

THE PEOPLE LIVING WITH HIV STIGMA INDEX

Lesotho Report 2.0

FINAL REPORT



Lesotho Network of People Living with HIV/AIDS
(LENEPWHA)

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Acronyms

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CCROA	Crime Prevention, Rehabilitation and Reintegration of Ex-Offenders Association
GIPA	Greater involvement of people living with HIV and AIDS
GNP+	Global Network of People Living with HIV and AIDS
HIV	Human immunodeficiency virus
ICW	International Community of Women Living with HIV
IPPF	International Planned Parenthood Federation
JHU	John Hopkins University
LCN	Lesotho Council of Non-Governmental Organisations
LENEPWHA	Lesotho Network of People Living with HIV and AIDS
LPPA	Lesotho Planned Parenthood Association
LTFU	Lost to follow-up
MMD	Multi month dispensing
MSM	Men who have sex with other men
PLHIV	People living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission of HIV
PWUD	People who use Drugs
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV and AIDS
UNDP	United Nations Development Programme
WFP	World Food Programme
WLSA	Women and Law in Southern Africa
WSM	Women who have sex with other women

Foreword

Lesotho Network of People Living with HIV and AIDS (LENEPWHA) extends their gratitude to the organisations which assisted in the formulation of this document, from the inception of the Stigma Index survey to the final stage of compiling this report that we proudly own today. The development of this report would not have been possible without the National Steering Committee (NSC) and the Technical Working Group who spearheaded the research endeavour.

The study was financially supported by UNAIDS, UNDP, and WFP Global Fund through PACT, without which this final product would not be possible. Our compliments to the think tank from the following organisations: National AIDS Commission, Ministry of Health, Bureau of Statistics, Lesotho Correctional Services, EGPAF, PACT, Lesotho Council of NGOs, National University of Lesotho, Phelisanang Bophelong, Matrix, Skillshare, CCROA, LPPA, Care for Basotho, LENASO, and WLSA. Their technical support in the implementation of this study – always going beyond the call of their respective organisations' duties to support us – is most highly acknowledged.

The Global Network of People Living with HIV and AIDS (GNP+) is acknowledged for the development of the global standardised questionnaire, the PLHIV Stigma Index, that guided the data collection for this study. We also thank them for their technical support throughout the entire process of data collection instruments drafting and clearing.

We thank John Hopkins University for developing the data collection platform REDcap and for subsequent training on its application. Using this platform has been a learning journey and we express our appreciation for the new knowledge JHU extended to our PLHIV and to our partner organisations. The technical input they provided in the preparation of this report is also commendable.

The development of this report was made possible by the study researcher Dr Malithapelo Mosuoë and the study coordinator Mrs Ellen Scout, who worked tirelessly from inception to the final stage of this research activity. The study was ably supported by Mr Lebohang Mohami, an IT Specialist who provided remote and on-site support during the data collection phase, ensuring that no stone was left unturned.

Our appreciation extends to our District Executive Committees for assisting with identification and recruitment of PLHIV interviewers. They were always available to meet our requests. We wish to thank the interviewers from the study districts for their tireless efforts to complete the data collection amidst COVID-19, which made movement from one point to the next almost impossible and shortened the collection time. In spite of this constraint, they soldiered on. Thank you.

Data collection would not be possible had it not been for our partners in the districts: DHMT who allowed us access to their health facilities, the CCROA which fielded three ex-inmates to support the study, Matrix, LPPA, Phelisanang Bophelong, Skillshare and Care for Basotho. These partners helped to identify key populations within the study sites to participate and allowed us to use their organisations as venues for conducting interviews with the peer interviewees. We really appreciate this partnership.

Maketekete A. Thotolo

Executive Director

LENEPWHA

Executive Summary

This report presents the findings, conclusions, and recommendations of the second study of the People Living with HIV (PLHIV) Stigma Index performed in Lesotho by LENEPWHA, the central HIV support network in the country. The PLHIV Stigma Index was developed by GNP+, ICW, UNAIDS, and IPPF in 2008 as a tool that would provide quantitative indicators of stigma in terms of both external experiences of stigma and discrimination, and internalised feelings of stigma. The tool is a questionnaire consisting of over 70 closed form questions about the experiences of stigma and discrimination in different parts of society (family life, social situations, work, health care), as well as open-ended questions for participants to offer detailed input on their specific experiences. The aim of the PLHIV Stigma Index is to increase evidence-based policy and programmatic interventions, promote greater involvement of people living with HIV and AIDS (GIPA), and ultimately reduce HIV-related stigma and discrimination. A revised version of the questionnaire, the PLHIV Stigma Index 2.0, was produced in 2018 and employed in this study. This latest version of the questionnaire gives particular attention to key populations of PLHIV who are particularly vulnerable, namely transgender people, sex workers, gay men and other men who have sex with men (MSM), and people who use drugs (PWUD).

LENEPWHA conducted the first PLHIV Stigma Index Study in Lesotho in 2013, surveying 1085 PLHIV from all 10 districts. The findings showed moderate levels of stigma and discrimination, with the highest indicator being discriminatory remarks or being gossiped about (40.6% of participants). The current study was conducted in 2020/2021 across four districts, selected for their HIV prevalence and ARV coverage, among other key factors: Mafeteng, Maseru, Mohale's Hoek, and Mokhotlong. A total of 1481 participants, including PLHIV from all the key populations and vulnerable groups (i.e., ex-inmates and those not in care), were interviewed by trained PLHIV interviewers at local health facilities using a modified version of the PLHIV Stigma Index 2.0 questionnaire. The questionnaire was updated to include questions for incarcerated PLHIV and food insecurity, for a total of 96 questions related to disclosure, human rights, health care services, overall wellbeing, and stigma and discrimination due to HIV status and other identity groups.

Key findings

The results of the study show a general reduction in the stigma and discrimination experienced by PLHIV in Lesotho since the first study in 2014. Indeed, most participants did not experience any form of stigma and discrimination (77%) or internalised stigma (84%) due to their HIV status. The most common experiences of stigma and discrimination were verbal: gossip, discriminatory remarks, and verbal abuse. Negative verbal discrimination was also the most common form of negative experience PLHIV reported from health care workers. Notably, transgender participants and those who did not identify as male, female, or transgender, experienced far more internalised stigma across every indicator, compared with male and female participants. Participants from these two key populations were also the mostly likely to experience stigma and discrimination due to their identity (60%).

Disclosure without consent remains an issue, particularly in schools and public institutions. Fear that others will find out about their HIV status also remains the most common factor in causing participants to go off treatment or to fail to restart. The rate of viral load suppression in the study, at 59% of participants, is far below the 95% global target. Among those who were not viral load-suppressed, their reasons indicate that education and resources for viral load testing are lacking. The 19% of participants with other health conditions who reported that they have not received treatment for those conditions also indicates that the general health of participants also needs attention.

The awareness of PLHIV of their human rights and legal protections was limited, with few participants involved in formal advocacy efforts. If PLHIV do take action to support PLHIV in some way, they are mostly acting locally, less formally, within their communities and in their own personal relationships. Support group membership was relatively low, for both HIV support networks (11.3%) and key population support networks (less than 45% for all).

Recommendations

A series of recommendations are proposed for the Ministry of Health, LENEPWHA, partner organisations, other local support networks, and health facilities to address the key findings. These recommendations are structured around three objectives for PLHIV: to reduce stigma and discrimination due to both HIV status and identity, to promote human rights advocacy and community involvement, and to improve health care. A few recommendations are most prominent.

LENEPWHA and the Ministry of Health should address verbal discrimination against PLHIV by creating community-targeted campaigns focused on reducing bullying of PLHIV or emphasising the negative “power of words” to hurt PLHIV.

LENEPWHA should promote group membership and advocacy among PLHIV by launching a communications campaign to sensitise community to the work they do and boost membership. Similar efforts should be undertaken by the key population support groups (MATRIX, Phelisanang Bophelong, Care for Basotho, Skillshare, LPPA).

The Ministry of Health should support viral load suppression work by dedicating more resources to maintaining their HIV Treatment Guidelines, which require strict monitoring, tracking, and retention of patients who fail to comply with viral load testing.

1 Introduction

1.1 The PLHIV Stigma Index

This report presents the results of the second study of the People Living with HIV (PLHIV) Stigma Index performed in Lesotho. The PLHIV Stigma Index was launched in 2008 in response to the call by the world leaders at the United Nations General Assembly Special Session (NGASS) 2001 to achieve universal access to HIV prevention, care, support, and treatment for PLHIV. The NGASS members recognised that full realisation of human rights and fundamental freedoms for PLHIV is essential in the global response to the HIV epidemic, including in the areas of treatment and support. They also recognised that addressing stigma and discrimination against PLHIV, as well as their families, is a critical element of ensuring and protecting their human rights. Subsequently, the PLHIV Stigma Index was developed by GNP+, ICW, UNAIDS, and IPPF as a tool that would provide quantitative indicators of stigma in terms of both external experiences of stigma and discrimination, and internalised feelings of stigma. The tool is a questionnaire consisting of over 70 closed form questions about their experiences of stigma and discrimination in different parts of society (family life, social situations, work, health care), as well as open-ended questions for participants to offer detailed input on their specific experiences. The aim of the PLHIV Stigma Index is to increase evidence-based policy and programmatic interventions, promote greater involvement of people living with HIV and AIDS (GIPA), and ultimately reduce HIV-related stigma and discrimination.

In line with the GIPA principle, countrywide PLHIV Stigma Index studies are carried out by teams constituted of local PLHIV networks and PLHIV, working in coordination with the International Partnership of the PLHIV Stigma Index (GNP+, ICW, and UNAIDS) and guided by a steering committee composed of different national stakeholders. A revised version of the questionnaire, the PLHIV Stigma Index 2.0, was produced in 2018 and employed in this study. This latest version of the questionnaire gives particular attention to key populations of PLHIV who are particularly vulnerable, namely transgender people, sex workers, gay men and other men who have sex with men (MSM), and people who use drugs (PWUD).

1.2 Study background

HIV/AIDS in Lesotho

The HIV epidemic has been a persistent issue in Lesotho, which currently has the second highest HIV prevalence in the world (Avert, 2021). Over the last five years, the country has implemented a range of interventions in HIV prevention, treatment, care, and support. In 2018, Lesotho launched the National HIV and AIDS Strategic Plan 2018/2019 – 2022/2023, which is aimed at: reducing new HIV infections by at least 50% by 2023 from 13,300 in 2017; reducing AIDS-related deaths by 50% by 2023 from 4,900 in 2017; and reducing mother to child transmission from 11.3% in 2017 to less than 5% by 2023. The country also launched a National HIV Prevention Roadmap 2020, which provided a framework for effective prevention programmes with mechanisms to strengthen accountability. The roadmap included a 10-point plan for accelerating HIV prevention for reducing new HIV infections by 75% by 2020.

Progress has been made towards the UNAIDS 95/95/95 targets for awareness of HIV status, sustained ARV treatment, and viral suppression by 2030. As of 2017, the country had achieved 81-92-88 among adults (ICAP, 2019). Innovative strategies to increase uptake and retain patients in care have been put in place, including test and treat, multi-month dispensing (MMD) for stable patients, scale up index HIV testing, roll-out of HIV self-testing (HIVST), and differentiated models of care.

Although national efforts have stabilised the HIV epidemic to a large extent, the response has not achieved the desired and necessary changes in the policy, legal, and regulatory aspects governing HIV-related issues in the country. According to the Legal Environment Assessment for HIV and AIDS done in 2016, there is limited and insufficient rights protection. The assessment found examples of laws, policies, and practices that were punitive or discriminatory, placing populations at higher risk and impacting negatively on PLHIV and key populations in particular. These populations continue to experience stigma, discrimination, and a range of human rights abuses.

Stigma and discrimination

HIV-related stigma is recognised as one of the greatest challenges to slowing the spread of the disease globally and in Lesotho in particular (Avert, 2021). Stigma refers to unfavourable attitudes and beliefs directed toward someone. HIV-related stigma encapsulates all unfavourable attitudes and beliefs directed toward PLHIV, or those perceived to be HIV-positive, and toward their significant others, loved ones, close associates, social groups, and communities (WHO, 2004). Those PLHIV from other groups that are already socially marginalised (i.e., MSM, PWUD, transgender people, and sex workers) frequently bear the heaviest burden of HIV-related stigmatisation (IIEP, 2007).

Discrimination is defined as treatment given to individuals or groups with partiality or prejudice. Discrimination is often discussed in terms of fundamental human rights and the entitlement of people to necessary things such as healthcare, employment, the legal system, social welfare, and reproductive and family education.

Stigma and discrimination are linked as stigmatised individuals may suffer discrimination and human rights violations as a result. Given this risk, people may find it difficult or even impossible to get tested HIV, disclose their status, or even seek treatment. HIV-related stigma and discrimination therefore present a significant challenge for governments, NGOs, and civil society to address the HIV and AIDS epidemic at the national and community level.

LENEPWHA and the 2014 PLHIV Stigma Index study

Formed in May 2005, the Lesotho Network of People Living with HIV and AIDS (LENEPWHA) is mandated to represent, protect, and promote the interests and needs of PLHIV in Lesotho. Guided by the GIPA principle, LENEPWHA has been at the forefront of mobilising PLHIV in the country and ensuring access to care, treatment, and support services through its membership of over 3000 members with about 200 support groups. All LENEPWHA's efforts are geared towards ensuring that PLHIV enjoy full human rights and live without fear of stigma and discrimination.

LENEPWHA conducted the first PLHIV Stigma Index study in Lesotho in 2013 across all 10 districts of the country, publishing the official report in 2014 (LENEPWHA, 2014). At the time, it was estimated that 365,000 people and 23% of adults were living with HIV in the country, but the HIV prevalence among key populations was unknown. The study, which included a sample of 1085 participants from the general PLHIV population identified through health facilities, found evidence of internalised stigma and fear (the indicator of lowest prevalence, suicidal feelings, was 6.7% (73 participants)), and experiences of stigma (the indicator of lowest prevalence, being discriminated against by other PLHIV, was 2.7% (29 participants)). Other key findings from the study are presented in Table 1.

