



Kingdom of Eswatini

HIV STIGMA INDEX REPORT 2019



FOREWORD

The Kingdom of Eswatini is firm in its goal to eradicate stigma and discrimination in all its forms and at all levels. The results from this report reflect on the experiences and the feelings of People Living with HIV in the country. The assessment of the manifestations of stigma, discrimination and human rights violations against People Living with HIV in the Kingdom of Eswatini contributes to the efforts to generate evidence and strategic information to inform programming and ensure focused interventions at all levels.

This report is a second following the first one released in 2011. It is the work of People Living with HIV, in their diversity, across the four regions of the country. Even though there were some population groups underrepresented among those interviewed, but the report provides lessons to guide our policies and programmes on HIV and AIDS. We learn from this report that about 1 in 10 of the respondents reported to have experienced stigma and discrimination. This is a sign that we are in the right direction, but we still need to deepen our effort to end AIDS epidemic by 2022.

The country has embraced the human rights principles of equality and non-discrimination. We must stop all forms of prejudice that labels other persons as socially unacceptable. Consequently, these individuals fear they will be discriminated against or judged negatively if their HIV status is revealed and this perpetuates the transmission of HIV. Internalized stigma can lead to feelings of shame, fear of disclosure, isolation, and despair and these feelings can keep people from getting tested and treated for HIV. Stigma remains a major barrier to accessing health care and quality of life.

The vision of ending AIDS as a public health threat is upon all of us. By taking necessary action within our spheres of operation we will contribute to the national vision. The words and actions we use in our everyday life can contribute to eradicating stigma and discrimination. Let us adopt supportive behaviours and talk about HIV openly to promote a conducive environment for all. Misconceptions on HIV must be corrected to promote positive behaviour towards each other. Let us be mindful about how we talk about HIV and address People Living with HIV.

I call on People Living with HIV to take the lead in addressing stigma and discrimination and create resistance and resilience to stigma and discrimination to achieve the desired social change. Finally, I again call for renewed commitment from all stakeholders in government, civil society, communities, People Living with HIV/AIDS and the country's development partners to continue with the fight against HIV and AIDS in particular, the further reduction of stigma and discrimination. This will contribute significantly into the vision of End AIDS by 2022.



Mr Nick Jackson
CHAIRPERSON ON NERCHA COUNCIL

ACKNOWLEDGEMENTS

The National Emergency Response Council on HIV/AIDS (NERCHA) would like to thank His Majesty's Government and the people living with HIV for sanctioning the assessment of the stigma index in the Kingdom of Eswatini. The stigma index report presents a picture of the current situation in terms of stigma and discrimination among people living with HIV in the Kingdom. The evidence presented can be used to design programmes and interventions to address some challenges faced in the HIV and AIDS response.

NERCHA is grateful for the support provided by the UNAIDS Regional Support Team (RATESA) and country office led by Mr Tim Rwabuhemba. We also appreciate the efforts of people living with HIV, including Ms Lindiwe Simelane, Ms Nombulelo Simelane and Mr Gavin Khumalo.

The success of the assessment and development of the report has been through the combined efforts of the national task team which included representatives from CANGO, FLAS, SNAP, International Community of Women Living with HIV and NERCHA. The team managed the study process and provide technical guidance to ensure that expectations of the study are satisfied.

The report is also as a result of contributions and guidance by the national steering committee which included Dr. V. Magagula (MoH), Dr Carolyn Ryan (PEPFAR), Dr Nomthantazo Lukhele (WHO), Mr Khanya Mabuza (NERCHA), Mr Ian Kaayo (PLHIV), Mr Emmanuel Ndlangamangdla (CANGO) and Mr Tim Rwabuwemba (UNAIDS). The committee provided leadership policy guidance and oversight of the study process and results.

Special thanks to the consultancy and field team and the respondents who participated in the gathering of information. The contributions of the principal investigators who provided the leadership and facilitation role is duly recognised.

Lastly, I wish to recognise the commitment and passion of His Excellency the Right Honourable Prime Minister, Mr. Ambrose Mandvulo Dlamini for leading the national multisectoral and AIDS response of the Kingdom.



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ACRONYMS

AIDS	Acquired Immuno-Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARV	Antiretroviral
CANGO	Coordinating Assembly for Non-Government Organizations
CDC	Centres for Disease Control: United States of America
FGD	Focus Group Discussion
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
ICW	International Community of Women Living with HIV and AIDS
HIV	Human Immuno-Suppression Virus
IPPF	International Planned Parenthood Federation
KI	Key Informant
MIPA	Meaningful Involvement of PLHIV
MOH	Ministry of Health
NERCHA	National Emergency Response Council on HIV and AIDSs
NSF	National Multisectoral HIV and AIDS Strategic Frameworks: 2018-2023
PEPFAR	Presidential Emergency Plan For AIDS Relief: United States of America
PLHIV	People living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
PreP	Pre-Exposure Prophylaxis
SNAP	Swaziland National AIDS Program
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
SWANNEPHA	Swaziland National Network of People Living with HIV and AIDS
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS

EXECUTIVE SUMMARY

The overall objective of the Eswatini HIV stigma index survey was to determine manifestations of stigma, discrimination and human rights violations against PLHIV. The survey reached 1,136 PLHIV in April 2019. Key informant interviews were conducted with 21 stakeholders, and 8 focus group discussions were held with PLHIV. The survey was based on The People Living with HIV Index 2.0 guideline.

Of the 1,136 respondents, 827 were females and 309 were males. All age groups were equally represented, with slightly more respondents at the ages 30-34 years. About 10% of respondents were in school, and about 42% were unemployed. Some 80% of respondents were in a sexual or intimate relationship. About 30% of respondents have known their HIV status for 1-5 years, and 26% have known their HIV status for 5-10 years. Most respondents, 59% mentioned that their partners were living with HIV.

Most respondents, some 93%, mentioned that their relatives or associates know about their HIV status. However, 72% of those reported that their HIV status was disclosed to their relatives or associates without their consent. Family members were the most mentioned to be aware of the HIV status of respondents. Disclosure of HIV status was empowering for others as they mentioned that it helps them deal with guilt. However, others had fears that disclosing HIV status to few people could lead to others being aware, suggesting lack of confidentiality. About 80% of people who disclosed their HIV status received support during disclosure.

HIV related stigma and discrimination was experienced by less than 10% of the respondents in the last 12 months. The most common reported stigma and discrimination was being targets of discriminatory remarks by other people and being verbally harassed. The respondents mentioned that discriminatory remarks are through different phrases such as “BMW”, “Li A”, “ingculaza”, “lifahlawane” and “phinduvuke” which portrays PLHIV as being promiscuous, sick and unproductive. Despite, this derogatory remarks against them, PLHIV have developed internal resilience. Over 70% of the respondents mentioned that living with HIV has no effect or has made them develop positive attitudes.

About 86% of the respondents mentioned that testing for HIV was a personal choice, and 28% of those, took the test because the service provider recommended it. About 98%, of the respondents were on HIV treatment. About 42% of those, started HIV treatment immediately after testing positive. The main reason for starting HIV treatment was knowing about the benefits of HIV treatment. This was mentioned by 87% of respondents. In the self-assessment of their health status, 64% mentioned their health was good, and 32% reported that it was fair. About 67% mentioned that they did not have mental health issues in the past two weeks.

About 4% of respondents identified themselves as sex workers, 1% as injecting drug users and fewer than 1% as transgender people. Majority of injecting drug users and transgender people mentioned that they never experienced stigma and discrimination because of their identity. However, about half of the sex workers reported that they were discriminated against.

The survey concludes that HIV related stigma and discrimination is experienced by fewer people. However, discriminatory attitudes and prejudice against PLHIV exist in communities and manifests through gossip during social gatherings. Disclosure of HIV status is difficult for PLHIV. The survey provides recommendations for PLHIV, and HIV and AIDS programme implementors to plan, educate, raise awareness and implement HIV stigma sensitive programmes.

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1. BACKGROUND

Global HIV epidemic and political commitments

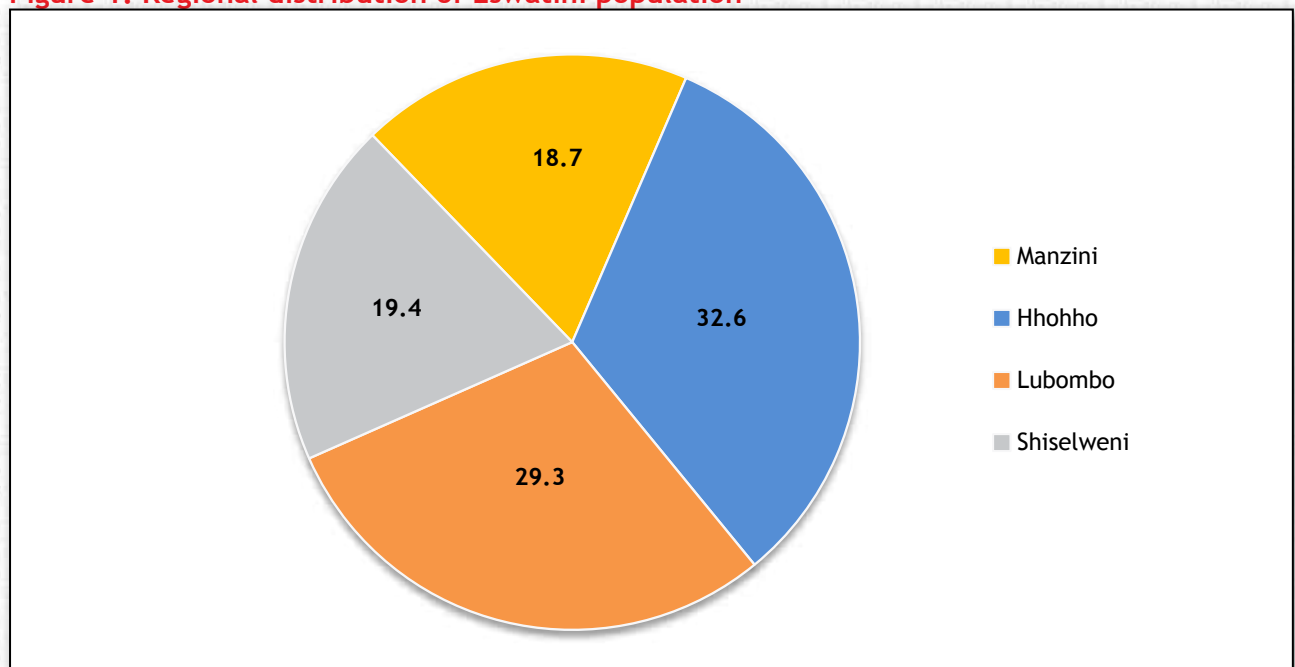
HIV and AIDS has been the most devastating epidemic in recent history. Globally, there are 37.9 million people living with HIV and annual new infections were estimated at 1.7 million (UNAIDS, 2018). AIDS-related deaths were estimated at 770 000 in 2018 (UNAIDS, 2018). The Eastern and Southern Africa (ESA) region is the epicenter of the epidemic. Almost half of new HIV infections, 800 000, occurs in the ESA region, and the region is home to over half of the people living with HIV globally (UNAIDS, 2018).

Ending AIDS by 2030 is an integral part of the Sustainable Development Goals (SDGs), which the United Nations member states adapted unanimously in 2015 (UN General Assembly, 2015). The commitment for a holistic approach to HIV and AIDS is enshrined in SDG 3: good health and well-being, SDG 5: gender equality, SDG10: Reduced inequalities, and SDG 10: Global partnerships (UN General Assembly, 2015). In 2016, the political declaration on ending AIDS by 2030 was adopted in United Nations General Assembly High-Level Meeting on Ending AIDS (UN General Assembly, 2016). The declaration commit countries to accelerate the AIDS response to end AIDS as a public health threat by 2030.

The Kingdom of Eswatini population

Eswatini has a total population of 1,093,238. Of the total population, 562,127 are females and 531,111 are males (Kingdom of Eswatini, 2017). Males form 51% of the population whilst females form 49% of the population (Kingdom of Eswatini, 2017). The country has four administrative regions, namely, Hhohho, Manzini, Lubombo, and Shiselweni. Manzini is the most populous region, followed by Hhohho (Figure 1).

Figure 1: Regional distribution of Eswatini population



HIV and AIDS in Eswatini and policy environment

HIV prevalence in Eswatini is estimated at 27%, and incidence at 1.36% (SHIMS, 2017). There are about 210 000 adults (15 years and older) living with HIV in the country (UNAIDS, 2018). About 7800 new HIV infections, and 2400 AIDS-related deaths occurred in the country in 2018 (UNAIDS, 2018). Despite, the country has made significant progress in the AIDS response. Some 84 percent of all adults living with HIV knew their HIV status, and 87 percent of those were accessing antiretroviral treatment (SHIMS 2, 2017). The total percentage of all HIV-positive adults with viral load suppression was 73 percent (SHIMS 2, 2017).

His Majesty King Mswati III has made a commitment to End AIDS epidemic by 2022, eight years ahead of the global target. This commitment is embodied in the National HIV and AIDS Strategic Framework (NSF), 2018-2023. The NSF has four targets to be achieved by 2023: reduction of HIV incidence among persons aged 15-49 years by 85%; reduction of incidence among persons aged 15-24 by 85%; reduction of new HIV infections among infants aged 0-1 year to less than 0.05%; and reduction of AIDS deaths by 50%. There are already major strides towards the realization of these targets. In 2016, Eswatini adopted the WHO guidelines for treating and preventing new HIV infections, known as 'test and start'. In 2018, the country started the transition to a more efficient and effective treatment, dolutegravir (DTG).

