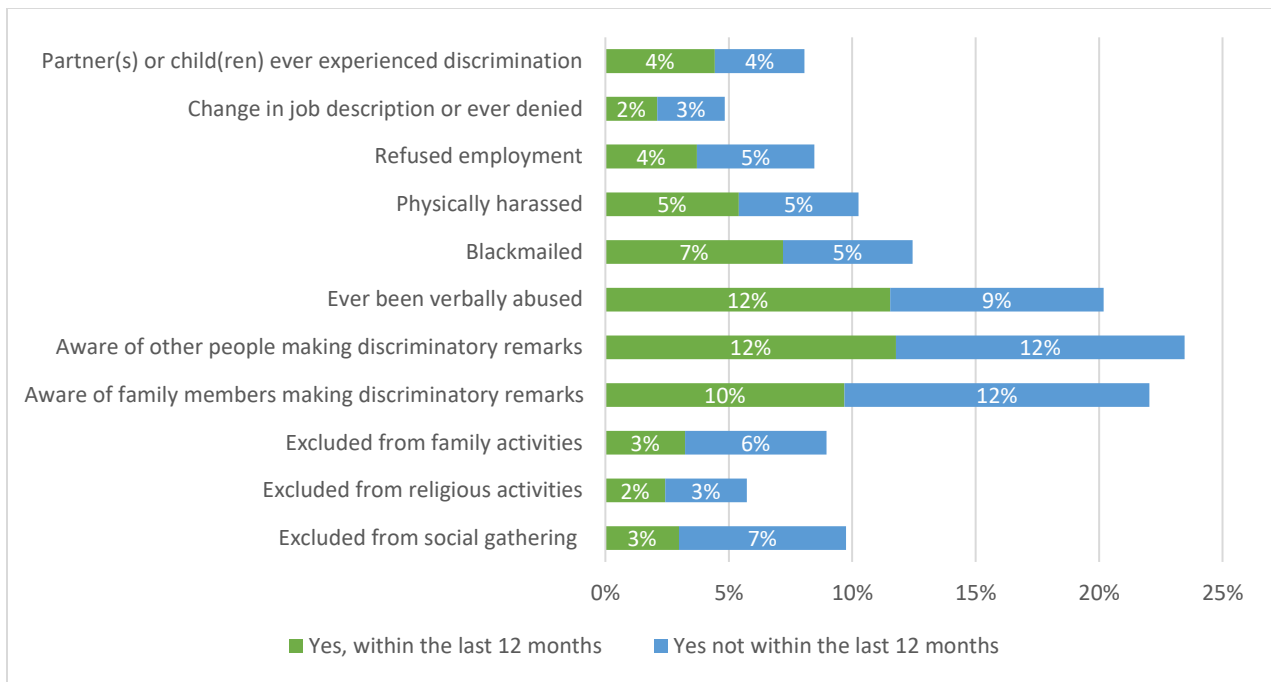
The most common forms of stigma and discrimination were use of words either by gossips, discriminatory remarks, and verbal harassment. Physical harassment was reported by 67 (5.4%) within 12 months and 60 (4.9%) beyond the last 12 months. The participants also identified some form of stigma and discrimination which had to do with their employments and exclusion from activities or social gatherings. 55 (4.4%) participants reported their partners or children have experienced discrimination within the last 12 months, and 45 (3.6%) beyond 12 months.

Most respondents from the FGDs indicated that they were victims of stigma and social abuse from family members, friends, neighbors, and colleagues. Many reported that they were being avoided, and have lost jobs and other opportunities due to their HIV status.

"Most people die not because of the virus but because of the stigma". – FGD Respondent (Gen Pop)

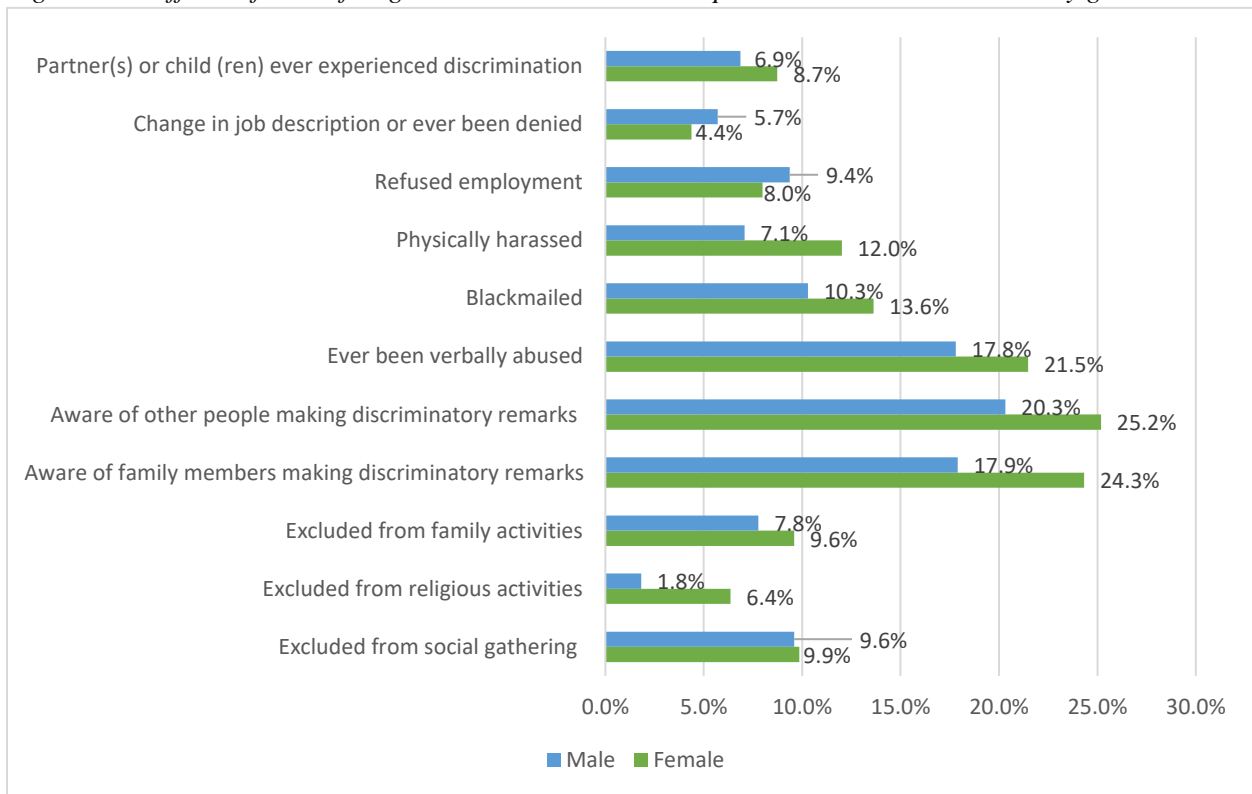
"I couldn't tell anyone because if I did, the stigma would be unbearable. I had to change my school, and my parents are still not aware of my status". – FGD Respondent (Adolescent and Young People Group)

Figure 8: Different forms of Stigma and Discrimination Experienced due to HIV Status.



Other forms of abuse experienced in higher proportion, compared to the male participants include discriminatory remarks by family members and other individuals, verbal abuse and blackmail, as shown in figure (8b) below

Figure 8b: Different forms of Stigma and Discrimination Experienced due to HIV Status by gender



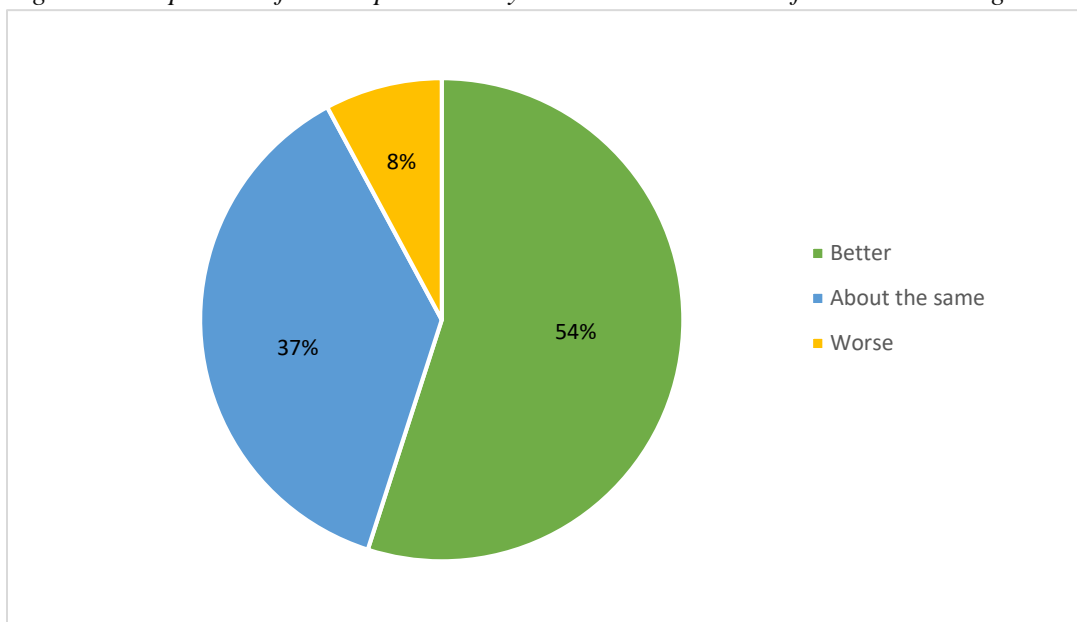
Internalized Stigma

The survey explored participants' ability to meet their needs before 12 months ago in comparison to within the last 12 months. Participants indicated whether their ability to meet these needs had been worse, better or about the same. More than half of the participants, 671 (54.2%) reported having a better ability to meet their needs before the last 12 months, 96 (7.8%) participants reported having worse ability to meet their emotional needs before the last 12 months, as shown below.

54.2% of respondents reported that their ability to meet emotional needs since being diagnosed was better for outside the 12 months than within the last 12 months.

Self-exclusion from social interactions (10.6%) and abstinence from sex (11.9%) were the most reoccurring self-stigmatizing actions taken against PLHIV because of their status.

Figure 9: Proportion of Participants ability to Meet their Needs before 12 months ago



More than two-third (75.6%) of the participants agreed that they find it difficult to tell people about their HIV status, while 15.2% reported that they feel dirty about their HIV status. Other participants in some category agreed that their HIV status makes them feel guilty, ashamed, or worthless, as shown below. Furthermore, 32.3% of the female participants agreed that they feel guilty of their HIV status, as opposed to the male participants 31.7%. Over two-third of male and female participants agreed that they find it difficult to disclose their status to people, as shown in the table below.

Table 5: Participants' Agreement with indicators of Internalized Stigma by gender

Characteristics	Male		Female	
	Agree	Disagree	Agree	Disagree



Difficult to tell people that I am HIV positive	74.1%	25.9%	76.43%	23.6%
Being HIV positive makes me feel dirty	16.0%	84.0%	14.7%	85.3%
Feel guilty that I am HIV positive	31.7%	68.4%	32.3%	67.7%
Ashamed that I am HIV positive	30.2%	69.8%	32.0%	68.0%
Sometimes feel worthless because I am HIV positive	24.5%	75.5%	24.0%	76.0%
Hide my HIV status from others	65.8%	34.3%	65.9%	34.1%

In trying to decipher the ability of PLHIV to meet emotional needs, the study found that majority of the participants reported that their HIV status have not affected them across all categories. 105 (9.3%) participants claimed that their ability to practice their religion/faith has been negatively affected due to their HIV status, while 161 (13.0%) have been affected positively by their desire to have children. Less than one-third (21.8%) of the participants also reported that their ability to secure a relationship has been affected negatively due to their HIV status over the past 12 months, while 19% of the participants reported that their self-confidence had been affected positively because of their HIV status over the past 12 months. Other categories considered in this measure of resilience includes ability to find love, ability to achieve personal/professional goals, and ability to contribute to the community, as shown in table (6) below.

Table 6: Degree to which Participants' Ability to Meet Emotional Needs is affected by their HIV status over the past 12 months

Characteristics	Positively affected	Not been affected	Negatively affected	N/A
My self-Confidence	19.0%	56.3%	20.7%	4.0%
My self-respect	18.1%	63.7%	14.3%	3.9%
Ability to respect others	17.3%	70.9%	7.6%	4.2%
Ability to cope with stress	15.3%	59.1%	21.4%	4.2%
Ability to have secure relationships	15.1%	58.3%	21.8%	4.8%
Ability to find love	15.8%	57.0%	19.9%	7.3%
Desire to have children	13.0%	59.3%	14.6%	13.0%
Achieve personal/professional goals	15.0%	62.7%	16.1%	6.1%
Ability to contribute to community	15.1%	65.8%	12.3%	6.8%
Practice a religion/faith as I want to	15.5%	69.8%	9.3%	5.4%

Out of 1,240 respondents that were asked about actions they took because of self-stigmatization, 116 (9.4%) reported that they had chosen not to attend social gatherings, of which 73 participants were women. 84 (6.8%) participants avoided going to the hospital when they needed to, 99 (8.0%) participants chose not to apply for jobs, 74 (6.0%) participants chose not to seek social support, 131 (10.6%) participants isolated

themselves from family and friends, and 108 women out of 147 (11.9%) participants decided not to have sex.

