

# Zero Stigma and Discrimination by 2020

## Stigma assessment of People living with HIV in Sri Lanka - 2017



**Experience of Stigma  
and Discrimination  
among People Living  
with HIV**

**Part 1**

**Conducive Environment for  
People Living with HIV**

Legal and Policy Frame works  
Government and Non-Government  
support for People Living with HIV

**Part 2**



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## Message from the Director General of Health Services



The first stigma assessment has been conducted in 2009/2010 and this publication is the second stigma assessment report on people living with HIV in Sri Lanka.

Stigma and discrimination are among the foremost barriers to HIV prevention, treatment, care and support. Specifically, research has shown that stigma and discrimination undermine HIV prevention efforts by making people afraid to seek HIV information, services and modalities to reduce their risk of infection and to adopt safer behaviours, lest these actions raise suspicion about their HIV status. Research has also shown that fear of stigma and discrimination, which can also be linked to fear of

violence, discourages people living with HIV from disclosing their status even to family members and sexual partners, and undermines their ability and willingness to access and adhere to treatment. Thus, stigma and discrimination weaken the ability of individuals and communities to protect themselves from HIV and to stay healthy if they are living with HIV.

Freedom from discrimination is a fundamental right founded on the principles of natural justice. Human rights derive from the individual's relationship with the State, and States have an obligation to respect, protect and fulfill human rights. For the last 50 years, human rights have been globally recognized and codified through the UN human rights instruments.

This type of research will be of utmost importance in building towards fast-tracking this goal by meeting the 90-90-90 targets: 90% diagnosis of people living with HIV, 90% of these diagnosed people receiving treatment, and 90% of those undergoing treatment to be virally suppressed by 2020.

A handwritten signature in blue ink, consisting of a long horizontal line that curves upwards at the right end, with a vertical line crossing it near the center.

**Dr. J. M. W. Jayasundara Bandara,**  
Director General of Health Services,  
Ministry of Health, Nutrition and Indigenous Medicine

## Message from the Deputy Director General – Public Health Services

Culture and religion can shape values, beliefs, attitudes, and behaviours. In Sri Lanka, as in most countries, among the many socioeconomic factors relating to HIV/AIDS, stigma and discrimination are a major concern.

Stigma and discrimination of PLHIV and its correlation with the disease status is an important aspect that needs to be given concern. Understanding the impact of stigma is an essential component to control and prevent HIV and to achieve the national and global targets. Since HIV is a chronic disease, which needs continuous lifelong treatment, it not only affects the persons' day to day life style but also the lives of his/her family and friends. It further worsens their social and economic status and acts as a vicious cycle.

Stigma and Discrimination prevents open discussion on the subject, impeding awareness and learning, and it discourages testing, as people are afraid of being stigmatized by society. This is one of the major challenges Sri Lanka faces on the path towards ending AIDS by 2025. Stigma and Discrimination hinders the path towards achieving an AIDS-free world, country, society, or community, hence 90-90-90 fast track targets by 2020. This Second Stigma assessment among people living with HIV in Sri Lanka will help to achieve the target of Zero discrimination by 2025.

This is why it is imperative that measures are taken to ensure that stigma and discrimination is stopped at all levels of society, as well as within the public and private health systems. This assessment will greatly help to identify the extent of the problem, and to implement programmes to reduce stigma and discrimination.

I extend my heartiest congratulations for publishing this detailed report of second stigma assessment study of PLHIV in Sri Lanka as it will pave the way to end the AIDS epidemic by 2025.



**Dr. Sarath Amunugama,**

Deputy Director General- Public Health Services - 1

Ministry of Health, Nutrition and Indigenous Medicine

## Message from the UNFPA Representative in Sri Lanka



The United Nations Population Fund (UNFPA) is happy to support the *Stigma Assessment of People Living with HIV in Sri Lanka 2017* done by the National STI/AIDS Control Programme of the Ministry of Health, Nutrition, and Indigenous Medicine.

As an organization that strives to ensure universal access to sexual and reproductive health and realization of reproductive rights, advocating for a world free of HIV/AIDS is an important part of our mandate. In Sri Lanka, we have partnered with the Government, international community, and civil society, to drive this work forward, and are committed to continue doing so.

Globally, since the first HIV case was detected, 78 million people have become infected with HIV. This is 78 million people who are vulnerable to stigmatization and cornering from society. This is why the world has come together to deliver the triple-zero goals: 'Zero AIDS-related deaths. Zero discrimination. Zero new infections'.

Sri Lanka is a low HIV prevalence country, due to the right investments by successive Governments in concentrating the situation. However, reasons such as the presence of a large youth population, internal and external migration, growing sex industry, and low level of condom usage, increases possibility for an HIV epidemic to take place.

Therefore, it is important that relevant protection methods, such as condoms, are used and normalized in society, to ensure such a situation does not arise.

In 2016, UNFPA was happy to support the first National Condom Strategy in Sri Lanka. This document highlighted that social stigma was one of the major barriers for condom programming in the country. This is further highlighted through the findings of this study, through which the People Living with HIV Stigma Index tool measures and detects changing trends in relation to stigma and discrimination experienced by people living with HIV in Sri Lanka.

This report is an important contribution to our efforts to ensure people living with HIV will not be left behind, not only in terms of receiving needed care and treatments, but also living a life with respect and dignity. Also, we hope that this data will serve as a baseline in measuring Sri Lanka's progress towards achieving the Sustainable Development Goals.

We at UNFPA assure our continuous support to the National STI/AIDS Control Programme and are confident that the findings of this study will help pave the way forward towards evidence-based policy interventions to build a Sri Lanka with no discrimination and stigmatization against people living with HIV.

A handwritten signature in blue ink, appearing to read 'Ritsu Nacken'.

**Ms. Ritsu Nacken,**

UNFPA Representative in Sri Lanka

## Preface



HIV/AIDS remains one of the world's most significant public health challenges, especially in low- and middle-income countries. In Sri Lanka, there has been an upward trend in the numbers of reported HIV/AIDS cases. This ought to serve as a reminder for the country to take more action, beginning with tackling cultural attitudes and stigma associated with HIV/AIDS, which continue to be roadblocks in addressing the issue.

Currently, Sri Lanka is experiencing a low level of HIV epidemic with a prevalence rate of less than 0.1% in the general population, as well as in the key population groups. During 2016, a total of 249 HIV cases were newly reported in Sri Lanka. This is the highest number reported in a year since the identification of the first HIV infected Sri

Lankan in 1987, and this amounts to about 21 persons newly reported with HIV for a month. However, the reported numbers represent only a fraction of HIV infected people in the country as many infected persons may perhaps not be aware of their HIV status, and in addition, stigma and discrimination towards HIV hinders seeking HIV testing services. Though being a country with low prevalence, the society still carries some level of stigma and discrimination towards PLHIV. Stigmatizing attitudes and behaviours have been widely documented and are found to constitute an important barrier for seeking, using and adhering to HIV prevention services and treatment.

It is very timely and significantly important to conduct a stigma assessment of People Living with HIV in Sri Lanka to identify the extent of the problem, and it will help to implement programmes to reduce stigma and discrimination to achieve 90-90-90 targets as the United Nations Member States unanimously adopted to end the AIDS epidemic by 2030, as part of implementing the Sustainable Development Goals. The world is embarking on a Fast-Track strategy to end the AIDS epidemic by 2030, whereas Sri Lanka has planned to reduce new HIV infections to zero by 2025.

I applaud the great effort of publishing this useful study report of “ Stigma Assessment of People Living with HIV in Sri Lanka – 2017” in order to achieve the state of Zero stigma and Discrimination by 2020. The ultimate target is to end the AIDS epidemic by 2030, which is the goal of the National STD/AIDS Control Programme by 2025 as well. These targets aim to transform the vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths into concrete milestones and end-points. I highly acknowledge Dr. Janaki Vidanapathirana, Consultant Community Physician, Dr. Buddhika Senanayake, Senior Registrar in Community Medicine, Dr. Nimali Wijegoonewardene, Registrar in Community Medicine, & Dr. Mekala Fernando, Registrar in Community Medicine, for their commendable contribution in writing this valuable report after conducting the assessment.

I also acknowledge the data collection team Mr. Palitha Vijayabandara, Mr. Sunimal Fernando, Ms. Inoka Prabhashani and Ms. Dammika Perera, for their commendable hard work in the field setup.



