# Assessment of Stigma, Discrimination and Psychosocial Distress among People Living with HIV in Sri Lanka

# 2023

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## Message from the Director, National STD/AIDS Control Programme (NSACP)

As the Director of the National STD/AIDS Control Programme, it is my privilege to present this comprehensive report on stigma, discrimination, and psychosocial distress among people living with HIV (PLHIV) in Sri Lanka. This study is a testament to our ongoing commitment to understanding and addressing the challenges faced by the PLHIV community.

Stigma and discrimination remain critical barriers to achieving our national goals of prevention, treatment, and support for PLHIV. Despite significant progress in policy and healthcare interventions, the findings of this report underscore the urgent need to strengthen our collective efforts. The voices and experiences of the respondents in this study highlight the profound impact of stigma on their lives, from social isolation and psychological distress to challenges in accessing care and treatment.

The results of this study provide invaluable insights that will guide evidence-based interventions to reduce stigma and discrimination. They also reaffirm the importance of fostering supportive environments, enhancing confidentiality in healthcare, and ensuring that PLHIV can live with dignity and equality. Our aim is to align these efforts with global targets, including the UNAIDS 10-10-10 goals and the Sustainable Development Goals, as we strive to eliminate HIV-related stigma by 2025.

I extend my heartfelt gratitude to the research team, DAST, World health organization Sri Lanka Office, and all those who contributed to this critical study. Most importantly, I wish to thank the respondents for their courage and willingness to share their experiences, which form the foundation of this report.

As we move forward, let us renew our resolve to create a future where stigma and discrimination are no longer obstacles, and where every individual living with HIV has the opportunity to thrive. Together, we can achieve this vision.

Dr. Janaki Vidanapathirana
Director
National STD/AIDS Control Programme

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# Acknowledgements

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Finally, we extend our heartfelt thanks to all individuals living with HIV for their courage in the face of various forms of stigma and discrimination, contributing to the creation of a better world for everyone.

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# List of Abbreviations

| | |
|---|---|
| ART | Antiretroviral Treatment |
| FSW | Female Sex Workers |
| MSM | Men Who Have Sex With Men |
| NSACP | National STD AIDS Control Programme |
| OI | Opportunistic Infections |
| PLHIV | People Living with HIV |
| PWN | Positive Women's Network |
| SEARO | South East Asia Regional Office |
| UNAIDS | United Nations Joint Programme on HIV/AIDS |
| WHO | World Health Organisation |

# Executive Summary

Stigma and discrimination remain formidable challenges for PLHIV, impacting prevention, treatment, care, and support. Despite existing policies envisioning protection from human rights violations, the lack of specific laws and policies perpetuates issues such as income loss, restricted marriage and childbearing options, inadequate healthcare, caregiving withdrawal, diminished hope, and damaged reputation.

United Nations Joint Programme on HIV/AIDS (UNAIDS) defines stigma as a dynamic process devaluing and discrediting individuals, leading to discrimination. This study offers updated insights into current attitudes, beliefs, and issues surrounding HIV and AIDS, facilitating the identification of trends and changes. Evolving policies and healthcare services necessitate a renewed understanding of their impact on PLHIV experiences. Additionally, the study aligns with the UNAIDS 10, 10, 10 targets.

Conducting interviews with 404 PLHIV, the study explores demographics and experiences. Participants, mainly aged 20-60, represent diverse backgrounds, with 75% being male. Noteworthy is the prevalence of MSM (54%), and a majority (66%) coming from the Western Province Districts. Employment rates were high, yet non-disclosure practices correlate with psychological distress. Nearly two-thirds of the participants (65%) were employed. Fifty-one participants (12%) have never been employed.

Duration of living with HIV influences stigma and disclosure, emphasizing the need for tailored interventions. Non-disclosure to family, friends, neighbours, and employers is prevalent, impacting psycho-social well being. Conversely, 70% disclose to other PLHIV, indicating a potential avenue for targeted support. Setbacks in employment and education, likely linked to non-disclosure, are infrequent.

Health-seeking behaviour is proactive, with 66.1% willingly undergoing HIV testing. Informed consent concerns arise, and expanding counselling services is crucial. Confidentiality with healthcare workers is paramount, with non-disclosure practices potentially contributing to limited reported stigma.

The study utilizes the Berger scale for HIV-related stigma and the Kesler scale (K10) for psychological distress assessment. Results indicated 85.1% reporting moderate levels of HIV stigma and 23.3% experiencing psycho-social distress. Fear of gossip, insults, harassment, and assault due to HIV-positive status contributes to moderate stigma levels, aligning with psychological distress data. Respondents showcased fear regarding gossip, insults, harassment, and assault due to their HIV-positive status. Despite infrequent reported instances, the fear itself contributes to the moderate levels of stigma identified in the study, aligning with psychological distress data. Internalized stigma manifests in self-blame, guilt, and shame, impacting life decisions. Human rights violations are reported by 3.7%, with a notable lack of legal redress due to fear of stigma.

Active participation in PLHIV organizations proves essential, offering crucial support. A detailed comparison with previous studies in 2010 and 2018 provides insights into evolving trends.

In conclusion, the study offers a nuanced understanding of the complex interplay between living with HIV, disclosure patterns, stigma, and psycho-social dynamics. Tailored interventions addressing disclosure-related challenges and fostering supportive environments are imperative to enhance the well being of individuals living with HIV in Sri Lanka.

## Key findings should go to the results sections

- A total of 404 PLHIV participated in the study. 46.8% of the respondents were between 40-60 years of age, and 75% were male. 59.6% have obtained secondary education. 65.8% of respondents were from the Western Province.
- Out of the respondents, 64.6% were currently employed. Out of those currently employed, over one-thirds (36.4%) were permanent employees.
- 54.7% of the respondents identified themselves as ‘Men who have sex with men’. 5% of the respondents had injected drugs, while 6.9% used drugs in other forms without injecting. 10.1% were past migrant workers.
- More than one fourth of the respondents (27%, n=109) were suffering from a chronic disease. The most commonly declared chronic diseases among the respondents were Hypercholesterolemia, Diabetes Mellitus and Hypertension. Government hospitals were reached by 74% for acute illnesses, as well as by 90.8% of respondents with chronic diseases.
- 54.5% of the respondents have lived with HIV for five or more years. For 12.9%, the duration of living with HIV has been 15 years or more.
- Assessment of HIV related stigma using the Berger scale revealed that 85.1% of the respondents reported encountering moderate HIV stigma, while 12.6% experienced high HIV stigma. Only 2.2% of the respondents reported low HIV stigma.
- 23.3% of the respondents were found to be experiencing psychological distress during the previous 30 days, as assessed using the Kessler 10 Psychological Distress scale.
- Looking into disclosure patterns of the HIV status to associates among the respondents revealed that 21.5% of the participants haven’t revealed their HIV status to their husband/ wife/ partner. A substantial proportion of 66.3% haven’t revealed to other adult family members. 70% have revealed their HIV status to other PLHIV. Only 6.4% have revealed to healthcare workers except STD clinic staff.

- 8.2% of the participants have experienced verbal insults, harassments and/ or threats based on their HIV positive status during the previous 12 months, while 5.7% have faced physical harassment and/ or threat.
- 61.6% of the participants feared being gossiped about, based on their HIV status, while almost half (49.3%) were afraid of being verbal insulted, harassed and/ or threatened based on their HIV positive status.
- Only a minority of 1.2% have lost their job or another source of income due to their HIV status during the previous 12 months.
- 66.1%, have willingly undergone HIV testing, whereas 24.8% have reported undergoing HIV testing without prior knowledge. 14.1% of the participants have undergone HIV testing for employment purposes, while 28.5% have tested out of their own desire to know the HIV status. For 27.7% of the respondents, the reason for testing has been referral due to suspected HIV related symptoms.
- A majority of 67.8% have accessed HIV testing services through government hospitals or clinics. 62.1% of the respondents have receiving both pre and post-test counselling, while 9.7% of the respondents haven't received any counselling.
- 93.6% of the respondents reported their HIV status was not disclosed by healthcare workers. 90.1% had confidence in the confidentiality of their medical records within healthcare institutions.
- A majority of 91.3% reported that they did not encounter stigma and discrimination when seeking admission to a hospital for specific procedures not related to HIV.
- With regard to internalized stigma, 17.1% had felt suicidal, 37.9% have had low self-esteem and 50% have blamed themselves due to their HIV status, during the previous 12 months, while 39.3% have expressed shame.
- Due to their HIV status, 30% have decided not to have children or to get married and 18.8% have decided to abstain from sexual activities, during the previous 12 months. Choosing to isolate themselves from their families/ friends was seen in 18.1%.

- 98.5% of the respondents had access to anti-retroviral treatment. 95.5% of respondents had received the opportunity to engage in discussions about treatment options and 95.3% of respondents have had the opportunity to engage in discussions about sexual and reproductive health, sexual relations, and emotional well being, with their healthcare service providers. 80.9% have received targeted counselling from healthcare professionals regarding reproductive options following their HIV diagnosis.
- 3.7% (n=15) of the respondents have reported facing human rights violations. 14.9% of the respondents believed that one would be subjected to further stigma and discrimination in seeking legal redress for violation of rights.
- 70.8% of the respondents were members of the PLHIV organizations, and obtained services from them, including mainly counselling services, treatment support and financial support.

# Section 01

# 1. Introduction

## 1.1.Background and Methodology

### 1.1.1. Epidemiology of HIV in Sri Lanka

Sri Lanka has a low HIV prevalence at 0.01 People Living with HIV (PLHIV) per 100,000 population (0.01 per 100,000 blood donors and 0.003 per 100,000 pregnant women). The HIV epidemic is currently concentrated among Key Population groups with an overall positivity rate of 0.5%. The positivity rate among Men who have Sex with Men (MSM) is 1.3%, while among transgender women, it is at 0.4%. The prevalence among Female Sex Workers (FSW) is at 0.1 per 100,000 population (National STD/AIDS Control Programme (NSACP), 2023).

There were 4100 people living with HIV in Sri Lanka, according to 2023 statistics of the National STD/AIDS Control Programme (NSACP). Although new HIV infections in Sri Lanka have remained relatively low, more recent data revealed a 48% increase of new cases in 2022 compared to 2021, of which 13% were females, while 86% were males and 1% were transgender. There were 648 reported cumulative deaths due to AIDS in 2022. The majority of the newly identified cases of HIV during 2022 were between the ages of 25-49 years. A total 82.5% of diagnosed patients were in the HIV stage in 2022. There have been no HIV cases reported due to blood transfusions since 2000, while in 2019 the World Health Organization certified the elimination of mother-to-child transmission for HIV and Syphilis. There are currently 2947 HIV patients under NSACP clinic care, while 1440 of them represent the three networks dedicated to PLHIV in Sri Lanka— Lanka Plus, Positive Women’s Network (PWN) and Positive Hopes Alliance (PHA).

Stigma and discrimination pose significant obstacles to the prevention, treatment, care and support of PLHIV. Despite the National HIV/AIDS Policy and the National Policy on HIV and AIDS in the world-of-work envisioning to protect PLHIV from human rights violations, stigma and discrimination, the PLHIV community continues to suffer from the lack of specific laws and policies that protect and promote their right to enjoy equality and non-discrimination. Negative attitudes through stigma towards HIV have create fear and have discouraged persons from seeking vital HIV information and services to reduce the risk of infection and adopt safer behaviour patterns. The first assessment of stigma among PLHIV in Sri Lanka was conducted in 2009, while the second was done in 2017—covering 150 PLHIV in Sri Lanka.

Stigma and discrimination towards PLHIV have significant consequences, including loss of income, marriage and childbearing options, poor healthcare, withdrawal of caregiving, diminished hope and damaged reputation. Addressing stigma is crucial for controlling and preventing HIV, as it impacts not only individuals but also their families and friends, perpetuating a harmful cycle of social, psychological, and economic challenges. Recognizing the importance of addressing stigma and discrimination, Sri Lanka has taken significant interventions to combat stigma and discrimination and aims to achieve a 10% reduction by 2025. These efforts seek to improve the lives of PLHIV and their families by reducing the social and economic impact of stigma.

### 1.1.2. Addressing Stigma and Discrimination Associated with HIV

Stigma is a term derived from a Greek word that refers to attitudes and beliefs that are associated with negative stereotypes, resulting in the classification of individuals as socially undesirable or rejected. This can affect an individual's reputation, behaviour, or attributes. Stigma can be divided into two types: perceived stigma (or felt stigma) and enacted stigma (or external stigma and discrimination) (Goffman, 1963).

UNAIDS defines stigma as a dynamic process that devalues and discredits an individual in the eyes of others by identifying certain attributes as discreditable or unworthy. When acted upon, stigma results in discrimination, which refers to any form of arbitrary exclusion or restriction based on an inherent personal characteristic or perceived membership of a particular group. Discrimination is a violation of human rights, and in the case of HIV, it can be based on a person's confirmed or suspected HIV-positive status, regardless of any justification for such actions. Stigma can be evaluated based on four components, including personalized stigma, negative self-image, disclosure concerns and public attitudes. These components were first outlined by Goffman (1963) and are commonly used to assess the impact of stigma on individuals (Goffman, 1963).

Stigma can arise from a variety of sources, such as certain diseases, behaviors, or other issues that are considered unacceptable by society. Stigma often arises from myths and phobias that have been passed down through different cultures and religions over time. A lack of knowledge about certain conditions and the possibility of cure is a major factor contributing to stigma among certain groups. Stigma and discrimination can have serious consequences, including negative impacts on health, social well being and economic opportunities. Stigmatized individuals may avoid seeking healthcare, leading to the spread of communicable diseases like HIV and creating a significant burden on public health systems and the economy. As a result of the stigma they experience, some individuals may develop depression and even consider suicide or self-harm. However, if stigma is reduced, these individuals may feel more comfortable accessing healthcare services and receiving treatment. Therefore, it is crucial to evaluate and address stigma among vulnerable populations to reduce its impact.

## 1.2. Justification

The quality of life is recognized as an indicator of the comprehensive health status of a person and stigma affects the quality of life of PLHIV. Stigma is identified as one of the main barriers that keeps the PLHIV community away from seeking health services. UNAIDS identifies separate 10-10-10 targets to improve the target of less than 10% of countries having punitive legal and policy environments that deny access to services, less than 10% people living with HIV and key populations experiencing stigma and discrimination, less than 10% women and children with HIV and key populations experiencing gender inequalities (2025 AIDS Targets, 2021). In line with the 2025 targets laid down by UNAIDS, Sri Lanka is geared to reduce stigma and discrimination among PLHIV to less than 10% by 2025. Many programmes and activities are being conducted to reach this target. However, research on stigma and discrimination among people living with HIV in Sri Lanka has not been carried out during the last five years, and social and cultural attitudes towards HIV and AIDS may have changed since the previous studies. Although 1st and 2nd stigma assessment among the PLHIV in Sri Lanka were conducted in 2009 and 2017 respectively (Vidanapathirana et al., 2017), the Berger HIV Stigma Scale short version (Reinius et al., 2017) which is considered as a tool to assess stigma among the people with HIV had not been used for these assessments. Also, the previous stigma surveys conducted among PLHIV have not assessed the psychological distress among PLHIV in Sri Lanka. Psychological distress and stigma go together, and it is important to assess psychological distress among the Sri Lankan PLHIV population. The current Sri Lankan HIV/STI strategic plan (2023-2027), previous Sri Lankan HIV/STI strategic plan (2019-2023) and Sri Lankan HIV/AIDS policy (2011) also recognize the elimination of stigma and discrimination among PLHIV as a strategy to increase utilization and access to services (NSACP, 2011; NSACP, 2019; NSACP, 2023). This research also studied the level of psychological distress among Sri Lankan PLHIV using the Kessler 10 Psychological Distress scale (Kessler et al., 2003).

This study provides updated information on the current attitudes, beliefs and issues pertaining to HIV and AIDS and helps to identify any changes or trends over time, thus providing recommendations into how they can be addressed. Policies and healthcare services related to HIV and AIDS have evolved since the last study. The new study provides an updated understanding of how these changes are impacting the experiences of PLHIV in Sri Lanka. Also, this study could be used to assess the 2nd target of the 10, 10, 10 targets of the UNAIDS.

Sri Lanka, as a member state of the United Nations, adopted ambitious targets of 95%-95%-95% (Frescura et al., 2022). By 2025 a total 95% of people with HIV should know their HIV status and a 95% target is set for people diagnosed with HIV to receive Anti-Retroviral Treatment (ART). The progression of the 95-95-95 target achievement at the end of year 2022 was 86%, 68% and 59%, respectively (NSACP, 2023). A major proportion of these targets consists of access and utilization of sexual health service, and it is affected by the existing stigma and discrimination towards the PLHIV community.

This research identifies the extent of stigma and discrimination and psycho-social distress among PLHIV, and provides insights into the barriers they face in accessing HIV prevention and treatment services. Even though the Ministry of Health has implemented various prevention and control measures, including expanding access to HIV testing and counselling, providing antiretroviral therapy to PLHIV, and promoting condom etc., there is still much to be done to ensure that all PLHIV in Sri Lanka have access to the HIV prevention and treatment services including psycho-social services that they need, where reduction of stigma and discrimination towards HIV could play a major part. This study also emphasizes the need for public education and awareness campaigns to reduce stigma and discrimination and provide support to people living with HIV.

This evidence is planned to be further used for the Global Fund GC7 proposal (USD 6.3 million) which is expected to be submitted by February 2024. This study is expected to contribute to identifying newer stigma reduction interventions, and new evidence from this study will contribute to strengthen Sri Lanka’s funding request to the Global Fund. Sri Lanka’s goal of elimination of HIV by 2030 will not be a reality if the targeted interventions are not delivered through efficient and evidence-based interventions. Therefore, the findings of the study will give an understanding as to what extent the new stigma strategies and activities should be implemented targeting PLHIV.

## 1.3. General Objective

1. To assess the stigma and discrimination associated with HIV and psycho-social distress among people living with HIV in Sri Lanka.

## 1.4. Specific Objectives

1. To describe the socio-demographic and economic profile of people living with HIV in Sri Lanka.
2. To conduct a judgmental validation of the Berger scale to assess stigma among people living with HIV in Sri Lanka.
3. To assess the status of stigma among people living with HIV in Sri Lanka using validated Berger HIV Stigma Scale.
4. To describe the status of psycho-social distress among people living with HIV in Sri Lanka using the Kessler Psychological Distress Scale (K10).
5. To describe the impact of HIV on the lived realities of the people living with HIV in relation to stigma and psycho-social distress.
6. To compare the current findings with the initial and subsequent stigma assessment studies among people living with HIV in Sri Lanka.

# 2. Methods

## 2.1. Study Design

This study was a descriptive cross-sectional study conducted in Sri Lanka. The study design was a network based, and assisted online based, descriptive cross-sectional study.

## 2.2. Study Population

The study population included all patients diagnosed as having HIV using a confirmatory test, irrespective of their antiretroviral treatment status, in all districts of Sri Lanka.

## 2.3. Study setting

Data collection was conducted at three positive organizations (Lanka Plus, Positive Women Network and Positive Hopes Alliance). Members of these organizations are spread across the country and access these organizations regularly for support to access HIV related services.

Data was also collected online to reach PLHIV who are not members and who are not associated with the above-mentioned organizations. This outreach was done through PLHIV peer educators or outreach workers who are already working within the national HIV response. This is explained in detail below.

## 2.4. Inclusion Criteria

PLHIV who were diagnosed for more than 3 months.

## 2.5. Exclusion Criteria

- Patients with HIV who are acutely ill at the time of the survey.
- PLHIV who are below 18 years of age.
- PLHIV who are taking current treatment for mental diseases.

## 2.6. Study Period

**1st of November to 15th of December 2023**

## 2.7. Sample size

As there were no local studies which used the validated Berger HIV Stigma Scale and K10 scale, and a composite percentage of stigma among PLHIV in Sri Lanka could not be determined, an expected prevalence rate of 50% was used, providing a reasonable baseline for sample size calculation and ensuring adequate representation of PLHIV experiencing stigma-related factors.

To calculate the sample size required for the proposed study, the Lwanga & Lemeshow formula (1991) was used (Lwanga & Lemeshow, 1991):

$n = [Z^2 \times P \times (1-P)] / d^2$

**Z** = 1.96 (for a 95% confidence level)

**P** = 0.50 (expected prevalence of stigma and discrimination)

**d** = 0.05

$n = (1.96)^2 * 0.5(1-0.5) / 0.05*0.05$

$= 0.9604/ 0.0025$

$= 384.16$

After adding a non-response rate of 5%, the final sample size would be:

$n = 384.16 * 100/95$

$= 404.37$

Therefore, a sample of **404** people living with HIV was interviewed using an interviewer administrated questionnaire, to assess the stigma and discrimination and psychological distress which they experienced.

Out of the PLHIV in Sri Lanka, the majority belong to the membership of the three PLHIV networks. Therefore, in this study, 75% of the participants (n= 303) out of the total sample of 404, who are accessible through the networks, were administered the questionnaire by trained interviewers, while the remaining 25% of the participants (n=101) were accessed virtually for data collection.

## 2.8. Sampling technique

The PLHIV community in Sri Lanka could be roughly categorized in to three: 01. PLHIV who are members of PLHIV organizations and who access HIV services through government clinics; 02. PLHIV who are newly diagnosed, not connected with PLHIV organizations and are accessing HIV services through government clinics; and 03. PLHIV who are not connected with PLHIV organizations and who are not accessing HIV services in Sri Lanka. The majority of PLHIV belong to the first category. PLHIV who are from younger cohorts and are socio-economically somewhat affluent belong to the second category, and the third category is a significantly small percentage. Based on the above, the data collection was done as follows.