"When I was diagnosed, my world crumbled, and I became suicidal as I was confused as to how I became infected" – FGD Respondent. (FSW)

"I went for an occasion, and I was asked to share food. On the process of sharing, one of the women in the setting, told me to stop sharing the food. Though she didn't say because of HIV, but I believed it's because she knows my status." - Survey Respondent (Benue)

Table 7: Self Stigmatizing Action Taken because of HIV Status by gender in the past 12 months

Characteristics	Female (n=802)	Male (n=438)	N=1240
Chosen not to attend social gatherings	9.1%	9.8%	9.4%
Avoided going to a clinic/hospital when I needed to	6.4%	7.5%	6.8%
Chosen not to apply for a job(s)	8.5%	7.1%	8.0%
Chosen not to seek social support	6.0%	6.0%	6.0%
Isolated myself from family and/or friends	10.9%	10.1%	10.6%
Decided not to have sex	13.6%	8.9%	11.9%

The study considered participants' agreement with measures of internalized stigma extent. It was reported that 936 (75.6%) participants found it difficult to tell people that they were HIV positive, and 812 (65.9%) participants hid their HIV status from others. However, fewer participants 188 (15.2%) agreed that being HIV positive made them feel dirty. 396 (32.1%) participants said they felt guilty that they were HIV positive, while 388 (31.4%) participants were ashamed that they were HIV positive. Also, 299 (24.2%) participants reported that they sometimes felt worthless because they were HIV positive.

Interactions with Healthcare system

HIV Testing and Treatment

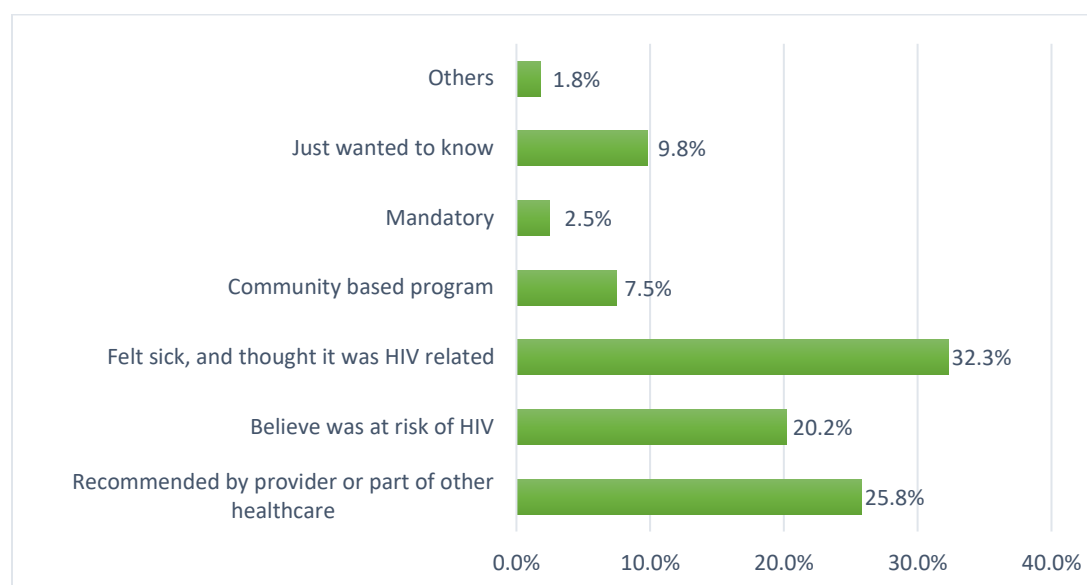
Participants who made a self-decision to be tested were 923 (74.4%). 115 (9.3%) participants reported they were pressured into getting tested for HIV, 175 (14.1%) participants reported they were tested without their knowledge and only found out after the test was conducted. 17 (1.4%) participants reported they were forced to take the HIV test. 10 (0.8%) participants reported they were born HIV positive. Additionally, participants who indicated it was their own choice to get tested for HIV were then asked how long it took them to make up their minds to get tested for HIV. 664 (64.0%) participants reported it was 6 months or less, while two third (23.1%) of the participants reported that it was over 6 months before making up their minds. 555 (53.3%) participants said the reason for their hesitation to get tested was caused by the fear of how other people would respond to their result outcome. More so, 268 (25.8%) participants said the test was recommended by provider or part of other healthcare, while 26 (2.5%) said the test was mandatory, as shown in figure (10).

Only 64% of the respondents reported that they got tested within 6 months of considering it.

Only 42% of respondents opted to commence treatment immediately after being diagnosed with HIV.



Figure 10: Reasons for getting tested for HIV.



Regarding commencing treatment, participants were asked about the reasons why they hesitated, delayed, or were prevented from initiating care or treatment for HIV. 472 (38.1%) said they were worried their partner/family/friends would find out, 363 (29.4%) participants reported they were worried other people who are not family/friends would find out. 291 (23.5%) participants were afraid of bad treatment from healthcare workers or disclosing their status without consent. 179 (14.5%) participants reported they delayed because they have had bad experiences with healthcare workers previously.

Among the 1,213 participants that responded if they have ever been on treatment, the study asked the reasons for starting HIV ARV treatment; 1,091 (89.9%) reported they were told the benefit and they chose to start it when it was offered to them. 85 (7.0%) reported they decided to wait and start later when the treatment was offered to them, 20 (1.7%) said they felt pressured or forced by health care staff to start the treatment, and 17 (1.4%) said they started the treatment for other reasons. The study also assessed the interval between HIV diagnosis and commencement of treatment. As shown in the table below, majority (42.6%) of participants started ART immediately after their HIV positive diagnosis.

Table 8: Period from time of HIV diagnosis to Treatment

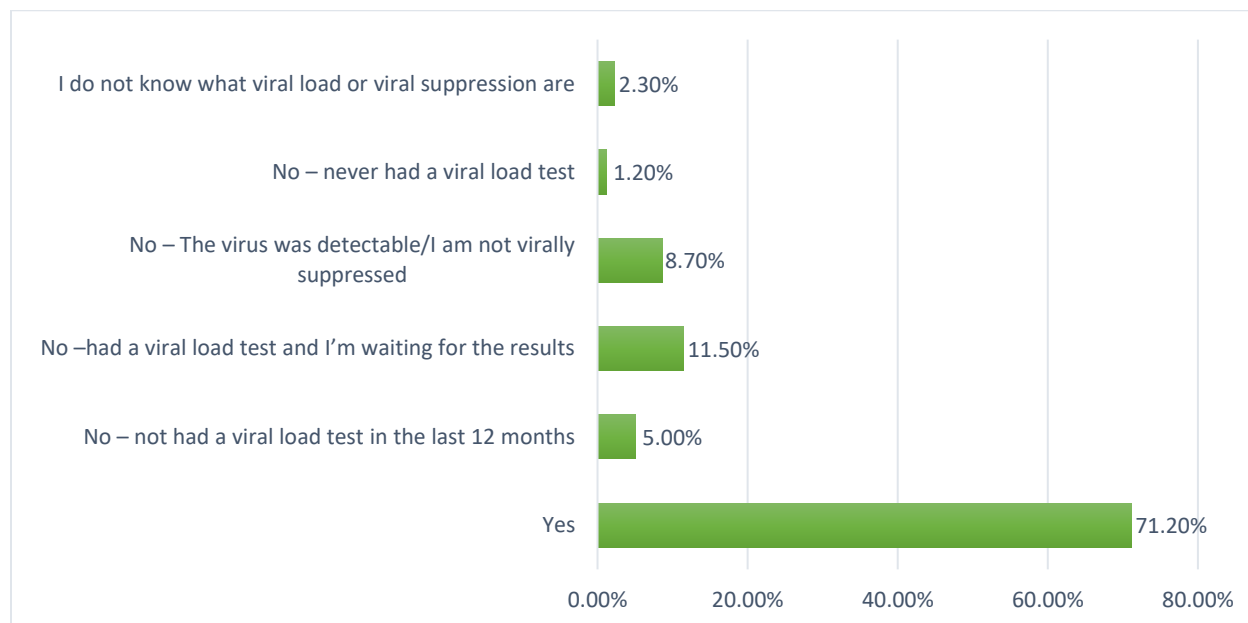
Characteristics	Number	Proportion
Immediately	517	42.6%
>1 day to 1 month after diagnosis	338	27.9%
>1 month to 6 months after diagnosis	181	14.9%
>6 months to 2 years after diagnosis	88	7.3%
>2 years after diagnosis	68	5.6%
I cannot remember	21	1.7%



Interaction with Healthcare Services

More than two-third (71.2%) of the participants responded that their most recent viral load test was undetectable in the last 12 months, while 28 (2.3%) do not know what viral load or viral suppression is, as shown in the figure below.

Figure 11: Viral Load Detection for Most Recent Viral Load Test



Regarding stopping or interruption of treatment, 143 (11.8%) participants reported they have ever stopped or interrupted their treatment. Treatment interruption or stoppage was largely (43.1%) due to worry about someone else finding out their HIV status. Other reasons for treatment interruption are depicted in the chart below.

Table 9: Reasons for stopping HIV treatment

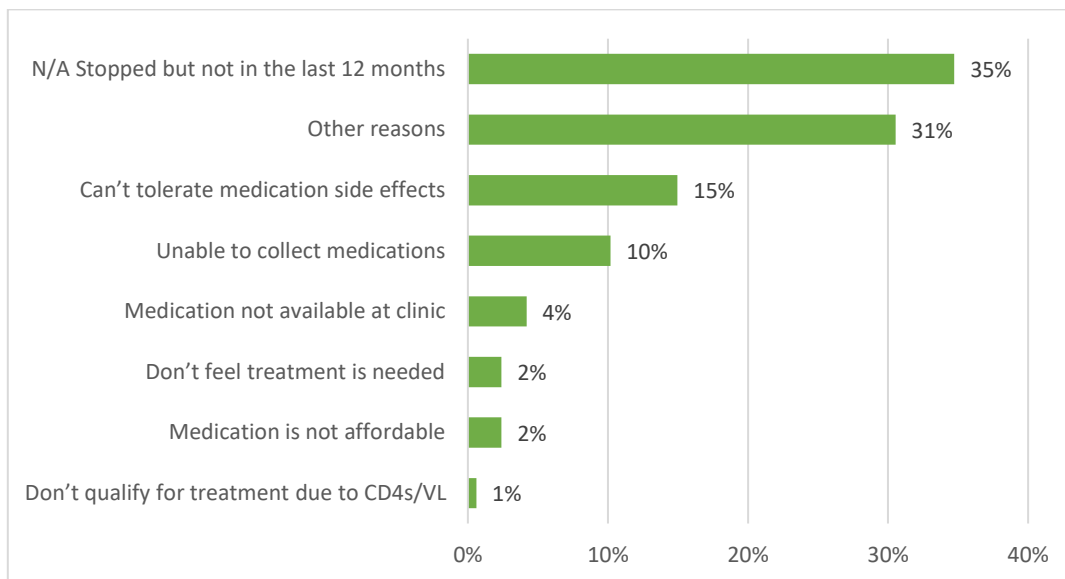
Characteristics	Number	Proportion
Worried that someone would find out my HIV status	62	43.4%
Not ready to deal with my HIV infection	12	8.4%
Worried the healthcare workers would treat me badly or disclose my HIV status without my consent	2	1.4%
Denied HIV treatment due to currently using drugs	0	0.0%
N/A- not been taking HIV treatment in the last 12 months or I have not stopped taking HIV treatment in the last 12 months	15	10.5%
Other reasons	53	36.4%

One hundred and sixty-seven (167) participants responded on non-stigma related reason for not currently taking HIV treatment or ever stopping it. Four (2.4%) reported the medication is not affordable, same proportion (2.4) reported that they did not feel the need for treatment, 17 (10.2%) said they were unable to collect medications at the clinic, 25 (15%) participants said they could not tolerate the side effects of the



medication, while other reasons mentioned by participants include travelled out of clinic location, lack of transport to visit the facility to collect their drugs, or resolved to herbal medicine.

Figure 12: Main non-Stigma related Reason for not currently taking ART.



Respondents were asked about their general health description, 1,099 (88.7%) reported they were in good state of health, 130 (10.5%) participants described their health as fair, and 10 (0.8%) participants reported their health to be in a poor state. The survey investigated the diagnosis of other diseases/conditions with HIV/AIDS. With 175 respondents (14.2%), opportunistic infections were the most reported to have been diagnosed, closely followed by sexually transmitted infections (12.4%), mental health conditions (7.3%), tuberculosis (5.5%), non-communicable diseases (5.1%), viral hepatitis (2.6%), and alcohol/drug dependency syndrome (2.4%). Among those diagnosed, 24.9% reported to have been offered treatment for these conditions, while 14.9% did not take any medication or treatment. An overwhelming population of respondents (60.2%) reported that they were not diagnosed with any of the conditions.

Table 10: General Health Condition and Disease Diagnosis.