**Dr. Sisira Liyanage,**

Director - National STD/AIDS Control Programme,  
Ministry of Health, Nutrition and Indigenous Medicine

# Zero Stigma and Discrimination by 2020: Stigma assessment of People living with HIV in Sri Lanka - 2017

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# **Zero Stigma and Discrimination by 2020: Stigma assessment of People living with HIV in Sri Lanka - 2017**

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## Executive Summary

Sri Lanka is experiencing a low level of HIV epidemic, with a prevalence of less than 5% in any defined key affected population, and less than 1% of the general population. Stigma and discrimination are among the foremost barriers to HIV prevention, treatment, care and support. This undermines HIV prevention efforts by making people afraid to seek HIV information, services and modalities to reduce their risk of infection and to adopt safer behaviours. Second Stigma assessment of people living with HIV in Sri Lanka – 2017 was carried out to assess the stigma among people living with HIV in Sri Lanka.

The assessment consisted of a descriptive cross-sectional study to assess stigma level (quantitative part), in-depth interviews to describe views from people living with HIV who are in positive networks (qualitative part), and a desk review to identify the supportive legal and policy frameworks and other available services for people living with HIV. A sample of 150 people living with HIV was interviewed using an interviewer administered questionnaire, to assess the stigma which they experienced using purposive sampling method. The respondents were selected from the membership of the networks of people living with HIV, but also included non-members who are not in the networks. All interviewees were drawn from existing community networks.

The study population consisted of 54% (n=81) males and the sample age varied from 15 to 70 years. The majority of the study participants (77%) have attended secondary school. Most of them (n= 134; 89.3%) had annual household income levels below 3000 USD, while only one person (0.7%) earned more than 5000 USD. Nearly two thirds (67.1%) of the participants were currently employed and among them, 12% (n=12) were in the government (public) sector. Most of the respondents (43.3%; n=65) did not belong to and have not in the past belonged to any of the key population groups. Vulnerable populations that are HIV positive include participants with a history of migrant work, which represent nearly one-third of the study population (33.3%). Many (68%; n=102) of the participants were living with HIV for 5 or more years.

Fourteen Participants (9.3%) have not declared their HIV status to their husband/ wife/ partner and they were not comfortable with friends, neighbours, co-workers, employers, and children finding out their status. HIV positive people have found it easiest to share their status with other people living with HIV. Exclusion from family activities, religious gatherings, and social gatherings, due to HIV status was as low as 11.4%, 4.6%, and 2%, respectively and this was mainly due to non-disclosure of their HIV status.

Verbal abuse, harassment and/ or threat due to HIV status was 10% and verbal insult due to HIV status conducted by healthcare workers accounted for only 2%, in the current study sample. The physical abuse, harassment or threat directly related to their HIV status was 4% (n=6), and only 6% (n=9) of the study population indicated that the loss of a job or another source of income was due to their HIV status. The Majority stated that the reported low levels of stigma and discrimination in the Stigma Index are due to non-disclosure of the HIV status.

Voluntary HIV testing among respondents was 47.3% (n= 71), and most of them were tested during employment. Nearly 50% (n=74) of the participants have received both pre and post-HIV testing counseling and around 75% (n= 112) of the respondents had confidentiality of their medical records in healthcare institutions related to HIV status. The majority (97.3%; n=146) have access to Anti-Retroviral therapy and had the opportunity to have a constructive discussion with a healthcare professional about sexual and reproductive health. The results of internal stigma showed that self-blame (46.7%) and shame (42.7%) were the most prevalent feelings, followed by guilt (31.3%), low self-esteem (25.3%; n=38), and suicidal thoughts (20%).

It is recommended to advocate government officials for rights of all people living with HIV and to raise public knowledge and awareness about HIV and AIDS by providing accurate and comprehensive knowledge to prevent stigma and discrimination. Special training activities need to be arranged for health care workers to prevent stigma and discrimination while treating and caring PLHIV. Further psychological interventions need to be implemented to overcome self-stigma among people living with HIV. Educating people living with HIV on their rights and positive living provides support to increase self-reliance. Involving PLHIV for policy making and effective implementation processes is necessary to minimize stigma and discrimination in the Sri Lankan context.

Although there are no separate laws and legal frameworks available for PLHIV, existing supportive laws & legal frameworks help to protect PLHIV. But it needs to be further strengthened to develop a conducive environment for PLHIV for protection of human rights at the implementation level.

## Content

	Page
<b>Introduction</b>	
Epidemiological analysis of HIV in Sri Lanka	1
Stigma and discrimination of HIV	2
General Objective	5
Specific Objective	5
<b>Methodology</b>	6
<b>Part 1 – Results of the quantitative part</b>	9
Socio-Demographic Characteristics	9
Socio-Economic Characteristics	14
Key populations and Vulnerable Groups	20
Chronic Diseases and Healthcare Seeking Behaviour	21
Experiences of Stigma and Discrimination	24
General Experiences	26
Harassment and Assault	28
Physical Harassment and Threat	31
Stigma and Discrimination during Employment and Education	35
Stigma in Healthcare Settings	38
Confidentiality and Disclosure within Healthcare Setting	41
Care and Support	44
Stigma Internalized: Feelings and Decisions of HIV Positive People	47
Rights, Laws and Policies	51
Perceived Obstacles Identified by PLHIV to prevent Stigma and Discrimination	52
Recommendations from people living with HIV to Minimise the Stigma and Discrimination	54
Some views Collected During Data Collection	54
<b>Part 2 – Desk Review: Conducive Environment for People Living with HIV</b>	58
Laws, policies, Plans, Programmes, and Committees	58
Management and Governance	66
Government and Non-Government support for People Living with HIV	67
Support Provided by Non – Governmental Organizations	75
Other Supportive Environment for People Living with HIV	77
Community based positive Organizations	77
In-depth interview of main focal points of three positive networks	81
<b>Conclusions and Recommendations</b>	84
References	87

## List of Tables

Table No.		Page No.
Table 3.1	Distribution of the Residing District of the Study Population	13
Table 3.2	Distribution of the Study Population by their Work Related Characteristics	17
Table 3.3	Occupational Categories of those Currently Employed according to the ISCO Classification	19
Table 3.4	Distribution of the Study Population by their type of Chronic Diseases	22
Table 3.5	Health Care Seeking Behaviour in the Study Population	23
Table 3.6	Patterns of Disclosure of the HIV Status among the Study Participants	25
Table 3.7	Distribution of the General Experience of Stigma and Discrimination in the Last 12 months among the Study Participants	27
Table 3.8	Perceived reasons for experiencing some form of HIV related stigma and discrimination in the last 12 months	37
Table 3.9	The Perceived Reasons for HIV Testing among the Study Participants	39
Table 3.10	Perceived Obstacles Identified by PLHIV to Prevent Stigma and Discrimination	52
Table 3.11	Perceived Factors that Prevent People from Seeking HIV/AIDS Care Services	53
Table 3.12	Support provided by PLHIV Organizations to their Membership	53

## List of Figures

Figure No.		Page No.
Figure 3.1	The Distribution of Sex in the Study Population	9
Figure 3.2	The Distribution of Age in the Study Population	10
Figure 3.3	The Distribution of Ethnicity in the Study Population	11
Figure 3.4	The Distribution of Religion in the Study Population	11
Figure 3.5	The Distribution of Marital Status in the Study Participants	12
Figure 3.6	The Distribution of the Study Population According to the Place of Residence	14
Figure 3.7	The Distribution of Education Level in the Study Participants	14
Figure 3.8	The Distribution of Annual Household Income in the Study Participants (in USD)	15
Figure 3.9	The Distribution of Current Employment Status of the Study Population	16
Figure 3.10	The Distribution of the Occupation Category in the Study Participants according to the ISCO Classification	18
Figure 3.11	The Distribution of Key Populations and Vulnerable Groups in the Study Participants	20
Figure 3.12	The Distribution of Chronic Disease Status in the Study Participants	21
Figure 3.13	The Distribution of the Duration of Living with HIV after Diagnosis, in the Study Participants	24
Figure 3.14	The Distribution of the Frequency of Verbal Insult, Harassment and /or Threat in the Study Participants ( <i>From all causes including HIV status</i> )	28
Figure 3.15	The Distribution of the Reason for Verbal Insult, Harassment and/ or Threat in the Study Participants	28
Figure 3.16	The Distribution of experiencing Verbal Insult, Harassment or Threat due to HIV status in the total Study Participants	29
Figure 3.17	The Distribution of the Person who Conducted the Verbal Insult, Harassment or Threat due to their HIV Status	30