Multi-model recruitment method was used to recruit the required sample.  This method includes both purposive sampling from the People living with HIV (PLHIV) network organizations and the online method. Traditional recruitment methods were combined with internet-mediated recruitment methods to form a multi-model recruitment strategy (McRobert, 2018). The objective of using this multi-model recruitment method was to capture both PLHIV who belong to PLHIV networks as well as PLHIV who are not associated with PLHIV networks. This helped reach a sample that would be representative of the PLHIV in Sri Lanka.

Members of these organizations visited the centres of the three organizations for various purposes (none of the organizations have branches). Irrespective of the days and their socio-demographic factors, PLHIV visit these places for various requirements. A reasonable number of PLHIV visit all three organizations.

Randomly selected days were decided, and data was collected from the PLHIV who visit the organizations. It was proposed that based on the purposive method 303 (75%) PLHIV be interviewed from these centres. Purposive sampling gives better insights and more precise research results. Because the researcher collects information from the best-fit participants, the results are relevant to the research context. However only 296 responses were collected through the organisations.

This method was combined with the online method to recruit PLHIV who typically belong to a higher socio-economic level and who do not associate with PLHIV networks. The purposive sampling method was used for the assisted online method, and initially expected to contact 101 PLHIV (25%). A total of 108 participants were reached through this method. Online respondents were reached through peer educators/outreach workers of organizations which deliver HIV services. These peer educators and outreach workers are in touch with their peers or clients who have had a positive diagnosis and who have no association with PLHIV organizations.

# 3. Data Collection Tool

## 3.1. Study Instruments

The data was collected using the interviewer administrated questionnaire for both participants of the physical and assisted online interviews. The questionnaires were the same although the mode of administration was different.

This instrument was developed by the principal investigating team following a thorough literature review and with the help of experts in the area of interest. The National STD/AIDS Control Programme was consulted for technical clarifications and final approval of the questionnaire.

Hence, an Interviewer administered questionnaire, which was pre-tested among PLHIV, was used for data collection. The questionnaire had the following sections.

**SECTION A-** Socio-economic and demographic data.

**SECTION B -** Part I - Experiences, feelings, and opinions - Berger Scale.

Part II - Experiences of stigma and discrimination.

Part III - Employment and education.

Part IV- Stigma in healthcare setting.

Part V- Internalized stigma.

Part VI - Rights, laws, and policies.

Part VII – Psychological impact- K 10.

Part VIII - Effective change.

## 3.2. Psycho social impact of stigma on PLHIV

Stigma and discrimination surrounding HIV/AIDS continue to be formidable barriers to the psycho-social well being of individuals living with HIV. The pervasive societal stigma attached to HIV often results in feelings of shame, guilt, and isolation among those affected. This psychological burden can significantly impact mental health, leading to increased rates of anxiety and depression. Studies have shown that the fear of judgment and rejection from peers, family and the broader community can hinder individuals from seeking necessary medical care and support, exacerbating the physical and psychological consequences of HIV.

Moreover, discrimination against people living with HIV not only affects their emotional state but also their social relationships and opportunities. Employment discrimination is a significant concern, with individuals facing job loss, reduced job opportunities, and workplace harassment due to their HIV status. Such experiences contribute to economic stress and can further undermine the psycho-social well being of those living with HIV. The intersectionality of stigma, encompassing not only HIV status but also factors like gender, race and sexual orientation, compounds the challenges faced by affected individuals, highlighting the need for multifaceted interventions to address the complex interplay of social determinants.

Efforts to combat stigma and discrimination surrounding HIV/AIDS must be comprehensive and involve public health campaigns, education programmes and legal protections. The success of interventions relies on fostering an environment of empathy, understanding and support, both within communities and institutions. By challenging stereotypes and promoting inclusivity, the society can contribute to the improved psycho-social well being of people living with HIV, ultimately reducing the negative impact of stigma on mental health and social integration. This approach aligns with the global commitment to achieving the United Nations' Sustainable Development Goal 3, which aims to ensure healthy lives and promote well-being for all, including those living with HIV/AIDS.

## 3.3. Berger Scale for assessment of Stigma among PLHIV

The Berger HIV Stigma Assessment tool was incorporated as part I of section B when compiling the questionnaire. The short version of the Berger scale was used to assess the stigma among PLHIV. It has 12 items in total, assessing personalized stigma (3 items), Disclosure concerns (3 items), Concerns about public attitudes (3 items) and Negative self-image (3 items). It has been used widely globally and not validated in Sri Lanka. Therefore, it was decided to conduct a judgmental validation of the Berger Scale.

## 3.4. Judgmental validity of the Berger Scale

The 12-item short version of the Berger Scale which is used for assessing HIV stigma was validated through a judgmental validation process. The face validity, content validity and the consensual validity of the instrument were assessed. The face validity was assessed by evaluating the relevance of the Berger Scale to the main domains under investigation, including disclosure concerns, concerns about public attitudes, personalized stigma and negative self-image. Then content validity of the instrument was assured with the meticulous process followed during the translation process and it was complemented with the assessment by the panel of multi-disciplinary experts involved. In addition to assessing the face and content validity of this scale, it was assessed by the selected group of identified experts for consensual validation under three aspects, using the Delphi Technique.

For consensual validation, a structured format was developed for obtaining the inputs of the experts about the scale based on the relevance in assessing HIV stigma, appropriateness of wording used and the cultural acceptability in the local context. The experts were requested to score each question on the above three aspects. The scores for each aspect were expected to be given out of five marks.

The expert group consisted of six members, including two Venereologists, two Consultant Community Physicians, a Sociologist and a PLHIV, selected based on their experience of working with PLHIV and their awareness on the social context of PLHIV. It was ensured that the panel consisted of individuals who had extensive knowledge and/or experience in the subject.

Each item was accepted as it was, if the scores given by each expert for the three aspects were either 4 or 5. If the score given for at least one of the aspects was 3 or less, the experts provided comments for improvement of the item, as requested in the structured format. In the first round, scores of three or less were received for only 4 items out of the 12, and slight changes were made to the respective items based on the comments received.

The version with the modifications incorporated was shared again with the experts and all the experts came to consensus on the modified version, and it was decided as final to be included in the questionnaire to be administered.

## 3.5. Assessment of the Kessler Psychological Distress Scale (K10)

The Kessler Psychological Distress Scale (K10) was incorporated as Part VIII of the questionnaire. The Kessler's psychological distress scale (K-10) consists of 10 items, which enquire about the feelings of an individual during the last 30 days. This K-10 questionnaire has been validated previously in Sri Lanka (Wijeratne et al., 2011). The respondents were expected to answer all the items with regard to how often they experienced that sort of feeling using a five-point scale. The frequency ranged from "none of the time" to "all of the time", where scores ranged from 0 to 4 for "none of the time" to "all of the time".

## 3.6. Pre-test of the instrument

Pretesting was done among five PLHIV who did not participate in the research as respondents approached physically or virtually. Furthermore, timing of the questions was assessed, and modifications were incorporated into the guide.

# 4. Data collection

1. **Interviewer administered questionnaire** among individuals from the three PLHIV networks in Sri Lanka.
2. **Assisted virtual data collection** was done among PLHIV who do not belong to any of the PLHIV networks. It was assisted by the online data collectors.

The same questionnaire was used for both physical and online administration. However, the information sheet was different for the two groups (Annex 1 and Annex 2).

## 4.1. Data Collectors

### 4.1.1. Data Collectors for Physical data collection

Six data collectors were recruited from the three PLHIV organizations (2 from each organization) who collected data from PLHIV networks. The PLHIV organizations maintain regular contacts with their members and support them for ART access and adherence. This relationship among members and the organization was used by the data collectors to reach out to respondents. All interviewers were PLHIV, drawn from existing community networks of people living with HIV. This was a joint exercise with a participatory spirit for all those involved. People living with HIV were at the centre of the process as interviewers and interviewees and as drivers of how the information was collected. The data collectors explained the purpose and objectives of the study to the participants and sought their written consent to participate. It took about 45 minutes to complete the survey.

### 4.1.2. Data Collectors for virtually assisted data collection

A number of key population organizations are currently operating as implementers of national HIV prevention interventions under the support of the Global Fund. Peer educators and outreach workers of these organizations escort clients for testing and in case of positive results facilitate the linkage between the client and the preferred STI clinic. These peer educators and outreach workers also continue their relationship with the clients who have received positive results. In consultation with these organizations, three virtual data collectors were recruited who in turn reached out to their previous/current clients through online means. The assisted virtual interviews were conducted mainly on phones using regular calls or other call platforms such as WhatsApp, and the participants were provided with the necessary instructions to participate. Each online data collector reached out to their current or previous clients and sought initial willingness to take part in the study. Upon their willingness, the online data collector sent the information sheet and the consent form to the respondent one day – 2 hours prior to the interview. The online data collector then set up a time with the respondent to conduct the interview online. As the questionnaire was long and some respondents needed support in understanding the questions, the online data collector interviewed the respondents and filled the questionnaire themselves on behalf of the respondent. At the start of the online interview, the online data collector explained the study and its objectives, provided clarifications required and then requested the respondents to send the consent form with their e signature or as a picture of the signed hard copy.

Through these two methods, data was gathered from a diverse group of PLHIV who belonged to diverse socio-economic demographics.

## 4.2. Training for data collectors

### 4.2.1. Training of assisted online data collectors

A one-day training programme was conducted for both physical and online data collectors. The training provided them with an understanding of the history, rationale, objectives and the components involved in the People Living with HIV Stigma Index, Berger Scale and the K10 questions. As these recruits are engaged in the national HIV programme, they have comprehensive understanding of HIV and related stigma. Hence a one-day training was conducted. The training provided an opportunity to consolidate their own understanding of the key concepts associated with HIV related stigma and discrimination, and to reflect on some of their own experiences. This training session gave additional capacity building on how to conduct assisted online data collection. Practical situations in online data gathering were discussed during the training.

## 5. Avoiding of duplication

To avoid duplication of data, each participant was assigned a Unique Identification Code (UIC). The UIC was generated by using the first letter of the first name of the interviewer/ last 4 digits of the respondents NIC, code number of the respondent's resident district/ response number.  The UIC was assigned sequentially as participants enrolled in the study. The participant's name and personal identifying information were not collected, and were not used in the study. The assigned UIC was used to identify the participant in all study documents, including the questionnaire and data entry forms.

## 6. Data Entry

Data entry was done using SPSS 21 version. The questionnaires were coded completely before entering. The data entry, data cleaning and data analysis were done by the research team. The data was randomly checked for accuracy.

## 7. Data Analysis

The data collected through the questionnaire was entered into a secure database for analysis. Data entry and analysis were carried out using the SPSS Version 21 Software. Descriptive data with regard to the different demographic and socio-economic characteristics of the participants, as well as their views and perceptions, were presented as frequencies in graphs and tables, as appropriate.

Based on the responses received for the 12-item Berger Scale, scores were given, and the total score for each participant was obtained by summing the individual scores received. The level of HIV stigma in the sample was categorized, based on the total scores.

As for the K-10 psychological distress scale, since it has been validated in Sri Lanka, the cut-off determined was used in this study to categorize the participants for presence or absence of psychological distress.

## 8. Ethical Issues

Participant details which disclose their identity was not collected at any point of the study. The research was thoroughly explained to the participants, and informed written consent was taken at the recruitment stage of the study. The study participants were informed that refusal to participate would have no impact on their privacy and confidentiality or access to services.

The confidentiality of the collected data was well-maintained by the research team by keeping the collected data under lock and key, and the data will be securely kept for 3 years and disposed of after that.

At any point of the study, information of PLHIV clients at STI clinics were not accessed. Respondents were reached through the existing connections of the PLHIV organizations, peer educators and outreach workers.

For respondents of physical interviews, a modest allowance was provided to cover food costs and any other incidental expenses. Online respondents were not provided with an allowance as it is assumed that they were taking the online interviews during their own free time.

It is expected that some of the respondents may experience psychological distress when talking about their previous experiences of stigma and discrimination. Each respondent was provided with a leaflet that carries information on free psychological services that could be accessed. If the respondents needed more support, the data collectors were guided to link them to required services through the PLHIV organisations or other organisations.

## 9. Consent

- The data collectors described in detail the purpose of this study to potential respondents and sought consent.
- Physical consent forms were signed by respondents who faced physical interviews for data gathering.

- The consent forms were sent to online respondents one day – 2 hours prior to the interviews. Once the study was explained and any clarification questions were answered, the online data collectors got the consent form with an e-signature or asked the respondents to send a picture of the signed hard copy of the consent form.

## 10. Ethical clearance

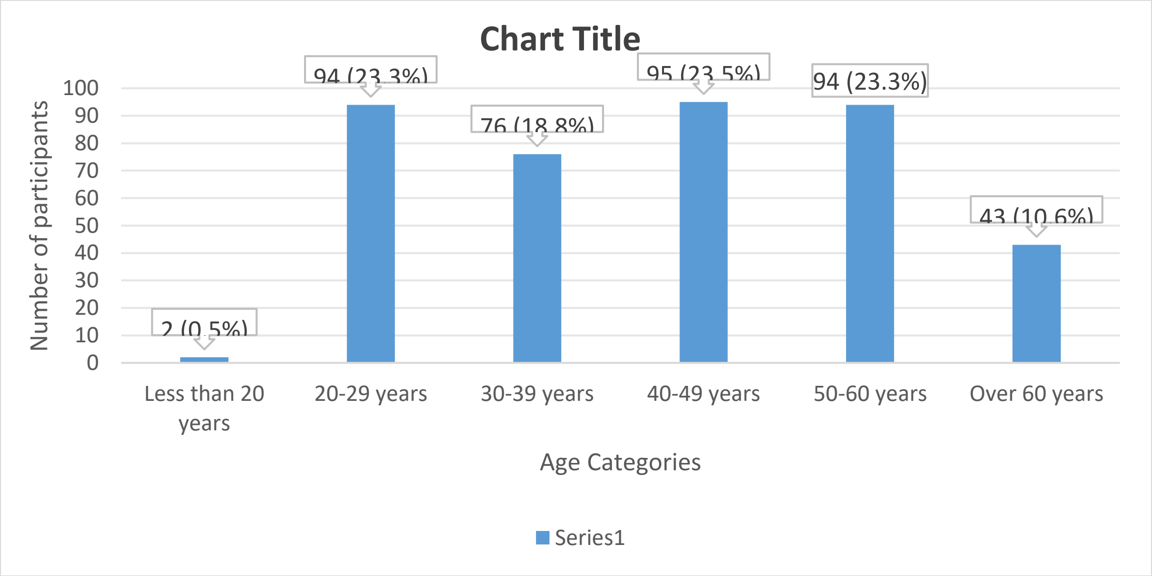
Ethical clearance for the study was obtained from the Ethics Review Committee of the Faculty of Medicine, University of Colombo and the Ethics Review Committee of World health organisation (WHO) South East Asia Regional Office (SEARO).

# Section 02

## Socio economic background of study participants

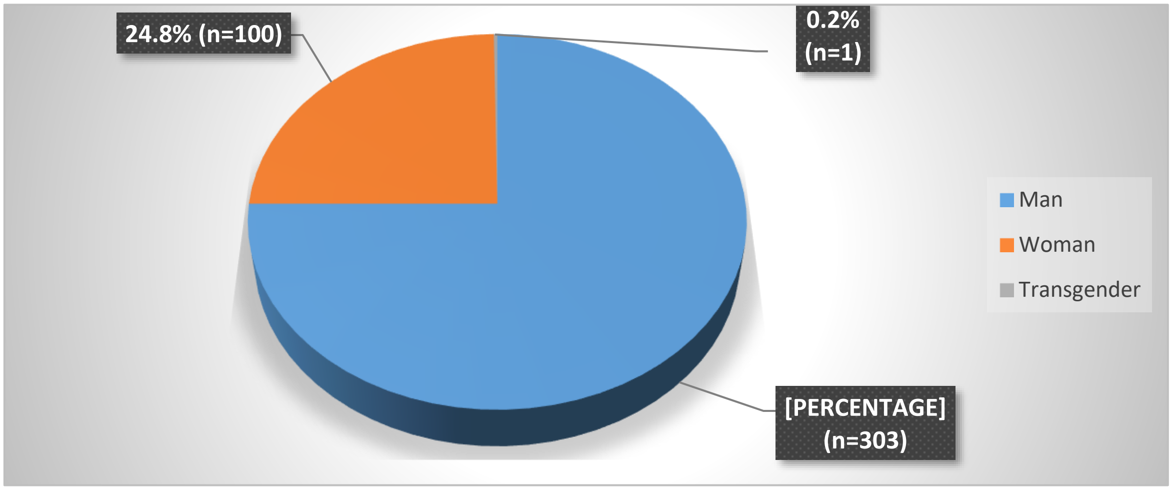
A total of 404 people living with HIV were interviewed during the study. 296 participants selected from the networks of people living with HIV were interviewed in person. The remainder of 108 comprised of non-members who were in contact with the networks and were interviewed online or via telephone.

**Graph 1 - Age distribution of the study participants**



Almost 90% of participants were between 20-60 years of age. Just below half (46.8%) were between 40-60 years of age.

**Graph 2 - Gender distribution of the study participants**



Three fourths of the participants (75%) were male. Only one participant (0.2%) identified as transgender, while 24.8% were women.

**Table 1 - Distribution of the marital status of the study participants**

| Marital Status | Frequency | Percentage |
|---|---|---|
| Married or cohabiting and husband/ wife/ partner is currently living in household | 156 | 38.6 |
| Married or cohabiting; but husband/ wife/ partner is temporarily living/ working away from the household | 4 | 1.0 |
| In a relationship, but not living together | 17 | 4.2 |
| Single | 178 | 44.1 |
| Divorced/Separated | 19 | 4.7 |
| Widow Widower | 30 | 7.4 |
| **Total** | **404** | **100.0** |

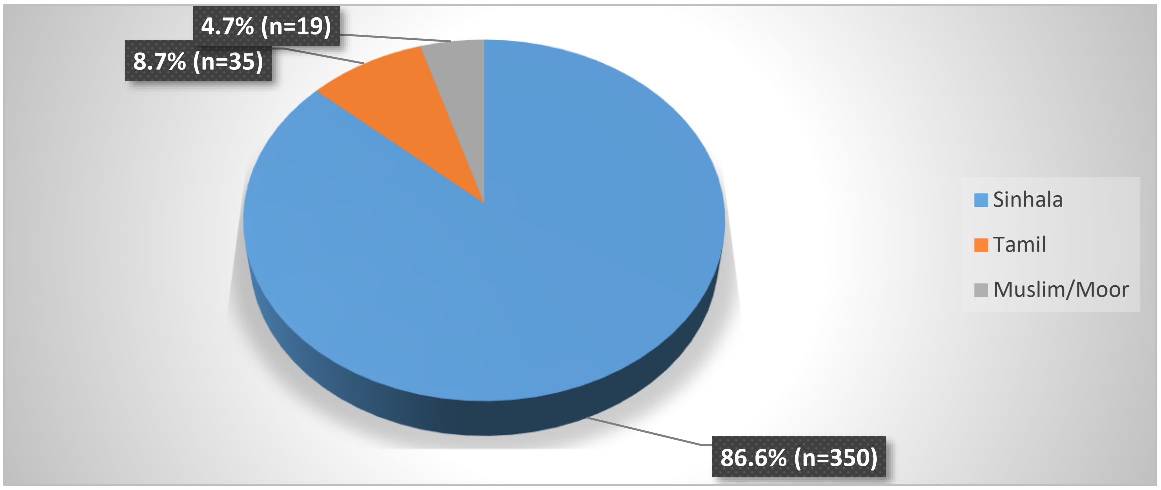
Over 40% of the participants identified themselves as single. Almost 40% were living with the partner in the same household, but only 1% had their partner living away from home.

**Table 2 - Distribution of the number of children of the study participants**

| **Number of children** | **Frequency** | **Percentage** |
|---|---|---|
| 0 | 211 | 52.2 |
| 1 | 67 | 16.6 |
| 2 | 83 | 20.5 |
| 3 | 37 | 9.2 |
| 4 | 5 | 1.2 |
| 5 | 1 | 0.2 |
| **Total** | **404** | **100.0** |

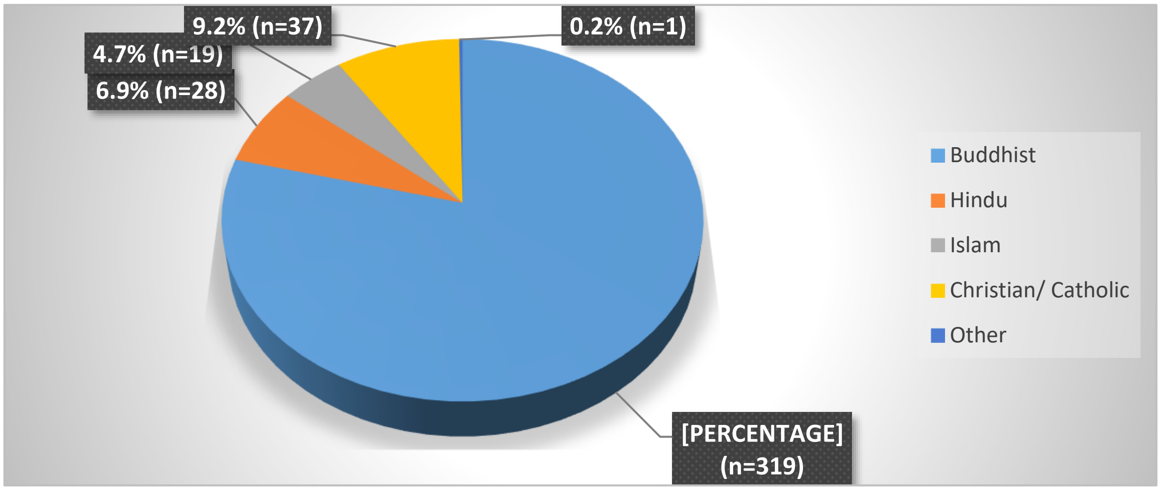
More than half of the participants (52%) didn't have any children. 46.3% of participants had 1 – 3 children. Only one (0.2%) had five children.