Characteristics	Number	Proportion
General Health Description		
Good	1,099	88.7%
Fair	130	10.5%
Poor	10	0.8%
Diagnosis with other Disease Conditions		
Tuberculosis	68	5.5%
Viral hepatitis	32	2.6%
Sexually transmitted infections	153	12.4%

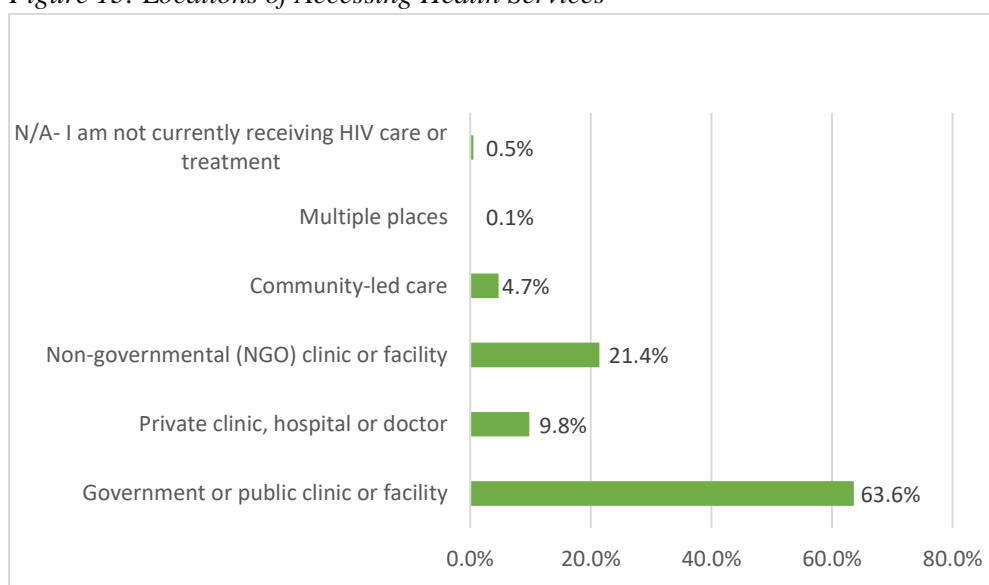


Mental Health Condition	91	7.3%
Non-communicable diseases	63	5.1%
Opportunistic Infections	175	14.2%
Alcohol/drug dependency syndrome	29	2.4%

Service Delivery Experience

More than half of the participants 788 (63.8%) confirmed that they received HIV care and treatment from Government/Public clinics and facilities, while 265 (21.4%) receive HIV care and treatment from NGO clinic or facilities. Only 1 (0.1%) reported receiving treatment from multiple places, while 6 (0.5%) reported that they are not currently on treatment.

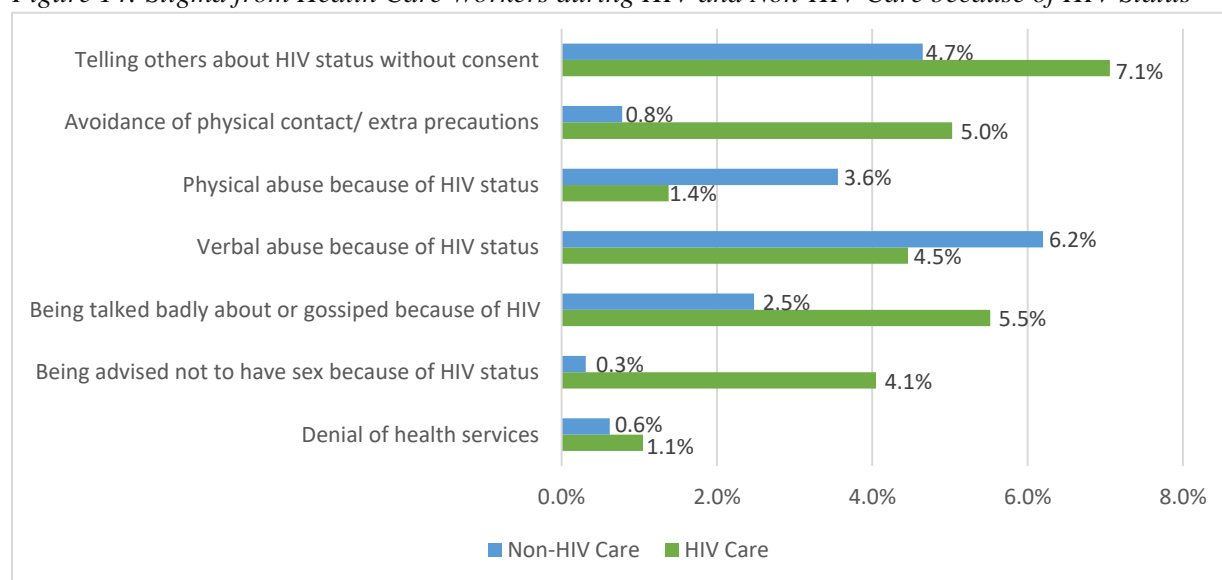
Figure 13: Locations of Accessing Health Services



When asked about stigma experienced from health facility staff because of their status when seeking HIV specific health care, 1.1% of participants reported denial of health services due to HIV care against 0.6% who reported denial of health services due to non-HIV care. Telling others about HIV status without consent was most common among 7.1% of the participants, as shown in figure (17).



Figure 14: Stigma from Health Care Workers during HIV and Non-HIV Care because of HIV Status



1 out of 4 participants (25%) of the total population) confirmed that their status was known to other individuals outside the facility (Clinic) where they received HIV care and treatment. Many of the respondents (1,020), accounting for 82.3% of the total interviewee population were confident that their medical records were kept confidential. 204 PLHIV (16.5%) were unconvinced and the remaining 1.3% claimed that their medical records were not safeguarded.

Sexual and Reproductive Health

The tables below present occurrences of negative actions of health workers towards PLHIV and female PLHIV by region. The most reoccurring action on PLHIV were health workers advising them not to mother/father a child because of their status. For actions on female PLHIV, the most reoccurring action was from health workers pressuring them to take HIV ART during pregnancy. Health worker action for both PLHIV and female PLHIV occurred the most in the South-South. No health worker action was reported in the North-West region for both PLHIV and female PLHIV.

;Table 11: Actions of Health Worker on PLHIV due to their HIV Status

Characteristics	North-East	North-Central	North-West	South-East	South-South	South-West	Total
Advised you not to mother/father a child	1	5	0	1	2	3	12 (1%)
Pressured or incentivized to get sterilized	0	0	0	0	3	1	4 (0.3%)
Sterilized you without your knowledge or consent	0	0	0	0	2	0	2 (0.2%)
Denied your contraception/family planning services	0	0	0	0	0	1	1 (0.1%)
Told you that you had to use contraception to get your HIV ART	0	1	0	0	0	1	2 (0.2%)

Table 12: Actions of Health Workers on Female PLHIV due to HIV Status within the last 12 months

Characteristics	North-East		North-Central		North-West		South-East		South-South		South-West		Total
	Yes	Yes ever	Yes	Yes ever	Yes	Yes ever	Yes	Yes ever	Yes	Yes ever	Yes	Yes ever	
Advised you to terminate a pregnancy	1	0	0	2	0	0	0	1	3	5	0	2	14 (1.8%)
Pressured you to use a specific type of contraceptive method	0	1	3	3	0	0	0	2	1	2	0	1	13 (1.6%)
Pressured you to use a particular method of giving birth/delivery option	0	0	1	6	0	0	0	0	1	5	2	8	23 (2.9%)
Pressured you to use a particular infant feeding practice	1	2	0	13	0	0	2	5	5	5	1	9	43 (5.4%)
Pressured you to take HIV ART during pregnancy	1	2	1	19	0	0	1	7	18	7	3	6	65 (8.1%)

Human Rights and Effecting Change

39 (3.2%) participants reported rape as the most common violation of human rights, of which 28 of these participants were women. 18 (1.5%) participants were forced to disclose their status during immigration screening exercises in the past 12 months and beyond, while 26 participants reported being forced to get tested for HIV or status disclosure to apply for a job or get a pension plan. Other categories are highlighted in the table (13) below:

"When I lost my husband, his brother started making sexual advances towards me. I refused and he threatened me violently. I had to move to another apartment because of his threats." – FGD Respondent (Gen Pop)

Table 13: Participants Experiences of Human Right Abuses

Characteristics	Female	Male	Total
Forced get tested for HIV or disclose my status to obtain a visa or to apply for residency/citizenship	10	8	18 (1.5%)
Forced to get tested for HIV or disclosure my status to apply for a job or get a pension plan	16	10	26 (2.1%)
Forced get tested for HIV or disclose my status to attend an educational institution or get a scholarship	9	7	16 (1.3%)

Forced get tested for HIV or disclose my status to get health care services	8	9	17 (1.4%)
Forced get tested for HIV or disclose my status to get medical insurance	6	7	13 (1.1%)
Arrested or taken to court on a charge related to my HIV status	6	2	8 (0.7%)
Detained or quarantined because of my HIV status.	7	3	10 (0.8%)
Denied a visa or permission to enter another country because of my HIV status	5	4	9 (0.7%)
Denied residency or permission to stay in another country because of my HIV status	7	4	11 (0.9%)
Forced to disclose my HIV status publicly or my status was publicly disclosed without my consent	18	5	13 (1.1%)
Forced to have sex	28	11	39 (3.2%)
Denied access to a domestic violence shelter.	13	5	18 (1.5%)
Partner's prevention from accessing (public/private/community-led) health services	10	2	12 (1%)

Many respondents (89.1%) from the survey claimed that their rights had never been infringed. Of the population who experienced abuse of their rights, only 32 (2.59%) participants sought redress, while 103 (8.3%) respondents opted not to. Among the PLHIV who sought corrective action to the abuse they received, 16 (50 %) reported that they filed complaints, 2 (6.3%) spoke out publicly while some of them reported that they contacted a Lawyer, or a government official, as shown below in figure15

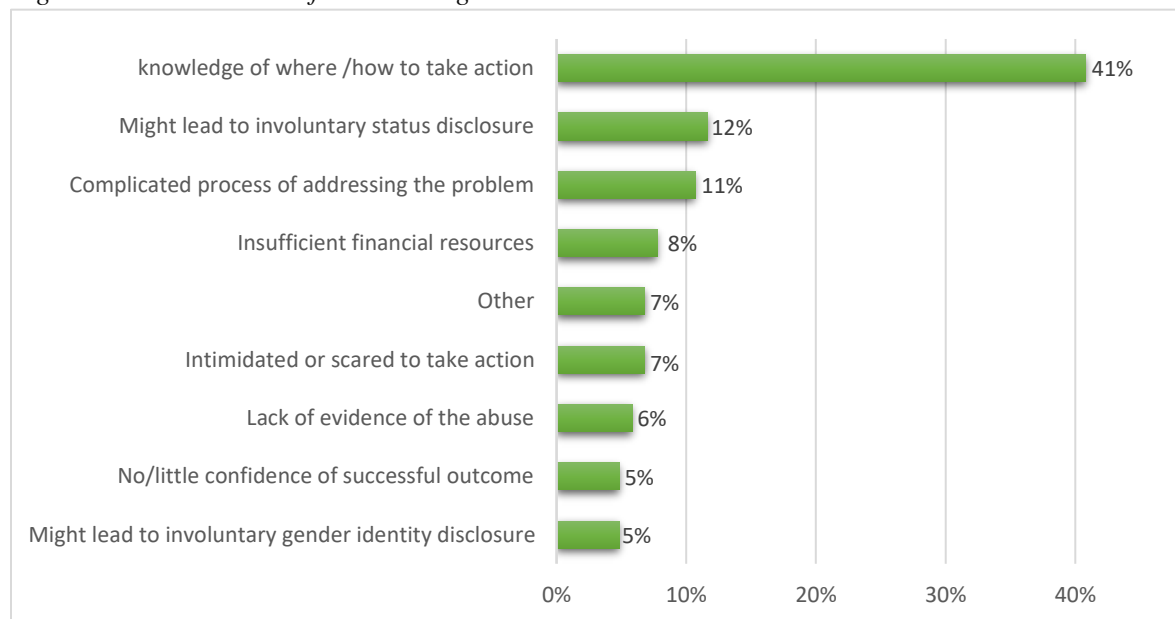
Figure 15: Some actions taken by participants after abuse of rights



Among those who acted, 84.4% confirmed that majority of these issues were addressed successfully. 6.25% disclosed that their grievances were being addressed, while 9.4% were unsuccessful in their pursuit of amends. The survey also probed for reasons why PLHIV did not act against the infringement of their rights. The most common denominator was that they were unaware of where to seek redress (42, 40.8%), as shown in figure (16) below.

Among the respondents whose rights were abused, only about one in four persons acted against the abuse.

Figure 16: Main Reasons for not taking action



Majority of the participants -633 (51.3%) indicated that they are aware of laws that protect their rights in Nigeria. However, 126 (10.2%) participants believed these laws were non-existent, and a total of 476 PLHIV were unaware of such laws.

To prevent frequent occurrences of stigma and discrimination, a proportion of the interviewed PLHIV embarked on educational campaigns to create awareness. In the past 12 months, 24.1% of PLHIV educated people, from whom they received abuse. A further 14.9% confirmed the same, but this occurred beyond the 12-month review period, as shown in table (15) below.

Table 14: Actions taken by Respondents.