Table 1. Selection of findings from the 2014 PLHIV Stigma Index study. Source: LENEPWHA (2014)

Experience of Stigma: Being gossiped about	Experience of Stigma: Loss of job or other sources of income	Experience of stigma: Denied access to health care	Internalised Stigma: Feelings of shame	Internalised Stigma: Avoiding having (more) children
440 (40.6%)	272 (25.1%)	37 (3.4%)	272 (25.1%)	361 (33.3%)

It was against this backdrop that LENEPWHA conducted the PLHIV Stigma Index 2.0 study in 2020/2021 to document the experiences and feelings of PLHIV and key populations related to stigma and discrimination on the basis of their HIV status, gender identity, sexual orientation, social identity, lifestyle choices, and behaviours.

1.3 Study overview

Study project team and partners

In preparation for the study, a National Steering Committee (NSC) and a Technical Working Group (TWG) were established in 2019 to guide the planning and implementation of the study in 2020. These committees were comprised of representatives from UN organisations, HIV and AIDS organisations, government, civil society organisations, international and local NGOs, and private sector organisations. The NSC and TWG advised the LENEPWHA study project management team, which consisted of one coordinator, one researcher, and one IT specialist to support the digital data collection.

LENEPWHA worked in consultation with the International Partnership to develop a research protocol for the study and obtain ethical clearance from the Lesotho Ministry of Health. John Hopkins University supported the study by hosting the digital cloud-based platform, Redcap, which enabled digital data collection on tablet devices and storage on a cloud-based server.

LENEPWHA recruited 30 people (20 females, 10 males) from the four selected districts to support the study as interviewers of participants in their own districts (Mafeteng 7, Maseru 13, Mohale's Hoek 6, Mokhotlong 4). These recruits were selected from local

district PLHIV support organisations based on being PLHIV who would be comfortable disclosing their status to participants and possessing a minimum of a diploma in social sciences, statistics, sociology, or adult education. PLHIV who were also gay or other MSM (4), sex workers (4), and ex-inmates (3) were also recruited through their organisations from each district to ensure participants from key populations could be interviewed by peers.

The 30 interviewers participated in a three-day training in October 2020 on research ethics, how to conduct interviews, teamwork, Covid-19 precautionary measures, and how to administer the questionnaire using the Redcap platform. A team of five supervisors (one for each district, except for Maseru that had 2 supervisors given the size of the district) were selected from the team to monitor interviewers as well as to oversee compliance with data collection exercise across the districts. They reported to the researcher.

Study goals and objectives

This study is intended to address Lesotho's National HIV and AIDS Strategic Plan 2018/19-2023/24 priority area of advocacy around stigma. By producing a rigorous, detailed inventory of HIV-related stigma and discrimination in the country, LENEPWHA aims to facilitate evidence-based programming that will protect the human rights and improve the quality of life of PLHIV, including those from key populations. To achieve this goal, the study set forth the following objectives:

1. To document the various experiences of PLHIV in Lesotho with HIV-related stigma and discrimination, as well as the experiences of PLHIV in Lesotho with intersectional stigma and discrimination.
2. To strengthen the capacity of PLHIV-led organisations and relevant stakeholders to address stigma and discrimination.
3. To uphold the principle of GIPA by putting PLHIV at the centre of the response.
4. To facilitate the creation of a safe space(s) for PLHIV in all their diversities.

Scope of the study

A total of 1481 adult participants provided responses to the PLHIV Stigma Index 2.0. The sample was within range of the target sample size and included representation from all the key populations (transgender people, MSM, sex workers, PWUD, and ex-inmates) as well as vulnerable groups identified in the study team (people who do not identify as male, female, or transgender, WSW, bisexual people, people not in care, and people LTFU). Small numbers of other vulnerable groups (migrant workers, ethnic minorities) were also present. A detailed overview of the sample composition is included in the Findings, section 3.1.

The interviews were conducted at 27 health facilities across four of Lesotho's 10 districts (Mafeteng, Maseru, Mohale's Hoek, and Mokhotlong) by a team of interviewers who administered the questionnaire verbally and recorded the results digitally on tablets. For those participants LTFU or not in care, interviews were conducted at LENASO, an organisation that supports PLHIV not in treatment or registered with health facilities. For

those participants from key populations who were recruited outside the health facilities, interviews were conducted by peer interviewers at the participants' preferred location.

1.4 Report structure

The remainder of this report is structured as follows:

Section 2 presents the research methodology, including the study planning, sampling techniques, research instrument, and data collection and analysis.

Section 3 presents the findings of the study through a quantitative analysis of the questionnaire data.

Section 4 presents a discussion of the findings in terms of key themes and trends and the limitations of the study.

Section 5 presents the conclusion, including a series of recommendations based on the study findings.

2 Methodology

2.1 Sampling method

Study population

The study population was selected from four of Lesotho's 10 districts. These districts were selected based on a number of factors, namely geography (urban or rural), ecological zones, HIV prevalence, ART coverage, and their prior inclusion in a previous study focusing on PLHIV (the 2018 Integrated Bio-behavioral Surveillance Survey for Key Populations (MoH, 2019)), with the following key considerations:

- **Regionally**, PLHIV residing in the Lowlands region have the greatest access to health services (in terms of proximity and availability of facilities), compared with those in the Foothills and Mountain regions. Meanwhile, those within the Senqu River Valley (e.g., Mohale's Hoek) have historically not been included in HIV/AIDS studies.
- **HIV prevalence** across Lesotho is 25.6% (corresponding to 306,000 people across the country), with Mohale's Hoek representing the district of highest infection rate (ICAP, 2018).
- **ART use** across Lesotho is 69.6%, with Mokhotlong representing the district of lowest ART coverage (ICAP, 2018).
- **The districts** of Maseru and Mafeteng were among the four included in the 2018 Integrated Bio-behavioral Surveillance Survey for Key Populations (along with Leribe and Butha-Bothe, which has the lowest HIV infection rate in the country).

As a result, Mafeteng, Maseru, Mohale's Hoek, and Mokhotlong were selected as the study sites (Figure 1 and Table 2).



Figure 1. Ecological zones of the Lesotho districts. Source: Mekbib et al. (2011)

A total of 27 health facilities, representing 25% of the facilities in each district, were selected as data collection sites. The specific study sites were also selected based on the availability of male clinics at the health facilities.

Table 2. Characteristics of selected district as of 2016. Source: BOS (n.d.) and ICAP (2019)

District	HIV Prevalence	ART Coverage	Total ART Health Facilities (Study Sites)	Study Site Geography + Ecological Zone
Mafeteng	28,355 (26.3%)	18,455 (72.1%)	23 (6)	Urban Lowlands (1) Rural Lowlands (3)* Rural Foothills (2)
Maseru	103,856 (27.8%)	71,206 (65.9%)	54 (13)	Urban Lowlands (6)* Rural Lowlands (4) Rural Mountains (2) Rural Foothills (1)
Mohale's Hoek	28,236 (29.3%)	14,988 (73.7%)	19 (5)	Urban Lowlands (1) Rural Lowlands (1) Rural Senqu River Valley (SRV) (3)
Mokhotlong	15,598 (26.1%)	8,240 (56.5%)	12 (3)	Urban Mountains (2)* Rural Mountains (1)
Total	176,135	112,889	108 (27)	

*contains one or more sites with a male clinic

Sample size

The target sample size (n) for the study was calculated using the following formula:

$$n = N \cdot X / (X + N - 1)$$

where:

$$X = Z_{\alpha/2}^2 \cdot p \cdot (1-p) / MOE^2$$

$Z_{\alpha/2}$ is the critical value of the normal distribution at $\alpha/2$ (where $\alpha = 1 -$ the confidence level)

MOE is the margin of error (also known as the level of precision)

p is the sample proportion

N is the population size

The following values were used to compute sample size:

- Using a confidence level of 95% ($\alpha = 0.05$), $Z_{\alpha/2} = 1.96$
- Based on the 2014 study, which contained a sample representing 33% of the target population of LENEPWHA members, $p=0.33$
- Using the total number of PLHIV in the districts selected for the study, $N = 176,135$
- Based on the guidelines Stigma Index Sample Size Calculation for determining level of precision based on the estimated level of prevalence, $MOE = 3\%$
 - The result from the PLHIV Stigma Index 1.0 - Section 2C - Question 2 (“I avoided going to a local clinic when I needed to” or “I avoided going to a hospital when I needed to”) was 4.7% for the 2014 Lesotho questionnaire, rounded up to 5% as the estimated prevalence level
 - Since participants were all recruited from health facilities, this result was considered an underestimation and therefore doubled for improved accuracy of prevalence level: 10%
 - According to the guidelines, the rule of thumb for an estimated prevalence of 0-10% is a target precision of 1.5-3%.

Using this approach, the target sample size, n , is 939. By comparison, the PLHIV Stigma Index sample size calculator tool provided by GNP+,¹ which offers a simplified calculation that does not take into account context-specific variables, produced a target sample size of 1537. A sample size within the range of 939-1537 was therefore considered valid.

Sample selection and distribution

The sampling approach aimed to include participants from the general population of PLHIV, as well as those from key populations of PLHIV, namely gay men and other MSM, sex workers, transgender people, and people who use drugs (PWUD). The study employed two sampling techniques: venue-based sampling and limited chain referral (LCR). Venue-based sampling was used for systematic sampling of the general PLHIV population who access HIV treatment at health facilities. This included the general population of PLHIV as well as those from key populations.

The LCR sampling was used to identify participants from the wider population of PLHIV that are difficult to access, namely those not in care, those lost to follow up (LTFU), ex-inmates, and PWUD. A coupon system was used to locate such hard-to-find PLHIV, whereby a total of 400 coupons were printed and given to interviewers to distribute to tracked participants from these target populations (called “seeds”) to recruit others within the same population. Each of the 30 interviewers was allocated 10-15 coupons to hand out to potential participants in order to limit the number of participants recruited by any given person and ensure diversity within the sample. Each seed was given a maximum of four coupons.

¹ https://hall.shinyapps.io/PLHIV_Stigma_Sample_Size_Calculator/

Based on the estimated population sizes of the different key populations, a target sample distribution based on the target sample size of 1537 was generated (Table 3).

Table 3. Target sample distribution among general and key populations by district

	MSM	Sex Workers	Trans-gender	Ex-inmates	PWUD	PLHIV Not in care	PLHIV LTFU	General PLHIV on ART	Total Sample Size
<i>Estimated Population</i>	2%	2.5%	5%	10%	-	30.4%		17.8%	-
Mafeteng	20	35	20	37	15	37	18	170	352
Maseru	35	65	26	41	33	43	39	366	648
Mohale's Hoek	20	30	20	39	15	38	15	142	319
Mokhotlong	15	20	10	37	5	36	9	86	218
Total	90	150	76	154	68	154	81	764	1537
Total actual sample size	48*	200	57	242	55	63	50	764	1481

*Includes gay men and other men who have sex with men, excludes bisexual men (26)

In addition to being members of the target populations, participants had to meet a series of eligibility criteria. Study participants had to be:

- a) adults aged 18 years and above
- b) living with HIV
- c) people with a stable mental capacity and able to consent to participate in the study
- d) Sesotho-speaking

The final sample for the study was 1481. A detailed overview of the sample composition is provided in the Findings, section 3.1.

2.2 Ethical considerations

Given the sensitive nature of the study, ethical clearance was sought and obtained from the Ministry of Health. A Research Protocol document for the study was prepared in regular consultation with the International Partnership of the PLHIV Stigma Index (GNP+, ICW, and UNAIDS) and presented to the Lesotho Ministry of Health Ethics Review Committee for ethical clearance. This protocol included provision for obtaining informed consent from participants and ensuring the safety and confidentiality of participants. Approval for the study was received in June 2020.

2.3 Data Collection and monitoring process

Research instrument

Structured interviews with participants about their experiences of stigma and discrimination related to their HIV status were conducted using the standardised PLHIV Stigma Index 2.0 questionnaire as the research instrument. The tool was translated into vernacular language, Sesotho, for ease of administration to the participants. Additional questions on stigma related to incarceration and food insecurity were included to address

the Lesotho context. Additional food security questions were based on the 2018 study that assessed nutritional status of People Living with HIV in the 5 districts of Lesotho Leribe, Berea, Maseru, Mafeteng and Mohale's Hoek: (EGPAF 2018) to assess the level of nutrition on PLHIV. The inclusion of ex-inmates was prompted by the fact that no data was available regarding the level of stigma and discrimination directed towards PLHIV who were once incarcerated. This resulted in a questionnaire that consisted of 96 questions in total. The questionnaire addressed the following ten key topics:

- A. Participant profile
- B. Disclosure
- C. Experience of stigma and discrimination
- D. Internalised stigma and resilience
- E. Interactions with health care services
- F. Human rights and effecting change
- G. Other sources of stigma
- H. Personal experience of stigma
- I. Stigma related to incarceration
- J. Stigma related to food insecurity

The English version of the questionnaire was uploaded onto the REDCap platform on tablets, which were used by for the interviewers.

Data collection

The field team administered the questionnaire on-site at the designated health facilities, organisations, and preferred locations of PLHIV from key populations between November 2020 and January 2021. The interviewers verbally administered the questionnaire to participants in Sesotho and recorded their responses using the REDCap Software on the tablets.

Regular, monthly, and ad hoc monitoring of data collection was performed by the research team. The IT specialist and JHU experts also provided on-site and remote technical assistance, respectively, for the tablets and REDCap platform.

As interviews were conducted in person during the COVID-19 pandemic, all safety precautions (PPE usage, social distancing, health survey) were undertaken.

Data analysis

The REDCap Software contains basic built-in reporting functions, which JHU supplemented with a descriptive statistics analysis using STATA software. These descriptive statistics results were checked by the research team through by manually performed an analysis of the raw data in Excel for reporting and generating representations of the data.