**Graph 3 - Ethnicity distribution of the study participants**



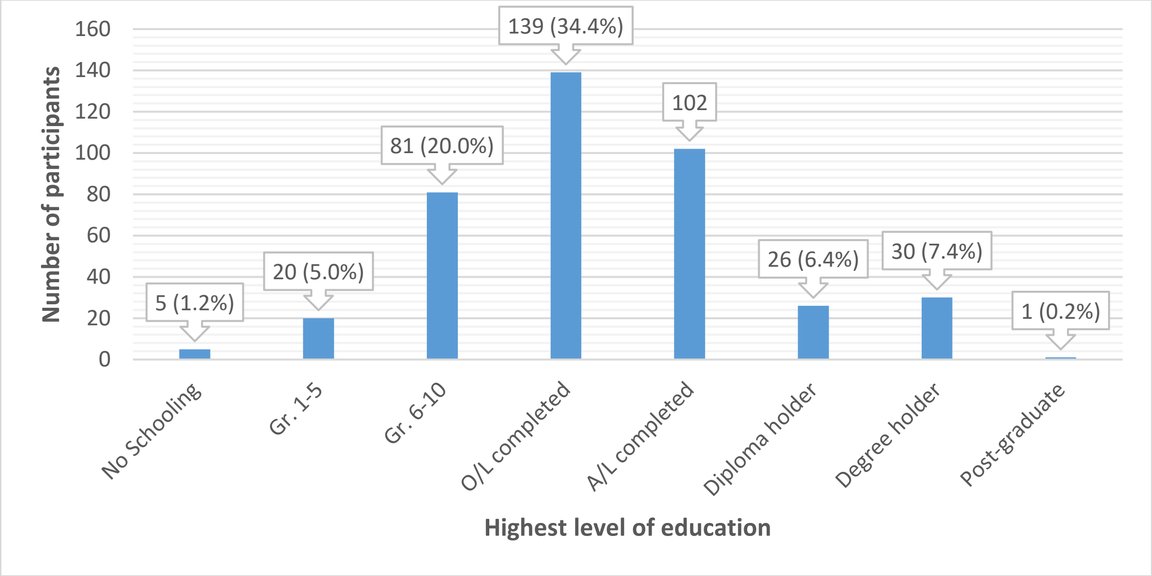
Almost 90% of the participants identified as Sinhala. This is 15% higher than the national percentage of 75%. The others were Tamil or Muslim/ Moor. There were no participants from smaller ethnic minority groups (e.g. Burgher).

**Graph 4 - Religion distribution of the study participants**



Almost 80% of the participants were Buddhists. This is 10% higher than the national average of 70%. One person (0.2%) identified themselves as 'Other'.

**Graph 5 - Distribution of the highest level of education of the study participants**



Five participants (1.2%) have had no schooling. The majority (59.6%) have completed Ordinary Level (34.4%) and Advanced Level (25.2%) – which qualifies as secondary education. Over 7% have obtained degrees, with one participant having a post-graduate degree.

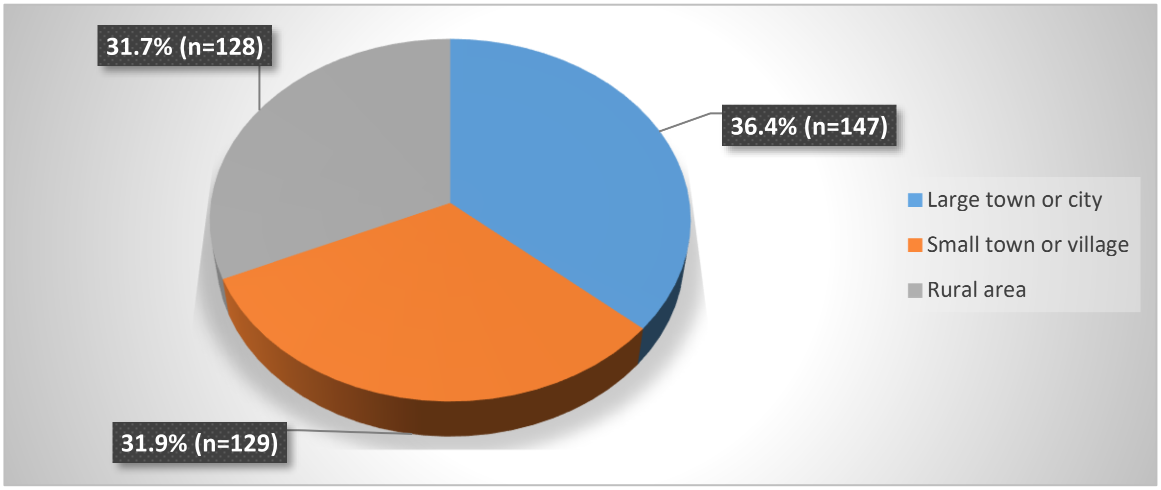
**Table 3 - Distribution of the district of residence of the study participants**

| District of residence | Frequency | Percentage |
|---|---|---|
| Colombo | 156 | 38.6 |
| Kalutara | 22 | 5.4 |
| Gampaha | 88 | 21.8 |
| Galle | 23 | 5.7 |
| Matara | 12 | 3.0 |
| Hambantota | 3 | 0.7 |

| | | |
|---|---|---|
| Kandy | 16 | 4.0 |
| Nuwaraeliya | 6 | 1.5 |
| Matale | 5 | 1.2 |
| Puttalam | 15 | 3.7 |
| Kurunegala | 11 | 2.7 |
| Anuradhapura | 4 | 1.0 |
| Polonnaruwa | 7 | 1.7 |
| Badulla | 3 | 0.7 |
| Monaragala | 2 | 0.5 |
| Ampara | 4 | 1.0 |
| Trincomalee | 2 | 0.5 |
| Ratnapura | 9 | 2.2 |
| Kegalle | 14 | 3.5 |
| Jaffna | 1 | 0.2 |
| Vavuniya | 1 | 0.2 |
| **Total** | **404** | **100.0** |

Almost two-thirds (65.8%) of participants were from the Western Province Districts of Colombo, Gampaha and Kalutara. The sample represented participants from 21 of the 25 districts in the country, and there were no participants from Batticaloa, Mannar, Kilinochchi and Mullaitivu districts.

**Graph 6 - Distribution of the geographic specification of the residence of the study participants**



The participants came from mixed areas of residence, with similar proportions from large towns or cities, small towns or villages and rural areas. Of these, the highest number was from large towns or cities (36.4%). This is likely because the majority of participants came from the Western Province which is the most urbanized and densely populated region in the country.

**Table 4 - Distribution of the study participants on present or past belonging to key populations and other risk groups for HIV**

| **Belonging to key populations** | **Number out of total respondents** | **Percentage out of total participants** |
|---|---|---|
| Men who have sex with men | 221 | 54.7 |
| Female Sex worker | 2 | 0.5 |
| Male Sex worker | 3 | 0.7 |
| Transgender woman | 0 | 0.0 |
| Transgender man | 1 | 0.2 |
| Prisoner | 4 | 1.0 |
| People Who Inject Drugs | 20 | 5.0 |
| People Who Use Drugs (without forms of injecting) | 28 | 6.9 |
| Migrant worker | 41 | 10.1 |
| Tourism Service Provider (Beach Boy) | 0 | 0.0 |
| Not belonging to any of the categories | 141 | 34.9 |

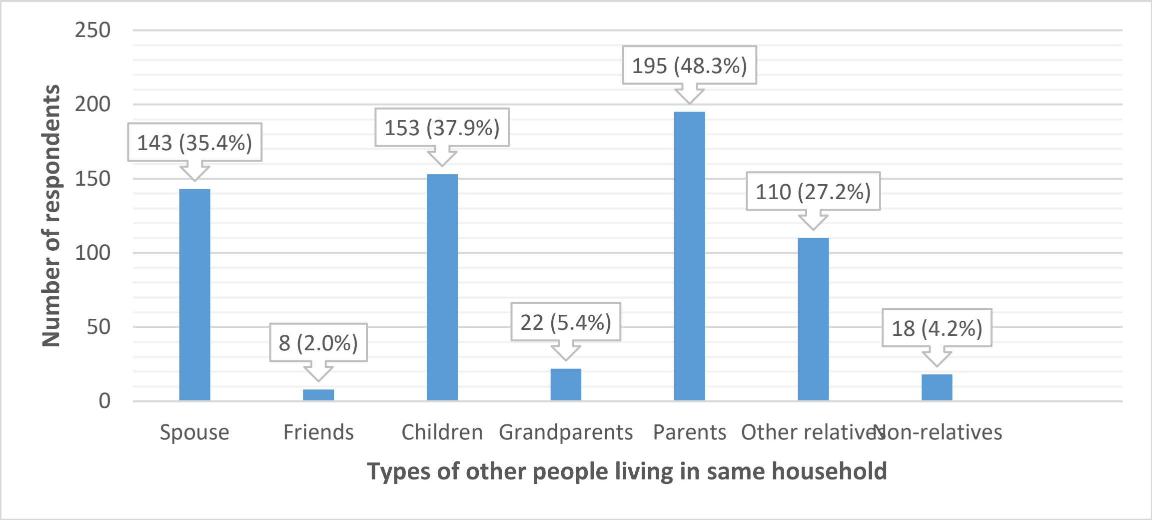
More than half of the participants (54.7%) identified themselves as ‘Men who have sex with men’. 10.1% of the participants were migrant workers. 5% injected drugs, while almost 7% claimed to have used drugs without injecting. Almost 35% identified as not belonging to any of the given categories. One participant identified as transgender man, while there were no transgender women participants.

**Table 5 - Distribution of the number of other people living in the same household with the study participants**

| Number of people | Frequency | Percentage |
|---|---|---|
| 0 | 28 | 6.9 |
| 1 | 36 | 8.9 |
| 2 | 74 | 18.3 |
| 3 | 53 | 13.1 |
| 4 | 32 | 7.9 |
| 5 | 22 | 5.4 |
| 6 | 11 | 2.7 |
| 7 | 5 | 1.2 |
| 8 | 2 | 0.5 |
| Missing data | 141 | 34.9 |
| **Total** | **404** | **100.0** |

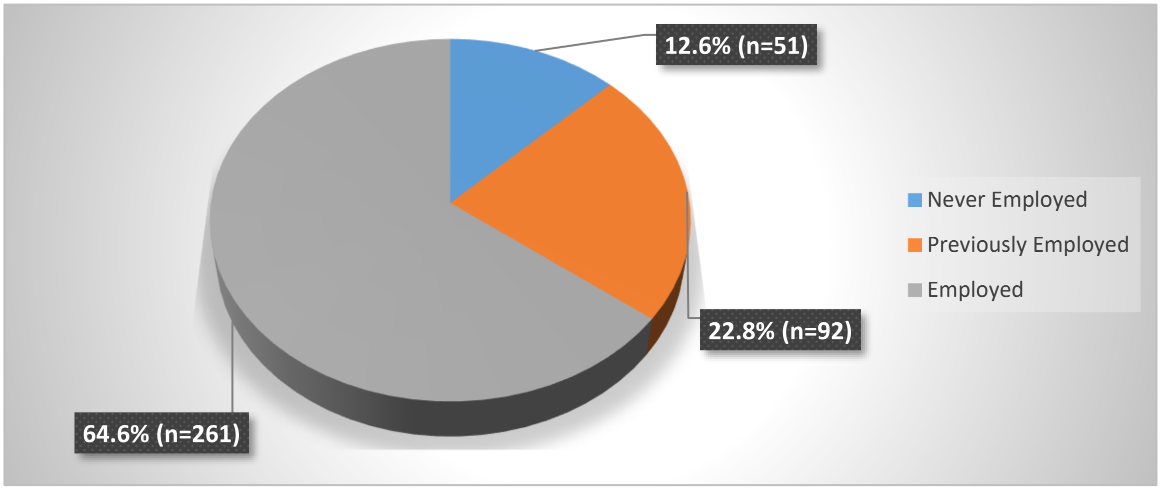
This question was answered by only about 65% of the participants. There were 28 participants who claimed to be living alone in the household.

**Graph 7 - Distribution of the types of other people living in the same household with the study participants**



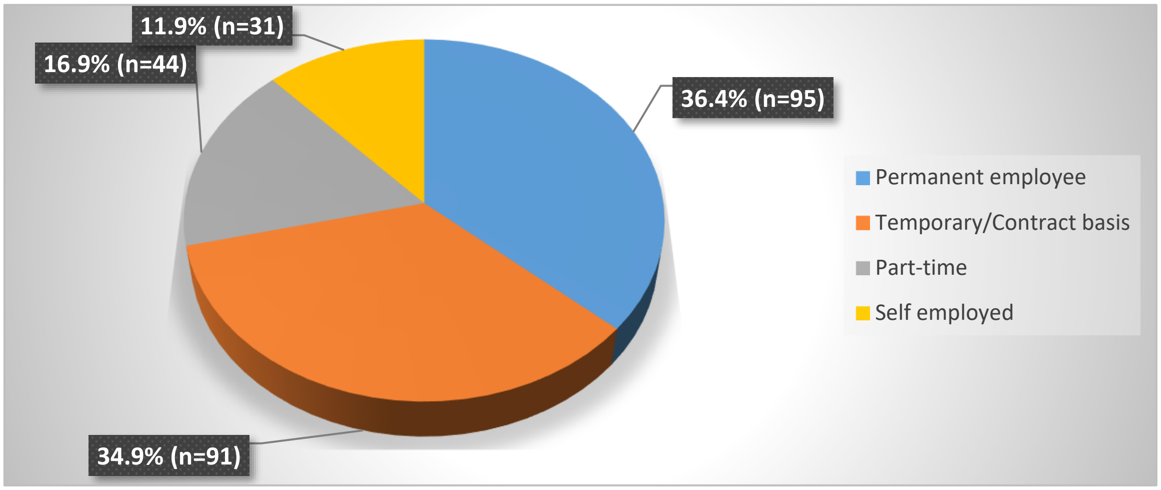
Many of those who lived with others at their residences, lived with parents, spouses and children. Around one-fourth of the participants (27%) also had other relatives living with them.

**Graph 8 - Distribution of the employment status of the study participants**



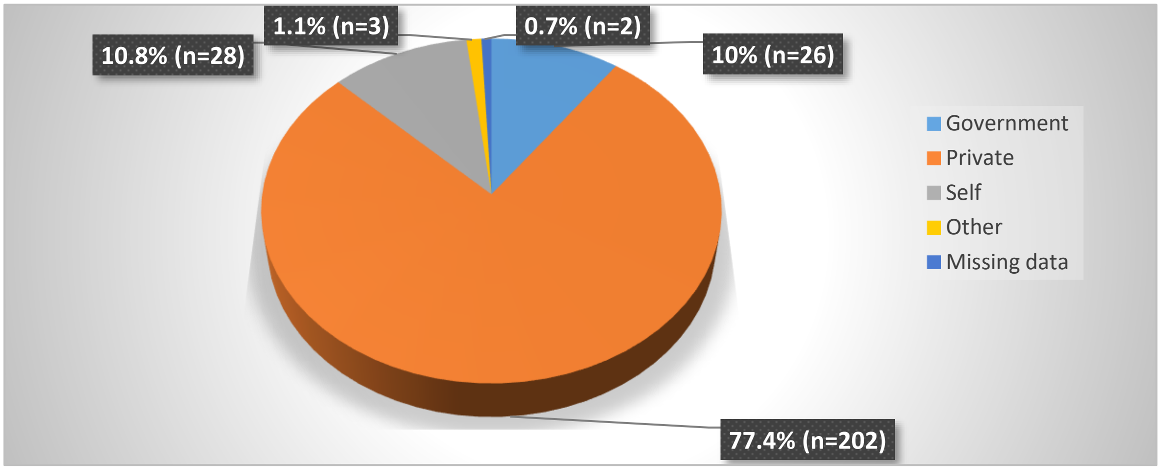
Nearly two-thirds of the participants (64.6%) were employed. Fifty-one participants (12.6%) have never been employed.

**Graph 9 - Distribution of the nature of employment of those who are currently employed among the study participants (n=261)**



Of those currently employed, over one-third (36.4%) were permanent employees, while another 34.9% were working on temporary/contract basis. Just over 10% were self-employed.

**Graph 10 - Distribution of the type of employer of those who are currently employed among the study participants (n=261)**



Of those currently employed, the majority (77.4%) were in the private sector, while 10% were government employees and another 10.8% were self-employed. The three participants in the ‘Other’ category were working in the semi-government and NGO sectors.

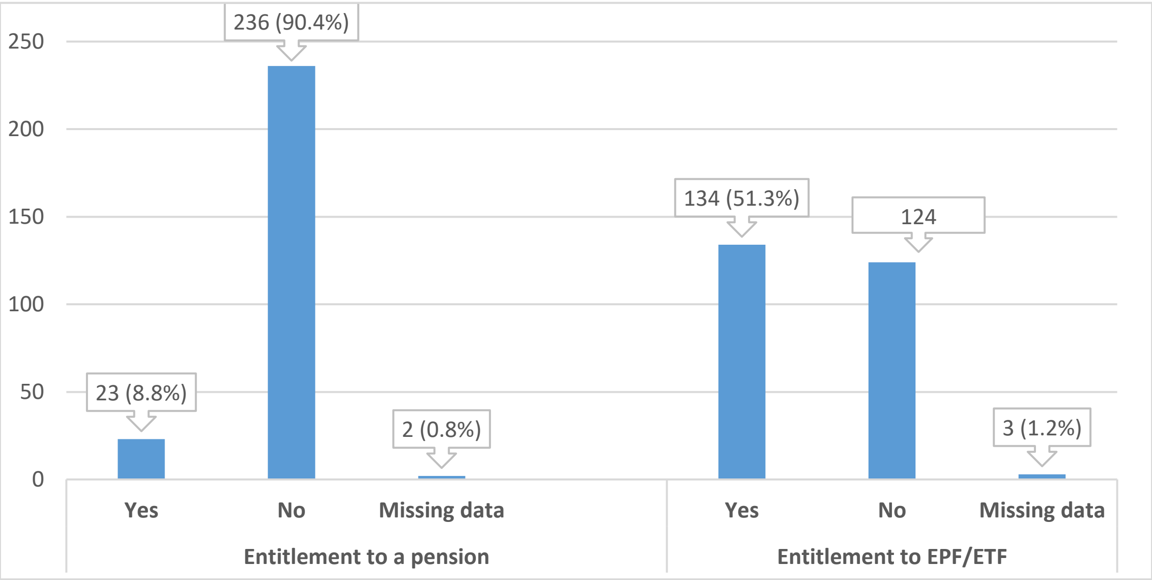
**Table 6 - Distribution of designations of the employed participants among the study sample (n=261)**

| **Designations** | **Frequency of responses** |
|---|---|
| Accountant | 6 |
| Armed forces / Police/ Prison Officers | 9 |
| Beautician / Hairdresser/ Spa worker | 5 |
| Contractor | 5 |
| Cultivator | 4 |
| Driver / Three-wheeler driver/ Taxi driver | 13 |
| Engineer / Software Engineer | 2 |
| Executive jobs / Manager/ Office jobs/ Clerk | 16 |
| Factory workers / Machine operator/ Welder | 10 |
| Garment sector workers | 12 |
| Hotel trade workers / waiter/ chef | 12 |
| Housemaid / caregiver/ cleaner | 21 |
| Journalist / Media/ Translator | 3 |
| Labourer | 30 |
| Marketing / Graphic designer | 3 |

| | |
|---|---|
| NGO worker / Self employed | 5 |
| Nursing staff | 1 |
| Quality controller / Status Controller/ Supervisor | 9 |
| Research assistant / Assistant jobs | 9 |
| Sales Assistant / shop worker/ Tailor | 20 |
| Security guard | 6 |
| Shop owners | 5 |
| Teacher / Trainer | 3 |
| Technical manager / Technician | 4 |
| Missing data | 48 |

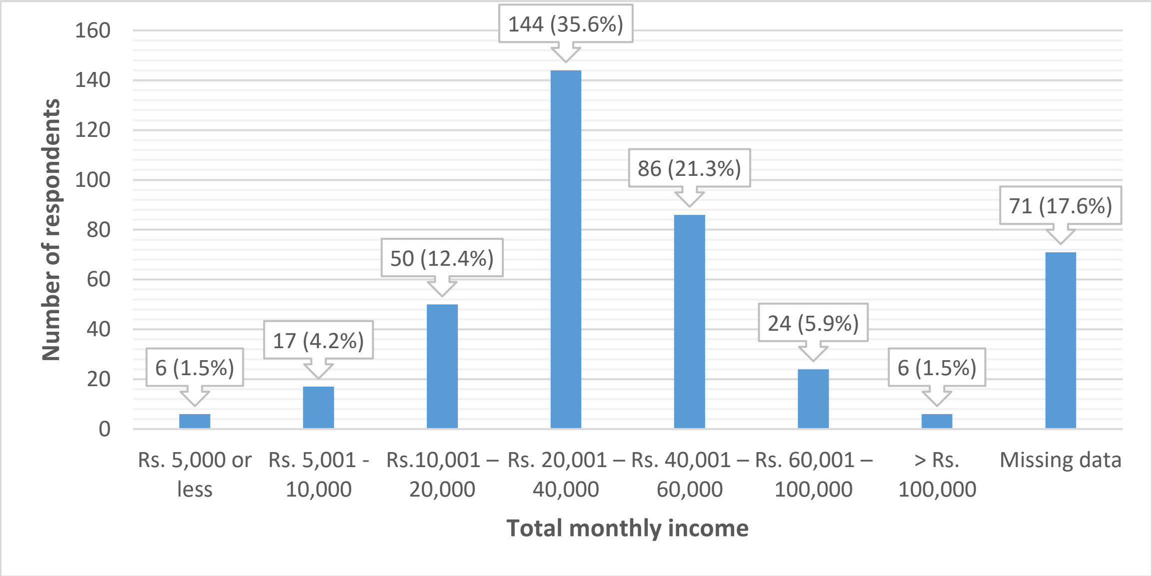
Of the 261 currently employed participants, 213 have answered this question. They represent a wide range of white-collar and blue-collar jobs from lower to middle-level scales. Most participants are typical working-class, employed as laborers, factory workers, hotel workers and domestic workers and caregivers.

