



**KENYA COUNTRY ASSESSMENT REPORT
2021**





PARTNERS



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NATIONAL EMPOWERMENT NETWORK OF PEOPLE LIVING WITH HIV IN
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P.O BOX 75654 - 00200

NAIROBI, KENYA

Website: www.nephak.or.ke

Email: info@nephak.or.ke

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THE KENYA PLHIV STIGMA INDEX 2.0 NATIONAL STEERING COMMITTEE

NAME	AFFILIATION	ROLE
Dorothy Onyango	WOFAK	Chairperson
Fridah Muinde	NACC	Co-Chair
Nelson Otwoma	NEPHAK	Coordinator
Jane Ng'ang'a	INERELA+ Kenya	Member
Lucy Ghati	ICW - Kenya	Member
Cindy Amaiza	Y+ Kenya	Member
Churchill Alumasa	DISCOK	Member
James Kamau	KETAM	Member
Anne Okaro	KENEPOTE	Member
Solomon Wambua	KPs Consortium	Member
Allan Maleche	KELIN	Member
Emily Muga	KRCS	Member
Ludfine A. Bunde	UNAIDS	Member
Sheilla Masasabi	UNDP	Member
Cynthia Oliech	UNDP	Member
Hellen Magutu	ILO	Member
Dr. Mary Mugambi	NASCOP	Member
Reuben Musundi	NACC	Member
Dr. Dorothy Odhiambo	UoN	Research Partner

ACRONYMS

AHA	AMREF Health Africa
aPNS	Assisted Partner Notification Services
ARVs	Antiretroviral
CCM	Country Coordinating Mechanism
CBOs	Community Based Organizations
CSOs	Civil Society Organisations
DISCOK	Discordant Couples Organization of Kenya
eMTCT	Elimination of Mother-to-Child Transmission
FGDs	Focus Group Discussions
FSWs	Female Sex Workers
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
HAPCA	HIV/AIDS Prevention and Control Act
HAT	HIV and AIDS Tribunal
HTS	HIV Testing Services
ICW	International Community of Women Living with HIV/AIDS
IEC	Information, education and communication
ILO	International Labour Organization
IPPF	International Planned Parenthood Association
KENEPOTE	Kenya Network of HIV Positive Teachers
KENPHIA	Kenya Population-Based HIV Impact Survey
KETAM	Kenya Treatment Access Movement
KIIs	Key Informant Interviews
KPC	KP Consortium
KPs	Key Populations
KRCS	Kenya Red Cross Society
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex
MIPA	Meaningful Involvement of People Living with HIV and AIDS
MNCH	Maternal New Born and Child Health
MSM	Men who have Sex with Men
MSWs	Male Sex Workers
NACC	National AIDS Control Council

NACOSTI	National Commission for Science and Technology Innovation
NASCOP	National AIDS and STIs Control Program
NEPHAK	National Network of people living with HIV/AIDS in Kenya
NCDs	Non-Communicable Diseases
NGOs	Non-Governmental Organisations
ODK	Open Data Kits
PLHIV	People living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
PPS	Probability Proportional to Size
PrEP	Pre-Exposure Prophylaxis
PWID	People Who Inject Drugs
PWUD	People Who Use Drugs
RAs	Research Assistants
RCs	Regional Coordinators
SAD	Stigma and Discrimination
SRHR	Sexual Reproductive Health Rights
SW	Sex Workers
TG	Transgender or Trans* community
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Program
UNGASS	United Nations General Assembly Special Session on HIV/ AIDS
VDT	Venue-Day-Time
WOFKA	Women Fighting AIDS in Kenya
Y+ Kenya	Network of Young People Living with HIV
WSW	Women Sex Workers



FOREWORD

More than 30 years into the HIV and AIDS, Kenya has made significant strides in the response to the epidemic. The significant strides have been as a result of the multi-sectoral response under the leadership of the National AIDS Control Council (NACC) and which has brought everyone to play their role in responding to the epidemic. People living with, at risk of and affected by HIV and related co-infections, including Tuberculosis and other non-communicable diseases (NCDs) continue to play an important role in the response. Regrettably, HIV-related stigma and discrimination continue to hamper the efforts aimed at delivering the HIV prevention, treatment and care targets.

The Kenya PLHIV Stigma Index 2.0 Report is a great milestone in the efforts in generating evidence that PLHIV and those who work with them need to confront HIV-related stigma and discrimination. The survey and the report under the leadership of the NEPHAK is a testimony to the fact that the Principle of Greater Involvement of people living with HIV and AIDS (GIPA) is alive in Kenya. Going forward, the PLHIV networks that have worked with NEPHAK in producing this report will need to be capacitated, empowered and resourced.

The PLHIV Stigma Index 2.0 report fits well with the Kenya AIDS Strategic Framework aspiration and strategic focus area that seeks to institutionalize progress monitoring of HIV-related stigma and discrimination and other health and human rights violation. As an update, this report confirms that HIV-related stigma and discrimination is reducing in Kenya. However, since the reduction is observed through a national summary, it is still important to note that there are certain aspects of stigma that remain high and rising. Equally, the stigma experienced by adolescent girls and young women (AGYW) and the key populations whether they are sex workers (SWs), men who have sex with men (MSM), the Trans Gender (TG) persons and people who inject and use drugs (PWIUD) remains high.

The report also suggests that the country will still need to do more to put the country in the path to eliminate HIV-related stigma and discrimination by 2030. This is an aspiration that the country has gotten into by being part of the Global Partnership for Action to eliminate all forms of HIV-related stigma and discrimination. The partnership calls for the elimination

of HIV-related stigma and discrimination in all its forms in learning institutions, workplaces and health care settings. This report is one key step towards the actions recommended by the global partnership.

Coincidentally, the PLHIV Stigma Index 2.0 report for Kenya is being unveiled exactly 40 years after the first case of HIV and AIDS was reported. While the HIV-related stigma has persisted for these 40 years, it should be noted that the vice is now manifesting in different ways and among different populations. For example, women and girls confront multiple, intersecting forms of violence, oppression, stigma and discrimination. During displacement and times of crisis, including during the COVID-19 pandemic, the risk of gender-based violence significantly increases for women and girls. This report sheds light on how to respond to HIV-related stigma among women and girls.



Dorothy Onyango, OGW.

CEO, WOFAK and Chair, Kenya PLHIV Stigma Index 2.0 National Steering Committee

ACKNOWLEDGEMENTS

The roll-out of the PLHIV Stigma Index 2.0 Survey in Kenya was realized through support and guidance from a number of individuals and institutions. We are grateful to the National Steering Committee (NSC) that provided leadership, guidance and oversight to the roll-out process: WOFAK, INERELA+ Kenya, ICW – Kenya, Y+KENYA, DISCOK, KETAM, KENEPOTE, KP Consortium, Isthar MSM, Hoymas, KELIN, KRCS, UNAIDS, UNDP, ILO-EA, NASCOP and the NACC.

Most importantly we would like to acknowledge the invaluable role of people living with HIV who participated in this study for their time and sharing their stories. We trust that these findings will contribute to improving the health and quality of their lives and that of people living with HIV and affected communities in general.

We specifically acknowledge the invaluable technical support from the Global Network of people living with HIV (GNP+) that empowered, capacity built and prepared NEPHAK to provide leadership to the Kenya PLHIV Stigma Index 2.0 roll-out. GNP+ provided the PLHIV User Guide and roll-out standards, including the questionnaire and templates that form the core of the PLHIV Stigma Index 2.0 roll-out and survey. GNP+ also provided revised guidelines for the survey sample.

Our acknowledgement also goes to the Ministry of Health and especially the NASCOP and the NACC for their invaluable technical support during the survey. The CASCOs and the NACC Regional Coordinators provided valuable technical input during the report validation and finalization. We highly appreciate their technical support.

We recognize and appreciate the PLHIV Stigma Index 2.0 survey team that comprised of the Research Partner, Regional Coordinators (RCs) and Research Assistants (RAs). Their commitment and strict adherence to research ethics and Confidentiality Agreement ensured that the survey process proceeded smoothly.

Special appreciation is extended to the AMREF Health Africa Ethics and Scientific Review Committee (AMREF-ESRC) and the National Commission for Science and Technology Innovation (NACOSTI) for providing the ethical approval and Research Permit for the survey to proceed.

We sincerely thank the Global Fund to fight AIDS, TB and Malaria (GFATM) for providing the grant for the roll-out of the PLHIV Stigma Index 2.0 in Kenya. Their generous consideration is appreciated. We thank the KRCS for the technical guidance on the use of finances in their capacity as the Principal Recipient for the GFATM grants.

Special thanks go to the UNDP - Kenya for supporting the printing of additional copies of the Kenya PLHIV Stigma Index 2.0 Report.

We would like to acknowledge the invaluable role of people living with HIV who participated in this study for **their time and sharing their stories.**

EXECUTIVE SUMMARY

Introduction

Kenya has made tremendous progress towards reducing new HIV infections and the general prevalence. However, HIV-related stigma and discrimination remain a major challenge in the response to HIV due to persistent negative attitudes towards people living with, at risk of and affected by HIV despite decades of public information campaigns and other awareness-raising efforts. This report documents the findings of the People Living with HIV Stigma Index 2.0 survey in Kenya. It presents the Greater Involvement of People Living with HIV (GIPA) Principle-driven preparation and implementation of the stigma index that is informed by a standard approach developed through the partnership among the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV (ICW), the International Planned Parenthood Association (IPPF), and UNAIDS.

Key Findings

HIV Status Disclosure

Some respondents had a positive experience with disclosure of their HIV status – 45.65 % received support from family members, while 16.71% were supported by non-family members. More than a third (36.38%) said that disclosure became easier over time.

Interactions with Healthcare settings and health status

- Common reason cited for getting an HIV test among women was mainly due to recommendation by a provider or as part of other forms of health care (e.g., antenatal, STI testing/treatment, PrEP; 30.03%) while majority of men tested following illness (29.18%) or for medical male circumcision for HIV prevention procedures.
- Delayed testing for HIV was attributed to fear of other people’s reaction (e.g., family, friends, employer, or community) in case found to be HIV positive (62.05%).
- Interrupted or stopped HIV (antiretroviral) treatment was majorly attributed to the fear of others finding out respondent’s HIV infection (47.15%) and forgetting (25.00%).
- Less than half (43.48%) of respondents sought treatment for opportunistic diseases in the last 12 months.

Human rights and effecting change

- Among PLHIV who experienced human rights abuses, the main actions taken included: contacting a community organization/network of PLHIV for support (45.08%) and filing complaints (22.13%) with a higher proportion being males (30.66%) compared to females (22.09%).
- Positive action taken by PLHIV to address rights abuse ranged from providing emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination (40.70% of female respondents vs 37.28% of male respondents), to challenging or educating someone who was engaging in stigma or discrimination against PLHIV (36.88% females Vs 34.44% males).

External Stigma and Discrimination

Over the last 12 months, the most reported form of stigma or discrimination experienced by PLHIV due to their status included: being subjected to discriminatory remarks or gossip by either family (20.14%) or non-family members (24.66%) and verbal harassment (20.14%).

There were no significant differences in the mean value of the external stigma and

discrimination index by socio-demographic characteristics – age and level of education.

Internalized Stigma and Resilience

Actions related to internalized stigma included: avoiding sex due to their HIV status (15.15% males vs. 19.06% females); isolation from family and/or friends (17.16% males vs. 15.39% females) or decision not to apply for a job due to their HIV status (13.36% males vs. 11.01% females). Relatedly, about 12% of respondents chose not to seek social support while less than 8% avoided going to clinics or hospitals when they needed services due to their HIV status.

Experiences of Stigma with Health Facility Staff

- Respondents reported various forms of stigma for HIV-related care in the hands of health facility staff including: gossip/talking badly of (14% of men and 13% of women); disclosure without consent (12% for both men and women); avoidance (10% for men vs. 9% for women).

- For both men and women instances of stigma for non-HIV-related healthcare included: disclosure of respondent's HIV status without their consent, denial of dental care, physical abuse, advice not to have sex, particularly for women compared to men (range 11-14%) and verbal abuse (10%)

Delayed testing for HIV was attributed to fear of other people's reaction (e.g., family, friends, employer, or community) **in case found to be HIV positive (62.05%)**

Experiences of Stigma and Discrimination among Key Populations

Key Populations face compounded stigma due to their identity and also due to their HIV status, with varying levels and forms for each group.

- Sex Workers reported high levels of stigma and discrimination including emotional violence (30.07%), physical violence (24.94%), blackmail (18.49%), and discriminatory remarks/gossip (23.39%).
- About 20% of Transgender community reported experiencing physical violence.
- About 1 in 5 (17.83%) of Sex Workers reported having avoided seeking healthcare services due to fear of being identified as Sex Workers within the last 12 months of the study and beyond.
- About 1 in 5 (20%) Transgender respondents reported having avoided seeking healthcare services to avoid disclosing their gender identity.
- About 1 in 5 (17.75%) of Persons Who Use or Inject Drugs (PWUD) reported being afraid of seeking health services or avoided seeking health services in the past 12 months due to fear of someone discovering that they use (had used) or inject drugs.

Recommendations

Status Disclosure

1. Develop and roll-out Guidelines on HIV Status Disclosure targeting all settings – health care settings, workplaces and; learning institutions.
2. Increase access to accurate information on HIV and HIV transmission using a range of media tools, including social media.
3. Build the capacity of PLHIV on HIV disclosure with special attention to parent-child disclosure and communication.
4. Train, mentor and support PLHIV openly living with the virus as ‘Anti-Stigma Champions’ to engage in media and community outreaches
5. Government and partners should roll-

out strategies to tackle the root causes of stigma, and ensure health and HIV services are inclusive, accessible and empowering to PLHIV in their diversities.

6. Develop a framework with clear indicators to track and monitor outputs resulting from the stigma associated with disclosure, especially disclosure without consent.

Stigma and Discrimination

Experienced for Reasons Other

Than HIV Status

1. Intensify targeted advocacy and communication aimed at repealing laws and policies that discriminate sex work, adult consensual same sex partnerships and; use of drugs.

About **1 in 5**
(17.75%) of
Persons Who Use
or Inject Drugs
(PWUD) reported
being afraid of
seeking health
services



This will increase uptake of health services that are stigma-free and non-discriminatory.

2. Continuously sensitize law enforcement officers, Court Users Committee (CUCs); religious and community leaders, media and healthcare service providers on anti-stigma and anti-discriminatory strategies and actions.
3. Invest in and expand Key Population-led interventions and programs.
4. Proactively and deliberately work towards the integration of Key Populations Services within public health facilities.
5. Ensure health services under universal health coverage (UHC) are Rights-based and HIV – sensitive.
6. Institutionalize pre-service and in-service training (e.g. focused on HIV-related stigma and discrimination and human rights) for health care workers and professionals who provide care to PLHIV and KPs.

Stigma and Discrimination

1. Continued sensitization and empowerment of PLHIV and family members to take action when violated and/or coerced to disclose their status without consent i.e., Data Protection Act, the role of HIV AIDS Tribunal (HAT) and the provisions of the HIV Prevention and Control Act (HAPCA) that govern privacy, confidentiality and consent.
2. Enhance HIV Treatment Literacy and ensure provision of psychosocial support to PLHIV who experience stigma and discrimination.
3. Review and roll-out workplace policies in public and private institutions to nurture stigma-free workplace environment
4. Strengthen networks (PLHIV, KPs and AYPLHIV) to counter HIV-related stigma and discrimination at national, county levels and community levels.
5. Undertake capacity building to PLHIV leaders to provide the voice and

“Invest in and expand

**Key Population-led
interventions and programs”**

visibility for those facing stigma and discrimination while being accountable to partners and constituents.

6. Invest in community and PLHIV-led monitoring to monitor, track, document, refer and mitigate HIV-related stigma and discrimination.