3 Findings

3.1 Participant demographics

This section presents demographic characteristics of the study participants in terms of age, sex, period of knowledge of one's HIV positive status, intimate relationships, partner's knowledge of their HIV status, number of children per household, education level, work status, employment status, ability to meet basic needs, respondents' belonging to various groupings as well as their membership in HIV and AIDS support groups.

Age, sex, gender, and vulnerable groups

Most of the study participants were in the 26-35 age group (33.8%) and the 36-46 age group (33.2%). The least represented age cohort was 69+ (1.7%).

Of the 1481 participants, 658 (44.4%) were assigned male sex at birth and 823 (55.6%) were assigned female sex. In terms of gender identity, 560 were male (37.8%), 822 (55.5%) were female, 57 were transgender (3.8%), 41 did not identify as male, female, or transgender (2.8%), and 1 preferred not to answer (0.07%).

The most common age-gender cohort in the study was women aged 26-35 years (291, 19.6%).

Table 4. Age group and gender distribution

Age group	Male	Female	Transgender	Do not identify as male, female, or transgender	Prefer not to answer	Total
18-25 years	32 (5.7%)	108 (13.1%)	10 (17%)	13 (31.7%)	0 (0)	163 (11.0%)
26-35 years	152 (27.1%)	291 (35.4%)	35 (61.4%)	22 (53.7%)	1 (100%)	501 (33.8%)
36-46 years	219 (39.1%)	260 (31.6%)	8 (14.0%)	5 (12.2%)	0 (0)	492 (33.2%)
47-57 years	95 (17%)	107 (13%)	3 (5.3%)	1 (2.4%)	0 (0)	206 (13.9%)
58-68 years	49 (8.8%)	44 (5.4%)	1 (1.8%)	0 (0)	0 (0)	94 (6.4%)
69 years & above	13 (2.3%)	12 (1.5%)	0 (0)	0 (0)	0 (0)	25 (1.7%)
Total	560 (37.8%)	822 (55.5%)	57 (3.8%)	41 (2.8%)	1 (0.1%)	1481 (100%)

Participants were asked if they belonged to any of seven types of vulnerable social groups. The most prevalent groups were people living with a disability (101, 6.8%) and migrant workers (98, 6.6%).

Table 5. Participants from vulnerable groups

Group	Yes	No	Prefer not to answer
Racial, ethnic, or religious minority	72 (4.9%)	1391	17
Indigenous or aboriginal group	37 (2.5%)	1427	17
Living with a disability	101 (6.8%)	1368	12
Refugee or asylum seeker	20 (1.4%)	1443	18
Migrant worker	98 (6.6%)	1365	16
Internally displaced person	7 (0.5%)	1456	15
Incarcerated person/in prison	56 (3.9%)	1401	17

HIV-positive status

Participants were asked how long they had known about their HIV-positive status. The average number of years across the entire study group was 5.8 years (min <1 year, max 29 years). A total of 240 participants (16.2%) did not recall how long they had known about their HIV-positive status. These participants are therefore omitted from the total numbers of participants reported in each category in tables 6 and 7.

Table 6. Period of HIV-positive status by age group

Period of HIV-positive status	18-25 years	26-35 years	36-46 Years	47-57 Years	58-68 Years	69+ years
minimum	<1 year	<1 year	<1 year	1 year	1 year	2 years
maximum	20 years	29 years	24 years	23 years	26 years	20 years
average	3.3 years	4.3 years	6.7 years	8.4 years	8.8 years	8 years
Total number participants	149	427	415	166	67	14

Table 7. Period of HIV-positive status by gender

Period of HIV-positive status	Male	Female	Transgender	Do not identify as male, female, or transgender	NA
minimum	<1 year	<1 year	1 year	2 years	1 year
maximum	23 years	26 years	29 years	13 years	1 year
average	6.2 years	5.7 years	5 years	4.9 years	1 year
Total number participants	441	702	53	41	1

Household structure

The majority of respondents (84.6%) have children in their households, with households of 1-3 children being the most common (61.5%). Notably, households with the largest number of children (10-14) were reported far more from participants who identified as transgender (35.1%) or did not identify as male, female, or transgender (43.9%), than men or women.

Table 8. Number of children in the household

Number of children in household	Male	Female	Transgender	Do not identify as male, female, or transgender	Prefer not to answer	Total
0	93 (16.6%)	32 (0.04%)	1 (0.02%)	2 (0.05%)	0 (0)	228 (15.4%)
1-3	234 (41.8%)	395 (48.1%)	11 (19.3%)	1 (0.02%)	0 (0)	911 (61.5%)
4-6	177 (31.6%)	335 (40.8%)	19 (33.3%)	12 (29.3%)	0 (0)	298 (20.1%)
7-9	17 (3.0%)	9 (22.5%)	6 (10.5%)	8 (19.5%)	0 (0)	37 (0.02%)
10-14	39 (7.0%)	51 (0.01%)	20 (35.1%)	18 (43.9%)	1 (100%)	4 (0.002%)
Total	560 (100%)	822 (100%)	57 (100%)	41 (100%)	1 (100%)	1481 (100%)

Education, work status, and basic needs

At the time of the study, 83 participants (6%) were pursuing some formal educational activity, while 91.4% of participants had formal education of some kind. The majority of participants had a maximum of primary/elementary education (641, 43.2%), followed by secondary education (543, 36.7%). Only 169 participants (11.4%) had tertiary, university, or vocational education.

Table 9. Formal education

Highest Formal Education Completed	Male	Female	Transgender	Do not identify as male, female, or transgender	Prefer not to answer	Total
No formal education	93 (16.6%)	32 (3.9%)	1 (0.02%)	2 (0.05%)	0 (0)	128 (8.6%)
Primary/ elementary/ local equivalent	234 (41.8%)	395 (48.1%)	11 (19.3%)	1 (0.02%)	0 (0)	641 (43.2%)
Secondary/ high school	177 (31.6%)	335 (40.8%)	19 (33.3%)	12 (29.3%)	0 (0)	543 (36.7%)
Trade/vocational school	17 (3.0%)	9 (1.1%)	6 (10.5%)	8 (19.5%)	0 (0)	40 (2.7%)
University/ tertiary Education	39 (7.0%)	51 (6.2%)	20 (35.1%)	18 (43.9%)	1 (100%)	129 (8.7%)
Total	560 (100%)	822 (100%)	57 (100%)	41 (100%)	1 (100%)	1481 (100%)

Most participants (693, 46.8%) were unemployed. Amongst those who were employed, the majority were full-time employees (265, 17.9%).

Table 10. Participants' work status

Work Status	Male	Female	Trans-gender	Do not identify as male, female, or transgender	Prefer not to answer	Total
Full-time employee	124 (22.1%)	115 (14.0%)	22 (38.6%)	4 (9.8%)	0 (0)	265 (17.9%)
Part-time employee	75 (13.4%)	76 (9.2%)	6 (10.5%)	3 (7.3%)	0 (0)	160 (10.8%)
Full-time business owner/self-employed	62 (11.1%)	141 (17.2%)	1 (1.8%)	4 (9.8%)	0 (0)	208 (14.0%)
Casual or informal part-time work	69 (12.3%)	49 (6.0%)	4 (7.0%)	4 (9.8%)	1 (100%)	127 (0.09%)
Retired	16 (2.9%)	12 (1.5%)	0 (0)	0 (0)	0 (0)	28 (0.02%)
Unemployed	214 (38.2%)	429 (52.2%)	24 (42.1%)	26 (63.4%)	0 (0)	693 (46.8%)
Total	560 (100%)	822 (100%)	57 (100%)	41 (100%)	1 (100%)	1481 (100%)

Participants were asked about their ability to meet their basic needs over the last 12 months, i.e., to provide food, shelter, and clothing. A majority of participants (1196, 80.8%) reported they were unable to meet their basic needs some of or most of the time. Notably, the transgender participants were more than twice as likely than women, and more than three times as likely as men, to meet their basic needs.

Table 11. Participants' inability to meet basic needs in the last 12 months by gender

	Male	Female	Trans-gender	Do not identify as male, female, or transgender	Prefer not to answer	Total
Never	118 (21.1%)	141 (17.2%)	21 (36.8%)	5 (12.2%)	0 (0)	285 (19.2%)
Some of the time	304 (54.3%)	399 (48.5%)	34 (59.6%)	31 (75.6%)	1 (100%)	769 (51.9%)
Most of the time	138 (24.6%)	282 (34.3%)	2 (3.5%)	5 (12.2%)	0 (0)	427 (28.8%)
Total	560 (100%)	822 (100%)	57 (100%)	41 (100%)	1 (100%)	1481 (100%)

Participants in the 58-68 age group were most unable to meet their basic needs most of the time (47, 50% of people in this cohort), followed by those in the 69+ age group (11, 44% of people in this cohort). Those in the 26-35 age group were most able to meet their basic needs (130, 25.9% of people in this cohort).

Table 12. Inability to meet basic needs in the last 12 months by age

	18-25 years	26-35 years	36-46 Years	47-57 years	58-68 years	69+ years	Total
Never	28 (17.2%)	130 (25.9%)	91 (18.5%)	23 (11.2%)	10 (10.6%)	3 (12.0%)	285 (19.2%)
Some of the time	89 (54.6%)	266 (53.1%)	251 (50.1%)	115 (55.8%)	37 (39.4%)	11 (44.0%)	769 (51.9%)
Most of the time	46 (28.2%)	105 (21.0%)	150 (30.4%)	68 (33.0%)	47 (50.0%)	11 (44.0%)	427 (28.8%)
Total	163 (100%)	501 (100%)	492 (100%)	206 (100%)	94 (100%)	25 (100%)	1481 (100%)

Intimate relationship and partner status

The majority of participants (77.0%) reported having an intimate/sexual relationship (whether married or unmarried) with one or more partners. Of those in intimate relationships, the most prevalent were women in the age cohorts of 26-35 (22.9%) and 36-46 (18.8%)

Table 13. Intimate relationship status

Intimate Relationship	Male	Female	Transgender	Do not identify as male, female, or transgender	Prefer not to answer	Total
Yes	447 (79.8%)	647 (78.7%)	25 (43.9%)	21 (51.2%)	0 (0)	1140 (77.0%)
No	113 (20.2%)	175 (21.3%)	32 (56.1%)	20 (48.8%)	0 (0)	341 (23.0%)
Total	560 (100%)	822 (100%)	57 (100%)	41 (100%)	0 (0%)	1481 (100%)

Of the 1140 participants with an intimate/sexual relationship, 654 (57.4%) have one or more partners who are HIV-positive. This represents 44.2% of the total sample. Men were more likely to have partners living with HIV (69.1%). Yet, an average of 18.2% of overall participants did not know the HIV status of their partner(s). This percentage was considerably higher for women (16.2%) and people who do not identify as male, female, or transgender (19%) than the other gender groups.

Table 14. Gender distribution of HIV status of partner(s)

Partner(s) HIV status	Male	Female	Transgender	Do not identify as male, female, or transgender	Total
Partner living with HIV	309 (69.1%)	326 (50.4%)	12 (48.0%)	7 (33.3%)	654 (57.4%)
Partner is not HIV-positive	98 (21.9%)	216 (33.4%)	10 (40.0%)	3 (14.3%)	160 (14.0%)
Unsure about partner's HIV status	40 (8.9%)	105 (16.2%)	3 (12.0%)	4 (19.0%)	208 (18.2%)
Total	447 (100%)	647 (100%)	25 (100%)	21 (100%)	1140 (100%)

Group membership

In total, 1312 participants (88.9%) reported not being members of a network or support group for people living with HIV. For the 168 who do belong to groups, the gender distribution is fairly consistent across cohorts.

Table 15. Gender distribution of PLHIV network/support group membership

	Male	Female	Transgender	Do not identify as male, female, or transgender	Total
Group member	53 (9.5%)	104 (12.7%)	7 (12.3%)	4 (9.8%)	168 (11.3%)
Total	560	822	57	41	1481

3.2 Disclosure

Disclosure status

Participants were asked about their HIV-status disclosure to different people and groups. In the cases where participants had their status disclosed without their consent, this most commonly occurred with authority figures (39% of cases), teachers and school administrators (33.3%), classmates (31.3% of cases), and local leaders (20.7% of cases).

Table 16. HIV disclosure status across different groups and people

Group	Yes	Yes, without consent*	No	NA
Husband/wife/partner(s)	1151 (77.7%)	158 (13.7%)	149 (10.1%)	178 (12.0%)
Children	985 (66.5%)	106 (10.8%)	261 (17.6%)	233 (15.7%)
Other family members	1322 (89.3%)	171 (12.9%)	143 (9.7%)	21 (1.4%)
Friends	1011 (68.3%)	138 (13.6%)	427 (28.8%)	38 (2.6%)
Neighbours	671 (45.3%)	107 (15.9%)	734 (49.6%)	73 (4.9%)
Employer(s)	204 (13.8%)	22 (10.8%)	540 (36.5%)	727 (49.1%)
Co-workers	204 (13.8%)	22 (10.8%)	528 (35.7%)	742 (50.1%)
Teacher(s)/school administrator(s)	30 (2.0%)	10 (33.3%)	395 (26.7%)	1048 (70.8%)
Classmates	32 (2.2%)	10 (31.3%)	405 (27.3%)	1033 (69.8%)
Local leaders	188 (12.7%)	39 (20.7%)	859 (58.0%)	421 (28.4%)
Authority figures (e.g., police, judges, law enforcement, etc.)	51 (3.4%)	20 (39.2%)	975 (65.8%)	432 (29.2%)

*Expressed as a percentage of "Yes" responses, (x%)

Experience with disclosure

An overwhelming majority of participants (more than 90%) reported positive experiences and being supported when disclosing to people close to them (e.g., partners, family members, and close friends). Positive experiences were less common when disclosing to people who were not close (56.2%), as was support (53.2%). Most participants (77.3%) agreed that disclosure became easier over time.

