

THE PEOPLE LIVING WITH HIV STIGMA INDEX SURVEY REPORT ROUND 2



ETHIOPIA



JUNE, 2021

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ACRONYMS

Antiretroviral Therapy	ART
Drop in Centre	DIC
Ethiopia Public Health Institute	EPHI
Family Guidance Association of Ethiopia	FGAE
Federal HIV/AIDS Prevention and Control Office	FHAPCO
Ministry of Health	MoH
Female Sex Workers	FSWs
Global Networks of People Living with HIV	GNP+
Human Immunodeficiency Virus	HIV
International Community of Women Living with HIV/AIDS	ICW
International Planned Parental Federations	IPPE
Joint United Nations Programme on HIV/AIDS	UNAIDS
Key Population	KP
Limited Chain Referral	LCR
Local Implementing partners	LIPs
Management Information System	MIS
Network of Networks of HIV Positives in Ethiopia	NEP+
Organization for Social Service, Health and Development	OSSHD
People Living with HIV/AIDS	PLHIV
People Who Inject Drugs	PWID
Population Services International /Ethiopia	PSI/Ethiopia
Prevention of Mother to Child Transmission	PMTCT
Probability Proportional to Size	PPS
Sexual and Reproductive Health	SRH
Stigma Index Survey	SIS
Time Location Sampling	TLS
Viral Load	VL

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EXECUTIVE SUMMARY

Introduction and objective

Concrete evidence showed that People living with HIV (PLHIV) usually face negative attitudes that keep them from seeking and accessing services, disclosing health information to providers, and adhering to treatment. The negative attitudes towards, PLHIV intern leads to specific actions by others or the PLHIV themselves that restrict the rights and freedoms of PLHIV such as breaches of confidentiality, labeling, gossip, verbal harassment, differential treatment and even denial of services.

To tackle such challenges of people living with HIV/AIDS (PLHIV), availability of a strong evidence- base on stigma and discrimination essential. This survey was aimed at generating evidence on the target population, to help program implementers and stakeholder, the affected population and donors working on PLHIV stigma and discrimination.

Method

The survey used venue based quantitative cross-sectional design. The survey was country-wide that covers all nine regional states, Addis Ababa city administration, and Dire-Dawa administration. In terms of content, the survey covers both internal and external HIV stigma experiences of PLHIV. The survey target populations were male and female PLHIV aged 18 years and above who knew their HIV positive status for at least 12 months prior to the survey. The respondents were from the general PLHIV population, and two key population; namely female sex workers (FSWs), and people who inject drug (PWID). All members of the study population who were under the influence of alcohol, drug or other substances, mentally unstable and unwilling to provide consent at the time of the survey were excluded.

The survey used venue-based time-location sampling (TLS), and limited chain referral (LCR) sampling approaches and completed 2312 interviews. Seventy-five percent of the sample participants were selected using TLS approach for all PLHIV population at the venues dedicated for the general population; while 25% were enrolled using LCR approach for KP (FSWs and PWID).

The total sample size was distributed to regions using power allocation approach in order to allocate reasonable sample size for all regions.

The study sample was selected in two-stages using probability proportional (PPS) to size, size being the number of PLHIV who receives ART and HIV care. At first stage Woredas /districts were selected and at second stage service facilities (venues). As a result of first stage sampling 260 Woredas that comprises 50% of the overall PLHIV in Ethiopia were selected among 1024 Woredas. All venues the selected Woredas were listed and cleaned for client load. Venues that serve more than ten PLHIV per day were taken as eligible for sampling in second stage. At second stage 57 venues from 123 venues that serve all population groups were selected using PPS and 30 respondents per venue were interviewed.

Further, venues that provide HIV care for PLHIV were identified including drop in centers (DIC), FSW confidential clinics, and rehabilitation centers for PWID to serve as entry point for sampling. Then, the venues were selected using PPS approach and resulted in inclusion of six

out of ten DICs, seven out of nine FSW confidential clinics, and three rehabilitation centers for PWID. However, only one center for rehabilitation of PWID in Addis Ababa was accessible to serve as entry point for respondents' recruitment at the time of the survey.

Respondents who were from the general population and who receive HIV care from public or private venues on the date of the interview were recruited using take all TLS approach. These potential respondents were directly approached by data collectors and informed about the survey. This approach continued till the predetermined number of interviews for the venues was achieved.

On the other hand, the KPs (FSWs and PWID) were recruited through LCR strategy using a peer-driven coupon system. Leveraging their availability at dedicated DIC or confidential clinic for FSWs and PWID rehabilitation center, potential interviewee was interviewed after screening for their eligibility and obtaining their consent for their participation. After completing the interview, respondents were asked to recruit their peers to participate through coupon system. Potential respondents who received coupons from referral system and able to handover their coupon to the interviewer, were interviewed face to face using structured questionnaire after screening for their eligibility.

Recruitment of appropriate data collectors and supervisors was led by NEP+ and a three-day training for the field team was conducted as part of ensuring the data quality. Further, the supervisors and the data manager supported the data collectors to improve the data quality.

The stigma index protocol for this survey was submitted to the Ethiopian Public Health Institute (EPHI) research and ethical review committee and approved after critical review.

Results

The level of external stigma index was about 32 % in the period earlier than the 12 month before the survey while it was 24% in the last 12 months prior to the survey. Despite the observed reduction, considerable proportion of respondents reported facing some form of stigma from their social environment because of their HIV status; these included forbidden from participating in public/social events, household chores such as cooking, eating together, and sleeping in the same room.

The index of self-stigma and discrimination due to HIV status was high (38%) during the 12 months prior to the survey. Females (41%), youngest age group 18 to 24 (47%) and Key Population (43%) respondents reported higher self-stigma and discrimination as compared to their counterparts. According to the result from the survey internal stigma and discrimination attitudes influenced decision of PLHIV on some aspects of their life as indicated by respondents; about 19% decided not to have sex, 17% have chosen not to attend social gatherings and isolated themselves from family and/or friends.

Comparing the level of self-stigma between the two rounds of stigma index surveys in Ethiopia, the proportion of respondents who reported feeling of guilt increase from 2011(43%) to 2021 (52%) and feeling of shame was the same during the two rounds which was about 46%.

Respondents reported they are still facing stigma and discrimination by healthcare facility staffs when seeking non HIV related services (42%) compared to facility staffs where they receive HIV care and services (30%) which could be the major problem in disclosing HIV status to health

care givers. Reasonably high proportion of female respondents (17%) reported S&D by health workers specifically in the area of sexual and reproductive health than males (7%). The most frequent manifestations of stigma and discrimination against PLHIV by healthcare workers in facilities that provide HIV care services was advice not to have sex (17%), followed by talked badly/ gossiped and avoidance of physical contact (8%), and verbal abuse (7%). Further, more respondents in 2021 (10%) have chosen not to seek healthcare compared to 7% in 2011 survey.

Though majority (84%) disclosed their HIV result to at least one person from their social environment it should be noted that there were about 16% who never disclosed their HIV status to anyone. However, it was also observed that 41% of respondents reported that disclosing their HIV status has become challenging as compared to respondents of 2011 (32%).

Further, involuntary (forced or without the knowledge of respondents) HIV positive status disclosure is reasonably high (23%) and females reported higher level of involuntary disclosure (25%) compared to males (20%). Moreover, there are regions where greater than national average (25%) of the respondents reported unauthorized disclosure of their HIV status (Somali, Gambella, Benshangul-Gumuz & Oromia regions) which calls for further investigation and learn the root causes that lead to breach of confidentiality. It was also observed that involuntary HIV positive status disclosure to members of close circle social environment (spouse/partner, family members, children, friend/neighbors) during the current survey was not significantly different from 2011 .

Encouraging results have been achieved towards voluntary HIV testing among PLHIV. Compared to the 2011 survey (89%), the proportion of respondents who voluntarily decide to get HIV test during the 2021 survey (98%) has significantly increased.

In the current survey, considerable proportion of PLHIV reported that they were not on ART (11%) at the time of the data collection. The main reported reason for those not on ART were, being not ready to deal with their HIV positive status (63%), followed by fear that family or friend would find out HIV status (56%), and fear that partner, family or friend would find out their HIV status (50%).

Among those who have ever initiated ART, 13% reported to have ever interrupted their treatment, which is even higher among KP (15%) than those not belong to KP (12%). Fear that someone would find out their HIV status was the main reason reported for their ART interruption.

The level of knowledge about the existence of laws that protect PLHIV is limited. Significantly higher proportion of respondents who don't belong to KP (61%) are aware of the laws that protect PLHIV against discrimination compared to who belong to KP (49%).

The index of PLHIV counteracting stigma and discrimination was 21% for the 12 months prior to the survey, and 23% for the period earlier than the 12 months showing no significant improvement in ability of PLHIV to counteract against stigma and discrimination between the times.

About 52% of FSWs reported that, they have encountered at least one manifestation of S&D during the last 12 months prior to the survey and in the period earlier than the 12 months. This result shows that stigma including self-stigma for being FSWs was not improving in the last 12

months compared to the previous time period. However, S&D among PWID was improving from the period earlier than 12 months (68%) to the last 12 months prior to the survey (32%).

Conclusion

- The composite index of self-discrimination for HIV status is still high and it is worse among the female PLHIV, among the younger age groups, the KPs (worse on FSWs than PWID) as well as those PLHIV who have shorter duration of life with HIV.
- Stigma and Discrimination due to HIV status is still significantly high, although it seems to be showing improvement, it is worse among the female PLHIV and the KP groups. It is also worse in Afar, Amhara and Tigray regional states.
- The rates of non-disclosure as well as non-consented disclosure are significantly high, and are worse among female than male. Both non-disclosure and disclosure without consent are high in school settings; unauthorized disclosure to social groups not close to the PLHIV has shown striking increment compared to the 2011 stigma index study reports
- Stigma and discrimination across health facilities in the 12 months prior to the survey remains high, i.e. 31.3%, while composite index of S&D by health workers against PLHIV in the area of sexual and reproductive health, solely because of their HIV status is significant, being 14%, and worse on the female, among those with lower duration of life with HIV, among PLHIV with lower level of education, as well as among PLHIV who belong to KP.
- Level of stigma and discrimination by health facility staff, regarding non-HIV service need was also found out to be high being 42% the magnitude being worse than the S & D at HIV related services.
- Involuntary/ forced HIV testing is highest among the age group 18 to 24 followed by 55 and above years of showing young and old age group respondents are facing violation of their rights compared to older age group respondents; forced/compulsory HIV testing is higher among respondents who avoided HIV treatment compared to those who are taking HIV treatment showing forced HIV testing is a push factor to avoid treatment.
- There is high rate of unemployment and failure to meet basic needs among the PLHIV. Employment is also associated with the ability of the PLHIV to defend their right compared to unemployed and positively affects viral suppression among the PLHIV.
- Significantly higher proportion of respondents who have no formal education and those who have tertiary level of education delayed their HIV test for six months and or more.
- The proportion of PLHIV who delayed to start ART once it is offered to them is high which is worse among the non-KPs than the KPs, the main reasons of delay including lack of readiness to deal with their HIV status, fear that family or friends partner, family or friend would find out their status (50%) as well as being afraid of health workers
- Among PLHIV who have ever been treated the proportion who delayed treatment initiation significantly increases with increasing duration of life with HIV, and is higher among respondents who have vocational or university level of education (about 69%)
- Both skipping, and ever interruption of HIV treatment are worse among the female the young PLHIV of age 18 to 24 , and PLHIV who belong to KP ; besides,13% of PLHIV who ever initiated ART treatment ever interrupted their treatment.

- Interruption of ART treatment gets worse with decreasing age of respondents. With significantly higher proportion of the youngest age group, compared to the older age group respondents ever interrupted their ART.
- VL testing and rate of suppression is good, but lower among those with less duration of life with HIV, among the unemployed respondents, and those who belong to the KP; as well as among respondents of the key population; FSWs has the highest level of undetectable viral load compared to the IDUs
- Opportunistic infections followed by sexually transmitted infection, non-communicable diseases; viral hepatitis, mental health condition, and alcohol and drug dependency are commoner health problems other than HIV.
- There is lower knowledge of community level HIV services among PLHIV who had shorter life with HIV; whereas PLHIV with no formal education, and those in the non KP groups are more aware of HIV care and treatment services available in the community
- Significantly higher proportion of respondents who don't belong to KP are aware of laws that protect PLHIV against discrimination compared to respondents who belong to KP.
- composite index of violation of the rights of PLHIV during the last year and earlier than the last year was 10% and 11% respectively showing violations of the rights of PLHIV is not significantly improving over time.
- The rights of women, KPs especially FSWs are more violated than men, and the non-KPs respectively in the last year prior to the survey.
- The index of PLHIV counteracting stigma and discrimination has continued to be low, and respondents who are employed/have income are more likely to defend for their right compared to unemployed
- Respondents who belong to the KP were found out to be more experienced in defending their rights and they acted more at combating stigma and discrimination against them or other than respondent who do not belong to KP
- The stigma and discrimination among FSWs, because they are FSWs is high, showing stigma and self-stigma because of belonging to FSWs is not improving over time.
- In the same analogy, about 79% of the IUDs had the experience of S&D in the 12 months prior to the survey.

Recommendation

- *Widely disseminate findings of the study, and use them to inform the national and subnational level development of HIV multi-sectoral joint plan.*
- *Design strategy to involve the mass and social media, peer service providers' programs in the dissemination of messages on stigma and discrimination, as well as availability of HIV services at community and health facility levels.*
- *Design strategies to improve literacy regarding policy and legal related issues, and coordinate implementation across all levels to address issues of stigma and discrimination, human rights and HIV AIDS.*
- *Review the current curriculum and service delivery guideline and tools of peer education program, which includes the PLHIV, adolescents, and KPs living or not living with HIV, adequately integrating issues of stigma and discrimination, human rights, consented disclosure focusing on the female, and scale up the*

delivery of standardized peer support group programs accordingly, for the general PLHIV, as well as to specific groups including the KP, adolescents and youths

- *Design and implement guideline to enable health facilities to provide PLHIV and KP friendly HIV services which effectively address S & D and HIV related human rights issues at scale.*
- *Integrate human rights and stigma and discrimination related issues in the activities of community actors including the CSOs, peer groups, DICs, as well as service providers.*
- *Build capacity of PLHIV associations to ensure more effective coordination of peer service program, accessible to the PLHIV in collaboration with the national HIV response coordination body and other relevant stakeholders.*
- *Strengthen and scale up community level support groups involving the PLHIV associations, for the general PLHIV as well as specifically for the PLHIV in the KP groups*
- *Scale up peer support among the PLHIV across all levels so that the PLHIV shall support each other, sharing experiences among themselves, also to improve consented disclosure, focusing on the female so that the PLHIV benefit from the positive effects of disclosure.*
- *Build capacity of health facility and community level HIV service providers as well as the relevant experts/teachers in schools and higher education institutes to minimize stigma and discrimination, non-consented disclosure and to improve for better support to enable the PLHIV to disclose their HIV status to whoever they prefer.*
- *Scale up adolescent PLHIV friendly HIV services at community and health facility levels to address the stigma and discrimination issues related to the adolescent PLHIV, as well as other gaps of accessing HIV services.*
- *Assess policy and legal gaps and limitations of enforcing available laws and policies in addressing stigma and discrimination, and human rights related problems on the female PLHIV and KPs and address the policy and legal gaps accordingly.*
- *Further studies needed on factors related to understanding reasons for high stigma and discrimination in Afar, Amhara and Tigray regional states, forced HIV testing, non-consented disclosure at schools and other social settings, delays in initiation of HIV treatment and the paradox of better defense of their rights by the KP PLHIVs verses lower knowledge regarding their rights and design strategies accordingly.*

1. INTRODUCTION

People living with HIV/AIDS (PLHIV) usually face negative attitudes that keep them from seeking and accessing services, disclosing health information to providers, and adhering to treatment (stigma). The negative attitudes towards PLHIV in turn leads to specific actions by others that restrict the rights and freedoms of PLHIV (discrimination) such as breaches of confidentiality, labeling, gossip, verbal harassment, differential treatment and even denial of services. Despite facing stigma and discrimination, many PLHIV either do not know what their rights are and how to protect them, or they are desperate to defend their rights¹.

Concrete evidence showed that Stigma and discrimination are creating barriers to accessing HIV prevention, testing and treatment services and putting lives at risk. A report by UNAIDS shows that PLHIV who experience high levels of HIV-related stigma are more than twice as likely to delay enrolment into care than people who do not perceive HIV-related stigma. Stigma and discrimination are an affront to human rights and puts the lives of PLHIV in danger² (UNAIDS, 2017).

According to the report on the Fast-Track to end AIDS (UNAIDS, 2015), in 35% of countries with available data, over 50% of people report having discriminatory attitudes towards PLHIV³. PLHIV continue to face stigma and discrimination based on their actual or perceived health status, socioeconomic status, age, sex, or other grounds.

The Ethiopian 2011 stigma index survey showed 69% of PLHIV reported family and community level gossip as the main manifestation of stigma towards them. Further, this survey showed that about three in four PLHIV who lost their job in the year prior to the survey attributed their lost job to their HIV status. About nine percent of the respondents (12% males and 7% of females) reported denial of health service because of their HIV status. More than 50% of PLHIV reported internalized stigma, blaming themselves for having HIV and exposed to low self-esteem⁴. However, there is no information on the number of PLHIV who avoided seeking for health service due to anticipated stigma and discrimination.

¹ <https://www.avert.org/professionals/hiv-social-issues/stigma-discrimination>

² *Confronting discrimination: overcoming HIV-related stigma and discrimination in health-care settings and beyond*, UNAIDS, 2017

³ *Fast-Track to end AIDS by 2030 report*, UNAIDS, 2015

⁴ <https://www.unaids.org/en/regionscountry>. Accessed April 27, 202

The 2016 Ethiopian Demographic and Health Survey showed 48% and 35% of women and men respondents respectively thought that children living with HIV should not be able to attend school with children who are HIV negative. Further, 55% and 47% of women and men respondents respectively reported that they would not buy fresh vegetables from a shopkeeper with HIV. This high-level stigma might have adversely affected people's willingness to be tested as well as their initiation of and adherence to antiretroviral therapy (ART)⁵.

According to The Ethiopian Public Health Institute (EPHI) 2020 spectrum report, the 2020 HIV prevalence rate in Ethiopia among adults aged 15 to 49 was estimated as 0.86 % and a total of 622,326 people of all ages were living with HIV⁶. This report also estimated that 11,715 people were newly infected with HIV and 12,685 people died from an AIDS-related illness in 2020. The same report indicated that only 86% of PLHIV knew their HIV status while 94% of those who know their status were on treatment. These Figures indicate that Ethiopia is below the 1st 90 targets by 2020⁷.

Addressing stigma and discrimination can play an important role in increasing access to and uptake of HIV services. Consistent focus on stigma and discrimination becomes important specifically when it is measured against its contribution to the successful achievement of the global targets mainly the three 95's (target 95-95-95) by 2030. HIV-related stigma and discrimination practices can prevent PLHIV from seeking services such as HIV testing, disclosing test results, taking ART and ARV prophylaxis. Besides, it forces them to keep their HIV status secret which in turn impedes their contribution in HIV prevention efforts.

Cognizant of the challenges related to stigma and discrimination in use of health services, the Federal HIV/AIDS Prevention and Control Office (FHAPCO) aims to strengthen the fight against stigma and discrimination through intensifying activities against stigma and discrimination such as increasing public awareness, knowledge on HIV transmission and prevention, access to HIV testing, prevention of mother to child transmission of HIV (PMTCT), enforcing the existing anti discriminatory laws of the land and improving the involvement of PLHIV in the service delivery. This survey is the second round of the "Stigma Index" surveys in Ethiopia (2011 and 2021),

⁵ <https://www.unaids.org/en/regionscountries/countries/Ethiopia>. Accessed April 27, 2020.

⁶ EPHI, 2020 HIV related estimates and projections for Ethiopia

⁷ <https://www.unaids.org/en/regionscountries/countries/ethiopia>. Accessed April 27, 2020.

*Ethiopia's strategic plan sets to achieve the 95-95-95 targets by 2025

which is jointly conducted by the “Network of Networks of HIV Positives in Ethiopia (NEP+)” and “FHAPCO” of Ethiopia.

The survey results will help to understand the extent, type and trends of stigma & discrimination (S&D) and to develop strategies to reduce and eliminate them. Overall, the findings would be of use to all parties involved in the national response against HIV leading towards the reduction and then elimination of stigma and discrimination.

2. OBJECTIVES

General Objective

The overall purpose of the stigma index survey (SIS) was to estimate the level and trend of S&D among the PLHIV, assess the association between stigma and HIV services and propose recommendations to mitigate negative impacts of stigma on PLHIV.

Specific Objectives

The specific objectives of the stigma and discrimination survey were:

- 2.1.1. To estimate the level of internal (individual feelings that lead to negative actions) and external stigma (family and community structure, workplace and service facilities stigma)
- 2.1.2. Assess how HIV stigma relates to HIV status disclosure, treatment and care services for the PLHIV; rights-based violations and missed opportunities due to fears.
- 2.1.3. Describe the action taken (resilience) by PLHIV to mitigate the impact of HIV stigma.
- 2.1.4. Assess trends in the HIV related stigma using two-data points (2011 versus 2021).

3. METHODS

This survey adopted the methodology developed by the joint collaboration of international organizations, including the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federations (IPPF), and the Joint United Nations Program on HIV/AIDS (UNAIDS).

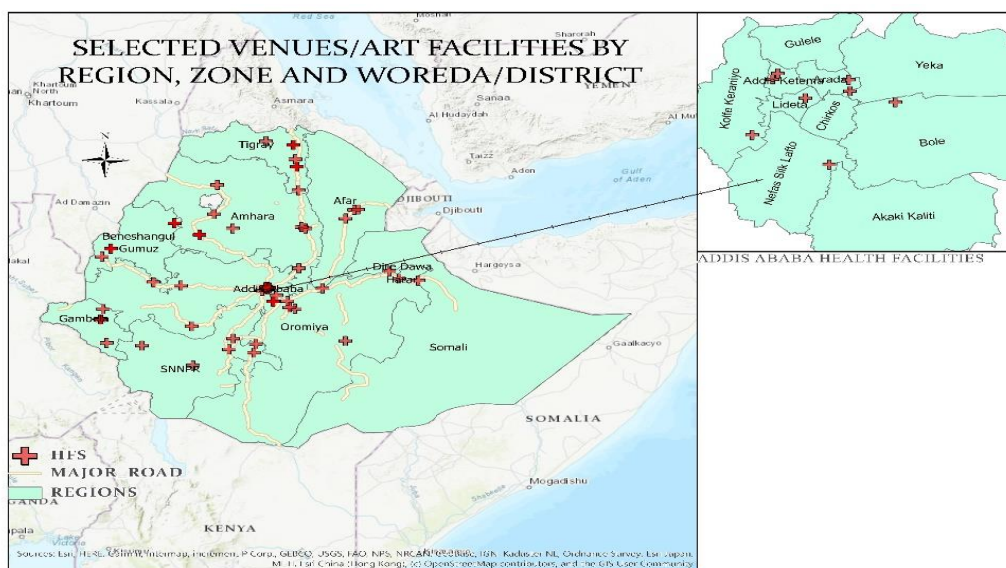
3.1. Study design

The survey used venue based quantitative cross-sectional design which allows comparison of indicators over time, within country and across countries.