Characteristics	Yes, within 12 months	Yes, not within 12 months
Challenged or educated someone who was engaging in stigma or discrimination against you	24.1%	14.9%
Challenged or educated someone who was engaging in stigma or discrimination against other PLHIV	33.4%	16.3%
Provided emotional, financial, or other support to help a PLHIV deal with stigma and/or discrimination	38.6%	13.3%
Participated in a campaign working to address stigma and discrimination against people living with HIV	29.6%	12.2%

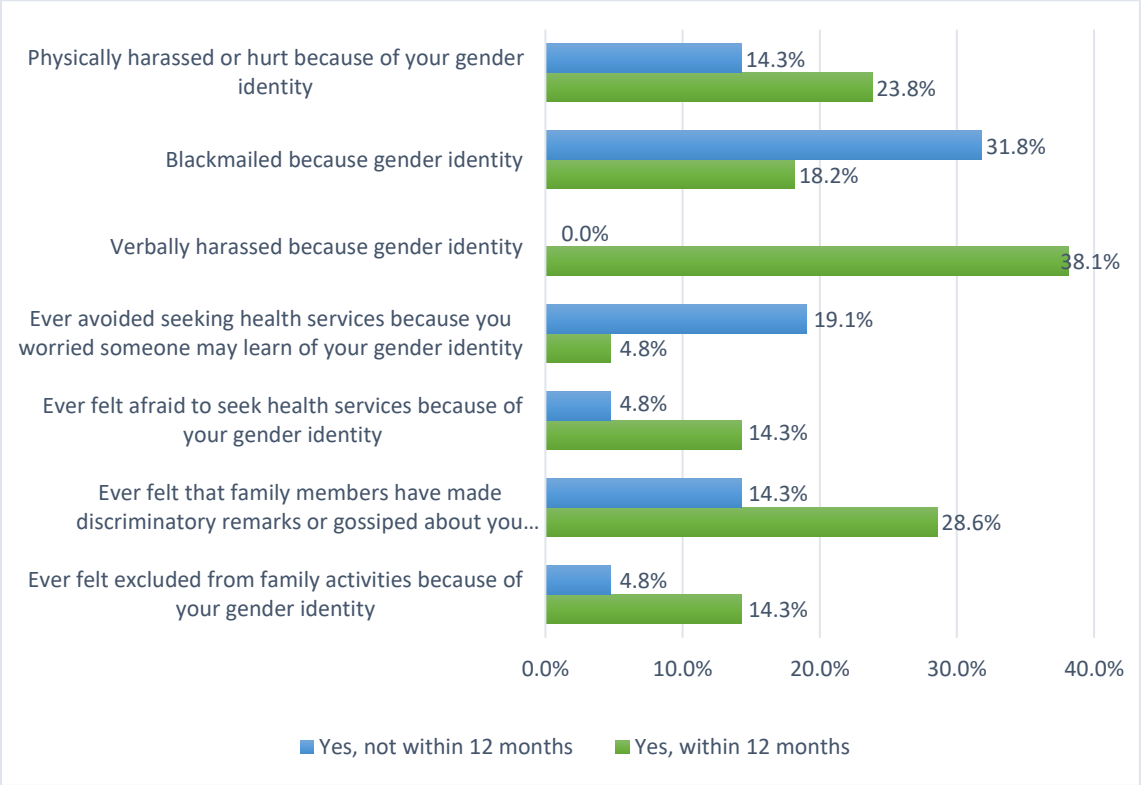
Encouraged a community leader to act about issues of stigma and discrimination against people living with HIV	23.2%	10.2%
Encouraged a government leader or a politician to take action on issues of stigma & discrimination against PLHIV	16.7%	7.7%
Spoke to the media about issues of stigma and discrimination against people living with HIV	10.8%	6.2%

Stigma experienced for reasons other than HIV

Gender Identity

There was a total of 21 (1.7%) participants who did not conform to the traditional gender roles and identities. They responded to questions with regards to being victims of several discriminatory acts and verbal abuse, even from family members over the past 12 months. Among this sub-group, 3 (14.3%) participants confirmed that they were excluded from family activities within the last 12 months. Participants also reported being afraid to seek health services due to their gender identity (14.3%, 3 PLHIV), and sometimes completely avoided visits to health facilities (1 PLHIV, 4.8%) as shown in figure (17) below:

Figure 17: Stigma Experienced due to Gender Identity.



Gay/Homosexual/MSM

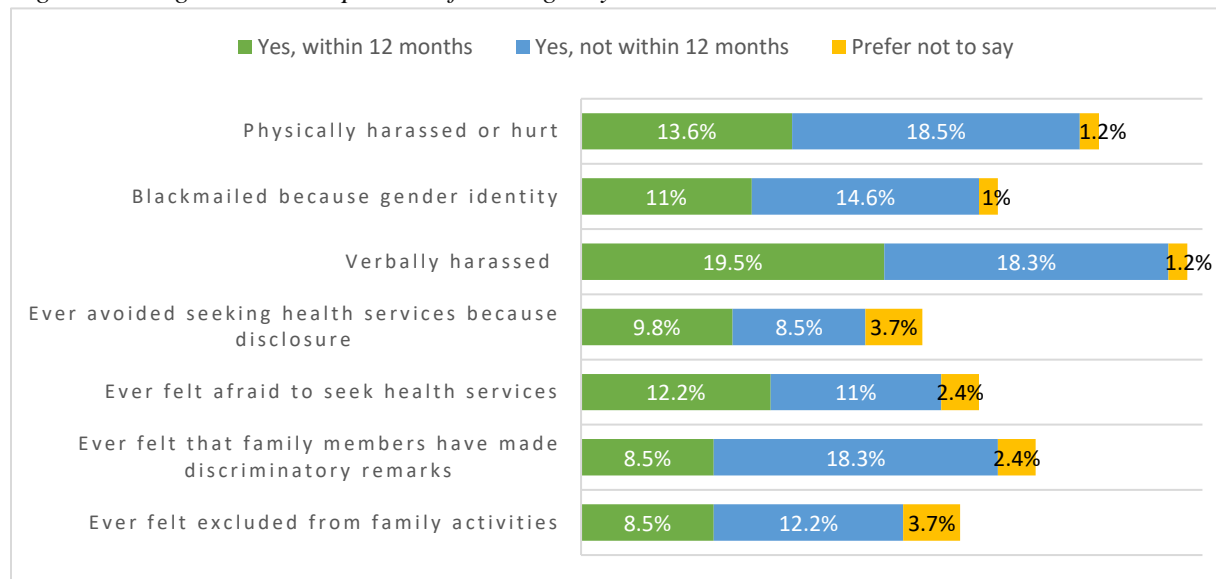
All interviewed PLHIV who identified as Gay/homosexual/MSM (6.6%) were asked if they had experienced any form of discriminatory acts and verbal abuse within the past 12 months. 7 (8.5%) confirmed that they were excluded from family activities, and received verbal abuse from their family



members, as shown in figure (18) below. Follow-up responses from the participants indicated that other homosexuals were aware of their status (72 MSM, 87.8%). 33 respondents (40.7%) and 23 respondents (29.5%) confirmed that their sexual orientation was known to family/friends and community members, respectively.

"The worst instance of rejection I have felt is from my parents. They refused to continue funding my education, stating that I wouldn't amount to anything good" – FGD Respondent (MSM).

Figure 18: Stigma Issues Experience for being Gay/Homosexual/MSM

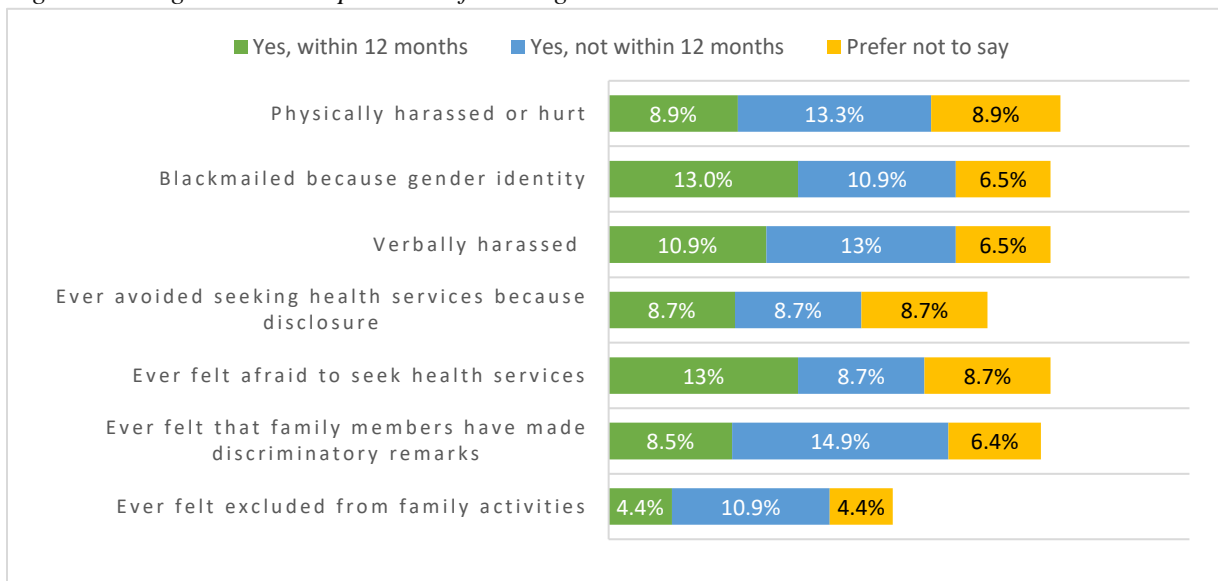


Lesbians/WSW

Participants who identified as Lesbians/women who have sex with women -46 (3.7%) were asked about their stigma experiences. Two respondents (4.4%) disclosed that they were excluded by their families from all social gatherings and activities. In addition, 4 respondents (8.5%) were verbally abused by their family members, as shown below in figure (19). However, some participants preferred not to disclose the disposition of their family members towards them. The survey questioned the awareness of other lesbians about the sexual identity of the respondents; 12 (26.1%) participants indicated that their family and friends were aware of their sexual orientation, while community members were aware of the sexual orientation of 18.2% of the participants.



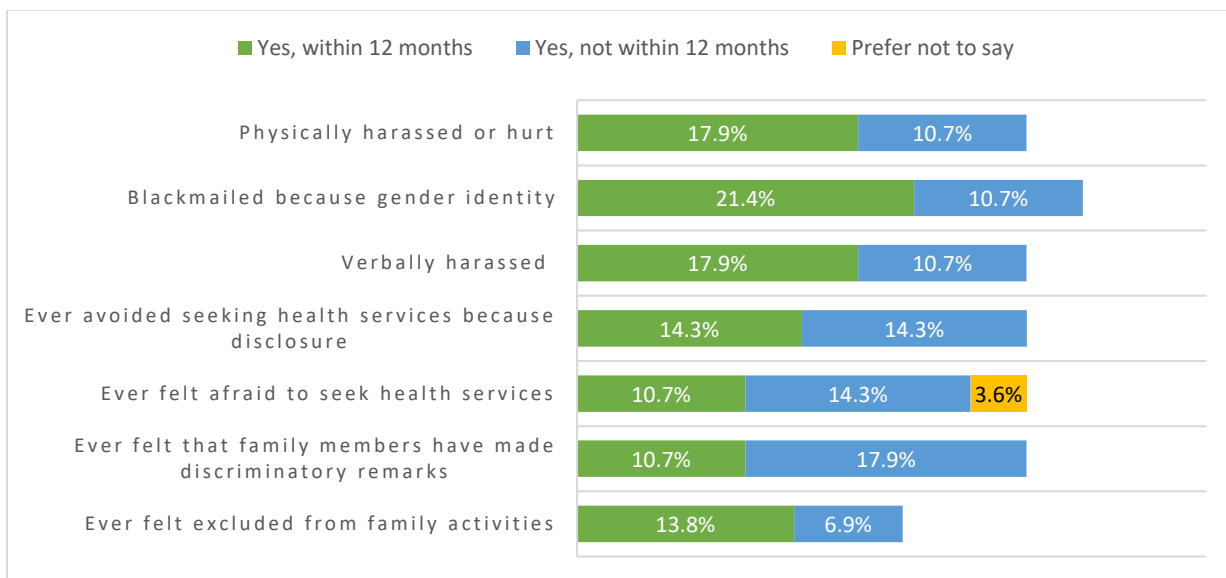
Figure 19: Stigma Issues Experienced for being Lesbian/WSW.



Bisexual Participants

Among the bisexual population (2.3%), the study documented that these participants received abuse and stigmatization from their family members and the rest of society. Within the past 12 months, 4 PLHIV (13.8%) confirmed that they were excluded from family activities. Their family members also made discriminatory remarks and gossiped about them. 3 PLHIV (10.7%) confirmed that this happened to them within the past 12 months, as shown in figure (20). In addition, 14 PLHIV (51.9%) claimed that their family and friends were aware as well. Community members were aware of the sexual orientation of just 9 respondents (34.6%). Follow-up responses indicated that 12 (42.9%) of these individuals belonged to Support Group for people who are bisexual/have sex with men and women.