Table 17. Experiences with disclosing to different groups of people

Disclosing experience	Agree	Somewhat agree	Disagree	NA
In general, disclosing your HIV status to people you are close to (e.g., partner, family, close friends) has been a positive experience	1265 (85.4%)	107 (7.2%)	101 (6.8%)	7 (0.5%)
In general, people you are close to, were supportive when they first learned about your HIV status	1220 (82.4%)	137 (9.3%)	109 (7.4%)	14 (0.9%)
In general, disclosing your HIV status to people you don't know very well has been a positive experience	603 (40.7%)	230 (15.5%)	516 (34.9%)	131 (8.9%)
In general, people you don't know very well were supportive when they first learned about your HIV status	565 (38.1%)	223 (15.1%)	529 (35.7%)	163 (11.0%)
In general, disclosing your HIV status has become easier over time	932 (63.1%)	209 (14.2%)	285 (19.2%)	51 (3.5%)

Disaggregating the negative experiences of disclosure (i.e., those who disagreed with each of the disclosure statements) by gender, those who do not identify as male, female, or transgender were more likely than others to have negative disclosure experiences in every way. Transgender participants were more likely to have negative disclosure experiences with people close to them compared with men and women. Yet, they were less likely than men and women to have negative experiences disclosing to people they did not know. Men and women had comparable experiences of disclosure, with the exception that men were 1.5 times more likely than women to have a negative experience disclosing to people close to them.

Table 18. Distribution of "Disagree" responses by gender, as percentage of total sample

Disclosing experience	Male	Female	Trans-gender	Do not identify as male, female, or transgender
In general, disclosing your HIV status to people you are close to (e.g., partner, family, close friends) has been a positive experience	42 (7.5%)	40 (4.8%)	8 (14.0%)	11 (26.8%)
In general, people you are close to, were supportive when they first learned about your HIV status	39 (7.0%)	50 (6.1%)	11 (19.3%)	9 (22.0%)
In general, disclosing your HIV status to people you don't know very well has been a positive experience	184 (32.9%)	296 (36.0%)	15 (26.3%)	21 (51.2%)
In general, people you don't know very well were supportive when they first learned about your HIV status	188 (33.6%)	304 (37.0%)	15 (26.3%)	22 (54.7%)
In general, disclosing your HIV status has become easier over time	118 (21.1%)	152 (18.5%)	9 (15.8%)	6 (14.6%)

3.3 Stigma and Discrimination

This section measured the level of stigma directed toward people living with HIV/AIDS by other people. Experiences of external stigma and discrimination were gauged in terms of 11 key experiences. The most common experience was discriminatory remarks and gossiping by both family members and other people, both in the last 12 months and prior to that point (all +/-3.6%).

Overall, however, an overwhelming majority of respondents did not experience the different kinds of discrimination (more than 90% in each category). In total, 1147 participants (77.4%) said they did not experience any of the forms of stigma and discrimination stipulated.

Table 19. Participants' experiences of stigma and discrimination

<i>Form of stigma or discrimination</i>	Yes, within last 12 months	Yes, but not in the last 12 months	No	NA
Excluded from social gatherings	38 (2.6%)	24 (1.6%)	1405 (94.9%)	12 (0.8%)
Excluded from religious activities or places of worship	22 (1.5%)	12 (0.8%)	1430 (96.6%)	15 (10.1%)
Excluded from family activities	36 (2.4%)	23 (1.6%)	1412 (95.3%)	10 (0.7%)
Aware of family members making discriminatory remarks or gossiping about you	54 (3.6%)	46 (3.1%)	1369 (92.4%)	11 (0.7%)
Aware of other people making discriminatory remarks or gossiping about you	60 (4.1%)	54 (3.6%)	1350 (9.1%)	15 (1.0%)
Verbally harassed	47 (3.2%)	33 (2.2%)	1390 (93.9%)	9 (0.6%)
Blackmail	25 (1.7%)	9 (0.6%)	1433 (96.8%)	10 (0.7%)
Physically harassed	22 (1.5%)	6 (0.4%)	1437 (97.0%)	11 (0.7%)
Refused employment or lost a source of income	18 (1.2%)	15 (1.0%)	1410 (95.2%)	33 (2.2%)
Job description or nature of your job changed	14 (1.0%)	3 (0.2%)	1339 (90.4%)	120 (8.1%)
Wife/husband, partner, or child ever experienced discrimination because of your HIV status	18 (1.2%)	10 (0.7%)	1384 (93.5%)	59 (4.0%)

Disaggregating by gender, those who do not identify as male, female, or transgender were the most likely to experience stigma or discrimination or stigma of some kind, while transgender participants were the least likely.

Table 20. Gender distribution of participants with 100% "no" responses

Male	Female	Transgender	Do not identify as male, female, or transgender	Prefer not to answer	Total
446 (79.6%)	622 (75.7%)	52 (91.2%)	27 (65.9%)	0 (0)	1147 (77.4%)

3.4 Internalised stigma

The level of participant's internalised stigma was also examined: how respondents perceived themselves as a result of being HIV-positive. Participants were asked to provide their experiences of stigma and discrimination both over the last 12 months, and prior to that point. The level of internalised stigma was assessed by how participants' HIV status affected the way they value/perceive themselves in terms of 10 key experiences over the last 12 months. In any given category, the overwhelming majority of respondents (more than 90%) did not report being negatively affected by their HIV-positive status. The categories where participants were most negatively affected by their status were self-confidence (7.3%), ability to cope with stress (6.8%), and desire to have children (6.1%).

Overall, 426 participants (28.8%) reported being positively affected by their HIV-positive status in one or more ways, while 243 participants (16.4%) reported being negatively affected in one or more ways.

Table 21. Participants' experience of internalised stigma

Personal experiences or feelings	Positively affected by HIV status	Not affected by HIV status	Negatively affected by HIV status	NA
<i>Self-confidence</i>	271 (18.3%)	1094 (73.9%)	108 (7.3%)	7 (0.5%)
<i>Self-respect</i>	240 (16.2%)	1179 (79.6%)	55 (3.7%)	7 (0.5%)
<i>Ability to respect others</i>	193 (13.0%)	1230 (83.1%)	47 (3.2%)	10 (0.7%)
<i>Ability to cope with stress</i>	176 (11.9%)	1192 (80.5%)	100 (6.8%)	12 (0.8%)
<i>Ability to have close/secure relationships with others</i>	176 (11.9%)	1220 (82.4%)	72 (4.9%)	11 (0.7%)
<i>Ability to find love</i>	182 (12.3%)	1190 (80.5%)	83 (5.6%)	24 (1.6%)
<i>Desire to have children</i>	174 (11.8%)	1134 (76.7%)	90 (6.1%)	80 (5.4%)
<i>Ability to achieve personal and professional goals</i>	187 (12.6%)	1198 (81.0%)	67 (4.5%)	27 (1.8%)
<i>Ability to contribute to one's community</i>	159 (10.8%)	1246 (84.2%)	49 (3.3%)	25 (1.7%)
<i>Ability to practice a religion/faith as one wants to</i>	183 (12.4%)	1238 (83.9%)	36 (2.4%)	19 (1.3%)

Disaggregating the negative experiences of stigma by gender, transgender participants and those who did not identify as male, female, or transgender were much more likely to experience internalised stigma than male or female participants, particularly with ability to find love, ability to have close/secure relationships, and ability to achieve professional goals. Those who did not identify as male, female, or transgender experienced the most internalised stigma as a proportion of any gender group in all categories.

Table 22. Gender distribution of participants negatively affected by HIV status

Personal experiences or feelings	Male	Female	Transgender	Do not identify as male, female, or transgender
Self-confidence	40 (7.1%)	57 (6.9%)	2 (3.5%)	8 (19.5%)
Self-respect	20 (3.5%)	21 (2.6%)	4 (7.0%)	9 (22.0%)
Ability to respect others	16 (2.9%)	20 (2.4%)	6 (10.5%)	5 (12.2%)
Ability to cope with stress	32 (5.7%)	51 (6.2%)	7 (12.3%)	9 (22.0%)
Ability to have close/secure relationships with others	17 (3.0%)	33 (4.0%)	10 (17.5%)	11 (26.8%)
Ability to find love	21 (3.7%)	37 (3.9%)	8 (14.0%)	16 (39.0%)
Desire to have children	28 (5.0%)	49 (6.0%)	5 (8.8%)	8 (19.5%)
Ability to achieve personal and professional goals	26 (4.6%)	24 (2.9%)	3 (5.3%)	14 (34.1%)
Ability to contribute to one's community	13 (2.3%)	25 (3.0%)	2 (3.5%)	9 (22.0%)
Ability to practice a religion/faith as one wants to	14 (2.5%)	16 (1.9%)	3 (5.3%)	3 (7.3%)

Participants were also asked how their ability to meet the internal needs described above had changed over the last 12 months. Overall, a minority of participants (125, 8.4%) felt they had gotten worse at meeting their internal needs. Disaggregating by gender, women were more likely than other groups to report a change for the worse, but also more likely to report positive changes, as they were the least likely group to report no changes.

Table 23. Gender distribution of how participants' ability to meet their internal needs have changed over the last 12 months

	Male	Female	Transgender	Do not identify as male, female, or transgender	Prefer not to answer	Total
Better	305 (54.5%)	481 (58.5%)	28 (49.1%)	6 (14.6%)	1 (100%)	821 (55.4%)
About the same	199 (35.5%)	230 (28.0%)	28 (49.1%)	33 (80.5%)	0 (0)	487 (32.9%)
Worse	33 (5.9%)	90 (10.9%)	1 (1.8%)	1 (2.4%)	0 (0)	125 (8.4%)
N/A	26 (4.6%)	21 (2.6%)	0 (0)	1 (2.4%)	0 (0)	48 (3.2%)
Total	560 (100%)	822 (100%)	57 (100%)	41 (100%)	1 (100%)	1481 (100%)

Negative feelings

Participants were also asked about negative feelings they might have associated with their HIV status. The most common negative feelings were difficulty telling people about their status (35.9%), hiding their HIV status from others (30.4%), and feeling guilty about being HIV-positive (18%). Women were more likely than average to have difficulty telling others about their status (38%). People who do not identify as male, female, or transgender were far more likely than average to have difficulty sharing their HIV-positive status with other people and hide their HIV status.

Table 24. Gender distribution of participants' negative feelings associated with HIV status

Negative feeling	Male	Female	Trans-gender	Do not identify as male, female, or transgender	Prefer not to answer	Total
<i>It is difficult to tell people that I am HIV-positive</i>	176 (31.4%)	312 (38.0%)	16 (28.1%)	26 (63.4%)	1 (100%)	531 (35.9%)
<i>Being HIV-positive makes me feel dirty</i>	86 (15.4%)	134 (16.3%)	11 (19.3%)	4 (9.8%)	1 (100%)	236 (15.9%)
<i>I feel guilty that I am HIV-positive</i>	100 (17.9%)	154 (18.7%)	12 (21.0%)	2 (4.9%)	1 (100%)	266 (18.0%)
<i>I am ashamed that I am HIV-positive</i>	91 (16.3%)	143 (17.4%)	14 (24.6)	2 (4.9%)	1 (100%)	251 (16.9%)
<i>I sometimes feel worthless because I am HIV-positive</i>	81 (14.5%)	116 (14.1%)	14 (24.6%)	4 (9.8%)	1 (100%)	216 (14.6%)
<i>I hide my HIV status from others</i>	163 (29.1%)	247 (30.0%)	21 (36.8%)	18 (43.9%)	1 (100%)	450 (30.4%)
Total Participants	560	822	57	41	1	1481

Stigma-related behaviours

Participants were asked if they had taken any of six negative actions because of their HIV status. For any given action, an overwhelming majority of participants (>95%) said they did not take the action because of their HIV-positive status. Among the actions that participants did take, the most common were choosing not have sex (3.5%), choosing not to attend family gatherings (2.7%), and choosing not to seek social support (2.6%) because of their HIV status.

Table 25. Actions taken by participants because of their HIV-positive status

Action	Yes	No	NA
<i>Chosen not to attend family gatherings</i>	40 (2.7%)	1430 (96.7%)	9 (0.6%)
<i>Avoided going to a clinic</i>	36 (2.4%)	1435 (97.0%)	9 (0.6%)
<i>Chosen not to apply for a job</i>	18 (1.2%)	1427 (96.4%)	35 (2.4%)
<i>Chosen not to seek social support</i>	38 (2.6%)	1434 (96.9%)	8 (0.5%)
<i>Isolated from family and/or friends</i>	30 (2.0%)	1441 (97.4%)	9 (0.6%)
<i>Decided not to have sex</i>	51 (3.5%)	1409 (95.3%)	19 (1.3%)

3.5 Interaction with healthcare services

Participants were asked about their experiences interacting with healthcare services in terms of HIV testing, HIV treatment, general health, health service delivery, and sexual and reproductive health.

HIV testing experiences

Overall, 1342 participants (90.6%) were tested by their own choice. Of the remaining participants, 78 (5.3%) reported having been pressured by others, 44 (3%) reported having been tested without knowing, 11 (0.7%) reported being forced to undertake a test, and 6 (0.4%) reported being born with HIV.

The most common reason for participants to get tested was that they felt sick and thought it was HIV-related (461, 31.1%), they believed they were at risk for HIV (335, 22.6%), and that they just wanted to know (298, 20.1%).