3.2. Survey area and scope

Ethiopia is located in the horn of Africa with an estimated population size of 114.9 million⁸ in 2020. Currently, Ethiopia is divided into ten regional states, Addis Ababa city administration, and Dire-Dawa administration.

Fig 3-1 Administrative structure of Ethiopia and selected venues for the survey



This survey was country-wide that covers nine regional states, Addis Ababa city administration, and Dire-Dawa administration. The 10th region (Sidama) was part of the Southern Nations and Nationalities People Region (SNNPR) at the protocol preparation stage of the survey. As a result, sample selection was undertaken as part of SNNPR. In terms of content, the survey covers both internal and external HIV stigma experiences of PLHIV.

⁸ <https://www.worldometers.info/world-population/ethiopia-population/> accessed June 2021

3.3. Study Population

The respondents of the survey were male and female PLHIV aged 18 years and above who knew they are HIV positive for at least 12 months prior to the survey. The respondents were HIV positive from the general PLHIV population, female sex workers (FSWs) and people who inject drug (PWID), who were able and willing to provide consent for interviews. The FSWs respondents were those who self-identify themselves/identified by others as female sex worker, and the PWID are also persons who are self-identifying/identified by others as PWID.

All members of the study population who were under the influence of alcohol, drug or other substances, mentally unstable (unable to communicate their thoughts and feelings effectively or unable to cooperate with interviewers) and unable or unwilling to provide consent at the time of the survey were excluded.

3.4. Sample Size determination and allocation by region

The sample size for the survey was calculated based on the guidance on sample size calculation for PLHIV⁹ received from Global Networks of People Living with HIV (GNP+). Accordingly, the prevalence of “avoidance of seeking healthcare” because of anticipated stigma is estimated from two variables of the 2011⁸ SIS result; i.e. “I avoided going to a local clinic when I needed to” and “I avoided going to a hospital when I needed to”. Further, doubling the average percentage of these two variables provided the estimated prevalence for avoidance of seeking health care as 14%. Doubling the average percentage is taken to adjust for the likely underrepresentation of the actual number of people avoiding healthcare when they needed to. This prevalence estimates and the following assumptions used to calculate sample size for the survey:

- Confidence level of 95%
- A 3% level of precision was assumed. This level of precision is considered to provide sufficient sample size (Ethiopia is a big country with a high number of PLHIV).

Using the sample size calculator for PLHIV SIS 2.0 the national sample size was determined as: n=2056.

⁹ PLHIV stigma index 2.0 sampling plan, April 2020 (soft copy received from GNP+)

Table 3-1 Planned and realized sample size by region

Region Name region/city administration	Planned (n)	Realized (n)	Percent realized
Addis Ababa City Administration	430	490	114.0
Somali	80	80	100.0
SNNPR	230	210	91.3
Tigray	200	180	90.0
Afar	120	120	100.0
Amhara	438	424	96.8
Benshangul-Gumuz	90	90	100.0
Dire-Dawa Administration	140	185	132.1
Gambella	120	122	101.7
Harari	106	106	100.0
Oromia	302	305	101.0
Total	2256	2312	102.5

This sample size was adjusted to 2256 in order to allocate reasonable sample size for regional estimates using power allocation approach. Further, according to the guidance for stigma index survey implementation about 25% (n=564) of the calculated sample size is allocated PLHIV who were FSWs and PWID, who were nationally identified key populations in the Ethiopian context. The more sample size realized in Addis Ababa city administration compared to the plan was due to the need to achieve the allocated sample size for KP (FSWs and PWID), due to insufficient number of KP for sampling in other regions. The lower realized sample size for SNNPR and Tigray regions compared to the plan was that we could not access sample PWID in the two regions at the implementation stage.

3.5. Sampling strategy and sample size allocation to target population

The SIS used two sampling strategies. The first is venue-based time-location sampling (TLS), and the other is limited chain referral (LCR) sampling approaches. Seventy-five percent of the sample participants were selected using TLS approach for all PLHIV population while 25% enrolled in the study using LCR approach for KP (FSWs and PWID).

3.6. Sampling strategy and sample size allocation to venues/service outlets

Sample for the general population of PLHIV was selected in two stages. At first stage 260 Woredas that included 50% of the estimated size of PLHIV in Ethiopia were selected using probability proportional to size (PPS) among 1024 Woredas. From the selected 260 woredas at first stage sampling, all venues that provide ART service were listed and cleaned for client load. As a result, 123 venues that serve more than ten PLHIV per day on-site were identified and

taken as eligible for second stage sampling. From the cleaned list of 123 venues, 57 venues that serve all population groups were selected using PPS. Then, 30 respondents per venue were selected TLS (take all clients at the venue) approach and interviewed. The total sample size calculated was allocated to the venues selected in regions.

Further, venues that provide HIV care for PLHIV who were KP were identified including drop in centers (DIC), FSW confidential clinics, and rehabilitation centers for PWID to serve as entry point for sampling. Then, these venues were selected using PPS approach and resulted in inclusion of six out of ten DICs, seven out of nine FSW confidential clinics, and three rehabilitation centers (available at design stage) for PWID. Following the selection of venues, the total calculated and determined sample size was allocated to the selected venues using PPS, taking in to account 25% of the total sample to KP.

For the KP, the venues are mainly located in Addis Ababa and Amhara region and more sample size was allocated to selected venues in Addis Ababa city administration and Amhara Region.

3.7. Interviewee recruitment procedures

As stated above, the survey used venues including public and private health facilities, DICs and confidential clinics for FSWs, and PWID rehabilitation center as an entry point to recruit respondents.

Prior to recruitment and contacting potential study participants, the investigators obtained official permission from responsible authorities at the selected venues (selected public/private facilities, DICs, Confidential Clinics, and PWID rehabilitation center

Interviewee recruitment followed TLS and LCR sampling procedures based on the type of target population and service venues. Respondents from the general population regardless of whether they belong to KP or not were recruited at public/private venues using TLS approach.

On the other hand, the KPs (FSWs and PWID) were selected using LCR approach using DICs, FSW confidential clinics and rehabilitation center for PWID as an entry point.

Respondents who were from the general population and who were receiving ART treatment from public or private venues on the date of the interview were recruited using take all TLS approach. The potential respondents were at public or private service venues were directly approached by data collectors and informed about the survey. This approach continued till the predetermined number of interviews for the venues was achieved. Respondents were assessed for eligibility and then asked their consent to participate in the study before any data collection.

On the other hand, the KPs (FSWs and PWID) were recruited through LCR strategy using a peer-driven coupon system. Leveraging their availability at dedicated DIC or confidential clinic for FSWs and PWID rehabilitation center, potential interviewee were interviewed after screening for their eligibility and obtaining their consent for their participation. After completing the interview, respondents were asked to recruit their peers to participate through coupon system. Potential respondents who received coupons from referral system and able to handover their coupon to the interviewer at the study venue, were interviewed face to face using structured questionnaire after screening for their eligibility receiving consent for their participation.

3.8. Compensation for participants

All participants of the study received 150 Ethiopian Birr (about \$4 at the time of the survey) to cover transport cost and compensate for the time spent during the interview.

3.9. Data Collection Methods

3.9.1. The study Instruments

A structured PLHIV Stigma Index-2.0 questionnaire which is developed by the GNP+ was adopted and translated into four local languages (Amharic, Afan Oromo, Tigrigna and Somali) considering the languages are widely spoken in Ethiopia. The questionnaire and methodological approach was piloted and inputs received incorporated in to the final version of the questionnaire.

3.9.2 Data quality measures

3.9.2.1. Recruitment of data collectors and supervisors

Data collection staff recruited as per the guidance from standard methodology for the PLHIV stigma index survey developed by GNP+. As the survey is for PLHIV by PLHIV, all data collectors and regional coordinators were PLHIV who openly disclosed their HIV positive status. Whereas, all supervisors were professional working at the NEP+ regional offices.

The field staff recruitment was led by the NEP+ office following the criteria set by the technical working group which was established to provide technical assistance in the implementation process of the survey. The criteria included openly living with HIV, 18 years or older, fluent in the dominant language of their respective regions, and willing to attend the interviewer/supervisor training.

The supervisors were responsible to guide the data collectors in ensuring confidentiality and data quality by implementing the informed consent forms and handling the list containing the names, contact details and unique identifying codes of all completed interview documents safety and security. .

3.9.2.2. Training of data collectors and supervisors.

Three days of training was organized for all data collectors and supervisors. The training session covered the objective of the study, procedures for selecting and interviewing respondents, inclusion and exclusion criteria, interview techniques, ethical concern and contents of the data collection instruments, and how to collect data using tablets. Further, simulation exercises were conducted to consolidate the knowledge and skills of data collectors to manage the second round stigma index survey data collection effectively. The training was an opportunity for interviewers to clarify concepts related to the index and to learn practical skills, on the quality check questions so that every interviewer understands how to complete the questions.

3.9.2.3. Data Quality Assurance

To ensure quality of data the paper based questionnaire was converted to electronic web based application (Appsheet platform). The data collection app was design to ensure data quality using validation rules such as must enter, skip, ranges, GPs coordinator, and time stamp. The application installed on the tablets/smart phones was prepared for data collection. Data collectors and supervisors were trained on how to use the App for the data collection and central support was given virtually for any challenges during implementation at the data collection.

A field data collection user guide on issues related to the data collection instrument, the role and responsibilities of each team was given to all survey team members. Field supervisors provided support for data collectors and overseen the data collection. Supervisors systematically checked the data to ensured data quality. The technical working group (TWG) for the survey supervised selected sample data collection sites and provided feedback to field team as necessary.

3.9.2.4. Data collection and management

Data collection was conducted from December 2020 to March 2021. The data manager was monitoring the progress and quality of the collected data and regularly sharing the results to the TWG. The collected data was synchronized from the electronic data collection devices to the server automatically except on days when there were network problems.

The data manager exported Meta data from server to excel spread sheet, then coding has been done for each response. Finally, raw data from excel was exported to Statistical Software for Social Sciences (SPSS) as part of preparation for analysis.

3.9.2.5. Data Cleaning and Analysis

The data was reviewed and cleaned by the lead technical consultant as part of preparation for data analysis. The data was also cleaned continuously using SPSS during the data analysis.

Following the data cleaning, univariate descriptive and comparative analysis including trends was undertaken as part of answering the objective of the survey. The analysis results were presented in the form of narration report, tables and graphs.

3.10. Ethical Consideration

The stigma index survey protocol was submitted to the Ethiopian Public Health Institute (EPHI) research and ethical review committee and approved after critical review. All comments from the committee were addressed before receiving the approval.

The privacy of respondents and confidentiality of information was ensured according to the approved protocol (personal identifiers were not recorded and data access was limited to data manager, investigators and consultants).

3.11. Limitations

Like many surveys, this survey was not without limitation. Few of the limitations are stated below:

- The sample was drawn from clients who were enrolled at HIV care venues. Despite the vast majority of PLHIV in Ethiopia were enrolled for HIV care, it is thought that there exist PLHIV who were not enrolled at service outlet and captured for the survey.
- Data analysis for some indicators was not possible due to the change of questions in 2021 from questions used 2011.

- The PWID sample was only from the Addis Ababa for our effort to recruit from other regions was not successful.
- Like other social science and health research, the responses of interviewee may have the tendency to incline to answers that were viewed favorably by others.

3.12. Disclaimer

The Ethiopian National people living with HIV Stigma Index Round 2 survey was conducted using customized version of the Guidance and tools developed by the GNP+; and the target population for the survey were PLHIV from different populations groups including the general population and the nationally identified key and priority population groups.

4. RESULTS

4.1 Characteristics of respondents

More than seven in ten (72%) of the respondents are female and 28% males. The age of respondents was normally distributed representing all ages (mean=37.4 and median =37 years) (Table 1.1). The majority of respondents are from Addis Ababa (21%), followed by Amhara region (18 %), and Oromia Region (13%).

Table 4-1 Background characteristics of sample respondents

	Number (n)	Percentage
Region		
Addis Ababa	490	21.1
Somali	80	3.5
SNNPR	210	9.1
Tigray	180	7.8
Afar	120	5.2
Amhara	424	18.3
Benshangul-Gumuz	90	3.9
Dire Dawa	185	8.0
Gambella	122	5.3
Harari	106	4.6
Oromia	305	13.2
Sex		
Female	1673	72.4
Male	639	27.6
Age Group		
18 to 24	157	6.8
25 to 34	713	30.8
35 to 44	901	39.0
45 to 54	416	18.0
55+	125	5.4
Mean age (Median) years	37.4 (37)	
Completed level of education		
No formal education	676	31.7
Primary/elementary	834	39.2
Secondary/high school	438	20.5
Vocational school	84	3.9
University/tertiary	100	4.7
Employment status of respondents		
Employed	1484	64.2
Unemployed	648	28.0
Retired/on pension	71	3.1
NA(student or not looking for employment)	109	4.7
Member of a network or support group of PLHIV	2132	36.4

The most sample size from Addis Ababa is qualified for most of the key populations (FSWs and PWID) are living in the city, and entry points for sampling such as DICs and PWID rehabilitation centers are not sufficiently available in the other regions. About 32% of respondents have no formal education and this is in agreement with the educational status of general adult population in Ethiopia. About 39% of the respondents have primary level of education and

more than 24% have an elementary level of education. More than 20% of the respondents have secondary/high school level of education and only about 5% of the respondent have tertiary level of education. About 28% of respondents were unemployed/have no income, while about 64% were employed/have income. About 5% of the respondents were not looking for employment and about 3% retired. About 36% of the respondents are member of a network or support group of people living with HIV.

About one in five (19%) of the respondents do not have children under their care. The majority of respondents have one (28%) child and about 26% two children. About 15% of the respondents have three children and about 12% reported having four or more children (the maximum number is 9 children as reported by two respondents. On average each PLHIV have two children under their care (Table 4.2). Respondents were asked how often they were not able to meet their basic needs in the last 12 months prior to the survey. Results showed that, about 21% were not able to meet their basic needs for most of the time, while 45% reported they were sometimes unable to meet their basic needs in the last 12 months. About 34% of the respondents reported that they were never unable to meet their basic needs. A Considerable proportion of respondents were belonging to other socially vulnerable groups. They include member of internally displaced persons (5 %), living with disability (5%), migrant worker (4%), refuge/ asylum seekers (2%).

Table 4-2 Other background characteristics of respondents

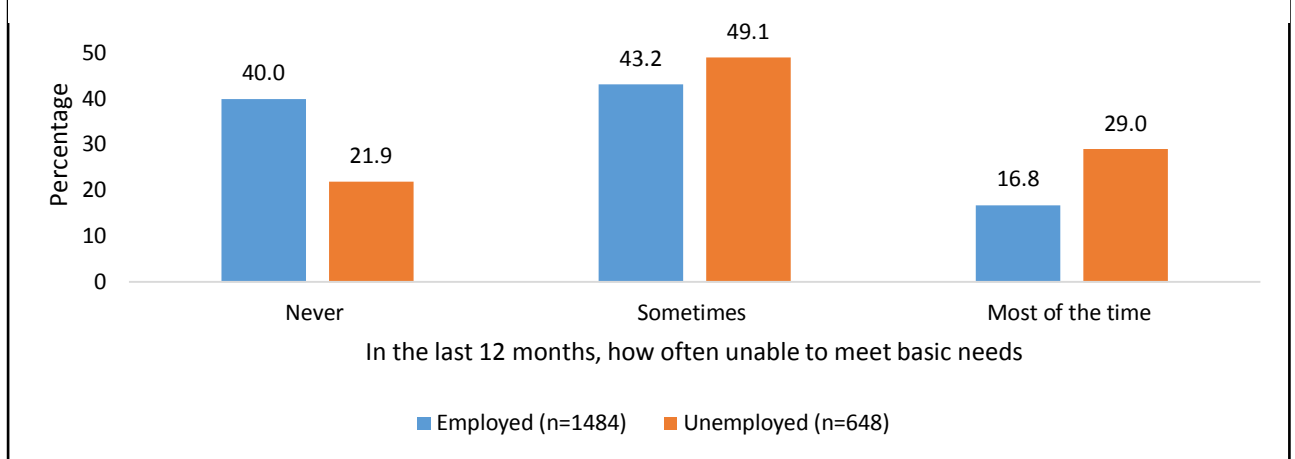
Other background characteristic	Number (n)	Percentage
Number of Children respondent have		
No children	441	19.1
One	638	27.6
Two	609	26.3
Three	356	15.4
Four and more	268	11.6
Mean (median)number of children	1.8 (2.0)	
How often respondents unable to meet their basic needs		
Never	792	34.2
Some times	1040	45.0
Most of the time	480	20.8
Currently belong to or have been a member of any of the groups		
Internally displaced person	2312	5.2
Living with a disability (vision, hearing, mobility, intellectual/developmental) of any kind (other than HIV)	2312	5.1
Migrant worker	2312	4.2
Refugee or asylum seeker	2312	2.3
Incarcerated/in prison	2312	2.2

Fig 4.1 shows how often respondents were unable to meet their basic need in the last 12 months by employment status (measure of income). Results showed that, significantly higher proportion of unemployed respondents (29%) were unable to meet their basic need for most of the time in the last 12 months prior to the survey compared to employed respondents

(17%). It is also observed that, significantly higher proportion of employed respondents (40%) were able (never unable) to meet their basic need compared to unemployed respondent (22%).

About 77% of respondents did not belong to key population (not female sex works or PWID, or

Fig. 4-1 Proportion of respondents who are unable to meet basic needs by employment status



FSWs who inject drugs), (Fig. 4.2). Among the KP more than three in four were FSWs (76%), about 17% PWID and the remaining 7% were FSWs who inject drugs.

Fig. 4-2 Proportion of subjects by type of population group

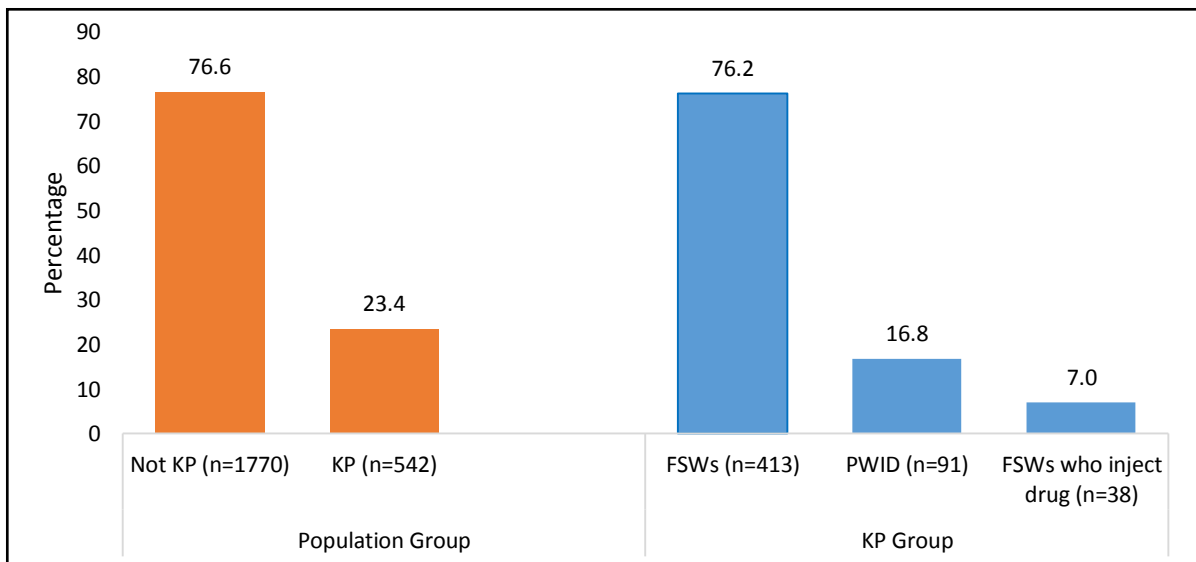
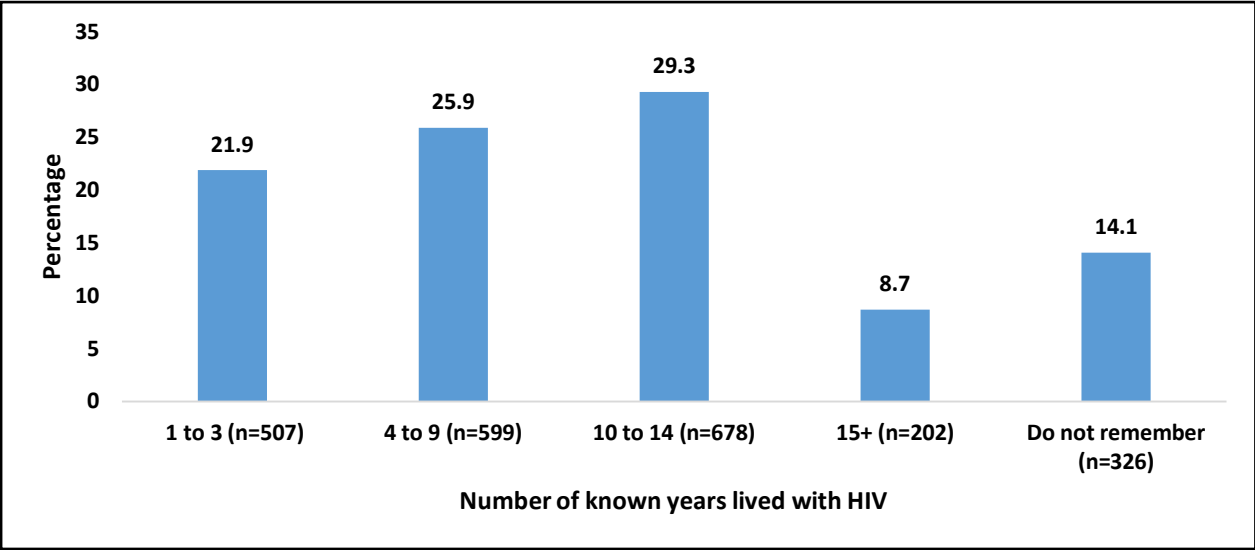


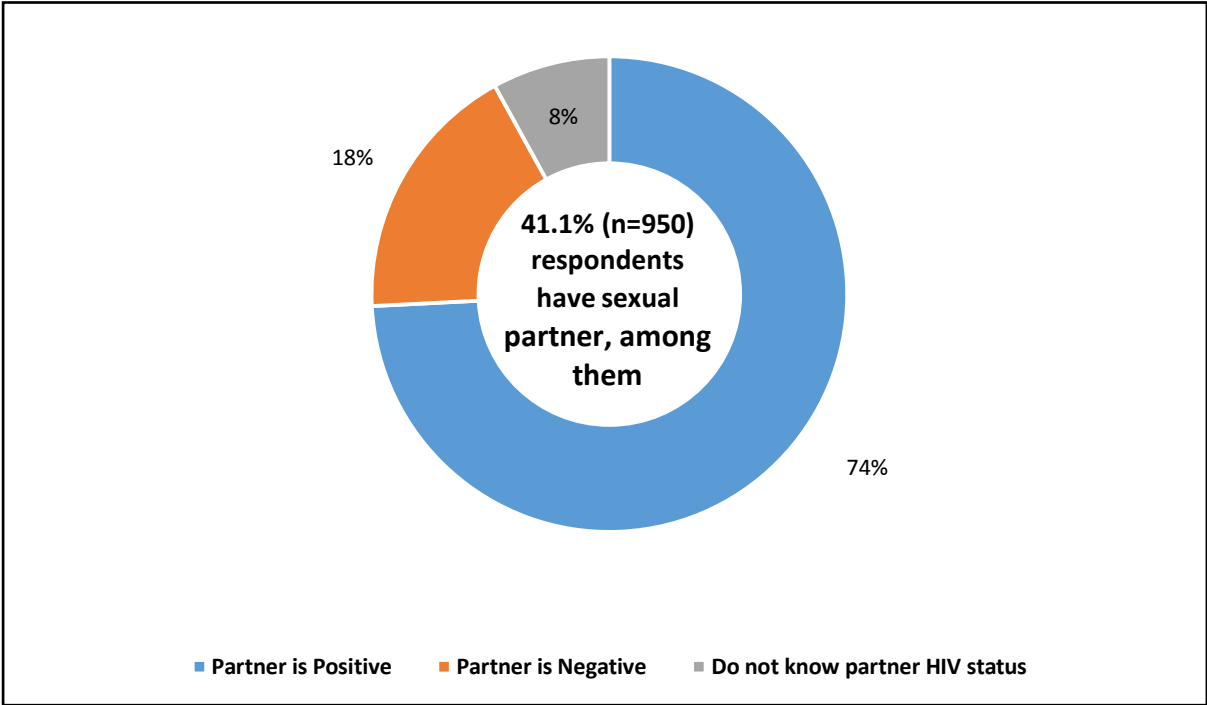
Fig. 4.3 shows the proportion of respondents who lived with HIV after diagnosis for 1 to 3 years (22%), 4 to 9 years (26%), 10 to 14 years (29%), and 15+ years (9%). About 14% of the respondents do not remember the number of years they lived with HIV after diagnosis. The maximum number of years lived with HIV after diagnosis was 28 years as reported by one respondent

Fig. 4-2 percentage of respondents by number years lived with HIV after diagnosis



More than four in ten (41%) of the respondents were having a sexual partner, regardless of their marital status (married or not). Among respondents who have intimate sexual partner, the proportions of those whose partners are HIV-positive are (74%), those who have HIV-negative sexual partner are (18%), and 8% of the respondent didn't know about the HIV status of their partner (Fig. 4.4)

Fig. 4-3 Percentage of respondents who have sexual partner and HIV status of their partners



4.2. Disclosure of HIV Status

About 84% of the respondents reported at least someone from the social groups such as family members, friends, and neighbors knew their HIV status (Table 4.3). It is observed that HIV status disclosure to close people such as family members, spouse friends' children and neighbors is relatively high compared to others in their social connections (coworkers, employers, local leaders, teachers, and class mates). Among those whose HIV status is disclosed, voluntary disclosure is relatively high for authority figures (93%) followed local leaders (91%) and spouse (88%), and for neighbors (80%) friends/children and family members (84%). Respondents are less likely to disclose their HIV status in school environment such as for class mates and teachers or school administrators.