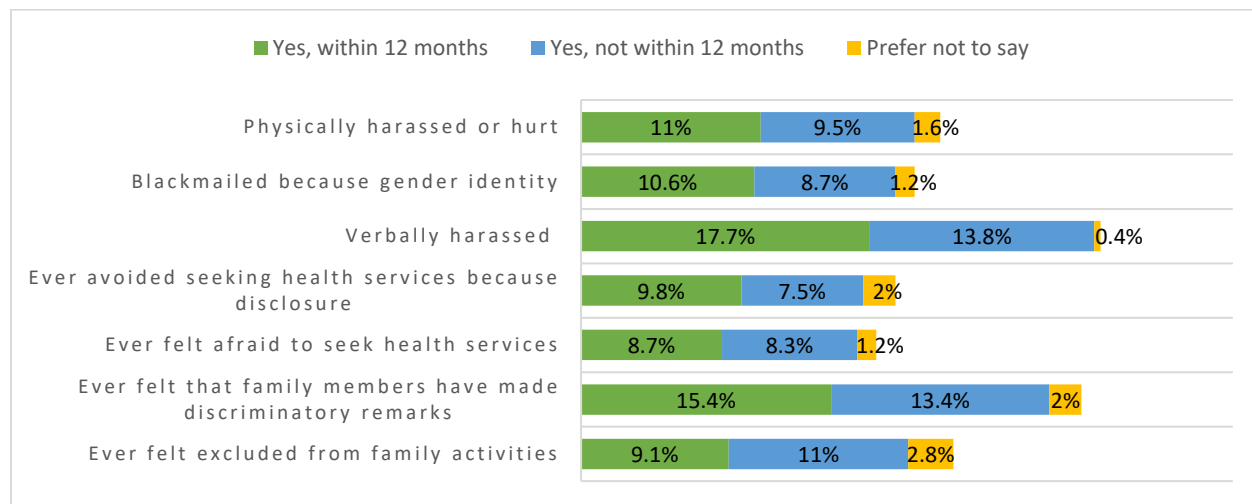
Figure 20: Stigma Issues Experienced for being Bisexual.



Sex Worker

Population of participants who identified as sex workers (14.4%) and people who have ever sold sex (20.5%) in this study also experienced discriminatory acts from family members and other individuals. Within the last 12 months, a total of 62 respondents were excluded from family activities, and were verbally assaulted, as shown in figure (21). In addition, 89 PLHIV (35.2%) indicated that their household knew about their occupation, while 121 (47.8%) of this population reported that they belong to a network or Support Group for people who are (or were) sex workers or sell (or sold) sex.

Figure 21: Stigma Issues Experienced for being a Sex Worker/Person who Sells Sex.



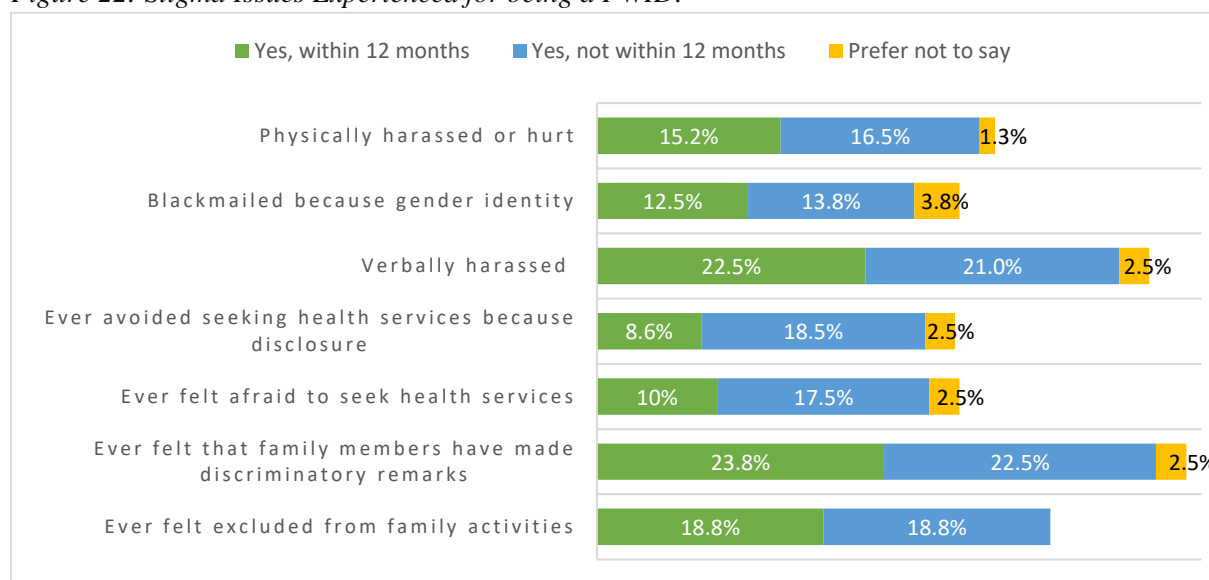
PWUDs

Within the survey sample size, 6.5% of enrolled participants identified as people who use drugs have also experienced some form of discrimination from their households. 15 respondents (18.8%) indicated that they have been excluded from family activities within the last 12 months, while 8 participants (10% of PWUDs) confirmed that they feared going to the facilities to access care and treatment because they were worried someone may learn they use (d) drugs, as shown in figure (22) below.

Majority of participants (83.8%) who use (d) drugs indicated that their peers were aware that they are/were drug users, while 44 (56.4%) indicated that their family and friends are/were unaware of their drug use. Additionally, 38 (47.5%) PWUDs belonged to Support Group for people who use drugs.

“I really feel bad whenever my mum calls me a drug addict, it makes me want to kill myself, I don't even know how to tell her am also HIV positive.” – Survey Respondent (Rivers)

Figure 22: Stigma Issues Experienced for being a PWID.



Results from Focus Group Discussions

Sociodemographic data

A total of 120 persons participated in 15 FGDs that were conducted in Benue, Akwa Ibom and Taraba States. The participants had a mean age of 31.4 years. The most participants (38, 31.7%) felt within age band of 25 – 34 years. In terms of gender identity, 53 (44.2%) and 62 (51.7%) participants were male and female, respectively, while 5 participants were transgender. Among the participants, 70 (58.3%) were single, and 41 (34.2%) were married. Regarding religion, participants came from one of two religious groups. 112 (93.3%) were Christians while 8 (6.7%) were Muslims. There were 79 (65.8%) participants that reported having a monthly household income of 15,000 Naira or less (equivalent to 30 USD). Other sociodemographic characteristics and sub-categories are presented in Table (15) below.

Table 15: Sociodemographic data of FGD Participants

Characteristics	N=120	
	N	(%)
Mean Age [SD]	31.4 [10.66]	
Age Categorized		
18 – 24	33	27.5%
25 – 34	38	31.7%
35 – 44	33	27.5%
45 – 54	11	9.2%
≥55	3	2.5%
Decline to answer	2	1.7%
Gender		
Male	53	44.2%
Female	62	51.7%

TG	5	4.2%
Marital Status		
Married	41	34.2%
Single	70	58.3%
Separated/Divorced	2	1.7%
Widow/Widower	7	5.8%
Religion		
Christianity	112	93.3%
Islam	8	6.7%
Education		
No formal education	1	0.8%
Primary	7	5.8%
Secondary	56	46.7%
Post-secondary (vocational studies)	9	7.5%
Tertiary	47	39.2%
Employment Status		
Employed	84	70.0%
Unemployed	36	30.0%
Household Income		
≤15000	79	65.8%
16000 – 45,000	22	18.3%
≥46000	17	14.2%
None	2	1.7%

Summary of Qualitative Findings

Some of the findings from the FGDs were applicable across the different subgroups. In general, all respondents indicated that they had never experienced access denial to health care services because of their HIV status. Additionally, nearly all respondents reported experiencing, at least, one form of stigma and discrimination from family, friends, colleagues, and sometimes health workers. Participants reported that people tend to avoid any form of contact with them, and that they have missed many opportunities due to their HIV status. Most of the respondents indicated that their self-esteem suffered when they learnt about their status. Many reported that they had become reclusive, and no longer participate in social activities. The respondents outline some of the challenges they faced, including self-stigma, lack of food, problems of access to ART drugs, difficulty finding work, or even life partners. However, some of the findings varied from one subgroup to the other and are presented below.

Adolescents and Young People

Many respondents in this subgroup reported experiencing extreme cases of internalized stigma. Some reported feeling suicidal when they learnt about their status, while some reported that they have fears of dying from the virus. One respondent from the AYP sub-group stated that most people that know their HIV status refuse to come close to them and stop eating or associating with them. These also include



discriminatory remarks such as being told that they are going to die whenever they fall sick. Another respondent reported that they are constantly called names and branded because of their HIV status. They have been denied normal everyday interactions such as handshaking because of fears they may transfer the virus. This causing shame, guilty and fear for AYPs. Some adolescents reported that healthcare workers discriminated against them openly because of their status.

“I feel bad that i cannot mingle with other people. I feel bad when taking the drugs that sometimes I even stay 2weeks without taking the drugs and it affects me a lot”

“Yeah, it was a very bad experience, I cannot go back to normal life again, because I have passed through hell, at one time I was depressed, I was contemplating suicide, yes but at the end of the day I moved on because it is not going to be the same again, it is never going to be the same”

General Population Living with HIV

Some respondents in this subgroup reported that they did not feel comfortable going to the facilities because of the risk of someone they know learning about their status. One respondent narrated his experience during a schedule facility visit. He came across a friend at the hospital who enquired from him the reason for his hospital visit. Unsatisfied with his response, the friend approached facility staff who revealed to him that the respondent was at the facility to collect ART. Some of the respondents did not trust that health facility staff kept their status confidential, they feel they (facility staff) may be discussing them with other patients.

“The facility I am accessing my treatment, they stigmatize a lot. One of the doctors will even speak to us anyhow, she is actually very rude, she always presses her phone even if people are on the queue and if you try to report her you will be the last person to get the drugs and last person to be attended to”

“...normally the stigma is about the facility, the way the staff look at me, the way they look at my colleague and the way they behave, you cannot touch the staff table, they will ask you to shift at the clinic”

Women Living with HIV

While most respondents reported not knowing how to act, following abuse of their rights, many respondents in this subgroup reported taking action after they experienced abuse of their rights. Some reported the issue to the Police, while others reported to persons of authority, and cautionary actions were taken on their behalf. Many respondents reported being discriminated against during social gatherings. One respondent explained that people refuse to eat with them, and on one occasion there was a bucket of food labelled ‘HIV food’.

“Yes, the stigma of keeping drugs pick up stations close to mortuary should stop, it shows PLHIV are half dead”

“...like 3 weeks to my wedding, when we went for the test, and we found out that I was positive, and the wedding was cancelled by the parent of the groom”

Female Sex Workers



Respondents in this subgroup have experienced discrimination from family and neighbors. A number of respondents in this category reported that their relationships ended because their partners found out about their status, and that they were thrown out of the home they shared with their partners. Others reported that being positive has affected their business, and that neighbors and friends gossip about them, and accuse them of trying to spread the virus. One respondent claimed she was accused of injecting her blood into the food she cooks and sells.

“My own experience was the first time I was tested HIV positive; it was lack of knowledge from my family, you know it’s not everybody that have knowledge about it, my family think, it can be contacted by sharing spoon, plate and toilet together, it was a serious battle before they understand that it can’t be transmitted that way”

“In the compound I’m living with my neighbors, they use to say that I inject my blood inside the food, so people don’t collect food from me to eat”

Men who have Sex with Men (MSM)

Some respondents in this subgroup reported experiencing discriminatory treatments from healthcare staff based on their sexuality as gay people and not just because of their HIV status. Many respondents disclosed that they often received abuse from members of their religious groups, their neighbors, and strangers in social gatherings/events because of the way they walk, talk or dance. People often become aggressive towards them, and usually threaten to throw them out. One respondent explained that being gay was a battle on its own in Nigeria. He reported that gay people are often taken to a centre where they are to get treated not because of their HIV status but because of their sexuality.

“The time I got stigmatized was when my neighbor who knew my status called her children behind my house and told them not to come close to me because I’m a dead person. Even when one of those children came to my house, she rushed and chased the child out and told people that I’m half dead”.

“I was stigmatized a day I went for a job. I was referred to carry out a test by my uncle because he the one helping me get the job. The man I was referred to then called my uncle and asked him why he would refer someone who is HIV positive right in my presence and that was the first time I knew my status. My uncle refused to give me the job, called my elder brother and told him that I am not ready to do anything useful with myself and that I am HIV positive”



Key Findings

- Over 25% of both female sex workers (FSWs) and men who have sex with men (MSM) experienced HIV status disclosure without their consent.
- PWIDs and MSM (26% and 31% respectively) experienced HIV-related stigma and discrimination in the last 12 months in greater proportions in comparison to other groups.
- North-East and North Central reported experiencing the greatest proportion of stigma and discrimination within the last 12 months.
- Verbal abuse, discriminatory remarks, and gossiping were reported as the most reoccurring type of stigma and discrimination experienced by PLHIV.
- 54.2% of respondents reported that their ability to meet emotional needs since being diagnosed was better for outside the 12 months than within the last 12 months.
- Self-exclusion from social interactions (10.6%) and abstinence from sex (11.9%) were the most reoccurring self-stigmatizing actions taken against PLHIV because of their status.
- Only 64% of the respondents reported that they got tested within 6 months of considering it.
- One in every four respondents reported that they were either pressured or that it was not their choice to get tested.
- Only 42% of respondents opted to commence treatment immediately after being diagnosed with HIV.
- Nearly one in every five respondents delayed starting treatment for more than one month after being diagnosed with HIV.
- Among the respondents whose rights were abused, only about one in four persons acted against the abuse.
- Among those who did not act, 40.8% reported that the reason for not acting was because they were unaware of where and how to seek redress.
- Health workers revealing respondents' HIV status to other people without their consent was the most reported stigma issue. This was reported by 7% of the respondents.
- Trends in stigma and discrimination over the last three waves (2011, 2014 and 2021) have shown improvements across key indicators.