HIV stigma and discrimination

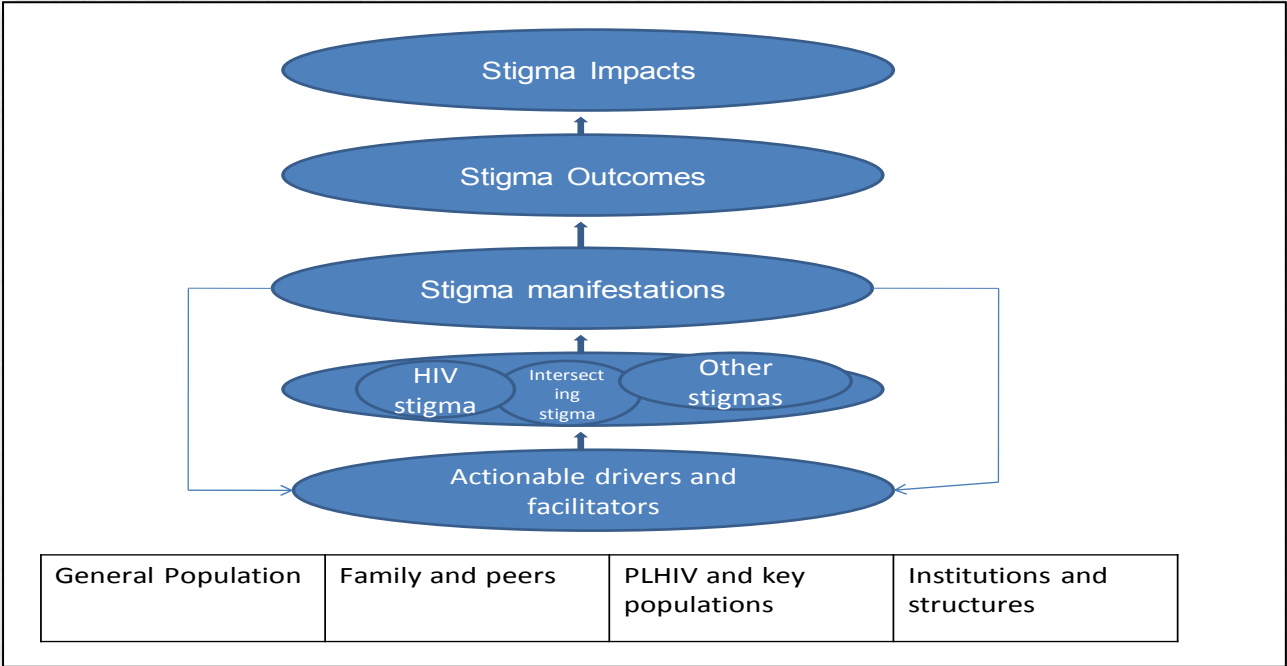
HIV related stigma and discrimination is a process of devaluation of people either living or associated with HIV and AIDS (UNAIDS, 2003). The effects of stigma and discrimination are largely negative and grossly affect the quality of life of PLHIV (ibid). The most common indicators of stigma and discrimination include rejection, isolation, moral judgments, self-exclusion and human rights violations. HIV related stigma and discrimination hinders access to prevention, treatment, care and support services. Among people living with HIV related stigma and discrimination contributes to late disclosure of HIV status and initiation on treatment as well as adherence to treatment.

HIV related stigma often builds upon and reinforces other existing prejudices, including those related to gender, sexuality and race (UNAIDS Factsheet, 2003). Efforts to address HIV related stigma and discrimination is undermined by the stigma associated with AIDS - as a non-curable disease. The stigma associated with HIV is also linked to already marginalized and stigmatized behaviors, which include sex work, drug use and transgender sexual practices (UNAIDS Factsheet, 2003).

HIV related stigma and discrimination take different forms and manifest at societal, community and individual levels: societal level stigma and discriminations manifest in the form of laws, policies, and administrative procedures, which are often justified as necessary to protect the general population. At the community level it presents in a form of cultural systems that promote individualism which may perceive contracting HIV as a result of personal irresponsibility, and thus individuals are blamed for contracting the infection. At individual level stigma and discrimination is accompanied by fear of being castigated which forces PLHIV to isolate themselves from seeking and/or accessing health services and support (Tomaszewski, 2012; Mbatha, 2013).

Figure 2 demonstrates the intricate relationship between the drivers of stigma, how it manifests itself and its outcomes as well as its impact in the general population, at family level among PLHIV and key populations, as well at institutional and structural levels (Stangl et al, 2012).

Figure 2: Reducing stigma and discrimination: A Framework for program implementation and measurement



The fear of casual transmission and perceptions of people living with HIV as being less productive have exposed people living with HIV to numerous social exclusions and oppressions. The negative social labels create a negative perception of self for people living with HIV and result in social withdrawal and self-exclusion. Stigma and discrimination experienced within community settings forces people living with HIV to seek health services in distant places where they are not known.

Justification of the Survey

The Kingdom of Eswatini is committed to ending AIDS as a public health threat by 2022. HIV stigma and discrimination is outlined as one of the key drivers of the epidemic in the country. Therefore, the country prioritizes efforts to eliminate HIV related stigma and discrimination. Eswatini last conducted an HIV stigma index Survey in 2011. Since then, there has been limited effort to document the experiences of stigma and discrimination among PLHIV. HIV Stigma Index Survey is an effective advocacy tool which supports the collective goal of the government, the health care delivery system, and civil society to reduce the stigma and discrimination linked to HIV and AIDS.

The HIV stigma index survey provides basis for programmatic adjustments of support provided to PLHIV in Eswatini. The survey will also inform policy and program improvements in health care delivery. The findings provide valuable insights into areas that need to be focused on or improved in programming of care and support for PLHIV. HIV Stigma Index survey is a voice of PLHIV as it articulates their experiences and their support needs.

2. OBJECTIVES OF HIV STIGMA INDEX SURVEY

The purpose of this survey is to join the global action in reducing stigma and discrimination related to HIV and AIDS through the creation of a supportive stigma reduction framework that will inform HIV and AIDS policy, advocacy and programming. The overall objective is to determine manifestations of stigma, discrimination and human rights violations against PLHIV in the Kingdom of Eswatini. The secondary objectives include:

- i. To measure where and when stigma and discrimination against people living with HIV and AIDS occurs;
- ii. To measure stigma and discrimination and its impact on the response to HIV especially disclosure and treatment;
- iii. To identify promising approaches to stigma and discrimination that can be taken to scale to achieve sufficient impact across the country;
- iv. To generate evidence and identify gaps in HIV programs that may fuel stigma and discrimination;
- v. To assess and document the experiences of PLHIV in general and key populations living with HIV, regarding stigma and discrimination; and
- vi. To profile PLHIV on matters related to human rights.

3. METHODOLOGY

Design

Eswatini HIV Stigma Index survey applied a mix-method approach combining both quantitative and qualitative methods. The quantitative method was a structured survey with the sample of PLHIV. The qualitative approach was implemented through Focus Group discussions (FGDs) with PLHIV and key informant interviews (KIs) with individuals representing stakeholder organizations, formations or constituencies.

Population

Participants of the HIV Stigma Index survey were adults PLHIV (18 years and older) in the four regions of the Kingdom of Eswatini. The survey reached stakeholder groups at national, regional and community levels as key informants.

Sample size and sampling

The survey sample was determined using Kish Leslie (1965) formula. The formula is used to calculate sample sizes for descriptive studies. It is denoted by:

$$n = (Z^2 \times p \times q \times de/d^2) \text{ or } n = (Z^2 pq/d^2) \times de$$

Where: n = sample size for PLHIV to be interviewed; Z = Z score corresponding to 95% level of significance is 1.96; p = Estimated national HIV prevalence (27%); $q = 1 - p$; d = absolute precision of 0.10; de = design effect of 1.5 used to account for heterogeneity in assessment population. The calculated sample size was, therefore, 425 participants. The sample size was adjusted to account for incomplete entries, and to sufficiently reach certain population groups. The sample size was increased to achieve sufficient representation of young people (18-24 years), sex workers, MSM, LGBTIs, and people living with disability. The total estimated sample size was 1 200 participants.

Some participants who completed a survey questionnaire were selected and invited for the FGDs. Their selection for FGDs was based on demographics, and self-identification as belonging to a certain population; for example, young people (18-24 years), LGBTI, and sex workers.

KIs participants were purposively selected from the list of organizations, formations or constituencies identified by the technical committee. KIs at regional level were identified during fieldwork. For example, health care workers were identified and selected during a visit to health care facilities for survey recruitment and interviews.

Inclusion and exclusion criteria

All PLHIV aged 18 years and above in the Kingdom of Eswatini were eligible. PLHIV below the age of 18 years were excluded for ethical reasons, as their participation would require consent from parents or guardians. PLHIV younger than 18 years were excluded also due to lack of capacity to provide support in the event of distress or other psychosocial needs. Key informants were included based on their roles in the organization or institution of affiliation and their roles in the representation of certain population groups in communities.

Participants recruitment

Participants were recruited from the health care facilities, and through individual referrals among members of the network of PLHIV. The individual referrals created a snowballing effect resulting in more people being reached even beyond those belonging to the network of PLHIV. Participants were recruited from all four regions of the country; namely, Hhohho, Manzini, Lubombo and Shiselweni. The survey reached 1, 136 participants. FGDs participants were recruited from those who completed survey interviews.

Data collectors confirmed appointments for the FGDs by telephone. The technical team provided support in securing appointments with key informants at the national level. Key informants in the regions were recruited by Field Supervisors during fieldwork.

Data collection

Survey data was collected through a self-administered paper questionnaire or tool. The survey questionnaire was adopted from The People Living with HIV Index 2.0. The questionnaire was translated into local language, siswati. Individual participants completed questionnaires and had an opportunity to ask questions and to discuss their observations with the Data Collector during the process. The survey interviews lasted for about an hour on average. Completed questionnaires were collected by a Field Supervisor for quality check and storage. Survey data was captured using an excel tool developed by GNP+.

FGDs and KIIs were conducted by the consultant and a Field Supervisor using interview guides. FGDs were on average an hour long, and KIIs about forty-five minutes long. Twenty-one KIIs and 8 FGDs were conducted (Table 1). Notes from the FGDs and KIIs were transcribed and stored in a word format.

Table 1: The number of KIIs and FGDs

Region	KII	FGDs
Hhohho	1	2
Shiselweni	1	2
Manzini	2	2
Lubombo	3	2
National level	14	
Total	21	8

Data management and analysis

Survey dataset was imported into SPSS for cleaning and analysis. Data cleaning and analysis was performed using SPSS. Checks for outliers and consistency of responses was performed for all variables. Frequencies were generated from individual variables and results are presented in tables and figures. Cross-tabulations were performed for some variables, mainly tabulated against age, sex and region variables. Composite variables were created by combining responses of some variables in order to determine the common trends on certain thematic areas.

FGDs and KIIs transcripts were imported into Nvivo11 for coding and analysis. Themes were pre-defined using the results from the survey as a guidance. The findings from FGDs and KIIs were integrated in the results of the survey. The findings are complimentary, in support or contrast, to the results from the survey. Selected quotes are included in the findings to illustrate the views and perceptions of the respondents.

Quality Control

The Eswatini HIV Stigma Index survey governing body, the steering committee, provided leadership and oversight for quality assurance. The technical committee provided technical guidance during the preparation of the research protocol, fieldwork, data analysis and report writing. The technical committee reviewed all technical outputs including the report to ensure technical strength and quality. The assignment was led by a consultant with skills and experience in HIV Stigma Index guidelines and tools.

Data collectors and data capturers were trained in quantitative and qualitative data collection. The consultant trained Data Collectors and Field Supervisors on HIV Stigma Index guideline and tools, discrimination, and human rights to ensure their competence. In consistence with the GIPA/MIPA principle, the data collectors were persons openly living with HIV and AIDS. Data collectors were supported by a supervisor for purposes of quality control. At the end of each day of data collection, supervisors would collect completed questionnaires to check for completeness and errors. Quality control observations were discussed with the consultant (team leader). Data collectors and supervisors were continually trained on quality control measures during debriefing meetings. Data quality check included detection and decisions on outliers, duplicates and incomplete entries.

Ethical considerations

Informed consent

Participation was voluntary, and all participants provided informed consent before interviews. HIV Stigma Index tools including information sheet, consent forms, questionnaire and interview guides were translated into local language, Siswati, for ease of reference and understanding by all participants. An information sheet was generated and provided to all potential participants with the contact details of the team leader - in case participants had any questions during or after an interview. Participants were informed about the participation process and the intended use of the information. All those who agreed to participate were requested to provide consent by signing a consent form. Participants were informed that their personal identifiers will be removed during data analysis, and that their responses will be combined with those of other participants. Interviewers were trained on how to identify and make referrals for participants who may need further support.

Confidentiality

Confidentiality forms were signed by all interviewers and members of the technical team who had access to participants information and identifiers. Confidentiality forms confirm obligations of data handlers to the principles of confidentiality or nondisclosure of information which may place participants at risk of any form. Interviews were conducted in venues selected by participants - and effort was made to ensure privacy. Participants information, including identifiers, was never communicated beyond individuals who signed confidentiality forms. Completed questionnaires were kept in the locked cabinet. Personal identifiers were removed during data capturing, and subsequently in the dataset.

Ethics approval

The Eswatini Stigma Index protocol was submitted to the Ministry of Health Research Ethics committee. The protocol was approved on the 29th January 2019. The Eswatini Stigma Index protocol reference number is No SHR058/2018.

Guiding principles

Eswatini HIV Stigma Index was conducted under the guidance of the broad philosophy of greater involvement and meaningful involvement of people living with HIV and AIDS (GIPA/MIPA). The other principles included respect for all involved, inclusion, trust, honesty and openness, compassion, shared responsibility and strict obligation by the survey teams, and fairness and justice to the participants.

4. RESULTS AND FINDINGS

Demographic characteristics of the respondents

Eswatini HIV stigma Index survey reached a total of 1,136 respondents. The survey reached more females than males - with a total of 827 female respondents compared to 309 male respondents. There were more respondents from Manzini than any other region (Table 2) .

Table 2: Distribution of respondents by region and sex

Region	Female		Male		Total	
	n	%	n	%	n	%
Hhohho	198	65.3	105	34.7	303	26.7
Lubombo	180	77.3	53	22.7	233	20.5
Manzini	280	73.9	99	26.1	379	33.4
Shiselweni	169	76.5	52	23.5	221	19.5
Total	827	72.8	309	27.2	1,136	100

Table 3 below shows the distribution of respondents by age and sex. The age distribution of respondents is even across the different age groups, but with a slightly more respondents at ages 30-34 and 50+ years. Females are more than males across all age groups. The survey has more females 25-29 years than any other group.

Table 3: Distribution of respondents by age and sex

Age (years)	Female		Male		Total	
	n	%	n	%	n	%
<25	116	81.69	26	18.31	142	12.51
25-29	124	84.35	23	15.65	147	12.95
30-34	151	81.62	34	18.38	185	16.30
35-39	119	71.69	47	28.31	166	14.63
40-44	111	67.27	54	32.73	165	14.54
45-49	75	65.22	40	34.78	115	10.13
50+	130	60.47	85	39.53	215	18.94

Table 4 shows the socioeconomic status of respondents. Only 10% of respondents were currently in school. Almost half, 48%, of the respondents attained secondary or high school education (table 3). About 30% had primary school education. There were 11% of respondents who had no formal education. About the same number, 10%, had trade or vocation school or tertiary education. Some 42% of the respondents were unemployed. About 18% of the respondents were employed full-time. The levels of poverty were probed through an inability to meet their basic needs such as food, clothing and housing. About 8% reported that they were not able to meet their basic needs most of the time. Slightly more than half the respondents were not able to meet their basic needs most of the time (table 4). Only 42% reported that they were able to meet their basic needs all the time.