**Graph 11 - Distribution of the entitlement for pension and EPF/ ETF among the employed participants in the study sample (n=261)**



Among those currently employed, 8.8% were entitled to a pension, and more than half (51%) were entitled to EPF/ ETF – indicating a more stable level of financial independence.

**Graph 12 - Distribution of income of the study participants from employment, rent/lease of land or other assets, selling products/ from estates, providing private services and other sources of income**



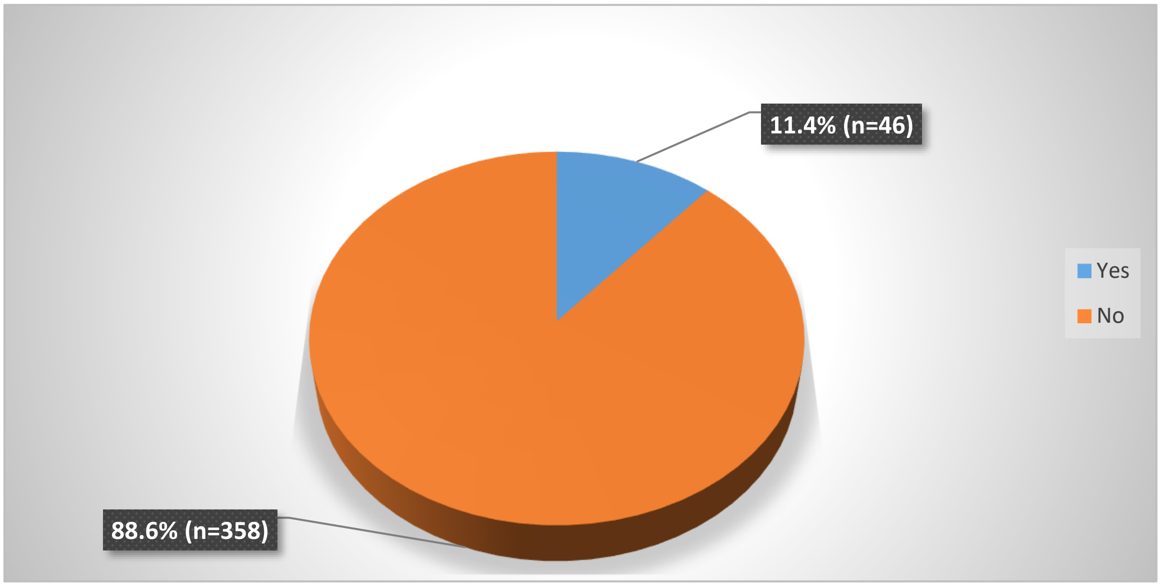
This question was answered by 333 participants, and out of them almost seventy percent had a total monthly income between 20,000 and 60,000 rupees. There were 6 participants each (1.5%) who earned above 100,000 rupees, and less than 5,000 rupees – the highest and lowest ranges, respectively.

**Table 7 - Details of financial support by others among the participants who are never employed or not currently employed (n=143)**

| Supporting category of people | Yes | No | Missing data |
|---|---|---|---|
| Husband/ Wife/ Partner | 22 (15.4%) | 108 (75.5%) | 13 (9.1%) |
| Family members | 56 (39.2%) | 74 (51.7%) | 13 (9.1%) |
| Siblings/ Children | 15 (10.5%) | 116 (81.1%) | 12 (8.4%) |
| Neighbours | 2 (1.4%) | 129 (90.2%) | 12 (8.4%) |
| Donors | 10 (7.0%) | 121 (84.6%) | 12 (8.4%) |
| Other | 4 (2.8%) | 127 (88.8%) | 12 (8.4%) |

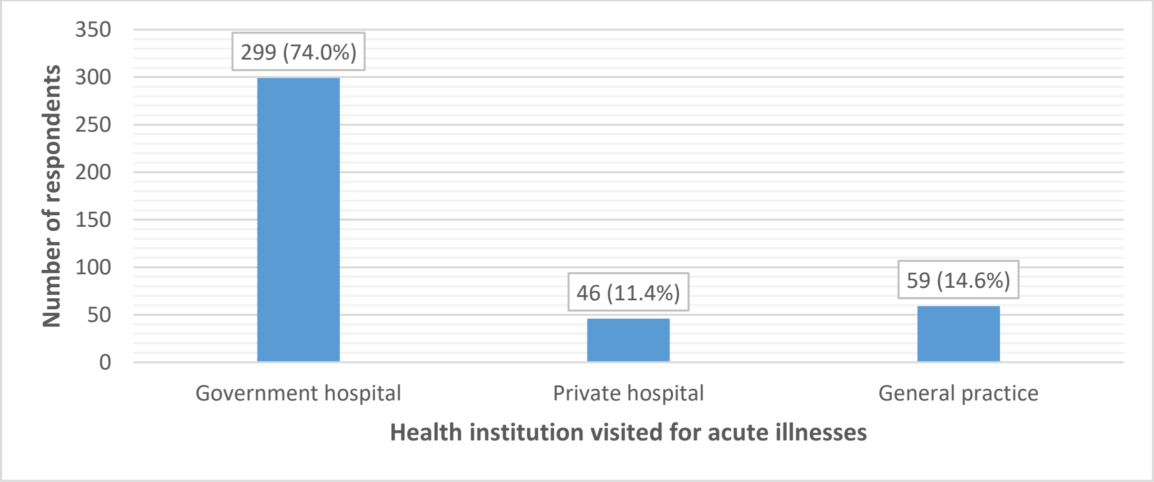
Of the 143 who were never employed or previously employed, husband/ wife/ partner and family members were the commonest sources of financial support. Four participants have stated ‘other’, specifying HIV organizations as their source of financial support.

**Graph 13 - Details of study participants of being a 'Samurdhi' recipient or receiving any other benefits**



Just over 10% of the participants were recipients of Samurdhi or other benefits. Almost 90% did not receive any benefits. This is significant considering that most participants are working-class employees (see Table 03).

**Graph 14 - Details of study participants on the health care institution they usually visit for acute illnesses**



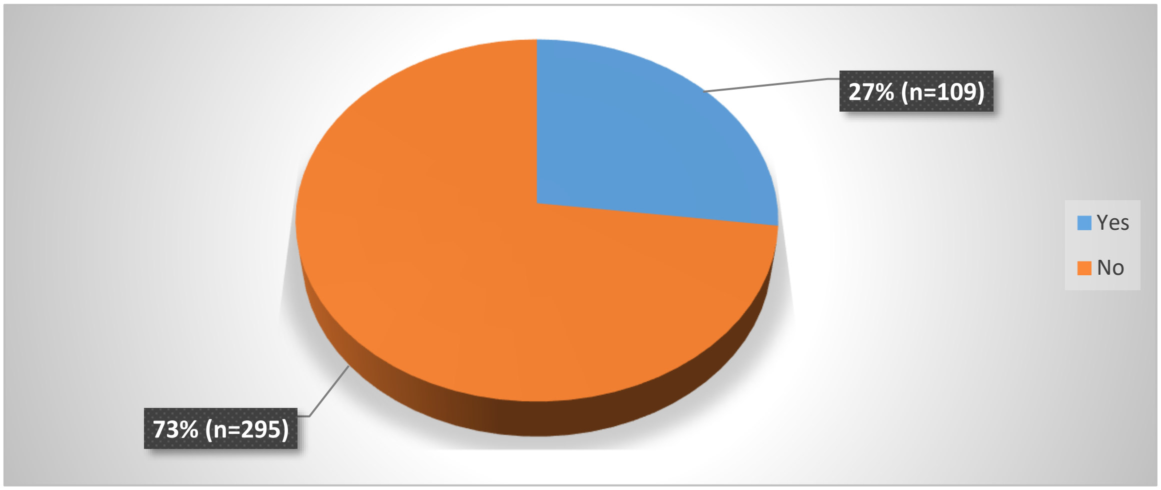
Of the participants, nearly 75% used government hospitals for acute illnesses, and 11.4% used private hospitals.

**Table 8 - Details of the distance to the visited healthcare institution for acute illnesses from their residence**

| **Distance to the healthcare institution from the residence** | **Frequency** | **Percentage** |
|---|---|---|
| <5 Km | 181 | 44.8 |
| 5-10 km | 97 | 24.0 |
| >10-20km | 73 | 18.1 |
| >20-50km | 39 | 9.7 |
| >50km | 14 | 3.5 |
| **Total** | **404** | **100.0** |

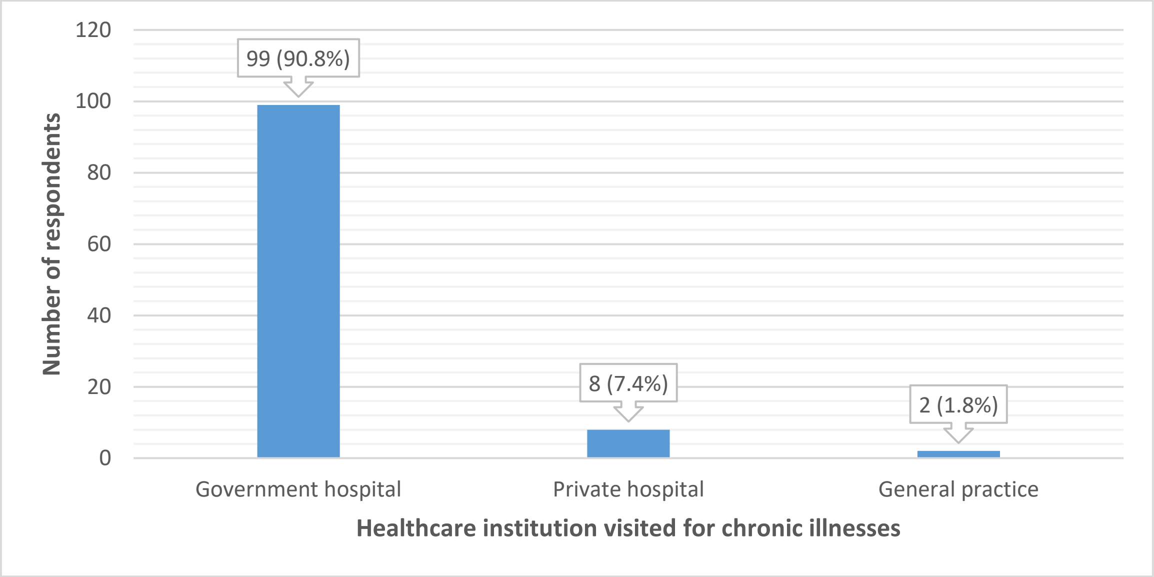
Many of the participants (68.8%) lived within 10kms of the healthcare institution they visited for acute illnesses. However, 14 participants claimed they travelled over 50kms to reach the health institution for acute illnesses.

**Graph 15 - Distribution of the study participants with regard to suffering from any chronic diseases**



Of the participants, 27% (n=109) were suffering from a chronic disease, while 73% were not.

**Graph 16 - Details of study participants with chronic diseases on the health care institution they usually visit for those chronic illnesses (n=109)**



More than 90% of participants who suffered from chronic diseases received treatment from government hospitals.

**Table 9 - Details of the distance to the visited healthcare institution for chronic illnesses from their residence (n=109)**

| Distance to the healthcare institution from the residence | Frequency | Percentage |
|---|---|---|
| <5 Km | 39 | 35.8 |
| 5-10 km | 30 | 27.5 |
| >10-20km | 20 | 18.3 |
| >20-50km | 16 | 14.7 |
| >50km | 4 | 3.7 |
| Total | 109 | 100.0 |

Most of the participants (81%) were living within 20kms of the healthcare institution they visited for treatment of chronic diseases.

**Table 10 - Details of the chronic diseases or mental illnesses the study participants are suffering from (n=109)**

| Chronic illness | Number | Percentage out of total respondents of 109 | Percentage out of total sample of 404 |
|---|---|---|---|
| Diabetes Mellitus | 49 | 45.0 | 12.1 |
| Ischaemic Health Diseases | 10 | 9.2 | 2.5 |
| Kidney diseases | 4 | 3.7 | 1.0 |
| Malignancy | 1 | 0.9 | 0.2 |
| Stroke | 3 | 2.8 | 0.7 |
| Hypertension | 23 | 21.1 | 5.7 |
| Tuberculosis | 21 | 19.3 | 5.2 |
| Depression | 8 | 7.3 | 2.0 |
| Hypercholesterolaemia | 54 | 49.5 | 13.4 |
| Other | 18 | 16.5 | 4.5 |

The most commonly declared chronic diseases among the participants were Hyperparathyroidism, Diabetes Mellitus and Hypertension. Apart from the chronic diseases assessed, the other chronic diseases specified were Arthritis/ Osteoporosis, Asthma/ respiratory illnesses, Epilepsy/ fits, eye diseases, liver disease and gastric disease.

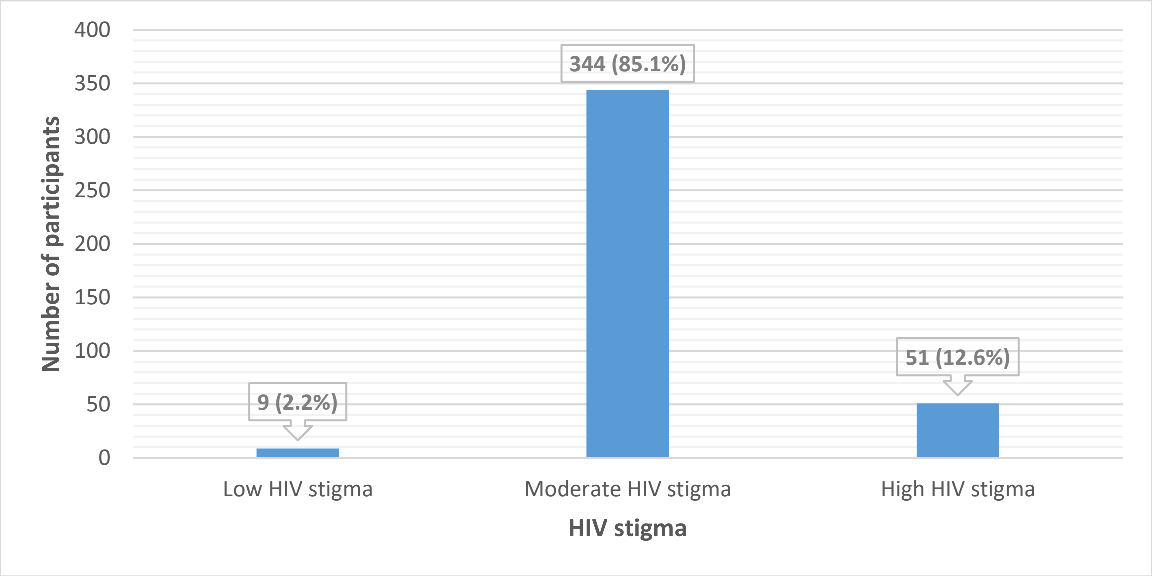
# Section 03

## Status of stigma among people living with HIV in Sri Lanka using validated Berger HIV Stigma Scale

The Berger HIV Stigma Assessment tool was incorporated as part I of section B when compiling the questionnaire. The short version of the Berger scale was used to assess the stigma among PLHIV. It has 12 items in total, assessing Personalized stigma (3 items), Disclosure concerns (3 items), Concerns about public attitudes (3 items), and Negative self-image (3 items).  It has been used widely globally and not validated in Sri Lanka. Therefore, a judgmental validation of the Berger Scale was carried out prior to using it in this study.

**Graph 17 - Categorization of HIV related stigma in the study participants according to the Berger Scale**

**(**Scores for the 12-item scale ranged from 12-48. 1-4 marks given for each item of the scale).



Categorization of HIV related stigma in the sample was carried out as follows: Low stigma – scores between 12-20 (below 25th percentile), Moderate stigma – scores between 21-39 (25th -75th percentile), High stigma – scores between 40-48 (above 75th percentile). As indicated by the data, a substantial proportion (85.1%) of the study participants have reported encountering moderate levels of HIV stigma. High HIV stigma was observed in 51 participants in the sample (12.6%). However, it is crucial to underscore that the majority of respondents have refrained from disclosing their HIV status to other adult family members (excluding spouses and partners), as well as to their children, friends, and colleagues (see Table 11 for details).

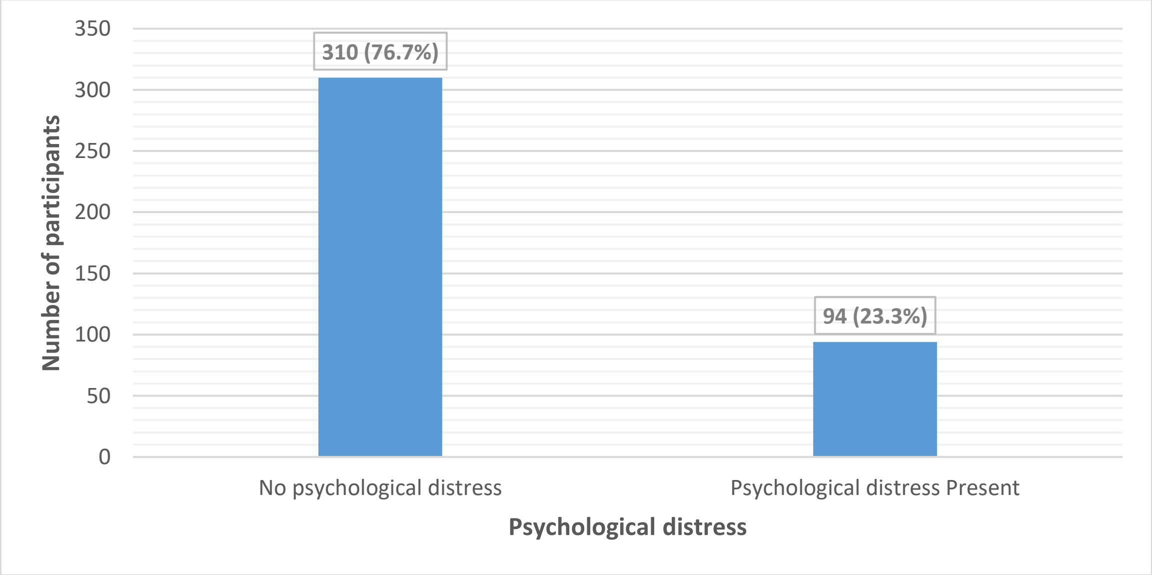
# Section 04

## Status of psycho-social distress among people living with HIV in Sri Lanka using the Kessler Psychological Distress Scale (K10)

The Kessler Psychological Distress Scale (K10) was incorporated as Part VIII of the questionnaire. The Kessler's psychological distress scale (K-10) consists of 10 items, which enquire about the feelings of an individual during the last 30 days. This K-10 questionnaire has been validated previously in Sri Lanka (Wijeratne et al., 2011) and the cut-off has been decided as 12 or more. The respondents were expected to answer all the items with regard to how often they experienced that sort of feeling using a five-point scale. The frequency ranged from "none of the time" to "all of the time", where scores ranged from 0 to 4 for "none of the time" to "all of the time".

**Graph 18 - Categorization of psychological distress in the study participants according to the Kessler-10 Scale**

Scores for the 10-item scale ranged from 0-40 (0-4 marks given for each item of the scale).



Categorization of psychological distress in the sample was carried out as follows: No psychological distress – between 0-11 marks, psychological distress present – between 12-

40 marks. As indicated by the data, a substantial majority (76.7%) of the participants did not report experiencing psychological distress throughout the assessed duration. It is noteworthy that a significant number of respondents refrained from disclosing their HIV status to close associates, encompassing family members, children, friends, colleagues, and employers.