External Stigma and Discrimination

1. Intensify efforts to address the myths and misconceptions associated with HIV & AIDS at the community, religious settings, workplaces and learning institutions.
2. National and county governments and partners providing health and HIV services to adopt rights-based HIV programming to more effectively promote human rights obligations, including the right to access quality health care for people living with HIV.
3. National and county governments and partners to strengthen access to justice by increasing funding for community-based legal support services, and by supporting PLHIV and KPs networks to monitor workplace discrimination and report violations; ensuring people living with HIV can report discrimination and have their complaints investigated without their names being made public;
4. The Public Service Commission through the AIDS Control Units and

in partnership with PLHIV networks to build capacity of managers, supervisors, workplace peer educators and counsellors to provide accurate and adequate HIV information to their peers in the workplace; ensure comprehensive care and support to PLHIV facing HIV-related stigma in the workplace.

5. Deliberately work towards delivering integrated people-centred health and HIV services (i.e. HIV testing and care services within MNCH and other programs).

Further Research

1. Undertake qualitative research to deepen understanding on different manifestations of HIV related stigma and mitigation strategies across different counties, regions, ages and populations.
2. Foster partnership with the Ministry of Education and undertake qualitative research to unravel the causes, manifestation and impact of HIV related stigma in learning institutions.
3. Undertake qualitative studies to improve the evidence based on work-related stigma and discrimination so that targeted and effective intervention strategies may be devised and implemented.

1.0 INTRODUCTION

1.1 Background

HIV and AIDS related stigma has been on the decline in many countries, especially those with high and rising prevalence. However, large proportions of people still hold stigmatizing and discriminatory attitudes. Distinctively, HIV-related stigma and discrimination is always talked about within the HIV and AIDS response, but it is difficult to quantify, therefore rarely discussed, measured or reported in many programme interventions.

Stigma and discrimination are exercised at multiple levels in the society: within individuals, families, communities, institutions and media, and in government policies and practices. Yet, despite the recognition of the significance and prevalence of stigma and discrimination as barriers to accessing HIV and other health services, few countries, have clearly outlined and prioritized activities to reduce or eliminate them in their national AIDS plans. The existence and persistent continuation of stigma and discrimination in many contexts undermine efforts devoted to attaining global HIV goals. HIV-related stigma and discrimination is a key barrier to accessing HIV prevention, treatment care and support, making it a significant threat to achieving the fast-track targets and ending AIDS by 2030. Stigma and discrimination is also a human rights issue.

In response to the prevalence of stigma and discrimination, the UNAIDS and partners came up with the Global Plan of Action to Eliminate all forms of HIV related Stigma and Discrimination by 2030. If the aspirations of the Global Plan are to be achieved, the stumbling blocks of stigma and discrimination (SAD) need to be addressed (Pulerwitz J, Bongaarts, 2014).

Whereas a lot is known about the influence of HIV-related stigma and discrimination, there is no coherent picture of its actual magnitude and impact on communities infected, affected and at risk of HIV. To address this lack of evidence, a measurement tool: The *People Living with HIV Stigma* Index was developed through an international partnership amongst the International Community of Women Living with HIV (ICW), the Global Network of People Living with HIV (GNP+), International Planned Parenthood Association (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) to quantify HIV stigma and discrimination related experiences; document evidence-based responsive strategies; describe the perceived stigma and discrimination by PLHIV; provide evidence-informed advocacy, policy reforms and service delivery; and broaden the understanding of the extent and forms of stigma and discrimination.

The People Living with HIV Stigma Index 2.0 is an updated version of the index that was finalized in 2017. The updates were made to reflect important changes in the response to HIV, such as, the recommendation for early initiation to treatment and increased evidence about how different populations are affected by stigma. Changes to the

original index in version 2.0 include greater attention to the experiences of PLHIV in relation to: accessing HIV testing, care and treatment; using and adhering to antiretroviral therapy and achieving viral load suppression; and experiencing stigma within HIV care and other health care settings. PLHIV Stigma Index version 2.0 also assesses stigma and discrimination experienced by PLHIV for reasons other than their HIV status – such as their sexual orientation or gender identity, or being involved in sex work or drug use.

New HIV infections declined from **75,000** in 2010 to **41,416** in 2019, an equivalent of a **44 percent** reduction of cases (NASCOP, 2020).

1.2 Kenya Country Context

Kenya has made progress towards reducing new HIV infection and the general prevalence. New HIV infections declined from 75,000 in 2010 to 41,416 in 2019, an equivalent of a 44% reduction of cases (NASCOP, 2020). HIV prevalence among adults (15-

49 years) in the general population, declined from a peak of about 10% in the mid-1990s to 4.5% in 2020. However, the HIV epidemic in Kenya continues to be disproportionately higher among females than males. The burden of HIV remains highest for the age category of 15-49 years. The epidemic shows a pattern of generalization across the country, concentrated among sub-populations, and a mix of both in some geographical locations. The geographical diversity of HIV prevalence ranges from a high of 20.1% in Homa Bay County to a low of 0.2% in Mandera and Wajir counties (Kenya HIV Estimates 2020).

Kenya needs to accelerate progress in the reduction of new HIV infections. However, HIV-related stigma and discrimination has been a major challenge in reducing HIV incidences due to persistent negative attitudes towards PLHIV despite decades of public information campaigns and other awareness-raising efforts. In Kenya, several interventions and anti-stigma strategies have been targeted at the general public through mass media and community-based approaches. The comprehensive program adopted include: increasing knowledge and awareness, promoting behavior change, counseling, and contact with affected groups through group therapies and community outreach.

HIV-related stigma and discrimination continue to manifest differently and in varying degrees, in different contexts, and often work to worsen existing social inequalities while intersecting with other forms of stigma, including gender-based discrimination, ethnicity, sexuality and those that are associated with particular behaviour and activities. This has serious implications for HIV prevention, treatment, care and support with reduced individual's willingness to be tested for HIV, to disclose their HIV status, to practice safer sex and to access health care. Stigma impedes the efforts of services to reach people most in need of prevention, treatment and

care and impacts an individual's capacity to acknowledge and manage their own HIV infection, affecting their physical and psychological well-being and quality of life. Furthermore, governments' efforts towards minimizing HIV transmission and guaranteeing of protection of the human rights of PLHIV are hampered by the social tolerance of stigma and discrimination.

Although Kenya was one of the first countries to come up with the HIV and AIDS Prevention and Control Act (HAPCA), this law also came along with additional challenges, including a section that ended up criminalizing HIV. Section 24 of HAPCA which provided for the prosecution of people who knowingly and recklessly infect others with HIV was later declared unconstitutional by the Court . HAPCA also came up with the HIV and AIDS Tribunal (HAT) with the mandate to litigate HIV-related violations as stipulated under HAPCA. One key constraint is that as a subordinate court, the HAT only litigates violations that meet a certain legal threshold. As such, prejudices and stereotypes, including key aspects of HIV-related stigma, are never attended to by the Tribunal.

¹The same criminalization is still found within the Sexual Offences Act, Section 26.

1.3 The People Living with HIV Stigma Index Survey in Kenya

The PLHIV stigma index 2.0 survey was implemented in Kenya by the National Empowerment Network of People Living with HIV and AIDS in Kenya (NEPHAK), with technical support from the National AIDS and STIs Control Program (NASCO), National AIDS Control Council (NACC), the UNAIDS, UNDP, KELIN and the Global Network of People Living with HIV (GNP+) with funding from the Global Fund to fight AIDS, TB and Malaria (GFATM) through the Kenya Red Cross Society (KRCS).

The survey used the Greater Involvement of People Living with HIV and AIDS (GIPA) principle in the preparation and implementation of the Stigma Index as a way of empowering both the PLHIV individuals and communities most affected by the epidemic. In addition to compiling evidence-based information on stigma and discrimination, the survey on the Stigma Index was expected to be a catalyst for fostering change in the communities in which it is used. PLHIV groups undertaking the survey process came to understand the dynamics of stigma and discrimination in their locality and gathered solid data to back their advocacy work around strategies to counter stigma.

In essence, the Kenya PLHIV Stigma Index survey defined and unearthed changes and

trends of stigma, tracked their underlying drivers, provided evidence for the success or failure of current programming, what these programmes entail and highlighted neglected areas for future action. The findings of the stigma index survey support policy reforms, programme changes in support of human rights of PLHIV, and pinpoint changing trends in stigma and discrimination experienced by PLHIV. Ultimately, it is hoped that the index will foster change within communities as it is being used, and become a powerful advocacy tool that acts to support the collective goal of governments, community-based organizations, activists and PLHIV alike to reduce the stigma and discrimination linked to HIV.

NEPHAK is a national 'Network' that unites people living with, at risk of and those affected by **HIV** and related co-infections

it is hoped that the index will **foster change** within communities as it is being used, and become a **powerful advocacy tool**

The reduction and where possible elimination of stigma and discrimination will enable countries to meet their UNAIDS fast track targets, including ending AIDS as a public health threat by 2030.

1.4 Objectives of the PLHIV Stigma Index Survey

The overall objective of the Kenya PLHIV Stigma Index 2.0 is to advance the understanding of the causes, extent, manifestation, and impact on care and service uptake, of stigma and discrimination experienced by PLHIV in Kenya.

The specific objectives of the survey were:

1. To quantify and document HIV-related stigma and discrimination experienced by PLHIV in Kenya in order to provide evidence based for improving policies, programs, and to better meet the needs of PLHIV.
2. To improve evidence-based advocacy on HIV-related stigma and discrimination to hasten the achievement of fast-track targets of ending AIDS by 2030.
3. To entrench the Greater Involvement of People Living with HIV and AIDS principle (GIPA principle) in local, regional, and national responses to HIV through an empowerment process that places individual PLHIV, their networks, and local communities at the centre.

2.0 METHODOLOGY

2.1 Study Design

The 2021 Kenya PLHIV Stigma Index survey was a cross-sectional survey targeting PLHIV across the 47 counties. The survey utilized quantitative research methods for data collection and analysis supplemented by a few case narratives of PLHIV lived experiences. In terms of scope, the survey covered the lived experiences of PLHIV on aspects of stigma and discrimination in the domains of access to care and treatment services, employment, reproductive rights and effecting change.

2.2 The Survey Setting

The survey was conducted among PLHIV including Key Populations (KPs) in all the 47 counties clustered into 10 regions based on the former administrative regions (provinces) of Kenya: Nairobi, Coast, Central, North Eastern, Lower Eastern, Upper Eastern, Western, Nyanza, North Rift and South Rift Valley (see Table 1). Nyanza region comprising of five counties: Siaya, Kisumu, Homa Bay, Migori, Kisii, Nyamira, had the highest number of respondents (24.42%) due to high HIV prevalence followed by Nairobi (15.76%) and Western region (10.64%). North-Eastern region had the least number of participants (3.39%) KENPHIA data was used for sampling.

Table 1: Regions of Kenya

Region	Counties	No of PLHIV Sampled	%
North Eastern	Garissa, Wajir, Mandera, Marsabit	72	3.39
Coast	Mombasa, Kwale, Kilifi, Tana River, Lamu, Taita-Taveta	159	7.48
Upper Eastern	Meru, Tharaka-Nithi, Embu, Isiolo	82	3.86
Lower Eastern	Kitui, Machakos, Makueni	116	5.46
North Rift Valley	Turkana, West Pokot, Trans-Nzoia, Uasin Gishu, Elgeyo-Marakwet, Nandi, Baringo	212	9.98
South Rift Valley	Laikipia, Nakuru, Narok, Kajiado, Kericho, Bomet, Samburu	206	9.69
Western	Busia, Vihiga, Kakamega, Bungoma	226	10.64
Nyanza	Siaya, Kisumu, Homa Bay, Migori, Kisii, Nyamira	519	24.42
Central Nyandarua	Kirinyaga, Nyeri, Muranga, Kiambu	198	9.32
Nairobi	Nairobi	335	15.76
Total (Kenya)		2125	100

2.3 Survey Population

The target population were PLHIV drawn from rural and urban settings from all 47 counties. The participants were PLHIV aged 18 years or more including KPs drawn from the following groups: Sex Workers, Transgender persons, Gay men, MSM, Lesbians, WSW, Sex Workers and People Who Inject or Use Drugs (PWU/IDs).

2.3.1 Survey Participant Inclusion and Exclusion Criteria

Below are the inclusion and exclusion criteria for eligibility to participate in the survey.

Table 2: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria on age and knowledge of HIV status
<ul style="list-style-type: none"> • 18 years of age or older • Is aware of their status as living with HIV • Has known that they were living with HIV for at least 12 months • Is mentally sound and capable of providing consent to participate • Speaks the dominant language (Kiswahili which is the national language and English which is the official language) • Has provided informed consent to participate in the study 	<ul style="list-style-type: none"> • One seen as being under the influence of alcohol or any substance likely to impair logical reasoning • One with a condition that, in the opinion of the Investigator, would preclude provision of voluntary informed consent, make participation in the survey unsafe, complicate interpretation of survey outcome data, or otherwise interfere with achieving the survey objectives. • Someone unwilling to provide consent for interviews or unable to provide any form of consent to participate in the survey.

2.3.2 Sample Size

The sample size for the PLHIV Stigma Index survey was based on a key area of the questionnaire that shows up as a common concern across settings: the avoidance of seeking healthcare because of anticipated stigma. The survey was powered at the national level based on the precision around the estimate of avoidance of seeking healthcare based on HIV status. According to the 2014 Kenya HIV stigma Index Survey, 6.7% of PLHIV avoided seeking healthcare because of anticipated stigma. Based on this data and a target precision of 2.20% at a confidence interval of 95%, a sample size of 1985 respondents was required (https://hall.shinyapps.io/PLHIV_Stigma_Sample_Size_Calculator/). The sample size was increased to 2,200 taking into consideration a 10% non-response. The sample was stratified by sex based on the sex ratio of PLHIV in 2018—the population of PLHIV was estimated at 1.3 million comprising 62% females and 38% males (NASCOP, 2020) Report.

Importantly, the Kenya PLHIV Stigma Index 2.0 was established to try and overcome assumptions about who is and who is not a key population. Enrolment was monitored to ensure that the distribution of the sample should be in range with what is known about the distribution of PLHIV. In

the absolute minimum, 25% of the overall sample was allocated to participants with a key population background (i.e., gay men, MSM, Lesbians, Transgender community, Sex Workers and PWU/IDs). Table 3 Presents the sample size distribution. A total of 2125 PLHIV were interviewed



6.7 percent of PLHIV avoided seeking healthcare because of anticipated stigma.

Table 3: Sample size Distribution

Category	Female n(%)	Male n(%)	Total n(%)
General Population	932(72.81)	572(367.50)	1504(70.78)
People Who Use & Inject Drugs	41(3.20)	39(4.62)	80(3.76)
Sex Workers (SW)	236(18.44)	75(8.88)	311(14.64)
Lesbian	9(0.71)	5(18.52)	14(0.66)
Gay/ Transgender (TG)	-	45(5.33)	45(2.12)
Men who have Sex with Men (MSM)	6(0.47)	8(0.95)	14(0.66)
Women who have Sex with Women (WSW)	-	71(8.40)	71(3.34)
Bisexuals	29(2.27)	-	29(1.36)
Total	27(2.11)	30(3.55)	57(2.68)
Total	1280 (100.00)	845 (100.00)	2125 (100.00)

2.3.3 Participant recruitment

Broadly, two approaches of the sampling were considered with a focus on proportional sampling at sites where PLHIV may visit, including treatment facilities and community venues/support groups (venue-based samples), as well as by leveraging social networks for limited chain-referral sampling (limited chain-referral) for Key Populations.

2.3.3.1 Venue-based Sampling

A two-stage stratified random sampling method was used to sample PLHIV. In the first stage, venues were identified and proportionately sampled in each region by the Regional Coordinators (RCs). These venues included treatment facilities such

as the traditional treatment sites but also settings where people living with HIV may be engaged including those less connected to HIV treatment such as community-based support groups and counseling centres. The RCs during pre-data collection visits mapped out and determined the location of treatment and health services and additional venues at a community level where PLHIV visit to receive different kinds of support.

In the second stage, PLHIV interviewers invited potential participants in person at selected venues or by phone by collaborating with NEPHAK. A total of 1,504 PLHIV out of 2125 were sampled using a venue-based approach.