Discussion

The purpose of this study was to describe the different forms of stigma and discrimination experienced by PLHIV in Nigeria. The results from the Nigeria Stigma Index Study 2.0 showed that the survey complied with set quota for recruitment for diverse PLHIV profiles and locations. Fairly balanced distributions were also achieved for recruited respondent characteristics, such as age groups, period from diagnosis, level of education, work status and household situation. A good proportion of respondents also identified as members of marginalized groups. The rich diversity of respondents suggests that the information generated from the survey reflects the experiences of different population groups and cultures. This means that the results can be generalized across a wider population. However, under gender distribution, female participants accounted for more than 64% of all the recruited respondents. This data was somewhat proportional to the overall female HIV population in Nigeria (960,000; 56% of PLHIV) and greater propensity for female to seek health care services over males.

Greater proportions of female sex workers (FSWs) and men who have sex with men (MSM) experienced HIV status disclosure without their consent. For both groups, over 25% of them reported involuntary status disclosure. The study also showed the effect of status disclosure on respondent psychological, mental health and self-esteem among this group. The greatest proportion of disclosure without consent happened among other family members. Involuntary disclosure of one's HIV status is still widely perceived as socially dangerous. Inadvertent or improper disclosure of PLHIV status can result in denial of employment, acts of violence, and many other collateral consequences. Respondents were fairly divided regarding their experiences with disclosing their status. Many agreed that voluntary status disclosure was a positive experience, while others disagreed. However, one study pointed out that HIV status disclosure to sexual partners was uncommon among Nigerian MSM and TGW, despite being associated with improved HIV care outcomes.¹⁵ This demonstrates the need to apply strategies that encourage HIV status disclosure and the necessary scale up of family/ index testing, especially among highly marginalized populations with a high burden of HIV infection.

The survey also showed that a greater proportion of PWIDs and MSM (26% and 31%, respectively) in comparison to other groups experienced HIV-related stigma and discrimination in the last 12 months. This is evidence of the increased risk of discrimination members of key population groups face due to their HIV status. It is also important to note that far more PWIDs and MSM reported experiencing stigma and discrimination within the last 12 months in comparison to those who experienced stigma and discrimination more than 12 months ago. This suggests that the experiences of stigma and discrimination among these groups is still a major problem. Younger and middle-aged adults experienced more stigma in relation to older adults. At least 21% of respondents within the 18 to 44 age bands reported experiencing stigma and discrimination. Less than 20% of respondents aged 45 and above experienced stigma and discrimination within the last 12 months. The FGD responses showed that many young people received judgmental and discriminatory remarks about their status from family members and hospital staff. In terms of region, greater proportions of respondents in the North-East and North Central reported experiencing stigma and discrimination within the last 12 months. This suggests the need to direct awareness and behavioral change

¹⁵ Tiamiyu, A. *et al.* (2020). HIV status disclosure by Nigerian men who have sex with men and transgender women living with HIV: A cross-sectional analysis at enrollment into an observational cohort. *BMC Public Health*. 20. 1282. 10.1186/s12889-020-09315-y



interventions to these regions. Verbal abuse, discriminatory remarks, and gossiping were reported as the most reoccurring type of stigma and discrimination experienced by PLHIV.

Overall, the data showed that 54.2% of respondents reported that their ability to meet emotional needs since being diagnosed was better for outside the 12 months than within the last 12 months. This suggests that many PLHIV are emotionally affected as suggested in many reports. Findings were consistent with the previous Nigeria Stigma Index Survey in 2014, where 39.2% and 29.9% felt shame and guilt respectively, because of their status. Additionally, the results showed that self-exclusion from social interactions (10.6%) and abstinence from sex (11.9%) were the most reoccurring self-stigmatizing actions taken by PLHIV because of their status. This perhaps stems from the desire of respondents to keep their status hidden from others for fear of stigmatizing and discriminatory treatment. Evidence from the findings, as well as focus group discussions suggests that social isolation, if unaddressed, will have adverse health consequences, including depression, impaired function, accelerated cognitive decline, and impaired immunity for PLHIV.¹⁶

The results contribute to the understanding that stigma and discrimination issues affect HIV testing and treatment efforts. Only 64% of the respondents reported that they got tested within 6 months of considering it. Even more worrisome is that only 42% of respondents opted to commence treatment after being diagnosed with HIV. The most reported reasons for delays in getting tested and delays in commencing treatment were that respondents were worried that someone would find out their HIV status. This data point further adds to the growing information that stigma and discrimination, resulting from status disclosure continue to affect many aspects of HIV programming. Survey data also pointed to several issues relating to interactions with health care workers. The results showed that the most reported stigma came from health workers disclosing respondents' HIV status to other people without respondents' consent. In addition, some clients (1.3%) felt that their hospital records were not kept confidential. Others reported negative actions of health workers, such as forcing them to sterilize/take contraceptives and advising them not to have children. These reported types of stigmatizing and discriminatory PLHIV interactions with healthcare workers will make it even more difficult to encourage PLHIV to access health services. Future research should explore reasons why health workers stigmatize and discriminate against PLHIV in the health care settings. Identifying these reasons will help illustrate the process of planning for developing suitable interventions directed towards the specific stigma and discrimination problem.

Regarding rights abuse, only very few respondents reported experiencing abuse of their rights. However, among those whose rights were abused, only about one in four persons acted. Many respondents reported that they did not know where and how to act. Also, many felt that nothing will come out of their action, while some reported that they feared that taking action will result in status disclosure. These problems suggest that PLHIV lacked the knowledge of what to do and the believe that their action will have a successful outcome. This means that many cases of PLHIV rights abuses will continue to stay unreported until the narrative is changed.

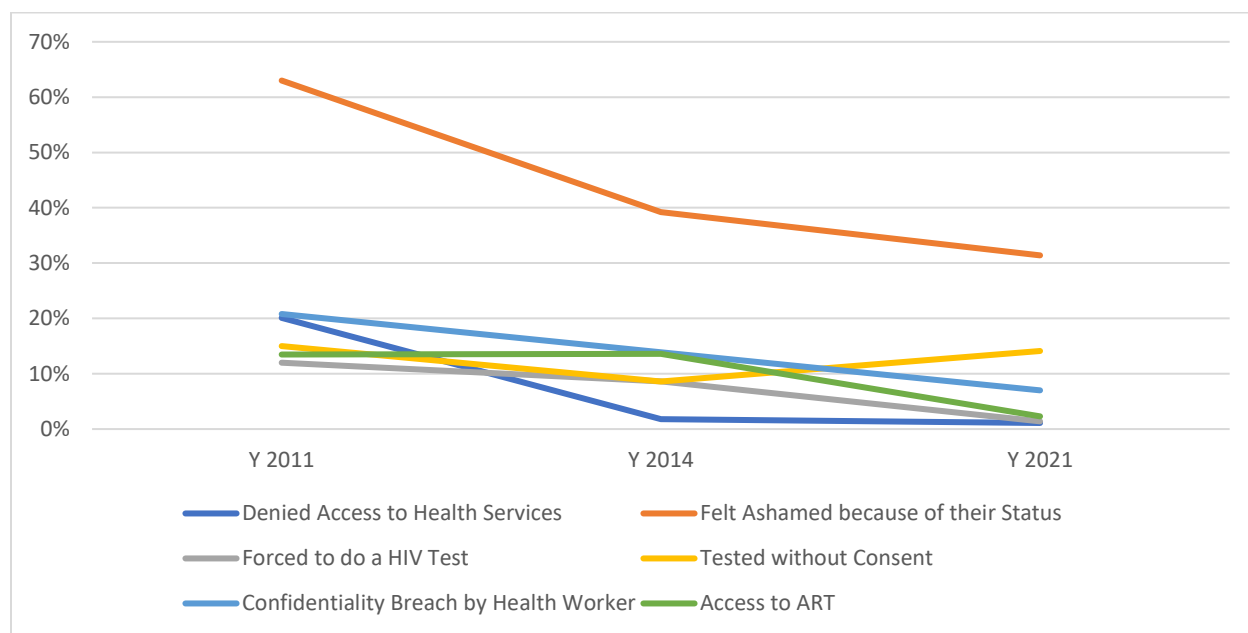
In terms of stigma experienced for reasons other than HIV, different respondent categories, including sex workers, gay/MSM, lesbians/WSW, PWUD and transgender, experienced stigma and discrimination for

¹⁶ Social Isolation and Mortality Among People Living with HIV in British Columbia, Canada; Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7427496/>



various reasons. For bisexuals and respondents with a different gender identity from their gender at birth, blackmailed was the most reported type of abuse experienced. For sex workers and gay/homosexual/MSM, the most reported abuse was verbal harassment. Lesbian and women who have sex with women reported physical harassment as the most frequent form of abuse, while PWIDs reported the most occurring stigma as family members making discriminatory remarks or gossiping about them. The 2014 Same-Sex Marriage Prohibition Act (SSMPA) effectively criminalizes lesbian, gay, bisexual, and transgender (LGBT) persons in Nigeria based on sexual orientation and gender identity. Following the signing of SSMPA into law, there has been increase in LGBT human rights abuses, including physical and sexual violence, aggression, arbitrary arrests, extortions, and persecutions. This has further exacerbated the situation of members of these subgroups. Considering these occurrences of abuse by respondent categories, interventions can be tailored to have the most effective outcome on the problem of stigma and discrimination.

Figure 23: Trend Analysis, Stigma Index Data 2011 to 2014 to 2021



A comparison of Stigma Index data over three waves was done and represented in the chart above. These looked at indicators covering access to health services and treatment services, felt stigma, abuse of rights, and interactions with health workers. The specific indicators tracked are presented in the trend chart above. There was a decline in the proportions of stigma and discrimination experienced by PLHIV across all 6 indicators from 2011 to 2021. However, one indicator (Tested without consent) experienced a rebound between 2014 and 2021 with 8.6% reported in 2014 and 14.1% reported in 2021. Overall, these trends demonstrate there are improvements in addressing stigma and discrimination. One must continue to recognize that the current levels of stigma and discrimination are still above tolerance levels. There are still widespread challenges, such as verbal abuses and disclosure of PLHIV status to others without their consent.

Health is influenced by a broad range of policy decisions, not just those in the medical or health field. A true health policy should therefore provide a framework for health-promoting and stigma-preventing actions and covering the social, economic, and environmental determinants of health. In this regard, the UNAIDS 2025 goals have recommended a greater focus on removing societal and legal impediments to



service delivery and a focus on providing people-centered approaches¹⁷. There is need for revising and reforming policies and laws that reinforce stigma and discrimination, including on age of consent, HIV non-disclosure, exposure and transmission, travel restrictions and mandatory testing. Analysis from other studies suggest that failure to make these policy changes on HIV-related stigma and discrimination would undermine efforts to reach the HIV testing, treatment and viral suppression targets, resulting in an additional 440 000 AIDS-related deaths globally, between 2020 and 2030¹⁸. Stakeholders, including Government, partners, programme, implementers, influencers, and the public must continue to work together to implement recommendation put forward in this report, as we all continue on the path to a stigma free Nigeria.

¹⁷ UNAIDS (2021) 2025 AIDS Targets. Available at: https://www.unaids.org/sites/default/files/2025-AIDS-Targets_en.pdf

¹⁸ UNAIDS (2021) Prevailing against Pandemics by putting People at the Center. Available at: https://aidstargets2025.unaids.org/assets/images/prevailing-against-pandemics_en.pdf



Study Limitations

There are some shortcomings of the Nigeria Stigma Index Survey 2.0. These limitations are presented based on information obtained during the study. Some of the main limitations include:

- Data Collectors were trained and equipped with a definition guide to help ensure respondents understand seemingly complex questions (e.g., opportunistic infections, coerced, etc.). However, respondent still noted difficulties relating to understanding (or misunderstanding) several terms on the structured questionnaires.
- Difficulty identifying respondents that understand English or Pidgin English in some study locations. There are very low levels of literacy in many rural communities in the Northern region of the country. This resulted in screening off many potential respondents. This language barrier could potentially introduce a class divide, causing a relatively skewed study population with a certain level of the English language proficiency.
- Challenges with accessing many communities. Due to issues of insecurity, Government imposed curfews and lockdowns, and by sheer remoteness of many study locations, it proved quite challenging to recruit participants from such communities. A conscious effort was made to access such communities so that persons within these groups are reached.
- There was a challenge in recruiting the required number of participants using the limited chain referral approach. Many PLHIV who received the business cards failed to contact the study team. This meant that the study did not reach the desired number of PLHIV groups who typically do not access services or belong to social/Support Groups. The study set out to achieve 25% of participant recruitment using limited chain referral, however, it achieved 21%.