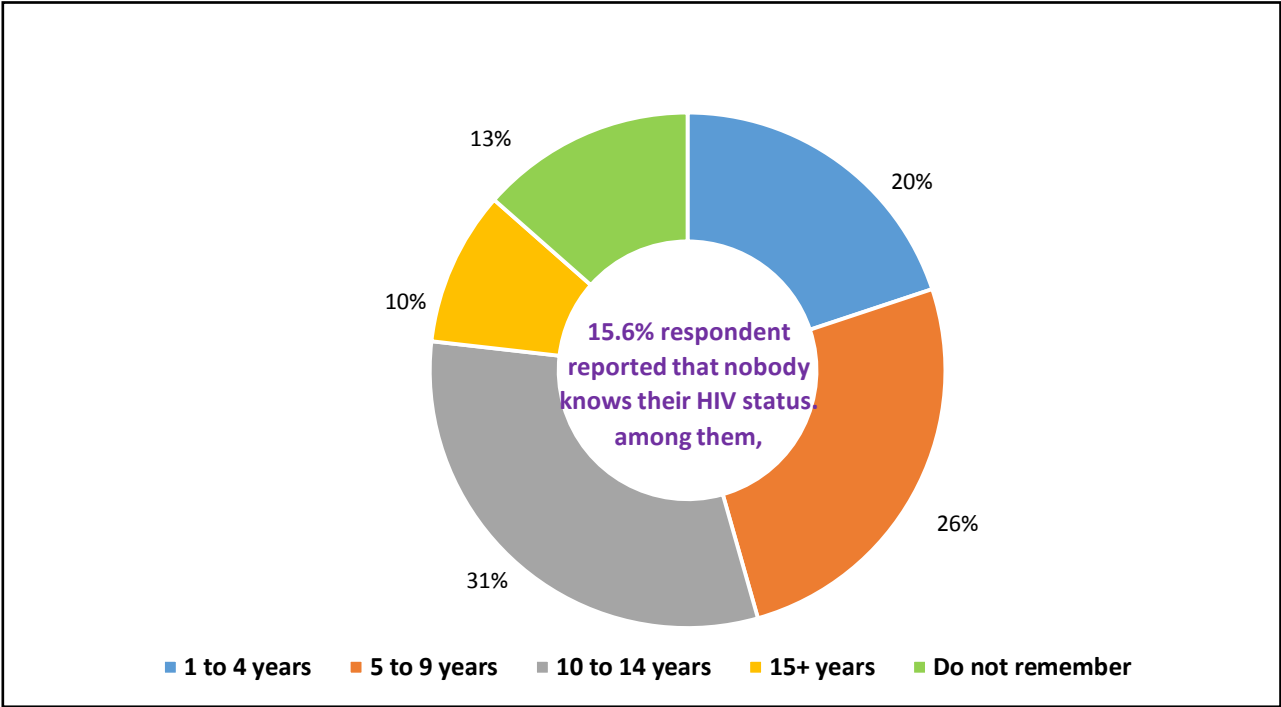
Among all respondents about 20% of them faced at least once non-consented disclosure of their HIV status, while about 23% of PLHIV with disclosed HIV status faced non-consented disclosure of their HIV status.

Table 4-3 The proportion of PLHIV whose HIV status has been disclosed to others (including without their consent)

Population group	Percent who know about the HIV status of the respondent	Among them, learned HIV status without the consent of the respondent	Proportion of involuntary disclosure among all respondents
Spouse or partner	65.5	11.9	5.7
Family members other than spouse/partner	54.5	15.1	7.8
Children	51.9	15.5	6.9
Friends	49.2	15.8	7.4
Neighbors	40.2	20.0	7.7
Co-workers	32.1	12.4	2.9
Employers	26.8	15.1	2.7
Local leaders	22.2	9.8	1.6
Authority figures	13.3	6.6	0.6
Teachers/school admin	8.0	18.8	0.7
Class mates	4.7	31.3	0.6
At least some one from the social groups	84.4	23.4	19.7

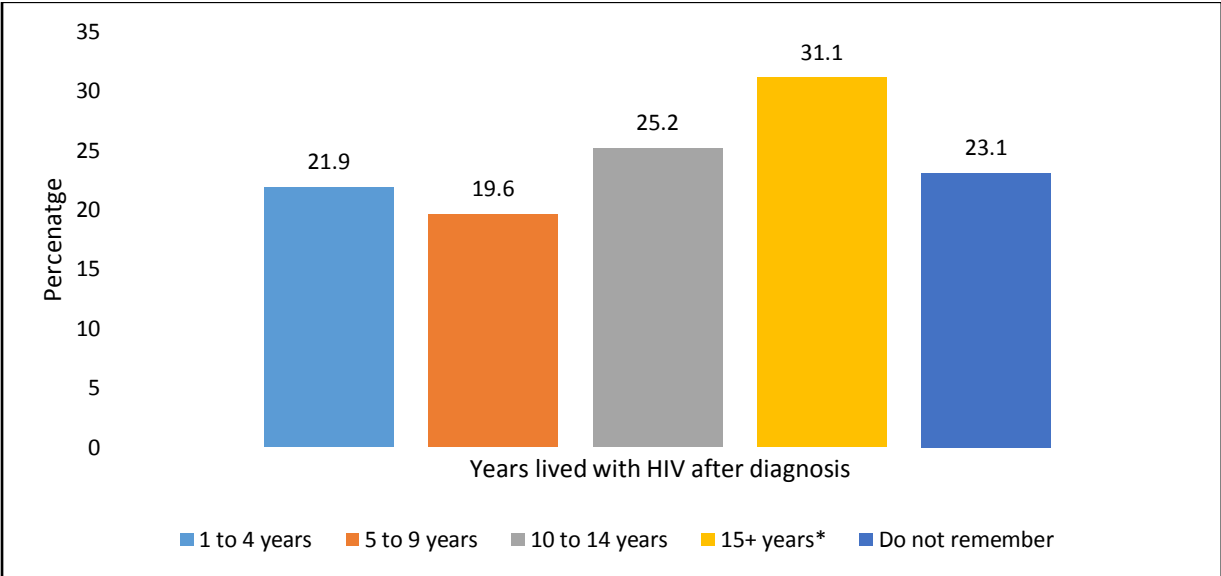
About 16% of the respondents reported that none of their social environment members such as family members, friends, and neighbors knew their HIV status. Non-disclosure of HIV status increases with number of years lived with HIV after diagnosis from 20% for those who lived one to three years, to 26% for those who lived 4 to 9 years, and to 31% to those who lived 10 to 14 year with HIV after diagnosis (Fig. 4.5). Non-disclosure of HIV status is lowest for respondents who lived 15+ years with HIV (10%).

Fig. 4-4 . Percentage of respondents, whose HIV status is undisclosed to any one of their social environments by number of years lived with HIV after diagnosis (n=361)



The proportion of respondents, who at least encountered once non-consented disclosure of HIV status with in their social environment increased with number of years lived with HIV after diagnosis (Fig.4.6). Level of non-consented disclosure (31%) was significantly higher among respondents who lived with HIV 15 years or more after diagnosis compared to respondents who lived 1 to 4 (22%) and 5 to 9 (20%) years with HIV after diagnosis.

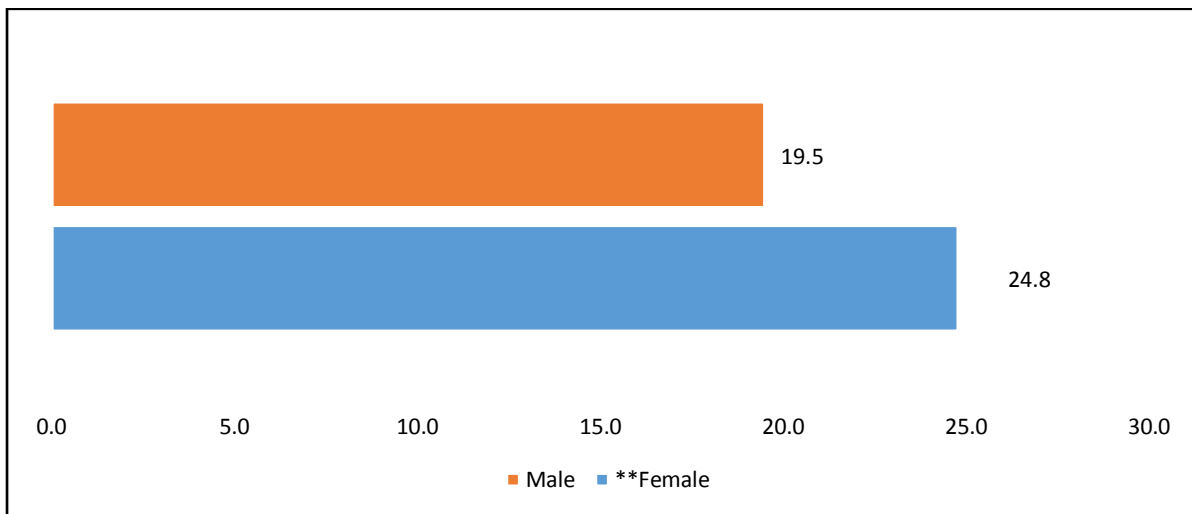
Fig. 4-5 Percentage of involuntary disclosure of HIV status by number of years lived with HIV after diagnosis (n=1951)



*Significant at p< 0.05, ** at p <0.01, and ***p< 0.001

The level of involuntary HIV status disclosure was statistically significant by sex (Fig.4.7). Females (25%) reported significantly higher level of non-consented HIV status disclosure compared to males (20%).

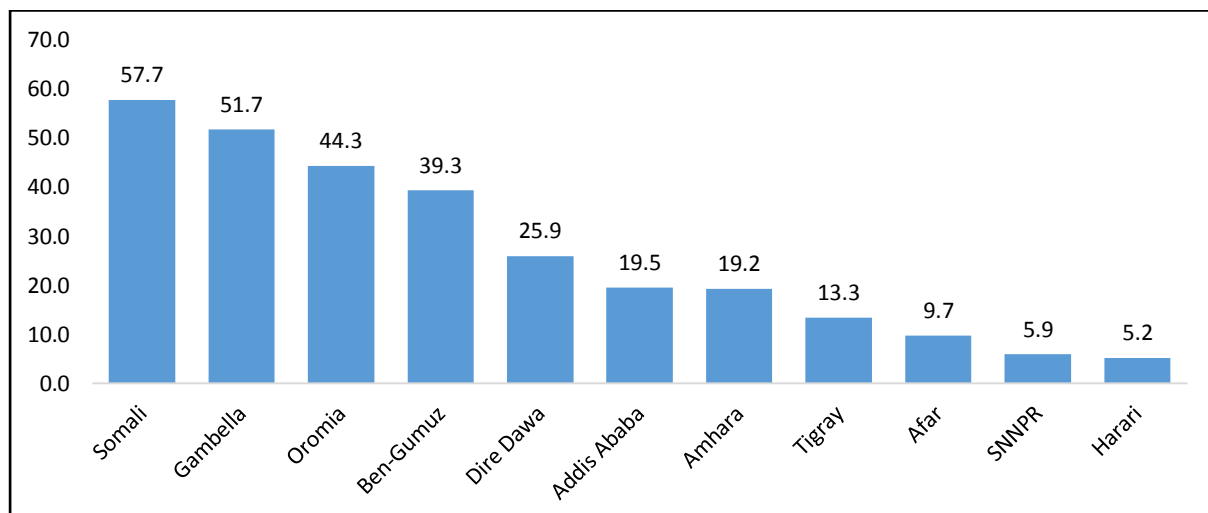
Fig. 4-6 Level of involuntary HIV status disclosure by sex of respondent (n=1951)



*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

Fig. 4.8 shows the level of unauthorized HIV status disclosure among who disclosed their HIV status by region. A statistically significant regional differences was observed by level of non-consented HIV status disclosure. The highest proportion of unauthorized HIV status disclosure was observed in Somali region (58%), followed by Gambella (52%), Oromia (44%), and Benshangul-Gumuz region (39%). On the other hand, less than 10% of the respondents in Afar, SNNPR and Harari reported unauthorized disclosure of their HIV status. The level of unauthorized HIV status disclosure in Addis Ababa is about 20%.

Fig. 4-7 Percentage of unauthorized HIV status disclosure by region (n=2312)



Other socio-demographic characteristics such as, age, employment status, educational status, and belonging to key population (KPs) didn't have statistically significant difference on involuntary disclosure of HIV status.

It was also observed that, unauthorized HIV status disclosure of PLHIV who do not belong to KPs was not significant (24%) compared to respondents belong to KP (23%). However, significant difference was observed among respondents belonging to KPs themselves (FSWs-23%, PWID-17%, and, FSW who inject drugs-38%) (Fig. 4-9).

Fig. 4-8 Level of unauthorized HIV status disclosure among KPs

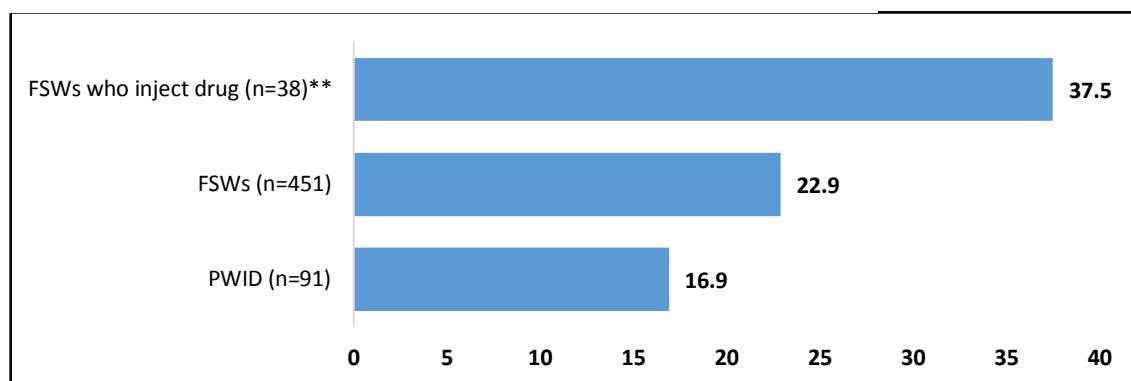


Table 4.4 shows the 2021 HIV status disclosure to members of the close circle social environment (spouse/partner, family members, children, friend/neighbors) was not significantly different from 2011. However, the proportion of unauthorized disclosure to those who were not close circle social environment (coworkers, employers, community leaders, authority figures and teachers'/school admin) was higher in 2021 compared to 2011.

Table 4-4 the frequency of unauthorized HIV status disclosure to members of the social environment among all respondents

	2011 (n=3359)	2021 (n=2312)
Spouse or partner	5.7	4.8
Family members other than spouse/partner	7.8	9.0
Children	6.9	4.0
Friends/Neighbors	20.1	23.9
Co-workers	2.9	9.6
Employers	2.7	6.6
Local/community leaders	1.6	11.0*
Authority Figures	0.6	3.4
Teachers/school admin	0.7	3.4

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

More than four in ten (41%) of the respondents in 2021 agreed or somehow agreed that disclosing their HIV status has become challenging over time as compared to respondents of 2011 (32%)

Table 4.5 shows that more than six in ten of the respondents (61%) agreed or somehow agreed that disclosure of HIV status to people whom they know close to them or they don't know very well was a positive experience. It is also observed that disclosure of HIV status to people close

to the respondents was having higher level of a positive experience (66%) compared to HIV status disclosure to people whom they don't know very well (50%). Similarly, disclosure to persons close to respondents is likely to get higher level of support (63%) compared to disclosure to persons' who don't know very well to respondents (44%).

Table 4-5 The proportion of PLHIV who agreed with the relevant statements about the experience of HIV status disclosure

	Experience of HIV status disclosure		
	to people who were close to them	to people whom they do not know very well	Over all
Disclosure of HIV status was a positive experience	65.7(n=2109)	49.5 (n=2006)	61.0
They were supportive when they first learned about HIV status	62.5 (2135)	43.6 (n=1991)	53.6
Respondents who reported disclosing HIV status has become easier over time	*	*	41.1

*Question was not asked separately for people who were close to and who were not known very well for the respondents

4.3. Stigma and discrimination from the social environment members

Stigma and discrimination (S&D) against PLHIV may be linked with communication of social circle (family members, relatives, partners, ...), the inner circle (friends, neighbors, acquaintances, colleagues, ...), as well as leadership, administration, staff members at places of employment or other institutional locations (hospitals, prisons, police, social services, etc.).

Table 4.6 shows that 12% PLHIV including 7% in the last years were not allowed to participate in public events/activities such as weddings, funerals, parties, and clubs. Further, 11% including 2% in the last year were not allowed to participate in household chores such as cooking, eating together, sleeping in the same room, etc. for their HIV status. About 5% of respondents including 2% in the last year were also not allowed to participate in religious events or prayer meetings.

About 6% of respondents (including 4%) in the last year reported about the experience of stigma and discrimination related to employment such as denial of employment, loss of work, and earnings. About 4% of respondents (including 3% in the last year) reported denial of promotion and change of job responsibilities.

An index of S&D from the social environment because of HIV status was calculated as the proportion of respondents who indicated at least one case of S&D in the last 12 months before the survey and for earlier than 12 months of the survey. The results showed that about 24% of the respondents were exposed to at least one form of S&D in the last 12 months preceding to the survey and about 32 % for period earlier than 12 months of the survey (Table 4.6).

Table 4-6 The experience of stigma and discrimination due to HIV status from the social environment, % (n=2312)

Manifestations of S&D against PLHIV due to HIV status (Multiple Response)	Yes, earlier than 12 months of the survey	Yes, in the last 12 months	No	N/A
They were not allowed to participate in public events or activities (e.g., weddings, funerals, parties, and clubs)	11.9	7.0	76.6	4.5
They were not allowed to participate in household chores (for example, cooking, eating together, sleeping in the same room, etc.)	10.6	5.8	79.2	4.4
They were not allowed to participate in religious events or visit prayer meetings	5.2	1.7	88.8	4.3
Other people (not family members) spoke negatively or gossiped	15.8	10.9	68.0	5.3
Family members spoke negatively or gossiped about PLHIV	13.1	9.2	73.4	4.3
Verbal abuse and violence by other persons (e.g., screaming and quarrels)	10.9	9.1	75.2	4.8
Blackmail	5.2	3.8	86.0	5.0
Physical violence by other persons (e.g., punches, pushes, and blows)	4.4	2.8	87.8	5.0
Denial of employment, loss of job or earnings	5.9	4.2	69.8	20.1
Changes in job responsibilities, type of activity, or refusal of promotion	4.1	3.0	64.3	28.6
Discrimination against spouse partner or child/ children	8.1	3.9	75.5	12.5
Index of S&D due to HIV positive status	32.1***	24.2	–	–

Table 4.7 shows that the index of S&D due to HIV positive status was associated with some background characteristics of the respondents. Thus, S&D was significantly higher among female respondents 26% compared to male respondents 20%. Respondents have no formal education faced more S&D due to HIV status (32%) compared to other level of educations (primary-22%, secondary-20%, university/tertiary-19%, and vocational school-15% level of education). S&D was significantly higher among respondents who belong to KP (32%) compared to respondents who do not belong to KP (22%). Respondents who were in sexual relationship faced less S&D (22%) due to their HIV status compared to respondent who were not in sexual relationship (26%) at the time of the interview.

Stigma and discrimination was not associated with years lived with HIV after diagnosis, employment status, and age of respondents.