2.3.3.2 Limited chain-referral

To complement the venue-based sampling, limited chain-referral sampling was used to leverage some of the advantages of the use of respondent-driven sampling including generating additional diversity such as of the KPs. The community-based organizations (CBOs) dealing with KPs in each region shared a list of registered members. Out of these lists, eligible potential respondents were met at places of convenience selected with the help of the CBO member who was in a position to identify the eligible participant. After identifying the eligible participant, snowball sampling methods were used to recruit and interview the other eligible members. A total of 621 KPs living with HIV were sampled using a limited chain-referral approach.

Enrolment and interview data were tracked on a weekly basis to identify representation of different affected populations. Adjustments of the sampling strategy were made on a weekly basis to increase recruitment of those underrepresented, including through the use of new participants that are known to be living with HIV but with networks of people less likely to be connected to the existing network or treatment centres.

2.4 Data Collection

2.4.1 Training of Regional Coordinators and Data Collectors

A three-day national induction workshop was held for 10 Regional Coordinators. The RCs were capacity built through the PLHIV Stigma Index protocol, User Guide and the processes involved in carrying out PLHIV Stigma Index 2.0 survey. The data collection team of PLHIV was recruited and trained to conduct data collection for the survey. The team underwent a 3-days training organized in 4 groups led by RCs and supported by NEPHAK, the National Steering Committee (NSC) members, and a consultant. The training of data collectors took place regionally to limit overcrowding and ensure adherence to COVID -19 protocols. The data collection team training was held between November-December 2020. The training comprised research ethics, data collection techniques, gender, sexuality, and other sensitive topics, as well as working with PLHIV and Key Populations. The survey teams were also trained on the Stigma Index 2.0 tool.

2.4.2 Data collection

Data collection was conducted between February-March 2021. Data collection was done electronically using Open Data Kit (ODK) programme installed on tablets running on the Android operating system. Data collection was conducted in a face-to-face approach (CAPI) by trained interviewers living with HIV. A structured questionnaire developed by the global partners (UNAIDS, GNP+, ICW, IPPF) was reviewed and adapted to the Kenyan context where necessary. The questionnaire was translated into Kiswahili, Kenya's national language spoken by more than 85 % of the population.

The questionnaire explored the following key areas: Experience of stigma and discrimination and their causes, disclosure,

The data collection team training ... comprised research ethics, data collection techniques, gender, sexuality, and other sensitive topics, as well as working with PLHIV and Key Populations.

internal stigma (the way PLHIV feel about themselves), rights, laws and policies, effecting change, interaction with healthcare services including HIV testing, human rights and effecting change, stigma and discrimination experienced for reasons other than HIV status, and personal experiences of stigma and discrimination. Each interview lasted approximately one-hour long. To ensure privacy and confidentiality during

the study, interviewers were trained to ensure that interviews were conducted in safe and secure locations. If privacy of a participant could not be ensured, interviewers were instructed to reschedule the interview. Data was transmitted to a secure server based at NEPHAK head office in Nairobi.

2.4.3 Field Pre-test

Before data collection began a field pre-test was conducted in selected sub-counties of Nairobi and Nyeri in January 2021. The pre-test involved a small sample of PLHIV who were capacity built through the entire survey process, including going through the questionnaire and submission of completed forms.

2.5 Ethical Consideration

Ethical clearance for the 2021 Kenya stigma Index survey was obtained from African Medical and Research Foundation Ethics and Scientific Review Committee (AMREF-ESRC). The National Commission for Science and Technology Innovation (NACOSTI) granted the research clearance. All survey participants were capacity built through the consenting process and were only interviewed after signing the consent form. In order to ensure confidentiality for participants in the survey, no personal identifiers were collected during recruitment or participation. In addition, potential participants' contact information were not recorded. Data was stored on a secure server with no personal identifiers. To reduce the potential breach of privacy and confidentiality, all survey staff were required to receive ethics training and be

committed to maintaining confidentiality throughout and after their interaction with the participants. Staff supporting the PLHIV stigma index survey also signed the Confidentiality Agreement to uphold the highest standards of ethics during the study.

Data was stored on a secure server with no personal identifiers. To

reduce the potential breach of privacy and confidentiality, all survey staff were required to receive ethics training and be committed to maintaining confidentiality

3.0 RESULTS

3.1 Background characteristics

This section presents the background characteristics of the respondents.

3.1.1 Sex and gender identity

Respondents living with HIV were asked to state the sex they were assigned at birth, on their birth certificate. Majority of the 2125 PLHIVs (60.2%) indicated they were female while the rest (31.76%) said they were male at birth (Table 4). For some respondents, their gender identity differs from the sex they were assigned at birth. The PLHIVs were therefore asked to state how they describe themselves. Whereas majority (98.55% female, 96.09% male, 98.52%) of the PLHIVs still identified themselves with their sex at birth, 14(0.66%) identified as transgender while a very small minority 10 (0.47%) did not identify as female, male, or transgender. Furthermore, 7 (0.33%) respondents preferred not to answer the question about their gender identity.

Table 4: Participants current gender identity

	Sex assigned at birth		Total
	Female	Male	
Gender identity	n(%)	n(%)	n(%)
Female	1261(98.52)	19(2.25)	1280(60.24)
Male	2(0.16)	812(96.09)	845(38.31)
Transgender	6(0.47)	8(0.95)	14(0.66)
Gender Non-conforming (Do not identify as female, male, or transgender)	9(0.7)	1(0.12)	10(0.47)
Prefer not to answer	2(0.16)	5(0.59)	7(0.33)

3.1.2 Age

The mean age of participants was 38.62 years with no significant difference between males and females. Table 5 presents the distribution of respondents by age group. About one-fifth (19.91%) of respondents were aged 50 years or more while the distribution was almost equal for respondents ages 20-29 years (26.87%), 30-29 years (25.79%) and 40-49 years (26.40%). Very few adolescents (18-19years) participated in the survey 22(1.04%).

Table 5: Participants age category

	Female	Male	Total
n(%)	Age category	n(%)	n(%)
11(1.30)	18-19	11(0.86)	22(1.04)
265(31.36)	20-29	306(23.91)	571(26.87)
163(19.29)	30-39	385(30.08)	548(25.79)
178(21.07)	40-49	383(29.92)	561(26.40)
228(26.98)	50 +	195(15.23)	423(19.91)
39.41(13.93)	Mean age (SD)	38.10(10.95)	38.62(12.24)

3.1.3 Period of time living with HIV

Respondents were asked to state how long they had known their HIV status (i.e., the number of years since they received their first diagnosis). Almost half of PLHIV interviewed (49.04%) indicated that they had known their HIV status for a period of 10 years or more (Table 6). Over 15% of PLHIV interviewed indicated knowing their HIV status for between 1-3 years or 4-6 years, while at least 1 in 10 (12.80%) knew their HIV status for 8-9 years. Less than 4% of respondents indicated they had known their HIV status for up to one year.

Table 6: Duration respondents had known their HIV-positive status

	Female	Male	Total
	n(%)	n(%)	n(%)
Up to 1 year	39(3.05)	31(3.67)	70(3.29)
1-3 years	166(12.97)	153(18.11)	319(15.01)
4-6 years	184(14.37)	143(16.92)	327(15.39)
7-9 years	175(13.67)	97(11.48)	272(12.8)
Above 10 years	660(51.56)	382(45.21)	1042(49.04)
Can't remember	56(4.38)	39(4.62)	95(4.47)

3.1.4 Relationship status and children

About three-quarters of women (74.91%) and two-thirds of men (63.98%) were currently in an intimate/sexual relationship (Table 7).

Respondents were asked to indicate the number of children living in their household and/or that they take care of (including feeding, educating, providing psychosocial support or shelter). Majority (8 in 10) of the respondents had at least one child in their household or whom they took care of. Almost a half (48.75%) had 1-3 children, more than a quarter (27.48%) had 4-6 children while 128(6.02%) had 7 or more children in their households.

Table 7: Relationships and Children

	Female n(%)	Male n(%)	Total n(%)
Currently in an intimate relationship	819(63.98)	633(74.91)	1452(68.33)
Partner living with HIV	437(53.36)	407(64.30)	844(58.13)
Number of Children in the household			
None	133(10.39)	244(28.88)	377(17.74)
1-3 children	689(53.83)	347(41.07)	1036(48.75)
4-6 children	388(30.31)	196(23.2)	584(27.48)
7+	70(4.84)	58(6.86)	128(6.02)

3.1.6 Level of education

A total of 196 (9.22%) of respondents were still attending school by the time of the survey. More than a third of the participants 775 (36.47%) had attained primary level of education or secondary education 796 (37.46%) while 266 (12.52%) had a higher level of education (university or tertiary).

Table 8: Distribution of respondents by highest level of formal education completed

	Male n (%)	Total n (%)	n (%)
Proportion currently attending school	101(7.89)	95(11.24)	196(9.22)
Highest level of formal education completed			
No formal education	111(8.67)	38(4.5)	149(7.01)
Primary	509(39.77)	266(31.48)	775(36.47)
Secondary	445(34.77)	351(41.54)	796(37.46)
Vocational school	77(6.02)	62(7.34)	139(6.54)
University/tertiary education	138(10.78)	128(15.15)	266(12.52)

3.1.7 Work status

Out of 2125 PLHIV interviewed, only 208 (9.79%) were engaged in full-time employment, 264 (12.42%) worked on a part-time basis while 601(28.28%) were self-employed or worked as casuals. More than a third of respondents were unemployed 756 (35.58%). A higher proportion of females than males were unemployed (38.28% vs 31.48%).

Table 9: Employment status

Employment status	Female n (%)	Male n (%)	Total n (%)
In full-time work (as an employee)	114(8.91)	94(11.12)	208(9.79)
In part-time work (as an employee)	150(11.72)	114(13.49)	264(12.42)
Working full-time, but not as an employee (self-employed or business owner)	172(13.44)	124(14.67)	296(13.93)
Doing casual or part-time work (self-employed or paid work for others)	354(27.66)	247(29.23)	601(28.28)
Unemployed	490(38.28)	266(31.48)	756(35.58)

3.1.8 Ability to meet basic needs

To provide a general idea of a PLHIV economic situation, respondents were asked to indicate how often, within the last 12 months, they had not been able to meet their basic needs, such as food and shelter. Nearly two-thirds 1389 (65.36%) of the PLHIV indicated that some of the times they were unable to meet basic needs in the past 12 months, whereas 403 (18.96%) expressed their inability to meet basic needs most of the time (Table 10).

Table 10: Ability to meet basic needs

	Female	Male	Total
Unable to meet basic needs in last 12 months	n (%)	n (%)	n (%)
Never	213(16.64)	120(14.2)	333(15.67)
Some of the time	825(64.45)	564(66.75)	1389(65.36)
Most of the time	242(18.91)	161(19.05)	403(18.96)

3.1.9 Membership of specific groups

Belonging to certain groups might contribute to one’s experience of HIV-related stigma and discrimination. More than one-fifth of the respondents identified as a member of a racial, ethnic, or religious minority (n=470), 4.47% identified as members of an indigenous group (n=95), 6.49% as identified as living with a disability (n=138). A smaller proportion of respondents (fewer than 3%) identified as members of refugee or asylum seeker, migrant worker, internally displaced person or experienced incarceration in prison before (Table 11).

Nearly **two-thirds** 1389 **(65.36%)** of the PLHIV indicated that some of the times they were unable to meet basic needs

Table 11: Group identity

Category of people	Response categories	Female (N= 1,280) n (%)	Male (N=850) n (%)	Total (N=2125) n (%)
Member of a racial, ethnic, or religious minority	Yes	299(23.36)	171(20.24)	470(22.12)
Member of an indigenous	Yes	63(4.92)	32(3.79)	95(4.47)
Living with a disability (vision, hearing, mobility, intellectual/developmental) of any kind (other than HIV)	Yes	74(5.78)	64(7.57)	138(6.49)
Refugee or asylum seeker	Yes	6(0.47)	6(0.71)	12(0.56)
Migrant worker	Yes	27(2.11)	13(1.54)	40(1.88)
Internally displaced person	Yes	30(2.34)	22(2.6)	52(2.45)
Incarcerated/in prison	Yes	15(1.17)	25(2.96)	40(1.88)

3.2 HIV STATUS DISCLOSURE

3.2.1 People who had disclosed their status

Figure 1 presents disclosure status to a selected category of people. Overall, disclosure was most common to husband/wife/partners, other family members, children as well as friends. In some instances, disclosure varied among women and men. Close to half of the respondents disclosed their status to their partner (59.9% of males vs. 49.1 % of females) and other family members (49.6% of men vs. 55.7% of women). More than a quarter of men (29.5%) disclosed their status to their children compared to 44.1% of women. Over a third of respondents disclosed their status to friends (36.3% of males vs. 39.1% of females). Disclosure was least common to neighbors, coworkers, employers, community leaders, classmates and teachers.

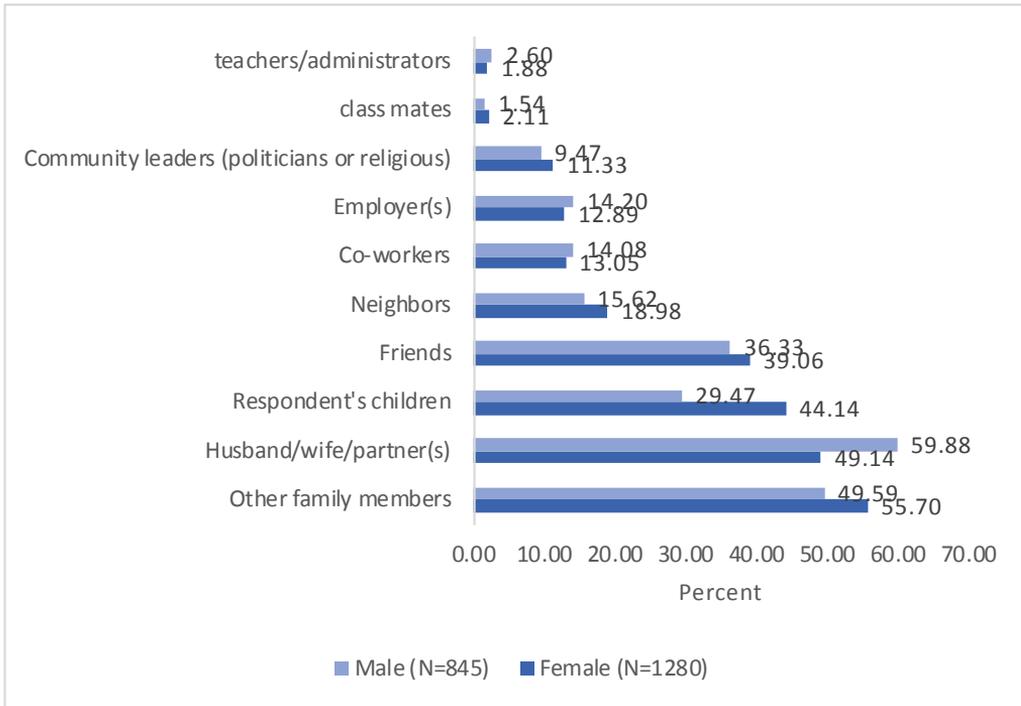


Figure 1: Disclosure of HIV status

3.2.2 Disclosure without Consent

The respondents were further asked whether their status was ever disclosed to different categories of persons/groups without their consent. While disclosure was most common to husband/wife/partners, other family members, children as well as friends, more than two-thirds (75%) of these disclosures were done with the consent of the respondent. However, almost half of disclosure among classmates and community leaders happened without consent.

Table 12: Proportion of respondents whose HIV status was ever disclosed without consent

	Yes	No	N
Husband/wife/partner(s)	20.39	79.61	1135
Respondents' children	20.44	79.56	814
Other family members	21.4	78.6	1132
Friends	24.48	75.52	807
Neighbors	31.71	68.29	375
Employer (s)	34.94	65.06	285
Co-workers	37.33	62.67	286
Your teachers/administrators	43.48	56.52	46
Your class mates	48.53	51.47	40
Community leaders	50.00	50.00	225

3.2.3 Experiences on HIV status disclosure

Table 13 presents the proportion of PLHIV with positive experiences when disclosing HIV status. Slightly less than a half of respondents reported having a positive experience disclosing status to people close to them (e.g., partner, family, close friends). About 45.65% of respondents indicated that family members were supportive when they first learned about the respondent's HIV status. About 19.29% (410) of PLHIV had a positive experience disclosing status to people they did not know very well. Similarly, 355 (16.71%) indicated that people they did not know very well were supportive when they first learned about the respondent's HIV status. More than a third of respondents 773 (36.38%) indicated that disclosure became easier over time.