<b>Figure No.</b>		<b>Page No.</b>
Figure 3.18	The Distribution of experiencing Verbal Insult, Harassment or Threat due to HIV status conducted by Healthcare Workers in the total Study Participants	30
Figure 3.19	The Distribution of Verbal Abuse occurring within and before 12 Months in the Study Participants	31
Figure 3.20	The Distribution of the Frequency of Physical Harassment and Threat in the Study Participants	32
Figure 3.21	The Distribution of the Reason for Physical Harassment and Threat in the Study Participants	32
Figure 3.22	The Distribution of experiencing Physical Harassment and Threat due to HIV status in the total Study Participants	33
Figure 3.23	The Distribution of the Person who had Committed the Physical Harassment and Threat	34
Figure 3.24	The Distribution of Physical Abuse Occurring Within and Before 12 Months in the Study Participants	34
Figure 3.25	The Distribution of the Frequency of Losing the Job or Income in the Study Participants	35
Figure 3.26	The Distribution of the Reasons for Losing the Job or Income in the Study Population	35
Figure 3.27	The Distribution of Losing the Job or Income due to HIV status in the total Study Participants	36
Figure 3.28	The Distribution of the Decision to Get Tested for HIV in the Study Population	38
Figure 3.29	The Distribution of the Place of HIV Testing in the Study Participants	39
Figure 3.30	The Distribution of the Type of Counseling Received During HIV Testing, in the Study Participants	40
Figure 3.31	The Distribution of Perceived Fearful Incidents Happened in Healthcare Settings, in the Study Participants	41
Figure 3.32	The Distribution of Perceived Fearful Incidents Happened in Healthcare Settings, among who have Faced such Incidents	42
Figure 3.33	The Distribution of Perceived Disclosure of HIV Status by Healthcare Workers without their Consent, in the Study Participants	42

<b>Figure No.</b>		<b>Page No.</b>
Figure 3.34	The Distribution of Perceived Confidentiality of Medical Records in Healthcare Institutions Related to HIV Status, in the Study Participants	43
Figure 3.35	The Distribution of Access to Anti-Retroviral Therapy (ART) in the Study Population	44
Figure 3.36	The Distribution of Access to Opportunistic Infection (OI) Medication in the Study Population	45
Figure 3.37	The Distribution of Experiencing Stigma and Discrimination in Specific Procedures at Healthcare Institutions	47
Figure 3.38	The Distribution of the Type of Perceived Feelings Experienced due to HIV Status, in the Study Participants	48
Figure 3.39	The Distribution of the Perceived Decisions Taken due to the HIV Status by the Study Participants	50



## Abbreviations

<b>ART</b>	Antiretroviral treatment
<b>CCMSL</b>	Country Coordinating Mechanism, Sri Lanka
<b>DU</b>	Drug Users
<b>EMTCT</b>	Elimination of Mother to Child Transmission
<b>FPASL</b>	Family Planning Association of Sri Lanka
<b>FSW</b>	Female Sex Workers
<b>GAM</b>	Global AIDS Monitoring
<b>GFATM</b>	Global fund to fight AIDS, Tuberculosis and Malaria
<b>HRH</b>	Human Resource for Health
<b>HRM</b>	Human Resource Management
<b>ILO</b>	International Labour Organization
<b>KP</b>	Key Populations
<b>M &amp; E</b>	Monitoring & Evaluation
<b>MSA</b>	Multi-country South Asia
<b>MSM</b>	Men who have sex with men
<b>NAC</b>	National AIDS Council
<b>NRL</b>	National Reference Laboratory
<b>NSACP</b>	National STD/AIDS Control Programme
<b>NGOs</b>	Non-Governmental Organizations
<b>PEP</b>	Post Exposure Prophylaxis
<b>PLHIV</b>	People Living with HIV
<b>STD</b>	Sexually Transmitted Diseases
<b>STI</b>	Sexually Transmitted Infections
<b>WHO</b>	World Health Organization
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS

## Introduction

### Epidemiological Analysis of HIV in Sri Lanka

Currently Sri Lanka is experiencing a low level of HIV epidemic. The prevalence of HIV among persons more than 15 years has been estimated to be <0.1%. According to the estimates for Sri Lanka as at the end of 2016, there are 3900 people living with HIV. There was a cumulative number of 2688 HIV cases reported to the National STD/AIDS Control Programme, at the end of the second quarter of 2017. This implies that more than 1200 cases of HIV are not detected yet, and remain in the community without initiation of treatment.

Out of reported cumulative cases, 1741 were males, while 947 were females. More than half had been reported from the Western province, with around one third of the cumulative cases coming from the Colombo district. During the third quarter of 2017, seventy-eight new HIV cases had been identified.

There are 690 AIDS cases identified so far in Sri Lanka, by the end of the third quarter of 2017. Two hundred and forty nine new cases of HIV were identified during the year 2016, and 47 AIDS deaths were reported. At present, the male to female ratio of reported HIV cases is 1.8:1. Eighty two vertically transmitted cases (mother to child transmission) of HIV have been reported in Sri Lanka so far.

Sexual transmission accounted for 88% of all cases reported during 2016. However, in 11% of the cases, adequate data was not available to ascertain the probable mode of transmission. A closer observation of data shows a small but a rising trend in the incidence of HIV infection among male to male or bisexual relationships over the years, while the predominant mode of HIV transmission still continues to be heterosexual. Further, during year 2016, out of the identified new HIV cases, 36.5% (more than one third) have got the virus transmitted through male to male sexual relationships, while more than half (51.4%) have contracted it through heterosexual (male-female) sexual relationships. There is an increasing trend observed throughout the years in Sri Lanka, with regard to the transmission of HIV through male to male homosexual relationships since 2011.

During 2016, nearly 50% of all males reported with HIV gave a history of male to male sexual contacts. Most of these men are married, thus causing added implications on transmission to women and to their babies. There are no HIV cases reported due to blood transfusions since year 2000.

The majority of the newly identified cases of HIV during 2016 were between the ages of 25-49 years, but twenty new cases were also identified among the age group of 15-24 years. It is observed that the number of new HIV cases identified among the 15-24 year olds has been increasing over the past years. The majority was diagnosed at the pre-clinical stage, while 21% were diagnosed at the AIDS stage during year 2016. Since 2013 there is a slight, but a consistent reduction of AIDS (later stage of HIV infection) stage patients among the reported HIV positive cases.

During the year 2016, the number of HIV tests that have been carried out was 1129246, where the sero-positivity rate has been 0.02% in 2016. The number of HIV testing has increased over the years, and the rapid test has been introduced for HIV screening since 2016. HIV screening tests are available in the government as well as the private sector, as well as through mobile and outreach clinics, but the confirmatory test for HIV is only available at the Central Clinic of the National STD/AIDS Control Programme. HIV testing is complemented by pre and post HIV test counselling.

The findings of the sentinel sero-surveillance survey in 2016, conducted among female sex workers, men who have sex with men, people who inject drugs and clients of sex workers, revealed that men who have sex with men were having the highest risk out of them, with a HIV prevalence of 1.5%, where 11 positive cases were identified through testing of blood from 739.

At present, the Treatment as Prevention strategy is implemented in Sri Lanka, where all identified HIV positives are treated with Anti-Retroviral Therapy (ART) irrespective of their CD4 cell count. All treatment is provided free of charge, and confidentiality is strictly assured.

During 2016, over 89% of the reported HIV cases were linked to care during the same year. Stringent measures taken over the years to motivate all diagnosed HIV positive cases to link with HIV services have been productive. Networking with private hospitals and laboratories and engaging with newly diagnosed PLHIV via telephone, have remarkably reduced the number of pre-ART loss to follow-up cases.

## **Stigma and Discrimination of HIV**

Stigma is derived from a Greek word meaning a mark or stain, and it refers to beliefs and/or attitudes. Stigma is an attribute, behaviour or reputation which is socially discrediting in a particular way. This mentally classifies an individual in an undesirable, rejected stereotype rather than in an accepted, normal one. Stigma can be further subdivided as perceived stigma (felt stigma) and enacted stigma (external stigma, discrimination) (Goffman, 1963). Shame and expectation of discrimination that prevents people from talking about their experiences and stops them from seeking help is referred to as perceived stigma. The experience of unfair treatment by others is referred to as enacted stigma. Perceived stigma can be as harmful as enacted stigma as it leads to withdrawal and restriction of social support (Gray, 2002).

According to UNAIDS, Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others, such as when certain attributes are seized upon within particular cultures or settings and defined as discreditable or unworthy. When stigma is acted upon, the result is discrimination. Discrimination refers to any form of arbitrary distinction, exclusion or restriction affecting a person, usually (but not only) because of an

inherent personal characteristic or perceived membership of a particular group. It is a human rights violation. In the case of HIV, this can be a person's confirmed or suspected HIV-positive status, irrespective of whether or not there is any justification for these measures. The terms stigmatization and discrimination have been accepted in everyday speech and writing, and they may be treated as plural.