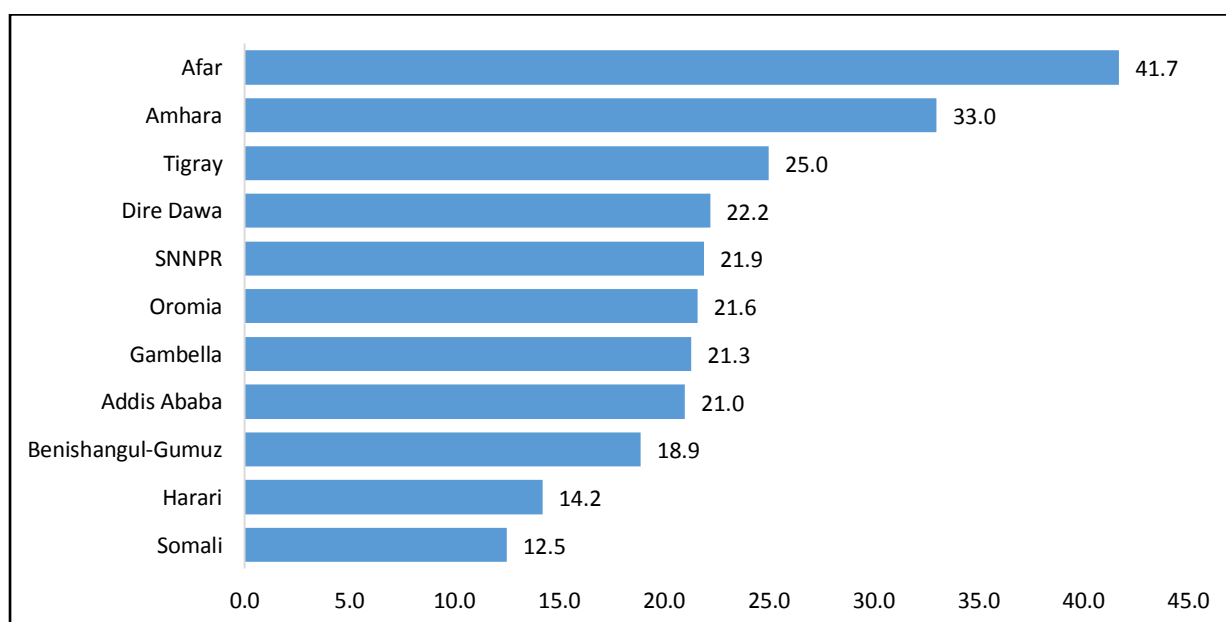
Table 4-7 Proportion respondents who experienced Stigma and discrimination due to HIV Positive status by background characteristics

Back ground characteristics of respondents	Sample (n)	Index of S&D due to HIV Positive status
Sex		
Female**	1673	25.8
Male	639	19.9
Currently have sexual relationship		
Yes*	950	21.9
No	1362	25.8
Completed level of education		
No formal education***	732	32.0
Primary/elementary	894	21.8
Secondary/high school	481	19.5
Vocational school	86	15.1
University/tertiary	119	19.3
Belonging to KP / not belonging to KP		
Not KP	1770	21.8
Belongs to KP***	542	32.1
FSW***	413	37.0
FSWs who inject drugs	38	31.6
PWID	91	9.9

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

Fig 4.10 shows proportion of S&D due to HIV positive status by region. The highest level of S&D was observed for respondents from Afar region (42%), followed by Amhara Region (33%), and Tigray region (25%). The Somali region reported the least S&D (13%), followed by Harari (14%).

Fig. 4-9 Level of stigma and discrimination due to HIV positive status by region



4.4 Internal stigma and discrimination and resilience of PLHIV

Establishing negative identity to oneself is likely to lead to self-stigmatization manifested in terms of limiting contacts with relatives and acquaintances, changing places of residence, retiring from employment by personal decision. The negative impact index of HIV positive status was calculated as the proportion of PLHIV who reported a negative impact on at least one aspect of their lives and the HIV status positive impact index as the proportion of PLHIV who reported a positive impact on at least one aspect of their lives from the list in Table 4.8.

Table 4.8 shows the proportion of respondents who reported their HIV positive status affecting on various aspect of their life positively or negatively. About 44% of respondents reported the positive impact of HIV positive status on their psychological and relationships with the social environment. The most reported positive impact were; improvement in their ability to cope with stress and self-confidence (25%) each respectively, followed by their ability to establish self-respect (22%), and their ability to find love, and their ability to have close and secure relationships with others (20%) each respectively.

On the other hand, about 45% of the respondents reported, their HIV positive status was negatively affecting their various aspect of life. Respondents reported their ability to cope with stress (24%), followed by their ability to find love and desire to have children (20%) each respectively, and their ability to have close and secure relationships with others (19%) were negatively affected. Further, the respondents reported that their HIV status was affecting negatively their self-confidence (19%), self-respect (15%), and ability to achieve personal and/or professional goals (14%).

A significant proportion of respondents (46% to 73%) reported that their HIV positive status did not affect either positively or negatively on their psychological well-being or relationships with the social environment.

Table 4-8 the level of positive and negative impact of HIV positive status on various aspects of respondents' lives, (n=2312)

Aspects of life	Affected positively	Did not affect	Affected Negatively	NA
Ability to cope with stress	25.0	48.6	23.5	2.9
Self-confidence	25.0	54.0	18.6	2.4
Self-respect	21.7	60.2	15.8	2.3
Ability to have close and secure relationships with others	20.3	58.1	19.0	2.6
Ability to find love	20.0	55.4	20.4	4.2
Desire to have children	18.8	46.0	19.8	15.4
Ability to achieve personal and/or professional goals	17.7	59.3	14.3	8.7
Ability to respect others	17.0	68.2	12.1	2.7
Ability to practice a religion/faith as I want to	12.7	73.3	11.0	3.0
Ability to contribute to my community	17.3	62.4	14.6	5.7
Index of HIV status on influence (positive or negative) of respondents life	43.5**		45.4*	

*The HIV negative impact index is calculated as the proportion of PLHIV who reported a negative impact on at least one aspect of their lives.

**The HIV positive impact index is calculated as the proportion of PLHIV who reported a positive impact on at least one aspect of their lives

Table 4.9 shows the negative impact index of HIV positive status on various lives of the respondents by background characteristics. The negative impact index of HIV positive status was significantly higher among female (47%) compared to male respondents (41%). The negative impact index of HIV positive status was decreasing with increasing years lived with HIV after diagnosis. In particular, the negative impact index of HIV status for respondents who lived with HIV after diagnosis for less than 10 years was about 50%; while the negative impact index of HIV status for respondents who lived with HIV for 15+ years after diagnosis was about 40%.

The negative impact index of HIV positive status among KP (FSWs and PWID) and those who were not KP was compared and the result indicated that the difference was not significant (46% and 45%) respectively. However, among the KP, FSWs (49%) were facing significantly higher negative impact of their HIV positive status compared to PWID (36%).

Table 4-9 The percentage of negative impact of HIV positive status on various aspects of respondents' lives by background characteristics

Background Characteristics	Sample (n)	Negative impact index
Sex		
Female***	1673	47.1
Male	639	41.0
Number of years lived with HIV after diagnosis		
1 to 3**	507	49.9
4 to 9**	599	49.4
10 to 14	678	43.5
15+	202	40.1
Do not remember	326	38.3
Belonging to KP / not belonging to KP		
Respondents not KP	1770	45.1
Respondents belong to KP	542	46.3
FSW**	413	49.2
FSWs who inject drugs	38	39.5
PWID	91	36.3

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

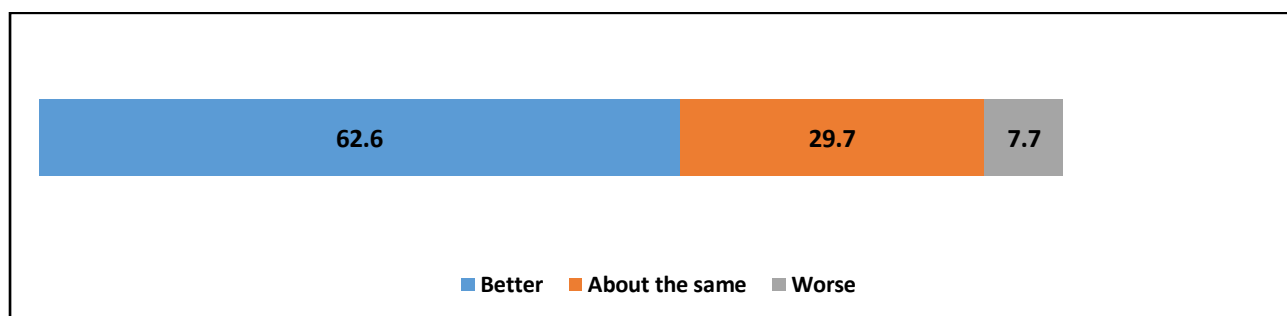
The difference in negative impact of HIV status by age, completed level of education, being in sexual relationship, or employment status was not statistically significant.

Respondents were asked to rate the effect of their HIV positive status on their ability to meet the needs described (resilience) in table 4.8 above (ability to cope with stress, self-confidence, self-respect and ability to respect others, desire to have children, ... etc.) in an earlier than 12 months' period compared to the last 12 months prior to the survey (Fig 4.1). The majority reported relative improvement (63%) in the 12 months compared to the period earlier than 12 months of the survey.

Nearly 30% of respondents reported the effect of HIV positive status to meet the various aspect of their life (resilience) was about the same in the last 12 months preceding the survey compared to the period earlier than 12 months of the survey. Only about 8% reported the

impact of HIV on various aspects of life was worse in the last 12 months prior to the survey compared to the earlier period.

Fig. 4-10 How respondents' rate the effect of HIV positive status on various aspect of their life in the last 12 months compared to the earlier than last 12 months, %



As depicted in Table 4.10 the majority (78%) of the respondents had difficulty of telling people that they are HIV positive; and about 52% reported that they hide their HIV status from others; and they also feel guilty that they are HIV positive (52%). About 43% sometimes felt worthless, 46% sensed shame, and 47% felt internal dirtiness.

A specific index of self-stigmatization, which relates to the respondents' feelings of shame, guilt, internal dirtiness, worthlessness, and hiding their HIV status, was created based on these five statements and the level of self-stigmatization was found out to be about 76%. On the other hand, the index generated from the six statements was inflated (88%) for more than three in four of the respondents agreed on "It is difficult to tell people that I am HIV positive". Therefore, we used the index generated from the five feelings to analyze the significance of self-stigmatization by various background characteristics of respondents.

Table 4-10 Percentage of self-stigmatization among respondents

Manifestation of self-stigmatization	Agreed	Index of self-stigmatization-6	Index of self-stigmatization-5
It is difficult to tell people that I am HIV positive	77.8	++	
I hide my HIV status from others	52.2	++	+
I feel guilty that I am HIV positive	52.0	++	+
Being HIV positive makes me feel internal dirtiness	45.7	++	+
I feel ashamed that I am HIV positive	45.6	++	+
I sometimes feel worthless because I am HIV positive	43.0	++	+
Self-stigmatization Index		88.6*	76.3*

++The index of self-stigmatization-6 is calculated as the proportion of respondents who agreed with at least 1 of the 6 statements (marked with "++")

+The index of self-stigmatization-5 is calculated as the proportion of respondents who agreed with at least 1 of the 5 statements (marked with "+")

Table 4.11 shows significantly higher level of self-stigmatization among female respondents (79%) compared to male respondents (70%). It was also observed that self-stigmatization among young respondents age 18 to 24 was significantly higher (90%) compared to other age groups.

Manifestations of self-stigmatization was found out to be significant by the years lived with HIV after diagnosis. Respondents who lived with HIV for less than four years after diagnosis (83%) have significantly higher level of self-stigmatization compared to respondents who lived with HIV for 10 to 14 years after diagnosis (73%) and those who lived with HIV 15+ years after diagnosis (68%).

The survey also showed significant difference of self-stigmatization by region. The highest proportion of respondents exposed to self-stigmatization were in Benshangule region (86%), followed by Dire Dawa administration (81%), Addis Ababa city administration (80%), and Oromia region (79%).

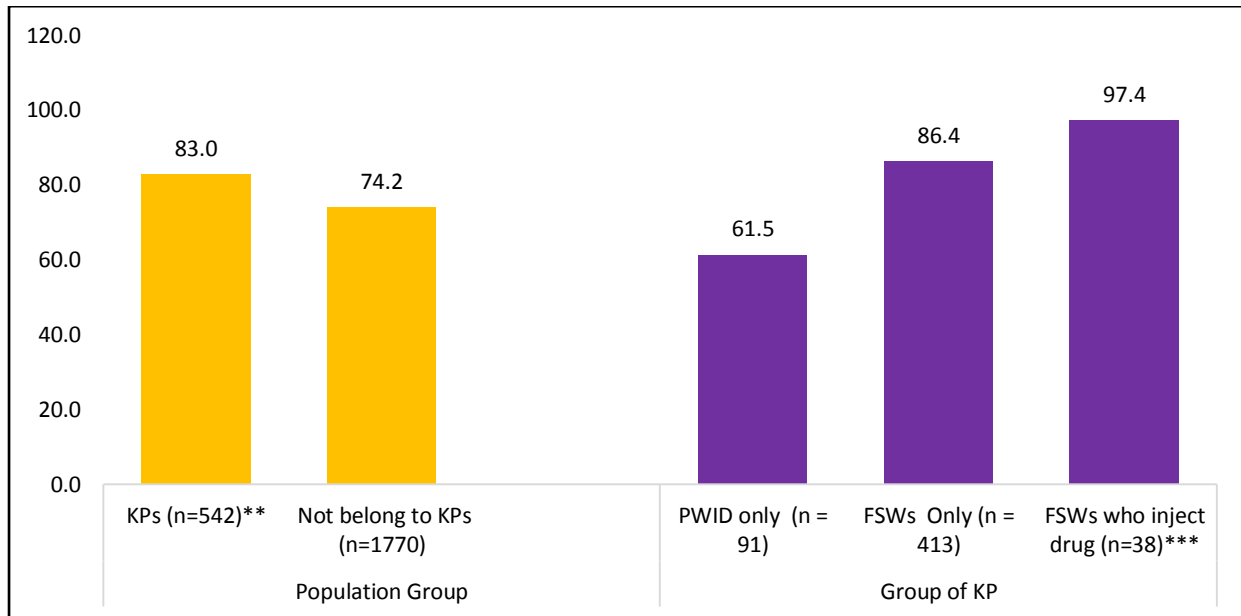
Table 4-11 The percentage of negative impact of HIV positive status on various aspects of respondents' life by background characteristics (n=2312)

Characteristics	Sample (n)	Level of self-stigmatization index
Sex		
Female***	1673	78.8
Male	639	69.6
Age		
18 to 24***	157	89.8
25 to 34	713	80.6
35 to 44	901	73.3
45 to 54	416	70.4
55+	125	75.2
Number of years live with HIV after diagnosis		
1 to 3**	503	82.6
4 to 9**	599	80.0
10 to 14	678	73.3
15+	202	67.8
Do not remember	326	70.9
Region		
Benshangule-Gumuz	90	85.6
Dire Dawa	185	80.5
Addis Ababa	490	79.6
Oromia	305	79.3
SNNPR	210	78.6
Gambella	122	78.3
Amhara	424	78.1
Afar	120	75.0
Tigray	180	68.9
Harari	106	61.3
Somali	80	42.5

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

Further, significant difference of self-stigmatization was observed among respondents who belongs to KP (83%) compared to those who do not belongs to KP (74%) (Fig.4.2). The level of self-stigmatization among FSWs (86%) is significantly higher than the PWIDs (62%). It is also observed that, self-stigmatization was likely to be universal among FSWs who inject drugs (97%).

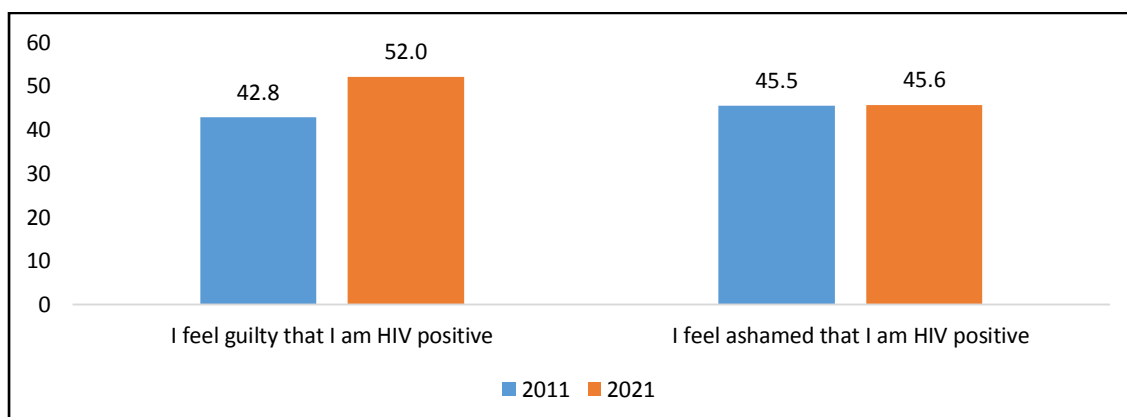
Fig. 4-11 Level of self-stigmatization of PLHIV by population group



The difference in level of self-stigmatization is not significant by educational status and employment status respondents. Hence compassion was not made in this report.

Comparing the finding from the 2011 SI survey with the current SIS, showed that, the feeling of guilt was increasing from 2011 (43%) to 2021 (52%). However, the feeling of shame was not changing, which was about 46% in both surveys (Fig. 4.13).

Fig. 4-12 Level of PLHIV self-stigma of (feeling of guilty and shame), % by survey period



This evidence show that, currently self-stigmatization was very high and not improving especially (in terms of the feeling of shame), and it is even getting worse in terms of the feeling of guilt over the survey periods.

In the last 12 months prior to the survey, self-stigmatization together with stigma and discrimination from the external environment led respondents to make their own decision. Significant proportion of respondents showed signs of resilience, and a desire to maintain their normal lifestyle. As a result, about 90% of respondents sought healthcare, 82 % social assistances, other 82% maintained contact with families and friends, 80% attended public events, 76% had chosen to apply for a job, and 73% did not decide to have sex (Table 4.11).

On the other hand, considerable proportion of respondents (19%) decided not to have sex, and 17% have chosen not to attend social gatherings or isolated themselves from family and/or friends because of their HIV status. About 14% of respondents also chose not to seek social support (14%), 10% not to seek health care, and another 10% not to apply for a job as means to escape stigma and discrimination (Table 4.12).

Table 4-12 Proportion of respondents according to decisions related to HIV status in 12 months prior to the survey

Decision	No	Not applicable	Yes
I decided not to have sex	72.6	8.0	19.4
I have chosen not to attend social gatherings	80.1	2.9	17.0
I have isolated myself from family and/or friends	82.1	1.4	16.5
I have chosen not to seek social support	82.1	4.2	13.7
I have chosen not to seek health care	89.7	0.6	9.7
I have chosen not to apply for a job(s)	75.6	15.3	9.1
Index of Self-discrimination			38.4*

*The self-discrimination index was calculated as the proportion of PLHIV who indicated that they had made at least one self-discrimination

A self-discrimination index was calculated as the proportion of PLHIV who indicated that they had made at least one self-discrimination decision from the list of decisions in Table 4.12. As a result, the calculated index of self-discrimination for HIV status was found out to be 38%.

According to 2021 survey, more respondents (10%) have chosen not to seek healthcare compared to 7% in 2011 survey (Fig. 4.14). About 9% of respondents in both 2011 and 2021 survey decided not to seek job.

Fig. 4-13 Decision as a result of self-discrimination in the areas of healthcare and employment by survey period

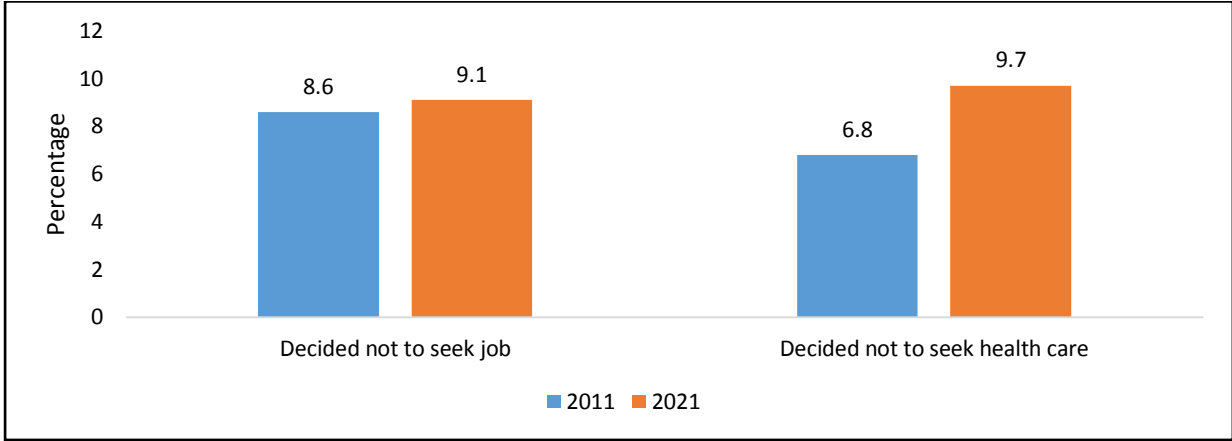
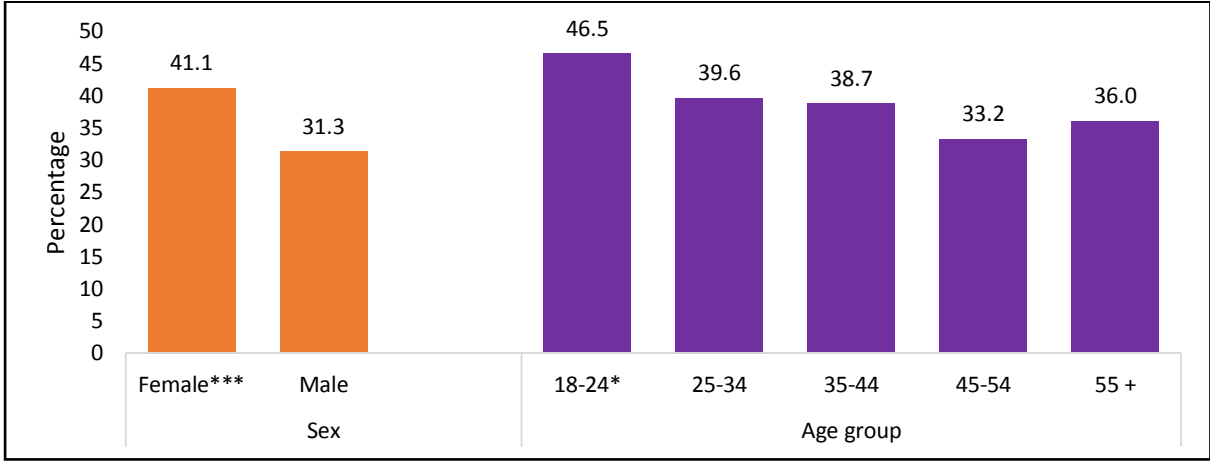


Fig. 4.15 shows that the index of self-discrimination on HIV status was significantly higher among females (41%) compared to males (31%). It can also be seen self-discrimination was declining with increasing age of respondents. The self-discrimination index was significantly higher (47%) among young age respondents (18 to 24) years compared to older age respondents (Index of self-discrimination of: 40% of age group 25 to 34 years, 39% of age group 35 to 44 years, 33% of age group 45 to 54 years).

Self-discrimination wasn't significantly varied by the number of years lived with HIV after diagnosis, educational status, and employment status.