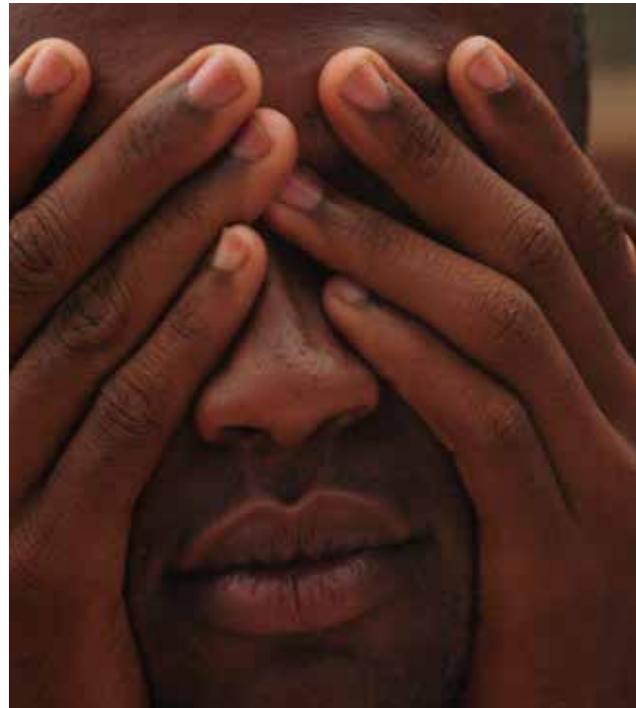


Table 13: Proportion agreeing with statements about positive experiences when disclosing HIV status

General views	Female n (%)	Male n (%)	Total n (%)
Disclosing your HIV status to people you are close to (e.g., partner, family, close friends) has been a positive experience.	607(47.42)	401(47.46)	1008(47.44)
People you are close to were supportive when they first learned about your HIV status.	578(45.16)	392(46.39)	970(45.65)
Disclosing your HIV status to people you don't know very well has been a positive experience	261(20.39)	149(17.63)	410(19.29)
People you don't know very well were supportive when they first learned about your HIV status.	224(17.5)	131(15.5)	355(16.71)
Disclosing your HIV status has become easier over time	498(38.91)	275(32.54)	773(36.38)

3.3 EXPERIENCE OF STIGMA AND DISCRIMINATION

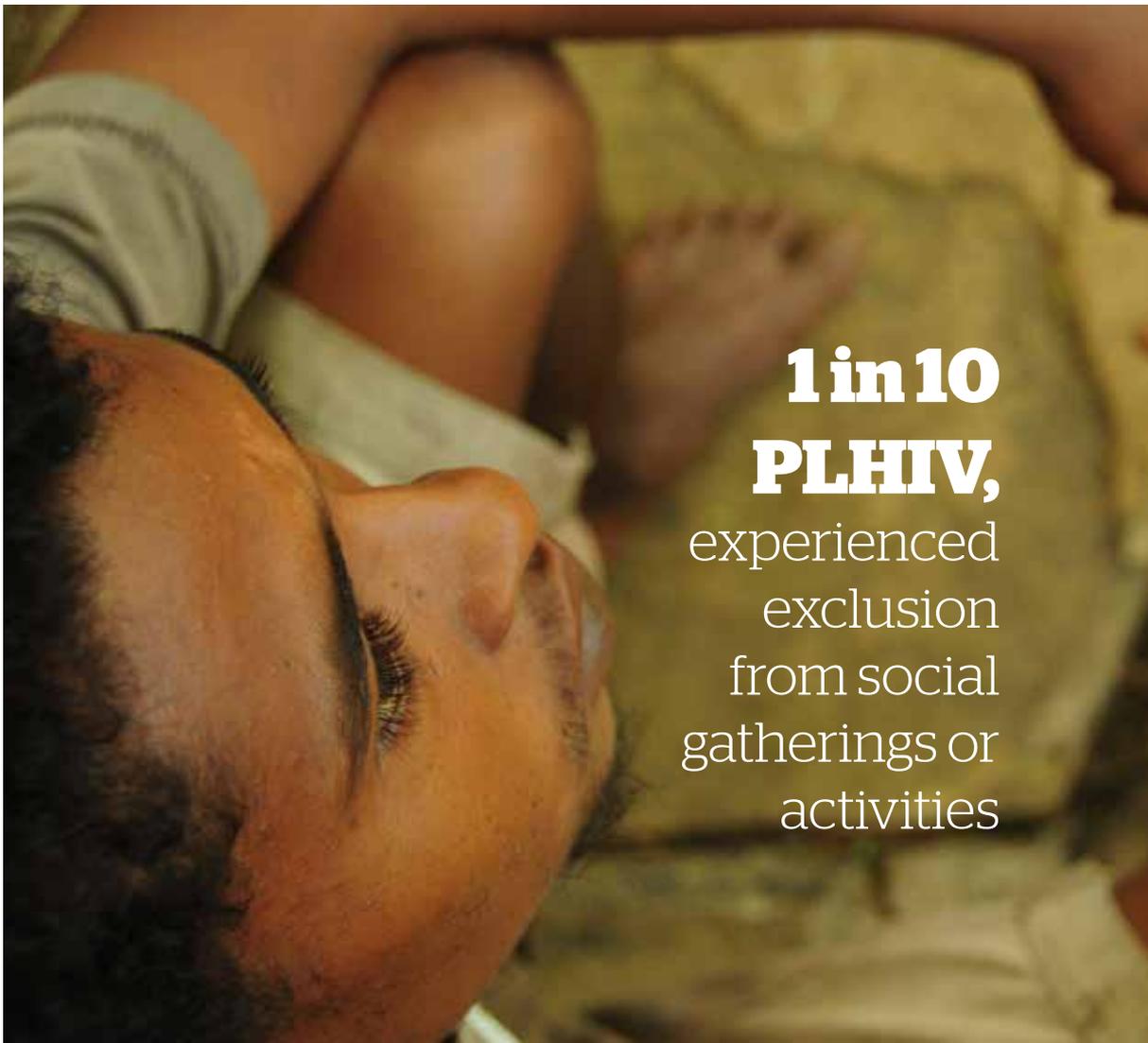
3.3.1 External Stigma and Discrimination

Respondents were asked to indicate if they had experienced stigma and discrimination due to their HIV status either before 12 months or during the last 12 months before the PLHIV stigma index survey. Experience of stigma and discrimination was captured by a series of 11 statements (Table 14) that assessed if a respondent had ever been excluded (from social or religious events); subject to discriminatory remarks or gossip

(by family or non-family members), verbally harassed, blackmailed, physically harassed or hurt, experience spouse/partner discrimination or denied employment or lost their income due to their HIV status.

Over the last 12 months, the most common form of stigma or discrimination experienced by PLHIV due to their status includes being subjected to discriminatory remarks or gossip by either family 428 (20.14%) or non-family members 524 (24.66%) and verbal harassment 428 (20.14%). Notably, at least 1 in 10 PLHIV, experienced exclusion from social gatherings or activities (e.g.,

weddings, funerals, parties, clubs), and family activities, were blackmailed, or experienced discrimination by spouse/partner or children due to their HIV status. The proportion of PLHIV who were denied employment/lost a source of income or job, denied promotion was 6.59% and 4.09%, respectively.



1 in 10
PLHIV,
experienced
exclusion
from social
gatherings or
activities

Table 14: Experiences of stigma and discrimination due to their HIV status

Female Nature of stigma and discrimination	Male Response categories (yes only)	Total		
		n (%)	n (%)	n (%)
Excluded from social gatherings or activities (e.g., weddings, funerals, parties, clubs)	Yes, within the last 12 months	128(10.00)	63(7.46)	191(8.99)
	Yes, not within last 12 months	163(12.73)	102(12.07)	265(12.47)
Excluded from religious activities or places of worship	Yes, within the last 12 months	67(5.23)	46(5.44)	113(5.32)
	Yes, not within last 12 months	113(8.83)	64(7.57)	177(8.33)
Excluded from family activities	Yes, within the last 12 months	133(10.39)	69(8.17)	202(9.51)
	Yes, not within last 12 months	170(13.28)	98(11.60)	268(12.61)
Aware of family members making discriminatory remarks or gossiping about me	Yes, within the last 12 months	278(21.72)	150(17.75)	428(20.14)
	Yes, not within last 12 months	256(20.00)	141(16.69)	397(18.68)
Aware of other people (other than family members) making discriminatory remarks or gossiping about me	Yes, within the last 12 months	337(26.33)	187(22.13)	524(24.66)
	Yes, not within last 12 months	258(20.16)	156(18.46)	414(19.48)
Ever been verbally harassed (e.g., yelled, scolded, or was otherwise verbally abusive)	Yes, within the last 12 months	282(22.03)	146(17.28)	428(20.14)
	Yes, not within last 12 months	206(16.09)	106(12.54)	312(14.68)
Ever blackmailed	Yes, within the last 12 months	157(12.27)	88(10.41)	245(11.53)
	Yes, not within last 12 months	129(10.08)	67(7.93)	196(9.22)

Table 14: (continued)

Female Nature of stigma and discrimination	Male Response categories (yes only)	Total		
		n (%)	n (%)	n (%)
Ever been physically harassed or hurt you (e.g., pushed, hit, or was otherwise physically abusive)	Yes, within the last 12 months	130(10.16)	67(7.93)	197(9.27)
	Yes, not within last 12 months	108(8.44)	64(7.57)	172(8.09)
Ever been refused employment or lost a source of income or job	Yes, within the last 12 months	92(7.19)	48(5.68)	140(6.59)
	Yes, not within last 12 months	107(8.36)	64(7.57)	171(8.05)
Job description or the nature of your job ever been changed, or denied a promotion	Yes, within the last 12 months	59(4.61)	28(3.31)	87(4.09)
	Yes, not within last 12 months	79(6.17)	55(6.51)	134(6.31)
Wife/husband, partner(s) or child(ren) ever experienced discrimination	Yes, within the last 12 months	148(11.56)	89(10.53)	237(11.15)
	Yes, not within last 12 months	119(9.30)	77(9.11)	196(9.22)

3.3.2 External stigma and discrimination index

The external stigma and discrimination index was constructed by adding up all “yes” responses to 11 questions on experience of external stigma and discrimination. Thus, the index ranged from 0 to 11 with the lower value on this index representing a lower experience of external stigma and discrimination. Results from Cronbach’s Alpha test for internal consistency suggest good reliability (11 items; Alpha=0.88).

About one-fifth of respondents reported that being HIV positive made them feel dirty.

Table 15 below presents the mean external stigma index for general and key populations. Overall, the mean value of the external stigma and discrimination index was 2.561 translating to a stigma index of 23.28% among PLHIV. PWU/IDs reported having experienced the highest stigma (38.47%) followed by Lesbian (32.01%) and Sex Workers (28.91%) There were no significant differences in the mean value of the external stigma and discrimination index by socio-demographic characteristics – age and level of education.

Table 15: External stigma and discrimination index

	N	Mean	SD	Index
Men who have Sex with Men (MSM) Gay	110	2.727	2.949	24.79%
Women who have sex with Women (WSW) or Lesbian	48	3.521	3.747	32.01%
Bisexuals	51	1.353	2.719	12.30%
Sex Workers	250	3.180	3.857	28.91%
People Who Use or Inject Drugs	56	4.232	3.330	38.47%
General Pop	1,179	2.458	3.282	22.35%
Over all	1694	2.561	3.351	23.28%

3.4 INTERNALISED STIGMA AND RESILIENCE

3.4.1 Internalized stigma

Definition:

Internalised stigma, also referred to as ‘felt’ stigma or ‘self-stigmatisation’, is used to describe the way a person living with HIV feels about themselves and, specifically, if they feel a sense of shame or discomfort about being HIV-positive. Such stigma can lead to low self-esteem, a sense of worthlessness and depression. Internalised stigma can also result in a person living with HIV withdrawing from social and intimate contact or excluding themselves from accessing services and opportunities out of a fear of having their status revealed or being discriminated against.

3.4.2 Feelings due to HIV Status

Internalized stigma was very high among both female and male respondents living with HIV. Seventy-one% of men and 69% of women reported that it was difficult to tell people about their HIV status (Figure 2). Sixty-two% of men and 64% of women indicated that they hide their HIV status from others. Almost a third of both men and women (range 31-34%) felt worthless or guilty because of their HIV status.

Men reported higher levels of shame than women (31.48% vs. 27.34%). About one-fifth of respondents reported that being HIV positive made them feel dirty.

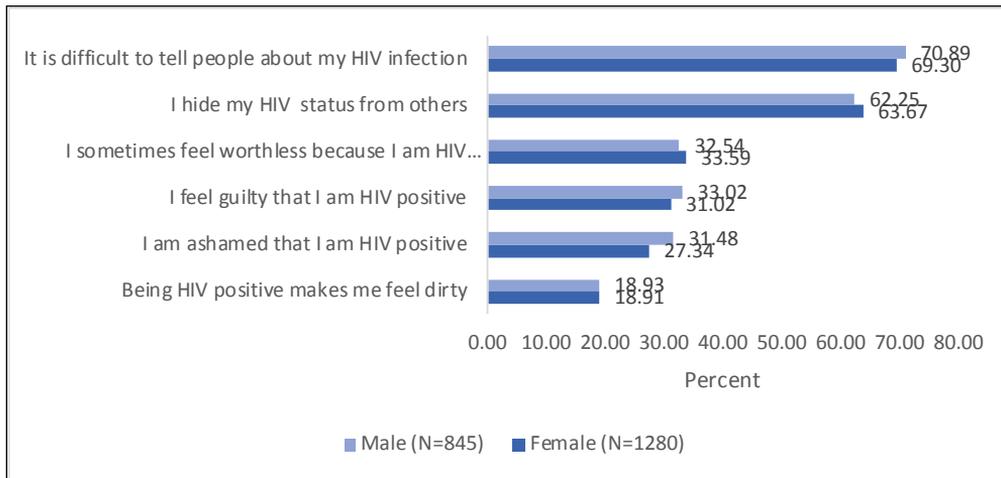


Figure 2: Feelings due to HIV status

3.4.3 Actions due to HIV Status

Figure 3 presents actions taken by PLHIV in the past 12 months. More women than men chose to avoid sex due to their HIV status (19.06% vs. 15.15%). Conversely, more men than women isolated themselves from family and/or friends (17.16% vs. 15.39%) or decided not to apply for a job due to their HIV status (13.36% vs. 11.01%). About 12% of men and women chose not to seek social support while less than 8% avoided going to the clinic or hospital when they needed to due to their HIV status.