Stigma is assessed under four components: personalized stigma (consequences of others knowing about one's behavior, including loss of friends and avoidance), negative self-image (shame, guilt and self-worthlessness), disclosure concerns (issues related to disclosing or hiding one's risky behaviour from others) and public attitudes (participant's perceptions and reactions of what others think about their behaviour) (Goffman, 1963).

Stigma can be due to a disease, behaviour or any issue which is unaccepted by the society. This is applicable especially for psychiatric illnesses and communicable diseases like leprosy, tuberculosis and HIV. This stigma is built in the society as phobias due to some myths coming from ancient times. Some of them are related to different cultures and religions. The main reason for stigma among certain groups is due to lack of knowledge regarding certain conditions and the state of curability of some stigmatizing diseases. However, stigma and discrimination result in serious consequences which are related to health, social and economic aspects. The main health related problem is avoidance of seeking health care. This increases the spread of communicable diseases like HIV in the community and brings a health and financial burden to the country.

In the meantime, some of them become depressed due to the stigma that they experience. Ultimately some of them end up in suicidal ideations and deliberate self-harm. If the stigma is minimized, the affected people will tend to access necessary health care services and get necessary treatment. Therefore, it is essential that the stigma among highly vulnerable people will be assessed and action will be taken to overcome stigma.

### **Stigma and Discrimination Towards HIV is Mainly due to Fear and Myths Related to HIV:**

- HIV and AIDS are always associated with death. The majority have no idea that it is a chronic disease.
- HIV is associated with behaviours that some people disapprove of (such as homosexuality, drug use, sex work or infidelity)
- HIV is transmitted through sex, which is a taboo subject in some cultures
- Some people wrongly believe that HIV infection is the result of personal irresponsibility or moral fault (such as infidelity) that deserves to be punished
- Inaccurate information about how HIV is transmitted, which creates irrational behaviour and misperceptions of personal risk

Stigma and discrimination are among the foremost barriers to HIV prevention, treatment, care and support. This undermines HIV prevention efforts by making people afraid to seek HIV information, services and modalities to reduce their risk of infection and to adopt safer behaviours. Fear of stigma and discrimination, which can also be linked to fear of violence, discourages people living with HIV from disclosing their status even to family members and sexual partners, and undermines their ability and willingness to access and adhere to treatment. Thus, stigma and discrimination weaken the ability of individuals and communities to protect themselves from HIV and to stay healthy if they are living with HIV.

Following consequences can be results of stigma and discrimination towards HIV:

- loss of income and livelihood
- loss of marriage and childbearing options
- poor care within the health sector
- withdrawal of caregiving in the home
- loss of hope and feelings of worthlessness
- loss of reputation

Stigma and discrimination of PLHIV and its correlation with the disease status is an important aspect that needs to be given concern. Understanding the impact of stigma is an essential component to control and prevent HIV and to achieve the national and global targets. Since HIV is a chronic disease, which needs continuous lifelong treatment, it not only affects the persons' day to day life style but also the lives of his/her family and friends. Stigma further worsens their social and economic status and acts as a vicious cycle.

### **The Second Stigma assessment among people living with HIV in Sri Lanka helps to:**

- **Identify the underlying drivers of stigma and discrimination and the extent of the problem**
- **Identify who is most affected by stigma and discrimination and plan future interventions**
- **Implement programmes to reduce stigma and discrimination**

## General Objective

To assess the stigma associated with HIV among people living with HIV in Sri Lanka and identify the supportive legal and policy frameworks for people living with HIV

## Specific Objectives

1. To describe the socio demographic and economic profile of people living with HIV in Sri Lanka
2. To describe the status of stigma among people living with HIV in Sri Lanka
3. To describe the impact of HIV on the life style of the people living with HIV in relation to stigma
4. To compare the 1<sup>st</sup> stigma assessment and 2<sup>nd</sup> stigma assessment of people living with HIV in Sri Lanka
5. To describe the supportive legal and policy frameworks for people living with HIV and available services and other supportive environment for people living with HIV
6. To make recommendations to achieve zero discrimination for people living with HIV by 2020.

## 2. Methodology

The assessment was carried out in three stages:

- **Quantitative part**
  1. Interviewer administrated questionnaire for people living with HIV to assess the stigma which they experienced
- **Qualitative Part**
  2. In-depth interview of main focal points of three positive networks to get the views from people living with HIV who are in positive networks
- **Desk Review**
  3. Desk Review to identify the supportive legal and policy frameworks for people living with HIV and available services and other supportive environment for people living with HIV

### Study Design and Setting of the Quantitative part

This was a descriptive cross sectional study conducted in Sri Lanka.

### Study Population of the Quantitative part

All patients diagnosed as having HIV, irrespective of their anti-retro viral treatment status in all districts of Sri Lanka

### Exclusion Criteria for the Quantitative part

- who are acutely ill/hospitalized at the time of the survey
- PLHIV who were below 15 years of age
- PLHIV who were diagnosed for less than 3 months

## **Sample size and Sampling Technique of the Quantitative Part**

A sample of 150 people living with HIV was interviewed using an interviewer administered questionnaire, to assess the stigma which they experienced. Purposive sampling method was used. This sampling method is recommended by the user guide of the people living with HIV stigma index, developed by the joint United Nations programme on HIV/AIDS (UNAIDS).

The respondents were selected from the membership of the networks of people living with HIV, but also included non-members who were not in the networks through the Family Planning Association of Sri Lanka.

## **Study Instruments of the Quantitative part**

An Interviewer administered questionnaire, which was pre-tested among PLHIV, was used.

The Stigma assessment tool was designed to gather detailed information on:

- Personal information - relationship status, education, employment and household income levels
- Experience of stigma and discrimination from others
- Access to work, health and education services
- Internal Stigma
- Knowledge of rights, laws and policies
- Experiences of effecting change - including efforts to challenge, confront or educate someone with stigmatizing behaviour
- Experiences around testing and diagnosis
- Issues of disclosure and confidentiality
- Knowledge and experiences around treatment
- Knowledge and experiences around having children
- General problems and challenges

## **Data Collection of the Quantitative part**

All interviewers were people living with HIV, and were drawn from existing community networks of people living with HIV and those who are not in the networks. This was a joint exercise with a participatory spirit for all those involved. People living with HIV were at the center of the process as interviewers and interviewees and as drivers of how the information is collected. A three-day training programme was conducted for interviewers at the National STD/AIDS Control Programme



to provide them with an understanding of the history, rationale, objectives and the components involved in the People Living with HIV Stigma Index. It 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. Hands on experience was given.

Data collection was carried out for a period of three months from 1<sup>st</sup> of April 2017 to 30<sup>th</sup> of June 2017, by four data collectors.

### **Data Analysis of the Quantitative part**

Data entry and analysis was carried out using the SPSS Version 21 Software. Descriptive data were presented as frequencies in graphs and tables.

### **Ethical Issues**

Informed verbal consent was taken prior to the interview and the confidentiality of the information was ensured. Ethics clearance was obtained from Ethics Review Committee of Faculty of Medicine of the University of Kelaniya (P/137/05/2017).

Post data analysis, a draft report was prepared and discussed with the research team and then shared with the National Partnership. Presentations on key findings in both English and Sinhalese were used for the respective consultations with the National Partnership and positive network membership, to discuss and plan future strategies using the Stigma Index as an advocacy tool.

### **Limitations of the Study**

Limited number of PLHIV who are in the professional category were included in the study as they were not willing to participate in the study.