Fig. 4-14 Level self-discrimination of PLHIV for their HIV status, % by sex and age

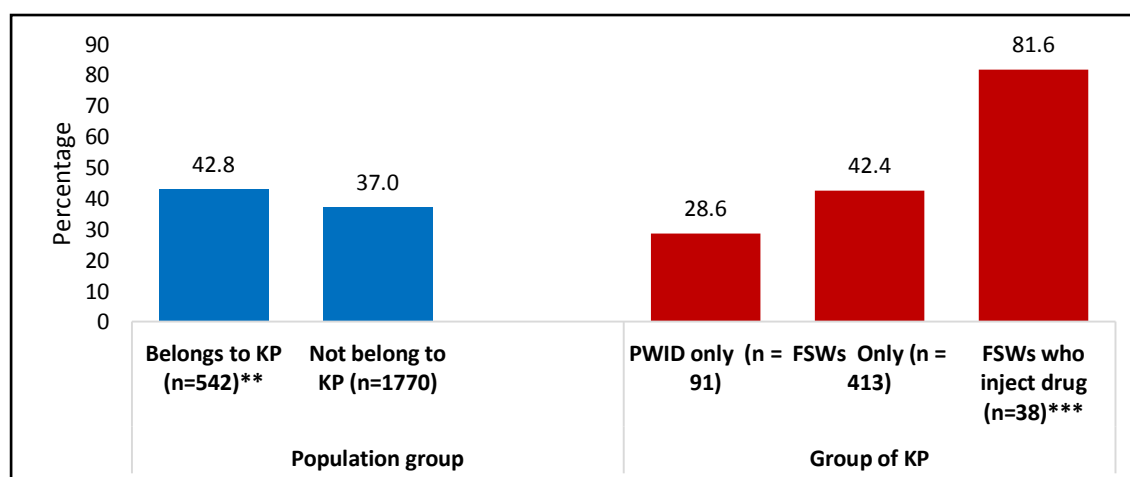


*Significant at p < 0.05, ** at p < 0.01, and ***p < 0.001

The results showed that the index of self-discrimination is significantly higher among respondents who belong to KP (43%) compared to those do not belong to KP (37%). Further, comparison of index of self-discrimination with in KP groups showed that FSWs who inject drugs (82%) are more exposed to self-discrimination as compared to FSWs (42%) and 29% PWIDs (Fig. 4.15).

Index of self-discrimination was not significant by the number of years lived with HIV after diagnosis, educational status and employment status.

Fig. 4-15 Level of PLHIV self-discrimination by population group



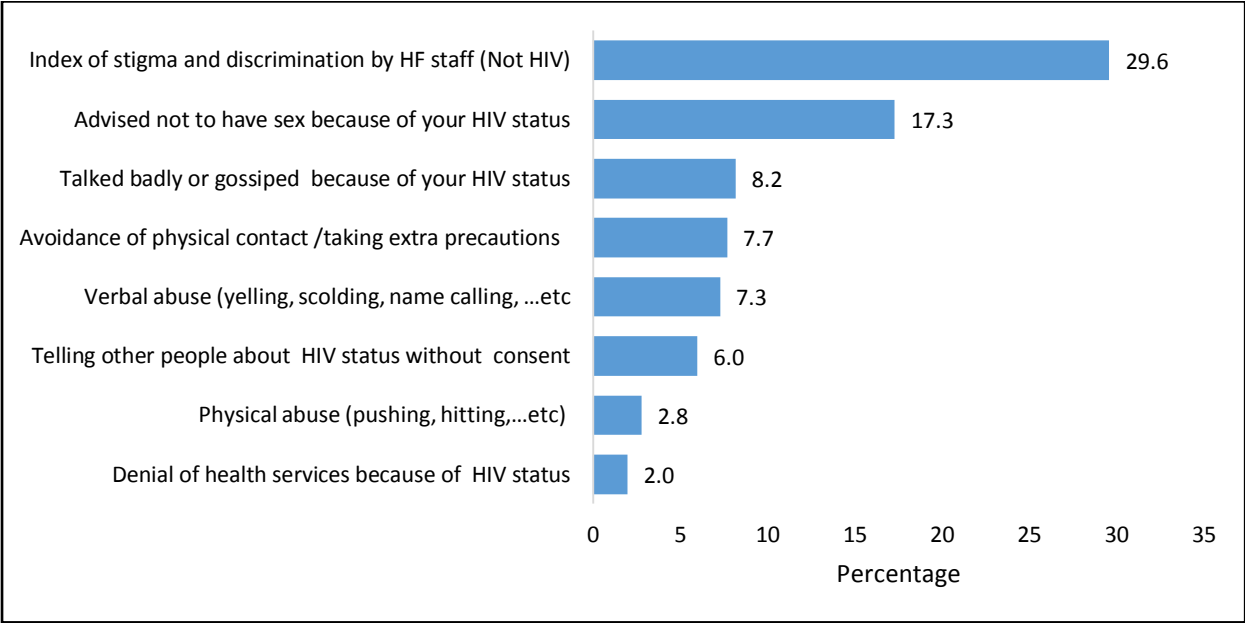
*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

4.5. Stigma and discrimination in healthcare facilities

4.5.1. Restrictions on access to health services and stigma & discrimination due to HIV status in the healthcare facilities.

To analyze the overall level of S&D against PLHIV in the healthcare facilities that provide HIV care, index of restrictions on access to health services was calculated. The S&D index by health facility staff that provide HIV care for PLHIV was calculated based on those who experienced at least one form of S&D. The overall level of stigma and discrimination by health facility staff in the 12 months prior to the survey was found out to be about 30%. The most frequent manifestations of S&D against PLHIV by healthcare workers in facilities that provide HIV care services was providing advice not to have sex (17%), followed by talked badly/ gossiped and avoidance of physical contact /taking extra precautions such as using double gloves (8%) respectively, and verbal abuse such as yelling, scolding, name calling (7%). The least form of S&D against PLHIV by facilities staffs that provide HIV care services was denial of health service 2% (Fig 4.17).

Fig. 4-16 Proportion of respondents who experienced stigma and discrimination by healthcare staff that provide HIV care services in the last 12 months prior to the survey (n=2205)



The index of S&D by health workers against PLHIV because of their HIV status was calculated as the proportion of all respondents who had experienced at least one S&D manifestation in the area of SRH (S&D manifestations shown in table 4.13). The results showed that about 14% of all the respondents were exposed to health professional S&D in the area SRH (including family planning), and S&D manifestations related to pregnancy, childbirth, and breastfeeding. Looking at the specific manifestations of S&D by health workers, in the area of SRH (Table 4.13), about 10% reported that they were told by the health worker to use a specific method of family planning in order to get ART.

Table 4-13 Percentage of respondents who experienced S&D at facilities PLHIV received SRH care service at during the last 12 months, (n=2312)

S&D manifestations related to family planning	Yes, within the last 12 months	No	NA	Prefer not to answer
They told you that you had to use (a specific method of) contraception in order to get your HIV (antiretroviral) treatment	9.8	68.2	19.9	2.1
They advised you not to be a mother/father	6.1	76.0	15.7	2.1
They pressured or incentivized you to get sterilized	2.6	77.7	18.1	1.6
They denied you contraception/family planning services	1.2	76.5	20.5	1.9
They sterilized you without your knowledge or consent	0.4	79.9	17.6	2.1
Index of professional S&D related to FP because HIV status	14.2			

Analysis of the association of S&D by health professional in the area of reproductive health with background characteristics of respondents showed that sex, age, educational status, number of years lived with HIV after diagnosis, and belonging to KP were found out to be strongly associated with the index of S&D by health workers (Table 4.14).

Table 4.14 shows that, more female respondents (17%) were exposed to S&D by health workers (HIV care) specifically in the area of SRH compared to male respondents (7%). It was also observed that respondents in the age group 25-34(19%) and 35-44(17%) are more stigmatized and discriminated by health workers at HIV care facilities than the youngest age group 18 to 24 (6%), age group 45 to 54 (7%), and 55+ (2%).

Stigma and discrimination by health workers in the area of SRH was significantly higher among respondents who have lived with HIV for 1 to 3 years after diagnosis (22%) and for respondents who have no formal education (19%). Stigma and discrimination decreased with increasing years lived with HIV after diagnosis and level of education. The results also showed that respondents who belong to KP (24%) were more exposed to S&D by health workers specifically in the area of SRH compared to respondents who do not belong to KP (11%). Among the KPs, respondents FSW who inject drugs (50%) were more exposed to health professional S&D compared to FSWs (26) and PWIDs (3%) (Table 4.14).

Table 4-14 Level of S&D by health professional (HIV care) in area of SRH by background characteristics

Characteristics	Sample size (n)	Level of S&D at HIV care facilities by health professional
Sex		
Female***	1673	17.1
Male	639	6.6
Age group		
18 to 24	157	5.7
25 to 34***	713	18.9
35 to 44***	901	16.9
45 to 54	416	7.0
55+	125	2.4
Period since diagnosed with HIV		
1 to 3***	507	21.7
4 to 9	599	12.9
10 to 14	678	12.8
15+	202	14.4
Do not remember	326	7.7
Education status		
No formal education***	732	18.7
Primary/local equivalent	894	14.4
Secondary/high school	481	10.0
Trade/ vocational school	86	7.0
University/tertiary	119	6.7
Belong to KP		
Do not Belong to KP	1770	11.1
Belong to KPs ***	542	24.2
FSWs	413	26.4
PWID	91	3.3
FSWs who inject drugs	38	50.0

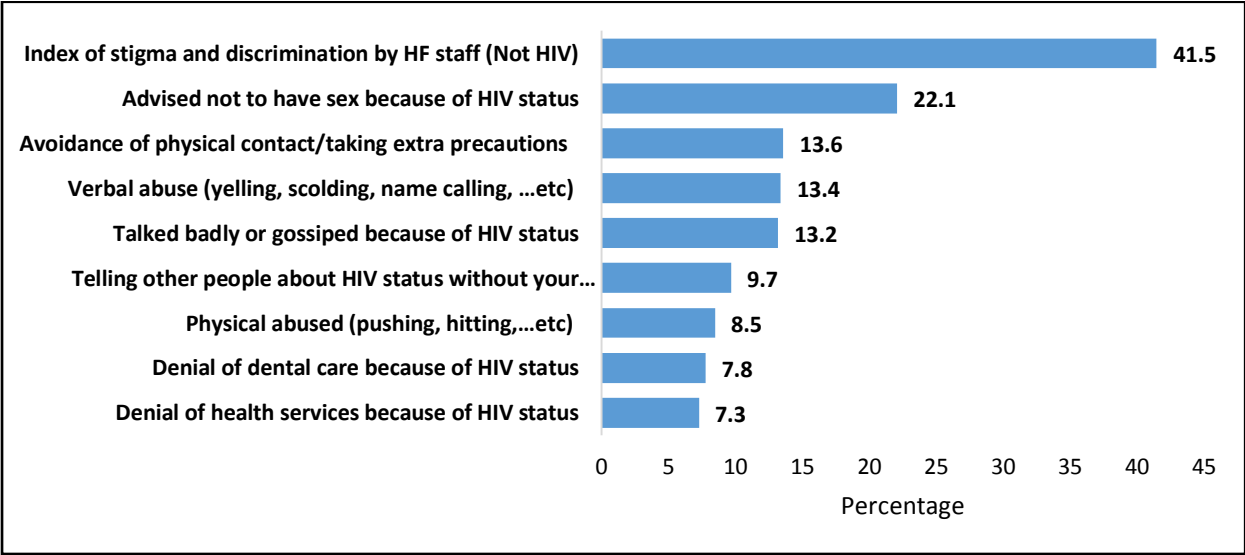
*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

A stigma and discrimination index against PLHIV for the last 12 months prior to the survey, due to their HIV status was calculated as a proportion of PLHIV who reported about their

experiences in healthcare facilities when seeking care for non-HIV related health needs such as malaria, flu, dental services, vaccinations and injuries in the last 12 months prior to the survey. Results showed that, among respondents who visited health facilities for non-HIV need, the overall level of S&D by health facility staff in the 12 months before the survey was found out to be about 42%. The most frequently reported manifestations of S&D from healthcare workers in the 12 months prior to the survey was advice not to have sex (22%), whereas the least was denial of health service (7%) (See Fig 4.18).

Here we can observe that PLHIV are facing more stigma and discrimination by healthcare facility staffs when seeking non HIV related services (42%) compared to facilities where they receive HIV services (30%).

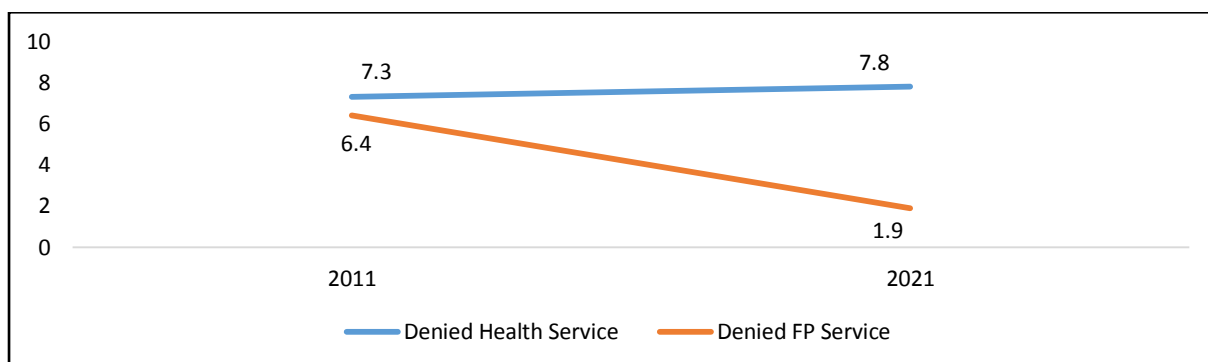
Fig 4-17 Manifestations of stigma and discrimination faced by PLHIV visiting healthcare facilities for non-HIV needs in the last 12 months prior to the survey, % (n=959)



The 2011 and 2021 Survey data on S&D by healthcare facility staff against PLHIV are not the same. We are therefore forced to assess discrimination of respondents by health care facility staff in terms of restriction to general health services and denial of family planning service.

The results showed that S&D in the health service facilities over the 2011 to 2021 survey period was not changing. However, the restriction of family planning services was decreasing from 6% in 2011 to 2% in 2021 (Fig. 4.19).

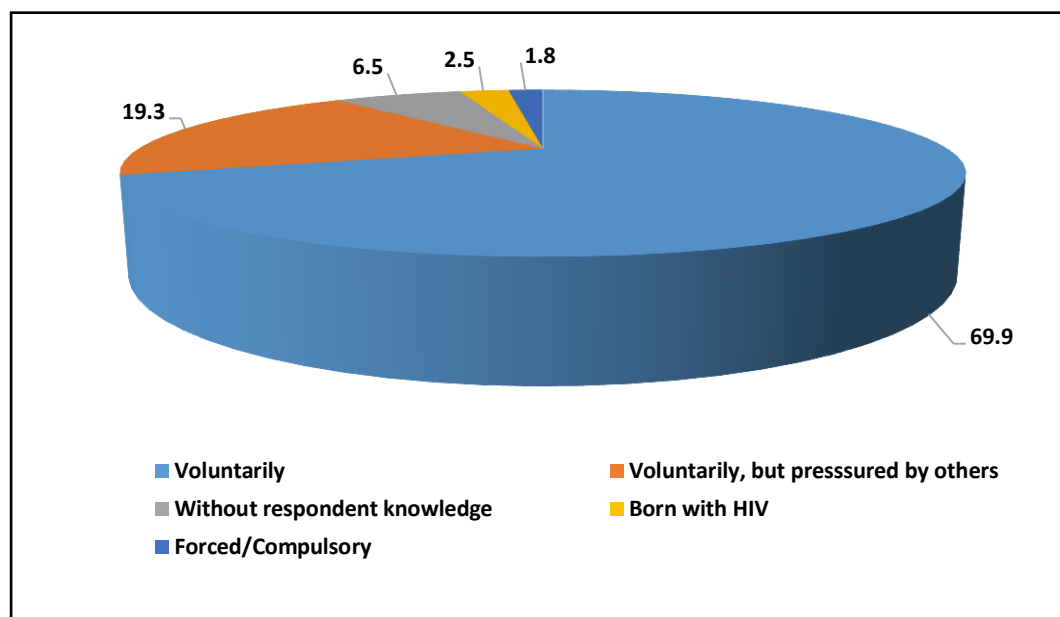
Fig 4-18 Level of restriction of health service by healthcare facility staff by survey period



4.5.2 HIV testing

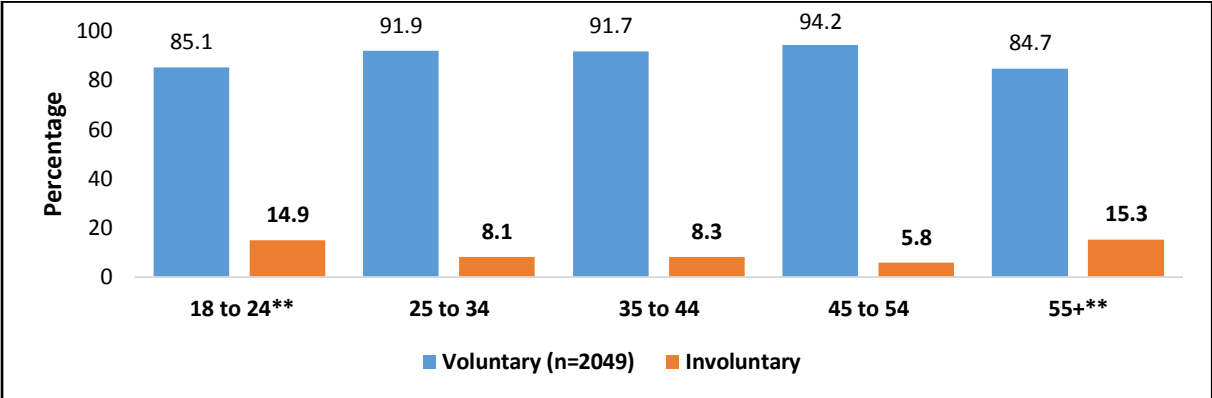
For the majority of respondents (89%), HIV testing was their own decision. However, only 70% decided to take the test voluntarily, while the other 19% decided to accept the testing pressure by others. About 7% reported that they were tested without their knowledge and they learned about it after taking the test, other 2% reported they were forced to take the HIV test without their consent. More than 2% of the respondents were born with HIV (Fig. 4.20)

Fig 4-19 Percentage on voluntary decision of respondents to take HIV testing



Voluntary HIV testing was significantly lower among respondents aged 18 to 24 years and age 55 years and above (85%) respectively compared to other age groups (92% or more) (Fig 4.21). Similarly, involuntary/ forced HIV testing was high among the age group 18 to 24 and age 55+ (15%) respectively.

Fig 4-20 Proportion of respondents who made voluntary decision to take HIV testing by age



*Significant at p< 0.05, ** at p <0.01, and ***p< 0.001

There was no significant difference in deciding for HIV testing by sex, being belong to KP, educational status, years lived with HIV after diagnosis, and employment status of respondents.

There was no significant difference in HIV voluntarily testing between respondents who were taking HIV care and treatment (72%) and those who did not have HIV treatment at the time of the survey (73%). It was also observed that forced/compulsory HIV testing was higher among respondents who avoided HIV treatment (4%) compared to those who were taking HIV treatment (2%). Contrary to this, HIV testing without the knowledge of respondents was higher among who were in HIV treatment (7%) compared to those who avoided HIV treatment (4%) (Table 4.15).

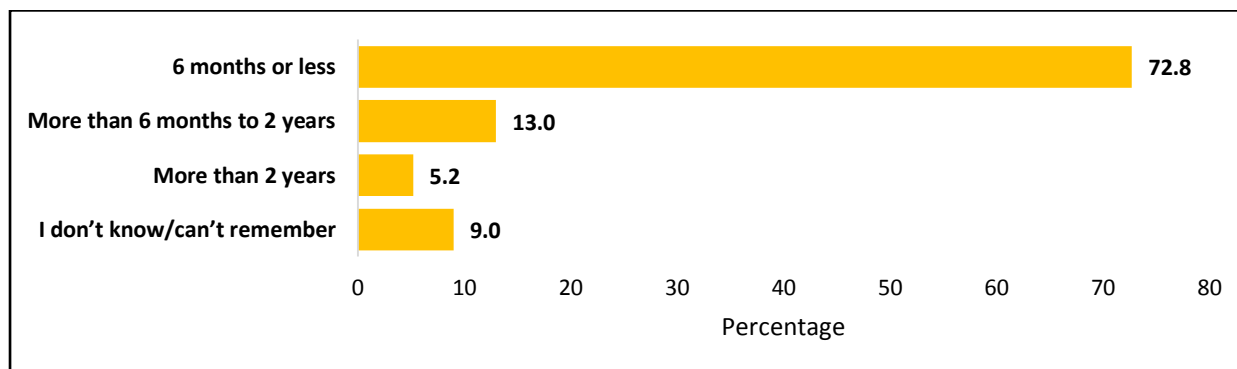
Table 4-15 Proportion of respondents to initiate HIV treatment by tested decision for HIV

How respondent decided to get tested	Have HIV treatment (n=1987)	Avoided HIV treatment (n=253)
Voluntarily	71.5	72.7
Voluntarily, but pressured by others	19.8	20.2
Without knowledge of respondent*	7.1	3.6
Forced/Compulsory*	1.6	3.6*

*Significant at p< 0.05, ** at p <0.01, and ***p< 0.001

For the majority of respondents (73%), the time interval between respondent first thought about taking HIV test and the moment they actually took the test was less than six months. About 5% of the respondents delayed the testing for more than two years (Fig. 4.22).

Fig 4-21 Proportion of respondents for the time interval between they first thought about taking HIV test and they took the test (n=2047)



Significantly higher proportion of respondents who have no formal education and tertiary level of education delayed their HIV test for six months and more. Further, 11% of respondents with university /tertiary level of education took more than two years between they first thought about taking HIV testing and they actually had the HIV test (Table 4.16).

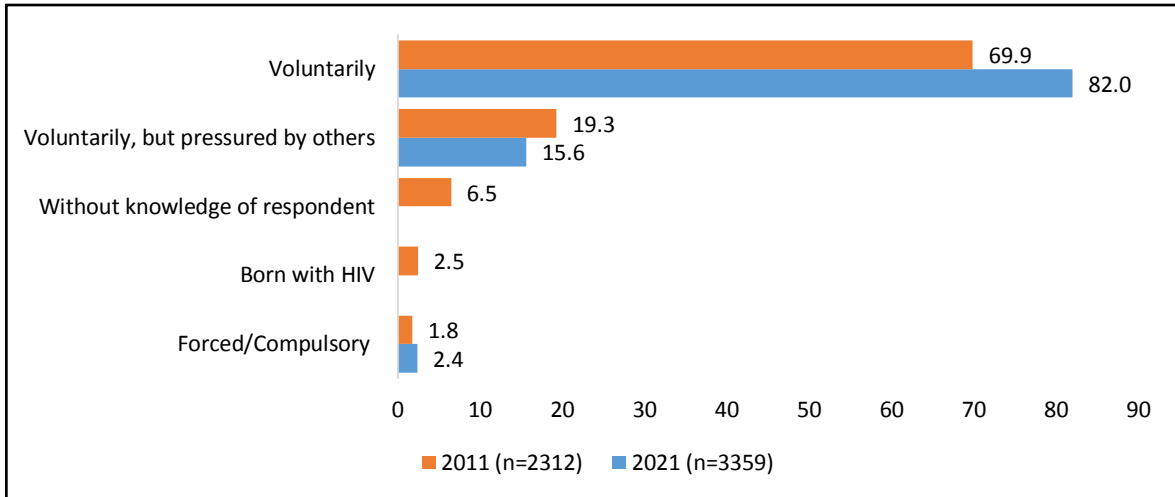
Table 4-16 Proportion of respondents for the time interval between they first thought about taking HIV test and they took the test by level of education

Time interval between thought taking HIV test and took the test	No formal education (n=662)	Elementary/ local equivalent (n=813)	Secondary/high school/ local equivalent (n=404)	Trade/ vocational (n=71)	University/ Tertiary (n=93)
Less than six months	70.2	75.8	71.5	78.9*	64.5
Six months to two years	14.4	10.9	16.2	5.6	12.9
More than two years	5.7	4.3	4.7	7.0	10.8
Do not know/ Cannot remember	9.7	9.0	7.6	8.5	11.8

There was no significant difference in time interval between the time respondent first thought about taking HIV test and they actually took the test by sex of respondent, age, period since diagnosed with HIV, belong to KP, and employment status of respondents.