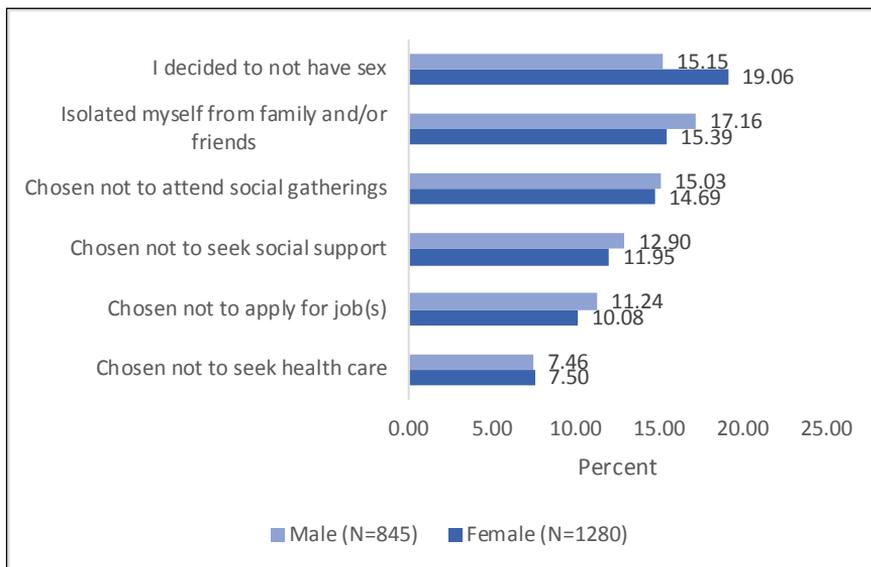


Figure 3: Actions due to HIV status

3.4.4 Internalized stigma index

The internalized stigma index was computed by adding up all “yes” responses to the 6 items on internalized stigma. Thus, the index ranged from 0 to 6 with a lower value on this index representing a lower level of experience of internalized stigma among respondents. Results from Cronbach’s Alpha test for internal consistency suggest good reliability (6 items; Alpha= 0.8393). Overall, the mean value of internalized stigma index was 0.6683 with a standard deviation of 1.2789. (21.32%).

3.4.5 Resilience

Respondents were asked how their HIV status has affected their desires and abilities. Responses in which desires and abilities were “positively affected”

by knowing their HIV status represent resilience. Figures 4 and 5 represent resilience among women and men living with HIV, respectively. Women tended to be more resilient compared to men in a number of aspects. At least 1 in 5 women (range 19-22%) reported that their self-confidence, self-respect, ability to respect other, cope with stress, have close relationship or find love, practice religion and contribute to the community was positively affected by their HIV status for men, the range was 17-22% (Figures 4 and 5). Among both women and men, the desire to have children and achieving personal goals were greatly negatively affected their HIV status.

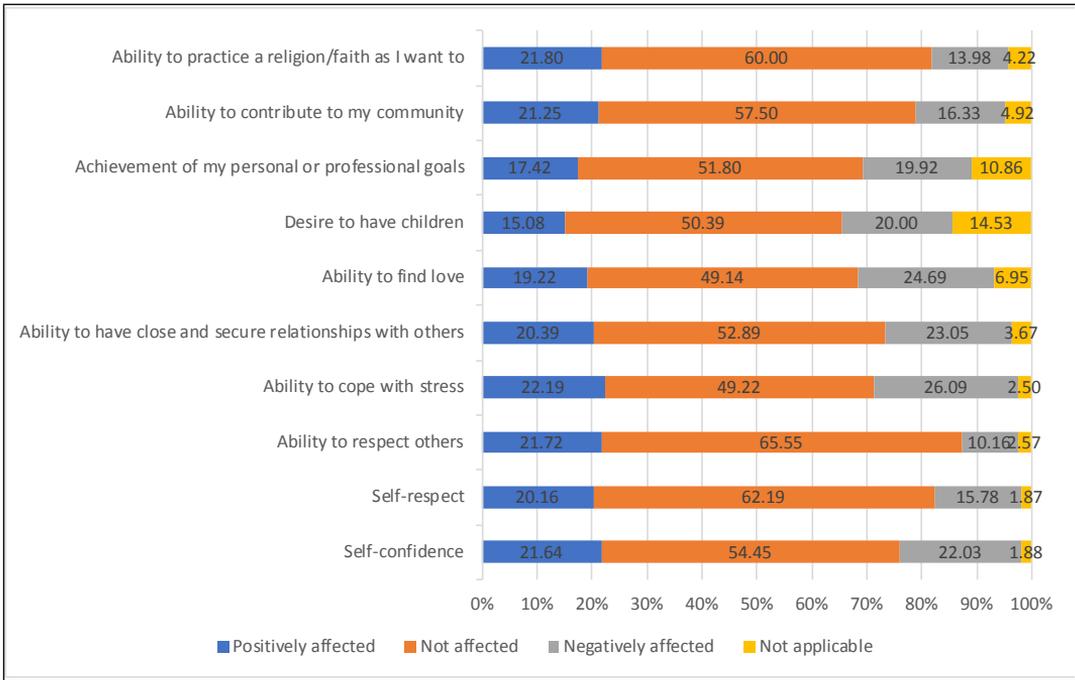


Figure 4: Resilience among women living with HIV (N=1280)

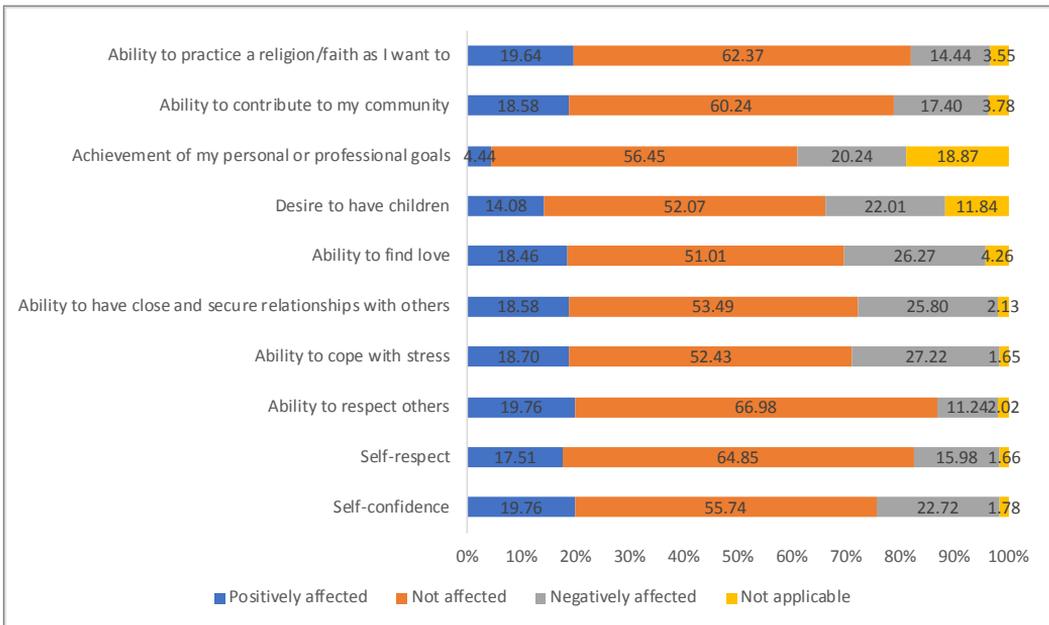


Figure 5: Resilience among men living with HIV (N=845)

Among both women and men, the desire to have children and achieving personal goals were **greatly negatively affected their HIV status.**

3.4.5.1 Previous internalized stigma

The survey assessed whether, in general, a person’s current experiences of having HIV have changed in comparison to before 12 months ago. About a third of women and men felt that their experience improved compared to before 12 months ago while about felt that their experience did not change (Figure 6).

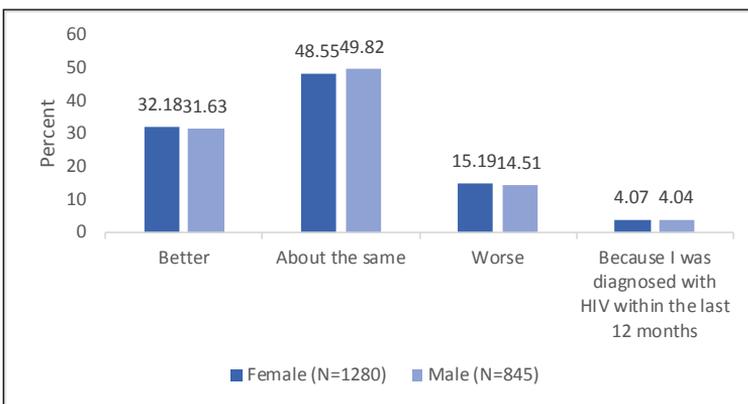


Figure 6: Previous internalized stigma

3.4.5.2 Resilience Index

The Resilience Index similarly adds up all “positively affected by HIV status” responses to all questions on resilience. Thus, a higher value of the index represents higher resilience or ability of the respondent to cope with their HIV status and fulfill their own needs. Table 16 below presents the mean external stigma index by socio-demographic characteristics. Overall, the mean value of the resilience index was 1.911 with a standard deviation of 3.239 (19.11%). There were significant differences in the mean value of the resilience index by gender

Table 16: Resilience Index

	N	Mean	SD	Resilience Index
Female	998	2.0311	3.2739	20.31%
Male	686	1.7362	3.1819	17.36%
Over all	1,684	1.9109	3.2390	19.11%

3.5 INTERACTIONS WITH HEALTHCARE SETTINGS

The section presents information regarding HIV testing, care and treatment experiences, the PLHIV general health status at the time of PLHIV survey and the service delivery experiences while seeking care either at a regular health facility or elsewhere and sexual and reproductive health services. Where possible, data is disaggregated by sex, except for indicators that are only applicable to females such as the reproductive health subsection.

3.5.1 HIV Testing, Care, and Treatment

3.5.1.1 Choice over testing experience

Majority of the respondents (74.78%) tested for HIV by their own choice (n= 1,776), 8.80% indicated being pressured while a similar proportion indicated that they were born with HIV or acquired HIV in infancy/ childhood and therefore were not aware if they had been tested. There was no major difference in the choice of HIV testing by sex.

Figure 7 shows the main reason for taking the HIV test among those who had been tested by their own choice (n=1776). The most common reason for getting an HIV test among women was that a provider recommended it, or as part of other health care (e.g., antenatal, medical male circumcision, STI testing/treatment, PrEP; 30.03%) followed by respondents falling sick (25.05%). Among men, the most common reason for getting an HIV test was that the respondent became ill (29.18%) followed by believing they were at risk (26,63%). About 18% of respondents took an HIV test just to know their status

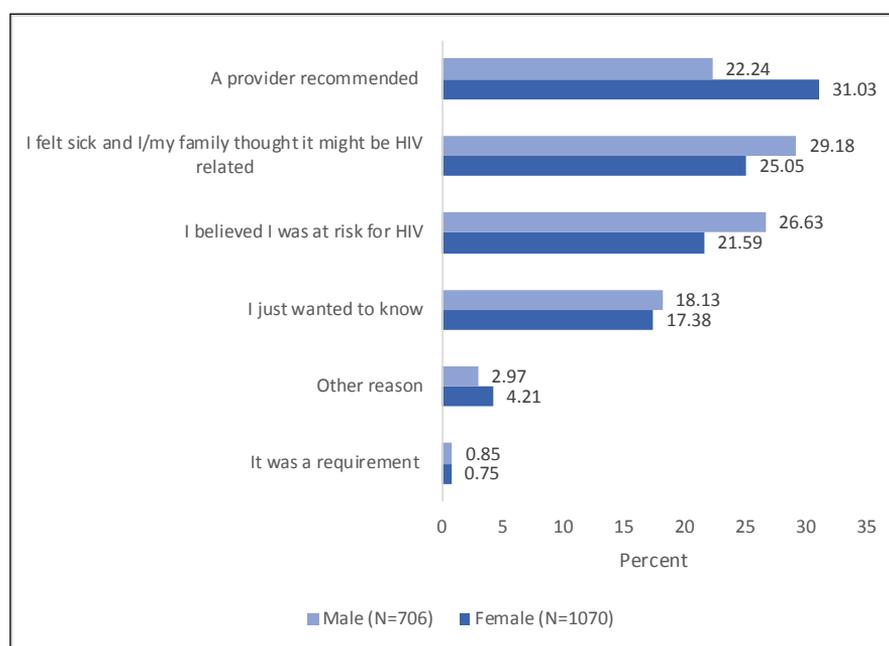


Figure 7: Main reason that test for HIV was taken

3.5.1.2 Time taken before testing for HIV

More than half of the respondents 1009 (56.81%) took up to six months to initially test for HIV after it was recommended to them, almost in equal proportions for both men and women at 58.36% and 55.79% respectively (Figure 8). Majority took some time before getting tested for HIV due probably to fears about how other people (e.g., your family, friends, employer, or community) would respond if they test positive 1102 (62.05%) with no significant difference by sex.

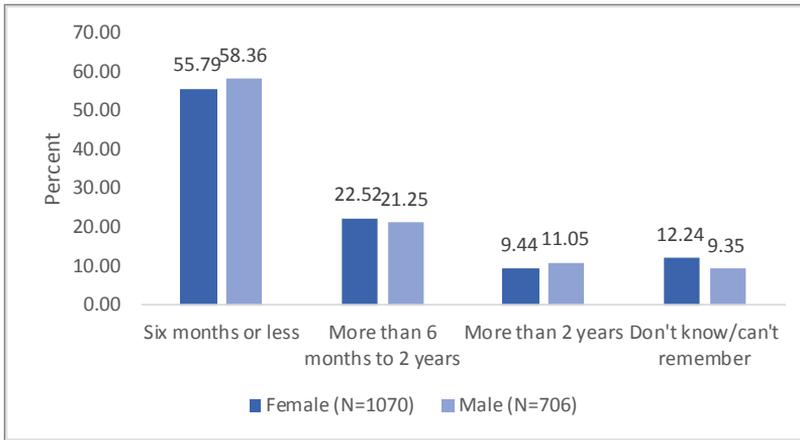


Figure 8: Time taken before testing for HIV

3.5.1.3 Time taken before taking HIV medication

Majority of respondents 2064 (97.13%) were currently on or had been on HIV treatment by the time of the survey (Figure 9). However, not all respondents started taking HIV care and treatment right after being diagnosed with HIV. Some respondents started their medication within six months from the time of diagnosis (15.96% males and 14.4% females) while others took more than six months (11.82% males and 16.01% females).

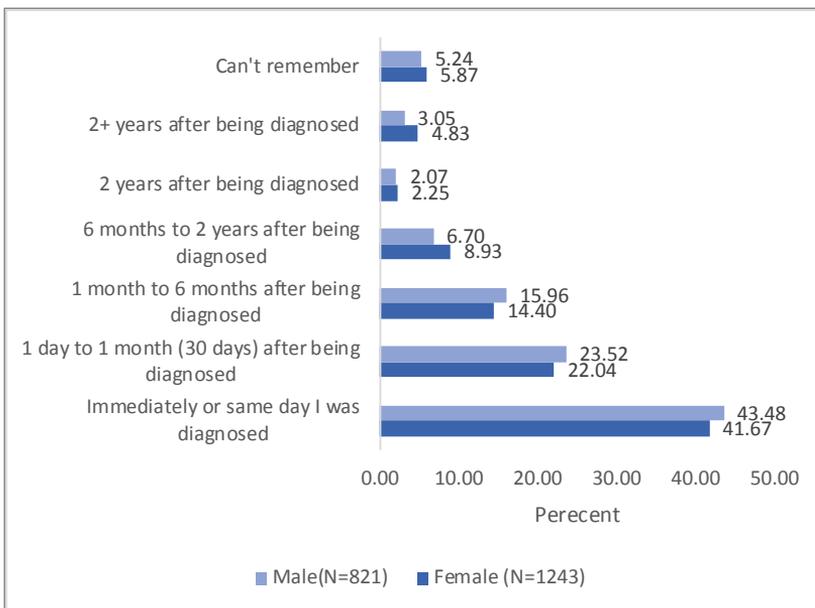


Figure 9: Time before taking HIV medication

3.5.2 Viral load Status

Almost three-quarters of respondents indicated being virally suppressed within the last 12 months with an undetectable viral load with no differences between men and women (72.23% vs 73.29%; Figure 10). A few (8.65 % of males and 8.67% of females) reported detectable viral load levels within the same period. About 1 in 10 respondents reported that they were waiting for their results.