Table 4: Socioeconomic status

Currently in school	n	%
Yes	99	8.7
No	1,035	91.3
Total	1,134	100
No formal education		
Primarily/elementary school	343	30.3
Secondary/high school	546	48.2
Trade/vocational school	20	1.8
University/tertiary education	92	8.1
Total	1,132	100
Employment status		
Part-time employment	99	8.8
Casual or part-time work	161	14.2
Full-time self employed	177	15.7
Full-time employee	213	18.8
Unemployed	480	42.5
Total	1,130	100
Inability to meet basic needs		
Most of the time	91	8.1
Never	465	41.2
Some of the time	574	50.8
Total	1,130	100

Among the respondents, about 10% reported that there were no children in their household. About 73% reported that there were 1-5 children living in their household. Only slightly more than 1% had more than 10 children living in their household.

Table 5: Number of children in the household

	n	%
None	110	10.1
1-5	796	73.3
6-10	165	15.2
More than 10	15	1.4
Total	1,086	100

Table 6 below shows the relationship status of respondents. About 80% mentioned they were currently in an intimate relationship, and the other 20% were not in a relationship.

Table 6: Sexual Relationship Status

Currently in relationship	n	%
Yes	897	79.5
No	231	20.5
Total	1,128	100

Table 7 below shows the duration in which respondents were aware of their HIV status and the responses about the HIV status of their partners. Majority of respondents have known their HIV status for a period between one and five years (table 7). About 9% of respondents have known their HIV status for less than a year, whereas, 6% have known their HIV status for more than 15 years. About 59% reported that their partners were HIV positive, and 21% that their partners were not HIV positive (table 7).

Table 7: Duration of knowing HIV status

Duration of knowing HIV Status	n	%
Less than 1 year	97	8.5
1 - 5 years	348	30.6
6 - 10 years	299	26.3
11 - 15 years	145	12.8
More than 15 years	73	6.4
Do not remember	174	15.3
Total	1,136	100
HIV status of partners	n	%
Partner (s) not HIV positive	185	21.1
Don't know HIV status of partner (s)	175	19.9
Partner (s) HIV positive	518	59.0
Total	878	100

About 79% of the respondents reported to be members of the racial, ethnic or religious minority. About 11% were living with a disability (vision, hearing, mobility, intellectual/developmental) of any kind (other than HIV), 11% were refugees or asylum seekers, and 12% were migrant workers. About 10% reported that they were internally displaced, and 11% reported that they have been incarcerated before.

Table 8 below shows that 28% of respondents were members of the network of people living with HIV. Most of the members of the network or support group of people living with HIV were below the age of 25 years or over the age of 45 years. Among females, 30% were members of the network or support group of people living with HIV. Among males, about 22% were members of the network or support group of people living with HIV.

Table 8: Member of the network or support group of people living with HIV by age groups

	<25	25-29	30-34	35-39	40-44	45-49	50+	Total
Yes	37.1	21.2	19.1	23.1	28.1	32.7	37.2	28.3
No	62.9	78.8	80.9	76.9	71.9	67.3	62.8	71.7

Disclosure of HIV status

Table 9 below provides responses on HIV disclosure. Respondents were asked if close associates were aware of their HIV positive status and whether consent was granted. About 93% of the respondents reported that their HIV status is known by at least one of their relatives or associates. Among those, 72% mentioned that their HIV status was disclosed without their consent. These findings are collaborated by KIs who indicated that some of the major reasons why PLHIV find it difficult to disclose their HIV status was fear of being called insulting names and being ill-treated. “Not many people disclose their HIV status to others especially sexual partners. This is because of a fear of the unknown,” (Policymaker, National level).

Table 9: Disclosure of HIV status to relation or associates

Relation/associates	Yes		No		Not Applicable		Total	Disclosure without consent	
	N	%	N	%	N	%	Total	N	%
Other family members	884	78.2	236	20.9	11	1.0	1,131	512	57.9
Spouse	857	75.7	181	16.0	94	8.3	1,132	489	57.1
Children	656	58.2	369	32.7	103	9.1	1,128	357	54.4
Friends	654	57.9	453	40.1	22	1.9	1,129	365	55.8
Neighbours	458	40.7	628	55.8	40	3.6	1,126	253	55.2
Employers	227	20.1	469	41.5	435	38.5	1,131	157	69.2
Community leaders	188	16.6	726	64.2	217	19.7	1,131	105	55.9
Co-workers	172	15.2	497	43.9	462	40.8	1,131	101	58.7
Classmates	48	4.3	421	37.4	658	58.4	1,127	43	89.6
Teachers	46	4.1	432	38.3	650	57.6	1,128	44	95.7

About 76% of respondents disclosed their HIV status to their spouses, 78% disclosed their HIV status to other family member and 58% of respondents have disclosed their HIV status to their children. Only 15% respondents disclosed their HIV status to their colleagues. Fewer respondents, 8.4% disclosed their HIV status the classmates and teachers. Among the people whose spouses or family member became aware of their HIV status, 57% mentioned their HIV status was disclosed without their consent. Among those who mentioned that their teachers or classmates became aware of their HIV status, over 95% reported that their HIV status was disclosed without their consent. Among the 20% respondents whose employers became aware of their HIV status, some 69% reported that their HIV status was disclosed without their consent.

The findings from focus group shows that PLHIV disclose their HIV status to their family members - parents, children, and other extended family members. Respondents add that disclosure of HIV reduces the feelings of regret and guilt. One respondent mentioned “*It helps in dealing with guilt associated with HIV by disclosing to family members*” (Female PLHIV, Lubombo Region).

However, respondents felt that disclosure of HIV status to many people could lead to many other people being aware of the person’s HIV status. “*This is a small country where most people are either related or are known to each other, and the risk of information landing in the hands of a family member is so high, and one is not sure of their reaction*” (PLHIV leader, national level). This quote also highlights the fear to openly live with HIV, and the preference to keep disclosure of HIV status to only close associates - such as family members.

The fears of openly living with HIV manifests through the secrecy on HIV status of children, and eventually, non-disclosure of HIV status by parents to their children. A key informant mentioned “*At family level, there are many situations of silence, where “the young people are given medicines, yet no one explains why they have to take medicines”* (Program Implementer, National level). The parents’ secrecy to HIV treatment for their children is triggered by fear that teachers will eventually be aware of the HIV status of their children and will disclose to other learners.

Key informants suggest that PLHIV disclose their HIV status to people they trust and those who could support them. “*People tend to disclose to those that they think will not judge them*” (Faith leader, National level). The perceived HIV stigma and discrimination prevents PLHIV from disclosing their HIV status to other people than those they could trust. Focus group respondents mentioned that PLHIV are labeled with names which reinforces discriminatory tones towards them. PLHIV are referred to as “*batista*” or “*wrestlers*” who build muscle by taking ARVs; or BMWs, a gesture used to depicts PLHIV as promiscuous people who changes sexual partners like fast-moving cars; or “*silwane*” (wild animals), “*lollipops*” (sweets on sticks) referring to the changes in appearance of some PLHIV as result of ARVs.

Other KIs indicated that at social gatherings such as funerals, there are people who still feel uncomfortable having PLHIV getting involved in preparing food. Other people discriminate against PLHIV because they feel they will contract HIV by coming to close to contact with them. In the focus group it was mentioned “*Others feel uncomfortable when I play with their children, they fear that I can infect them,*” (Female PLHIV, Shiselweni Region).

Experience with disclosure of one’s HIV positive status

Disclosure of HIV status could lead to different experiences by PLHIV. Table 10 below captures summaries of experience with disclosure of HIV status. Most respondents reported a positive experience with disclosure of their HIV positive status. About 80% of the respondents reported to have received support after disclosure. Similarly, 78% of the respondents reported that close associates were supportive when they got to know their HIV positive status. About 51% of the respondents reported that disclosure to non-close people had not been a positive experience. Despite, there were about 9% of the respondents who reported that disclosure to close people had not been a positive experience.

Table 10: Experience with disclosure of one’s HIV positive status

	Agree		Somewhat agree		Disagree		Not Applicable		
	n	%	n	%	n	%	n	%	
Disclosure to close	906	79.9	111	9.8	107	9.4	10	0.9	1,134
Close people were	883	77.9	120	10.6	113	10.0	17	1.5	1,133
Disclosure to non-close	296	26.2	196	17.3	573	50.7	65	5.8	1,130
Non-close people were	302	26.8	194	17.2	551	49.0	78	6.9	1,125
Disclosure has become	788	69.7	101	8.9	192	17.0	49	4.3	1,130

Key informants have narrated that PLHIV experience challenges with disclosing their HIV status. A key informant mentioned “*as care workers, sometimes we have to probe a lot to get the patients share with us their status*”, (A health care worker, Hhohho Region). The difficulty in disclosing HIV status is caused by the fear of being stigmatized and perceived as being promiscuous. Other key informants highlighted that PLHIV do not want to disclose their HIV status as they are continually discriminated against. “*The environment is not conducive for PLHIV to disclose their HIV status, there is so much to lose*”, (PLHIV leader, National).

The key informants also highlighted the different experiences between women and men when they

disclose their HIV status. “Disclosure is a problem. Women are often afraid to disclose their HIV status to partners for fear of rejection, yet they do not use protection during sex,” Female health care worker, Manzini Region. This quote suggests that women do not disclose their HIV status to their partners because of fear of rejection. Again, they cannot negotiate condom use as they believe the partner will suspect that they are living with HIV. In some instances, women choose not to disclose their HIV status because of fear of being hurt by their partners. *“Women live in silence for fear of rejection and violence”*, PLHIV. Key informants highlight that stigma and discrimination is experienced differently between men and women. There are men who wait to get their HIV status results through their partners. *“Usually it is women who go to hospitals for PMTCT and we hear they get assaulted when men demand to know their HIV status”* (Law enforcement officer). In some instances, the HIV disclosure process could lead to gender-based violence.

The decision to openly live with HIV involves both partners as *“spouses fear to have their partners HIV status known in the community”*, Female PLHIV, Lubombo region. The unmarried PLHIV face even higher stigma because they fear they will never get married” Female PLHIV, Lubombo region. Key informants also highlighted some of the difficulties with openly living with HIV. *“Many people will not want to have a sexual relationship with a person known to have HIV”* Program implementer.

Experience with stigma and discrimination

Table 11 below provides summaries of experiences of HIV stigma and discrimination at the social gatherings. Experiences of HIV stigma and discrimination at the social gatherings was reported by less than 10% of the respondents. However, being targets of discriminatory remarks by other people and being verbally harassed were the most common reported experiences in the past 12 months. Some 9% among females and 6% among males being targets of discriminatory remarks by other people in the past 12 months. About 9% among females and 5% among males have been verbally harassed in the past 12 months.

Table 11: Experience with stigma and discrimination because of HIV status

	No		Yes, within the last 12 months		Yes, but not within the last 12 months		Not Applicable		Total
	N	%	N	%	N	%	N	%	
Exclusion from social	1,057	93.9	41	3.6	16	1.4	12	1.1	1,126
Exclusion from religious	1,029	91.3	28	2.5	14	1.2	56	5.0	1,127
Exclusion from family	1,013	90.1	42	3.7	27	2.4	42	3.7	1,124
Being gossiped about / insulted	973	86.3	74	6.6	41	3.6	40	3.5	1,128
Being targets of discrimination	932	83.1	99	8.8	47	4.2	43	3.8	1,121
Being verbally harassed	952	84.4	94	8.3	46	4.1	36	3.2	1,128
Being blackmailed	1,058	93.7	20	1.8	16	1.4	35	3.1	1,129
Being physically assaulted	1,044	92.7	32	2.8	12	1.1	38	3.4	1,126
Refused employment or source of income	998	88.4	29	2.6	11	1.0	91	8.1	1,129
Having a job changed or denied a promotion	901	79.8	20	1.8	12	1.1	196	17.4	1,129
Sexual partner being discriminated against	984	87.2	37	3.3	13	1.2	94	8.3	1,128

Stigma and discrimination at social gatherings manifest in different ways. Participants in the focus group highlighted some of the signs used to discriminate against PLHIV. People use head movement to point at the person living with HIV. Others used different phrases with meanings of hidden discrimination against PLHIV. Phrases such as “Li A” could be used to refer to AIDS while pointing at the person living with HIV. Other phrases are “*ingculaza*” meaning chronically sick or “*lifahlwane*” meaning that ARV tins make noise, or “*phinduvuke*” meaning a person resurrected from the dead. Others just cross the two index fingers, meaning positive, referring to PLHIV quietly during conversations.

The figures on table 11 indicates an improvement in stigma and discrimination. A majority of respondents reported that they had not to been stigmatized in 2019 while in 2011 more than 15% of the respondents were targets of gossip and about 8% were verbally insulted, harassed and threatened.

The imposed control over the sexual lives of PLHIV has been another bad experience. HIV awareness messages have featured less of the sexual and reproductive needs of PLHIV but has been more about prevention of HIV. This approach has been less empowering for PLHIV. *“There is so much control over people’s sexual life and pleasure because of HIV. HIV awareness messages have been abacas dos and don’ts, without giving people independence and empowerment to make informed decisions”*, A health Care Worker.

The design of programmes targeting PLHIV has led to unintended disclosure of PLHIV status. A vegetable growing project and teen clubs, unintentionally, discloses PLHIV’s HIV status to community members. Community members concludes that all people associated with these projects are people living with HIV. The PLHIV who are in school are afraid of taking their sick note to school for the fear of disclosing their HIV status. Particularly if the sick note is from the an organization which is known to provide HIV services.

Internalized stigma and resilience

Table 12 provides responses on the effect of living with HIV on respondents’ internal feelings and abilities in the last 12 months. Nearly half of the people mentioned that living with HIV has no effect within their internal feelings and abilities. Similarly, about more than 30% reported positive internal feelings and abilities. The positive feeling related to self-confidence was reported by 43% of the respondents. The ability to secure relationships with other people was reported by 40%, and 38% of the respondents indicated ability to find love. About 10% of respondents mentioned that living with HIV has a negative effect within their internal feelings and abilities.