# Section 05

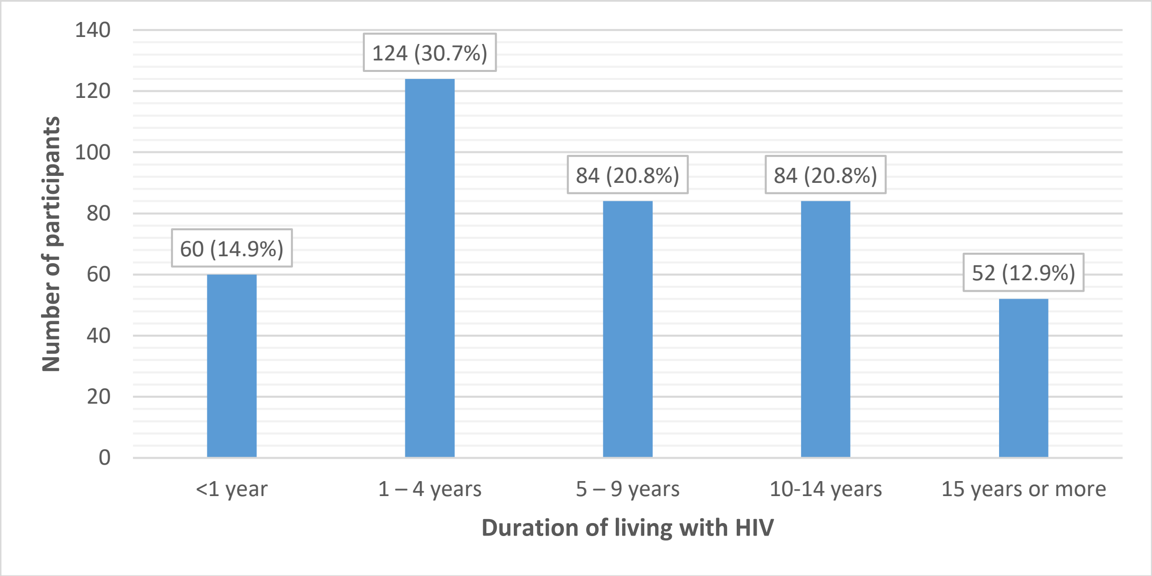
## Impact of HIV on the lived realities of the people living with HIV in relation to stigma and psycho-social distress

The impact of HIV on the lived realities of individuals navigating the complexities of stigma and psycho-social distress is a critical facet of understanding the broader implications of HIV. As a chronic illness, HIV not only presents physiological challenges but also introduces profound social and psychological dimensions into the lives of those affected. Stigma, rooted in misconceptions and fear, can significantly shape the experiences of people living with HIV, influencing their interactions with society, healthcare, and even their own perceptions. Concurrently, the psycho-social distress stemming from the diagnosis and societal attitudes towards HIV can have enduring effects on mental well-being.

### ❖ Duration of living with HIV in the study participants

The stipulated respondent inclusion criteria for this study mandated that each participant must have been living with HIV for a minimum duration of three months. This criterion was incorporated based on the presumption that individuals newly diagnosed with HIV may require a certain period to encounter stigma associated with their condition. Of the respondents, marginally more than half (54.5%) have reported a time period of living with HIV exceeding five years, while 12.9% have surpassed the 15-year threshold. The distribution of respondents demonstrates a relatively uniformed spread across the spectrum of years they have been living with HIV.

**Graph 19 - Duration of living with HIV in the study participants**



## ❖ Patterns of disclosure

Exploring the patterns of disclosure of HIV status among individuals living with HIV unveils a complex and multifaceted dimension of the lived experiences of PLHIV. The decision to disclose one's HIV status is a deeply personal and intricate process influenced by various factors, including societal attitudes, stigma, and individual coping mechanisms. Understanding these patterns is paramount not only for comprehending the psycho-social dynamics of those affected, but also for informing targeted interventions and support systems. This study did not extensively investigate the patterns of disclosure among the respondents.

**Table 11 - Patterns of disclosure of the HIV positive status by the study participants to their family and community**

| Category of people | Disclosed by the respondent | Disclosed by someone else with the consent of the respondent | Disclosed by someone else without the consent of the respondent | Not disclosed | Not applicable |
|---|---|---|---|---|---|
| Husband/wife/ partner | 155 (38.4%) | 7 (1.7%) | 4 (1.0%) | 87 (21.5%) | 151 (37.4%) |
| Other adult family members | 94 (23.3%) | 10 (2.5%) | 11 (2.7%) | 268 (66.3%) | 21 (5.2%) |
| Children in the family | 53 (13.1%) | 4 (1.0%) | 6 (1.5%) | 242 (59.9%) | 99 (24.5%) |
| Friends | 76 (18.8%) | 1 (0.2%) | 10 (2.5%) | 291 (72.0%) | 26 (6.4%) |
| Neighbours | 7 (1.7%) | 1 (0.2%) | 11 (2.7%) | 351 (86.9%) | 34 (8.4%) |
| Other people living with HIV | 283 (70.0%) | 9 (2.2%) | 1 (0.2%) | 90 (22.3%) | 21 (5.2%) |

| | | | | | |
|---|---|---|---|---|---|
| People working with | 10 (2.5%) | 2 (0.5%) | 4 (1.0%) | 258 (63.9%) | 130 (32.2%) |
| Employer(s) | 11 (2.7%) | 1 (0.2%) | 4 (1.0%) | 239 (59.2%) | 149 (36.9%) |
| Clients | 1 (0.2%) | 0 (0.0%) | 1 (0.2%) | 227 (56.2%) | 175 (43.3%) |
| Injecting drug partners | 3 (0.7%) | 0 (0.0%) | 0 (0.0%) | 80 (19.8%) | 321 (79.5%) |
| Religious leaders | 4 (1.0%) | 0.(0.0%) | 3 (0.7%) | 223 (55.2%) | 174 (43.1%) |
| Community leaders | 28 (6.9%) | 0. (0.0%) | 3 (0.7%) | 194 (48%) | 179 (44.3%) |
| Health care workers (except STD clinic staff) | 26 (6.4%) | 11 (2.7%) | 7 (1.7%) | 221 (54.7%) | 139 (34.4%) |
| Social workers | 51 (12.6%) | 0 (0.0%) | 4 (1.0%) | 202 (50.0%) | 147 (36.4%)table heading for the new page |

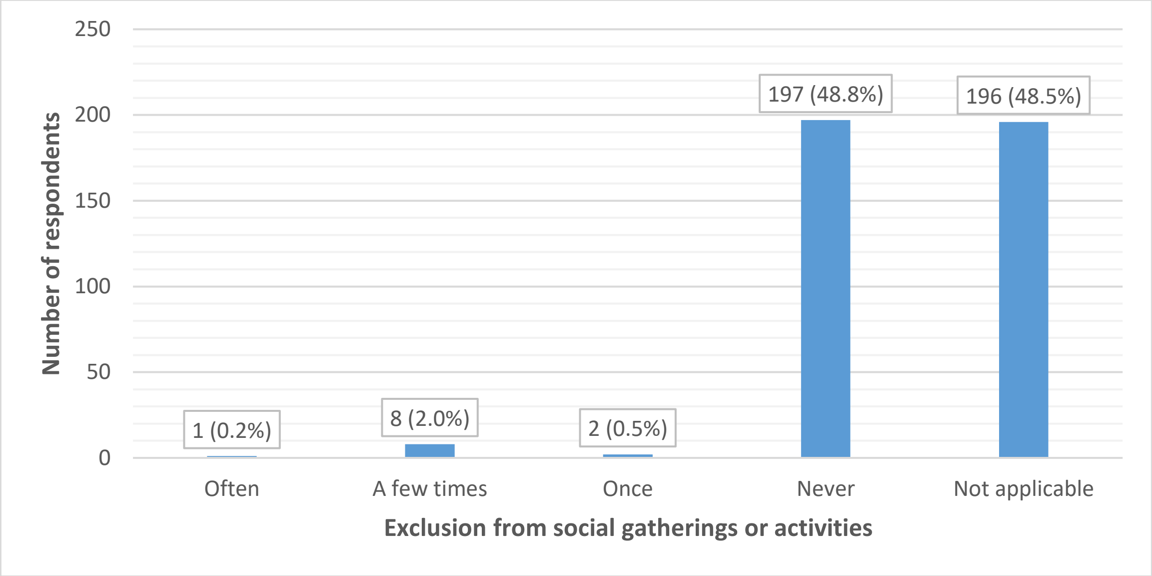
| | | | | | |
|---|---|---|---|---|---|
| Teachers | 1 (0.2%) | 0 (0.0%) | 2 (0.5%) | 199 (49.3%) | 202 (50.0%) |
| Government officials | 3 (0.7%) | 1 (0.2%) | 2 (0.5%) | 199 (49.3%) | 199 (49.3%) |
| Media | 4 (1.0%) | 0 (0.0%) | 0 (0.0%) | 160 (39.6%) | 240 (59.4%) |

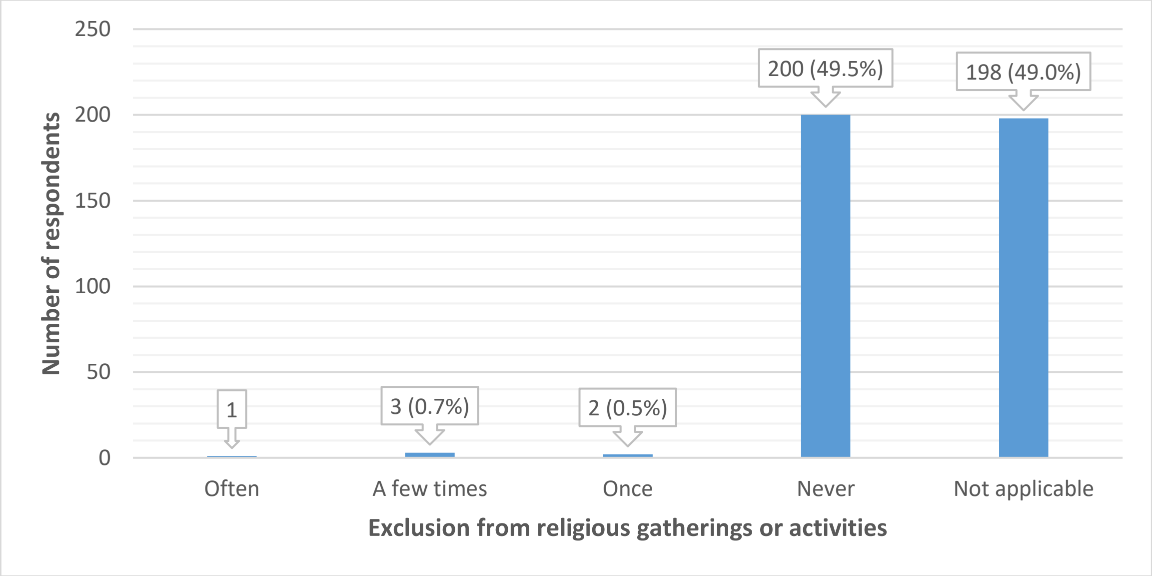
The data distinctly indicates a noteworthy prevalence of non-disclosure concerning various categories, encompassing other adult family members (excluding spouses or partners), children within the family, friends, neighbors, people working with, and employers. Notably, these categories represent potential sources of support in coping with stress, anxiety, and related challenges. Conversely, 70% of respondents have chosen to disclose their HIV status to other people living with HIV, suggesting a discernible pattern that could be strategically leveraged to extend psycho-social support to PLHIV.

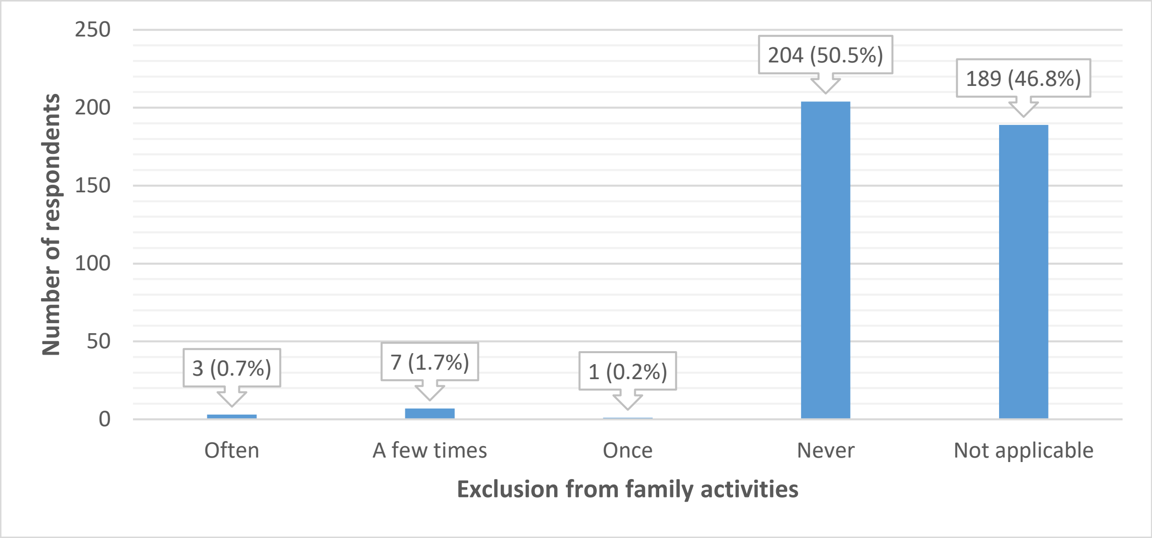
## ❖ Family and social exclusion

The predominant proportion of respondents have not reported instances of exclusion from social gatherings or activities, exclusion from religious gatherings or activities and exclusion from family activities, based on their positive HIV status. In each of these categories, approximately half of the respondents (48.5%, 49.0%, and 41.1%, respectively) have indicated that these circumstances are not applicable to them. This trend could be attributed to the likelihood that they have refrained from disclosing their HIV status to individuals pertinent to these situations, as revealed in the preceding sections. Hence, it is crucial to observe that limited levels of disclosure may be associated with reduced instances of social exclusion.

**Graph 20 - Family and social exclusion faced by the study participants based on their HIV positive status during the last 12 months**



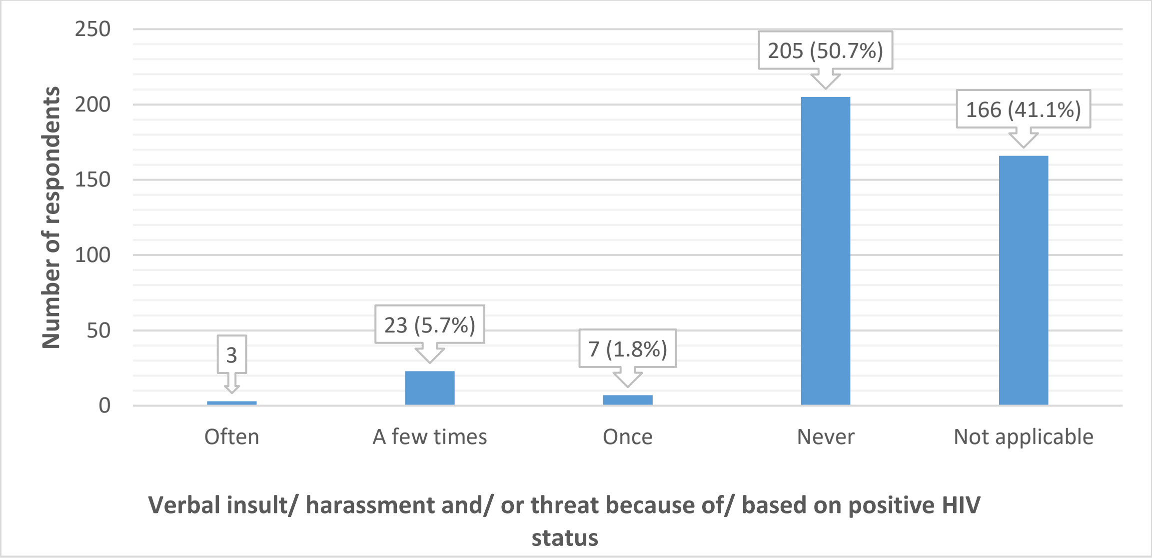




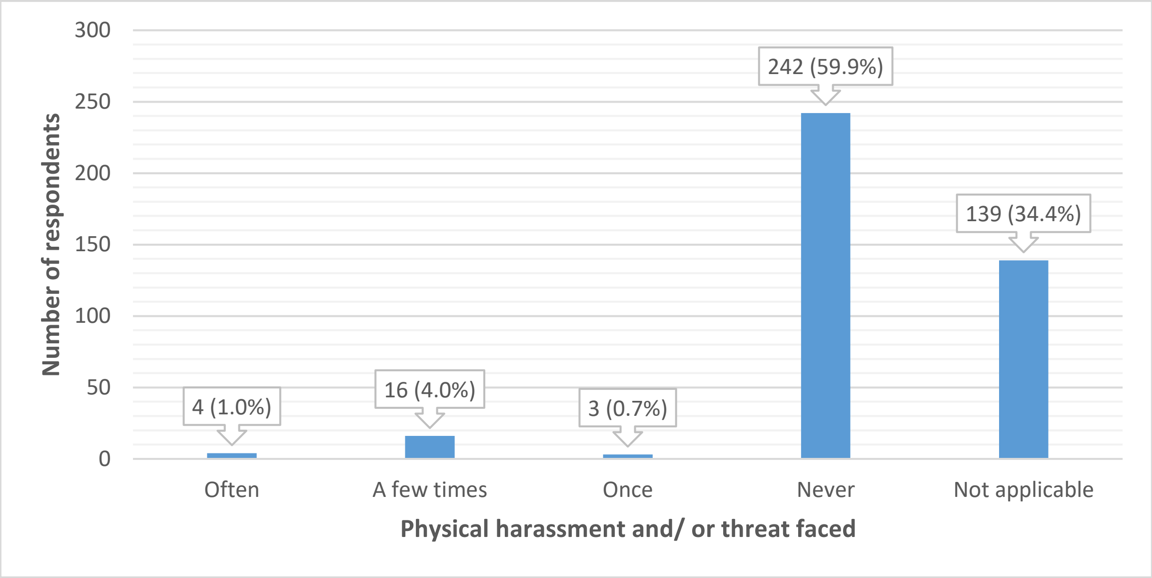
## ❖ Verbal and physical harassments

There is a minimal occurrence of verbal harassment and physical harassment or threat experienced by respondents attributed to their HIV status. Once more, this phenomenon may stem from the prevalent trend of the majority refraining from disclosing their HIV status to close associates.

**Graph 21 - Verbal insults, harassments and/ or threats faced by the study participants based on their HIV positive status during the last 12 months**



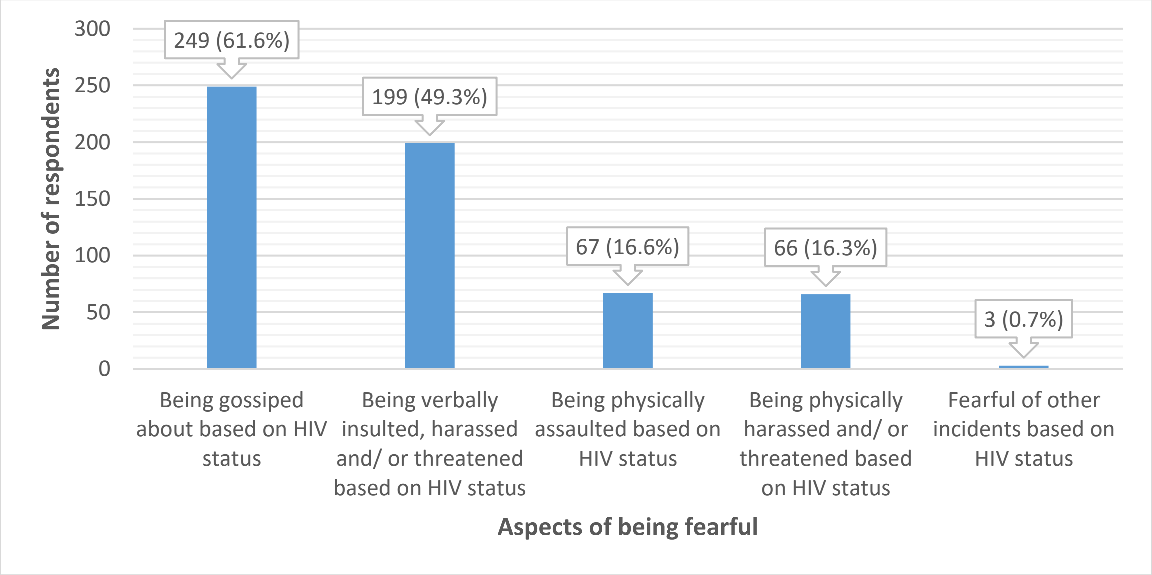
**Graph 22 - Physical harassments and/ or threats faced by the study participants based on their HIV positive status during the last 12 months**



## ❖ Fear of being gossiped about, verbally insulted and physically assaulted due to HIV status

The apprehension of experiencing gossip, verbal insults, harassment, threats, and physical assault due to one's HIV-positive status adds an intricate layer to the already complex social dynamics surrounding HIV. These fears not only reflect individual concerns about personal safety but also underscore the pervasive stigma that persists in society. Individuals living with HIV grapple not only with the physiological challenges of the condition but also with the constant threat of social marginalization and discrimination.

**Graph 23 - Details of the study participants on being fearful of being gossiped about, verbally insulted, harassed or threatened and being physically assaulted, harassed or threatened, during the last 12 months due to their HIV positive status**



A significant majority of the respondents disclosed their fear regarding potential gossip related to their HIV status (61.6%), with 49.3% expressing fear of verbal insults, harassment, and/or threats based on their HIV-positive status. Similarly, 16.6% and 16.3% of respondents expressed fear about potential physical assault or harassment tied to their HIV status. While the reported instances of both verbal and physical harassment are relatively infrequent, it is imperative to acknowledge the pervasive fear among respondents, which may directly contribute to the moderate levels of stigma identified among study participants through the Berger scale.