## 3. Results

### Part 1

#### 3. Results of the Quantitative Data Analysis

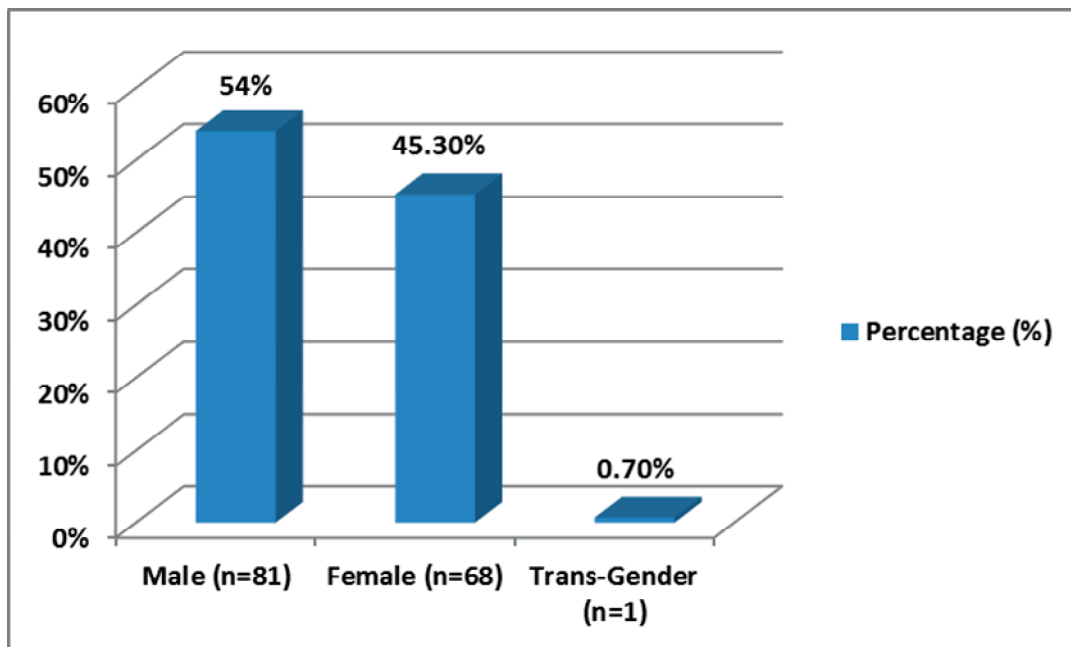
A total of 150 people living with HIV were interviewed. An appropriate sampling method was used according to the user guide of the people living with HIV stigma index, developed by the joint United Nations programme on HIV/AIDS (UNAIDS). Participants selected from the networks of people living with HIV was 140 (93.3%), while the rest (6.7%; n=10) comprised of non-members who were in contact with the networks.

It is noted that some participants from the 'high social class' were not willing to participate in this research.

#### 3.1. Socio-Demographic Characteristics

##### 3.1.1 The Distribution of Sex in the Study Population

**Figure 3.1: The Distribution of Sex in the Study Population**



This study population consisted of 54% (n=81) males, 45.3% (n=68) females and one (0.7%) trans-gender person.

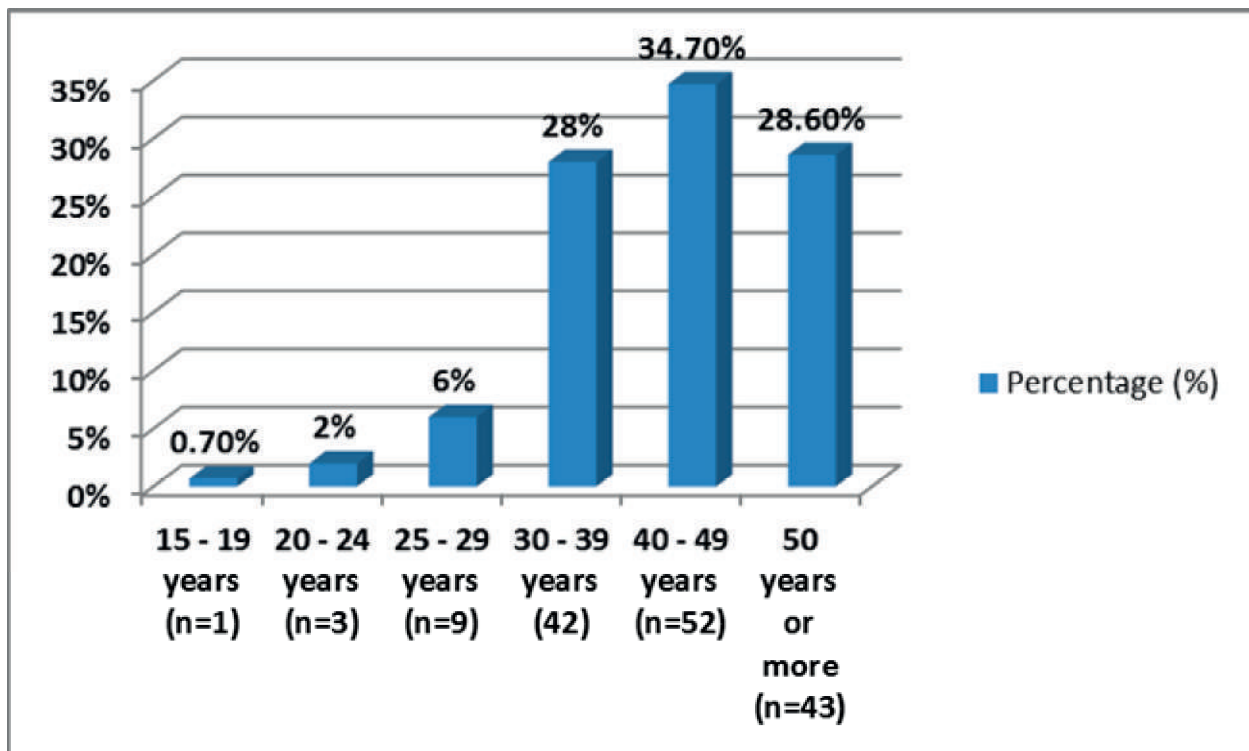
A total of 1614 males and 886 females were cumulatively reported as being HIV positive by the end of 2016, resulting in a male to female ratio of 1.8:1.\*

In this current study, the male to female ratio is 1.2:1.

\*Annual Report, NSACP, 2016

### 3.1.2 The Age Distribution of the Study Population

Figure 3.2: The Distribution of Age in the Study Population



The age of this study population varied from 15 to 70 years. The mean age was 43.5 years (Standard Deviation = 10.2). The median age was 44 years. Most of the respondents were between 40 to 49 years of age. Almost equal proportions (28% - 29%) were distributed among the 30-39 age group and the more than 50 years age group.

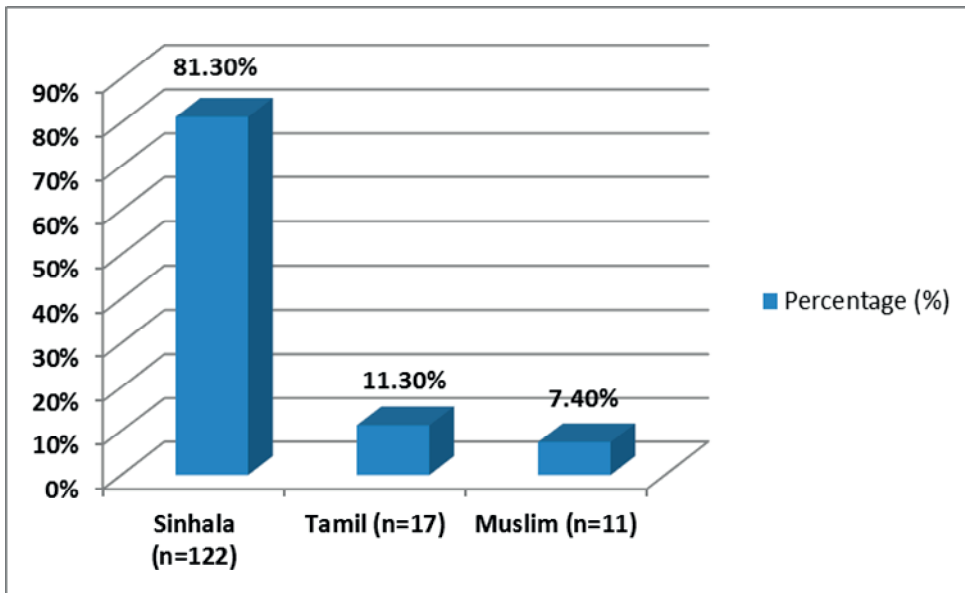
The reported number of cumulative HIV positives among the 25- 49 year age category was accounted to be 75.9% out of all reported cases.\*

In the current study, 68% of the participants were from the 25 -49 years age group.