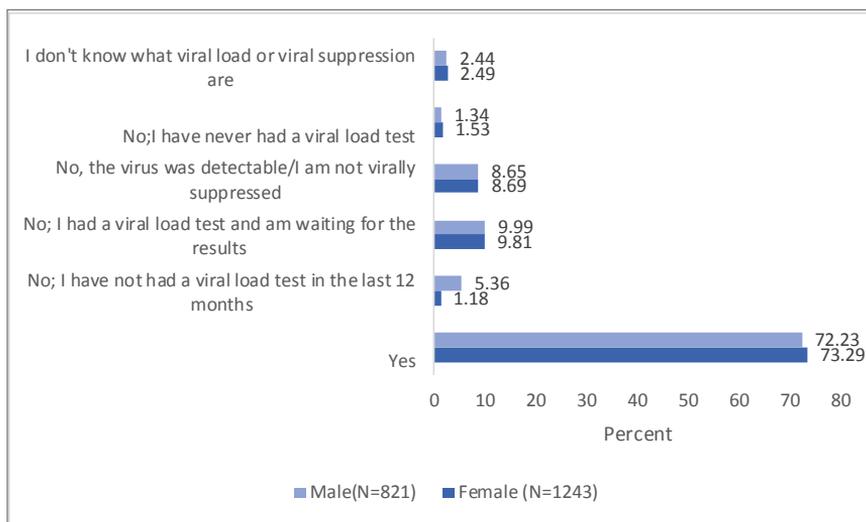


Figure 10: Viral load testing and suppression within the last 12 months

About a quarter of respondents had ever interrupted or stopped their HIV (antiretroviral) treatment. The top reasons for interrupted or stopped HIV (antiretroviral) treatment were being worried that others would find out their HIV infection 215 (47.15%) and other reasons 114 (25.00%) such as forgetting.

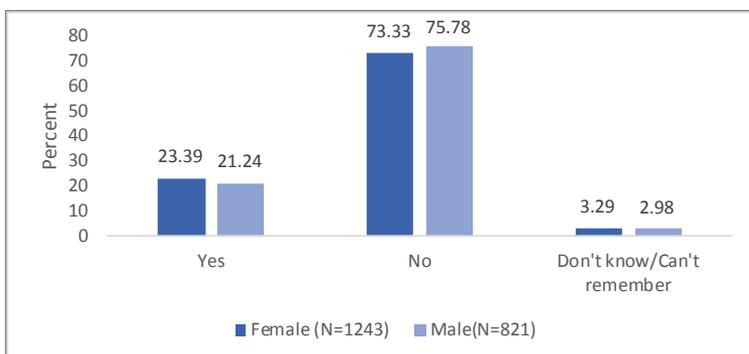


Figure 11: Ever interrupted or stopped your HIV (antiretroviral) treatment

3.5.3 General health and other health conditions

Overall, most respondents reported their health to be good or fair (Figure 12). Less than 2 percent of respondents reported poor health.

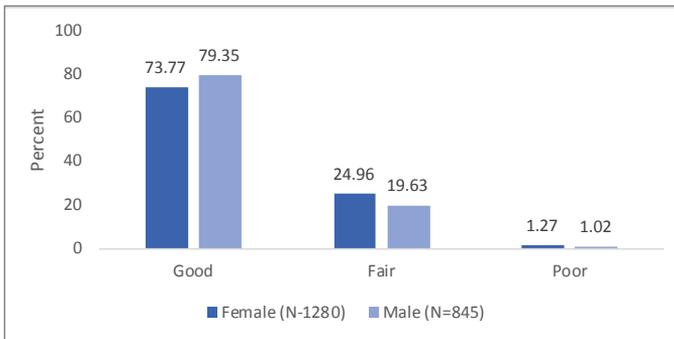


Figure 12: General health status

In the last 12 months, approximately 1 in 5 respondents had been diagnosed with opportunistic infections as the most common health condition (Figure 13). More men than women were diagnosed with sexually transmitted diseases (STDs), mental health conditions tuberculosis and alcohol/drug dependency syndrome. Overall, less than half (43.48%) of respondents who had a diagnosis of at least one of these four diseases reported that they had treatment for these health problems.

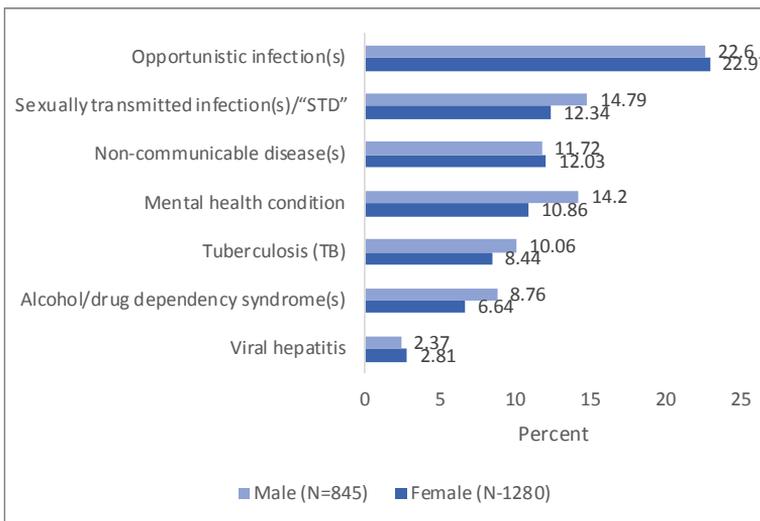


Figure 13: Diagnosis of other health conditions in the last 12 months

3.5.4 Healthcare Stigma

The stigma index survey captured experiences of HIV-related stigma while seeking HIV-specific and non-HIV-related care from health workers during the last 12 months before the study. Among those who sought HIV-specific healthcare within the last 12 months (2112), there were low levels of experiences of healthcare stigma. However, 14% of men and 13% of women reported that health facility staff talked badly or gossiped about them. Almost 12% of respondents (same for both men and women) reported health facility staff disclosed their HIV status to others without their consent (Figure 14). More men reported avoidance of physical contact by facility staff compared to women (10% vs. 9%, respectively).

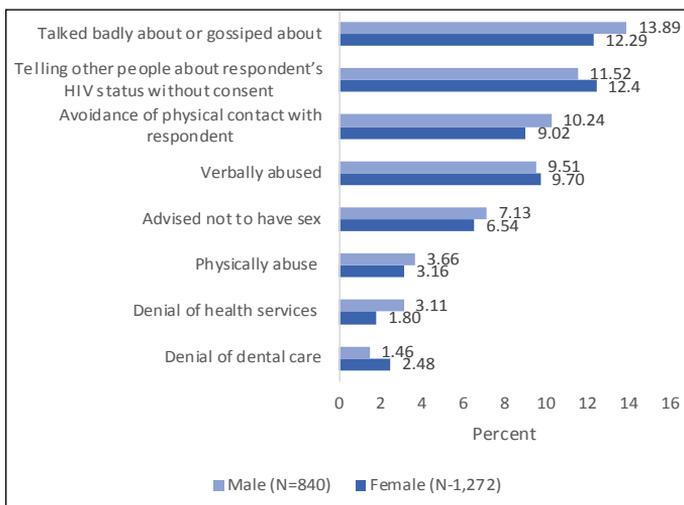


Figure 14: Experiences of stigma when seeking HIV-specific healthcare in the last 12 months

Figure 15 presents experiences when seeking non-HIV-specific health care within the last 12 months. Among those who sought non-HIV-related healthcare within the last 12 months (n=1434), incidences of healthcare stigma were also low levels in general. However, instances of healthcare staff telling other people about respondent's HIV status without their consent, denial of dental care, physical abuse and advise not to have sex were particularly for women compared to men (range 11-14%). Verbal abuse was also notably common among men and women (10%).

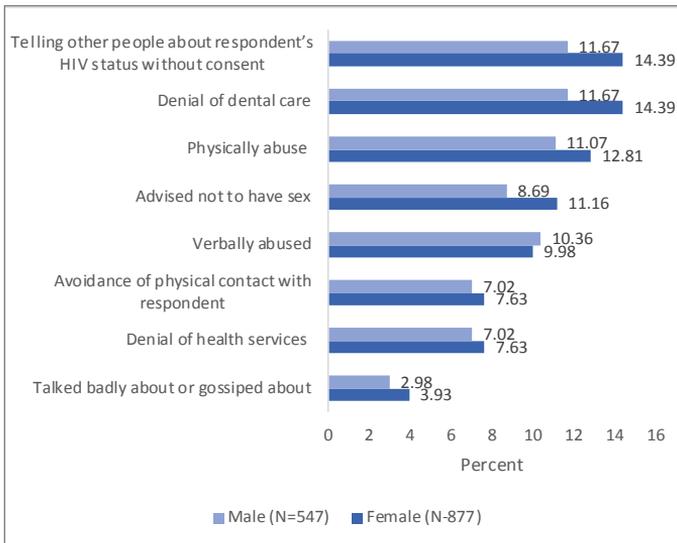


Figure 15: Experience when seeking non HIV-specific health care within the last 12 months

Sexual and reproductive health

This section highlights the stigma presented by the attitude of healthcare professionals towards PLHIV on issues of their reproductive health in the last 12 months.

Among those who sought sexual and reproductive healthcare within the last 12 months, there were low levels of experiences of healthcare stigma and discrimination in general. However, instances of healthcare staff advising PLHIV clients not to have a child (0.83% for men vs. 3.28% for women) or insisting that client had to use contraception, or a specific method of contraception in order to get your HIV (antiretroviral) treatment were noted, especially among women (0.95% vs 2.19%; Figure 16).

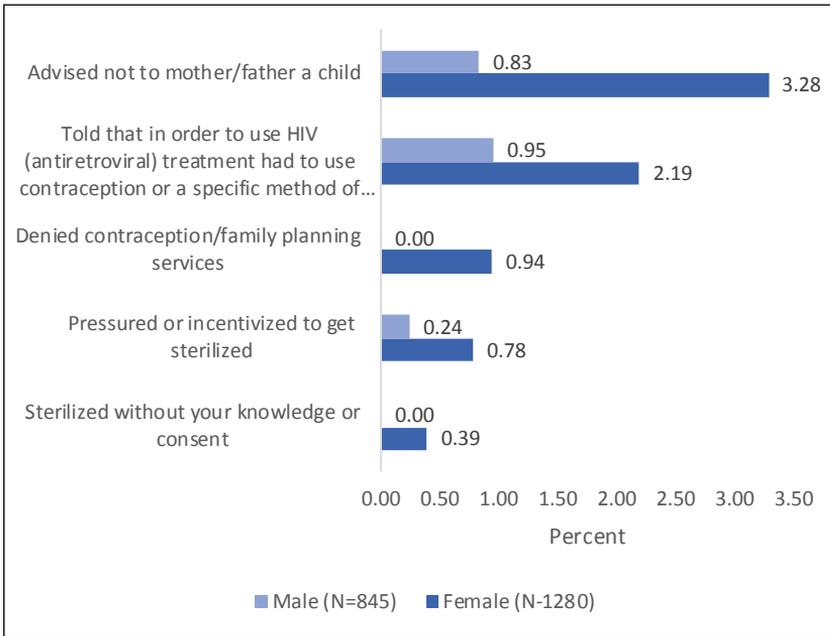


Figure 16: Reported actions taken by health workers solely because of the clients HIV status

Further, there were instances where women reported experiencing various forms of stigma within the last 12 months and beyond (Table 17) Between 4-5% reported being pressured, use a particular infant feeding practice or take antiretroviral treatment during pregnancy to reduce the chance of HIV transmission rather than counseling. About 3% reported being told to use a specific type of contraceptive method rather than counseling on a range of available options.

About 3% reported being told to use a specific type of contraceptive method rather than counseling on a range of available options.

Table 17: Reported actions by health workers done to women solely because of their HIV status

	Yes, within the last 12 months n(%)	Yes, but not within the last 12 months n(%)	No n(%)	Prefer not to answer n(%)
Advised to terminate a pregnancy	13(1.02)	35(2.73)	1026(80.16)	26(2.03)
Pressured to use a specific type of contraceptive method rather than counseling on a range of available options	37(2.89)	57(4.45)	1023(79.92)	23(1.8)
Pressured to use a particular method of giving birth/delivery option	30(2.34)	48(3.75)	1004(78.44)	25(1.95)
Pressured to use a particular infant feeding practice	52(4.06)	62(4.84)	931(72.73)	31(2.42)
Pressured to take antiretroviral treatment during pregnancy to reduce the chance of HIV transmission rather than counseling	59(4.61)	60(4.69)	929(72.58)	31(2.42)

3.6 HUMAN RIGHTS AND EFFECTING CHANGE

The section presents human rights violations and abuses experienced by PLHIV. It highlights the proportion of PLHIV being forced to get tested for HIV or to disclose their HIV status as types of human rights abuses. The reference period for all the factors listed out is either before 12 months or during the last 12 months before the PLHIV stigma index survey.

3.6.1 Abuses of rights

Human rights violations and abuses experienced by PLHIV were established by asking respondents to indicate if they had ever been forced to get tested for HIV or disclose their status in order to obtain services such as visa, job or scholarship application, healthcare or medical insurance. In addition, respondents were asked to indicate if they experienced the following abuses because of their HIV status: arrested/taken to court, detained/quarantined, denied visa or permission to

travel to another country, denied residency/permission to live in another county, sexual violence, denied access to domestic violence shelter and being prevented from accessing (public/private/community-led) health services by a partner (Table 18).

The proportion of PLHIV who reported to have experienced human rights violations and abuses was relatively low (less than 5%) and mostly occurred beyond the last 12 months before the PLHIV stigma survey. Nonetheless, any level of human rights abuse should be a major concern. The most reported form of human rights abuse was being coerced to get tested for HIV or disclose status in order to get a job or get a pension plan (3.25%), obtain a visa or apply for residency/ citizenship in a country (3.11%) and receive healthcare (3.11%).



The most reported form of human rights abuse was **being forced to get tested** for HIV or disclose status

Table 18: Proportion of PLHIV who experienced Human Rights violations and abuses

	Yes, within the last 12 months	Yes, but NOT within the last 12 months	No	Prefer not to answer or N/A
I was forced to get tested for HIV or disclose my status in order to:	n(%)	n(%)	n(%)	n(%)
Obtain a visa or to apply for residency/ citizenship in a country	28(1.32)	66(3.11)	1988(93.55)	43(2.02)
Apply for a job or get a pension plan	35(1.65)	69(3.25)	1967(92.56)	54(2.54)
Attend an educational institution or get a scholarship	29(1.36)	61(2.87)	1965(92.47)	70(3.29)
Get health care	59(2.78)	66(3.11)	1966(92.52)	34(1.6)
Get medical insurance	31(1.46)	60(2.82)	1983(93.32)	51(2.4)
Experiences of specific abuses of rights of PLHIV				
I was arrested or capacity built to court on a charge related to my HIV status	22(1.04)	41(1.93)	2008(94.49)	54(2.54)
I was detained or quarantined because of my HIV status	17(0.8)	45(2.12)	2010(94.59)	53(2.49)
I was denied a visa or permission to enter another country because of my HIV status	32(1.51)	49(2.31)	1965(92.47)	79(3.72)
I was denied residency or permission to stay in another country because of my HIV status	26(1.22)	49(2.31)	1971(92.75)	79(3.72)
I was forced to disclose my HIV status publicly or my status was publicly disclosed without my consent	26(1.22)	55(2.59)	1998(94.02)	46(2.16)
I was forced to have sex when I did not want to. "Forced" means physically forced or coerced.	46(2.16)	53(2.49)	1988(93.55)	38(1.79)
I was denied access to a domestic violence shelter	24(1.13)	58(2.73)	1993(93.79)	50(2.35)
My partner(s) prevented me from accessing (public/private/community-led) health services	30(1.41)	59(2.78)	1960(92.24)	76(3.58)

3.6.2 Taking action on abuses of rights

Respondents who reported to have experienced any of the abuses in the past 12 months before the survey were asked to indicate if they tried to do something about the matter. Taking action on abuses of rights was notably low. Out of 446 respondents who reported experiencing at least one abuse in the past 12 months before the survey, more than a quarter (27.35%) took some actions (n=122). The proportion of male PLHIV who took action was higher than that of females (30.66% vs. 22.09%; Figure 17). The main actions on abuses of rights taken by PLHIV include contacting a community organization/network of PLHIV for support 55 (45.08%), filing complaint 27(22.13%) and other actions 21(17.21%). Few respondents reported contacting a lawyer, a government official or politician, speaking out publicly (below 10%).