Table 12: Effect of HIV positive status on internal feelings and abilities

	Positive		No effect		Negative		Not Applicable		Total
	n	%	n	%	n	%	n	%	
Self confidence	483	43.0	513	45.6	99	8.8	29	2.6	1,124
Self-respect	423	37.7	596	53.1	55	4.9	48	4.3	1,122
Ability to respect others	437	39.0	574	51.2	57	5.1	53	4.7	1,121
Ability to cope with stress	449	39.9	518	46.1	92	8.2	65	5.8	1,124
Ability to secure relationships with other people	459	40.6	534	47.8	64	5.7	66	5.9	1,118
Ability to find love	424	37.8	530	47.3	71	6.3	96	8.6	1,121
Desire to have children	338	30.1	470	41.9	82	7.3	233	20.7	1,122
Achievement of personal and Professional goals	349	31.1	523	46.7	62	5.5	187	17.7	1,121
Ability to contribute to community	342	30.5	555	49.5	51	4.6	173	15.4	1,121
Ability to practice religion/ faith as I want	361	32.2	582	51.9	45	4.0	134	11.9	1,121

The internal feelings and abilities are different for older people and younger people living with HIV. Young people have ambitions for stable relationships, and the difficulty with disclosure of HIV status and fears of rejection by potential partners affect their internal feelings and abilities. A key informant mentioned *“Living with HIV is harder for young people and adolescents who have desires to get married. HIV affects their relationships where they have an additional burden to disclose their HIV status to partners”* (Program implement).

Figure 3 shows summaries of respondents internal feelings and abilities in the past over 12 months. More than half of the respondents mentioned that they feel better, 36% feel about the same and 6% feels worse than they were more than 12 months ago.

Figure 3: Effect of HIV positive status on internal feelings and abilities beyond 12 months

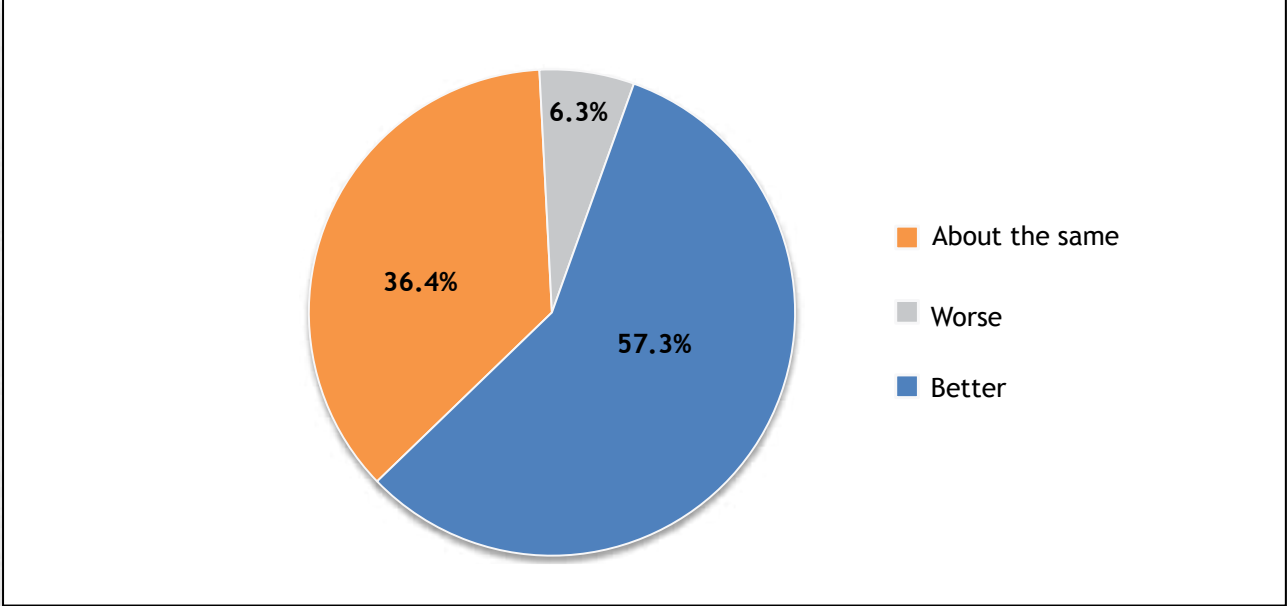


Table 13 below shows the effect of living with HIV. The most common effect was deciding not to have sex followed by choosing not to attend a social gathering. There were less than 5% of respondents who mentioned choosing not to seek healthcare, not to apply for job or not to seek social support.

Table 13: Effects of HIV status on internal feelings and abilities within 12 months

	No		Yes		Not Applicable		Total
	N	%	N	%	N	%	
Choosing not to attend social gatherings	1,017	90.5	87	7.7	20	1.8	1,124
Choosing not to seek health care	1,073	95.1	27	2.4	28	2.5	1,128
Choosing not to apply for jobs	1,004	89.2	32	2.8	89	7.9	1,125
Choosing not to seek social support	1,029	91.5	47	4.2	48	4.3	1,124
Isolating self from family and friends	1,046	92.9	42	3.7	38	3.4	1,126
Deciding not to have sex	934	83.0	132	12.1	55	4.9	1,125

On effects of the HIV status on personal emotions slightly more than half of the respondents reported that it was difficult to tell people about their HIV status as shown by table 14. About 21% mentioned that living with HIV makes them feel dirty. Above a quarter of respondents reported that living with HIV makes them feel guilty, ashamed and sometimes worthless. Around 19% of respondents mentioned that they hide their HIV status from others.

Table 14: Effects of HIV status on personal emotions in 2019

	Yes		No		Total
	N	%	N	%	
It is difficult to tell people about my HIV status	582	51.7	544	48.3	1,126
Being HIV positive makes me feel dirty	236	21.1	883	78.9	1,119
I feel guilty that I am HIV positive	192	17.1	928	82.9	1,120
I am ashamed that I am HIV positive	197	17.6	923	82.4	1,120
I sometimes feel worthless	192	17.2	926	82.8	1,118
I hide my HIV status from others	211	18.9	906	81.1	1,117

The internal feelings of guilt, regret and worthlessness were mentioned by key informants. A key informant reported that “*stigma manifests itself in a feeling of unworthiness, a feeling that one has done something wrong*”, (PLHIV leader, National). These feelings have negative effects on the emotions of some PLHIV.

Experience with HIV testing and diagnosis of HIV

Figure 4 shows responses for HIV testing decisions. The decision to test for HIV was a personal choice for most respondents. About 86% of the respondents took a decision on their own to test for HIV. However, 6% percent mentioned that they took a decision to test for HIV under pressure. These include pregnant women who take mandatory HIV testing as prescribed in the national guidelines. Some 5% of respondents reported that they were born with HIV. The other 3% of respondents were either tested without their knowledge or forced to take an HIV test.

Figure 4: Decision to test for HIV

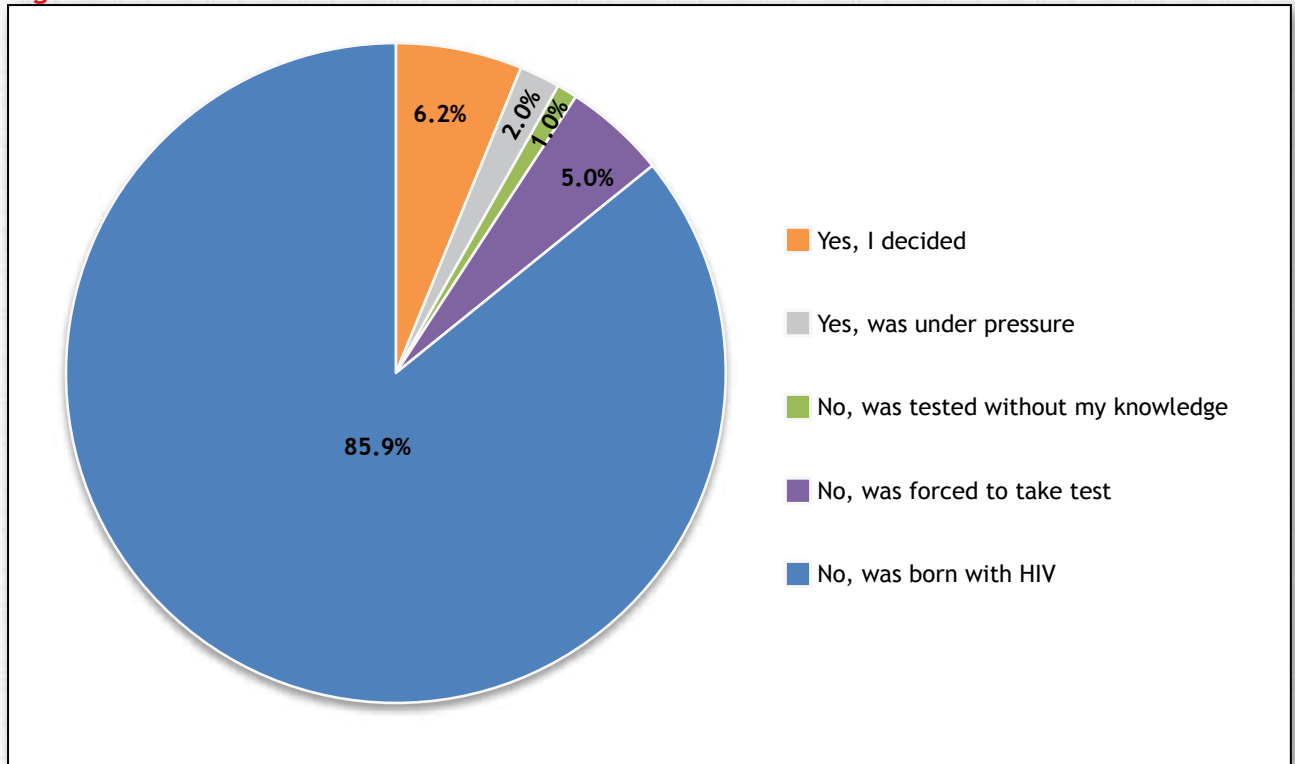


Figure 5 presents the several reasons for taking an HIV test. About 28% of the respondents took an HIV test because a service provider recommended. About 23% reported to have taken an HIV test because they were sick and needed to be aware of their HIV status. Almost 20% tested because they wanted or either perceived themselves as being at risk for HIV infection. There were respondents who took an HIV test as a screening for PreP. Less than 5% of respondents took an HIV test because it was a requirement, or the test was offered during community services.

Figure 5: Reasons for taking an HIV test

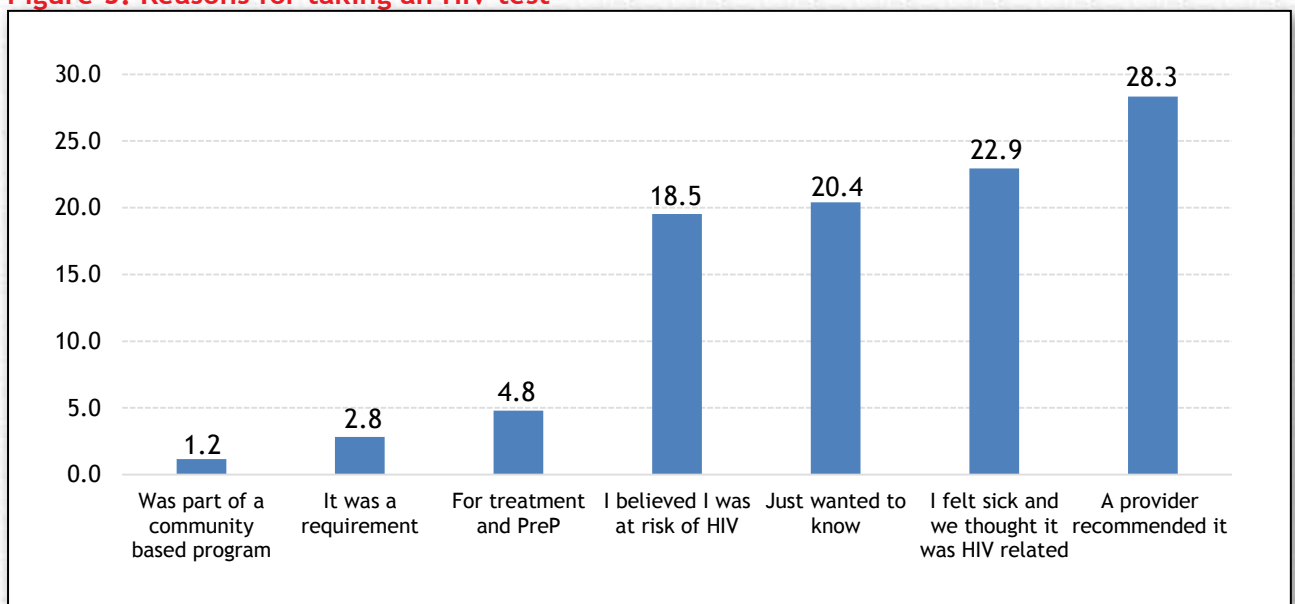
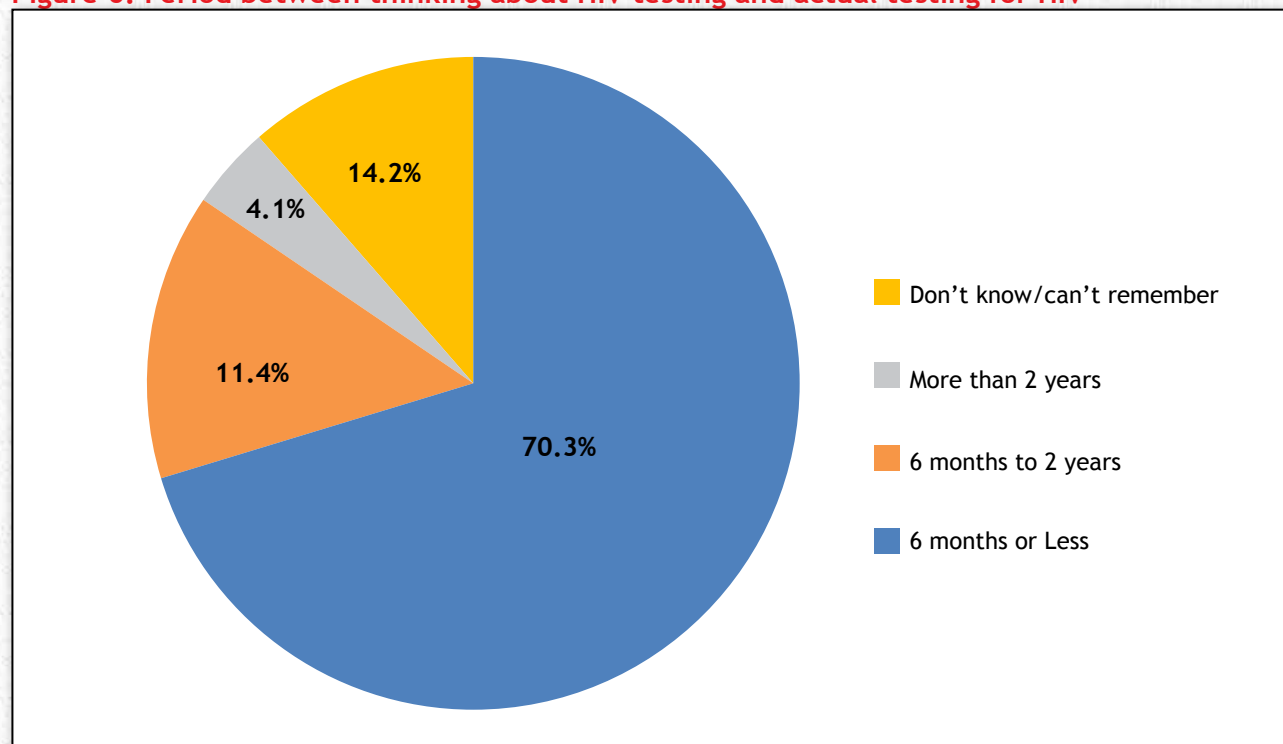


Figure 6 shows the time lag period between the time they thought of taking an HIV test and the time they tested. For more than two thirds, 70% of the respondents took them six months or less. About 11% of the respondents took six months to two years thinking about HIV testing before they tested.