Table 26. Gender distribution of participants' reasons for getting tested for HIV

<i>Reason to get tested</i>	Male	Female	Trans-gender	Do not identify as male, female, or trans-gender	Prefer not to answer	Total
<i>A provider recommended it, or as part of other health care (e.g., antenatal, medical male circumcision, STI testing, PrEP)</i>	94 (16.8%)	142 (17.3%)	10 (17.5%)	7 (17.1%)	0 (0)	253 (17.1%)
<i>I believed I was at risk for HIV</i>	131 (23.4%)	176 (21.4%)	18 (31.6%)	10 (24.4%)	0 (0)	335 (22.6%)
<i>I felt sick and I/someone close to me though it might be HIV-related</i>	178 (31.8%)	257 (31.3%)	18 (31.6%)	9 (22.0%)	0 (0)	461 (31.1%)
<i>As part of or because of a community-based programme</i>	5 (0.9%)	10 (1.2%)	1 (1.8%)	1 (2.4%)	0 (0)	17 (1.1%)
<i>It was mandatory (e.g., employment, visa, marriage, incarceration, access to antenatal care)</i>	4 (0.7%)	10 (1.2%)	0 (0)	0 (0)	0 (0)	14 (0.9%)
<i>I just wanted to know</i>	103 (18.4%)	175 (21.3%)	9 (15.8%)	10 (24.4%)	1 (100%)	298 (20.1%)
<i>Other</i>	20 (3.6%)	21 (2.6%)	0 (0)	0 (0)	0 (0)	41 (2.8%)
<i>Not answered</i>	31 (5.5%)	25 (3.0%)	1 (1.8%)	4 (9.8%)	0 (0)	61 (4.1%)

Participants were asked how long they waited to get tested for HIV after first thinking they should be tested. A large majority (1053, 71.1%) got tested within six months of thinking about testing. Considerably fewer waited between six months and two years (165, 11.1%), waited more than two years (58, 3.9%), or could not remember (142, 9.6%).

Participants were then asked if they hesitated to test for fear of how other people would react if they tested positive to HIV. Only 326 participants (22%) said “yes”, that this fear was a factor in making them hesitate to get tested.

HIV treatment and disruption

Overall, 1417 of the participants (95.7%) were either on treatment or had received treatment at some stage. All transgender participants had received treatment at some stage. Men and women were twice as likely as those who do not identify as male, female, or transgender to never receive treatment.

Table 27. Gender distribution of those who have never received HIV treatment

Male	Female	Transgender	Do not identify as male, female, or transgender	Prefer not to answer	Total
24 (4.3%)	38 (4.6%)	0 (0)	1 (2.4%)	0 (0)	63 (4.3%)

The participants were asked if specific fears played a role in making them hesitate, delay, or never initiate care or treatment for HIV. Overall, 474 participants (32%) reported that one or more of the specified fears played a role in inhibiting their initiation of treatment. The most common fears were not being ready to deal with their HIV infection (375, 25.3%), being worried that other people (not friends or family) would find out about their status (351, 23.7%), and being worried that partners, family, or friends would find out about their status (318, 21.5%). People who do not identify as male, female, or transgender were almost twice as likely to report these fears as the average.

Table 28. Fears that inhibited participants from initiating HIV care or treatment

Fears	Male	Female	Transgender	Do not identify as male, female, or transgender	Prefer not to answer	Total
<i>I was worried my partner, family or friends would find out about my status</i>	81 (14.5%)	208 (25.3%)	11 (19.3%)	18 (43.9%)	0 (0)	318 (21.5%)
<i>I was worried other people (not my family or friends) would find out my status</i>	96 (17.1%)	230 (28.0%)	8 (14.0%)	17 (41.5%)	0 (0)	351 (23.7%)
<i>I was not ready to deal with my HIV infection</i>	110 (19.6%)	236 (28.7%)	12 (21.0%)	17 (41.5%)	0 (0)	375 (25.3%)
<i>I was afraid health workers (doctors, nurses, staff) would treat me badly or disclose my status without my consent</i>	55 (9.8%)	119 (14.5%)	3 (5.3%)	3 (7.3%)	1 (100%)	181 (12.2%)
<i>I had a bad experience with a health care worker previously</i>	33 (5.9%)	55 (6.7%)	1 (1.7%)	2 (4.9%)	0 (0)	91 (6.1%)

Participants were asked if they began taking ARV treatment by choice or whether they were pressured by someone to start treatment. Their reasons were as follows:

- I was told the benefits and chose to start as soon as it was offered: 1288 (87.0%)
- When treatment was offered, I decided to wait and start later: 94 (6.6%)
- I felt pressured or forced to start by health care staff: 17 (1.2%)
- Other: 60 (4.1 %)

The majority of respondents (894, 60.4%) started treatment within one day of being diagnosed. Far fewer started treatment within one month of diagnosis (265, 17.9%), one to six months after diagnosis (117, 7.9%), six months to two years (45, 3.0%), and more than two years after diagnosis (60, 4.1%). The remainder, 100 (6.8%), could not recall.

Participants were asked if fears about other people learning their HIV status led them to miss a dose of their ARV treatment in the last 12 months. A large majority of respondents (1213, 81.9%) said “no”. Participants who were transgender (15.8%), women (14.8%), and do not identify as male, female, or transgender (14.6%) were most likely to miss a treatment in the last 12 months out of fear that someone would discover their status. Transgender participants in the 26-35 age group (9.8%) were the most likely gender-age cohort to miss treatment for this reason overall.

Table 29. Age and gender distribution of participants who missed treatment

Age group	Male	Female	Trans-gender	Do not identify as male, female, or transgender	Prefer not to answer	Total
18-25 years	3 (0.5%)	25 (3.0%)	2 (3.5%)	3 (7.3%)	0 (0)	33 (2.2%)
26-35 years	16 (2.9%)	49 (6.0%)	4 (9.8%)	2 (4.9%)	1 (100%)	72 (4.8%)
36-46 years	27 (4.8%)	34 (4.1%)	2 (3.5%)	1 (2.4%)	0 (0)	64 (4.3%)
47-57 years	5 (0.3%)	10 (1.2%)	1 (1.8%)	0 (0)	0 (0)	16 (1.1%)
58-68 years	4 (0.3%)	4 (0.3%)	0 (0)	0 (0)	0 (0)	8 (0.5%)
69 years & above	3 (0.5%)	0 (0)	0 (0)	0 (0)	0 (0)	3 (0.2%)
Total	58 (10.3%)	122 (14.8%)	9 (15.8%)	6 (14.6%)	1 (100%)	196 (13.2%)

Participants were asked about their most recent viral load test done in the last 12 months. The majority of participants (871, 58.8%) reported that their results showed their viral load was suppressed. The other responses were as follows:

- Not having done the test in the last 12 months: 66 (4.5%)
- Still awaiting results: 182 (12.3%)
- Results showed the virus was not yet suppressed: 160 (10.8%)
- Never done a viral load test: 43 (2.9%)

- Did not know what viral suppression is: 92 (6.2%)

Participants were asked if they had ever interrupted or stopped their treatment. A total of 77 participants (5.2%) said they had interrupted treatment at some point, while 31 (2.1%) were not sure or could not remember. Participants who stopped treatment at any point over the past 12 months were asked to identify factors that led them to stop their HIV care and treatment.

Table 30. Gender distribution of stigma-related reasons for stopping treatment in the last 12 months

<i>Reason for stopping treatment</i>	Male	Female	Trans-gender	Do not identify as male, female, or transgender	Total
<i>I am worried that someone would find out my HIV status</i>	6 (1.1%)	21 (2.6%)	2 (19.3%)	0 (0)	29 (21.5%)
<i>I am not ready to deal with my HIV infection</i>	2 (0.4%)	7 (0.9%)	0 (0)	1 (2.4%)	10 (23.7%)
<i>I am worried the health care workers would treat me badly or disclose my HIV status without my consent</i>	1 (0.2%)	1 (0.1%)	0 (0)	0 (0)	2 (25.3%)
<i>I was denied HIV treatment due to currently using drugs</i>	1 (0.2%)	0 (0)	0 (0)	0 (0)	1 (12.2%)
<i>N/A - I have not been taking HIV antiretroviral treatment in the last 12 months or I have not stopped taking HIV (antiretroviral) treatment in the last 12 months</i>	5 (0.9%)	5 (0.6%)	1 (1.7%)	1 (2.4%)	12 (6.1%)
<i>Other reasons</i>	18 (3.2%)	12 (1.5%)	0 (0)	2 (4.9%)	32 (2.2%)

There were 32 participants (37.2%) who provided reasons for treatment disruption other than the stigma-related reasons provided. These included long distance to travel to access health facilities, negative experiences with treatment side effects, issues of relocation to another region without necessary transfers, concerns (unfounded) of treatment causing extensive damage to the liver, fear of one's employer noticing the treatment, being tired of taking a life-long treatment, undetectable viral load, a hatred of treatment, and resorting to taking medicinal herbs.

Participants who stopped treatment at any point over the past 12 months were asked to identify factors that delayed them or prevented them from restarting their HIV care and treatment. The most common reasons for participants not to restart their treatment were being worried other people would find out about their status (28) and not being ready to deal with their HIV infection (28).

Table 31. Reasons for not restarting HIV care or treatment

Reason for not restarting care or treatment	Yes
<i>I was worried my partner, family or friends would find out about my status</i>	25
<i>I was worried other people (not my family or friends) would find out my status</i>	28
<i>I was not ready to deal with my HIV infection</i>	28
<i>I was afraid health workers (doctors, nurses, staff) would treat me badly or disclose my status without my consent</i>	19
<i>I had a bad experience with a health care worker previously</i>	10

The most common non-stigma related reasons for not taking HIV treatment or stopping treatment in the past were being unable to collect medication from a health facility (29) and not feeling treatment was needed (21).

Table 32. Main non-stigma related reason for not taking HIV (ARV) treatment

Non-stigma related reason for not taking ARVs	Yes
<i>Medication is not available at the clinic (based on policy or stock outs)</i>	13
<i>Medication is not affordable to me</i>	9
<i>I am unable to collect medications at the clinic or pharmacy</i>	29
<i>I cannot tolerate medication side effects</i>	12
<i>I do not feel treatment is needed</i>	21
<i>I was in prison or detention and treatment was not available</i>	2

Among the other reasons participants provided for not taking treatment, were work-related activities which interfered with treatment check-ups, delayed services at the health facilities, use of intoxicating drugs, as well as the urge to stop taking medication.

General health status

Participants were asked about the general state of their health. The majority of participants reported being in good health (1090, 73.6%), 324 participants (21.9%) reported “fair” health, and 66 participants (4.5%) reported “poor” health. Participants were asked about additional health conditions they were diagnosed with in the last 12 months. Overall, 443 participants (30%) reported having one of these additional conditions.

Table 33. Diagnosed health conditions

Health Condition	Yes
Tuberculosis	148 (10.0%)
Viral Hepatitis	10 (0.7%)
Sexually transmitted Infections	220 (14.9%)
Mental Health	76 (5.1%)
Non communicable Diseases	87 (5.9%)
Opportunistic infections	100 (6.8%)
Alcohol dependency syndrome	106 (7.2%)

Participants were asked if they have been offered treatment for their conditions. 341 reported receiving treatment for all of their ailments. Of those 443 participants who reported having one or more diagnosed health conditions, 85 were not offered treatment (5.7% overall, 19.2% of this cohort).

Table 34. Gender distribution of those not offered treatment for all ailments

Male	Female	Transgender	Do not identify as male, female, or transgender	Prefer not to answer	Total
32 (5.7%)	49 (6.0%)	1 (1.8%)	2 (4.8%)	1 (100%)	85 (5.7%)

Service delivery experiences

A large majority of participants (1297, 87.6%) accessed their HIV care from government and public facilities. Other participants accessed their care from NGO-owned facilities (89, 6.0%), private facilities (60, 4.1%), community-led facilities (4, 0.3%), and multiple places (2, 0.1%). Only 28 participants (1.9%) reported not receiving HIV care or treatment. Participants were surveyed about the HIV-related services offered in community-led facilities. The scarcest services were peer support groups (688, 46.5%) and case management (870, 58.7%).

Table 35. HIV-related health services offered at community-led health facilities

Health services	Yes	
HIV information	1205	(81.4%)
HIV treatment	1128	(76.2%)
Adherence counselling	1082	(73.1%)
HIV care and testing	1059	(71.5%)
HIV prevention services	976	(65.9%)
Case management	870	(58.7%)
Peer support (groups)	688	(46.5%)

Participants were asked about bad treatment from health care workers in the past 12 months, both regarding their HIV-related care and their non-HIV-related care. 472 participants (31.9%) reported receiving health care for non-HIV related health needs in the past 12 months. An overwhelming majority (1416, 95.6%) did not report receiving any bad treatment from a health worker at any time. The most common bad treatment across both HIV and non-HIV-related services was being talked badly about.

Table 36. Negative experiences of participants with HIV and non-HIV-related health care

Bad treatment from health care workers	HIV-related health care	Non-HIV related health care
Denial of health services because of HIV Status	12 (0.8%)	2 (0.1%)
Denial of dental care	-	0 (0)
Being advised not to have sex because of HIV status	13 (0.9%)	1 (0.1%)
Being talked badly about or gossiped about because of HIV status	33 (2.2%)	10 (0.7%)
Verbal abuse because of HIV status	26 (1.8%)	8 (0.5%)
Physical abuse because of HIV status	9 (0.6%)	4 (0.3%)
Avoidance of physical contact because of HIV status	11 (0.7%)	6 (0.4%)
Telling other people about your status without your consent	27 (1.8%)	8 (0.5%)

When going outside their HIV clinics for general (non-HIV related) health services, 832 participants (56.2%) said they do not usually disclose their HIV status.

Regarding confidentiality of medical records, 1236 participants (83.5%) were sure that their medical records were kept confidential and that they would not be shared without their written informed consent. Other participants said they did not know whether their medical records were kept confidential (210, 14.2%) or that their medical records were not being kept confidential (34, 2.3%).

Sexual and reproductive health

Participants were asked about their experiences of receiving services for sexual and reproductive health care. They were asked whether they had experienced any of five specific forms of bad treatment from health care workers in the last 12 months. An overwhelming majority of participants (1469, 99%) reported that they did not experience any of these forms of bad treatment. The most common experiences of bad treatment were being advised not to mother/father a child (7) and being pressured or incentivised to get sterilised (3).

Table 37. Bad treatment experienced while receiving sexual or reproductive health services over the last 12 months

Bad treatment from health care workers	Yes
Advised you not to mother/father a child	7
Pressured or incentivised you to get sterilised	3
Sterilised you without your consent or knowledge	0
Denied you contraception/family planning services	1
Told you that you had to use a specific method of contraception in order to get your HIV (antiretroviral) treatment	2

Participants who identified as women were asked about an additional set of experiences while receiving reproductive health. Overall, 25 participants (1.7%) reported that they had experienced one or more of these forms of bad treatment.