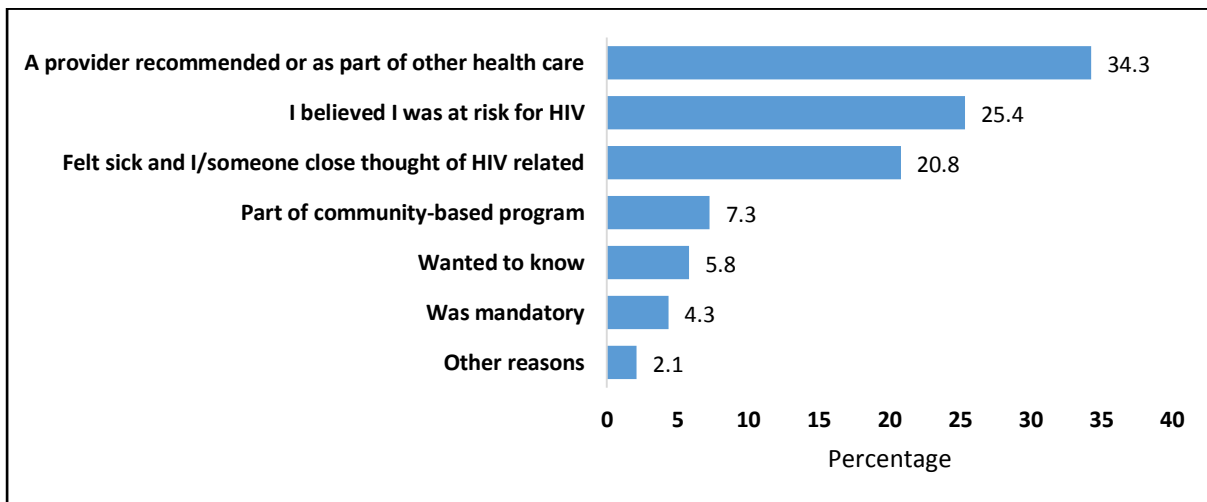
Compared with 2011 survey, the proportion of respondents who voluntarily decide to get HIV test in the 2021 survey has decreased. In the 2011 survey, about 98% of the respondents voluntarily decided (including voluntary, but pressured by others) to test for HIV compared to 89% in 2021. It was also observed that, testing without the knowledge of the respondents was about 7% in the 2021 survey, but such experience was not reported during the 2011 survey. More forced/compulsory HIV testing was reported in the 2011 survey (3%) compared to the 2021 survey (2%). Overall involuntary HIV testing increased from 2% in 2011 to 8% in 2021.

Fig. 4-22 The proportion of respondents decided to get tested for HIV by survey period



The commonly mentioned reasons for taking HIV test among respondents who got tested voluntarily or voluntary but pressured by someone were recommendation by health care provider or as part of other health care requirement (34%), followed by perceived risk for HIV infection (25%), and felt sick and respondent or someone thought it might be HIV related (21%) (Fig. 4.24).

Fig. 4-23 Main reason for HIV testing in percent (n=2047)



More respondents who do not belong to the KP (36%) took HIV tests following recommendation of health providers or as part of other health care than respondents who belong to the KP (29%) (Table 4.17). Contrary to this, the main reason for respondents who belong to the KP (31%) was perceived risk of HIV compared to those who do not belong to KP (24%). Considerable proportion of respondents who belong to KP (23%) and respondents who did not belong to KP (20%) tested for HIV after they felt sick and they/someone close to them thought it might be HIV related.

Table 4-17 Main reason for HIV testing among respondents belong to KP and not belong to KP, (%)

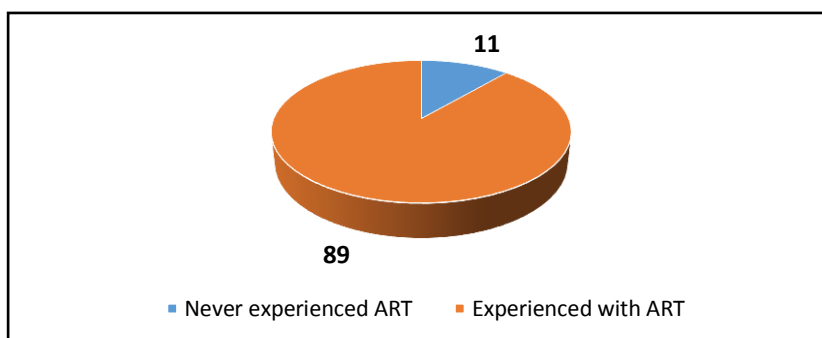
Main reason for HIV testing	Belong to KP (n=483)	Not belong to KP (n=1564)	FSWs (n=391)	PWIDs (n=72)
A provider recommended it, or as part of other health care	28.6	36.1**	28.4	27.8
I believed I was at risk for HIV	30.6**	23.7	30.9	29.2
I felt sick and I/someone close to me thought it might be HIV related	22.6	20.3	23.3	22.2
As part of or because of a community-based program	6.8	7.4	5.9	8.3
It was mandatory	3.7	4.5	3.6	4.2
I just wanted to know	6.6	5.6	7.2	5.6
Others	1.0	2.4	0.8	2.8

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$; FSWs who inject drugs were excluded from analysis for they were small in sample size (n=31)

There was no significance difference for the main reason of HIV testing by almost all background characteristics of respondents including sex, age, period since diagnosed with, educational status, and employment status of respondents.

4.5.3 Experience in HIV treatment and adherence to ART

Fig. 4-24 Proportion of respondents by their ART experience



Among all respondents, 11% had never received ART (Fig 4.25) because of refusal (spiritual), willing to start ART, but they were on pre ART and some of them were on treatment of other opportunistic infections during the interview. From the total, 4% of them were key population. Among those who have initiated ART, the majority (95%) decided to take ART voluntary (78%) were told the benefit of ART by provider and chose to start as soon as it was offered to them and 16% waited sometime after they were offered to start. Only about 5% of respondents reported they were pressured/forced by health care provider to start the HIV treatment (Table 4.18).

Table 4-18 Reason for voluntary decision to initiate ART, % (n=1986)

Reason for voluntary decision to initiate ART	Percent
They were told the benefits and chose to start as soon as it was offered to them	78.4
When treatment was offered to them, they took the decision to wait and started at a later time	16.4
They felt pressure from the healthcare staff and they forced them to start treatment	4.9
Other	0.3

Among respondents who voluntarily tested for HIV (including voluntarily, but pressured by others), about 65% were not ready to deal with their infection and hesitated or delayed their HIV testing, 57% worried about non-family, and 51% worried about how family (such as partner, family, friends), would react if they tested positive and make them hesitate and delay their HIV test. About one in four (26%) also hesitated and delayed for HIV test for the reason they were afraid health workers (doctors, nurses, staffs) would treat them badly or disclose their HIV positive status without their consent, and 13% had bad experience with health workers previously (Table 4.19).

Table 4-19 Proportion of respondents by reasons that delayed ART HIV testing (n=2047)

Reasons that delayed/prevented ART initiation	Percentage
I was not ready to deal with my HIV infection	64.6
I was worried other people (not family or friends) would find out my status	57.2
I was worried that my partner, family or friends would find out my status	51.2
I was afraid health workers (doctors, nurses, staff) would treat me badly or disclose my status without my HIV testing consent	25.6
I had a bad experience with a health worker previously	13.0

Significantly higher proportion of respondent who belong to KP (84%) chose to start as soon as the treatment was offered to them compared to those who did not belong to KP (77%). Similarly, significantly higher proportion of respondents who did not belong to KP (18%) decided to start ART at later time after the treatment was given to them compared to those who belong to KP (10%). Among respondents who belong to KP, significantly higher proportion of PWIDs (10%) were forced/pressured to initiate ART compared to FSWs (5%) (Table 4.20).

Table 4-20 Voluntary decision to initiate ART, % by belonging to KP

Voluntary decision to initiate ART	KPs			Not belong to KP (n=1543)
	FSWs (n=361)	PWID (n=62)++	KP (n=444)	
They were told the benefits and chose to start as soon as it was offered to them	87.3	66.1	83.5**	76.8
When treatment was offered to them, they took the decision to wait and started at a later time	7.2	24.2	10.1	18.2*
They felt pressure from the healthcare staff and they forced them to start treatment	5.0	9.7	5.6	4.7
Other	0.6	0.0	0.5	0.3

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$,

++ FSWs who inject drugs were excluded from the analysis for they were small in sample size (n=21)

4.5.4. Delay in initiation of ART treatment

For the purpose of this study the proportion of delayed treatment asked “Did any of the following make you hesitate, delay, or prevent you from initiating care of treatment for HIV?” From the list of five statements, if the respondent answered at least one reason as “yes” then the calculate result is defined as index of delayed ART.

Among respondents who ever started ART (excluding who were born with HIV), 75% reported delaying the start of ART. The main reason for the treatment delay was that they were not ready to deal with their HIV status (63%), feared that people who are not their family or friend would find out their status (56%), and feared that their partner. About one in four of the respondents delayed ART for they were afraid health workers (doctors, nurses, and staff) would treat them badly or disclose their status without their consent and 11% mentioned previous bad experience with a health worker as a reason for delayed ART initiation. More respondents who lived with HIV for five or less years (82%) after diagnosis delayed ART initiation compared to respondents who lived with HIV for more than five years (73%) after diagnosis for various reason (Table 4.21).

Table 4-21 Reasons for delaying ART among respondents who voluntarily tested for HIV (% who delayed)

Reasons for ART initiation delay	Years lived with HIV after diagnosis		
	Five or less years (n=543)	More than five years (n=1506)	All (n=2049)
They were not ready to deal with my HIV infection	69.4	60.8	63.1
They were worried that my partner, family or friends would find out my status	65.9	52.1	55.7
They were worried other people (not family or friends) would find out my status	59.5	46.7	50.1
They were afraid health workers (doctors, nurses, staff) would treat me badly or disclose my status without my consent	30.8	21.6	24.1
They had a bad experience with a health worker previously	12.9	10.6	11.2
Index of ART treatment delay for the reason*	81.2	73.1	75.3

*The index of delayed treatment was calculated as the proportion of respondents who chose at least one reason for delaying treatment for the question “Has any of the following forced you to delay the start of medical care and treatment for HIV?”

Among all respondents who have ever been treated, 38% initiated ART immediately/ the same day they were diagnosed, while about 62% delayed ART treatment initiation. On the other hand; significantly higher proportion (51%) of respondents who lived with HIV for five or less years after diagnosis initiated ART immediately compared to respondents who had lived with HIV more than five years after diagnosis (34%). It was also observed that higher proportion (20%) of respondents who lived more than five years with HIV after diagnosis than respondents who lived five or less years after diagnosis. About 8% of respondents who lived with HIV for five or more years after diagnosis and 4% of respondents who lived with HIV for five or less years after diagnosis delayed ART treatment for more than two years (Fig 4.22).

Table 4-22 Level of ART initiation by time of initiation

Time taken for Art initiation	Years lived with HIV after diagnosis		
	Five or less years (n=543)	More than five years (n=1506)	All (n=2049)
Immediately/the same day of diagnosed**	51.4	33.7	38.4
One day to less than a month after diagnosis	22.4	23.9	23.5
One month to 6 months after diagnosis	14.8	20.3	18.9
>6 months to 2 years after being diagnosis	5.1	9.1	8.0
>2 years after being diagnosis	3.9	8.3	7.1
I can't remember	2.4	4.7	4.1

Among all respondents, significantly higher proportion of respondents who lived five and less years with HIV after diagnosis initiated ART immediately/same day (53%) compared to respondents who lived more than five years after diagnosis (35%). Among respondents who lived 5 and less years with HIV after diagnosis and aged 18-24 years, the proportion of respondents who initiated ART immediately was significantly higher (64%) compared to all other upper age groups (range 33% to 53%) and respondents who lived 5 and more years with HIV after diagnosis (41%). Significantly lower proportion of respondents (9%) who lived 5 and less years after diagnosis initiated ART after six months of diagnosis compared to respondents who lived five and more years with HIV after diagnosis (18%) (Annex 1).

Timely/immediate initiation of ART was significantly higher among respondents who belong to KP and lived with HIV 5 and less years after diagnosis (57%) compared respondents who do not belong to KP (44%). Among the key populations, 39% FSWs who lived five and less years with HIV after diagnosis delayed ART initiation compared to 64% FSWs who lived more than 5 years with HIV after diagnosis (Annex 1).

It was also observed that delayed ART initiation increases with increasing respondent's level of education for both respondents who lived five and less years after diagnosis and those who lived five and more years with HIV after diagnosis. As shown in Table 4.24, delayed ART initiation was significantly higher among respondents who have vocational (75%) and university level of education (58%) and lived five and less years with HIV after diagnosis. ART initiation delay among respondents who lived more than five years with HIV after diagnosis is even worse for all level of education except those who have vocational education.

There was no significant difference in initiation of HIV treatment by sex and employment status of respondents.

4.5.5. HIV Treatment Interruptions

Among respondents who ever started ART 27% have skipped a dose of ART fearing that someone might learn about their HIV status within 12 months prior to the survey. The proportion of females who skipped a dose of ART was higher (28%) than males (23%); young respondents age 18 to 24 years (40%) than respondents who belong to all older age groups. Significantly higher proportion of respondent who belong to KP (32%) compared to who didn't belong to KP (25%) skipped a dose of ART in the last 12 months prior to the survey. The highest proportion of respondents who skipped ART were those who lived with HIV 4 to 9 years' after diagnosis (32%) (Table 4.23).

Table 4-23 Proportion of respondents who skipped ART in last month prior to the survey

Background characteristics	Sample size (n)	% skipped ART within last month
Sex		
Female*	1477	27.6
Male(n=572)	572	23.4
Age group		
18-24**	130	40.0
25-34	607	26.9
35-44	799	25.3
45-54	393	24.4
55 and above	120	24.2
Years lived with HIV after diagnosis		
1-3	439	27.3
4-9 ***	544	32.0
10-14	613	26.8
15 and more years	185	18.4
Do not remember	268	18.7
Belonging to KPs		
Belong to KPs **	464	31.5
FSWs	362	30.9
PWIDs	70	20.0
Do not belong to KPs	1585	25.0
All respondents	2049	26.5

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$,

FSWs who inject drug were excluded from analysis for they were small in sample size (n=32)

Among respondents who have ever initiated ART, 13% reported to have ever interrupted their ART; and 87% have never interrupted. Interruption of ART decreases with increasing age of respondents. Significantly higher proportion of the youngest age group respondent (21%) compared to the older age group (11%) ever interrupted their ART. The proportion of respondents who have ever interrupted ART range from 16% among respondents who lived 4 to 9 year after diagnosis with HIV to 9% among respondents who didn't know or remember number of years lived with HIV after diagnosis (Table 4.24)

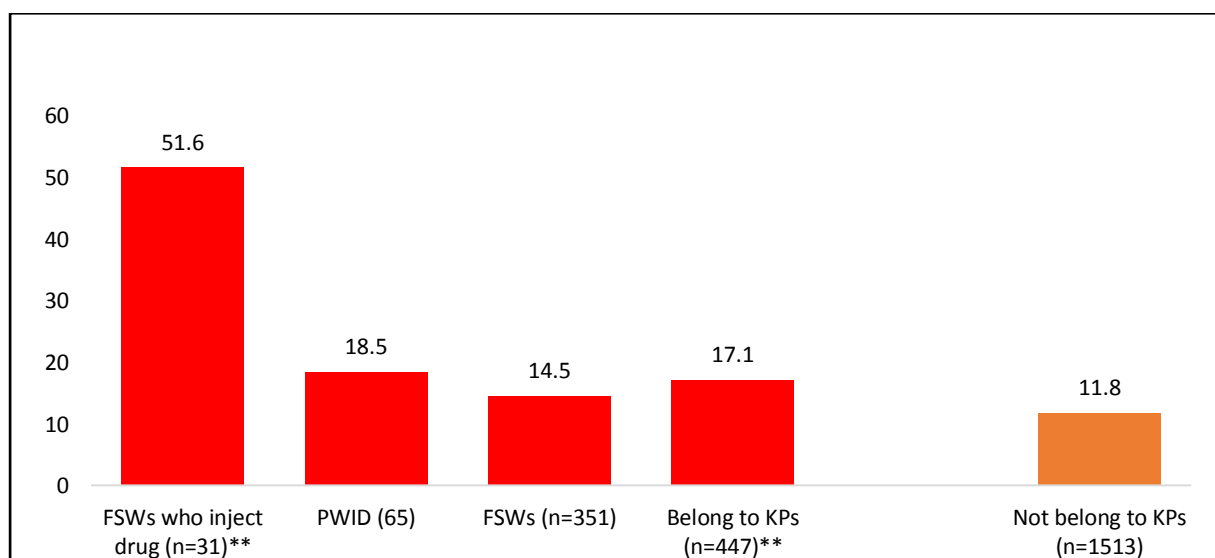
Table 4-24 Proportion of respondents who interrupted ART by background characteristics

Background characteristics	Sample (n)	Ever interrupt ART treatment
Age group		
18-24*	117	20.5*
25-34	577	15.1
35-44	775	11.5
45-54	377	12.2
55 and above	114	10.5
Years lived with HIV after diagnosis		
1-3	415	14.5
4-9 *	517	15.9*
10-14	587	12.3
15 and more years	179	11.7
Do not remember	262	8.8

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

Treatment interruption was significantly higher among respondents who belong to KP (17%) compared to those who didn't belong to KP (12%) (Fig.5.25).

Fig. 4-25 Level of ART interruption by population group



*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

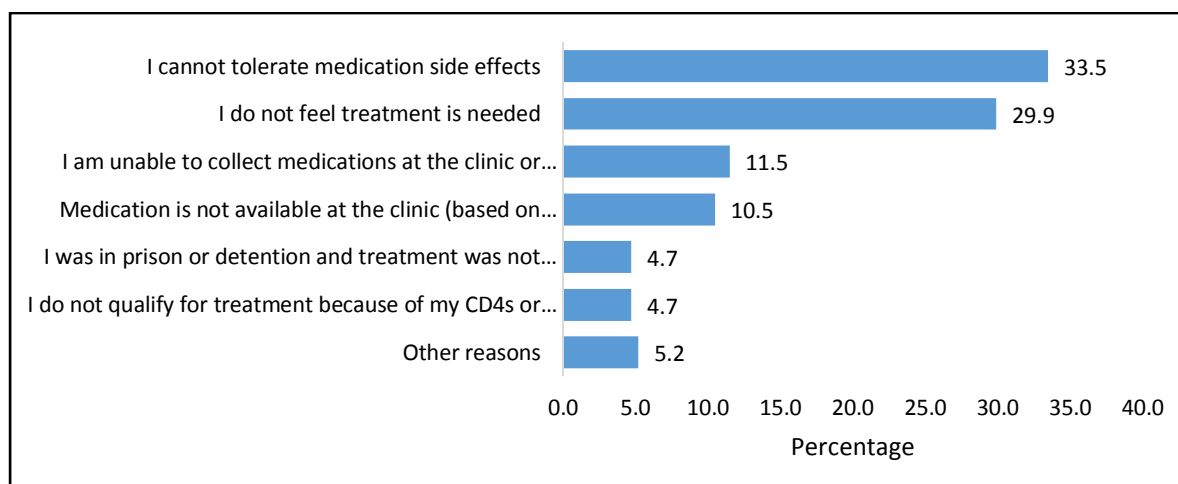
Among respondent who interrupted ART, 54% reported that they feared someone would find out their HIV status as the main reason for their ART interruption, followed by unwillingness to do anything about their HIV status (27%), and feared that health care workers would treat them badly or disclose their HIV status without their consent (8%). About 6% reported that afraid of health workers (doctors, nurses, and staff) would treat them badly or disclose their status without their consent as a reason for ART interruption. Insignificant number of respondents also reported various reasons such as thinking that they are cured, getting sick, change of place of residence, lack of food, preference to use holy water, and forgetfulness as reasons for ART treatment interruption (Table 4.25).

Table 4-25 Reasons for ART interruption, % (n=1960)

Reason for treatment interruption	Percentage
They were not ready to deal with their HIV infection	53.5
They were worried other people (not family or friends) would find out my status	27.0
They were worried that their partner, family or friends would find out their status	7.7
They were afraid health workers (doctors, nurses, staff) would treat me badly or disclose their status without their consent	5.7
Others (using holy water, lack of food, forgetfulness...etc.)	6.1

Among respondents who have ever started ART 10% interrupted ART in the last 12 months prior to the survey for reason not related to stigma. The main non stigma related reason for ART interruption were that they cannot tolerate side effect of the ART (33%); followed by the conviction that treatment was not needed (29%), unable to collect medication from health facility (11%), and unavailability of medication at health facility due to drug shift or stock outs (10%) (Fig 4.27).

Fig 4-26 Percentage of respondents who interrupted ART at the time of the survey for reason not related to stigma (n=191)



The main reasons for delaying restart of interrupted ART was unwillingness to do anything about HIV (76%); followed by fear other people who did not family or friends (71%) would found out status; and fear of partner, family and friend would found out status (62%). Overall about 82% of the respondent delayed ART restart for one or more of the reason in Table 4.26.

Table 4-26 Reasons for delaying the restart of ART, % those who delayed (n=258).

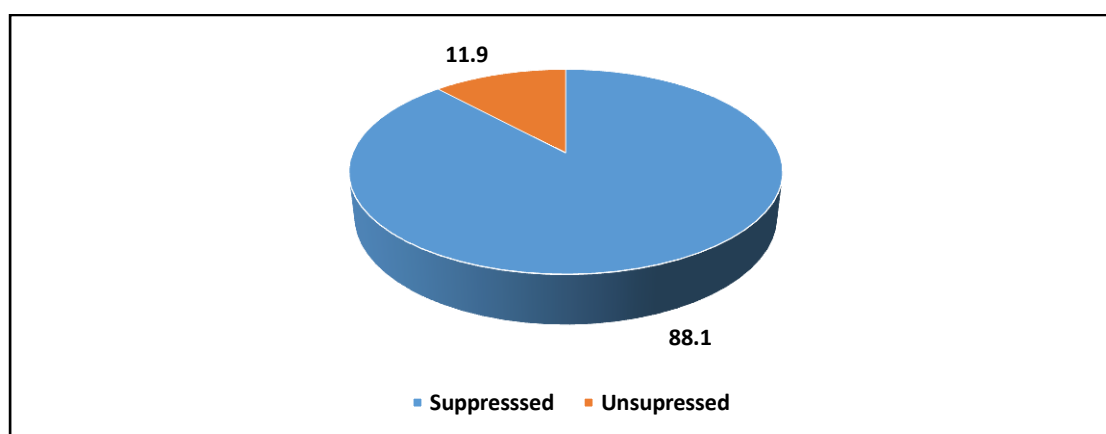
They were not ready to deal with their HIV infection	76.4
They were worried other people (not family or friends) would find out my status	70.5
They were worried that their partner, family or friends would find out their status	62.4
They were afraid health workers (doctors, nurses, staff) would treat me badly or disclose their status without their consent	36.8
They had a bad experience with a health worker previously	26.0
Index of delaying ART retreatment among who interrupted ART*	81.8

* It was calculated as the proportion of respondents who chose at least one reason in the table for delaying retreatment.