Figure 6: Period between thinking about HIV testing and actual testing for HIV



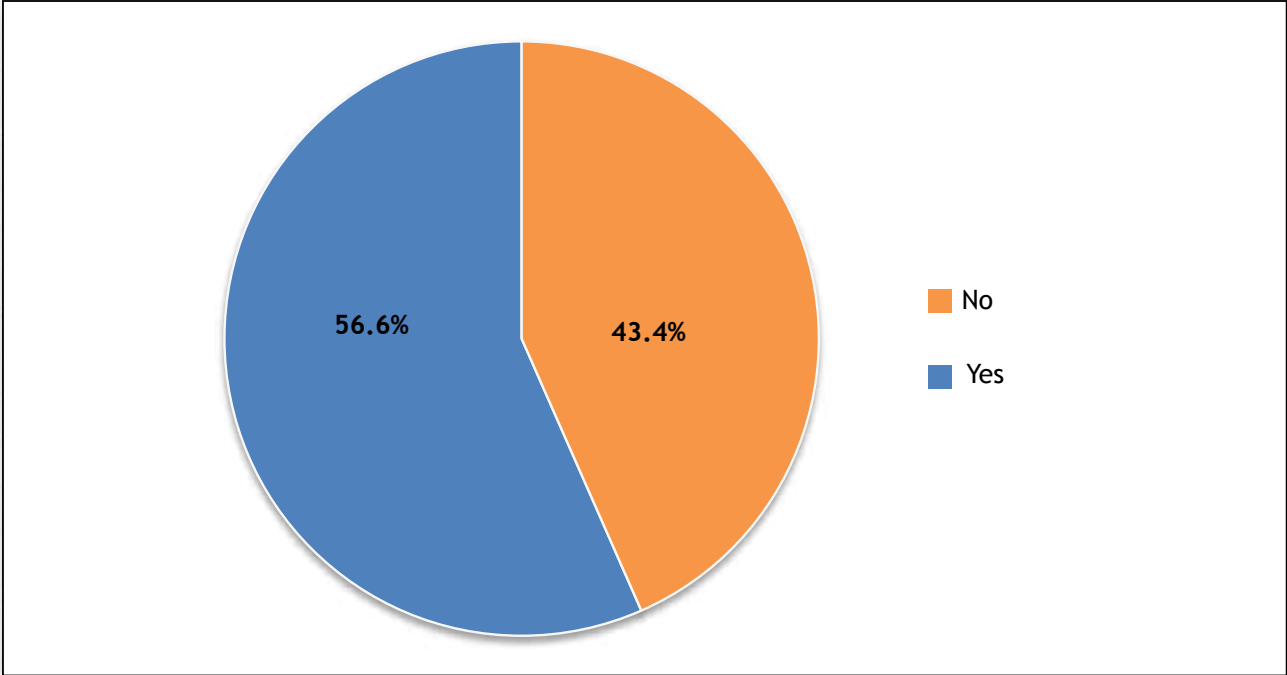
About 73% females and 69% males reported to have taken less than six months to decide to test for HIV as shown by table 15. Among respondents under the age of 25 years, some 52% tested for HIV within 6 months of being aware of a need to test. Similarly, among sex workers, 68% tested for HIV within 6 months of being aware of a need to test.

Table 15: Period between thinking about HIV testing and actual testing for HIV by sex

	Female	Male
6 months or less	68.8	73.2
6 months to 2 years	11.6	10.9
More than 2 years	4.2	3.6
Don't know/can't remember	15.4	12.3

The fears of HIV testing could include concerns about others knowing the HIV status of the person tested without disclosure or consent. Respondents were asked if they had fears about how other people would react to them if they tested HIV positive. Figure 7 indicates that 57% of the respondents have fears about how other people would respond if they tested HIV positive.

Figure 7: Fears about how other people would react if tested HIV positive



HIV care and treatment issues

The reasons for concerns about HIV care and treatment is shown by figure 8. Those concerns could dictate the timing of HIV treatment initiation and adherence. The main concerns about care and treatment initiation, at 39% was not being ready to deal with the HIV positive status. This highlights shock or the process of internal coping mechanisms experienced by people recently tested HIV positive. More than a third, 36% of the respondents were worried that others would be aware of their HIV status if they started care and treatment. Similarly, about 32% were worried that family members, partners or friends would find out of their HIV positive status if they started HIV care and treatment. The bad experience with health care workers was the least concerns for starting HIV care and treatment. Only 7% reported bad experience with health care workers as a concern for starting HIV treatment.

Figure 8: Reasons for concerns about initiating HIV care and treatment

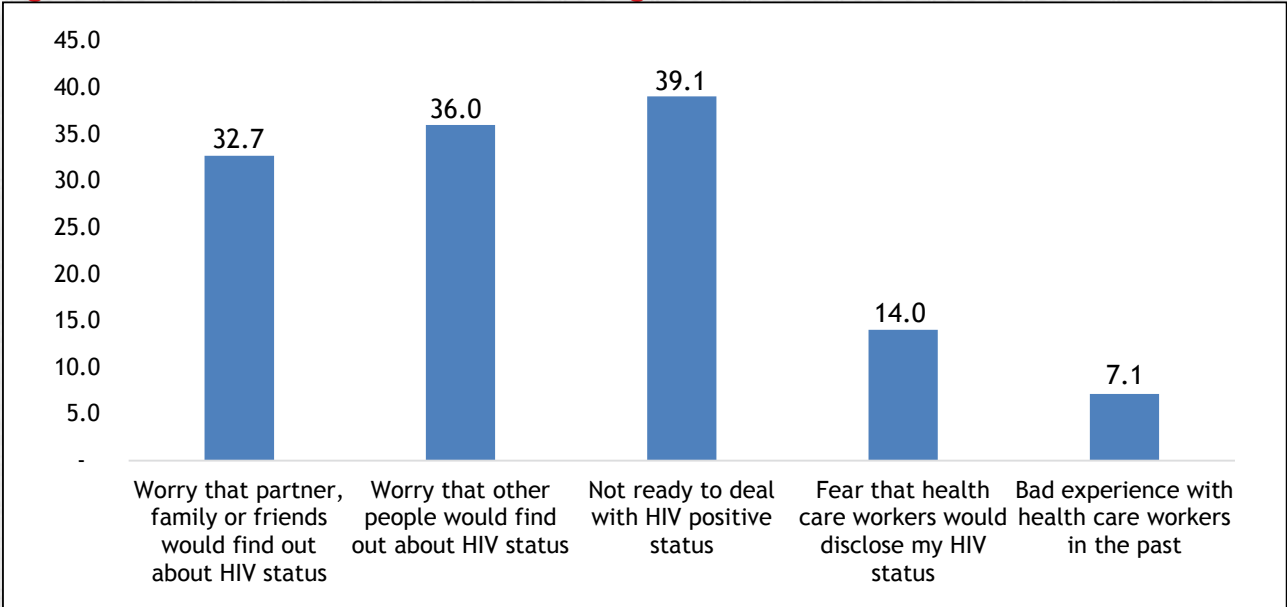


Table 16 indicates that among females the main concerns about initiating HIV care and treatment include not being ready to deal with HIV positive status at 43%, 36% worry that partner, family or friends would find out about HIV status at 39% and worry that other people would find out about HIV status at 39%. The same reasons were most common among males.

Table 16: Reasons for concerns about initiating HIV care and treatment by sex

	Female	Male
Worry that partner, family or friends would find out about HIV status	35.7	24.2
Worry that other people would find out about HIV status	38.6	28.7
Not ready to deal with HIV positive status	42.9	28.3
Fear that health care workers would disclose my HIV status	16.1	8.1
Bad experience with health care workers	7.7	5.6

Despite all the concerns about initiating HIV care and treatment, almost all respondents were on HIV treatment. Figure 9 shows that more than 98% of the respondents were on ARV treatment. The remaining less than 2% reported not to be on treatment and requires encouragement to eliminate their concerns about HIV treatment.

Figure 9: Respondents who reported being on ART

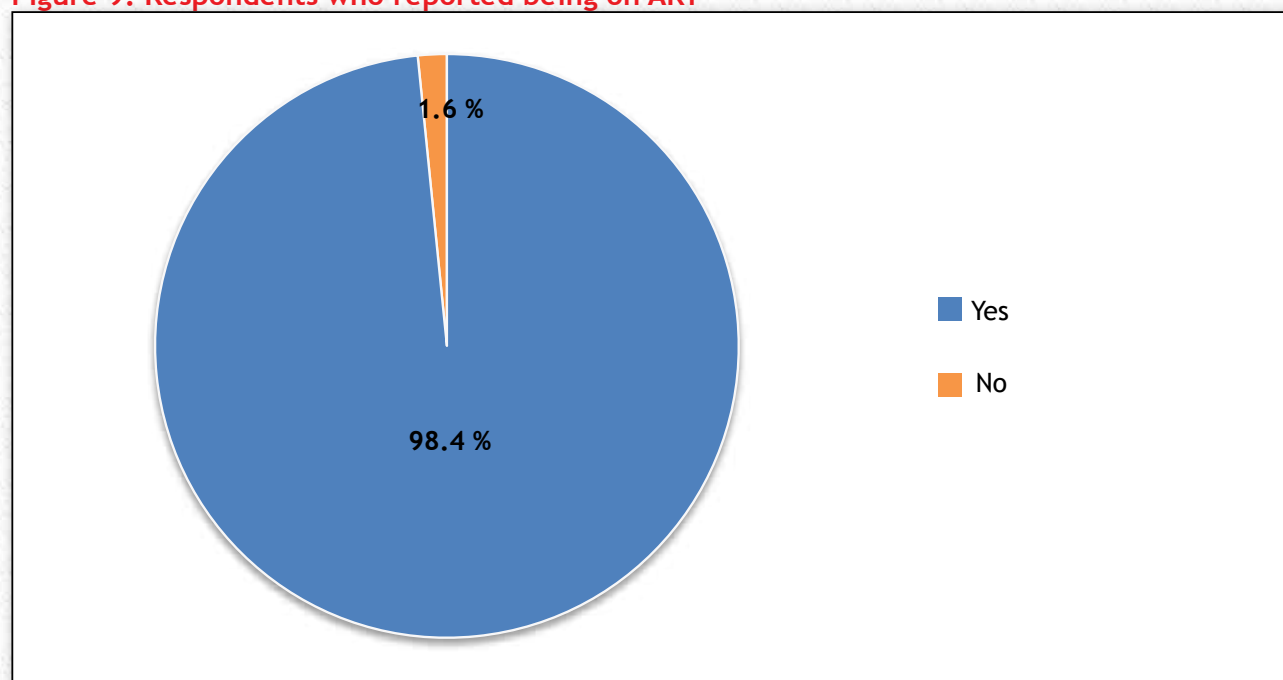
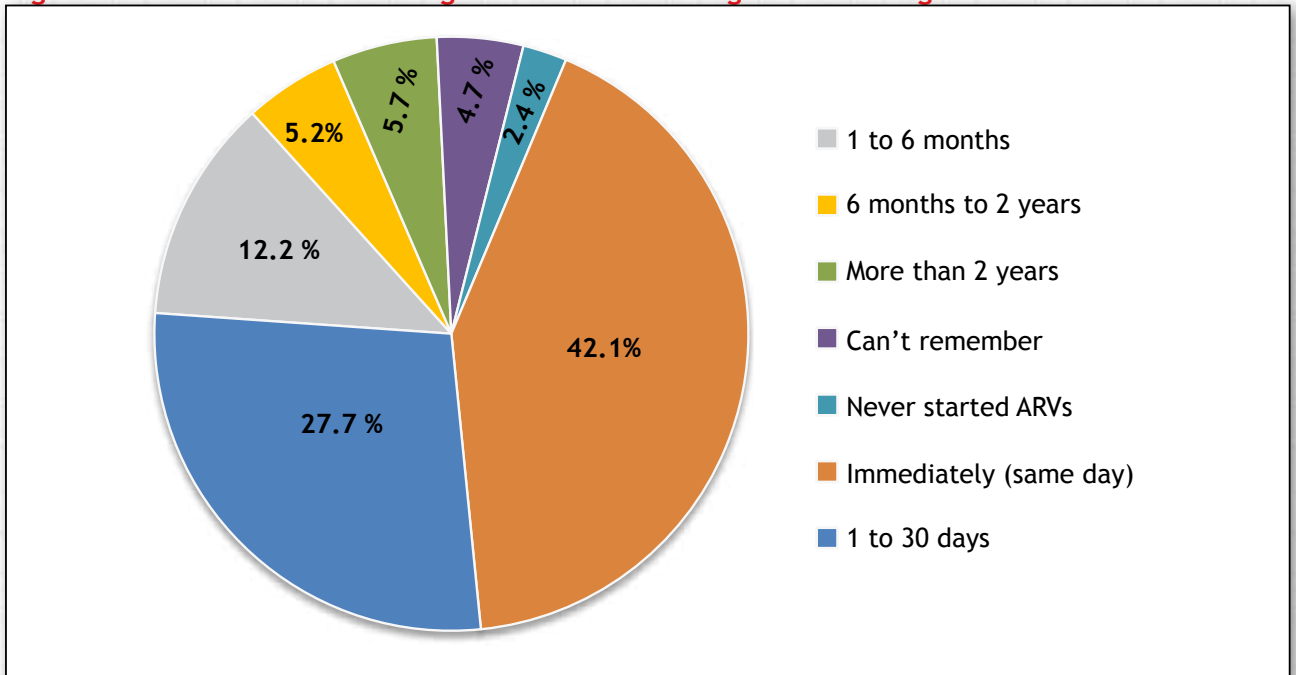


Figure 10 shows the time lag period between being aware of HIV status and initiating HIV treatment. About 68% of the respondents started HIV treatment immediately after knowing about their HIV status. Some 12% of the respondents took six to twelve months to start treatment. Almost 6% started HIV treatment after 2 years of being aware of their HIV status.