Table 38. Bad treatment experienced by participants who identified as women while receiving sexual or reproductive health services

Bad treatment from health care workers	Yes, within the last 12 months	Yes, but not within the last 12 months
Advised to terminate pregnancy	2 (0.2%)	4 (0.5%)
Pressured to use a specific type of contraception	4 (0.5%)	5 (0.6%)
Pressured to use a particular method of giving birth/delivery option	2 (0.2%)	2 (0.2%)
Pressured to use a particular infant feeding practice	8 (1.0%)	4 (0.5%)
Pressured to take HIV treatment during pregnancy	11 (1.3%)	4 (0.5%)

3.6 Human rights and effecting change

This section explores the human rights abuses experienced by participants, as well as the actions taken by participants to effect change for PLHIV.

Abuses of human rights

An overwhelming majority of participants (1445, 97.6%) reported that they did not experience any of the specified human rights abuses, either in the last 12 months or previously. Amongst the 36 participants (2.4%) who did report experienced abuses of some kind, the most common in the last 12 months were forced disclosure in order to get a job (6), to get medical insurance (4), and in public (4). The most common prior to the last 12 months were forced disclosure to get health services (10), to obtain a visa (7), and apply for a job or get pension plan (6).

Table 39. Participants' experiences of forced disclosure or HIV testing

<i>I was forced to get tested for HIV or disclose my status in order to...</i>	Yes, within the last 12 months	Yes, but not within the last 12 months
<i>... obtain visa</i>	2	7
<i>...apply for a job or get pension plan</i>	6	6
<i>...attend an education institution</i>	2	2
<i>...get health care services</i>	3	10
<i>...get medical insurance</i>	4	3

Table 40. Participants' experiences of human rights abuses based on their HIV-positive status

Other human rights abuses	Yes, within the last 12 months	Yes, but not within the last 12 months
<i>I was arrested or taken to court on charge related to HIV status</i>	1	3
<i>I was detained or quarantined because of HIV status</i>	3	2
<i>I was denied a visa or permission to enter another country</i>	1	2
<i>I was denied residency or permission to stay in another country</i>	2	2
<i>I was forced to disclose HIV status publicly without my consent</i>	4	1
<i>I was forced to have sex when I did not want</i>	2	4
<i>I was denied access to domestic violence shelter</i>	2	2
<i>My partner prevented me from accessing health services</i>	1	3

Of the 14 participants who experienced one of the listed human rights abuses in the last 12 months, only three reported that they did anything about it. In these instances, the participants reported the following action and outcome:

- Contacting a lawyer (outcome: matter has been dealt with)
- Sat down and had a conversation with their partner to explain that ARVs were not “destroying my looks and body shape” (outcome: matter has been dealt with)
- “I reported my village chief” (outcome: nothing happened/the matter was not dealt with)

Of the 33 who reported not taking action to their human rights abuses, the most common reason for not taking action was not knowing how to take action (7).

Table 41. Participants' reasons for not taking action against human rights abuses

Reasons for not taking action against abuse	Yes
Not knowing where to go or how to take action	7
Not having sufficient financial resources to take action	2
Being worried that taking action might lead people to learn about their HIV status	1
Feeling intimidated or scared to take action	2
The process for addressing the problem seem too complicated	1
Having no/little confidence that the outcome would be successful	1

Participants were asked if they were aware of any laws in the country that protect PLHIV from discrimination. Overall, the majority of participants (941, 63.5%) said that they did not know of any laws that protected the rights of people living with HIV, while 335 participants (22.6%) said there were laws and 201 participants (13.6%) said there were no laws.

Effecting change

Participants were asked what they had done to bring about change in the stigma or discrimination directed toward PLHIV. Overall, 608 participants (41.1%) reported participating in some action to effect change within the last 12 months (392 participants) or prior to that (290 participants). The most common change actions in the last 12 months were challenging or educating someone who was engaging in stigma or discrimination against other PLHIV (296, 20%), challenging or educating someone who was engaging in stigma or discrimination against themselves (251, 16.9%), and providing emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination (232, 15.7%).

Table 42. Actions taken by participants to effect change

<i>Actions to effect change</i>	Yes, within the last 12 months	Yes, but not within the last 12 months
<i>Challenged or educated someone who was engaging in stigma or discrimination against you</i>	251 (16.9%)	159 (10.7%)
<i>Challenged or educated someone who was engaging in stigma or discrimination against other people living with HIV</i>	296 (20%)	185 (12.5%)
<i>Provided emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination</i>	232 (15.7%)	163 (11%)
<i>Participated in an organization or educational campaign working to address stigma and discrimination against people living with HIV</i>	158 (10.7%)	86 (5.8%)
<i>Encouraged a community leader to take action about issues of stigma and discrimination against people living with HIV</i>	98 (6.6%)	47 (3.2%)
<i>Encouraged a government leader or a politician to take action about issues of stigma and discrimination against people living with HIV</i>	47 (3.2%)	39 (2.6%)
<i>Spoke to the media about issues of stigma and discrimination against people living with HIV</i>	53 (3.6%)	32 (2.2%)

3.7 Stigma for reasons other than HIV status

Stigma and discrimination for being transgender

Of the 1481 participants, 57 identified as transgender; 41 do not identify as male, female, or transgender; 1 was assigned female at birth but identified as male gender; and 4 were assigned male at birth but identified as female gender. Overall, 62 participants (4.2% overall and 60.2% of this cohort) reported experiencing some form of discrimination or stigma for being transgender over the last 12 months and/or prior to that time. Within the last 12 months, the most common acts of stigma and discrimination directed at transgender people were discriminatory remarks from family (46, 44.7%), verbal harassment (42, 40.8%), exclusion from family activities (39, 37.9%), and being blackmailed (39, 37.9%).

Table 43. Other forms of stigma and discrimination against transgender participants

<i>Other forms of stigma and discrimination</i>	Yes, within the last 12 months	Yes, but not within the last 12 months
<i>Have you felt excluded from family activities because of your gender identity?</i>	39 (37.9%)	8 (7.8%)
<i>Have you ever felt that family members have made discriminatory remarks or gossiped about you because of your gender identity?</i>	46 (44.7%)	7 (6.8%)
<i>Have you ever felt afraid to seek health services because of your gender identity?</i>	31 (30.1%)	5 (4.9%)
<i>Have you ever avoided seeking health services because you worried someone may learn of your identity?</i>	25 (24.3%)	6 (5.8%)
<i>Has someone ever verbally harassed you because of your gender identity?</i>	42 (40.8%)	6 (5.8%)
<i>Has someone ever blackmailed you because of your gender identity?</i>	39 (37.9%)	6 (5.8%)
<i>Has someone ever physically harassed or hurt you because of your gender identity?</i>	30 (29.1%)	7 (6.8%)

In total, 22 participants (21.4%) reported belonging to a network or support group for transgender people or people whose gender identity differs from the sex they were assigned at birth. In terms of who knew their gender identity participants reported:

- Others who are transgender or whose gender identity differs from the sex they were assigned at birth (83, 80.6%)
- Family and friends (81, 78.6%)
- Other people in the community (73, 70.9%)

Stigma and discrimination experienced by gay men and other MSM

The participants who identified as male gender (560) identified as follows:

- MSM (42, 7.5%)
- Gay/homosexual (6, 1.1%)
- Bisexual (26, 4.6%),
- “None of the Above” (486, 86.8%)

Among those men who said “none of the above”, 2 reported that they had at some point had sex with another man, while 461 said no, and 23 preferred not to answer. For those men who identified as gay or MSM or had previously had sex with a man (50), the most common experiences of stigma over the last 12 months were discriminatory remarks from family members (11, 22%), verbal harassment (9, 18%), blackmailing (8, 16%), and feeling excluded from family activities (8, 16%).

Table 44. Other forms of stigma and discrimination against gay men and other MSM participants

Other forms of stigma and discrimination	Yes, within the last 12 months	Yes, but not within the last 12 months
<i>Have you felt excluded from family activities because you are gay/homosexual/MSM/have sex with men?</i>	8 (16%)	5 (10%)
<i>Have you ever felt that family members have made discriminatory remarks or gossiped about you because you are gay/homosexual/MSM/have sex with men?</i>	11 (22%)	6 (12%)
<i>Have you ever felt afraid to seek health services because you are gay/homosexual/MSM/have sex with men?</i>	6 (12%)	2 (4%)
<i>Have you ever avoided seeking health services because you worried someone may learn you are gay/homosexual/MSM/have sex with men?</i>	6 (12%)	2 (4%)
<i>Has someone ever verbally harassed you because you are I gay/homosexual/MSM/have sex with men?</i>	9 (18%)	1 (2%)
<i>Has someone ever blackmailed you because you are gay/homosexual/MSM/have sex with men?</i>	8 (16%)	0 (0)
<i>Has someone ever physically harassed or hurt you because you are gay/homosexual/MSM/have sex with men?</i>	1 (2%)	0 (0)

In total, 18 participants (36% of this cohort) reported belonging to a network or support group for people who are gay/homosexual/MSM. In terms of who knew their sexual identity participants reported:

- Others who are gay/homosexual/MSM (47, 94%)
- Family and friends (23, 46%)
- Other people in the community (11, 22%)

Stigma and discrimination experienced by lesbians and other WSW

The participants who identified as female gender (822) or assigned male at birth and transgender (56) and one additional individual, identified as follows:

- Women who have sex with women (2, 0.2%)
- Lesbian/gay (13, 1.5%)
- Bisexual (16, 1.8%),
- “None of the Above” (848, 96.5%)

Among those who said “none of the above”, 1 reported having previously had sex with another woman at some point, while 767 said no.

For the 16 participants who identified as a lesbian or other WSW, the most common experiences of stigma and discrimination over the last 12 months was avoiding seeking health services because they were worried someone would learn that they were lesbian/gay/WSW 3.

Table 45. Other forms of stigma and discrimination against lesbians and other women who have sex with other women participants

Other forms of stigma and discrimination	Yes, within the last 12 months	Yes, but not within the last 12 months
<i>Have you felt excluded from family activities because you are lesbian/gay/have sex with women?</i>	2	3
<i>Have you ever felt that family members have made discriminatory remarks or gossiped about you because you are lesbian/gay/have sex with women?</i>	2	2
<i>Have you ever felt afraid to seek health services because you are lesbian/gay/have sex with women?</i>	1	2
<i>Have you ever avoided seeking health services because you worried someone may learn you are lesbian/gay/have sex with women?</i>	3	1
<i>Has someone ever verbally harassed you because you are lesbian/gay/have sex with women?</i>	2	2
<i>Has someone ever blackmailed you because you are lesbian/gay/have sex with women?</i>	2	1
<i>Has someone ever physically harassed or hurt you because you are lesbian/gay/have sex with women?</i>	1	1

In total, 7 (43.8% of this cohort) reported belonging to a network or support group for people who are lesbian/gay/WSW. In terms of who knew their sexual identity participants reported:

- Others who are lesbian/gay/WSW (13, 81.3%)
- Family and friends (13, 81.3%)
- Other people in the community (11, 68.9%)

Stigma and discrimination experienced by people who identify as bisexual

Collectively, 43 participants (2.9%) identified as bisexual. Of these, 21 participants reported experiencing stigma or discrimination of some kind over the past 12 months and/or prior to that point because of their sexual identity. The most common experiences of stigma or discrimination over the last 12 months were feeling excluded from family activities (20), discriminatory remarks from family members (20), and verbal harassment (19).

Table 46. Other forms of stigma and discrimination against bisexual participants

Other forms of stigma and discrimination	Yes, within the last 12 months	Yes, but not within the last 12 months
<i>Have you felt excluded from family activities because you are a bisexual/have sex with men and women?</i>	20	1
<i>Have you ever felt that family members have made discriminatory remarks or gossiped about you because you are bisexual - who a lesbian/gay/have sex with men and women?</i>	20	1
<i>Have you ever felt afraid to seek health services because you worried someone may learn you are bisexual/have sex with men and women?</i>	11	1
<i>Have you ever avoided seeking health services because you worried someone may learn you are bisexual/have sex with men and women?</i>	2	1
<i>Has someone ever verbally harassed you because you are bisexual/have sex with men and women?</i>	19	1
<i>Has someone ever blackmailed you because you are bisexual/have sex with men and women?</i>	16	0
<i>Has someone ever physically harassed or hurt you because you are bisexual/have sex with men and women?</i>	2	0

In total, 16 (37% of this cohort) participants reported belonging to the network or support group for people who are bisexual. In terms of who knew their identity as a bisexual person, or someone who has sex with men and women, participants reported:

- Others who are bisexual or have sex with men and women (37, 86%)
- Family and friends (21, 48.8%)
- Other people in the community (17, 39.5%)

Stigma and discrimination experienced by sex workers

Participants were asked if they had ever exchanged sex for money or goods 227 (15.4%) participants said yes, 1182 (80.2%) said no, and 65 (4.4%) preferred not to answer. Of those who had sold sex or preferred not to answer, 200 participants identified as sex workers. The most common forms of stigma or discrimination experienced by participants due to their identity as a sex worker within the last 12 months were physical harassment (59, 26%), blackmail (58, 25.6%), and verbal harassment (44, 19.4%).