4.5.6 Viral load

Among respondents who initiated ART, about 75 % (n=1533) were tested for viral load measure and received their viral load (VL) result in the last 12 months prior to the survey. Among respondents who were tested and received their viral load results 88% reported that they had been informed about their suppressed viral load result (Fig. 4.28). Among respondents who have not had viral load result (n=516), 55% reported that they have tested for viral load in the last 12 months but waiting for the result, 25% have not had viral load test in the last 12 months, and about 16% were not tested in the last 12 months prior to the survey. About 4% of the respondents did not know what meant by viral load/viral suppression.

Fig 4-27 Level of suppressed viral load among respondents who were tested for viral load received their results (n=1533)



The level of suppressed viral load was significantly higher among females (90%) compared to males (84%). More females (18%) did not know what VL suppression means than males (13%); and more females (5%) have never had VL test compared to males (1%) (Table 4.27).

Table 4-27 Proportion of respondents according to viral load status and sex in the last 12 months prior to the survey (n=2049)

Respondents who had tested for viral load and received result	Females (n=1089)	Males (n=444)
Virus was suppressed	89.9*	83.6
Virus was unsuppressed	10.1	16.4
Respondents who have not had viral load test result	(n=388)	(n=128)
Tested for VL and they were waiting for the results	24.7	27.3
Not tested for VL in the last 12 months and received test result	52.8	59.4
Have never had VL test	4.9	0.8
I don't know what viral load or viral suppression are	17.5	12.5

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

The level of suppressed viral load was highest among respondents age 45 to 54 (91%) and lowest among respondents aged 55+ (83%). Significantly high proportion of respondents aged 18 to 24 have never had VL test (12%) compared to all other age groups (Table 4.28).

Table 4-28 Proportion of respondents according to viral load status and age in the last 12 months prior to the survey

Respondents who had tested for viral load and received result	18 to 24 years (n=89)	25 to 34 years (n=428)	35 to 44 years (n=603)	45 to 54 years (n=326=)	55+ years (n=87)
Virus was suppressed	87.6	86.7	88.1	91.4*	82.8
Virus was unsuppressed	12.4	13.3	11.9	8.6	17.2
Respondents who have not had viral load test result	(n=41)	(n=179)	(n=196)	(n=67)	(n=33)
Tested for VL and they were waiting for the results	29.3	20.1	31.1	25.4	15.2
Not tested for VL in the last 12 months and received test result	53.7	53.1	52.0	62.7	60.6
Have never had VL test	12.2*	5.0	2.6	1.5	0.0
I don't know what viral load or viral suppression are	4.8	21.8	14.3	10.4	24.2

*Significant at p< 0.05, ** at p<0.01, and ***p< 0.001

Significantly high proportion of FSWs (97%) and respondents who do not belongs to key population (90%) has their virus suppressed compared to other population groups. The highest level of unsuppressed viral load was observed among PWID (89%) compared to FSWs (3%) (Table 4.29).

Table 4-29 Percentage of respondents who reported suppressed viral load by population group (KP and not KP)

Is your viral load undetected/suppressed?	not belong to KP (n=1192)	KPs		
		Total belong to KP (n=341)	FSWs (n=270)	PWID (n=47)
Virus was suppressed **	89.5	83.0	97.0**	10.6
Virus was unsuppressed	10.5	17.0	3.0	89.4

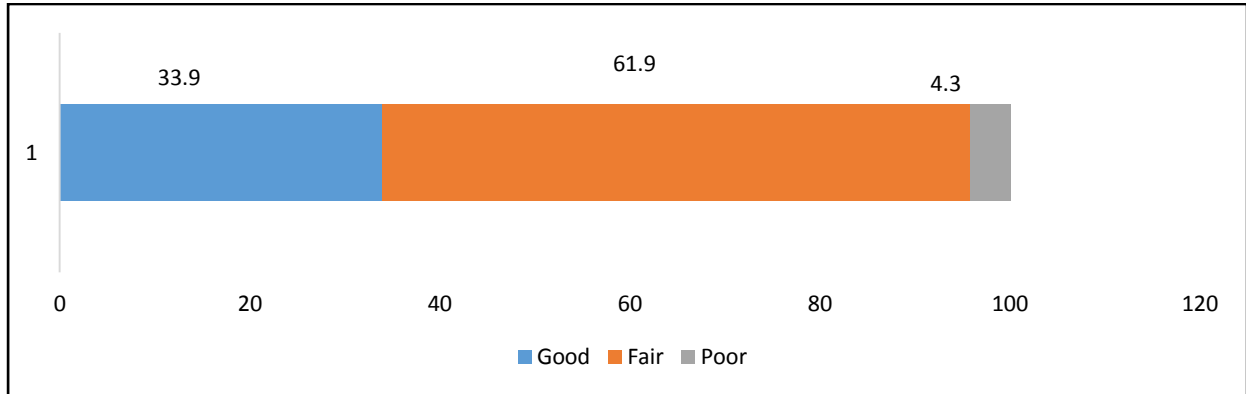
*Significant at p< 0.05, ** at p<0.01, and ***p< 0.001

Undetected viral load was not significant by years lived with HIV after diagnosis, employment status and education level.

4.5.7. General Health Status

About 34% of the respondents rated their health as good, 62% as fair and 4% as poor their health status at the moment of the interview (Fig 4.29).

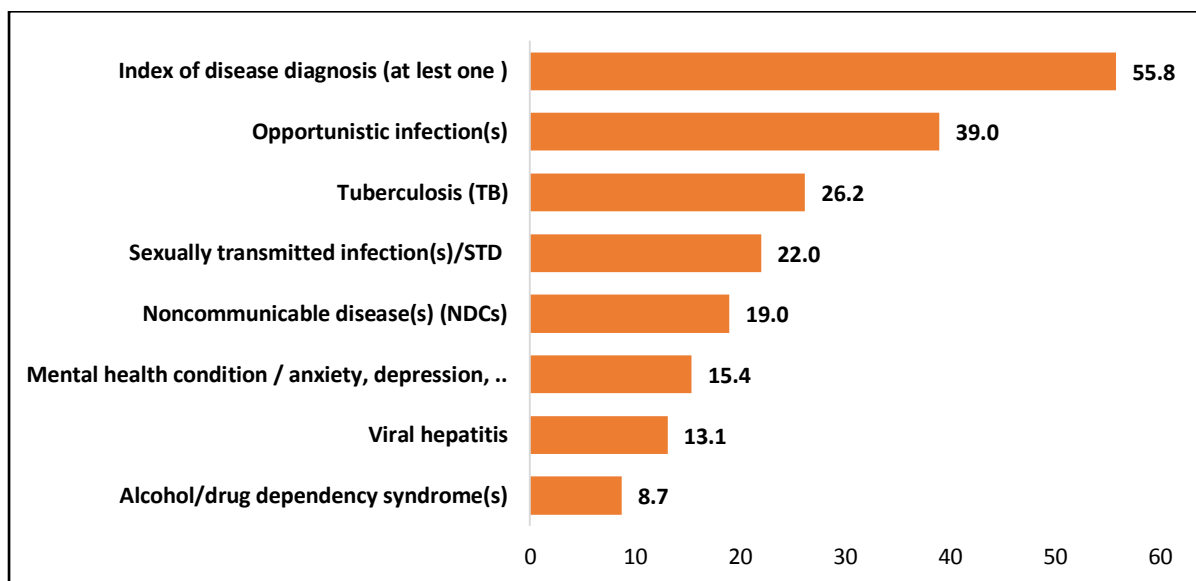
Fig. 4-28 How respondents describe their health at the moment of the survey, % (n=2312)



Despite, significant proportion of respondents described their health status as good, 56% reported that they had been diagnosed for at least one disease/ health problem in the last 12 months prior to the survey. The most common reported health problems were opportunistic infections (39%), followed by sexually transmitted infection (22%), non-communicable diseases (19%); viral hepatitis (13%), mental health condition (15%), and alcohol and drug dependency (9%) (Fig 4.30)

Nine in ten (89%) of those who had any of the disease conditions reported that they received treatment in the last 12 months prior to the survey.

Fig 4-29 Proportion of respondents who were diagnosed with disease/health problem in the last 12 months, % (n=2312)



Significantly high proportion of female respondents (59%) reported that they were diagnosed with at least one type disease health problem compared to male respondents (48%). Respondents who belong to KP (70%) reported significantly higher proportion of health

problem compared to respondents who were not KP (51%). Among the KP, FSWs reported significantly higher proportion of health problem compared to FSWs who inject drug (66%) and PWID (33%). Respondents who lived 1 to 3 years with HIV and those who lived 15+ years with HIV after diagnosis (61%) respectively reported more health problem compared to respondents who lived 4 to 9 years (55%) and 10 to 14 years (50%) after diagnosis Table 4.30).

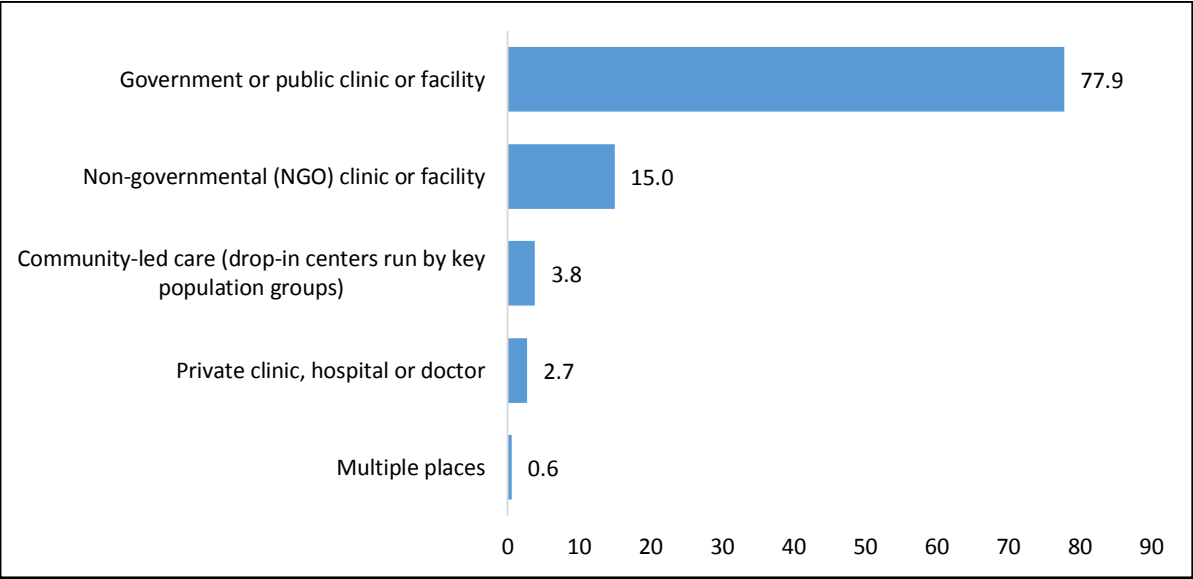
Table 4-30 Proportion of respondents who were diagnosed with disease/ health problem in the last 12 months, % by background characteristics

Background characteristics	Sample (n)	diagnosed with disease/health problem in the last 12 months
Sex***		
Female	1673	58.8
Male	639	47.9
Respondent belongs:		
Not KP	1770	51.3
KP***	542	70.3
FSW	413	78.9
PWID	91	33.0
FSW who inject drug	38	65.8
Years lived with HIV after diagnosis **		
1-3 **	507	60.6
4-9	599	55.3
10-14	678	50.3
15+ years**	202	60.9
Do not remember	326	57.4

*Significant at p< 0.05, ** at p <0.01, and ***p< 0.001

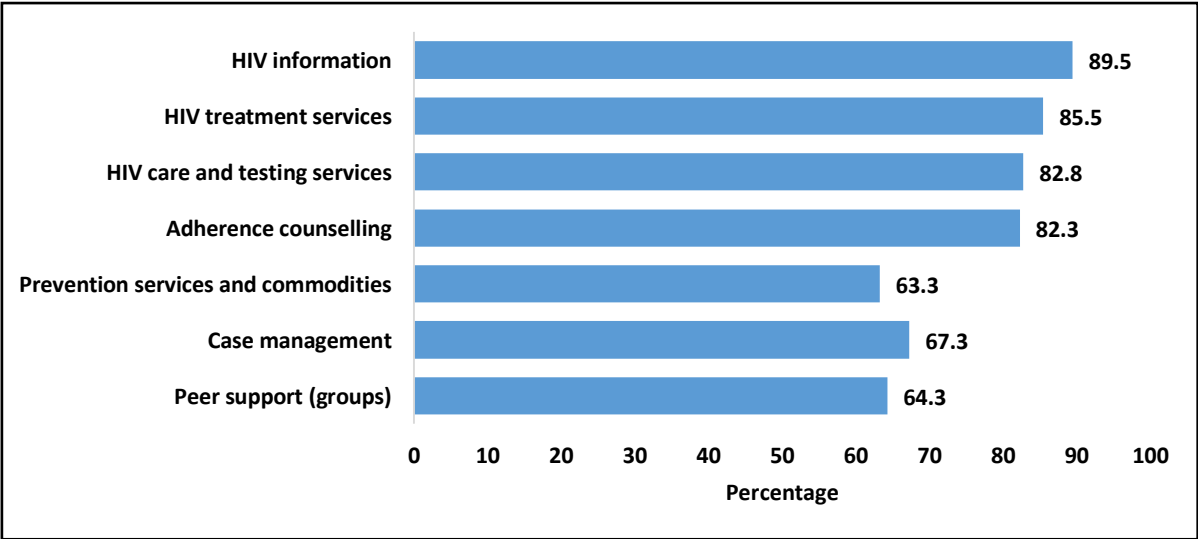
The majority of respondents (99%) said they ever received services related to HIV care and treatment, out of these 78% received the services at public health facility, followed by Non-Governmental Organization (NGO) facilities (15%). Others also mentioned using private clinic, hospital or doctor (4%), and community-led care outlets such as DICs for key population (3%) for their HIV care and treatment needs (Fig. 4.31)

Fig 4-30 Types of health facilities where PLHIV received health and HIV care and treatment, % (n=2291)



Among respondents who received HIV treatment services, about 40% knew the existence of community led clinics that can be accessed, of those only 43% reported accessed them for their HIV care and treatment needs. Among respondents who knew community led facilities that provide HIV care and treatment services, the vast majority were aware of specific services they could receive in those facilities. The vast majority were aware of the specific service they can access in the community led facilities, including HIV information (90%), ART (86%), HIV care and Testing (83%) and adherence counselling (82%) (Fig. 4.32).

Fig 4-31 Proportion of respondents who mentioned specific service provided in community based clinics, % (n=522)

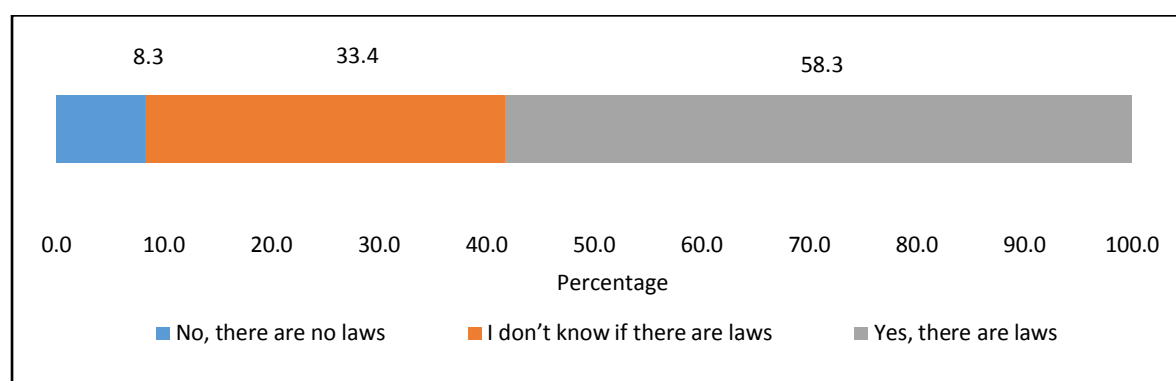


4.5.8 Human rights and changes

There are laws that include general non-discrimination provisions and provisions that mention HIV in relation to schooling, housing, employment, healthcare etc. Mandatory HIV testing for employment was strictly prohibited in the country's Labor law and civil service work place guideline¹⁰. Additionally, the Civil Service Workplace HIV/AIDS Guideline of the country protects PLHIV from discrimination by employers¹¹. The promotion and protection of human rights of people infected and affected by HIV was also explicitly mentioned in the Ethiopian HIV/AIDS policy^{12, 13}

However, the level of knowledge about the existence of laws that protect PLHIV was limited. Only 58% of the respondents were aware, and 33% were not aware of the laws (Fig.4.33)

Fig. 4-32 Level of awareness about laws that protect PLHIV against discrimination (n=2312)



There was no significance difference between female and male (58% each) respondents about awareness of laws that protect PLHIV against discrimination. However, statistically significant differences was observed by age, level of education, number of years lived with HIV after diagnosis, and belong to KP or not.

Awareness of the laws was significantly lower among people with no formal education (47%) compared to those who have elementary or above elementary (59%).

Respondents who lived 15 and more years with HIV after diagnosis were more aware of the laws (70%) compared to respondents who lived with HIV for less than 15 years after diagnosis. Respondents who didn't know years lived with HIV after diagnosis were less aware of the laws (47%) (Fig. 4.34).

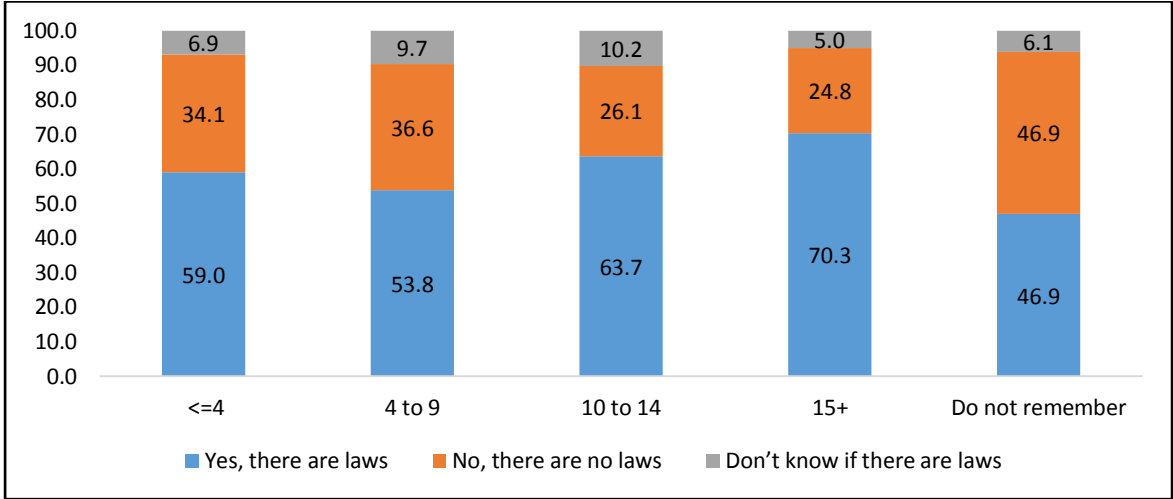
¹⁰ Ethiopian Federal Civil Servants Proclamation No. 262/2002. January 2002, Federal Negarit Gazeta,2002,1670-8

¹¹ Ethiopian Federal Civil Service Proclamation No. 515/2007. 19th February, Federal Negarit Gazeta, 2007,3540-15

¹² Federal Democratic Republic of Ethiopia, Ministry of Health: HIV/AIDS and the Health-related Millennium Development Goals: The experience in Ethiopia. 2010, Addis Ababa, Ethiopia.

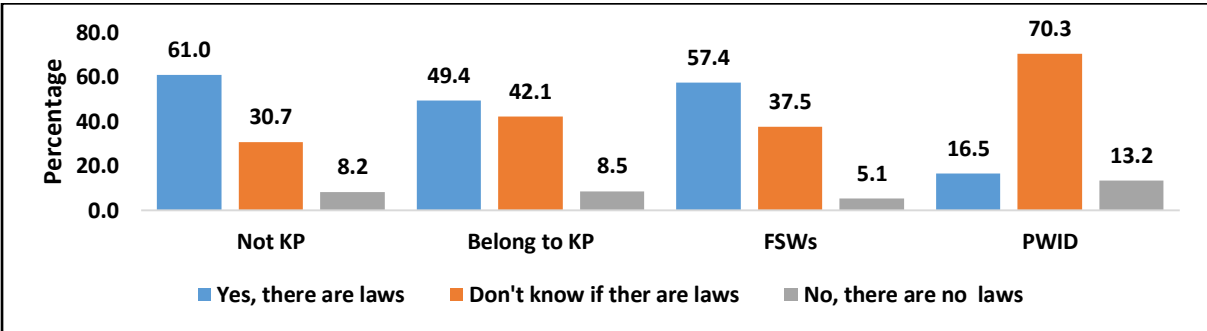
¹³ FHAPCO: Report on Progress towards Implementation of the UN Declaration of Commitment on HIV/AIDS. 2010

Fig 4-33 Level of awareness of laws that protect PLHIV against discrimination, by years lived with HIV after diagnosis (n=2312)



Higher proportion of respondents who didn't belong to KP (61%) were aware of the laws that protect PLHIV again discrimination compared to respondents who belong to KP (49%). Only about 17% of PWIDs were aware of the presence of the laws, and about 13% reported that there are no such laws (Fig 4.35).

Fig. 4-34 Level of awareness of laws that protect PLHIV against discrimination, by population group, (n=2312)



The index on the proportion of respondents who encountered violations of their rights was calculated based on the items listed in Table 4.33 (forced HIV test, HIV status disclosure and other right violation...etc.). Based on this the proportion of respondents who have encountered at least one form of right violations during 12 months prior to the survey and earlier than the last 12 months was 10 % and 11% respectively (Table 4.31).

In the 12 months prior to the survey, the most encountered violations of the rights of the respondents was forced to have HIV test or HIV status disclosure to obtain citizenship in other country (4%) or get healthcare services (3%). Other violations of right of PLHIV such as denied entry visa to other country (4%) and forced to have sex against their will (3%). Violations of the rights of PLHIV in earlier than the 12 months range from 2-4% (Table 4.31)

Table 4-31 Percentage violations of PLHIV (n=2200)

	Earlier than the last 12 months	last 12 months before the survey
Compulsory/forced HIV test or HIV status disclosure for...		
obtaining a visa, submitting documents for a residence permit/ citizenship in a country	1.0	3.7
Apply for employment get pension plan	0.7	2.7
Attending an educational institution or get a scholarship	0.7	2.2
Getting healthcare services	2.2	3.1
Getting medical insurance	0.8	2.1
Other forms of violation of the PLHIV rights caused by HIV status		
The respondent was arrested or convicted because of HIV status	0.8	2.1
The respondent was detained /quarantined because of HIV status	0.7	1.9
The respondent was denied a visa or permission to enter another country due to HIV status	0.8	3.5
The respondent was denied residency or permission to stay in a country because of his/her to HIV status	1.0	2.7
The respondent was forced to disclose his/her HIV status publicly or the status was disclosed without his/her consent	0.6	2.5
The respondent was forced to have sex against the will	1.7	2.8
index of violations of the rights of PLHIV	*10.2	*11.1

There was a differences in violation of the rights by sex of respondent, showing the violated rights of female was (11%) than male (8%) in the last 12 months prior to the survey. The violation of right for respondents who belong to KP (13%) was significantly higher than respondents who do not belong to KP (9%). Among KP respondents FSWs (14%) were the most exposed to violated rights in the last year prior to the survey (Table 4.32).