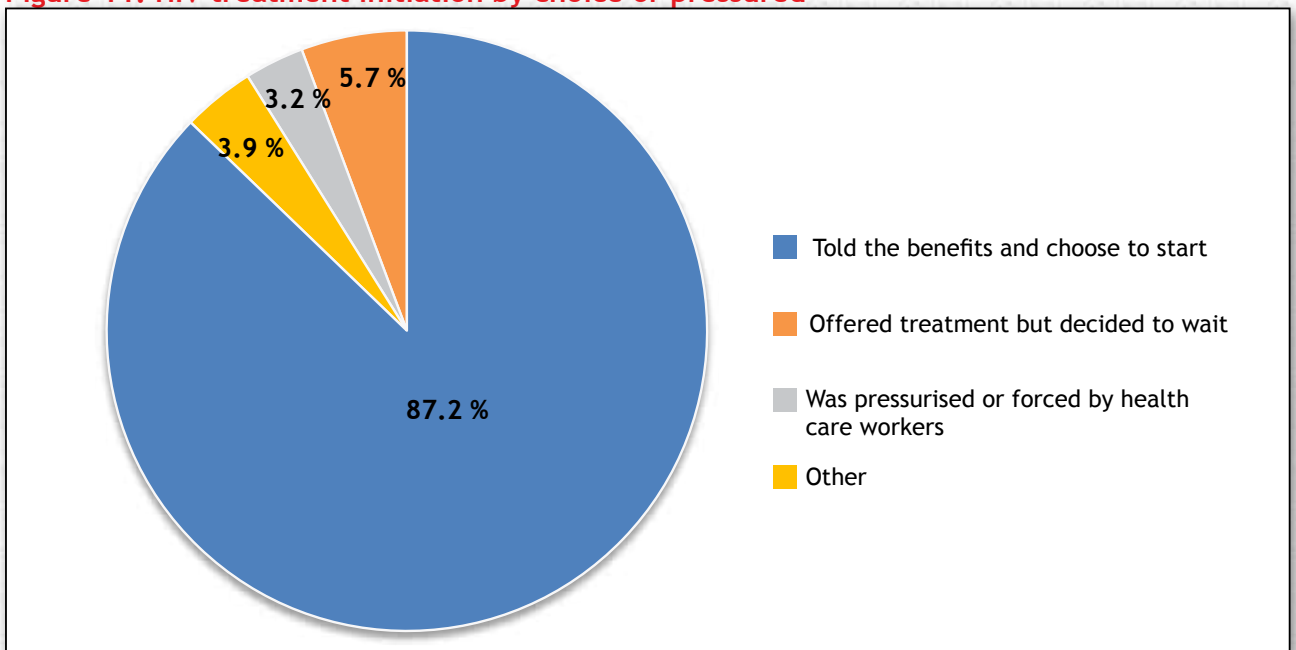
Figure 10: Period between being aware of HIV testing and initiating HIV treatment



Late ART initiation could also be due to fears of unintended disclosure of HIV status to people they know. The key informant highlighted that other clients start HIV treatment far from the place they live. This is illustrated by the quote *'some people travel long distances to get ARVs so that they are not seen by people they know'* - (Health care worker, Shiselweni Region).

Respondents mentioned several reasons and motivators which informed their decision to start HIV treatment indicated in figure 11. About 87% of the respondents started treatment because they were told about the benefits and almost 6% of the respondents decided to wait instead of starting treatment immediately. About 3% of the respondents mentioned that they were pressured by the healthcare worker to start HIV treatment.

Figure 11: HIV treatment initiation by choice or pressured



There were reasons offered by respondents on why they were not on HIV treatment. Some of the reasons includes high CD4s, side effects of ARVs, or they could not afford the medicines. The reasons on affordability of medicines was not probed further. But HIV treatment is provided by the government with no charge to clients in Eswatini.

Key informants, however, argued that fear of unintended disclosure of HIV status could be another reason for the respondents not to start or adhere to HIV treatment. A key informant mentioned *“PLHIV tend to hide medicine from spouse to whom they have not disclosed their HIV status, and this results in missing doses when they visit their partners who are not aware of their HIV status”* (Female PLHIV, Lubombo Region).

Other key informants held the view that delays in treatment initiation and adherence is due to discrimination by faith communities and churches. A key informant narrated *“They (churches) preach healing and not medicine and people tend to default from ARVs,”* (Female PLHIV, Lubombo Region). Another key informant mentioned *“Some pastors lie to congregants that they will be cured of HIV, in the process, some people stop taking ARVs,”* (Female PLHIV, Hhohho Region).

Experiences at the health facilities could also influence treatment adherence. Key informants mention that it’s hard for a client to return to the health facility for treatment if they experience stigma. A key informant shared his experience at the clinic and how it impacts on his treatment adherence. *“The nurses stigmatize us and we really get traumatized. When I think of going back to the clinic, I rather go home,”* (Male PLHIV from Hhohho Region).

A key informant noted that *“in trying to avoid being known, many PLHIV avoid being in places which are known to be frequented by other PLHIV including clinics, support groups as well as teen clubs.”* Other key informants noted that some PLHIV stop taking medication and resort to using traditional herbs. Another key informant mentioned that because of stigma and discrimination, PLHIV want to carry their medicines in a very discrete way. *“At many ART clinics, patients change their ARVs from original containers so that they will not be recognized”* (PLHIV leader, national level).

Some 47% among females and 51% among males missed a dose of HIV (antiretroviral) treatment because of fears about someone learning about their HIV status. Among adults older than the age of 50 years, 56% reported missing a dose of HIV (antiretroviral) treatment because of fears about someone learning about HIV status. The same was reported by 41% among people below the age of 25 years. About 44% of sex workers reported that they missed a dose of HIV (antiretroviral) treatment because of fears about someone learning about HIV status.

Key informants noted that HIV treatment default leads to unexpected deaths in communities. *“Many PLHIV start ARVs but default because of stigma and discrimination”*, PLHIV leader, national level. He added that *“we have lost a number of relatives unnecessarily. The moment they feel better, they get off TB medication, and the next time you hear, they are too sick, or they have died”*

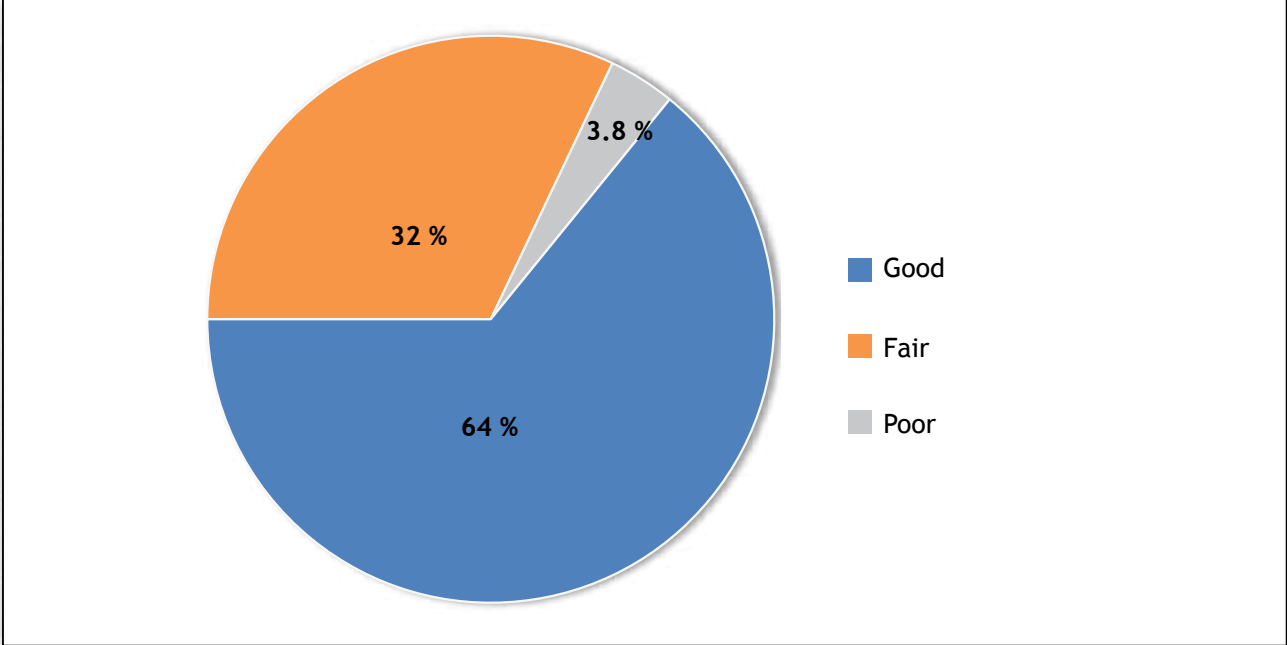
About 70%, 67% and 61% among females, males and sex workers respectively, have reported to have an undetectable viral load or are virally suppressed.

Health status of the respondents

Figure 12 shows respondents’ self-assessment of wellness. The self-assessment of wellness was based on three indicators: good, which is generally the ability to go about one’s daily activities unhindered by health conditions, fair, which is generally being challenged by health conditions and poor, where one is incapacitated in daily life as a result of health challenges.

The majority of respondents reported that they were generally able to go about their daily activities unhindered by health conditions. Figure 12 shows that 65% of the respondents mentioned that they were in good health. About 32% mentioned that their health condition was fair. Almost 4% reported they were incapacitated in daily life as a result of health challenges.

Figure 12: Respondents describe their health



The HIV stigma index survey included questions on other health conditions - tuberculosis, hepatitis, sexually transmitted infections, and mental health conditions in the last 12 months as shown by table 17. Some 11% of respondents reported that they had tuberculosis in the last 12 months. Some 9% of the respondents had sexually transmitted infections, 8% had mental health challenges and 5% had hepatitis in the last 12 months.

Table 17: Number of participants reporting Tuberculosis, Hepatitis, STIs, Mental Health

	YES		NO		Total
	n	%	n	%	
Tuberculosis	128	11.4	997	88.6	1,025
STIs	107	9.6	1,033	90.4	1,020
Mental Health	89	7.9	1,033	92.1	1,022
Hepatitis	53	4.7	1,069	95.3	1,022

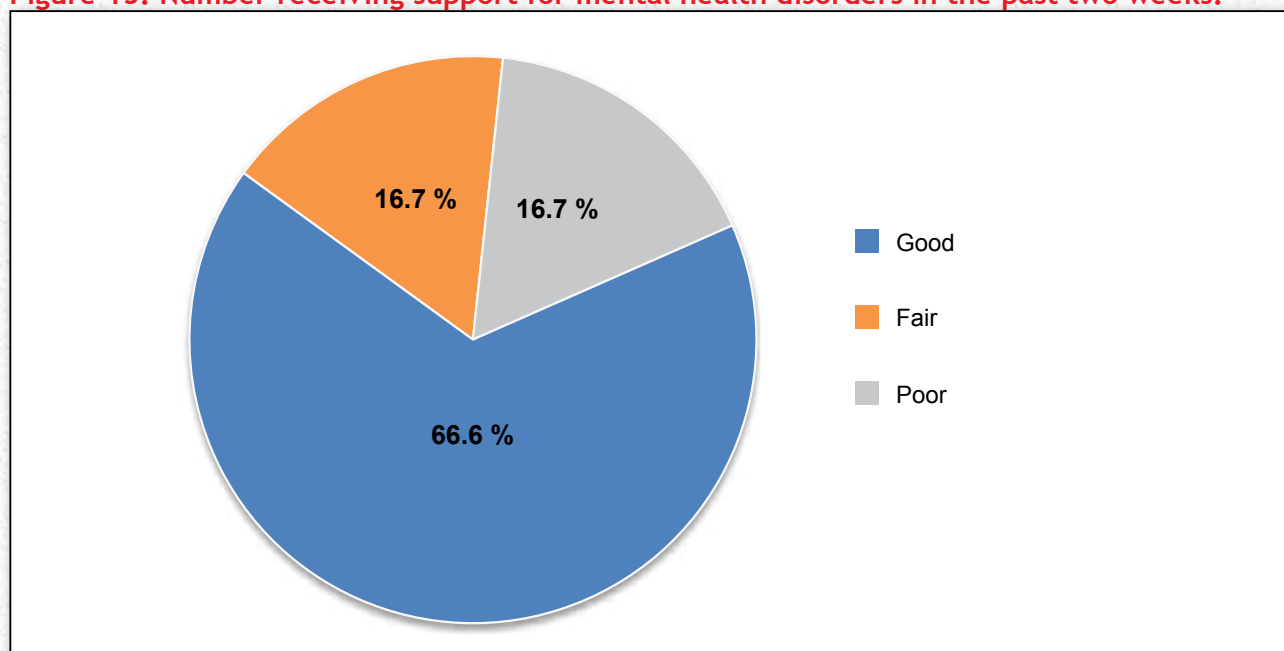
The survey further probed for specific mental health disorders. The question was restricted to two weeks preceding the survey. The most commonly mentioned disorders were feeling anxious, nervous or on the edge (table 18). Most respondents reported that they did not experience any of the probed mental health conditions. But, 18% of the respondents reported not being able to stop or control worrying, and 18% were feeling nervous, anxious or being on the edge in the past two weeks. About 11% reported having little interest or pleasure in doing things.

Table 18: Recent history of mental disorders

	Never		Once / twice		Several times		Most of the time		Total
	n	%	n	%	n	%	n	%	
Feeling nervous anxious or on the edge	822	73.5	207	18.5	51	4.6	39	3.5	1,119
Not being able to stop or control worrying	805	72.1	185	16.6	73	6.5	53	4.7	1,116
Feeling down, depressed or hopeless	837	74.9	143	12.8	76	6.8	62	5.5	1,118
Little interest or pleasure in doing things	883	79.3	126	11.3	62	5.6	43	3.9	1,114

Figure 13 below shows the number of respondents who received support for mental health disorders in the past two weeks. Some 17% of respondents reported receiving psychosocial support, and about the same number preferred not to provide a response. Most of the respondents, 67% did not receive support for mental health disorders experienced in the past two weeks.