Table 47. Other forms of stigma and discrimination against sex workers

Other forms of stigma and discrimination	Yes, within the last 12 months	Yes, but not within the last 12 months
<i>Have you felt excluded from family activities because you are or were a sex worker or sell or sold sex?</i>	26 (11.5%)	16 (7.0%)
<i>Have you ever felt that family members have made discriminatory remarks or gossiped about you because you are or were a sex worker or sell or sold sex?</i>	30 (13.2%)	12 (5.3%)
<i>Have you ever felt afraid to seek health services because you worried someone may learn you are or were a sex worker or sell or sold sex?</i>	28 (12.3%)	9 (4.0%)
<i>Have you ever avoided seeking health services because you worried someone may learn you are or were a sex worker or sell or sold sex?</i>	27 (11.9%)	6 (2.6%)
<i>Has someone ever verbally harassed you because you are/ were a sex worker or sell or sold sex?</i>	44 (19.4%)	4 (1.8%)
<i>Has someone ever blackmailed you because you are or were a sex worker or sell or sold sex?</i>	58 (25.6%)	4 (1.8%)
<i>Has someone ever physically harassed or hurt you because you are or were a sex worker or sell or sold sex?</i>	59 (26%)	3 (1.3%)

In total, 88 participants (38.8% of this cohort) reported being a member of a network or support group for sex workers. In terms of who knew their identity as a sex worker or someone who sells/sold sex, participants reported:

- Other sex workers/peers in the community (186, 80.6%)
- Family and friends (75, 33%)
- Other people in the community (37, 16.3%)

Stigma and discrimination experienced by PWUD

Participants were asked if they had ever injected or habitually used drugs such as heroin, cocaine, or methamphetamines. A majority of participants (1373, 92.7%) said they do not use or had not used drugs, while 59 (4.0%) indicated they had, and 45 (3%) preferred not to answer. Of those who had taken drugs or preferred not to answer, 55 participants (87.3%) said they identified as people who uses or used drugs, 7 (11.1%) said no, and 1 (1.6%) preferred not to answer.

Overall, 16 participants reported experiencing some form of stigma or discrimination over the last 12 months and/or prior to that point because they use or had used drugs. The most common forms of stigma and discrimination experienced by participants due to their drug usage were being gossiped about by family members (7, 11.5%) and physical harassment (5, 8.1%).

Table 48. Other forms of stigma and discrimination against people who use drugs

Other forms of stigma and discrimination	Yes, within the last 12 months	Yes, but not within the last 12 months
<i>Have you felt excluded from family activities because you use or used drugs?</i>	3 (4.9%)	6 (9.8%)
<i>Have you ever felt that family members have made discriminatory remarks or gossiped about you because you use or used drugs?</i>	7 (11.5%)	3 (4.9%)
<i>Have you ever felt afraid to seek health services because you worried someone may learn you use or used drugs?</i>	2 (3.2%)	2 (3.2%)
<i>Have you ever avoided seeking health services because you worried someone may learn you use or used drugs?</i>	2 (3.2%)	2 (3.2%)
<i>Has someone ever verbally harassed you because you use or used drugs?</i>	5 (8.1%)	3 (4.8%)
<i>Has someone ever blackmailed you because you use or used drugs?</i>	4 (6.5%)	2 (3.2%)
<i>Has someone ever physically harassed or hurt you because you use or used drugs?</i>	5 (8.1%)	0 (0)

A total of 37 participants (62.7% of this cohort) who use(d) drugs reported belonging to a network or support group for PWUD. In terms of who knew their identity as someone who used drugs participants reported:

- Other people use drugs (57, 96.6%)
- Family and friends (25, 42.4%)
- Other people in the community (21, 35.6%)

Stigma and discrimination during incarceration

A total of 242 respondents reported that they have been incarcerated for the following periods of time:

- Less than 6 months (114, 47.1%)
- 6 months to 1 year (40, 16.5%)
- More than 1 year (32, 13.2%)
- More than 2 years (53, 21.9%)
- Prefer not to answer (3, 1.2%)

In terms of knowledge of their HIV status, 145 participants (61.2%) reported they did not have knowledge prior to incarceration, while 88 participants (37.1%) did know their status before incarceration and 4 participants (1.7%) did not respond.

Among those who were aware of their HIV-positive status, 82 participants (88.2%) reported that they were on HIV treatment while incarcerated, 9 (9.7%) were not, and 2 (2.1%) did not respond. The 9 participants who did not access HIV treatment during incarceration were asked about the reasons for this. The most common reason was fear of peers finding out about their status (3 participants).

Table 49. Reasons for not accessing HIV treatment while incarcerated

	Yes	No
<i>I was worried my peers would find out my status</i>	3 (33.3%)	6 (66.7%)
<i>I was worried prison officers would find out my status</i>	2 (22.2%)	7 (77.8%)
<i>I was not ready to deal with my HIV infection</i>	2 (22.2%)	7 (77.8%)
<i>I was afraid health workers (doctors, nurses Prison staff would treat me badly and disclose my status without my consent</i>	2 (22.2%)	7 (77.8%)
<i>HIV Treatment was not available</i>	1 (11.1%)	8 (88.9%)

A total of 21 participants (9.0%) who were previously incarcerated reported belonging to a network or support group for people who were previously incarcerated.

Stigma related to food insecurity

A total of 18 participants (1.2%) reported that someone in their household has been denied supplementary or nutritional support due to their HIV status (or perceived HIV status). These participants identified as follows:

- Female (7)
- Male (3)
- People with different genders (8)

In terms of where this stigma and discrimination took place, 1 reported at a health facility, while 17 reported at a community distribution location.

A total of 18 participants (1.2%) reported that they were denied participation or enrolment in a social safety net programme as a result of their (known or perceived) HIV-positive status:

- Public works programmes (10)
- Vulnerable group feeding (3)
- Child grant (2)
- Take home rations (2)
- Income Generation projects (1)

These incidents of stigma and discrimination took place:

- Within the last month (3)
- Between 1 month and 6 months ago (9)
- Between 6 months and 1 year ago (5)

- More than 1 year ago (2)

The majority of participants (902, 60.9%) reported that they did not have access to nutritional status services provided by their health facilities, while 394 (26.7%) did, and 180 (12.2%) said their facilities did not provide this service. For those that had access to the service, they reported their last check took place:

- Within the last month (208, 52.2%)
- 1-6 months (91, 22.9%)
- 6 months to 1 year (37, 9.3%)
- More than 1 year (62, 15.6%)

4 Discussion

This section contains a discussion of the key findings that emerged from the study and is structured to align with the order of the findings section.

4.1 Disclosure

Disclosure difficulties outside of friends and family

For participants generally, the rates of disclosure are significantly higher for people and groups who are “close to them” (e.g., partners, family members, friends) compared to those who are more removed (e.g., employers, co-workers, teachers, local leaders, authority figures), with the highest rate of disclosure being to family members (89.3%). This pattern was substantiated by the reports of positive experiences around disclosure and being supported by people after disclosing, which were more than twice as high for “close” groups (85.4% and 82.4%, respectively), and for people participants didn’t know well (40.7% and 38.1%, respectively).

Disclosure without consent school and in public

The rates of disclosure without consent among these groups followed a similar, but more dramatic pattern. While the average rate of disclosure without consent (i.e., number of incidents of disclosure that occurred without the participant’s consent), the average rate for “close” people and groups, as well as employers and co-workers was 12.6%. Meanwhile, the rates were almost three times as high with teachers (33.3%) and with classmates (31.3%). The highest rate of forced disclosure was with authority figures (39.2%); the rate for local leaders were 20.7%.

These figures suggest that education around HIV disclosure in public institutions, such as local governments, schools, law enforcement, may be lacking and/or that the nature of interactions between PLHIV and people from these institutions are more likely to require them to disclose their status. Follow-up studies of people in these spaces on the treatment of PLHIV, the understanding of HIV, and knowledge of stigma and discrimination are needed to pinpoint the precise issues that are leading to forced disclosure and would provide the basis for effective actions to reduce forced disclosure. Generally speaking, organisations might target schools and public institutions with educational outreach activities as a first step.

4.2 Stigma and discrimination

Verbalised stigma and discrimination

More than 77% of participants reported that they did not experience any of the forms of HIV-related stigma or discrimination specified in the questionnaire. This pattern which held across gender groups, with participants who do not identify as male, female, or transgender having the most substantial negative deviation at 65.9%, and transgender participants having the most positive deviation at 91.2%. Amongst the 334 participants who did experience stigma or discrimination, the most common (3.2-4.1%) were verbal actions: discriminatory remarks, gossiping, and verbal abuse. Public and community-

targeted campaigns to destigmatise HIV might focus on reducing bullying or emphasising the negative “power of words” to hurt PLHIV.

Limited stigma and discrimination of family members

Notably, very few participants (18, 1.2%) reported that their family members, partners, or children had experienced stigma as a result of their status. Only one participant overall reported family members had experienced stigma or discrimination, while they themselves experienced no form at all. Of the 18 who reported family stigma, 12 were women. This may be because female participants were more aware of the negative experiences of their family members, or were more likely to have family members in the home (e.g., women in this study were more likely than other gender groups to have children in their household). Efforts to address this secondary stigma should therefore likely focus on women living with HIV.

4.3 Internalised stigma

Increased stigma for transgender PLHIV and PLHIV who do not identify as male, female, or transgender

For any of the given forms of personal experiences or feelings specified by the questionnaire – from self-confidence to ability to contribute to one’s community – more than 90% of participants reported that they have either not been affected by their HIV status or they have been positively affected by it, with many more reporting the former (>73%). The categories where participants were most negatively affected by their status were self-confidence, ability to cope with stress, and desire to have children. In terms of how such feelings manifested in actions and behaviours, the most common actions taken as a result of participants’ HIV status were deciding not to have sex, not to attend family gatherings, and not seeking social support. Although, notably, these were all 3.5% of participants or fewer. Therefore, overall, internalised stigma did not have an outsized impact on people’s lives, in terms of work, family, or social life, in any particular way. However, making support groups or tools accessible to PLHIV may help to educate, reassure, and increase the confidence of PLHIV to live their “normal” lives without fear or internalised stigma.

Overall, participants who do not identify as male, female, or transgender were far more likely to report experiencing internalised stigma, particularly with ability to find love (39% of this cohort) and ability to achieve personal or professional goals (34% of this cohort). They were also far more likely than average to have difficulty disclosing their status (63.4%) and to hide their status (43.9%). Meanwhile, transgender participants tended to track with the similar rates of internalised stigma as their male and female peers, except when it came to ability to respect others, cope with stress, have close relationships, and find love. PLHIV who do not identify as male, female, or transgender and transgender PLHIV therefore present as particularly vulnerable to internalised stigma and outreach and support activities should focus on the highlighted areas.

Impacts of 2020

As this study was conducted at the end of 2020, and therefore amidst the COVID-19 pandemic, any questions about change throughout the past year likely captured the increased stresses and challenges created by the pandemic. This makes it difficult to assess any trend about improvement or decline in internal wellbeing in general. Interestingly, in spite of pandemic conditions, a minority of participants (125, 8.4%) reported that their ability to meet their internal needs had worsened over the last year. However, a disproportionate number of these were women (90, 10.9% of this cohort) – far more than any other gender group.

4.4 Healthcare services

Testing by choice

Overwhelmingly, participants got tested for HIV by their own choice (90.6%) and did so within six months of considering getting tested (71.1%). Most of these participants chose to get test because they felt sick, they thought they were at risk for HIV, or they just wanted to know. Interestingly, only 1.1% said that they got tested because of a community programme, while only 0.9% got tested because it was mandatory – the least common reasons overall. This suggests that testing is largely being demand-driven or pushed by PLHIV, rather than supply-driven or pulled by organisations. Importantly, however, 22% said that they did hesitate to get tested for fear of stigma from others.

Fears inhibit treatment

Over 95% of participants had received treatment or were currently on treatment at the time of the study and 87% reported that they started treatment because they were told about the benefits and started as soon as it was offered. However, 32% still reported that certain fears kept them from getting treatment, namely not being ready to deal with it or being worried other people would find out about their status. Among these, participants who do not identify as male, female, or transgender were twice as likely to report that fear inhibited their seeking treatment. Transgender participants in the 26-35 year age group were the group most likely to miss treatment out of fear of disclosure, while transgender, women, and participants who do not identify as male, female, or transgender were generally all above average in this regard. Fear of others finding out was also the most common reason for interrupting treatment (21.5%) and not restarting treatment after disruption. These findings suggest that more information is needed during the testing services about how PLHIV can protect their privacy and obtain treatment discretely.

Importantly 32 participants reported other reasons for stopping treatment, which are worth noting as they were cited by multiple participants: long distance to travel to access health facilities, negative experiences with treatment side effects, issues of relocation to another region without necessary transfers, concerns (unfounded) of treatment causing extensive damage to the liver, fear of one's employer noticing the treatment, being tired of taking a life-long treatment, undetectable viral load, a hatred of treatment, and resorting to taking medicinal herbs. These reasons suggest that participants may be obtaining inaccurate health information outside of health facilities and that health providers should be more

proactive in drawing out these ideas from patients (i.e., in creating discussions and counselling services that address these concerns) so that they may provide more accurate information and persuade patients to continue with treatment.

These findings are particularly salient in light of the fact that at community-led health facilities, the services that were least available/accessible were peer support groups and case management. However, only 0.3% of participants reported accessing the HIV care through community-led facilities, making it unclear if these kinds of services are readily available at public and private health facilities where most people access care.

Insufficient viral load suppression

Although 58.8% of participants reported that their viral load tests within the last year were virally suppressed (and 12.3% were still awaiting results), this falls far short of the global 95/95/95 goal. For the other participants, 10.8% found they were not virally suppressed, 6.2% did not know what viral suppression was, and 2.9% had never done a viral load test. Meanwhile, a number had not had a test in the last year (4.5%), which may have been due to the pandemic lockdown conditions, which made it more challenging for many to access treatment and care. This is substantiated by the most common non-stigma related reason for not taking HIV treatment: not being able to collect medication. Other non-stigma reasons for not taking HIV treatment were not feeling treatment was needed, medication not being available, not being able to tolerate side effects, work-related activities interfering with treatment check-ups, delayed services at the health facilities, use of intoxicating drugs, and the urge to stop taking medication. Attention should therefore be directed to differentiated service delivery models to ensure that patients can easily access testing, care, and treatment services, even in extreme conditions such as a pandemic.

Other health care concerns

While the majority of participants (73.6%) reported being in good health, 30% had one or more additional diagnosed health conditions, the most common of which were other sexually transmitted infections and tuberculosis. Of those with other medical conditions, 19.2% were not offered treatment for their ailments. Greater efforts and resources should be dedicated to educating communities about early detection, seeking treatment, and ensuring PLHIV receive care for all of their conditions.