\*Annual Report, NSACP, 2016

### 3.1.3 The Ethnic Composition of the Study Population

Figure 3.3: The Distribution of Ethnicity in the Study Population



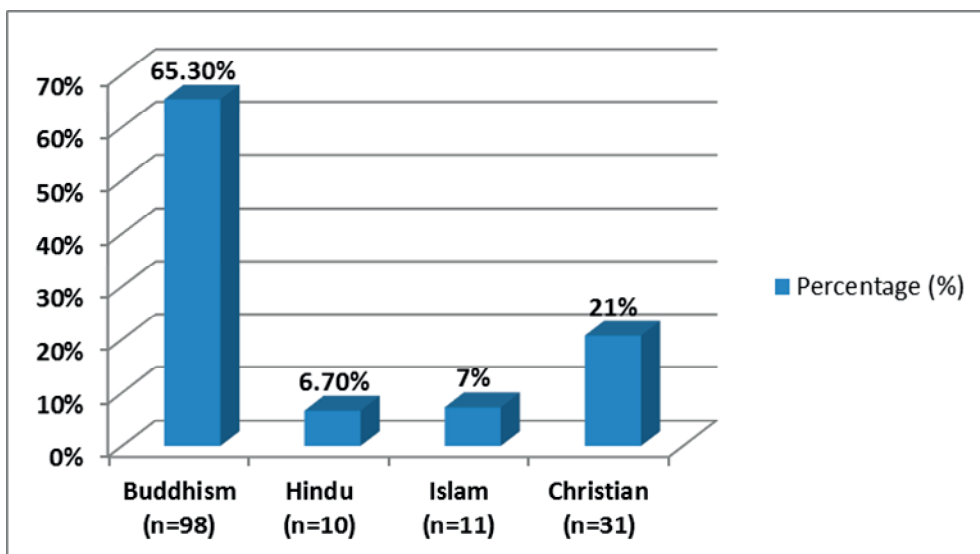
Sinhalese were the largest ethnic group consisting of 81.3% (n=122) of the study population.

According to the Census of Population and Housing of Sri Lanka in 2012, Sinhalese consisted of 74.9% of the total population\*. In this study, 81.3% of the participants were from the Sinhala ethnic group.

\*Department of Census and Statistics, 2012

### 3.1.4 The Distribution of Religion in the Study Population

Figure 3.4: The Distribution of Religion in the Study Population



The distribution of religion shows that the majority of the study participants were Buddhists (65.3%), followed by Christians (20.7%) and followers of Islam (7%).

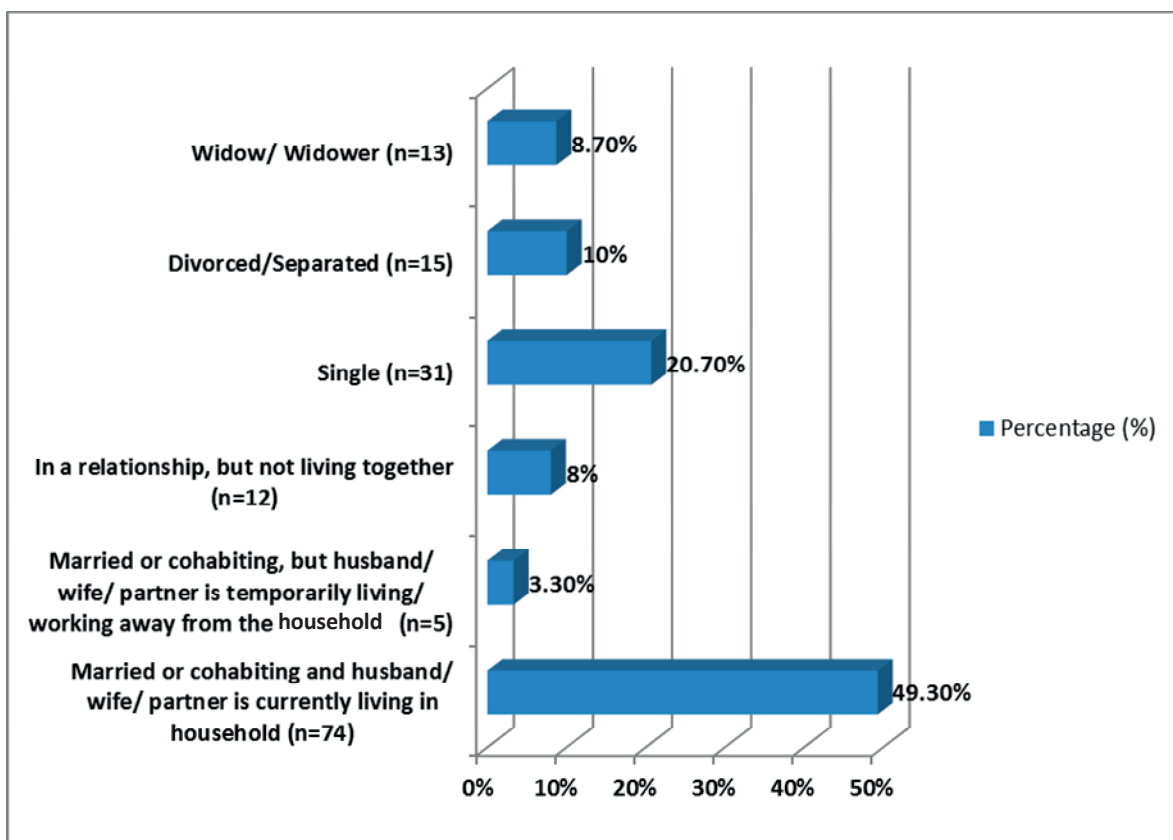
**According to the Census of Population and Housing of Sri Lanka conducted in 2012, the majority of the population were Buddhists (70.1%), followed by Islamic (9.7%) and Christians (7.6%)\*.**

**In current study, there were 65.3% Buddhists, 20.7% Christians and 7% Islamic study participants.**

- *Department of Census and Statistics, 2012*

### 3.1.5 The Marital Status of the Study Population

**Figure 3.5: The Distribution of Marital Status in the Study Participants**



Nearly half (49%) of the respondents were currently either married or cohabiting with their partner. One fifth of the participants (20.7%) were single and 10% were divorced or separated, while 9% were widowed.

**According to 2009/2010 Stigma Report, 49% of the study participants were married or cohabiting with their partner\*.**

**In the current study, 49.3% of the study participants were married or cohabiting with their partner.**

### 3.1.6 The Distribution of Residential District of the Study Population.

**Table 3.1: Distribution of the Residing District of the Study Population**

Name of the district	Number	%
Ampara	2	1.3
Anuradhapura	2	1.3
Badulla	4	2.7
Batticaloa	2	1.3
Chilaw	2	1.3
Colombo	27	18.0
Galle	10	6.7
Gampaha	39	26.0
Hambantota	1	0.7
Kalutara	3	2.0
Kandy	10	6.7
Kegalle	5	3.4
Kurunegala	12	8.0
Matale	3	2.0
Matara	4	2.7
Monaragala	2	1.3
Polonnaruwa	2	1.3
Puttalam	6	4.0
Ratnapura	3	2.0
Vavuniya	2	1.3
District not declared	9	6.0
<b>Total</b>	<b>150</b>	<b>100.0</b>

This study gathered information from people living with HIV across 20 districts in the country. Most of them were residing in Gampaha (26%, n= 39) and Colombo (18%, n=27) districts. Others were clustered around Galle, Kandy, and Kurunegala districts.

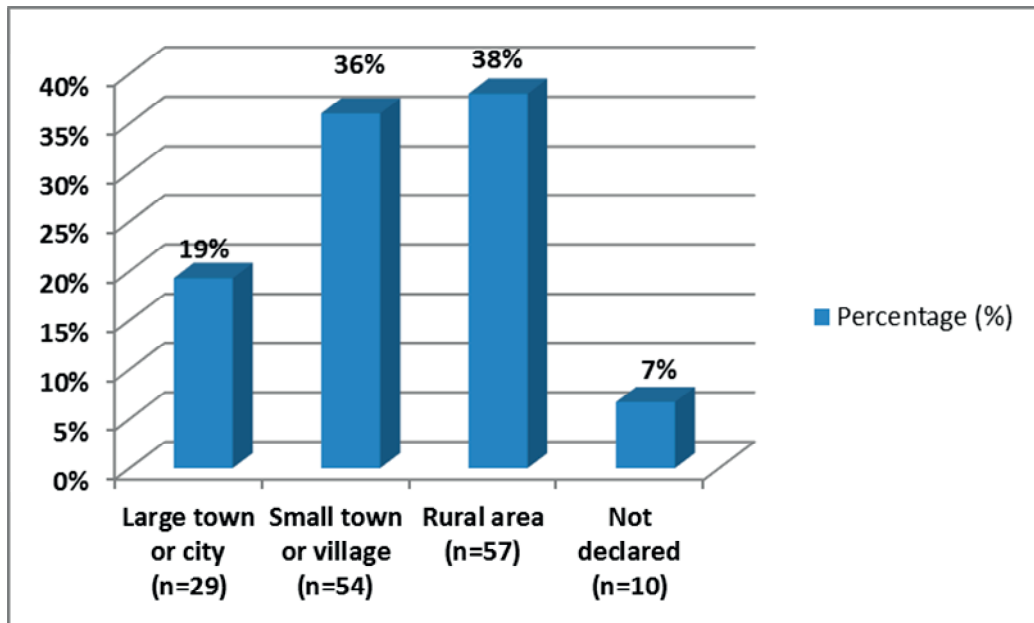
**The cumulative number of HIV cases reported from 1987 to 2016 showed that most of the people were reported from Colombo and Gampaha districts, with a cumulative HIV rate of 35.1 and 18.8 cases per 100,000 population, respectively\*.**