## ❖ Losing employment and education opportunities

The instances of respondents or their children encountering employment or educational setbacks attributable to their HIV status are infrequent. Only 64.6% of respondents mentioned that they are currently employed. The infrequency of facing instances of respondents or their children encountering employment or educational setbacks attributable to their HIV status can be directly associated with the substantial rates of non-disclosure to individuals in professional capacities, including colleagues (63.9%), employers (59.2%), and teachers (49.3%). Correspondingly, a notable proportion, encompassing 32.2%, 36.9%, and 50.0%, respectively, asserted that these circumstances are not applicable to them. Therefore, it is crucial to underscore that the limited occurrences of employment and education-related challenges may not necessarily stem from diminished levels of stigma and discrimination. Rather, these may be attributed to the prevailing non-disclosure, resulting in relevant parties being uninformed about the HIV status of the individuals concerned.

**Table 12 - Details of the study participants on losing employment and educational opportunities during the last 12 months due to their HIV positive status**

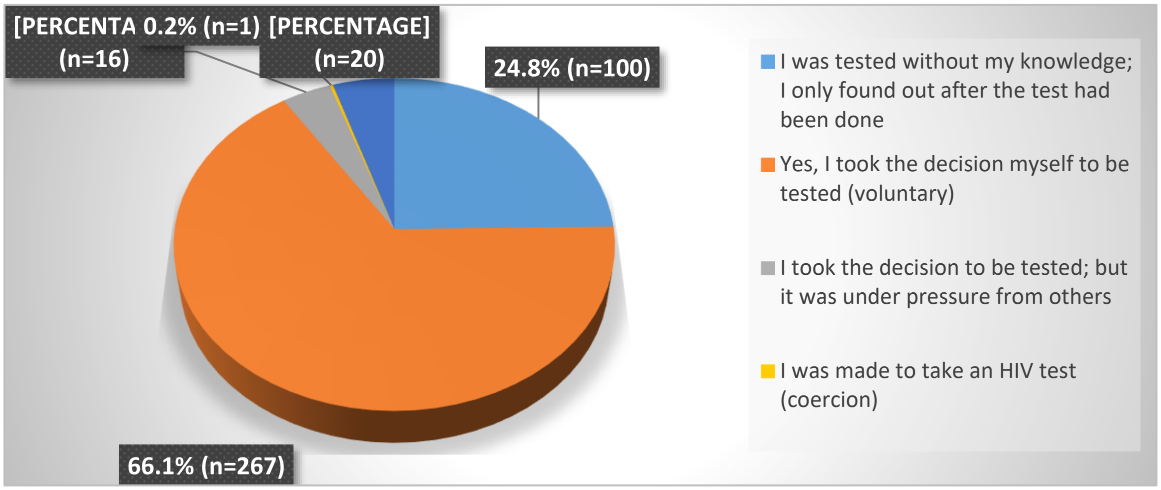
| **Facing loss of employment and educational opportunities due to HIV positive status during last 12 months** | **Number and percentage out of all participants** | | | |
|---|---|---|---|---|
| | **A few times** | **Once** | **Never** | **Not applicable** |
| Lost your job or another source of income | 1 (0.2%) | 4 (1.0%) | 180 (44.6%) | 219 (54.2%) |
| Being dismissed, suspended, or prevented from attending educational institutions | 0 (0.0%) | 3 (0.7%) | 161 (39.9%) | 240 (59.4%) |
| Children being dismissed, suspended, or prevented from attending educational institutions | 1 (0.2%) | 0 (0.0%) | 146 (36.1%) | 257 (63.6%) |

## ❖ Decisions and reasons to get tested for HIV

The decision to undergo HIV testing represents a pivotal aspect of individual health management, emphasizing the crucial intersection of informed decision-making and personal agency. Opting for an HIV test is a multifaceted process that involves weighing potential risks, dispelling misconceptions, and considering the broader implications for one's well-being. The significance of voluntary HIV testing is underscored by the proactive role it plays in public health, allowing individuals to ascertain their HIV status with autonomy and contributing to the collective efforts in disease prevention and awareness. Making an informed decision about HIV testing not only empowers individuals with knowledge about their health but also fosters a climate of openness and de-stigmatization surrounding HIV.

It is imperative that individuals opting for an HIV test possess awareness of the procedure and provide informed consent. Among the study respondents, an appreciable majority, constituting 66.1%, have willingly undergone HIV testing—a commendable proportion that underscores proactive health-seeking behaviour. However, it is noteworthy that a significant segment, nearly a quarter of respondents (24.8%) reported that they underwent HIV testing without prior knowledge, discovering their serostatus only after the test had been conducted. This emphasizes the importance of ensuring informed consent and the need for further examination of factors contributing to instances of testing without explicit knowledge or consent.

**Graph 24 - Details of the study participants with regard to their decision to get tested for HIV**



The reasons to undergo an HIV test is influenced by a myriad of factors, reflecting the diverse motivations individuals harbour for seeking clarity about their health status. Beyond routine health check-ups, people often decide to get an HIV test for a range of compelling reasons. These motivations may stem from recent or past sexual encounters that pose potential risks, a desire for a comprehensive understanding of one's health, or considerations tied to job opportunities and migration.

**Table 13 - Details of the study participants with regard to their reason for getting tested for HIV**

| Reason for getting tested for HIV | Frequency | Percentage |
|---|---|---|
| For employment | 57 | 14.1 |
| Referred due to suspected HIV related symptoms | 112 | 27.7 |
| Husband/ wife/ partner/ family member tested positive | 35 | 8.7 |
| I just wanted to know | 115 | 28.5 |

| | | |
|---|---|---|
| For pregnancy | 7 | 1.7 |
| Referred by a clinic for sexual transmitted infections | 40 | 9.9 |
| Illness or the death of husband/ wife/ partner/ family member | 15 | 3.7 |
| Other | 23 | 5.7 |
| **Total** | **404** | **100.0** |

Within the surveyed population, a notable subset of respondents, comprising 27.7%, underwent an HIV test in response to prevalent symptoms associated with HIV. Additionally, a commendable proportion of 28.5% sought HIV testing solely driven by a personal desire to know their serostatus—an initiative that could be further encouraged.

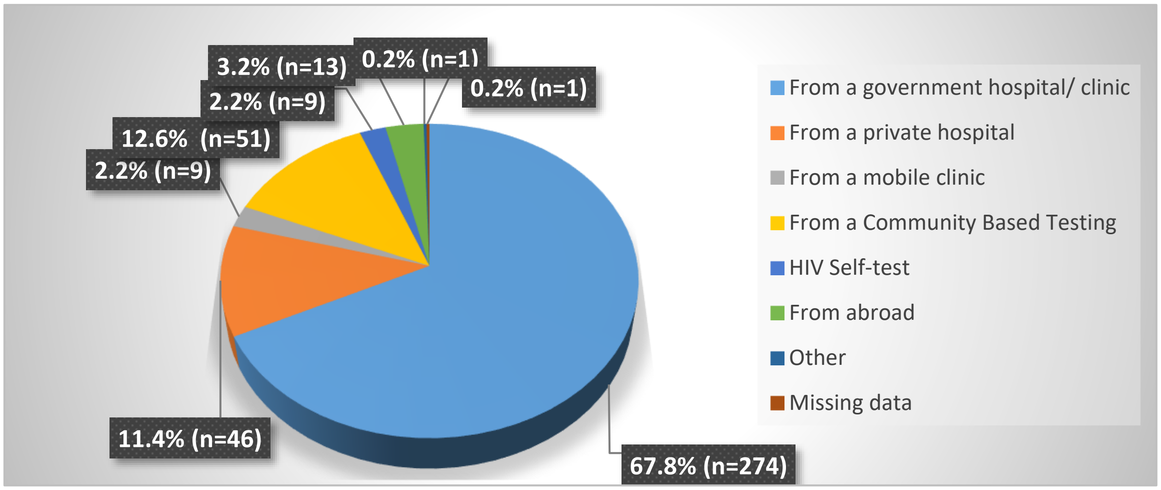
A total 23 participants provided different other reasons for getting an HIV test. These included being tested during treatment for other illnesses (6), as a result of blood donation (10), during routine body check-ups (3), while they were abroad (2), migration for education (1) and as part of forensic recommendation (1).

## ❖ HIV testing locations

The accessibility and environment in which HIV testing services are offered play a pivotal role in shaping individuals' decisions to undergo testing and subsequently impact the overall effectiveness of HIV prevention and awareness efforts. The locations chosen for HIV testing services should prioritize ease of access, cultivate a friendly atmosphere, and critically foster an environment free from stigma and discrimination. These considerations are paramount in ensuring that individuals feel encouraged and comfortable seeking HIV testing, thereby contributing to increased testing rates and early diagnosis.

A substantial majority of respondents in the study, accounting for 67.8%, reported accessing HIV testing services through government hospitals or clinics. This prevailing trend is commendable, given that it facilitates the seamless transition of newly diagnosed individuals with HIV to immediate treatment and care. Notably, HIV treatment in Sri Lanka is mainly administered through government clinics, making this choice of testing location instrumental in ensuring prompt access to essential healthcare services for those diagnosed with HIV.

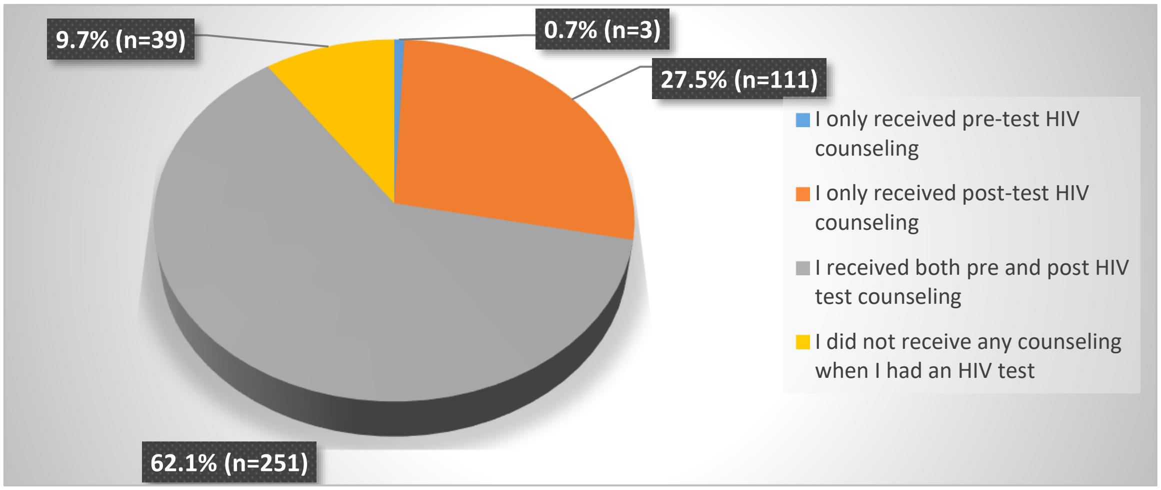
**Graph 25 - Details of the study participants with regard to the place from where they got tested for HIV**



## ❖ Pre and post-test HIV counselling

HIV pre and post-test counselling stands as a cornerstone in the comprehensive framework of HIV prevention, diagnosis and care. Recognizing the profound impact of an HIV diagnosis on an individual's physical and mental well-being, pre-test counselling serves as a preparatory foundation, offering essential information, addressing concerns, and fostering informed decision-making before the actual testing process. Post-test counselling, on the other hand, plays a pivotal role in guiding individuals through the aftermath of an HIV diagnosis, providing support, addressing emotional implications, and outlining strategies for effective coping and future health management.

**Graph 26 - Details of the study participants with regard to the counselling they received counselling when they were tested for HIV**



A substantial majority of respondents, constituting 62.1%, reported receiving both pre and post-test counselling—a commendable figure indicative of a positive trend. However, it is imperative to underscore the significance of further expanding this percentage to encompass the entirety of individuals opting for an HIV test. Equally noteworthy is the revelation that nearly 10% of respondents indicated a lack of any counselling. This finding demands serious consideration, as HIV testing without adequate pre and/or post-test counselling may have adverse implications for the individual, emphasizing the critical need for comprehensive counselling services to accompany HIV testing initiatives.

## ❖ Perception on the disclosure of their HIV status by health care workers and confidentiality of their medical records at healthcare institutions

Maintaining the confidentiality of HIV medical records within medical institutions is an ethical imperative crucial to fostering a trusting relationship between healthcare providers and individuals living with HIV. The sensitive nature of HIV status underscores the necessity for rigorous safeguards and stringent privacy measures within medical settings. As medical records serve as a repository of an individual's health history, ensuring their confidentiality is not only a legal obligation but also a fundamental element of promoting open communication between healthcare professionals and patients. It is important to provide assurances to clients regarding the confidentiality of their medical records, thereby instilling confidence in their ability to access services without apprehension about the unauthorized disclosure of their information. This commitment to maintaining confidentiality is essential in fostering a trustful environment, ensuring that individuals can seek healthcare services without fear of their sensitive information being divulged without explicit consent.

**Table 14 - Perceptions of the study participants on the disclosure of their HIV status and confidentiality of their medical records at healthcare institutions**

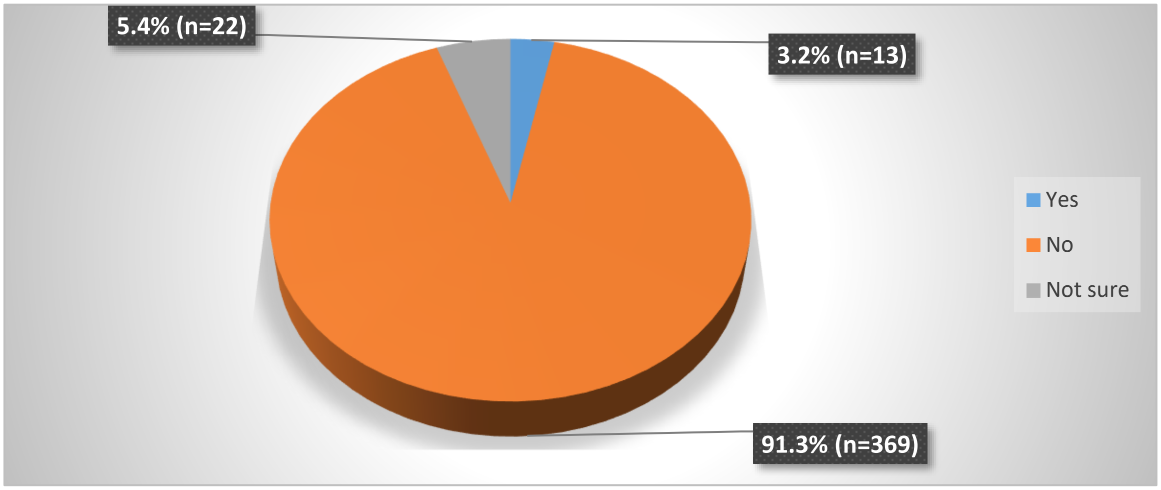
| **Perceptions on disclosure and confidentiality at healthcare institutions** | **Perception** | | |
|---|---|---|---|
| | **Yes** | **No** | **Not sure** |
| Healthcare workers ever disclosed the participant's HIV status without consent | 26 (6.4%) | 378 (93.6%) | Not assessed |
| Believing on the confidentiality of medical records in healthcare institutions related to the HIV status | 364 (90.1%) | 16 (4.0%) | 24 (5.9%) |

A substantial majority of respondents, accounting for 93.6%, reported that their HIV status has never been disclosed by healthcare workers, and an impressive 90.1% expressed confidence in the confidentiality of their medical records within healthcare institutions. While these figures are highly encouraging, it is paramount to address any instances where healthcare workers have disclosed HIV status without consent and to attend to individuals who harbour doubts or uncertainty regarding the confidentiality of their medical records. Ensuring redressal for these concerns is vital to maintaining the integrity of healthcare services and upholding the trust individuals place in the healthcare system.

## ❖ Stigma and discrimination at other health care settings

The pervasive stigma and discrimination faced by individuals living with HIV extend beyond the specialized realm of HIV healthcare settings, posing significant challenges to their overall wellbeing. In many instances, healthcare workers outside of HIV-specific contexts may lack the training and awareness necessary to provide sensitive care to PLHIV. This deficiency in knowledge and sensitivity can inadvertently contribute to an environment where individuals with HIV encounter stigmatizing attitudes and discriminatory practices, hindering their willingness to seek essential healthcare beyond HIV-related services. The repercussions of such stigma and discrimination in broader healthcare settings are profound, potentially leading to the avoidance of necessary medical care and, consequently, negatively impacting the overall health and wellbeing of those living with HIV.

**Graph 27 - Details of the study participants on experiencing stigma and discrimination when getting admitted to a hospital for other specific procedures during the past 12 months**



A significant majority of respondents, constituting 91.3%, have reported not encountering stigma and discrimination when seeking admission to a hospital for specific procedures unrelated to HIV. It is noteworthy, however, that 54.7% of respondents have refrained from disclosing their HIV status to healthcare workers other than those within STD clinics. Around 75% of the respondents and 90% of the respondents accessed services from government hospitals for acute and chronic illness, respectively. The observed absence of stigma in accessing other healthcare services may be attributed to this prevalent non-disclosure practice. This underscores the potential impact of withholding one's HIV status on the experience of stigma within healthcare settings and emphasizes the need for nuanced interventions to address disclosure dynamics and mitigate potential instances of discrimination in various healthcare contexts.

## ❖ Internalized stigma and among PLHIV

Internalized stigma, experienced by PLHIV constitutes a profound and often overlooked dimension within the broader landscape of HIV-related challenges. This form of stigma manifests when individuals internalize societal prejudices and negative beliefs associated with HIV, contributing to the perpetuation of perceived or actual social stigma. Internally held feelings of shame, self-blame, and diminished self-worth can significantly impact the mental and emotional well-being of PLHIV, exacerbating the challenges they face. Internalized stigma not only hinders individuals from seeking the support they need but also acts as a catalyst for increased psychological distress.

**Table 15 - Feelings related to internalized stigma felt by the study participants due to their HIV status, during the last 12 months**

| Feelings related to internalized stigma | Number who felt the particular feeling | Percentage out of all respondents |
|---|---|---|
| Felt suicidal | 69 | 17.1 |
| had low self-esteem | 153 | 37.9 |
| Blamed myself | 202 | 50.0 |
| Felt ashamed | 161 | 39.9 |
| Felt that he/ she should be punished | 63 | 15.6 |

| | | |
|---|---|---|
| Blamed others | 88 | 21.8 |
| Felt guilty | 168 | 41.6 |
| Other | 6 | 1.5 |

Half of the respondents (50%) acknowledged self-blame for their HIV status, while 41.6% reported feelings of guilt, and 39.9% expressed shame. These figures align with the moderate level of stigma experienced by the respondents, as indicated by the Berger scale (85.1%), and the noteworthy percentage of respondents facing psychological distress (23.3%). Additionally, 37.9% reported experiencing low self-esteem.

Internalized stigma among PLHIV manifests in behaviors that can further marginalize them from society and close associates, thereby contributing to the perpetuation of societal stigma and an increase in psycho-social distress. This internalization of negative attitudes is evident in the decisions reported by respondents, with 30% each opting not to have children and not to get married. Additionally, 18.8% decided to abstain from sexual activities, and 18.1% chose to isolate themselves from their families/ friends. Despite being a chronic disease that can be effectively managed with advanced medications and the principle of Undetectable equals Untransmittable (U=U), HIV should not dictate that individuals living with HIV forego fundamental life choices such as marriage or parenthood. Therefore, it is crucial to equip PLHIV with information and knowledge that can empower them to overcome these internalized negative attitudes, enabling them to fully participate in their day-to-day lives.