Although, an overwhelming majority (95.6%) did not report bad treatment from health care workers at their health facilities – whether it was for HIV or non-HIV care. As in the case of experiences of stigma and discrimination, the most common experiences of poor treatment from health care workers were verbal: being talked about badly or verbal abuse. Improved training of health care workers on proper care of PLHIV and oversight of this inappropriate behaviour towards PLHIV by facilities is therefore required.

4.5 Human rights concerns

Lack of information about protections

An overwhelming majority of participants (1445, 97.6%) reported that they did not experience any of the specified human rights abuses, either in the last 12 months or previously. Notably, nearly half of those who reported a human rights abuse did not take action. The most common reason for inaction was not knowing where to go or how to take action. Relatedly, 63.5% said they did not know of any laws that protected PLHIV, while 13.6% said there were no such laws. This suggests that greater education is needed around legal protections for PLHIV and where to go for support.

Acting locally to effect change

Of the 41% who reported engaging in some activity to reduce stigma or discrimination at some point, most engaged in activities at the personal or hyper-local level: educating someone who was discriminating against them or other PLHIV and provide supporting to a PLHIV. There was less involvement in more organisational, community-level, public, or mass-media efforts to reduce stigma and discrimination. This may be because of lack of awareness about wider opportunities to effect change, or because local efforts are easier, more convenient, and suitable to participants. Depending on which explanation is more valid, there might be a need for organisations to provide greater education around opportunities to effect change, or to make greater use of the local support capacity of PLHIV in their own communities.

4.6 Other sources of stigma

Transgender and people who do not identify as male, female, or transgender experience most stigma

Among the key populations, transgender participants were the most likely to experience stigma and discrimination because of their identity (in this case, gender identity), with 59.6% of the cohort of transgender and participants who do not identify as male, female, or transgender reporting discrimination of some kind because of their identity. Again, the most common experiences were discriminatory remarks and gossip, and being verbally abused. Exclusion from family gatherings and blackmail were also widely reported. Participants who were bisexual reported similar, though lower, levels of stigma across these same forms of discrimination.

The high rates of discrimination may be linked to the fact that transgender participants had disclosed their gender identity across all groups (>70% for family, friends, other transgender people, and other community members), compared with other key populations who reported that fewer people overall knew about their identities. Indeed, the low rates of gay men and other MSM who disclose their sexuality to people outside other gay men and MSM may indicate that this group actually faces more stigma and would experience higher rates of discrimination if their sexuality were known.

Low group membership

PWUD were the most likely key population to belong to a network or support group for PWUD, at 62.7%. Overall, the rates hovered much lower for the other key populations,

all less than 45%. Availability or awareness of these kinds of support groups may be the inhibiting factor. Demand or need for group support related to this aspect of one’s identity may also be factors, particularly if participants are already members of other support organisations for PLHIV, their community, religious faith, etc. A follow-up inquiry would need to be conducted to investigate further.

4.7 Food insecurity

Overall, 1.2% of participants reported that they (or someone in their household) has been denied nutritional support due to their known or perceived HIV-positive status. 1.2% also reported being denied enrolment in a social safety net programme due to their known or perceived HIV-positive status. These experiences largely took place within the last year.

4.8 Comparison with the 2014 study

Recalling the key indicators from the 2014 study highlighted in the introduction, a comparison with the same indicators from the current study suggest that overall, stigma and discrimination associated in HIV-positive status have declined over the past seven years. Note that the figures in the table below reflect the total number of participants who reported this form of stigma or discrimination, both in the last 12 months and previously. The biggest decline was in the experience of being gossiped about or hearing others make disparaging remarks, which is notable given that verbal-based actions were the most common forms of stigma and discrimination reported in the current study. Importantly, internalised stigma in terms of feelings of shame due to HIV status, which is among the highest indicators, is still comparably high and has not declined by much.

Table 50. Comparison of key study indicators from the 2014 and 2021 study

	Experience of Stigma: Being gossiped about	Experience of Stigma: Loss of job or other sources of income	Experience of stigma: Denied access to health care	Internalised Stigma: Feelings of shame	Internalised Stigma: Avoiding having (more) children
2014 Study	440 (40.6%)	272 (25.1%)	37 (3.4%)	272 (25.1%)	361 (33.3%)
2021 Study	100 (6.8%)	17 (1.1%)	14 (0.9%)	251 (16.9%)	90* (6.1%)

*In the new 2.0 questionnaire, this indicator is now “desire to have children”

Another key indicator, discussed in the methodology section, is the stigma-related behaviour of “avoiding going to a clinic”, which 4.7% of participants in the 2014 survey reported doing, compared with 2.4% (36 participants) in the current study.

4.9 Study Limitations

Influence of COVID-19

While planning for this study began in 2019, with plans to implement in 2020, the onset of the COVID-19 pandemic required changes to be made to the testing protocol and data collection plans. The biggest impact of the pandemic in the study, aside from the delay in data collection to the end of 2020, was that only health facilities were used in the venue-based sampling approach. Under ordinary circumstances in which “non-essential” services and organisations were not required to close doors, a more diverse sample could have been obtained by sampling from other kinds of public-facing and community organisations, particularly as regards those PLHIV LTFU or not in care.

Importantly, when the mandatory lockdown was announced, action was taken by the government, health facilities, and HIV organisations to ensure continuity of care for PLHIV throughout the pandemic (e.g., continued availability of the health facilities, multi-month dispensing of ARVs, and in-community care). Therefore, there should not have been interruptions to HIV treatment due to the pandemic for the study participants. However, given the additional pressures introduced by the pandemic and the lockdown conditions – those medical, psychological, and practical – these circumstances may have influenced the experiences of PLHIV in anomalous ways. For instance, the requirements to social distance, stay home, and refrain from public activities (like social and religious gatherings), may have reduced all social interaction significantly, such that the low instances of stigma reported in the last year do not reflect what PLHIV would have experienced in a more normal living situation.

Alternatively, or in addition, the added stress of the pandemic might have created greater stress for participants, increasing their reporting of negative feelings in ways that do not directly reflect the state of stigma toward PLHIV in Lesotho but a more complicated set of anxieties that follow from the COVID-19 conditions. While it is not possible to quantify this, future studies should take this factor into account when comparing data. Smaller follow-up studies on specific elements of stigma over the next few years may also help to confirm or dispel anomalies.

Data collection issues

Inconsistencies in the data collection, or in the responses from participants, were noted throughout the raw questionnaire data. Specifically, a pattern of participants providing answers to questions they should have skipped was recurring throughout the dataset. The extent of the issue was not prevalent enough to significantly affect the outcomes of any one indicator. However, it may be an indication of researcher error, in which case future study teams should take care that this point is emphasised during training.

Another issue was found in the wording of one of the additional questions added to address the locally relevant issue of food security. Specifically, the question in reference was not clear in asking the participant whether the stigma they received was from their HIV status or needing food assistance. This data therefore had to be omitted from the report. Careful review of new questions, perhaps by a third-party or member of the steering committee, is therefore advised in future studies.

Representation of key populations

With the exception of the key population of gay men and MSM, which represented a total of 48 participants (excluding the number of bisexual men (26)), all the key populations were represented in this study with samples of more than 50 participants. These numbers tended to be very different than the targets laid out in the methodology. As the first Stigma Index study to intentionally collect data and draw conclusions about key populations of PLHIV, this project provides learnings for future research teams with regard to the methodology. Future studies should revisit the approach to calculating the target sample distribution to be both representative and achievable within the study context.

Sample selection

Data was collected from four of the 10 districts in Lesotho, which the clear rationale that these sites represented the most vulnerable populations of PLHIV. A lighter touch study of stigma across all 10 districts may be appropriate to confirm this assumption and therefore to confirm whether the same study sites should be included for the next PLHIV Stigma Index study, and to ensure that meaningful longitudinal comparisons can be made.

5 Conclusion

5.1 Key learnings

The Lesotho PLHIV Stigma Index 2.0 study has shown encouraging signs that stigma and discrimination of general PLHIV in the country have decreased over the past seven years. Indeed, extrapolating from the study participants, most PLHIV in Lesotho have not experienced any of the typical forms of stigma and discrimination – social exclusion, verbal abuse, physical abuse, denial of job opportunities – that pose such a threat to the wellbeing and human rights of PLHIV. Still, a few outstanding concerns regarding the roles of government, community, and health actors in supporting PLHIV and reducing stigma and discrimination remain.

As the first study of this kind to include an intentional focus on key populations and vulnerable groups, the study establishes a baseline of stigma and discrimination for specific groups of PLHIV for comparison in future study. Conducted in a year fraught with logistical challenges for accessing hard-to-reach groups (e.g., those not in care) due to the COVID-19, this baseline may be contentious. Still, relative to the other key populations, the findings point to higher levels of stigma and discrimination experienced by people who are transgender or who do not identify as male, female, or transgender because of their gender identity. Given the low membership of key populations overall in support groups and networks, such organisations may be an important focal point of future work.

For PLHIV in general, participation in support networks is key for promoting advocacy, networking, sharing information and knowledge, and capacity building for implementing effective PLHIV-led interventions. A large portion of the recommendations focus on increasing public awareness of support networks and advocacy work. Relatedly, awareness raising efforts about the existence of PLHIV and key populations, and their human rights and legal protections, need to be intensified at all institutional levels (families, communities, law enforcement agencies, and other relevant stakeholders). At the moment, the study shows that most PLHIV in Lesotho are not involved in human rights advocacy or even aware of legal protections for their groups.

Among these rights and protections is access to health care services, which the study suggests may be another issue for PLHIV. HIV treatment adherence monitoring through regular viral load tests is key for attaining the 95/95/95 global targets, and for ensuring quality of life for PLHIV. Where just over half of participants confirmed that their viral load was suppressed at the time of study, greater resources and planning must be dedicated to adherence monitoring and viral load testing.

Beyond HIV treatment and care, the PLHIV are not receiving sufficient general health care services to treat other ailments, an issue that needs to be addressed from both the PLHIV side in terms of early detection and seeking care, and the health facility side in terms of offering care and education.

5.2 Recommendations

Following the discussion of the study findings, the study team proposes a series of recommendations for reducing stigma and discrimination, promotion human rights advocacy and community involvement, and improving health care for PLHIV.

For reducing stigma and discrimination

- To enhance understanding of why PLHIV commonly experience disclosure without consent in schools and public institutions, LENEPWHA or Ministry of Health should conduct a further study of how people in these spaces view PLHIV, their understanding of HIV, and awareness of stigma and discrimination.
- To counter disclosure without consent in schools and public institutions, based on results of the further study, that National AIDS Commission should revive the HIV task forces within these institutions and capacitate them on increasing disclosure awareness.
- To counter the forms of verbal discrimination against PLHIV, LENEPWHA, and the Ministry of Health, should create community-targeted campaigns focused on reducing bullying of PLHIV or emphasising the negative “power of words” to hurt PLHIV.
- To reduce the stigma and discrimination directed toward family members of PLHIV, health facilities and support networks should actively discuss this issue with women living with HIV, who are more likely to report this experience. These discussions may point to additional tools and resources that support networks can provide to PLHIV to reduce the negative experiences of their family members, particularly children and partners.

To reduce stigma and discrimination among key populations, health facilities, support networks should give particular attention to PLHIV who are transgender or do not identify as male, female, or transgender. In particular, efforts should focus on internalised stigma, specifically on ability to find love, ability to have close/secure relationships, and ability to achieve professional goals.

For promoting human rights advocacy and community involvement

- To increase human rights realisation for PLHIV, political leaders at the district and local levels should mainstream issues of human rights within their programmes.
- To increase human rights realisation for key populations, the community support networks (LENEPWHA, MATRIX, Phelisanang Bophelong, Care for Basotho, Skillshare, LPPA and all key populations organisations) should engage in activities to sensitise communities and families on the rights of key populations. Involvement of the Lesotho Council of NGOs and the National Human Rights Commission is key to this initiative.
- To increase the involvement of PLHIV in support groups for key populations, LENEPWHA, MATRIX, Phelisanang Bophelong, Care for Basotho, Skillshare, LPPA, and all key populations organisations should conduct short follow-up studies with their constituents and prospective members about their reasons for not joining, support needs, and goals.

- To increase the involvement of PLHIV in support networks, LENEPWHA should conduct activities to sensitise communities about the organisation's role and mandate. Leaders at the secretariat level mobilise resources to support awareness creation efforts.
- To improve the activity and efficacy of support networks like LENEPWHA, ongoing capacity building at district and community levels is key.

For improving health care

- To reduce discrimination from health care workers toward PLHIV, particularly through verbal abuse and discriminatory remarks, health facilities and support networks should provide improved training about appropriate treatment of PLHIV. Health facilities should also ensure they have oversight mechanisms in place for staff behaviour.
- To improve viral load suppression rates, the Ministry of Health should dedicate more resources toward its HIV Treatment Guidelines, which require strict monitoring, tracking, and retention of patients who fail to comply with viral load testing.
- To improve the services PLHIV can access in their community-led health facilities, look into differentiated models of peer support groups/services.
- To improve the sexual reproductive health of women and their knowledge about the HIV status of the intimate partners, LENEPWHA should play a leading role intensifying partner indexing and partner notification. This initiative should be done in collaboration with the ongoing DREAMS project and other HIV implementation partners in both health facilities and communities.
- To decrease the incidents of coercion regarding specific sexual and reproductive health services or treatments, LCN, the National Human Rights Commission, and WLSA should sensitise communities about their sexual and reproductive rights.
- To counter the trend of untreated health conditions among PLHIV, LENEPWHA should engage the ongoing DREAMS project as well as other organisations working in HIV prevention (Jhpiego, PSI, EGPAF, CRS) to educate communities on the importance of early detection and treatment of opportunistic infections.
- To counter and reduce misinformation about HIV treatment and care, counselling and health care services should actively solicit concerns and fears from PLHIV in order to provide accurate information and persuade patients to continue with their treatment.

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