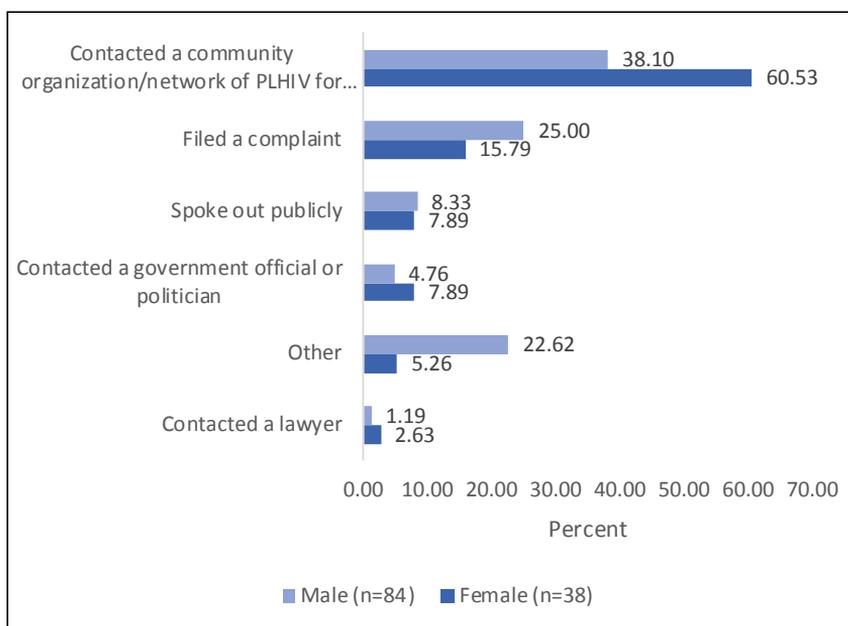


Figure 17: Action taken on abuses

3.6.3 Reason for not taking action

Among PLHIV who did not attempt to take any action despite experiencing abuse of their rights, almost a half did not know where to go or how to act (50.00% of women and 47.89% of men) while about 1 in 10 believed that the process of addressing the problem was complicated or taking any action would lead people to learn their HIV status. As shown in Figure 18, 5.22% of men and 8.95% of women felt intimidated or scared to act.

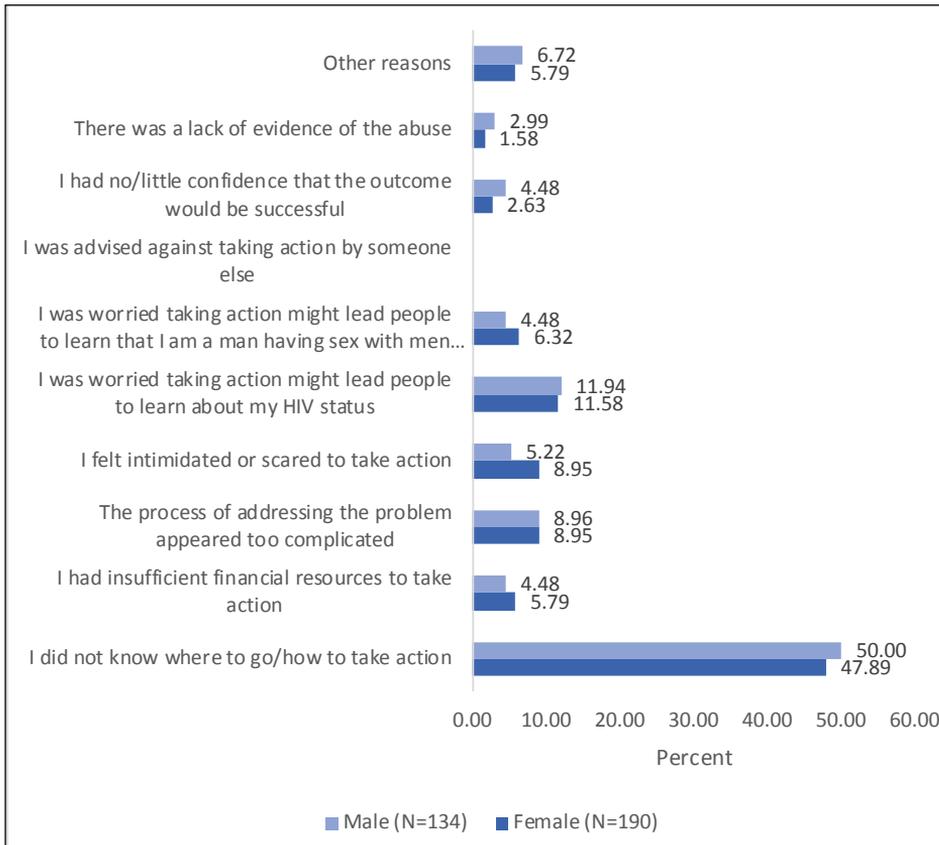


Figure 18: Reason for not taking action

3.6.4 Actions by PLHIV to effect positive changes

Table 19 presents actions taken by PLHIV to address any rights abuses they identified in the last 12 months before or beyond the PLHIV stigma index survey. More than half of the respondents indicated ever taking positive action to address rights abuses mostly within the last 12 months before the survey. The most common type of positive action taken within the last 12 months before the survey was providing emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination (40.70% females Vs 37.28% males). More than a third of respondents reported challenging or educating someone who was engaging in stigma or discrimination against other PLHIV (36.88% females Vs 34.44% males). However, less than 15% of the respondents indicated speaking to the media or encouraging a government leader or a politician to take action on issues of stigma and discrimination against PLHIV during the last 12 months before the survey.

Table 19: Actions by PLHIV to effect positive changes

	No		Yes, but NOT within the last 12 months		Yes, within the last 12 months	
	Female n(%)	Male n(%)	Female n(%)	Male n(%)	Female n(%)	Male n(%)
Challenged or educated someone who was engaging in stigma or discrimination against you	656(51.25)	425(50.30)	196(15.31)	161(19.05)	428(33.44)	259(30.65)
Challenged or educated someone who was engaging in stigma or discrimination against other people living with HIV	567(44.3)	375(44.38)	241(18.83)	179(21.18)	472(36.88)	291(34.44)
Provided emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination	539(42.11)	360(42.6)	220(17.19)	170(20.12)	521(40.70)	315(37.28)
Participated in an organization or educational campaign working to address stigma and discrimination against people living with HIV	687(53.67)	443(52.43)	199(15.55)	163(19.29)	394(30.78)	239(28.28)
Encouraged a community leader to take action about issues of stigma and discrimination against people living with HIV	841(65.7)	546(64.62)	165(12.89)	122(14.44)	274(21.41)	177(20.95)
Encouraged a government leader or a politician to take action about issues of stigma and discrimination against people living with HIV	957(74.77)	629(74.44)	149(11.64)	103(12.19)	174(13.59)	113(13.37)
Spoke to the media about issues of stigma and discrimination against people living with HIV	1049(81.95)	694(82.13)	133(10.39)	92(10.89)	98(7.66)	59(6.98)

3.7 STIGMA AND DISCRIMINATION EXPERIENCED FOR REASONS OTHER THAN HIV STATUS

This section presents stigma and discrimination associated with belonging to known groups or behaving in ways that the individual does that are more closely related to key population categories and not HIV-positive status. Among PLHIV, key populations are situated at the intersection of HIV-related stigma and prejudice against their identities, occupations, or behaviour, often exacerbating their experiences of stigma and discrimination (Friedland et.al., 2018).

Table 20 below presents data on Key Population constituents of: Transgender, Men who have Sex with Men (MSM), Bisexuals, Sex Workers and People Who Use Drugs. All KPs were asked a question on whether other people including (those in their category, family or friends, others in the community) knew their sexual orientation or belonged to the KP category.

Table 20: Key Population (KP) group

Key Population (KP) group	Total N	Other similar people/group of KPs aware that the respondent belongs to the KPs group n (%)	Family members or friends aware that the respondent belongs to the KPs group n (%)	Other community members that the respondent belongs to the KPs group n (%)	A member of a network of a similar group of KPs n (%)
Transgender	35	24(68.57)	19 (54.29)	17 (48.57)	14(40.00)
Men who have Sex with Men (MSM)	122	69(56.56)	33(27.05)	18 (14.75)	51(41.80)
Bisexuals	56	42(75.00)	25(44.64)	21(37.50)	15(26.79)
Sex Workers	449	307(68.37)	153(34.08)	136(30.29)	257(57.24)
People Who Use or Drugs	80	65(81.25)	59(73.75)	51(63.75)	39(48.75)

Among PLHIV, key populations are situated at the intersection of HIV-related **stigma and prejudice against their identities, occupations, or behaviour**, often exacerbating their experiences of stigma and discrimination

3.7.1 Experiences of Transgender respondents

A total of 35 respondents were categorized as transgender, that is, people who were assigned a sex category on their original birth certificate that does not match their current gender identity or preference. Out of 35 transgender respondents, 24 (68.57%) reported that other transgender persons, 19 (54.29%) family members or friends of the transgender persons and 17 (48.57%) other community members knew their identities. 14 (40.00%) indicated belonging to a network or support group for transgender people.



Table 21 summarizes the non-HIV related stigma and discrimination among transgender respondents. Almost a third (31.43%) reported experiencing emotional violence in the past 12 months while 1 in 5 experienced physical violence or felt excluded from family activities due to their gender identity. More than a quarter (25.71%) were afraid of seeking health services in the past 12 months while 7 (20.00%) avoided seeking health services because they feared someone would discover their sexual identity as transgender.

Table 21: Proportion of respondents experiencing non HIV-related stigma and discrimination among the transgender group

Type of stigma and discrimination	Yes, within past 12 month n(%)	Yes, but not in past 12 months n(%)	No n(%)	Preferred not to answer n(%)
Ever felt excluded from family activities	7(20.00)	10(28.57)	16(45.71)	2(5.71)
Ever felt that family members have made discriminatory remarks or gossiped about you	8(22.86)	10(28.57)	14(40.00)	3(8.57)
Ever felt afraid to seek health services	9(25.71)	6(17.14)	18(51.43)	2(5.71)
Ever avoided seeking health services because you worried someone may learn of your gender identity	7(20.00)	7(20.00)	19(54.29)	2(5.71)
Someone ever verbally harassed you because of your gender identity	11(31.43)	6(17.14)	16(45.71)	2(5.71)
Someone ever blackmailed you because of your gender identity	6(17.14)	7(20.00)	19(54.29)	3(8.57)
Someone ever physically harassed or hurt you because of your gender identity?	7(20.00)	6(17.14)	18(51.43)	4(11.43)

3.7.2 Experiences of MSM

A total of 122 respondents were categorized as men who have sex with men (MSM). 69 (56.56%) reported that other MSM were aware of their sexual identity, 33 (27.05%) family members or friends and 18 (14.75%) other community members knew respondents' sexual identity. Out of the 133 MSM, 51 (41.80%) reported belonging to a network or support organization of MSM.

Table 22 presents the proportion of respondents who experienced non-HIV related stigma and discrimination among

MSM. Almost a half 60(49.18%) reported experiencing emotional violence, a third 41 (33.61%) being blackmailed while 33 (27.05%) physical violence in the past 12 months. More than a third 43 (35.25%) were afraid of seeking health services while 36 (29.51%) avoided seeking health services in the past 12 months because they feared someone would discover they were MSM. 37 (30.33%) felt excluded from family activities while at least 4 in 10 reported discriminatory remarks or gossip about them by family members

Table 22: Proportion of respondents experiencing non HIV-related stigma and discrimination among MSM

Type of stigma and discrimination	Yes, within past 12 month n(%)	Yes, but not in past 12 months n(%)	No n(%) n(%)	Preferred not to answer n(%)
Ever felt excluded from family activities	37(30.33)	22(18.03)	55(45.08)	8(6.56)
Ever felt that family members have made discriminatory remarks about or gossiped about you	51(41.8)	22(18.03)	44(36.07)	5(4.1)
Ever felt afraid to seek health services because you worried someone may learn you are an MSM	43(35.25)	16(13.11)	58(47.54)	5(4.1)
Ever avoided seeking health services because you worried someone may learn you are an MSM	36(29.51)	16(13.11)	65(53.28)	5(4.1)
Someone ever verbally harassed you because you are an MSM	60(49.18)	17(13.93)	40(32.79)	5(4.1)
Has someone ever blackmailed you because you are an MSM	41(33.61)	11(9.02)	65(53.28)	5(4.1)
Someone ever physically harassed or hurt you because you are an MSM	33(27.05)	11(9.02)	72(59.02)	6(4.92)

3.7.5 Experiences of Sex Workers

Out of 449 respondents categorized as Sex Workers (SWs), 307 (68.37%) reported that other SWs were aware that they were SW, 153 (34.08%) family members or friends of the SWs and 136 (33.29%) other community members knew that the respondent engaged in sex work. The majority of the SWs 257 (57.24%) were members of a network or support organization of SWs.

Table 23 presents the proportion of respondents experiencing non HIV-related stigma and discrimination among SWs. At least 1 in 3 (30.07%) of SWs reported experiencing emotional violence, 112 (24.94%) physical violence while

83 (18.49%) being blackmailed in the past 12 months. Eighty (17.83%) were afraid of seeking health services while 74 (16.48%) avoided seeking health services in the past 12 months because they feared someone would discover they were SW. Nearly a quarter (23.39%) of SWs reported discriminatory remarks or gossip about them while 76 (16.93%) felt excluded from family activities or by family members in the past 12 months.



(16.48%) avoided seeking health services in the past 12 months because they feared someone would discover they were SW.

Table 23: Proportion of respondents experiencing non HIV-related stigma and discrimination among Sex Workers

	Yes, within past 12 month	Yes, but not in past 12 months	No n(%)	Preferred not to answer
Type of stigma and discrimination	n(%)	n(%)	n(%)	n(%)
Ever felt excluded from family activities	76(16.93)	97(21.6)	252(56.12)	24(5.35)
Ever felt that family members have made discriminatory remarks about or gossiped about you	105(23.39)	106(23.61)	218(48.55)	20(4.45)
Ever felt afraid to seek health services because you worried someone may learn you are a Sex Worker	80(17.82)	63(14.03)	288(64.14)	18(4.01)
Ever avoided seeking health services because you worried someone may learn you are a Sex Worker	74(16.48)	67(14.92)	289(64.37)	19(4.23)
Someone ever verbally harassed you because you are a Sex Worker	135(30.07)	82(18.26)	214(47.66)	18(4.01)
Has someone ever blackmailed you because you are a Sex Worker	83(18.49)	67(14.92)	280(62.36)	19(4.23)
Someone ever physically harassed or hurt you because you are a Sex Worker	112(24.94)	62(13.81)	257(57.24)	18(4.01)

3.7.6 Experiences of PWU/IDs

A total of 80 respondents were categorized as People who use or inject drugs (PWU/IDs). Sixty Five (81.25%), reported that other PWU/IDs were aware that they use/used or inject drugs, 59 (73.75%) family members or friends of the PWU/IDs and 51 (63.75%) other community members knew that the respondents use (used) or inject drugs. Out of the 80 PWU/IDs, 39 (48.75%) reported belonging to a network or support organization of PWU/IDs.

Table 24 presents the proportion of respondents experiencing non HIV-related stigma and discrimination among PWU/IDs. More than a third 30 (37.50%) had experienced emotional violence in the last 12 months, 16 (20.00%) had been blackmailed while 15 (17.75%) had experienced physical violence. Fourteen (17.75%) were afraid of seeking health services or avoided seeking health services in the past 12 months because they feared someone would discover they use (had used) or inject drugs.