Conclusion

The Stigma Index Study was able to effectively document the experiences of stigma and discrimination among PLHIV in Nigeria as well as strategies to address these challenges. Generally, trends in stigma and discrimination over the last three waves of the PLHIV Stigma Index study shows there has been improvements recorded across key indicators. From 2011 to 2014 to 2021, there has been a steady decline in the proportions of respondents that reported feeling ashamed because of their HIV status, as well as for proportion of respondents that reported being denied access to healthcare services because of their HIV status. There was also a steady decline in the proportion of respondents that were forced to submit to HIV test or a medical procedure. Despite some of these gains, widespread challenges continue to plague PLHIV. Issues such as verbal abuses and disclosure of PLHIV status to others without their consent, continue to occur in significant number. Furthermore, stigma and discrimination for reasons other than HIV status, such as gender identity, sexual identity, sex workers and drug use have emerged as a growing challenge. Therefore, Nigeria has an obligation to address stigma and discrimination issues that affect PLHIV human rights and health outcomes. Stakeholders must work collectively and collaboratively to reduce the levels of stigma and discrimination experienced by PHIVs. Removing barriers in access to HIV and non-HIV health information and services, creating awareness and educating the public, as well as implementing laws and regulations that aim to support and promote better health outcomes, are actions that must be taken serious by stakeholders.



Recommendations

Following the results from this report, the following recommendations were formulated:

1. There is a need to create more awareness and sensitize the general population against stigma and discrimination. Government, through the National Orientation Agency and its media partners should expand campaign activities that will help dissuade people from abusing PLHIV and KPLHIV. Campaign activities should give special focus on HIV-related stigma and discrimination faced by KPLHIV. Main issues campaign efforts are to address should cover verbal abuse, discriminatory remarks, and involuntary disclosure. Campaign could also convey in media, the image of PLHIV - including from key populations - who are fulfilled and integrated in society or in their community. This could also help to dispel myths about transmission of HIV and promote the U=U campaigns.
2. PLHIV must be educated on their rights especially around their sexual and reproductive rights. This is especially important for female PLHIV. PLHIV should be educated on actions they can take to address issues of abuse of their rights. Systems should be put in place to identify and act on cases of PLHIV rights abuses. Community Based Organizations and Social Workers have a key role to play in ensuring that PLHIV know their SRH rights. This awareness effort should not only target PLHIV but also the health workers that provide these services. This will go a long way in uncovering unreported cases of abuses and subsequently preventing further abuses.
3. Key population living with HIV should be educated on their right and ways of seeking redress when their human rights are violated. Mechanisms and guidelines should also be put in place to facilitate better reporting, documenting and redress of stigma and related abuses of PLHIV and KPLHIV. The National Human Rights Commission is a relevant stakeholder to lead this process.
4. Continuous training and retraining especially on interpersonal communication (stigma and discrimination). Educating health care workers will help promote the delivery of “stigma-free” HIV and non-HIV services to PLHIV. This will encourage PLHIV to utilize HIV testing and treatment services. Training should raise awareness and promote health care worker action to challenge HIV and key population stigma and discrimination. In addition, there is need to develop a tracking tool to know the working status of health workers that have been trained on interpersonal communication (IPC). Additionally, every health worker providing HIV Services, must be assessed and receive certification on Stigma. Resource materials for this assessment should be made available free-of-charge and provided through an online platform. Candidates should also be able to register and take the assessment using the same platform. Certificates can be accessed and printed by persons who pass the test.
5. Engage and train community leaders, women’s groups, faith-based organizations, youth groups, NGOs and CSOs about HIV and stigma to disseminate information in their community. These interventions can reduce fear and misperceptions, increase understanding of HIV, and can increase interaction between people living with HIV and other members of the community.
6. Better support systems, provision of mental health services and psychosocial support including enhanced client engagement must be put in place to help with PLHIV coping mechanisms and address felt stigma. These can come in the form of distribution of IEC materials, increasing membership of PLHIV to relevant support groups, guidance and counselling and provision of youth friendly services. These will help mitigate the impact of self-exclusion from social isolation and other forms of self-stigmatizing actions taken by PLHIV because of their status.
7. National HIV programs and implementing partners, should recognize the existing stigma and discrimination challenges PLHIV face and how this affects case finding efforts, linkage to



treatment, retention in care and achievement of viral load suppression. Adequate strategies to address stigma should be embedded in all HIV program designs. These strategies must be applied to counselling, psychological support, differentiated services etc. Sustained counselling and self-care services should be intensified for PLHIV to address internalized stigma and other related issues. Government of Nigeria and funding partners must make it a priority for their implementing partners to address stigma and discrimination issues in their programme approach.

8. Concerted effort should be made to implement laws and policies that seek to protect the rights of PLHIV and KPLHIV. The Ministry of Justice, Ministry of Labour and Productivity, the Nigerian Police force must all work together to ensure compliance with the provisions of existing laws protecting the rights of PLHIV. The Government should enforce the domestication of the Anti-Stigma and Discrimination Act in all the states and create awareness.
9. Government should provide HIV sensitive social protection programme for the vulnerable PLHIV. This will enhance the standard of living of PLHIV. Additionally, Government should increase initiatives to reduce HIV-related stigma and discrimination within work and employment settings, including employers' associations, trade unions and corporatist associations of the legislation concerning the rights of PLHIV.
10. Track and report on HIV related stigma and discrimination indicators across different health facilities and states. Also, systematically document the presence of underlying factors of stigma and discrimination.

NEPWHAN and KP Secretariat are to work collaboratively with identified stakeholders to see that these recommendations are implemented.



Annexes

Appendix A: FGD Guide

THE PEOPLE LIVING WITH HIV STIGMA INDEX 2.0 **Focus Group Discussion Guide**

Name of Interviewer: _____

Type of PLHIV group: _____ Community area: _____

LGA: _____ State: _____ Date: _____

Intro:

After obtaining individual informed consents, the facilitator should start off by introducing him or herself to the ground and saying,

“We are meeting to discuss your experiences related to stigma and discrimination. What we discuss here will remain confidential. We ask that everyone respects each other’s privacy and not share what is said here outside of the group later. We are recording the discussions and taking notes to help us remember the details later, but no one’s name will be connected to what they say. The entire discussion will probably take about one hour. The discussion will focus on what you have experienced relating to your HIV status. There are no right or wrong answers. During the conversations, feel free to tell us about any experiences and concerns you have.”

The facilitator should introduce the co-facilitator who is present, and invite members of the focus group to introduce themselves and briefly say who they are, and the area where they live.

Discussion

1. “Could each of you please think for a moment about a time you may have experienced stigma or discrimination because of your HIV status. Now, very briefly, would you each of you please describe at least one example for us. Then we will go around to discuss some of your experiences in more detail. Who would like to start?”

After each story, the facilitator can follow-up with questions, including the participant’s opinion about what aspects of the events were most stigmatizing and how things could have been done differently. The facilitator should then open the discussion up to the rest of the group. This process should be repeated for the next questions where applicable.

2. “Please describe to us how your HIV status has affected the way you feel about yourself.”
3. “Please describe to us a time you were denied access to health care services because of your status.”

The facilitator can probe for prevention, testing, treatment services, and other SHRH services.

4. “In the past 12 months, when seeking HIV specific services, have you experienced any form of discriminatory treatment from health facility staff working in the place you receive your HIV care? If yes, please describe your experience.”



5. “Have you experienced any form of abuses of your rights because of your HIV status? If yes, please describe the forms of abuses you have experienced.”
6. “If any of these rights abuses happened to you in the last 12 months, did you try to do anything about the matter? If yes, what did you do about the matter?”
7. “Have you ever experienced stigma or discrimination because of groups you belong to, ways you self-identify, or things that you do? If yes, please describe your experience. Remember, you can refuse to answer any question that makes you feel uncomfortable.”
8. “Is there anything else you would like to share about your experiences?”
9. “What are the major challenges other people living with HIV are facing?”
10. “What do you think can be done, that is not already happening, to help address these problems?”

Closing:

“I would like to thank you all for participating”.

Appendix B: Referral Form

THE PEOPLE LIVING WITH HIV STIGMA INDEX 2.0 Referral Form

Please fill out Part A and ask client to take it to the referral receiving organization.

Please fill out one form per service needed.

Please fill out Part B and return to NEPWHAN state coordinator for future follow-up.

PART A: Client Referral Slip	
Name of client:	
Address:	
Date:	Phone Number:
Age:	Sex:
Name of Referring Organization: NEPWHAN/KP Secretariat	
Address:	
Phone:	
Name of person referring client:	
Designation:	
Name of organization referred to:	
Address:	
Name of referral focal person:	
Phone:	
Services Required:	Sign:

PART B: Client Information for Follow-up	
Name of client:	
Client location:	Phone Number:
Age:	Sex:
Name of organization referred to:	
Name of referral focal person:	
Phone:	
Services Provided	Date of follow-up
Additional Comments:	



Appendix C: Information Sheet

INFORMATION SHEET

THE PEOPLE LIVING WITH HIV STIGMA INDEX

Note to interviewers: this information sheet is designed for the interviewees to take away as a summary of the project if they are interested. Take some spare copies with you to the interview. However it is best not to read through the whole information sheet in the interview itself, as much of this information is covered in other parts of the interview process (for example in the informed consent form).

This information sheet tells you about a questionnaire that has been developed to find out more about the experiences of people living with HIV, particularly their experiences of stigma and discrimination.

Each questionnaire that is administered forms part of a larger survey conducted in a country that aims to document the extent of stigma and discrimination experienced by people living with HIV in that particular country. The questionnaire, together with the idea of conducting such a survey, was developed by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV/AIDS (ICW), with financial and management support from the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). The Network of People Living with HIV and AIDS in Nigeria (NEPWHAN) has received funding from the Global fund through Family Health International (FHI360) to conduct the Nigeria Stigma Index Survey. This research is being implemented by NEPWHAN and the Key Population (KP) Secretariat in Nigeria in collaboration with the National Agency for the Control of AIDS (NACA), Society for Family Health (SFH), ASHWAN, Nigeria Human Rights Commission, PEPFAR, and UNAIDS.

THE PURPOSE AND NATURE OF THE PEOPLE LIVING WITH HIV STIGMA INDEX SURVEY

The People Living with HIV Stigma Index survey was created to find out more about the experiences of people living with HIV, especially experiences of stigma or discrimination. There are a number of organizations campaigning against stigma and discrimination and fighting for the human rights of people living with HIV. It is hoped that this survey will one day provide information that will help these efforts.

In order to collect such information (i.e. on what HIV-positive people are experiencing, specifically in relation to stigma and discrimination), the questionnaires and survey will be administered and managed by organizations or networks of people living with HIV in a country. The information that is collected from the questionnaires will then be put together and presented in a way that presents a general picture of the experiences of people living with HIV in that country. It is not information about individual experiences of stigma and/or discrimination. For example, in documenting the results of the survey, information will be presented in the report on “What percentage of people living with HIV experienced discrimination last year”, as opposed to presenting information on your own, personal experiences of stigma and discrimination.



Ultimately, the main aim of this project is to broaden the understanding of stigma and discrimination faced by people living with HIV in different countries, and to be able to find out if there have been changes over a period of time. The organizations involved in this project intend to use the information as a national and global advocacy tool to fight for the human rights for people living with HIV.

PROCEDURES AND PROCESSES INVOLVED IN PARTICIPATING

I would like to make clear that your participation in this project is entirely voluntary. It is your choice whether to participate or not. If you choose to participate, you are also free to not answer any of the questions, and you can also decide to stop participating in the interview at any time that you wish.

In terms of process, if you choose to participate in the survey, we will complete a questionnaire that asks you questions about your social environment, work, access to health services, knowledge about your rights, HIV testing and treatment. Please feel free to ask to see the questionnaire at this stage if you would like to take a more detailed look at the questions.

If you participate in the survey, we will fill in the questionnaire together. You can type in the answers and I will help explain anything that is not clear to you. Or, if you prefer, I can fill it in for you while you sit beside me checking that I am ticking the right boxes and recording your responses correctly.

I will ask you to fill in a form to provide us with your contact information. If you provide consent to be contacted, this form will help us to reach you in case we can help provide referrals, in case we have a follow up question for you, or to invite you to participate in future research opportunities. Your name and contact information will be stored in a locked filing cabinet, and it will not be kept with any information about the study (for example, your survey responses).

At the end of the survey, I may offer you business cards which contain the contact phone number and email address for the study. If you would like, you may take these business cards and provide them to friends or acquaintances who you think might be eligible and interested in participating. It is your choice whether or not to take the business cards, and whether or not to distribute them.

Lastly, before we begin to administer the questionnaire, we need to obtain informed, verbal consent from all potential survey participants. This ensures that all those agreeing to participate in the survey are voluntarily willing to participate and that they have obtained all the information they needed in order to make an informed choice about their participation.

CONFIDENTIALITY AND POTENTIAL RISKS OF PARTICIPATING IN THE SURVEY

This project is taking every possible step to ensure confidentiality, i.e. to prevent any personal information from being known to people outside the research team. We know that breaches of confidentiality could lead to problems for interviewees, so we have put in place measures to avoid this from happening. For example, we do not write the name of the interviewee (i.e. the person being interviewed who is providing us with information about their experiences of living with HIV) on the questionnaire, and we do not write down anything that would allow someone to link the completed questionnaire to the interviewee. All paper forms (such as the informed consent form) used in this project will be stored in a locked cabinet or cupboard.