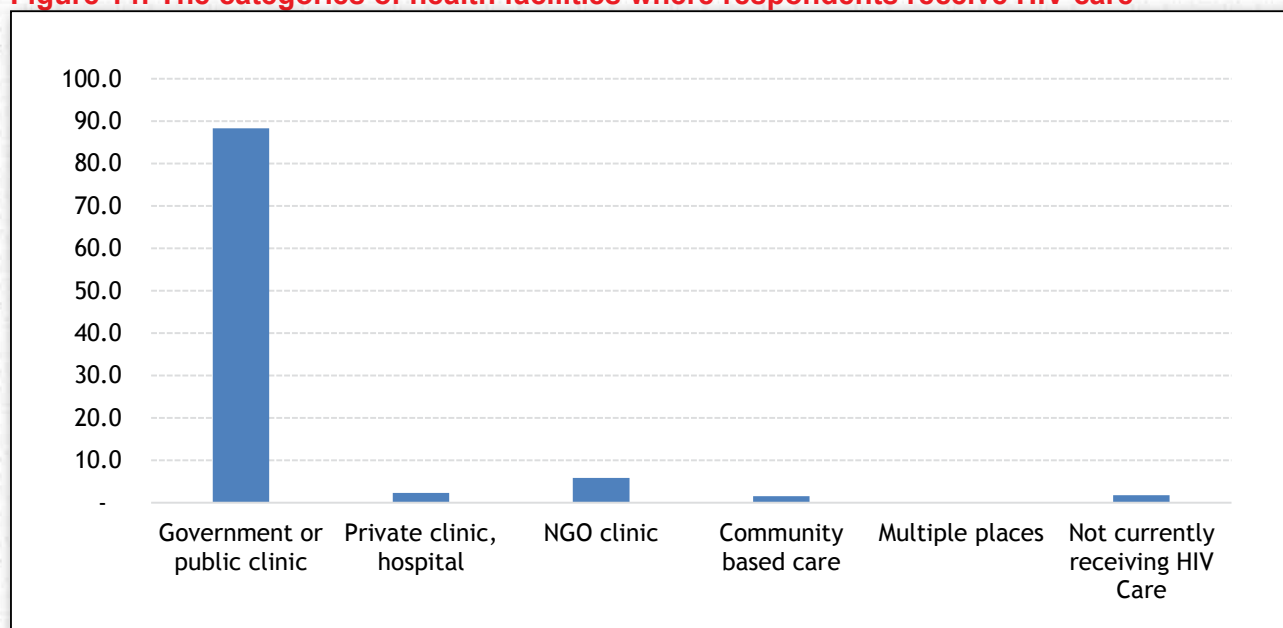
Figure 13: Number receiving support for mental health disorders in the past two weeks.



Service delivery experiences

Figure 14 shows categories of health facilities where respondents receive their HIV services. Most respondents receive HIV care and treatment from government or public clinic. Almost 6% received HIV services from the NGO clinic, and 3% from private clinics or hospital.

Figure 14: The categories of health facilities where respondents receive HIV care



Experiences of stigma and discrimination from health care workers could have impact on HIV treatment initiation and adherence. Table 19 shows experiences related to stigma and discrimination from health care workers in the past 12 months. Less than 10% of respondents reported experiencing stigma and discrimination from health care workers. The most common discrimination attitude was being advised not to have sex because of their HIV status, verbal abuse, and being gossiped about.

Table 19: Experience of stigma and discrimination when seeking HIV care

	No		Yes		Total
	n	%	n	%	
Denial of health services because of HIV status	1,048	96.3	40	3.7	1,088
Advised not to have sex because of HIV status	1,002	90.8	101	9.2	1,103
Gossiped about	1,034	93.7	70	6.3	1,104
Verbal abuse	1,020	92.4	84	7.6	1,104
Physical abuse	1,068	96.7	37	3.3	1,105
Avoidance of physical contact with you	1,067	96.6	37	3.4	1,104
Telling other people about your HIV status	1,041	94.3	63	5.7	1,104

The experiences of stigma and discrimination in the healthcare setting was also discussed by key informants. “Health care workers talk loud and insult patients who come to pick ARVs, especially those who come late. They brand us as being mentally sick” Female PLHIV, Lubombo Region. Another KII noted “the attitudes of some nurses and service providers are often stigmatizing PLHIV. They treat us as useless being” (PLHIV leader, National level).

A key informant narrates an argument which shows healthcare workers ‘fatigue as they serve a lot of patients daily - both PLHIV and those seeking healthcare for other conditions. “Some health care workers act as if people who come to public hospitals are bothering them. It is a day’s process to go through the lines in most of the public hospitals and clinics” (Faith leader, National level).

The colour and labelling of files at health facilities could lead to unintended disclosure of the HIV status of PLHIV. *“The way we used to provide care also contributed to stigma and discrimination. There are green files branded HIV care. The patients carry the files from one station to the other and anyone can see that this person has HIV,”* Female health care worker, Manzini Region. Some health facilities would have a dedicated healthcare office for PLHIV.

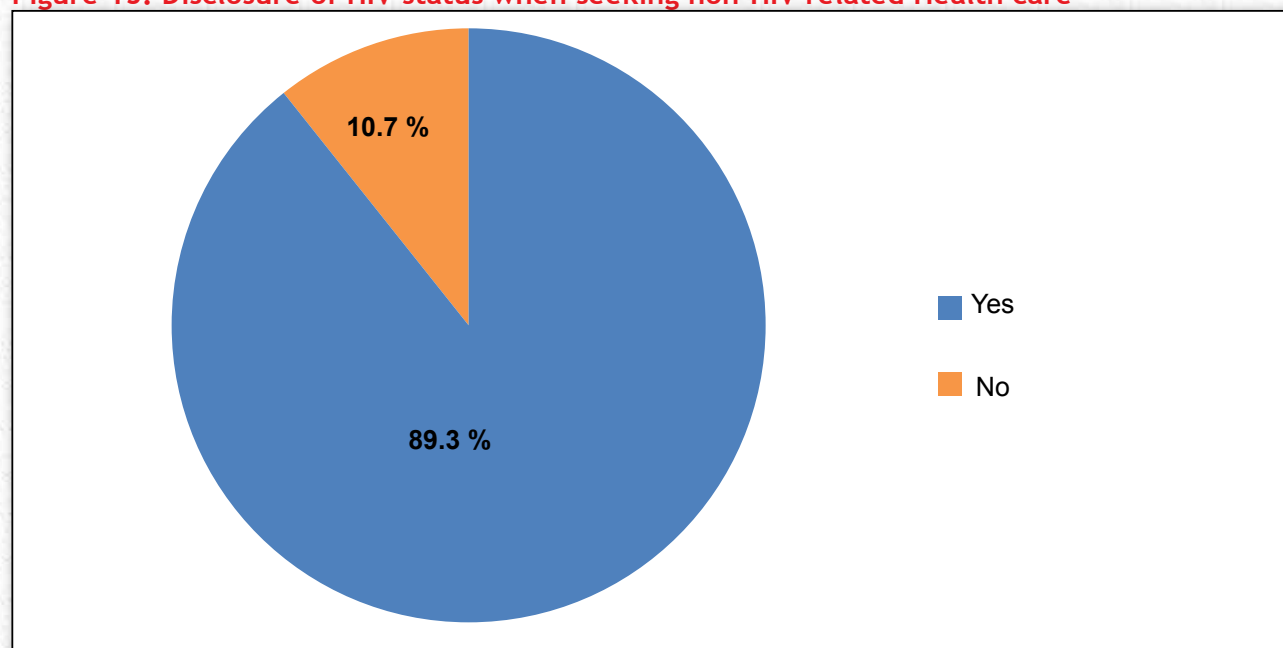
Table 20 indicate experiences of stigma and discrimination when seeking non-HIV care. Among those who experienced stigma and discrimination in non-HIV care, most reported being gossiped, advised not to have sex because of HIV status, and verbal abuse.

Table 20: Experience of stigma and discrimination when seeking non-HIV care

	No		Yes		Total
	n	%	n	%	
Denial of health services because of HIV status	212	93.0	16	7.0	228
Denial of dental services because of HIV status	208	94.5	12	5.5	220
Being advised not to have sex because of HIV status	199	86.9	30	13.1	229
Being gossiped about because of HIV status	193	86.5	30	13.5	223
Verbal abuse	200	89.7	23	10.3	223
Physical abuse	205	93.6	14	6.4	219
Avoidance of physical contact with you	206	93.2	15	6.8	221
Telling other people about your HIV status	195	88.6	25	11.4	220

The disclosure of HIV status was common even when seeking non-HIV health related care as shown by figure 15. Some 89% of respondents mentioned that they were requested to disclose their HIV status when seeking non-HIV health related care.

Figure 15: Disclosure of HIV status when seeking non-HIV related Health care



The handling of clients' records is important - as mishandling could lead to unintended disclosure of HIV status. Respondents were asked if they believed their medical records were kept confidential when they go to seek health care services. Most respondents, about 79% reported that they have trust that their medical records were kept confidential. Meaning that other people would not have access to the medical records, but only health care workers attending to the PLHIV.

Experience on matters related to sexual reproductive health (SRH) services and rights

Table 21 below provides a list of negative experiences related to sexual and reproductive health issues by PLHIV in the healthcare settings. Over 85% of the respondents did not experience any negative sexual and reproductive health and rights issues. However, other respondents had concerns that they were pressured to take HIV treatment during pregnancy. Others mentioned that they were pressured to use a specific method of contraceptive.

Table 21: Experience on matters related to reproductive health rights in health care settings

	No		Yes		Total
	n	%	n	%	
Advised not to mother/father a child	939	90.0	104	10.0	1,043
Pressurized to get sterilized	1,013	97.4	27	2.6	1,040
Got sterilized without knowledge or consent	1,015	97.6	25	2.4	1,040
Denied contraception/ family planning services	1,014	97.7	24	2.3	1,038
Advised that in order to get ART, you had to use contraception	1,005	96.9	32	3.1	1,037
Women only					
Advised to terminate a pregnancy	749	97.3	21	2.7	770
Pressurized to use a specific type of contraception	700	93.8	46	6.2	746
Pressurized to use a particular delivery option	716	96.4	27	3.6	743
Pressurized to use a particular feeding practice	676	90.9	68	9.1	744
Pressurized to use ARVs during pregnancy	661	86.6	102	13.4	763

The key informants mentioned that there are discriminatory attitudes towards young people seeking HIV or sexual and reproductive health services. However, health programmes mitigate stigma and discrimination towards young people through integration of HIV and sexual and reproductive health services and community outreach programmes. *“What some programs have done is to integrate SRH services for all young people including mobile clinics irrespective of HIV status,”* (Program implementer, Hhohho region).

Human rights violations and effecting change against stigma, discrimination and human rights abuses

Table 22 shows the experiences of human rights violation in relation to forced HIV testing. More than 90% of respondents did not mention human rights violation in relation to forced HIV testing. Among those who mentioned human rights violation, the most commonly mentioned was being forced to test for HIV. When applying for medical insurance, visa or citizenship in another country (Table 19).

Table 22: Experience of human rights violations

	No		Yes, but not in the last 12 months		Yes, but not in the last 12 months		Prefer not to answer		Total
	n	%	n	%	n	%	n	%	
Forced to get tested/ disclose status in order to:									
Obtain a visa or apply for citizenship	1,10	97.3	20	1.9	1	0.1	7	0.7	1,038
Apply for a job or get a pension plan	1,05	95.9	8	0.8	3	0.3	32	3.1	1,048
Attend an educational institution or get a scholarship	995	94.8	9	0.9	1	0.1	45	4.3	1,050
Get health care	984	93.8	8	0.8	0	0.0	57	5.4	1,049
Get medical insurance	988	94.2	22	2.1	6	0.6	33	3.1	1,049
I was arrested or taken to court on a charge related to my HIV status	969	92.4	6	0.6	2	0.2	72	6.9	1,049
I was detained or quarantined based on my HIV status	1,008	96.2	4	0.4	1	0.1	35	3.3	1,048
I was denied a visa or permission to stay in another country	1,012	96.5	1	0.1	2	0.2	34	3.2	1,049
I was denied residency in another country	1,009	96.4	3	0.3	3	0.3	32	3.1	1,047
I was forced to disclose my HIV status publicly	1,014	97.2	1	0.1	2	0.2	26	2.5	1,043
I was forced to have sex when I did not want	1,017	97.3	1	0.1	1	0.1	26	2.5	1,045

Figure 16 shows reports on the existence of laws to protect PLHIV from discrimination. About half of the respondents reported that they know about the law which protect PLHIV from discrimination. About 5% mentioned that there are no laws to protect PLHIV from discrimination.

Figure 16: The number of respondents who knows about laws to protect PLHIV from discrimination

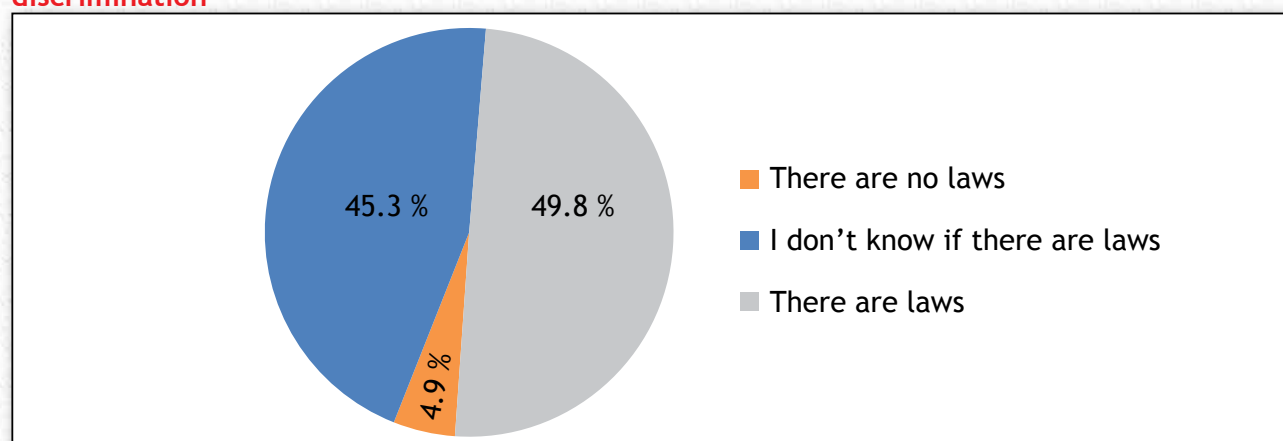


Table 23 provides a list of actions taken by respondents against human rights abuses. Respondents mentioned challenging or educating someone who was stigmatizing or discriminating against PLHIV, providing emotional and financial support or other support to help a PLHIV deal with stigma and discrimination. Engaging a government leader or media about issues of HIV stigma and discrimination was least mentioned (Table 20).