**In current study, a somewhat similar geographical distribution was noted from the study population.**

\*Annual Report, NSACP, 2016

### 3.1.7 The Distribution of the Study Population According to the Place of Residence

Figure 3.6: The Distribution of the Study Population According to the Place of Residence

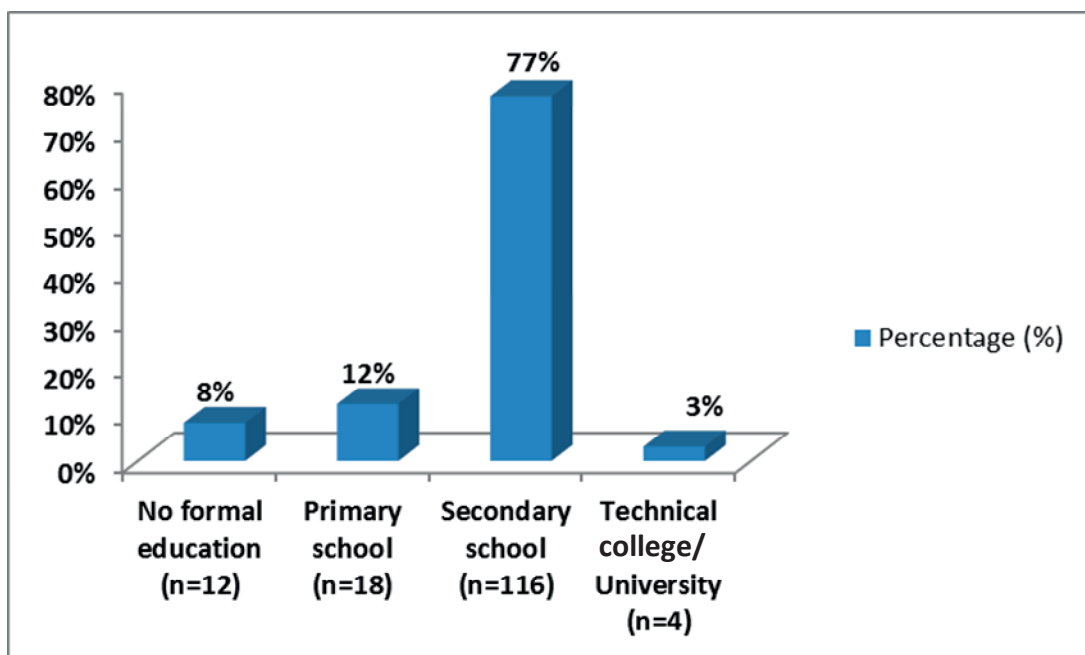


Most of the study population were residing in rural areas (38%) and small towns or villages (36%).

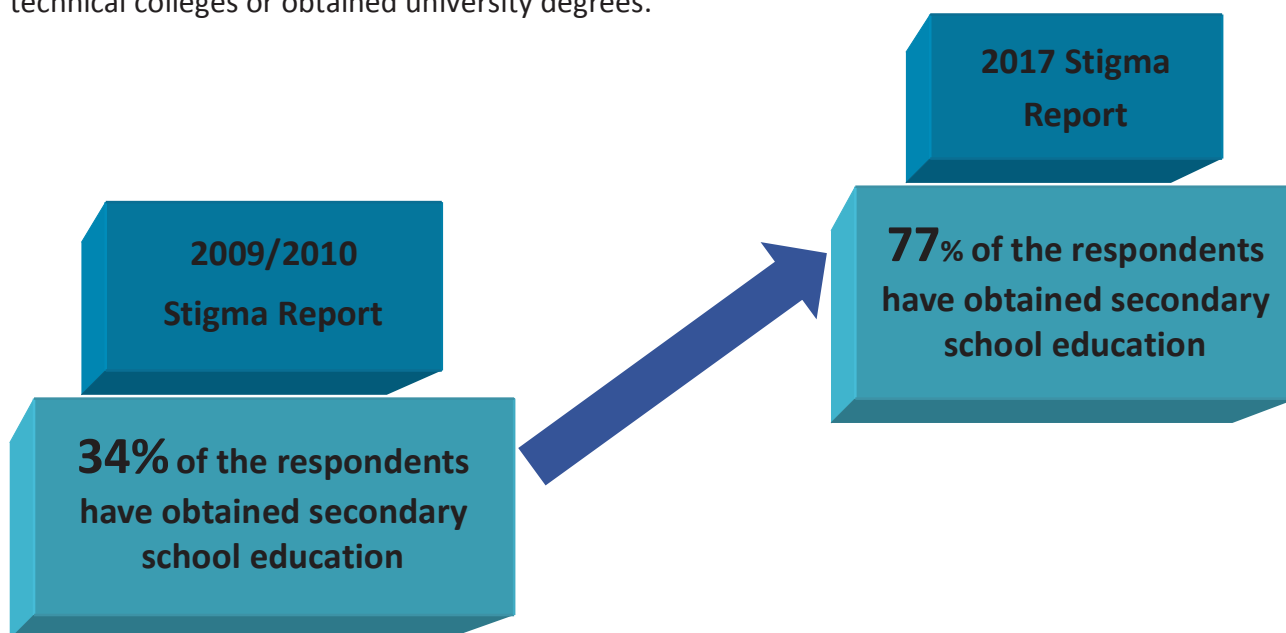
## 3.2 Socio-Economic Characteristics

### 3.2.1 The Distribution of Education Level in the Study Participants

Figure 3.7: The Distribution of Education Level in the Study Participants



The majority of the study participants (77%) have attended secondary school, while 12% managed to have primary education. Only three percent of the respondents received education from technical colleges or obtained university degrees.



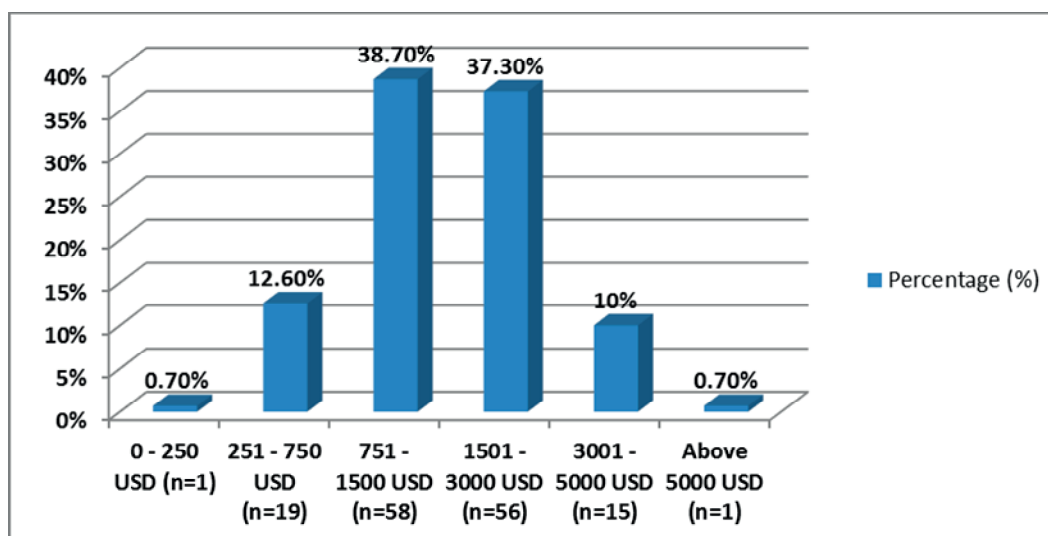
### 3.2.2 Characteristics of the Living Household

The mean number of members in the family was 3.4 (SD=1.6) and the median was three. Families with six members and above consisted of 10% of the total sample. Most of them were living with their spouses (46%; n = 69) and with their children (56%; n = 84).