Electronic data will be kept on secured, password protected computers in a password protected and limited access database. These data will be destroyed as soon as they are no longer needed.

Nevertheless, in all studies like this there is a very small risk that a breach of confidentiality could take place. If this were to happen, your HIV status or other personal information might become known to someone who does not already know your HIV status. As a result, it is possible that you could face stigmatizing treatment from someone. In the most extreme situations, you might experience discrimination in your workplace, loss of access to services, media exposure or physical violence. While this is a very small risk, it is our duty to warn you of this.

DISCOMFORT THAT YOU MIGHT EXPERIENCE AS A PARTICIPANT

The questionnaire asks personal questions that may make you feel uncomfortable at times, and it may bring up topics that are difficult to talk about. We do not wish for this to happen. We want you to know that you do not have to answer any question or take part in the interview if you feel the questions are too personal or if talking about them makes you uncomfortable. If you find you feel uncomfortable at any point during the interview, you can decide to pause or stop the interview at this time – it is completely up to you to decide this and to indicate to me, as the interviewer, that you wish to pause or stop the interview process. Sometimes people want to explore certain issues and experiences in more depth after the interview. In case you need psychological or physical support, such as counselling or legal assistance or advice concerning educational, health or social support, we have developed a list of professional support services in our community. I will be happy to share this information with you.

POTENTIAL BENEFITS FOR YOU AND THE COMMUNITY IN RELATION TO YOUR PARTICIPATION

We hope that the process of going through the questionnaire is an interesting one for you as it might cover some issues that you may not have thought about in detail. We also hope that you will learn from the interview process and from any discussions which may arise from it. However it is hoped that, through you and other people living with HIV participating in this project, we will be able to produce rich and valuable information that will assist both our national and global efforts to reduce HIV-related stigma and discrimination and ultimately improve the lives of all people living with HIV.



Appendix D: Informed Consent

THE PEOPLE LIVING WITH HIV STIGMA INDEX 2.0

Informed consent form

Notes to the country team:

- *The informed consent form is to be completed by the interviewee and the interviewer.*
- *Please ensure the interviewer has sufficient copies of the consent form, as participants have the right to obtain a copy.*
- *The specific requirements for informed consent may differ per context. Sometimes verbal consent may be sufficient, while written consent is necessary in other situations. Please be sure to check the requirements for the informed consent process in your country and adjust this template accordingly.*

My name is _____

I am administering a questionnaire about the experiences of people living with HIV, particularly in relation to stigma and discrimination.

You have been provided with an information sheet that describes the purpose of this questionnaire and how the information collected will form part of a larger study that is being conducted in this country to document the experiences by people living with HIV related to stigma and discrimination. The information sheet also outlines what types of information you will be asked during this interview, how we will keep this information confidential, and the potential risks involved in your participation in this study.

Before we begin the questionnaire, I would like to make sure that you are voluntarily willing to participate in this study and that you have obtained all the information that you need to make an informed choice about your participation.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. You do not have to decide today whether or not you will respond to this questionnaire. Before you make a decision, you can talk to anyone you feel comfortable with about the questionnaire and/or the study.

Please feel free to contact the country coordinator or the National Health Research Ethics Committee of Nigeria (NHREC) if you have any questions or concerns about this questionnaire or the study. These are the contact details for the country coordinator and the NHREC:

Country coordinator

Abdulkadir Ibrahim
35, Justice Sowemimo street, off TY Danjuma, Asokoro-Abuja
08032522393
nepwhan.coord@yahoo.com

Local ethics committee

Ado Danladi
Department of Health Planning, Research and Statistics,
Federal Ministry of Health, Abuja
deskofficer@nhrec.net



If you choose to respond to this questionnaire and participate in the study, I will ask you some questions about some of your experiences as a person living with HIV, in particular those related to stigma and discrimination. I expect that the interview will take between one and two hours.

Before asking you whether or not you would like to be a participant, I would like you to know that...

- ... your participation in this project is entirely voluntary. It is your choice whether to participate or not.
- ... you are free to not answer any of the questions in the questionnaire.
- ... you may stop participating in the interview at any given time and this will not have any consequences.

The information collected in this interview will be kept strictly confidential. To help ensure confidentiality, I will not write your name on the questionnaire or this form, and I will not write down particular details that would allow you to be identified. If you would like to know more about the measures that we are taking to protect confidentiality, please ask me to provide you with these details.

If you wish, your participation will include my providing you with a list of services that are available in our community, including health care, social support and legal services.

Do you consent to participating in the interview?

- Yes
- No

→If 'No': Thank you for your time

→If 'Yes': Thank you for agreeing to take part in this study

By saying 'yes', that means that you have read the information on the information sheet, or it has been read to you. You have had the opportunity to ask questions related to the questionnaire and the People Living with HIV Stigma Index study and any questions you have asked, have been answered to your satisfaction. You consent voluntarily to be a participant in this study, and you understand that you have the right to end the interview at any time.

If you agree, I will now sign this form to confirm that your consent has been obtained.

Signature/initials of the interviewer: _____

Date: _____

Your verbal consent and or signature is all that is needed to go ahead with the interview. If you feel comfortable enough in doing so, you can also sign your name or initials below to indicate that you have consented in writing to participate in this interview.

I have read the information on the information sheet, or it has been read to me. I have had the opportunity to ask questions related to the questionnaire and the People Living with HIV Stigma Index study, and any questions I have asked, have been answered to my satisfaction. I consent voluntarily to be a participant in this study and understand that I have the right to end the interview at any time.



Signature/initials of interviewee: _____

Date: _____

Appendix E: Eligibility Screening Tool

Appendix 8: Screening Survey Tool

1. What is your year of birth? _____
2. Have you ever been diagnosed as living with HIV?
Yes
No
Prefer not to answer
3. When did you first learn that you were living with HIV? _____
4. What sex were you assigned at birth, on your original birth certificate? (Select one)
n Female
n Male
5. For some people, their gender identity differs from the sex they were assigned at birth. How do you describe yourself? (Check all that apply)
n Female
n Male
n Transgender
 Transgender woman
 Transgender man
n Non-binary or gender non-conforming
n Do not identify as female, male, or transgender
n Prefer not to answer
6. How do you identify in terms of sexual orientation?
Gay
Lesbian
Straight/Heterosexual
Bisexual



Queer

Other: Please describe _____

Prefer not to answer

7. Have you ever, even once, used a needle to inject drugs such as heroin, cocaine, methamphetamines or any other drugs in order to get high?

Yes

No

Prefer not to answer

8. Do you make a living receiving money or goods in exchange for sex?

Yes

No

Prefer not to answer

9. Have you ever had sex with someone who identifies as male/man?

This question should be asked to people who identify as male.

Yes

No

Prefer not to answer

Script: Thank you! You have now completed the screening questionnaire.

[Note to interviewer: Please review the participant's responses, and determine if they are eligible to participate. As a reminder, the eligibility criteria are as follows:

Inclusion criteria:

- Aged 18 years and above.
- Self-report that they are living with HIV and have been aware of their status for at least 12 months.
- Are willing to participate into the study.
- Are mentally sound and capable of providing consent to participate
- Speaks English or Pidgin English

In this study, key terms are defined as additional selection criteria for each target group:

- PWID: People living with HIV for at least 12 months who report injecting drugs at least once in their lifetime.
- FSW: women living with HIV for at least 12 month who report exchanging sex for money at least once in their lifetime, through any modality (e.g. internet, street, venue-based sex work among others)



- MSM: Men living with HIV for at least 12 months who self-identify as gay or having sex with men at least once in their lifetime.
- TG: PLHIV for at least 12 months who were assigned a different sex at birth from what they currently self-identify as (regardless of whether or not the participant has undergone or intends to pursue physical gender affirmation options such as hormone therapy or surgery.)

Exclusion Criteria:

- Younger than 18 years of age.
- Self-report that they are not living with HIV (HIV negative).
- Self-report that they are living with HIV, but have been recently diagnosed within the past 12 months.
- Unwilling or incapable of providing consent.
- Do not understand the predominant languages (English or pidgin English)

Is this interviewee eligible to participate in the Stigma Index Interview?

No à Script: *I am very sorry, based on your responses, you are NOT eligible to participate in the study today. Thank you for your time and willingness to speak with us, and for your openness!*

Yes à *Thank you! Based on your responses, you ARE eligible to participate in this study. Are you interested in learning a bit more about this study and continuing on with informed consent procedures?*

If Yes à Proceed to 1) Consent 2) Interview.

If No à Thank participant for their time.



Appendix F: Supportive Supervision Tool

Monitoring Tool: Spot Checking during field Visits

Instruction

This tool is to be administered by monitoring teams during field visits to data collection sites. The tool will be used to assess the performance of the data collectors and match them to the expected standards. The data collection process should be appraised fairly, using the checklist below. Inconsistencies noted during the visit should be documented appropriately for further action. One checklist is to be used per site visit. The monitor should observe at least one full interview during site visits.

Name of Visiting Monitor: _____

Name of Data Collection Site: _____

Name of LGA: _____

Name of DC Covering Site: _____

Monitoring Checklist

Presentation				
S/N	Questions	Yes	No	Comments
1	Data collector was present on the field at the time of visit?			
2	Was data collector appropriately dressed during the visit?			
3	Did the data collector have with him/her the devices needed for data collection?			
4	Did the data collector have enough copies of the following tools? <ul style="list-style-type: none"> • Information Sheet • Informed Consent Forms • Referral Sheets • Limited Chain Referral Business Cards • Back-up paper questionnaire • Eligibility Screening tool 			
5	The interview was setup in a location that is comfortable and guarantees privacy.			
Starting an Interview				
S/N	Questions	Yes	No	Comments
6	The data collector correctly introduced him/herself to the respondent?			
7	The data collector correctly explained the study to the respondent?			
8	The data collector screened potential participants to determine eligibility?			
9	The data collector provided the respondent with a signed copy of the informed consent?			
10	The data collector provided the respondent with an information sheet?			

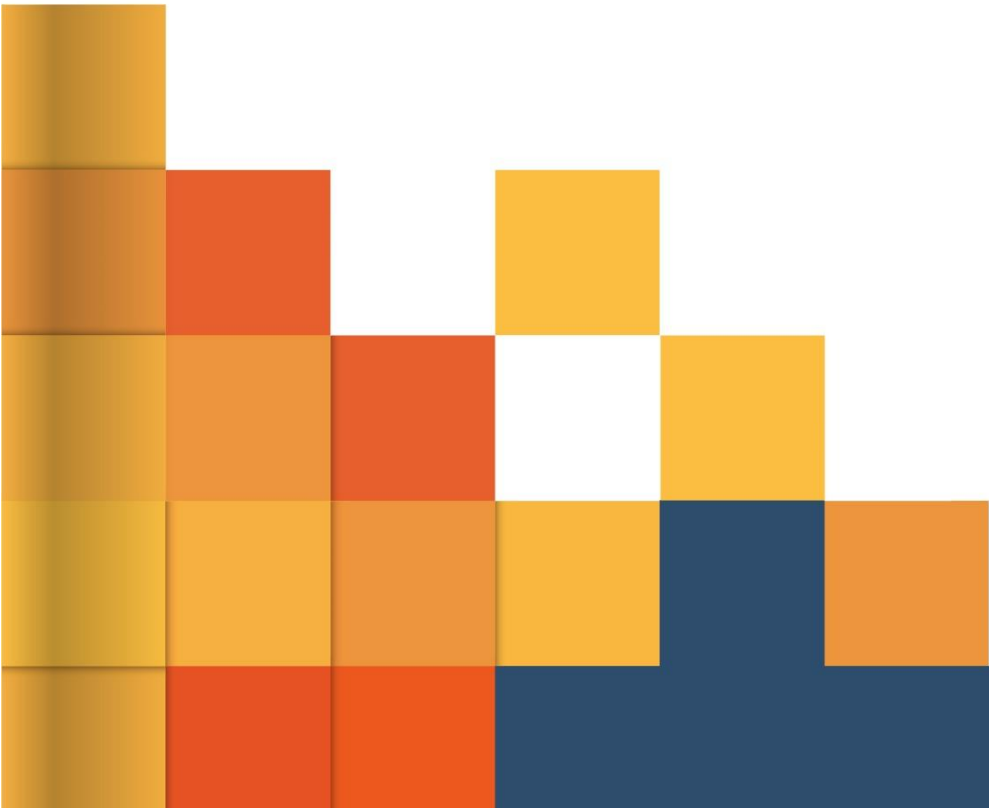
11	Did the data collector and respondent have face masks on before starting the interview?			
During the Interview				
S/N	Questions	Yes	No	Comments
12	The data collector read the questions the way they appeared on the questionnaire?			
13	The data collector prompted the respondent at the right time and to the right extent?			
14	The data collector is familiar and confident with the questions?			
15	The data collector is proficient in the language to communicate the questions effectively?			
16	The data collector shows patience and respect towards the respondent?			
17	The data collector remained neutral and objective throughout the interview?			
18	The data collector was engaging enough to keep the attention of the respondent?			
Closing the Interview				
S/N	Questions	Yes	No	Comments
19	Did the data collector thank the respondent correctly for their participation?			
20	Did the respondent sign the voucher for receiving incentives?			
21	Did the data collector review the captured data at the end of the interview?			

Summary issues identified. _____

Next Steps _____

Signature: _____ Date: _____





The PLHIV Stigma Index