Table 23: Action against human rights abuses

Action taken	No		Yes, but not in the last 12 months		Yes, but not in the last 12 months		Total
	n	%	n	%	n	%	
Challenged or educated someone who was stigmatizing or discriminating against you	755	74.0	186	18.2	79	7.7	1,020
Challenged or educated someone who was stigmatizing or discriminating against other PLHIV	699	68.9	214	21.1	101	10.0	1,014
Provided emotional, financial or other support to help a PLHIV deal with stigma and/or discrimination	739	73.2	184	18.6	83	8.3	1,006
Participated in an organization or educational campaign that addresses stigma and discrimination	770	76.5	159	15.8	78	7.7	1,007
Encouraged a community leader to take action about issues of stigma and discrimination against PLHIV	857	85.0	112	11.1	39	3.9	1,008
Encouraged a government leader or a politician to take action about issues of stigma and discrimination against PLHIV	916	90.8	67	6.6	26	2.6	1,009
Spoke to the media about issues of stigma and discrimination against PLHIV	939	92.9	53	5.2	19	1.9	1,011

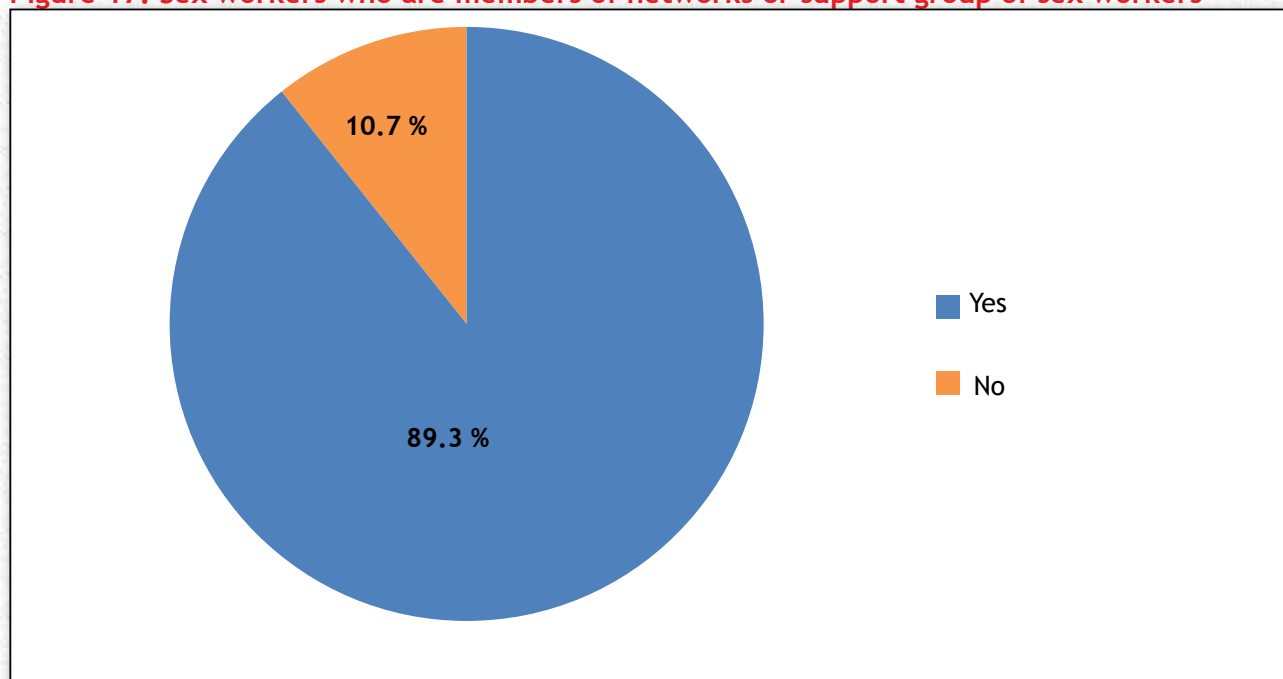
Stigma and discrimination for reasons other than HIV

HIV stigma survey had a specific module on most at risk for HIV populations including LGBTI, MSM, sex workers, IDUs, and people living with disability. In the survey questions, respondents were probed to self-identify with most at risk for HIV populations.

Some respondents identified themselves as transgender. Among the transgender people, about 85% have not disclosed their identity to other transgender people - as only 15% of the respondents indicated that other transgender people know about their gender identity. Some 33% of transgender people mentioned that they are members of the networks or groups of transgender people. There was only one respondent who indicated that they were bisexual. Similarly, there were two respondents who indicated that they were man having sex with other men (MSM).

About 4% of the respondents reported ever having sex in exchange for money, goods or services. However, among those who ever had sex in exchange for money, goods or services. About 40% identified themselves as sex workers. Among those who self-identified themselves as sex workers, 55% indicated that they had not experienced stigma and discrimination because of sex work. However, 38% indicated that they had been verbally harassed. About 69% of sex workers mentioned that other sex workers knew that they were sex workers, But, 52% of sex workers indicated that family and friends did not know that they were sex workers. Some 88% of sex workers were on HIV treatment. Figure 17 shows sex workers who are members of the of the support groups. About 89% of sex workers are members of networks or support group of sex workers.

Figure 17: Sex workers who are members of networks or support group of sex workers



Only 1% of respondents reported to have ever used or injected recreational drugs. However, among those who reported to have ever used or injected recreational drugs, only 27% identified themselves as persons who use drugs. About 82% of the respondents who used or injected drugs indicated that they never experienced stigma and discrimination because of drug use. But those who mentioned stigma and discrimination, reported being gossiped about by family members and being verbally harassed. Slightly over half, 52%, of those who use or inject drugs mentioned that family and friends know of their drug use or injection. About 30% of those who use or inject drugs are members of networks and support groups of people who use drugs.

In the key informant interviews, care for key populations was discussed. Key informants mentioned that it was difficult for some key populations to get care. *“Some providers are not comfortable providing care to some key populations. The most at-risk populations have challenges getting services”* Female health care worker, Manzini Region

5. DISCUSSION

Disclosure of HIV status

The voluntary disclosure of HIV status was only done by less than half of people in the survey. Despite, most people mentioned that family members, spouses, teachers and employers were aware of their HIV status. The circumstances in which they became aware of the HIV status of PLHIV are unclear. But they report that their HIV status was disclosed without their consent. This points to a need to generate a community wide stigma and discrimination competence so that every person is familiar with the need to hold HIV related information confidentially except when they get express permission from the individual.

Some regarded HIV disclosure to be empowering, as it helped them overcome internal feelings of guilt. Most respondents prefer to disclose their HIV status to family members such as parents, siblings, spouses and children. However, others express concerns that disclosure of HIV status to close associates could lead to many others being aware. This concern is real as the findings shows that employers, teachers, spouses came to know about their HIV status without their consent. Disclosure of HIV status has been a positive experience for most of the respondents. But for women disclosure of HIV status is still a concern as they mentioned that they would be accused of infecting their partners.

Experience with HIV stigma and discrimination

Denial and lack of accurate information about HIV transmission are responsible for discriminatory attitudes some of the community members harbour towards PLHIV. Some people fear that casual contacts can lead to transmission, while others fear that if their close associates' HIV status (e.g. spouses, children) is disclosed, they will also be branded or known to be HIV positive. Respondents mentions discriminatory practices particularly at the family and community level, and during social gatherings.

The survey has also found that HIV and AIDS is associated with death, sickness and loose sexual morals. Some respondents expressed concerns on the way society has been conditioned to treat PLHIV as sexually irresponsible individuals, sick and unproductive. These attitudes have an impact on the dignity and self-esteem of PLHIV, and to certain extent to family members of the PLHIV.

This survey shows low levels of stigma and discrimination in Eswatini. However, there were few PLHIV who still live with fear of stigma and discrimination which is projected through perception that someone is judging and condemning them. Some respondents were scared to start HIV treatment because a family member or someone would become aware of their HIV status. Others mentioned changing medicine containers or taking treatment where they would not be seen by other people. However, most of the respondents have overcome these fears and live openly with HIV and there are not afraid of taking treatment. Despite, the hidden stigma and discrimination among the few respondents needs to be addressed at individual, community and societal level so as to create an environment where PLHIV will not feel stigmatized or discriminated.

Internalized stigma and resilience

Respondents mention that living with HIV does not have an effect on their lives. Others even mention that they are positive about living with HIV. Despite the positive internal feelings about living with HIV, it is important to note that, individual prejudices towards PLHIV still manifests at different social spaces such as funerals and places of worship. These prejudices are through labelling of PLHIV with names which portray them as promiscuous, sick or people who resurrected from the dead. The gestures and phrases used are often derogatory and expressed through sign communication or gossips.

Interaction with health care services

The majority of respondents mentioned that testing for HIV was a personal choice; and most of them even mentioned that it took them less than six months to test after being aware of the need to test. For those that made the decision to test, the biggest motivation was having received a recommendation from a health provider. This points to the strengths of provider-initiated testing and a need for strengthening provider-initiated HIV testing. HIV testing among other respondents was triggered by feeling sick. This has an effect on the well-being of PLHIV and HIV prevention efforts - as people live unaware of their HIV status until they are sick.

Almost all respondents were on HIV treatment, and most of them started treatment immediately after testing positive. But there were fewer respondents who were not on treatment. The main concerns about starting HIV treatment was side-effects, could not afford treatment or their CD4 was high. Some of these responses apply for the period where HIV treatment was prescribed to people depending on their CD4 cells levels. Most respondents started HIV treatment earlier because they were told about the benefits of HIV treatment.

Discrimination for reasons other than HIV

There were respondents who identified themselves as transgender, sex workers and IDUs. Most of the transgender respondents have not disclosed their sexual identities to other people. Over half of the sex workers have not disclosed to other people that they are sex workers. Only fewer transgender and IDUs people reported experiences of stigma and discrimination. This could be because that they have not disclosed that they are transgender or IDUs. Almost half of sex workers mentioned experiences of stigma and discrimination.

6. CONCLUSION

The overall conclusion is that Eswatini has made significant strides in dealing with HIV related stigma and discrimination. But prejudice directed against PLHIV remain and manifests through demeaning reactions towards PLHIV at social gatherings, and the labelling of PLHIV with derogatory phrases. Despite, PLHIV have strong resilience as most were of the view that living with HIV has no effect in their lives. In fact, some have even developed negative attitudes. Disclosure of HIV status is still difficult for PLHIV. Family members and associates become aware of the HIV status of PLHIV through other people, and without the consent of PLHIV. This undermines the rights of PLHIV to consent for the disclosure of their HIV status. PLHIV have access to HIV services and almost all people in the survey were on HIV treatment.

7. RECOMMENDATIONS

Advocacy for GIPA: the greater involvement of PLHIV in the HIV response towards the target of ending AIDS by 2022 will encourage people to live openly with HIV. PLHIV should be engaged in the design and implementation of HIV prevention and treatment programmes. The greater involvement should include strengthening of PLHIV support groups for community activism to break the silent discrimination of PLHIV at social gatherings.

Develop a national strategy on HIV related stigma and discrimination: PLHIV and all stakeholders should develop a national strategy on HIV related stigma and discrimination. The strategy will guide all actors in the AIDS response towards prevention of HIV related stigma and discrimination, and investment of resources to eliminate all forms of HIV related stigma and discrimination.

Develop HIV stigma-sensitive programmes: HIV response programmers must ensure that HIV prevention and treatment programmes are HIV stigma sensitive. All HIV programmes should have a plan on how it aims to destigmatize HIV and how to address HIV related discrimination. The HIV stigma - sensitive programmes will also screen for communication or phrases such as mbululave, which are found to impose discrimination against PLHIV.

Strengthening sexual and reproductive health (SRH) programs for adolescents and general youth friendly services: SRH programs for all young people are an excellent entry point to introduce not only HIV prevention awareness and competence among young people, but also an opportunity to create stigma and discrimination competence among the clients. Such programs should be implemented in a non-judgmental way using an approach of providing information about HIV related stigma and discrimination while cultivating interest among the young people to seek HIV testing services.

Strengthen campaigns on HIV related stigma and discrimination: the campaigns should focus on HIV related stigma and discrimination and empowerment of PLHIV to disclose their HIV status and to live openly with HIV. The campaigns should discourage disclosure of other people's HIV status without their consent. The campaigns should be led by PLHIV and should target all media platforms with messages cascaded, in the form of dialogues, at community level through support groups and other organised forums of PLHIV.

Designating anti-stigma ambassadors: ambassadors will encourage PLHIV to speak openly about their HIV status, and this will break the silence on HIV stigma and discrimination and the labelling of PLHIV with demeaning phrases. Different community formations such as schools, performing artists, media houses, workplaces, and places of worship should appoint anti-stigma ambassadors or champions from among their own ranks to consistently mobilize the group on issues of HIV related stigma and discrimination

Targeted empowerment programmes for PLHIV: the targeted programme will build internal resilience and positive internal feelings among PLHIV. The programmes should be led by PLHIV with the support of stakeholders involved in the AIDS response.

Nurturing family and social support systems: family members are the people that PLHIV often disclose their HIV status to. Therefore, they should be empowered to provide support to PLHIV during the process of disclosure. Communication pamphlets, and media stories should anchor messages on how family members could support PLHIV during disclosure of HIV status.

Documenting good practices that dispel stigma and discrimination: the country should document the lessons learnt on prevention of HIV related stigma and discrimination. The documentation should focus at policy, programmes and case studies from health service delivery levels. PLHIV formations should lead the documentation with the support of partners involved in the AIDS response.

Conducting HIV related stigma and discrimination survey among MARPS: This Survey was only able to reach a very small number of individuals who identified themselves as MARPs, including MSM, CSWs, drugs users and transgender people. In order to document the extent of stigma and discrimination among this population, there is a need to design a survey that exclusively targets this population.

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Disclaimer:

The PLHIV Stigma Index 2.0 is designed as a research tool for capturing data on the experiences and perceptions of PLHIV regarding stigma, discrimination and human rights violations against people living with HIV. In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower PLHIV on human rights related to HIV. Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow-up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. The respondents in this survey have a right to anonymity and confidentiality regarding their responses. In addition to the empowerment function, appropriate uses of the data are for advocacy and in order to inform stigma/ discrimination reduction programming and policy formulation in the national response to HIV. The data is not available as a source of allegations of individual instances of wrong doing.