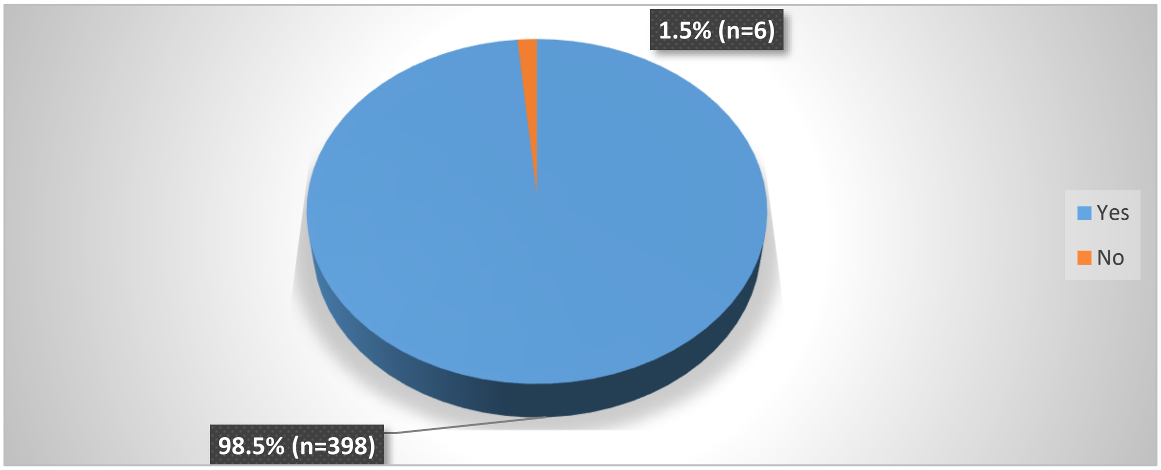
**Table 16 - Actions/ decisions taken by the study participants due to their HIV status, during the past 12 months**

| **Actions/ decisions taken by the study participants due to their HIV status** | **Number who took such decision** | **Percentage out of all respondents** |
|---|---|---|
| Avoided going to the local hospital when needed to | 32 | 7.9 |
| Avoided going to all other hospitals when needed to | 7 | 1.7 |
| Decided not to have children | 121 | 30.0 |
| Decided not to get married | 121 | 30.0 |
| Decided not to have sex | 76 | 18.8 |
| Decided not to apply for a job/ work or for a promotion | 24 | 5.9 |
| Withdrawn from education/ training | 21 | 5.2 |
| Decided to stop working | 17 | 4.2 |
| Isolated oneself from family and/ or friends | 73 | 18.1 |
| Chose not to attend social gatherings | 34 | 8.4 |
| Other | 11 | 2.7 |

## ❖ Access to Arts, opportunistic infections (OI) treatment and opportunities to discuss treatment options

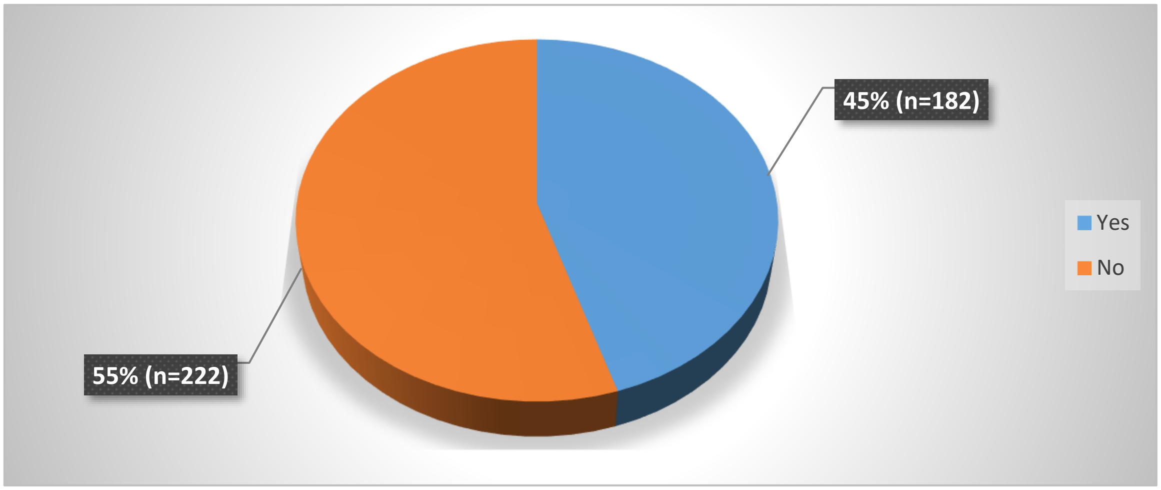
Access to ART and treatment for OI stands at the forefront of comprehensive care for PLHIV, playing a pivotal role in not only managing the HIV condition but also maintaining overall health and well-being. The availability and accessibility of ART have transformed HIV from a once-debilitating condition to a manageable chronic illness. Similarly, treating and preventing OI is essential in safeguarding the health of individuals with compromised immune systems.

**Graph 28 - Details of the study participants with regard to having access to Anti-Retro viral therapy (ART)**



An overwhelmingly positive indication is evident from the data, with 98.5% of the respondents affirming their utilization of ART. This figure aligns seamlessly with the ambitious UNAIDS target, aiming for 95% of those aware of their HIV status to be on HIV treatment by 2030—an essential milestone in the collective effort to curtail the HIV epidemic. However, a small percentage, 1.5% of respondents reported not being on ART. Reasons cited for this include fears of societal ostracization, hating life, and the interruption of ART use due to severe side effects. It remains imperative for Sri Lanka to ensure that all individuals living with HIV are accessing and adhering to ART, thereby sustaining momentum towards the goal of ending HIV as an epidemic.

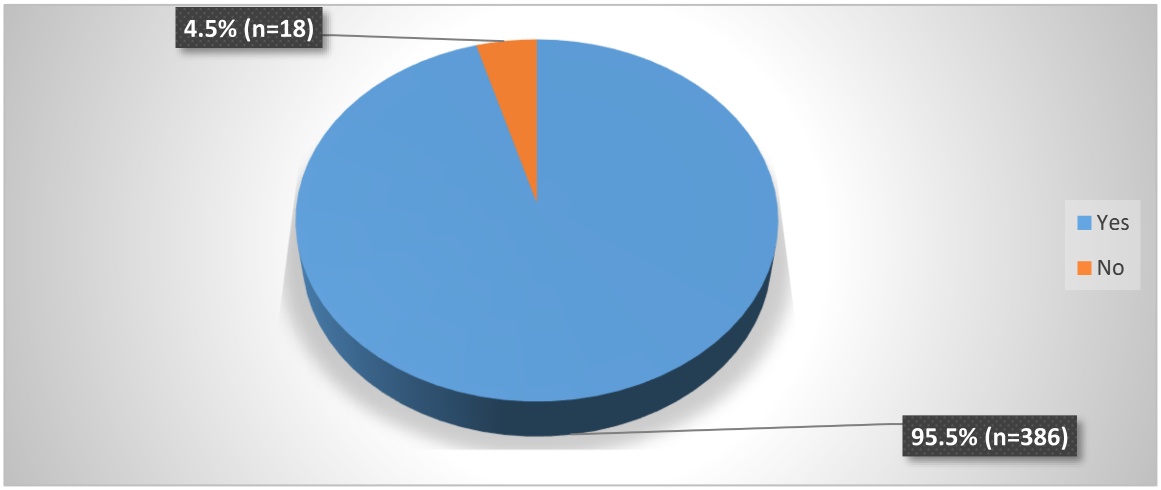
**Graph 29 - Distribution of the study participants on having access to Opportunistic Infection (OI) medication**



55% of the study respondents have indicated a lack of access to OI treatment. However, a nuanced examination is warranted to refine this data, as it remains unclear whether respondents have a comprehensive understanding of both OI and the associated treatment. Further data collection is essential to provide a more detailed and accurate portrayal of the accessibility and comprehension of OI treatment among the study participants.

The opportunity for individuals living with HIV to engage in discussions about HIV treatment options is a cornerstone of patient-centred care, underscoring the significance of informed decision-making and collaborative healthcare partnerships. Recognizing the dynamic landscape of HIV treatment advancements, providing individuals with the space to discuss treatment options becomes essential in tailoring therapeutic approaches to their unique needs.

**Graph 30 - Distribution of the study participants on having the opportunity for discussing HIV related treatment options with healthcare professionals**

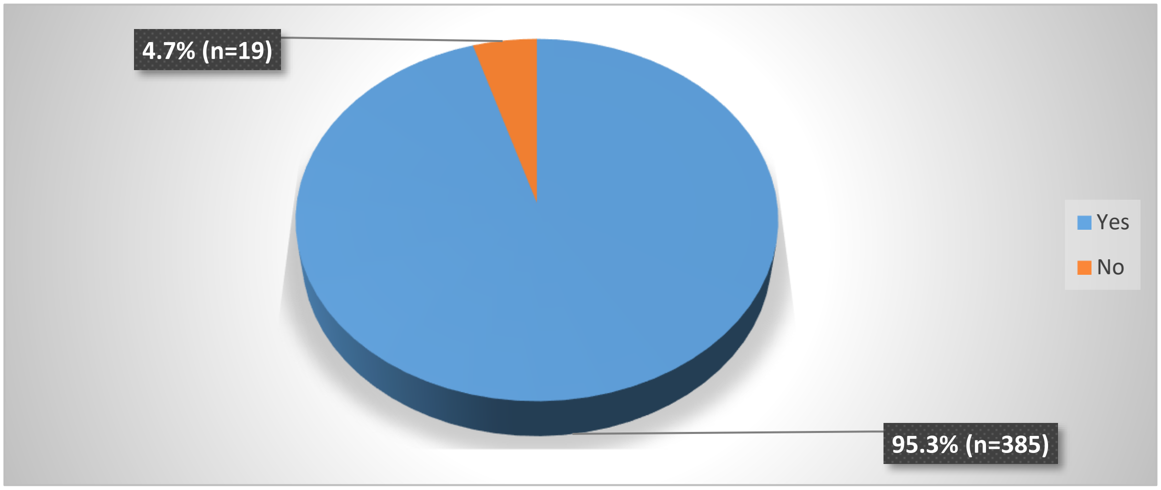


An impressive 95.5% of respondents affirmed having had the opportunity to engage in discussions about treatment options with their healthcare providers. This substantial figure underscores a commendable commitment to a patient-centred treatment approach, fostering an environment where individuals feel empowered and are actively involved in decisions related to their healthcare journey.

## ❖ Sexual and reproductive health and living with HIV

Navigating the intersection of sexual and reproductive health (SRH) while living with HIV is a multifaceted aspect of holistic care, demanding attention to both the unique needs and rights of individuals. PLHIV are entitled to comprehensive sexual and reproductive health rights, necessitating unhindered access to a spectrum of SRH services. Recognizing that SRH is integral to overall health and well-being, it becomes imperative to acknowledge and address the diverse and complex needs of PLHIV in this domain.

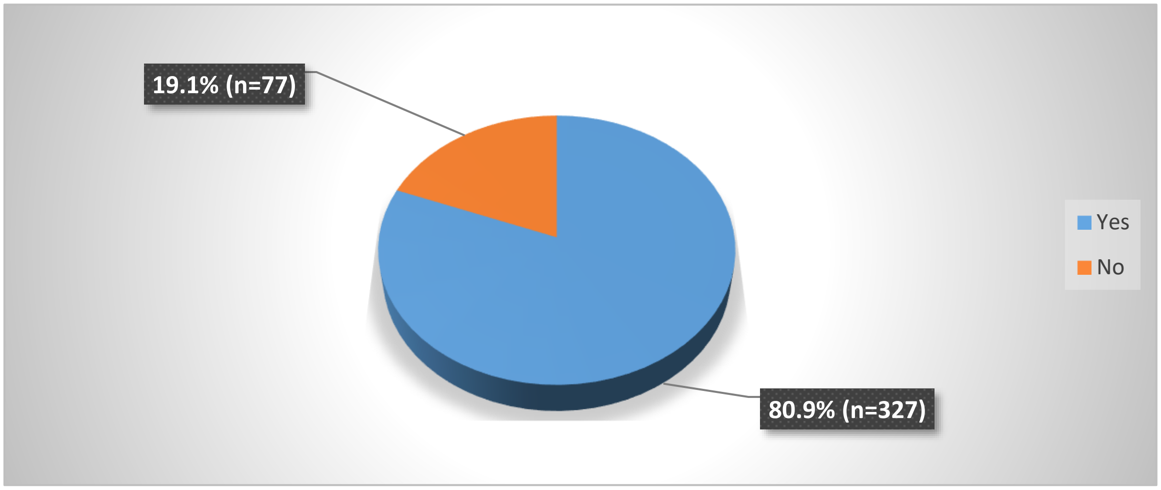
**Graph 31 - Distribution of the study participants on having the opportunity for discussing issues of sexual and reproductive health, sexual relationships and emotional well-being with healthcare professionals**



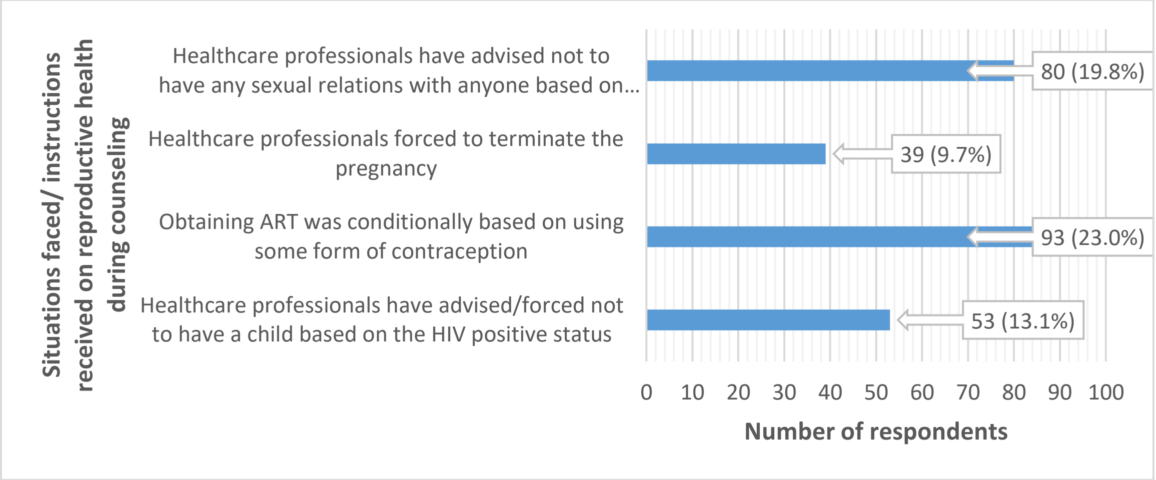
A notable 95.3% of respondents reported having had the opportunity to engage in discussions about sexual and reproductive health, sexual relations, and emotional well-being with their healthcare service providers. This substantial percentage underscores a commendable commitment to facilitating open dialogue on these crucial aspects of health among PLHIV. This opportunity for discourse not only empowers PLHIV to exercise greater control over their sexual lives but also contributes significantly to both their physical and psychological well-being. This emphasis on comprehensive healthcare engagement aligns with the broader goal of promoting holistic health among individuals living with HIV.

Likewise, 80.9% of the respondents reported receiving targeted counselling from healthcare professionals regarding reproductive options subsequent to their HIV diagnosis. Regardless of the specific outcomes, the noteworthy aspect lies in the proactive engagement of healthcare workers in discussions about reproductive options with their clients living with HIV.

**Graph 32 - Distribution of the study participants on receiving specific counselling from healthcare professionals on reproductive options after being diagnosed with HIV**



**Graph 33 - Details of the study participants on some situations faced / instructions received on 'reproductive health' during counselling**

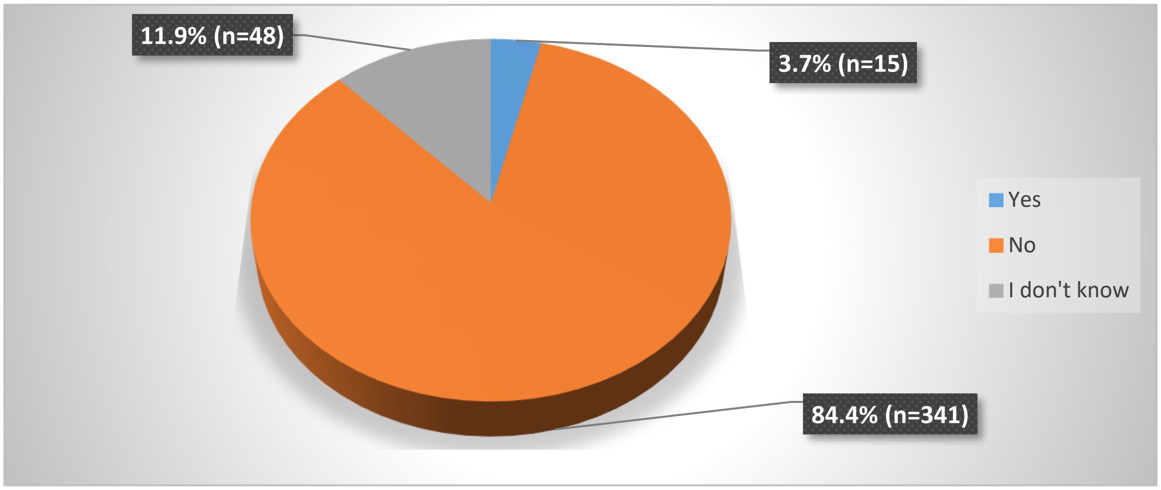


Nevertheless, amidst the data analysis, certain disconcerting situations emerged. Approximately 23% of respondents disclosed that obtaining ART was contingent upon their use of some form of contraception. Furthermore, 13.1% reported being advised or coerced not to have children, and 19.8% were advised against engaging in any sexual relations. Despite the opportunity for respondents to discuss their sexual and reproductive health needs, along with their reproductive options, the observed outcomes in some instances do not align entirely with a rights-based approach. Addressing these issues is paramount, particularly concerning healthcare workers, given that SRH services constitute an integral component of an individual's overall healthcare framework.

## ❖ Living with HIV and Human Rights

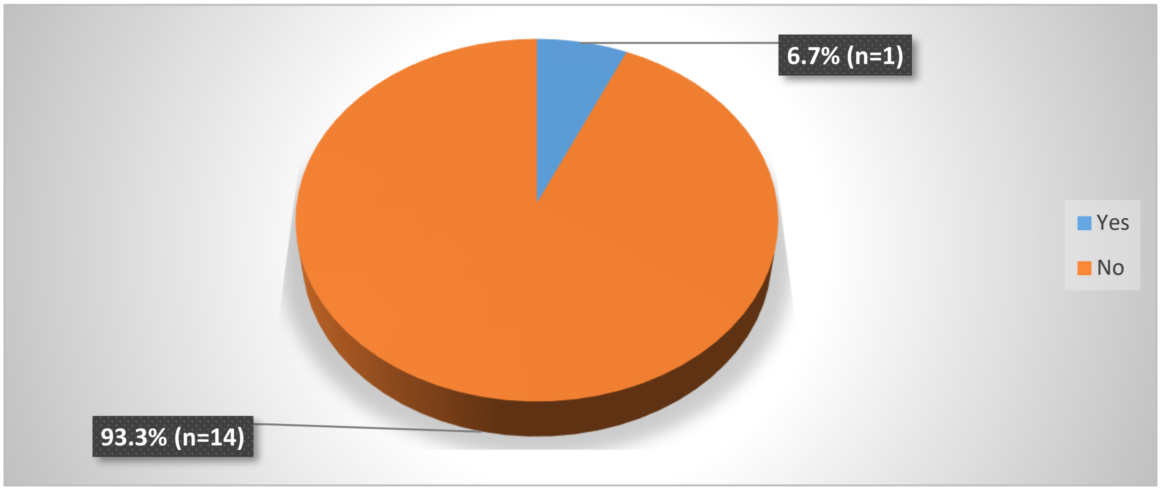
Living with HIV intersects with a fundamental aspect of human existence—the inherent possession of human rights, irrespective of health status. Despite the challenges posed by health conditions, every individual remains entitled to the full spectrum of human rights. Crucially, one's HIV status should never serve as grounds for the denial or infringement of these rights. It is the duty of the state to safeguard and advance the human rights of all its citizens. However, regrettably, the reality faced by many PLHIV includes instances of human rights violations directly linked to their HIV status.

**Graph 34 - Distribution of the study participants with regard to violation of their human rights due to their HIV positive status**



84.4% of the respondents have indicated that they have not encountered situations involving human rights violations, a trend that most probably could be attributed to non-disclosure of their HIV status. In contrast, 3.7% of the respondents have reported facing human rights violations. Among those who experienced such violations, employment and healthcare emerged as the primary areas of concern, with instances of job termination or discrimination within healthcare settings due to their HIV status. Notably, 11.9% of respondents expressed uncertainty regarding whether they had faced human rights violations. This underscores the importance of fostering awareness among all citizens about their human rights, enabling them to take appropriate actions in the event of any infringements.

**Graph 35 -Details on receiving legal redress for incidents of human rights violations of the study participants (n=15)**



Of those who experienced human rights violations, only one individual sought legal redress, while the remaining 14 did not pursue legal remedies. The cited probable reasons for abstaining from seeking legal redress could include a fear of potential exacerbation of stigma and discrimination as a consequence of pursuing legal action for rights violations, considering the responses received from the participants in general, where 60 participants agreed to that.