Table 24: Proportion of respondents experiencing non HIV-related stigma and discrimination among PWU/IDs

	Yes, within past 12 month	Yes, but not in past 12 months	No n(%)	Preferred not to answer
Type of stigma and discrimination	n(%)	n(%)	n(%)	n(%)
Ever felt excluded from family activities	19(23.75)	35(43.75)	26(32.5)	0(0.00)
Ever felt that family members have made discriminatory remarks about or gossiped about you	23(28.75)	35(43.75)	22(27.50)	0(0.00)
Ever felt afraid to seek health services because you worried someone may learn you use (or used) drugs	14(17.50)	14(17.50)	52(65.00)	0(0.00)
Ever avoided seeking health services because you worried someone may learn you use (or used) drugs	14(17.50)	14(17.50)	52(65.00)	0(0.00)
Someone ever verbally harassed you because you use (or used) drugs	30(37.50)	28(35.00)	22(27.50)	0(0.00)
Has someone ever blackmailed you because you use (or used) drugs	16(20.00)	10(12.50)	54(67.50)	0(0.00)
Someone ever physically harassed or hurt you because you use (or used) drugs	15(17.75)	25(31.25)	40(50.00)	0(0.00)



3.8 PERSONAL EXPERIENCES OF STIGMA AND DISCRIMINATION

This section highlights some of the voices of PLHIV who have experienced stigma and discrimination within their families and communities particularly following disclosure of their HIV-positive status and internalized stigma.

3.8.1 Experiences of Males and Females

“I dropped out of college when I learnt that I was HIV positive during a free testing drive at the health centre close to my school. In my mind, I opted to test just for the sake of it and after all, it was free and I knew that there was no way I could have HIV. The shock and denial that followed was immeasurable. When I dropped out of school. My parents were not aware; neither did I disclose to them my HIV status. To me, there was no point for pursuing education because in my mind, I knew that everybody could tell that I was having HIV”. **Female respondent- Kisumu**

“I disclosed my HIV status to my birth mother who then disclosed it to the rest of the family and the public during social events. They have sold my land, which I bought jointly with my sister, and are now treating my children and I as outcasts”, **Male-Mombasa.**

“I have not disclosed my status because I have a fear of rejection and violence. I have 4 sons who are young men, and they are fond of weapons like guns and machetes, I am afraid what they will do to me if they found out I am HIV positive”. **Male-Turkana.**

“I disclosed my status to my best friend, who told members of our Chama, when the members found out about my status, they refused to lend me money claiming I would die without paying them their money”. **Female-Kibera, Nairobi.**

*“I disclosed my HIV status to my wife, she started denying me my conjugal rights. Since I am still virile, I had to run away from home to another place and find another woman to satisfy my sexual needs”. Male partner in a HIV **Discordant relationship-Makueni***

*“My employer who is also a close friend disclosed my status to my fellow workmates which became a gossip among them, one of my workmates told me “You can’t paint because the paint will affect your HIV virus. **Male respondent -Bungoma***

*“A Lady friend threatened that she would disclose my status to my then boyfriend if I didn’t give her some amount of money that she requested”. **Female respondent -Taita Taveta***

*“Whenever there is an argument in the family involving me, my step-mother and other family members gossip that I am a walking corpse in the presence of my children when I was away and eventually my children would tell me “**Female respondent -Kilifi***

*“I was an usher at my church, was single and wanted to marry a lady from the church. We both approached the pastor to share our intention and ask for church blessings. We were asked to get an HIV test. We both tested positive and even after agreeing to marry, the pastor refused and we stopped being members of that church “**Male respondent -Babadogo, Nairobi***

*“My wife insisted that I clean my private parts using disinfectant or else there is no engaging in sexual intercourse “**Male respondent -Kiambu***

*“I am a member of boda boda riders merry go round savings group. When it was my turn, some group members refused to lend me money because of my HIV status claiming I would die and not pay them during their turn” **Male respondent, Kakamega***

3.8.2 Experiences of Key Populations

*“I disclosed my HIV status and line of work to a friend who was also my neighbor. She gossiped about me with others and eventually I was forcefully evicted. Another time I was denied the opportunity to work in a hotel because I am a Sex Worker living positively. **Female Sex Worker - Nairobi.**”*

*“When my family found out that I am a sex worker and I am also HIV positive, none of them wanted to be associated with me including my sister who was closest to me. I was mentally disturbed and I had to relocate from Kisumu, where we used to live, to the Busia border.” **Female Sex Worker Busia.**”*

*“We were arrested at the hotspots for being MSMs. I got injured in the process of being pushed to get into the lorry. This made me start isolating myself and avoiding places where I feel I might be stigmatized.” **Male Sex Worker- Nairobi**”*

4.0 KEY FINDINGS

The key findings of the stigma index survey are described below. The first part highlights HIV testing and treatment; disclosure and Human rights abuses and response. The second part presents experiences of stigma and discrimination among PLHIV in their diversities.

HIV Status Disclosure

- Half of the respondents had disclosed their status to their partners (59.9% of males vs. 49.1 % of females) and other family members (49.6% of males Vs 55.7% of females).
- More females (44.1%) than males (29.5%) had disclosed their status to their children. More females (39.1%) compared to males (36.3%) disclosed their status to friends.
- Some respondents had a positive experience with disclosure of their HIV status – 45.65 % received support from family members, while 16.71% were supported by non-family members. More than a third (36.38%) said that disclosure became easier over time.

Interactions with Healthcare settings and health status

- The most common reason for getting an HIV test among women was mainly due to a recommendation by a provider

or as part of other health care (e.g., antenatal, STI testing/treatment, PrEP; 30.03%) while majority of men tested following illness (29.18%).

- Delayed testing for HIV was attributed to fear of other people’s reaction (e.g., family, friends, employer, or community) in case found to be HIV positive (62.05%).
- Interrupted or stopped HIV (antiretroviral) treatment was majorly attributed to the fear of others finding out respondent’s HIV infection (47.15%) and forgetting (25.00%).
- Less than half (43.48%) of respondents sought treatment for opportunistic diseases in the last 12 months.

Human rights and effecting change

- The most reported form of human rights abuse was coerced testing for HIV or disclosure of status in order to get a job or get a pension plan (3.25%), obtain a visa or apply for residency/ citizenship in a country and receive healthcare (3.11%).
- Among PLHIV who experienced human rights abuses, the main actions taken include: contacting a community organization/network of PLHIV for support (45.08%) and filing complaints

(22.13%) with a higher proportion of males (30.66%) compared to females (22.09%).

- Positive action taken by PLHIV to address rights abuses ranges from providing emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination (40.70% female respondents' vs 37.28% male respondents) to challenging or educating someone who was engaging in stigma or discrimination against other PLHIV (36.88% females Vs 34.44% males).

External Stigma and Discrimination

- Over the last 12 months, the most common form of stigma and discrimination experienced by PLHIV due to their status include: being subjected to discriminatory remarks or gossip by either family (20.14%) or non-family members (24.66%) and verbal harassment (20.14%).
- The mean value of the external stigma and discrimination index was 2.561 translating to a stigma index of 23.28% among PLHIV. PWU/IDs experienced the highest stigma (38.47%) followed by WSW or Lesbian (32.01%) and Sex Workers (28.91%).

- There were no significant differences in the mean value of the external stigma and discrimination index by socio-demographic characteristics – age and level of education.

Internalized Stigma and Resilience

- A high proportion of both males (71%) and females (69%) living with HIV found it difficult to tell people about their HIV status.
- Nearly a third of both males and females (range 31-34%) living with HIV felt worthless or guilty because of their HIV status.
- More males than females living with HIV reported higher levels of shame (31.48% vs. 27.34%).
- One-fifth of PLHIV reported that being HIV positive made them feel dirty.
- Actions related to internalized stigma included: avoiding sex due to their HIV status (15.15% males vs. 19.06% females); isolation from family and/or friends (17.16% males vs. 15.39% females) or decision not to apply for a job due to their HIV status (13.36% males vs. 11.01% females).

- About 12% of PLHIV chose not to seek social support while less than 8% avoided going to clinics or hospitals when they needed due to their HIV status.
- Overall, the mean value of internalized stigma index was 0.6683 with a standard deviation of 1.2789 (or internalized stigma index = 14.21%)

Experiences of Stigma with Health Facility Staff

- Respondents reported various forms of stigma for HIV-related care in the hands of health facility staff including: gossip /talking badly (14% of men and 13% of women); disclosure without consent (12% for both men and women); avoidance (10% for men vs. 9% for women).
- For both men and women instances of stigma for non HIV-related healthcare included: disclosure of respondent's HIV status without their consent, denial of dental care, physical abuse, advice not to have sex particularly for women compared to men (range 11-14%) and verbal abuse (10%)
- Reported stigma related to respondent's reproductive health was minimal and mainly in the form of advice not to have a child (0.83% for men vs. 3.28% for women); specific contraceptive use as pre-condition for HIV (antiretroviral) treatment especially among women (2.19%).

Experiences of Stigma and Discrimination among Key Populations

Key populations face compounded stigma due to their identity and nature of work with varying levels and forms for each target group.

- Sex Workers reported the highest levels of stigma and discrimination including emotional violence (30.07%), physical violence (24.94%), blackmail (18.49%), and discriminatory remarks/gossip (23.39%).
- About 20% of transgender people reported experiencing physical violence.
- Male Sex Workers face double stigma, for being Sex Workers and also men who have sex with men.
- A majority of MSM did not report experiencing any form of stigma in the listed categories. This may be attributed to low disclosure— only 27.05% of MSM had disclosed to their families or friends.

- About 1 in 5 (17.83%) of Sex Workers reported having avoided seeking healthcare services due to fear of being identified as sex workers within the last 12 months of the study and beyond.
- At health facilities, Sex Workers who test HIV positive face double stigma due to their status and nature of work.
- About 1 in 5 (20%) Trans* community respondents reported having avoided seeking healthcare services to avoid disclosing their gender identity.
- About 1 in 5 (17.75%) of PWU/IDs reported being afraid of seeking health services or avoided seeking health services in the past 12 months due to fear of someone discovering that they use (had used) or inject drugs.

5.0 CONCLUSION

Overall, the study findings indicate a reduction in HIV stigma and discrimination in Kenya due to HIV programming interventions. Notably, there has been increased awareness of HIV by the general population and meaningful involvement of community stakeholders including: school teachers, parents/guardians, religious leaders and PLHIV in their diversities in the HIV programming by national and

community-based organizations working in the HIV response. Enhanced access to HIV treatment and provision of comprehensive care for PLHIV has led to reduced morbidity and mortality and healthier lives for persons living with the virus translating into reduced stigmatization of PLHIV.

It is important to note that the overall stigma index for Kenya in 2014 was 45% while the findings of the current PLHIV stigma survey index is at 23.28%. Notably, the current PLHIV stigma index survey used a standard tool generated by the global partnership on stigma index (GNP, ICW, IPPF and UNAIDS). This tool differentiated the indicators of external stigma, internalized stigma and resilience. The external stigma and discrimination index (23.28) was calculated as a mean value of the yes responses to eleven stigmatizing experiences (exclusion from :social gatherings, religious and family activities ;gossip, verbal and physical harassment; refusal of employment ;change of job description ;spousal and child discrimination).On the other hand, the national stigma index survey by MOH /NACC (2014) was a cumulative score derived from five categories (disclosure; non-invasive contact; shame, blame and judgment ;enacted stigma).

Despite all the efforts the country has put in place to deal with the negative impact of HIV stigma and discrimination, the vice still persists in several domains such as key population, religious settings, healthcare facilities, schools and certain aspects of community. The most common forms of stigma and discrimination include: being gossiped about, exclusion from social, religious and family activities, verbal and physical abuse among other stigmatizing actions. Stigma was highest among key populations especially Men who have sex with men, male and female sex workers, and people who use drugs. This was majorly attributed to homophobic, judgmental and negative attitudes towards gay, bisexual, and other men who have sex with men. These attitudes can lead to rejection by friends and family, discriminatory acts and violence, and laws and policies with negative consequences. In addition, there is evidence that some PLHIV experience internalized stigma, which affect their adherence, retention to care and even acceptance and decisions about futuristic plans.

6.0 RECOMMENDATIONS

1. Develop and roll-out Guidelines on HIV Status Disclosure targeting all settings – health care settings, workplaces and; learning institutions.
2. Increase access to accurate information on HIV and HIV transmission using a range of media tools, including social media.
3. Build the capacity of PLHIV on HIV disclosure with special attention to parent-child disclosure and communication.
4. Train, mentor and support PLHIV openly living with the virus as ‘Anti-Stigma Champions’ to engage in media and community outreaches
5. Government and partners should roll-out strategies to tackle the root causes of stigma, and ensure health and HIV services are inclusive, accessible and empowering to PLHIV in their diversities.
6. Develop a framework with clear indicators to track and monitor outputs resulting from the stigma associated with disclosure, especially disclosure without consent.

Stigma and Discrimination Experienced for Reasons Other Than HIV Status

1. Intensify targeted advocacy and communication aimed at repealing laws and policies that discriminate sex work, adult consensual same sex partnerships and; use of drugs. This will increase uptake of health services that are stigma-free and non-discriminatory.

2. Continuously sensitize law enforcement officers, Court Users Committee (CUCs); religious and community leaders, media and healthcare service providers on anti-stigma and anti-discriminatory strategies and actions.
 3. Invest in and expand Key Population-led interventions and programs.
 4. Proactively and deliberately work towards the integration of Key Populations Services within public health facilities.
 5. Ensure health services under universal health coverage (UHC) are Rights-based and HIV – sensitive.
 6. Institutionalize pre-service and in-service training (e.g. focused on HIV-related stigma and discrimination and human rights) for health care workers and professionals who provide care to PLHIV and KPs.
- support to PLHIV who experience stigma and discrimination.
 3. Review and roll-out workplace policies in public and private institutions to nurture stigma-free workplace environment
 4. Strengthen networks (PLHIV, KPs and AYPLHIV) to counter HIV-related stigma and discrimination at national, county levels and community levels.
 5. Undertake capacity building to PLHIV leaders to provide the voice and visibility for those facing stigma and discrimination while being accountable to partners and constituents.
 6. Invest in community and PLHIV-led monitoring to monitor, track, document, refer and mitigate HIV-related stigma and discrimination.

Stigma and Discrimination

1. Continued sensitization and empowerment of PLHIV and family members to take action when violated and/or coerced to disclose their status without consent i.e., Data Protection Act, the role of HIV AIDS Tribunal (HAT) and the provisions of the HIV Prevention and Control Act (HAPCA) that govern privacy, confidentiality and consent.
 2. Enhance HIV Treatment Literacy and ensure provision of psychosocial
- ## External Stigma and Discrimination
1. Intensify efforts to address the myths and misconceptions associated with HIV & AIDS at the community, religious settings, workplaces and learning institutions.
 2. National and county governments and partners providing health and HIV services to adopt rights-based HIV programming to more effectively promote human rights obligations, including the right to access quality health care for people living with HIV.

3. National and county governments and partners to strengthen access to justice by increasing funding for community-based legal support services, and by supporting PLHIV and KPs networks to monitor workplace discrimination and report violations; ensuring people living with HIV can report discrimination and have their complaints investigated without their names being made public;
4. The Public Service Commission through the AIDS Control Units and in partnership with PLHIV networks to build capacity of managers, supervisors, workplace peer educators and counsellors to provide accurate and adequate HIV information to their peers in the workplace; ensure comprehensive care and support to PLHIV facing HIV related stigma in the workplace.
5. Deliberately work towards delivering integrated people-centred health and HIV services (i.e. HIV testing and care services within MNCH and other programs).
2. Foster partnership with the Ministry of Education and undertake qualitative research to unravel the causes, manifestation and impact of HIV related stigma in learning institutions.
3. Undertake qualitative studies to improve the evidence based on work-related stigma and discrimination so that targeted and effective intervention strategies may be devised and implemented.

Further Research

1. Undertake qualitative research to deepen understanding on different manifestations of HIV related stigma and mitigation strategies across different counties, regions, ages and populations.

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DISCLAIMER

The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination.

In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower People living with HIV on human rights issues related to HIV.

Survey questions, therefore, focus on experiences and perceptions and do not represent factual investigations, with follow-up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research participants' interviewees have a right to anonymity and to confidentiality regarding their responses.

In addition to the empowerment function, appropriate uses of the data are for advocacy and to inform stigma/discrimination reduction programming and policy responses in the national response to HIV as well as contribute to what we know (from the lived experience of PLHIV) about HIV related stigma globally.





*...say yes
to life*