Table 4-32 Level of violations of the rights of PLHIV by background characteristics

Background characteristics	Sample (n)	Earlier than the last 12 months	Within the last 12 months
Sex			
Female	1673	10.9	11.3
Male	639	8.1	10.6
Population group			
Not belong to KP	1770	9.4	9.5
Belong to KP	542	12.7	11.3
FSW	413	13.8	9.2
PWID	91	7.7	29.7
FSW who inject drug	38	13.2	60.5

Significant at p< 0.05, ** at p <0.01, and ***p< 0.001

During the last 12 months before the survey, about 12% of PLHIV challenged or educated someone who was engaged in S&D against the respondents, and it was about 9% during the period earlier than the last 12 months of the survey. Similarly, 10% in the last 12 months prior to the survey and 11% during the period earlier than 12 months of the survey challenged or educated someone who was engaged in stigma and discrimination against other PLHIV. As part of combating S&D 10% of respondents provided emotional, financial, and other kinds of support to PLHIV who encountered S&D in the last 12 months before the survey and the period earlier than the 12 months of the survey. About 8% of respondents participated in an organization or educational campaign and the same proportion encouraged a community leader to take action to address S&D against PLHIV in the last year prior to the survey. About 5% of respondents encouraged a government leader or a politician to take action, and about 3% spoke to the media on S&D against PLHIV in the last year prior to the survey. The proportion of those who acted on the same issue earlier than the 12 months of the survey ranges from 4-7%. These were the lowest level of actions by PLHIV to counter S&D against PLHIV. The index of PLHIV counteracting S&D was found out to be 21% for the 12 months before the survey and 23% for the period earlier than the 12 months (Table 4.33)

Table 4-33 Level of counteracting stigma and discrimination against PLHIV by employment status of respondents, %

Options for counteracting	Yes, but earlier than 12 months ago	Yes, in the last 12 months
Challenged or educated someone who was engaging in S&D against them	11.7	8.6
Challenged or educated someone who was engaging in S&D against other PLHIV	10.6	9.9
Provided emotional, financial, or other support to help PLHIV deal with S&D	10.1	10.4
Participated in an organization or educational campaign working to address S&D against PLHIV	9.8	7.7
Encouraged a community leader to take action about issues of S&D against PLHIV	8.6	7.8
Encouraged a government leader or a politician to take action about issues of S&D against PLHIV	6.8	5.2
Spoke to the media about issues of S&D against PLHIV	4.2	2.6
index of combating S&D	23.4	20.5

Regarding respondent’s involvement in counteracting S&D against PLHIV related with employment status, education status and belonging to KP; about (22%) respondents who were employed/have income defended for their right compared to unemployed (17%) in the last year before the survey as well as earlier than the 12 months before the survey (25% employed; 21% unemployed defended violations of their right) . It was also observed that counteracting S&D increases with increasing level of education level. Significantly high proportion of respondents with tertiary level of education (27%) counteracted S&D compared to respondents who have no formal education (18%) in the last 12 months prior to the survey.

Respondents who belong to the KP were more likely to defend their rights. They acted more at combating S&D against them or other PLHIV (24% in the last year, and 26% earlier than the last year ago) than respondent who do not belong to KP (19% in the last year, and 22 earlier than the last ago). Among KP respondents, more FSWs acted against S&D (26%) compared to PWIDs (19%) and during the last year before the survey. However, PWIDs were more to act against S&D (65%) with who were FSW (16%) (Table 4.34).

Table 4-34 Level of counteracting stigma and discrimination against PLHIV by background characteristics

Background characteristics	Sample (n)	Earlier than the last 12 months	within the last 12 months
Employment status*			
Employed	1484	25.3	22.4
Unemployed	719	21.1	17.4*
Employment status*			
No formal education	732	16.7	18.3
Elementary local equivalent	894	23.0	21.1
Secondary/high school/local equivalent**	481	31.6	20.8
Trade/vocational	86	29.1	22.1
University/tertiary	119	29.4	26.9
Population group			
Not belong to KP	1770	22.3	19.3
Belong to KP	542	26.2	24.4
FSW	413	15.3	26.2
PWID**	91	64.8	18.7

Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$

During the 2011 survey the leading reasons prevented respondents to defend their violated right was the feeling of intimidation (26%), followed by lack of confidence whether the outcome will be successful or not (23%), problematic bureaucratic process (20%), and insufficient financial resources (19%). In the 2021 survey the leading reason was lack of knowledge where to go for action against violated right (28%). Among the other reason for refusing to take action against their violated right, insufficient financial resource (19%) during both 2011 and 2021 surveys was reported. Lack of confidence if outcome of their action will be successful was improving from 23% in 2011 to 17% in 2021. The process of bureaucratic challenge to address violated right was also improving from 20% in 2011 to 9% in 2021 (Table 4.35).

Table 4-35 Reasons that prevented from defending violated rights, % among who have faced violations of their rights in the last 12 months, but not tried to defend them

In 2011 (n =369)		In 2021 (n =47)	
Lack of confidence whether the outcome successful or not	23.3	Lack of confidence outcome will be successful	17.0
Insufficient finance resource to take action	19.0	Insufficient resource to take action	19.1
The process of addressing the problem appears to be bureaucratic	19.5	The process of addressing the problem appears to be bureaucratic	8.5
Felt too intimidated or depressed to take any actions	25.5		
		Don't know where to go or take action	27.7

4.6. Stigma and discrimination for reasons not related to the HIV status

Previous evidence showed that certain population groups are more exposed to S&D not only because of their HIV status, but also for belonging to key populations: PWID, FSW, and others. This part of the report describes S&D for reason not related to HIV, but for belonging to FSWs and PWIDs social group.

4.6.1. Female sex workers

About 20% of the overall respondents are representative of FSWs. Among the female respondents 27% reported they had ever had sex in exchange for money or other benefits.

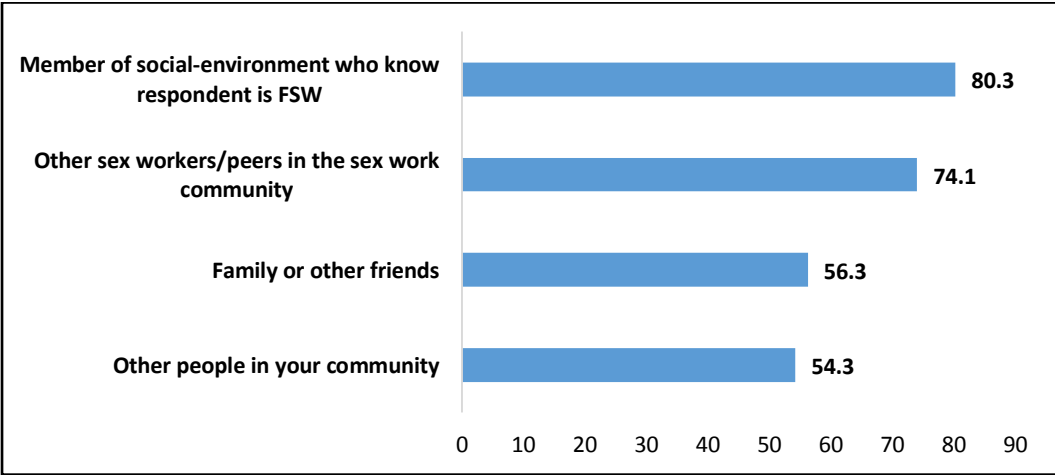
A stigma index was calculated, if FSW encountered at least one manifestation of the S&D listed in Table 4.37. About 52% of FSWs ever faced manifestation of S&D in the last 12 months prior to the survey as well as earlier than the 12 months before the survey. because they belong to FSWs social group. The most common manifestations of S&D ever encountered to FSWs were verbal harassment, and discriminatory/gossip remarks by family members (51% each respectively) and exclusion from family activities (50%). About 33% of FSWs were ever afraid to seek health service and 27% avoided seeking the service for some one will know they are sex workers (Table 4.36).

Table 4-36 Prevalence of S&D towards FSWs, % encountered S&D among FSWs (n = 451)

Stigma and discrimination acts	Yes		No	Prefer not to answer
	Earlier than the last 12 months	Within the last 12 months		
Someone ever verbally harassed you because you are (or were) a sex worker or sell (or sold) sex?	20.8	30.6	45.5	3.1
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?	23.5	27.7	46.1	2.7
You ever felt excluded from family activities because you are (or were) a sex worker or sell (or sold) sex?	25.3	25.1	46.6	3.1
Someone ever blackmailed you because you are (or were) a sex worker or sell (or sold) sex?	21.1	23.9	28.2	28.8
Someone ever physically harassed or hurt you because you are (or were) a sex worker or sell (or sold) sex?	20.4	20.2	56.3	3.1
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?	17.5	15.3	66.5	0.7
You ever avoided seeking health services because you worried someone may learn you are (or were) a sex worker or sell (or sold) sex?	17.1	10.2	71.6	1.1
Index S&D for being FSW	51.9	52.3		

As depicted Fig 4.36, 80% of FSWs reported at least one member from their social environment knew about they belonged to the FSWs group. Other sex workers are the most to know respondent was a sex worker (74%), followed by family or other friends (56%), and other people in their community (54%). About 35% of the FSWs reported that they are not belong to a network for sex worker.

Fig. 4-35 Awareness of the social environment about the belonging of respondents to the group of sex workers, % among FSWs (n=451)



4.6.2 People who injected drugs

About 6% of the respondents reported that they had experienced using injecting drugs such as heroin, cocaine, and methamphetamine. Among respondents who had experienced drug use about 70% identified themselves as PWIDs. The remaining 30% didn't identify themselves as PWIDs, the follow up question was interviewed assuming they could be identified by others.

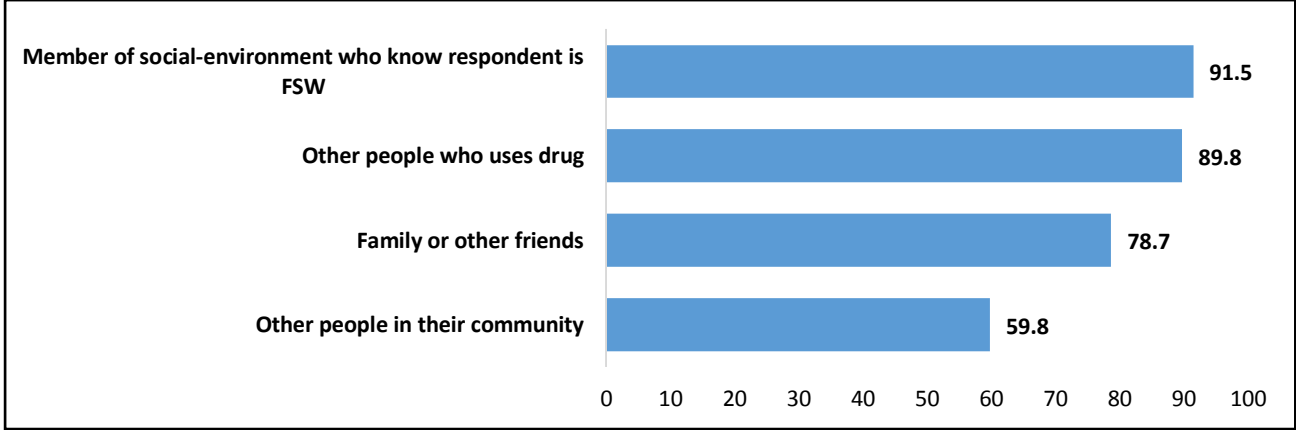
Among PWIDs 79 % reported that they had ever encountered or self-stigmatization for being PWIDs; of these 32% encountered S&D in the 12 months prior to the survey. The most common reported manifestations of S&D among PWIDs in the last 12 months and prior to the last 12 months were verbal harassment (55%) and being blackmailed (53%), fear to seek health services (46%) (Table 4.37).

Table 4-37 Prevalence of S&D towards PWIDs, % encountered S&D among FSWs (n = 129)

	Yes,		No	Prefer not to answer
	Earlier than the last 12 months	Within the last 12 months		
Someone ever verbally harassed you because you use (or used) drugs	43.4	11.6	38.8	6.2
Someone ever blackmailed you because you use (or used) drugs?	38.8	14.0	41.1	6.2
You ever felt that family members have made discriminatory remarks or gossiped about you because you use (or used) drugs?	36.4	12.4	39.5	11.6
You ever felt afraid to seek health services because you worried someone may learn you use (or used) drugs?	38	7.8	51.2	3.1
You ever felt excluded from family activities because you use (or used) drugs?	31	8.5	50.4	10.1
You ever avoided seeking health services because you worried someone may learn you use (or used) drugs?	30.2	3.9	64.3	1.6
Someone ever physically harassed or hurt you because you use (or used) drugs?	26.4	2.3	65.9	5.4
Index S&D for being PWIDs	68.2	31.8		
Index S&D for being PWIDs	79.1			

Nearly 92% of the PWIDs reported that members of the social environment knew about them that they are PWIDs. Other PWIDs (89.8%), family members or friends (79%) and other people in their community (60%) knew that they were PWIDs. About 23% of reported that they belong to a network or support group for PWID (Fig. 4.37).

Fig. 4-36 Awareness of the social environment about the belonging of respondents to the group of PWIDs, % among PWIDs (n=129)



5. CONCLUSIONS

Addressing HIV related stigma and discrimination have been recognized as one of the main facilitators for HIV prevention, care and treatment. The stigma index survey was intended to gain understanding on the level of stigma and discrimination (Internal and external) against PLHIV, how it influenced HIV status disclosure, utilization of treatment and care services, and also the resilience of PLHIV to overcome stigma and discrimination. Based on the result of the study the following conclusions were made:

- The composite index of self-discrimination for HIV status is still high and it is worse among the female PLHIV, among the younger age groups, the KPs (worse on FSWs than PWID) as well as those PLHIV who have shorter duration of life with HIV.
- Stigma and Discrimination due to HIV status is still significantly high, although it seems to be showing improvement, it is worse among the female PLHIV and the KP groups. It is also worse in Afar, Amhara and Tigray regional states.
- The rates of non-disclosure as well as non-consented disclosure are significantly high, and are worse among female than male. Both non-disclosure and disclosure without consent are high in school settings; unauthorized disclosure to social groups not close to the PLHIV has shown striking increment compared to the 2011 stigma index study reports
- Stigma and discrimination across health facilities in the 12 months prior to the survey remains high, i.e. 31.3%, while composite index of S&D by health workers against PLHIV in the area of sexual and reproductive health, solely because of their HIV status is significant, being 14%, and worse on the female, among those with lower duration of life with HIV, among PLHIV with lower level of education, as well as among PLHIV who belong to KP.
- Level of stigma and discrimination by health facility staff, regarding non-HIV service need was also found out to be high being 42% the magnitude being worse than the S & D at HIV related services.
- Involuntary/ forced HIV testing is highest among the age group 18 to 24 followed by 55 and above years of showing young and old age group respondents are facing violation of their rights compared to older age group respondents; forced/compulsory HIV testing is higher among respondents who avoided HIV treatment compared to those who are taking HIV treatment showing forced HIV testing is a push factor to avoid treatment.
- There is high rate of unemployment and failure to meet basic needs among the PLHIV. Employment is also associated with the ability of the PLHIV to defend their right compared to unemployed and positively affects viral suppression among the PLHIV.
- Significantly higher proportion of respondents who have no formal education and those who have tertiary level of education delayed their HIV test for six months and or more.
- The proportion of PLHIV who delayed to start ART once it is offered to them is high which is worse among the non-KPs than the KPs, the main reasons of delay including lack of readiness to deal with their HIV status, fear that family or friends partner,

family or friend would find out their status (50%) as well as being afraid of health workers

- Among PLHIV who have ever been treated the proportion who delayed treatment initiation significantly increases with increasing duration of life with HIV, and is higher among respondents who have vocational or university level of education (about 69%)
- Both skipping, and ever interruption of HIV treatment are worse among the female the young PLHIV of age 18 to 24 , and PLHIV who belong to KP ; besides,13% of PLHIV who ever initiated ART treatment ever interrupted their treatment.
- Interruption of ART treatment gets worse with decreasing age of respondents. With significantly higher proportion of the youngest age group, compared to the older age group respondents ever interrupted their ART.
- VL testing and rate of suppression is good, but lower among those with less duration of life with HIV, among the unemployed respondents, and those who belong to the KP; as well as among respondents of the key population; FSWs has the highest level of undetectable viral load compared to the IDUs
- Opportunistic infections followed by sexually transmitted infection, non-communicable diseases; viral hepatitis, mental health condition, and alcohol and drug dependency are commoner health problems other than HIV.
- There is lower knowledge of community level HIV services among PLHIV who had shorter life with HIV; whereas PLHIV with no formal education, and those in the non KP groups are more aware of HIV care and treatment services available in the community
- Significantly higher proportion of respondents who don't belong to KP are aware of laws that protect PLHIV again discrimination compared to respondents who belong to KP.
- composite index of violation of the rights of PLHIV during the last year and earlier than the last year was 10% and 11% respectively showing violations of the rights of PLHIV is not significantly improving over time.
- The rights of women, KPs especially FSWs are more violated than men, and the non-KPs respectively in the last year prior to the survey.
- The index of PLHIV counteracting stigma and discrimination has continued to be low, and respondents who are employed/have income are more likely to defend for their right compared to unemployed
- Respondents who belong to the KP were found out to be more experienced in defending their rights and they acted more at combating stigma and discrimination against them or other than respondent who do not belong to KP
- The stigma and discrimination among FSWs, because they are FSWs is high, showing stigma and self-stigma because of belonging to FSWs is not improving over time.
- In the same analogy, about 79% of the IUDs had the experience of S&D in the 12 months prior to the survey.

6. RECOMMENDATIONS

From the results and conclusions stated in the previous sections of this report the following recommendations are generated:

1. Advocacy and communication

- Widely disseminate findings of the study, and use them to inform the national and subnational level development of HIV multi-sectoral joint plan.
- Design strategy to involve the mass and social media, peer service providers' programs in the dissemination of messages on stigma and discrimination, as well as availability of HIV services at community and health facility levels.

2. Policy, laws and guidelines

- Design strategies to improve literacy regarding policy and legal related issues, and coordinate implementation across all levels to address issues of stigma and discrimination, human rights and HIV AIDS.
- Review the current curriculum and service delivery guideline and tools of peer education program, which includes the PLHIV, adolescents, and KPs living or not living with HIV, adequately integrating issues of stigma and discrimination, human rights, consented disclosure focusing on the female, and scale up the delivery of standardized peer support group programs accordingly, for the general PLHIV, as well as to specific groups including the KP, adolescents and youths
- The HIV multi-sectoral response needs to have guideline to address issues related to stigma and discrimination across all levels, among the PLHIV through building capacity of the PLHIV, improving and enforcing related policies and laws, creating awareness among the service providers, law enforcement sectors, as well as the media with due focus on the female, and KPs
- Design and implement guideline to enable health facilities to provide PLHIV and KP friendly HIV services which effectively address S & D and HIV related human rights issues at scale.
- Integrate human rights and stigma and discrimination related issues in the activities of community actors including the CSOs, peer groups, DICs, as well as service providers.

3. Capacity building

- Build capacity of PLHIV associations to ensure more effective coordination of peer service program, accessible to the PLHIV in collaboration with the national HIV response coordination body and other relevant stakeholders.
- Strengthen and scale up community level support groups involving the PLHIV associations, for the general PLHIV as well as specifically for the PLHIV in the KP groups
- Scale up peer support among the PLHIV across all levels so that the PLHIV shall support each other, sharing experiences among themselves, also to improve

consented disclosure, focusing on the female so that the PLHIV benefit from the positive effects of disclosure.

- Build capacity of health facility and community level HIV service providers as well as the relevant experts/teachers in schools and higher education institutes to minimize stigma and discrimination, non-consented disclosure and to improve for better support to enable the PLHIV to disclose their HIV status to whoever they prefer.

4. Prioritize specific target group for anti S&D implementations

- Scale up adolescent PLHIV friendly HIV services at community and health facility levels to address the stigma and discrimination issues related to the adolescent PLHIV, as well as other gaps of accessing HIV services.
- Assess policy and legal gaps and limitations of enforcing available laws and policies in addressing stigma and discrimination, and human rights related problems on the female PLHIV and KPs and address the policy and legal gaps accordingly.

5. Further studies

- Further studies needed on factors related to understanding reasons for high stigma and discrimination in Afar, Amhara and Tigray regional states, forced HIV testing, non-consented disclosure at schools and other social settings, delays in initiation of HIV treatment and the paradox of better defense of their rights by the KP PLHIVs versus lower knowledge regarding their rights and design strategies accordingly.

ANNEX

Annex 1: Percentage for timing of initiation of ART by background characteristics

Back ground characteristics	Lived with HIV five or less years after diagnosis Sample (n)	Lived with HIV five or more years after diagnosis Sample (n)	ART-Immediately/ same day of diagnosed		ART- from day two to less than a month after diagnosis		ART- from one to 6 months after diagnosis		ART- after 6 months of diagnosis	
			Lived Five/less years after diagnosis	Lived more than five years after diagnosis	Lived five/less years after diagnosis	Lived more than five years after diagnosis	Five/less years after diagnosis	Lived more than five years after diagnosis	Five/less years after diagnosis	Lived more than five years after diagnosis
Age										
18 to 24**	66	44	63.6	40.9	22.7	31.8	3.1	11.4	10.6	15.9
25 to 34	249	338	53.4	43.5	20.9	21.3	14.5	19.8	11.2	15.4
35 to 44	168	603	49.4	36.3	25.6	24.9	17.9	18.7	7.1	20.1
45 to 54	40	339	47.5	27.7	22.5	26.8	25	26.3	5	19.2
55+	9	109	33.3	26.6	33.3	28.4	33.4	29.4	0	15.6
Educational status/level										
No formal education**	183	436	54.1	37.6	23.5	24.8	15.8	19.7	6.6	17.9
Elementary/equivalent**	205	569	59.5	34.1	21.5	27.8	15.1	20.9	3.9	17.2
Secondary/high school/ local equivalent	104	309	43.3	36.6	23.1	19.1	11.5	23.6	22.1	20.7
Trade/ vocational	16	44	25.0	31.8	31.3	29.6	31.3	22.7	12.4	15.9
University/Tertiary	24	75	41.7	29.3	25.0	26.7	16.7	24.0	16.6	20.0
Belonging to :										
Not KP	310	1207	49.7	33.7	26.1	25.7	16.8	23.0	7.4	17.6
KP **	222	226	56.8	44.2	18.5	21.2	13.1	12.4	11.6	22.2
FSWs	191	162	61.3	35.8	19.4	25.9	12.0	14.8	7.3	23.5
PWIDs	15	50	26.6	76.0	20.0	12.0	26.7	4.0	26.7	8.0
All respondents			52.6	35.4	22.9	22.0	15.2	21.4	9.2	18.2

*Significant at $p < 0.05$, ** at $p < 0.01$, and *** $p < 0.001$; Data excluded those who did not remember time of ART initiation