**Table 17 - Perceptions of the study participants on seeking legal redress for human rights violations**

| **Perceptions on seeking legal redress for violation of human rights** | **Yes** | **No** | **Not sure** | **Missing data** |
|---|---|---|---|---|
| Confidence in seeking legal redress for violation of human rights | 52 (12.9%) | 17 (4.2%) | 65 (16.1%) | 270 (66.8%) |
| Perception that one would be subjected to further stigma and discrimination in seeking legal redress for violation of rights | 60 (14.9%) | 27 (6.7%) | 52 (12.9%) | 265 (65.6%) |

### ❖ Recommendations suggested by the study participants for action to minimize stigma among PLHIV

**285 (70.5%) suggest to advocate for rights of all people living with HIV**

**260 (64.4%) suggest to advocate for rights and support for marginalized (key) populations**

**293 (72.5%) suggest to provide support to people living with HIV**

**312 (77.2%) suggest to educate people living with HIV about living with HIV**

**361 (89.4%) suggest to raise public knowledge and awareness about HIV and**

Offer to educate PLHIV

Support nutrition of PLHIV

Support PLHIV to learn to stand up for themselves

Positive counselling for PLHIV

Social inclusion of PLHIV

Correct Misconceptions in society

Make the society aware that it is a common disease

Have a practical action plan for attitude change

Attitude changes from school age

Community awareness of treatment

Change laws that have become a problem for the high risk community

14 (3.5%) had other suggestions

## ❖ Perceptions of the study participants on the factors which prevent people from seeking HIV/AIDS care services

**266 (65.8%) think that one factor is that people are unaware about the services available**

**294 (72.8%) think that the feeling of ‘people may reject me’ is a barrier for seeking services**

**154 (38.1%) agree that one of the factors is the advice by a family member saying it is harmful/ shameful to the family**

**Not thinking of HIV as a health problem is seen as a factor by 170 (42.1%)**

**88 (21.8%) think that the Services not being available in a client friendly manner is one of the factors**

**277 (68.6%) agree that PLHIV feeling afraid/ shy to go to a treatment centre is one of the reasons**

13 (3.2%) mentioned other factors which prevent people from seeking HIV/AIDS care services

232 (57.4%) find financial difficulties as one of the reasons for not seeking services

Public unawareness

Community myths

Due to lack of socialization

Inability to take leave from work

Interference with daily activities

Lack of sex education

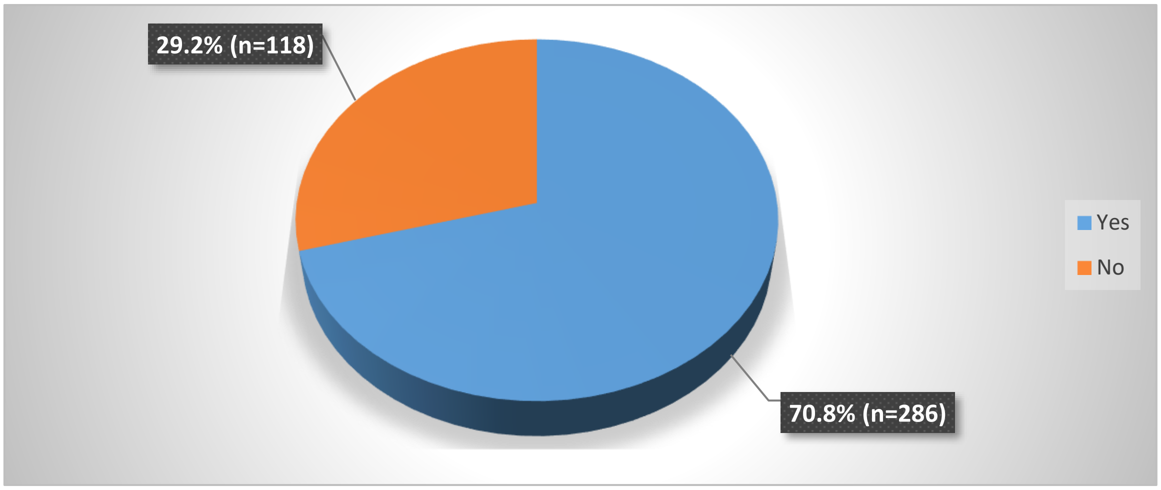
13 (3.2%) mentioned other factors which prevent people from seeking HIV/AIDS care services

109 (27%) think that longer time to get services / longer waiting period is a factor.

## ❖ Engagement with organizations of people living with HIV

The organization of PLHIV plays a pivotal role in crafting an empowering and supportive environment for individuals navigating the complexities of HIV. These organized groups, often formed by and for those living with HIV, serve as critical advocates, sources of mutual support, and catalysts for positive change within the broader community. By uniting under a common cause, PLHIV organizations work towards dismantling stigmas, amplifying the voices of those affected, and fostering a sense of community resilience.

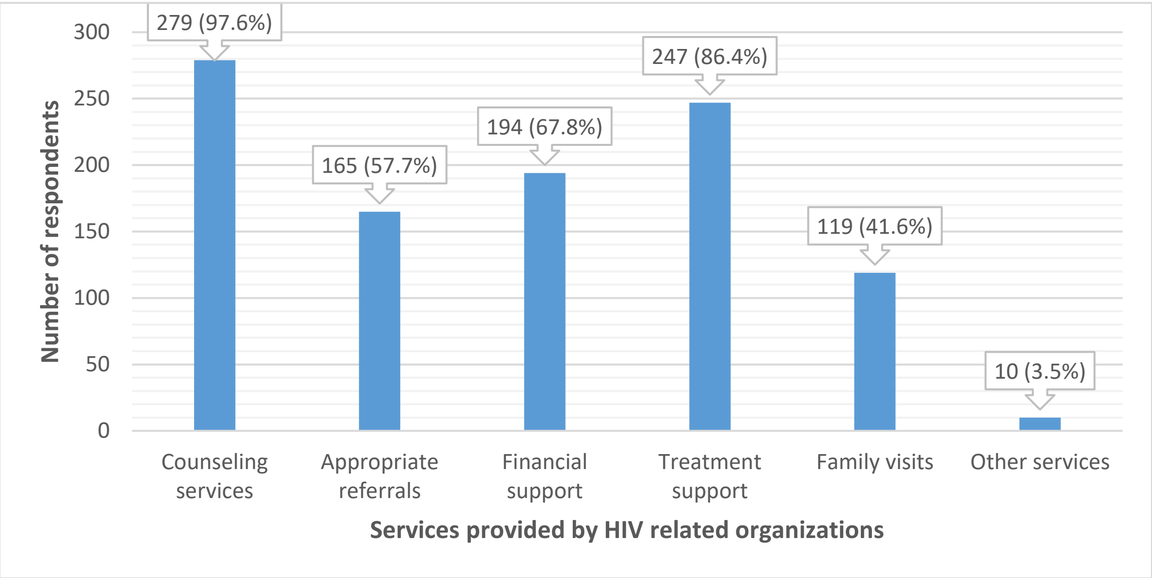
**Graph 36 - Distribution of the study participants on being a member of a HIV related organization**



Among the respondents 70.8% were members of the PLHIV organizations in the country (Lanka Plus, Positive Women’s Network and Positive Hopes Alliance).

These members access the organizations to obtain various services, including mainly counselling services, treatment support, and when possible financial support. Other services specified included helping family members and children, and functioning as a drop-in centre.

**Graph 37 - Details of the services provided by the HIV related organizations to the study participants who have joined those organizations (n=286)**



# Section 06

## Comparison of the current findings with the initial and subsequent stigma assessment studies among people living with HIV in Sri Lanka in 2010 and 2018.

A higher percentage of male respondents (75%) were interviewed in 2023 compared to 2018, which was 54%. In 2023 and 2018 the percentage of female respondents was 25% and 45% respectively. Total number of respondents in 2023 was 404, compared to 150 in 2018, marking a significant increase in participation levels. On respondents identified as being transgender in both studies. In terms of age distribution, the largest number of participants in 2010, 2018 and 2023 continued to be the 30-60 age group. However, the 2023 study had 23% of respondents below the age of 30.

**Table 18 - Comparison of the current findings with the initial and subsequent stigma assessment studies conducted in 2010 and 2018 among people living with HIV in Sri Lanka**

| | Thematic area | 2010 findings | 2018 findings | 2023 findings |
|---|---|---|---|---|
| 01 | Duration of living with HIV in the study participants. | N/A* | 40% of respondents had lived with HIV for 5-9 years.<br>26% had lived with it for 1-4 years and 20% for 10-14 years. 9% had lived with HIV for over 15 years. | 124 respondents had lived with HIV for 1-4 years. 84 had lived with HIV for 5-9 and 10-14 years respectively. 52 respondents had lived with HIV for over 15 years. |
| 02 | Patterns of disclosure. | 76% of respondents chose to disclose their HIV status to other people living with HIV. | 80% of respondents chose to disclose their HIV status to other people living with HIV. | 70% of respondents chose to disclose their HIV status to other people living with HIV. |

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|---|---|---|---|---|
| 03 | Family & social exclusion. | Exclusion from social and religious gatherings, and family activities due to HIV status was 10%, 3%, and 5% respectively. 5% were forced to change their residence due to HIV status. | Exclusion from family activities, religious gatherings and social gatherings, due to HIV status was 11.4%, 4.6%, and 2%, respectively. This was mainly due to nondisclosure of their HIV status. | 48.5% of respondents did not report instances of exclusion from social gatherings, 49.0% did not report exclusion from religious gatherings and 41.1% did not report exclusion from family activities, based on their positive HIV status. |
| 04 | Verbal and physical harassment. | 12% of respondents reported verbal harassment and 5% reported physical harassment based on their HIV status.<br>to their HIV status | 16% had experienced some form of verbal harassment or threat, of which 10% said the<br>It was based on their HIV status. 4% reported physical harassment based on their HIV status. | Minimal cases of verbal and physical harassment based on respondents' HIV status. This could be due to most not disclosing their HIV status to close associates. |
| 05 | Fear of being gossiped about, verbally insulted and physically assaulted due to HIV status. | 65% of respondents' feared gossip related to their HIV status. | 57% of respondents' feared gossip related to their HIV status. | 61.6% of respondents' feared gossip related to their HIV status. 49.3% feared verbal insults, harassment, and/or threats based on their HIV status. 16.6% and 16.3% feared potential physical assault or harassment tied to their HIV status. |

| | | | | |
|---|---|---|---|---|
| 06 | Losing employment and education opportunities. | 11% of respondents lost their job or income due to their HIV status. No respondents were dismissed, suspended or prevented from attending educational institutions. | 6% of respondents lost their job or income due to their HIV status. 2% had been dismissed, suspended or prevented from attending educational institutions. | 64% of respondents were employed.<br>Non-disclosure of HIV status to was 64% colleagues, 59% to employers and 49% to teachers.<br>0.7% had been dismissed, suspended or prevented from attending educational institutions. |
| 07 | Decisions and reasons to get tested for HIV. | 37% of respondents willingly underwent HIV testing. Most were tested without their knowledge, including 78% who tested for employment reasons, which was the most common reason. | 47% of respondents willingly underwent HIV testing. 20% underwent testing in response to prevalent HIV symptoms. Most common reason for testing was employment - 28%. | 66.1% of respondents willingly underwent HIV testing. 24.8% underwent testing without prior knowledge, discovering their serostatus only after the test had been conducted. 4% underwent testing due to pressure from others. 27.7% underwent testing in response to prevalent HIV symptoms. 28.5% sought testing solely driven by a personal desire to know their serostatus. |
| 08 | HIV testing locations. | N/A | 69% of respondents accessed HIV testing services through government hospitals or clinics. | 68% of respondents accessed HIV testing services through government hospitals or clinics. |

| | | | | |
|---|---|---|---|---|
| 09 | Pre and post-test HIV counselling. | 11% of respondents received both pre and post-test counselling. 8% did not received any counselling. | 49% of respondents received both pre and post-test counselling. 6.7% did not received any counselling. | 62% of respondents received both pre and post-test counselling. 10% did not receive any counselling. |
| 10 | Perception on the disclosure of HIV status by healthcare workers and confidentiality of medical records at healthcare institutions. | 23% claimed to have knowledge of healthcare workers disclosing their HIV status without consent. 64% were unsure as to how confidential their medical records related to the HIV status remained. | 75% expressed confidence in the confidentiality of their medical records within healthcare institutions. However 12.7% claimed to have knowledge of healthcare workers disclosing their HIV status without consent, while 33% indicated they were unsure whether healthcare workers had disclosed their status. 23% were unsure as to how confidential their medical records related to the HIV status remained. | 93% of respondents said their HIV status has never been disclosed by healthcare workers. 90% expressed confidence in the confidentiality of their medical records within healthcare institut |

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|---|---|---|---|---|
| 11 | Stigma and discrimination at other healthcare settings. | N/A | N/A | 90% of respondents reported not encountering stigma when seeking admission to a hospital for procedures unrelated to HIV. However 55% have refrained from disclosing their HIV status to healthcare workers. |
| 12 | Internalized stigma and among PLHIV. | 54% of respondents expressed shame while 51% reported feelings of guilt for their HIV status. 43% acknowledged self-blame. | 46% of respondents acknowledged self-blame for their HIV status. 43% expressed shame while 31% reported feelings of guilt. | 50% of respondents acknowledged self-blame for their HIV status, while 41% reported feelings of guilt. 39% expressed shame and 38% reported experiencing low self-esteem. |
| 13 | Access to ARTs, opportunistic infections treatment and opportunities to discuss treatment options. | 76% of respondents had access to ART. | 97.3% of respondents had access to ART. | 98.5% of respondents had access to ART. 1.5% reported not being on ART. |

| | | | | |
|---|---|---|---|---|
| 14 | Sexual and reproductive health and living with HIV. | 56% of respondents had a constructive discussion with a healthcare professional about sexual and reproductive health. | 99% of respondents had a constructive discussion with a healthcare professional about sexual and reproductive health. | 95.5% of respondents had the opportunity to discuss sexual and reproductive health, sexual relations, and emotional well-being with healthcare service providers. 81% reported receiving targeted counselling from healthcare professionals on reproductive options. |
| 15 | Living with HIV and Human Rights. | N/A | 16% of respondents claimed their rights had been abused, but only 25% attempted to get legal redress. | 84.4% of respondents indicated they had not encountered human rights violations, most probably due to non-disclosure of their HIV status. 3.7% reported facing human rights violations. 12% were uncertain whether they had faced human rights violations. |

|  |  |  |  |  |
|---|---|---|---|---|
| 16 | Recommendations suggested by the study participants for action to minimize stigma among PLHIV. | 48% of respondents advocated for rights of all people living with HIV. 22% wanted support provided to people living with HIV. 19% wanted to raise public knowledge and awareness about HIV. 4% wanted to educate people living with HIV about living with HIV and 7% advocated for rights of and supported marginalized populations. | Recommendations (no %): Advocate government officials for rights of all people living with HIV.<br>Raise public knowledge and awareness about HIV and AIDS to prevent stigma and discrimination.<br>Educate people living with HIV and provide them support.<br>Educate rights of PLHIV and key population groups<br>Involve PLHIV for policy making and effective implementation processes | 89% suggested to raise public knowledge and awareness about HIV and AIDS. 70.5% suggested to advocate for rights of all people living with HIV. 77% suggested to educate people living with HIV about living with HIV. 72.5% suggested providing support to people living with HIV and 64% suggested to advocate for rights and support for marginalized populations. |
| 17 | Perceptions of study participants on the factors which prevent people from seeking HIV/AIDS care services. | 50% of respondents said they had no discussions with healthcare professionals on HIV related treatment options. | 64% of respondents are afraid or shy to go to a treatment centre. 63% felt that ‘people would reject me’. 57% were unaware of services available. And 12% did not think of it as a health problem. | 73% think the feeling that ‘people may reject me’ is a barrier for seeking services. 67% think people are unaware about available services. 57% find financial difficulties as one of the reasons for not seeking services. |
| 18 | Engagement with organizations of people living with HIV. | N/A | N/A | 71% of respondents were members the PLHIV organizations in Sri Lanka. |

# Section 07

# Recommendations

## ❖ Health Care Systems, Protocols and Practices

- **Integrate Psychosocial Support:**

Implement a robust and inclusive approach to healthcare by integrating psychosocial support as a non-negotiable component within the comprehensive care packages delivered collaboratively with organizations of PLHIV. This initiative aims to holistically address the emotional and mental well-being of individuals living with HIV, recognizing the profound impact of psycho-social factors on their overall health.

- **Ensure Informed Consent in HIV Testing:**

Institute and rigorously enforce policies that guarantee the full and informed consent of clients undergoing HIV testing across government, community, and private settings. This initiative seeks to uphold ethical standards, educate clients on their rights, and empower them to report any incidents of non-consent transparently through existing mechanisms.

- **Mandatory Pre and Post-Test Counselling:**

Institutionalize the practice of mandatory pre and post-test counselling across all HIV testing settings. This includes government, community, and private facilities. Strengthen existing protocols and practices, progressively incorporating community counsellors alongside medical professionals to offer comprehensive support during the testing process.

- **Promote Voluntary HIV Testing:**

Launch targeted communication campaigns aimed at transforming public perceptions of HIV testing. Shift the narrative from fear to empowerment by positioning HIV testing as an integral and voluntary aspect of overall health. Empower individuals to take charge of their health through informed decision-making and proactive testing.

## ❖ Policy Environment

- **Protect Sexual and Reproductive Rights:**

Spearhead the development and implementation of policies that explicitly safeguard and promote the sexual and reproductive rights of PLHIV. This includes ensuring full access to reproductive rights. Additionally, advocate for an update to the National AIDS policy to comprehensively incorporate the sexual and reproductive rights of individuals living with HIV, acknowledging their holistic health needs.

- **Championing Human Rights:**

Embark on a comprehensive advocacy initiative to safeguard the human rights of PLHIV through adopting required policy measures to proactively address and eradicate stigma and discrimination rooted in their HIV status. This multifaceted approach involves strategic collaboration with key governmental bodies, including the Ministry of Health, Ministry of Justice, Human Rights Commission Sri Lanka, and other relevant institutions.

## ❖ Community Engagement

- **Establish a PLHIV follow up system:**

Pave the way for an innovative joint community-STI clinic system designed to proactively monitor and follow up on all PLHIV. This system would provide regular check-ins, offering counselling and psychological support as required, thereby fostering a continuous and supportive healthcare environment that extends beyond traditional clinical settings.

- **Deploy Trained Community Counsellors:**

Enhance the quality of care for newly diagnosed PLHIV by strategically deploying trained community counsellors within STI clinics. Alternatively, develop robust referral systems that seamlessly connect individuals with peer counselling. This targeted approach aims to address specific challenges related to stigma, discrimination, self-stigma, and other psychological issues, ensuring a more personalized and empathetic support system.

- **Support Self-Help Groups:**

Champion the establishment and sustenance of PLHIV self-help groups through active support for organizations working with key populations. These groups serve as invaluable platforms for fostering a sense of community, providing group counselling and therapy sessions to address nuanced psychological conditions such as self-stigma, self-blame, self-shaming, and guilt.

- **Support PLHIV Organizations:**

Provide substantial financial and technical support to fortify PLHIV organizations, enabling them to not only sustain but also expand their networks. This support aims to enhance the organizations' capacity to deliver comprehensive services, fostering empowerment, and community resilience among PLHIV.

# Annexes

## ❖ Responses received for each item of the Berger scale:

| | Item | Strongly Disagree | Disagree | Agree | Strongly Agree |
|---|---|---|---|---|---|
| **1** | Some people avoid touching me once they know I have HIV. | 32 (7.9%) | 191 (47.3%) | 111 (27.5%) | 70 (17.3%) |
| **2** | People I care about stopped calling after learning I have HIV. | 33 (8.2%) | 188 (46.5%) | 126 (31.2%) | 57 (14.1%) |
| **3** | I have lost friends by telling them I have HIV. | 29 (7.2%) | 188 (46.5%) | 122 (30.2%) | 65 (16.1%) |
| **4** | Telling someone I have HIV is risky. | 7 (1.7%) | 59 (14.6%) | 190 (47.0%) | 148 (36.6%) |
| **5** | I work hard to keep my HIV a secret. | 12 (3.0%) | 34 (8.4%) | 211 (52.2%) | 147 (36.4%) |
| **6** | I am very careful who I say that I have HIV. | 9 (2.2%) | 21 (5.2%) | 224 (55.4%) | 150 (37.1%) |
| **7** | People with HIV are treated like outcasts. | 15 (3.7%) | 93 (23.0%) | 175 (43.3%) | 121 (30.0%) |
| **8** | Most people believe a person who has HIV is dirty. | 119 (29.5%) | 137 (33.9%) | 105 (26.0%) | 43 (10.6%) |

| | | | | | |
|---|---|---|---|---|---|
| **9** | Most people are uncomfortable around someone with HIV. | 110 (27.2%) | 145 (35.9%) | 110 (27.2%) | 39 (9.7%) |
| **10** | I feel guilty because I have HIV. | 118 (29.2%) | 147 (36.4%) | 95 (23.5%) | 42 (10.4%) |
| **11** | People's attitudes about HIV make me feel worse about myself. | 106 (26.2%) | 194 (48.0%) | 67 (16.6%) | 36 (8.9%) |
| **12** | I feel I'm not as good a person as others because I have HIV | 111 (27.5%) | 202 (50.0%) | 65 (16.1%) | 26 (6.4%) |

## Responses received for each item of the K-10:

| **STATEMENT** | **None of the time** | **A little of the time** | **Some of the time** | **Most of the time** | **All the time** |
|---|---|---|---|---|---|
| During the last 30 days, about how often did you feel tired out for no good reason? | 164 (40.6%) | 72 (7.8%) | 129 (31.9%) | 29 (7.2%) | 10 (2.5%) |
| During the last 30 days, about how often did you feel nervous? | 171 (42.3%) | 114 (28.2%) | 89 (22.0%) | 25 (6.2%) | 5 (1.2%) |
| During the last 30 days, about how often did you feel so nervous that nothing could calm you down? | 256 (63.4%) | 82 (20.3%) | 54 (13.4%) | 10 (2.5%) | 2 (0.5%) |

| | | | | | |
|---|---|---|---|---|---|
| During the last 30 days, about how often did you feel hopeless? | 250 (61.9%) | 74 (18.3%) | 66 (16.3%) | 10 (2.5%) | 4 (1.0%) |
| During the last 30 days, about how often did you feel restless or fidgety? | 260 (64.4%) | 84 (20.8%) | 42 (10.4%) | 14 (3.5%) | 4 (1.0%) |
| During the last 30 days, about how often did you feel so restless you could not sit still? | 308 (76.2%) | 51 (12.6%) | 30 (7.4%) | 11 (2.7%) | 4 (1.0%) |
| During the last 30 days, about how often did you feel depressed? | 130 (32.2%) | 90 (22.3%) | 120 (29.7%) | 48 (11.9%) | 16 (4.0%) |
| During the last 30 days, about how often did you feel that everything was an effort? | 256 (63.4%) | 74 (18.3%) | 48 (11.9%) | 20 (5.0%) | 6 (1.5%) |
| During the last 30 days, about how often did you feel so sad that nothing could cheer you up? | 226 (55.9%) | 81 (20.0%) | 55 (13.6%) | 34 (8.4%) | 8 (2.0%) |
| During the last 30 days, about how often did you feel worthless? | 289 (71.5%) | 45 (11.1%) | 39 (9.7%) | 18 (4.5%) | 13 (3.2%) |

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