According to the current study, 12% of people living with HIV are living alone. No data is available to compare this value with the previous report.

### 3.2.3 The Annual Household Income of the Participants

Figure 3.8: The Distribution of Annual Household Income in the Study Participants (in USD)





The mean annual income of the participants was 1409.7 USD (standard deviation – 1092 USD) with a median value of 1128 USD. Forty-eight percent had an annual household income of 1501 USD or more per year. Only one percent had an annual income of more than 5000 USD per year, while another 1% reported that they had an annual income less than 250 USD.

**Sixteen households (10.7%) were identified as receiving the ‘samurdhi’ beneficiary.**

**In 2016, Sri Lanka had a Gross Domestic Product Per Capita (GDP Per capita) value of 3835 USD\*.**

**In current study, only six (6) participants had an annual income more than Sri Lanka’s GDP Per Capita value.**

*\*Central Bank Report, 2016*

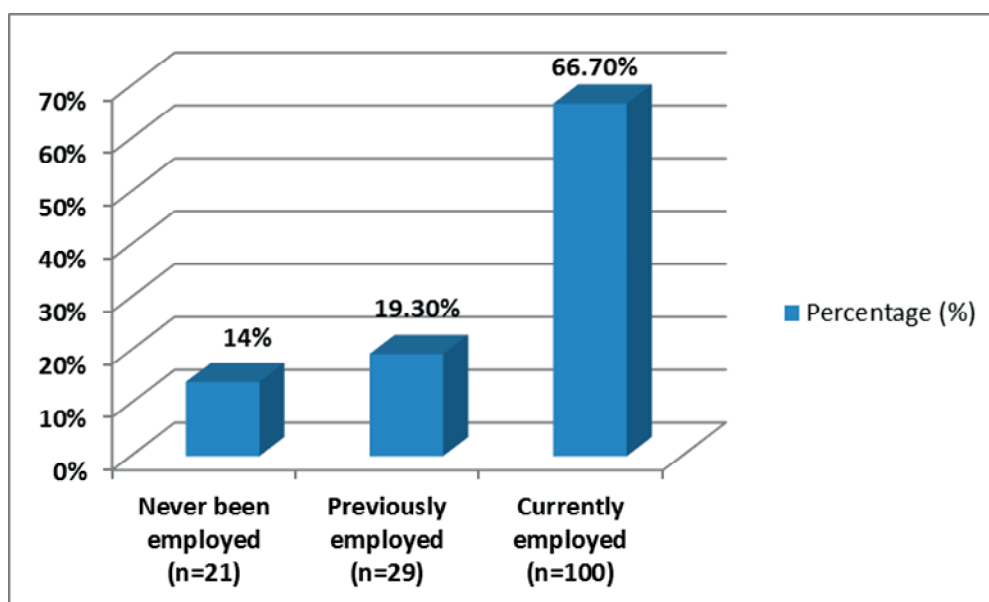
**The official poverty line value for the month of June, 2017 was Rs. 4352/=\*.**

**In current study, there was only one (1) participant with a monthly income value below the poverty line.**

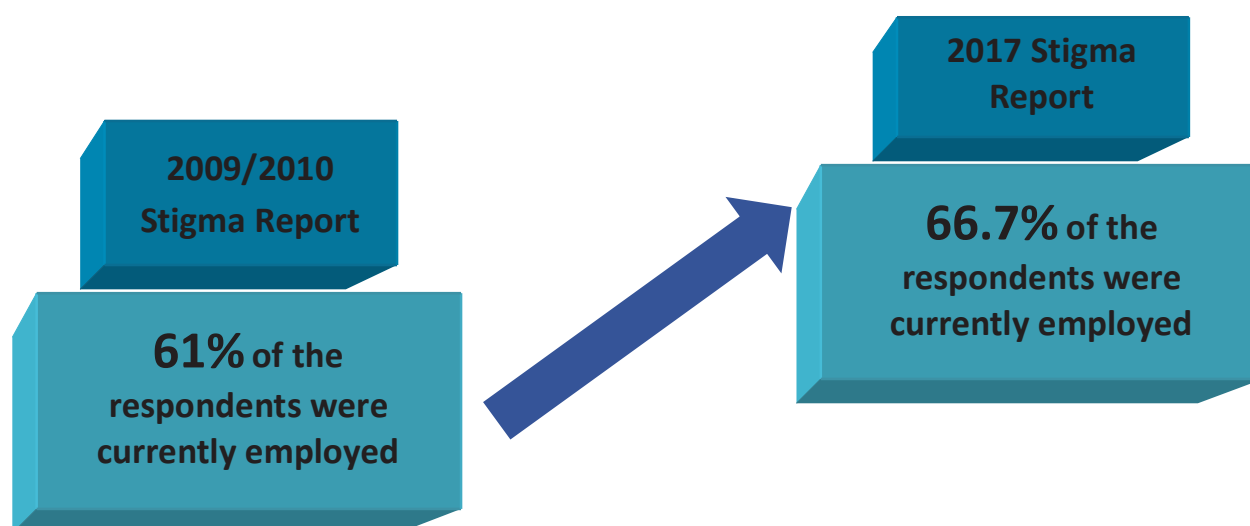
*\*Department of Census and Statistics, 2017*

### 3.2.4 The Employment Status of the Study Population.

**Figure 3.9: The Distribution of Current Employment Status of the Study Population**



Nearly two thirds (67.1%) of the participants were currently employed, while 14% have never been employed in their life.

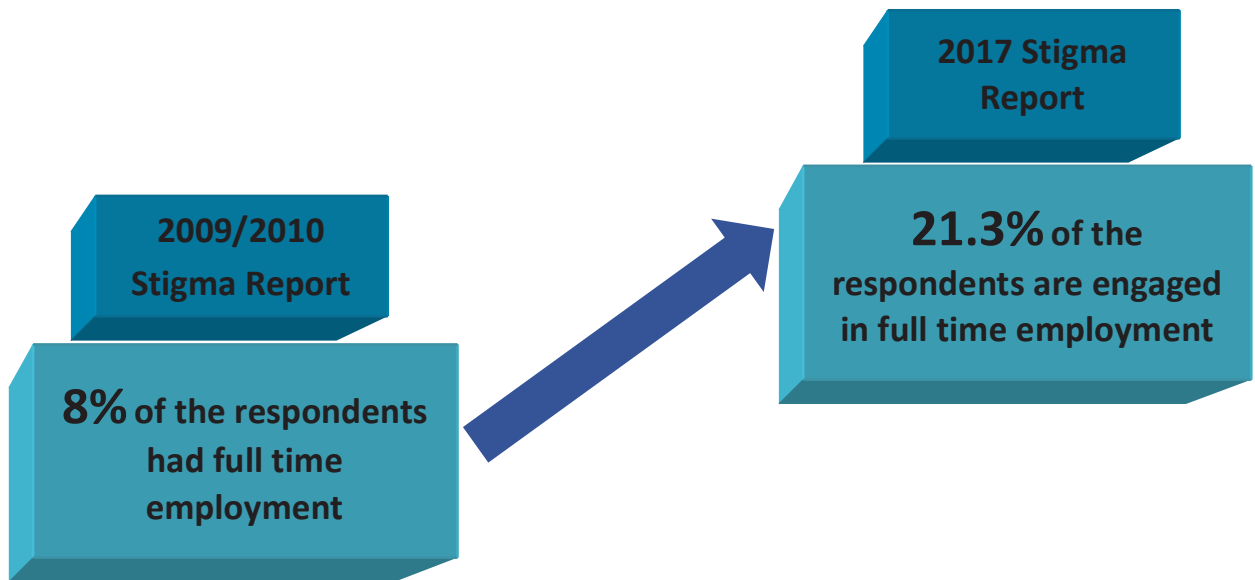


### 3.2.5 The Distribution of Some Work Related Characteristics of the Study Population

**Table 3.2: Distribution of the Study Population by their Work Related Characteristics**

Work related characteristics	Male		Female		Total	
	No.	%	No.	%	No.	%
<b>Type of employment (n=100)</b>						
Government	11	91.7	1	8.3	12	12.0
Private	38	62.1	24	37.9	62	62.0
Self employed	21	83.3	5	16.7	26	26.0
<b>Additional income generation (n=100)</b>						
Yes	10	71.4	4	28.6	14	14.0
No	60	69.8	26	30.2	86	86.0
<b>Current working position (n=100)</b>						
Permanent	25	78.1	7	21.9	32	32.0
Probationary	15	60.0	10	40.0	25	25.0
Contract basis	30	69.8	13	30.2	43	43.0

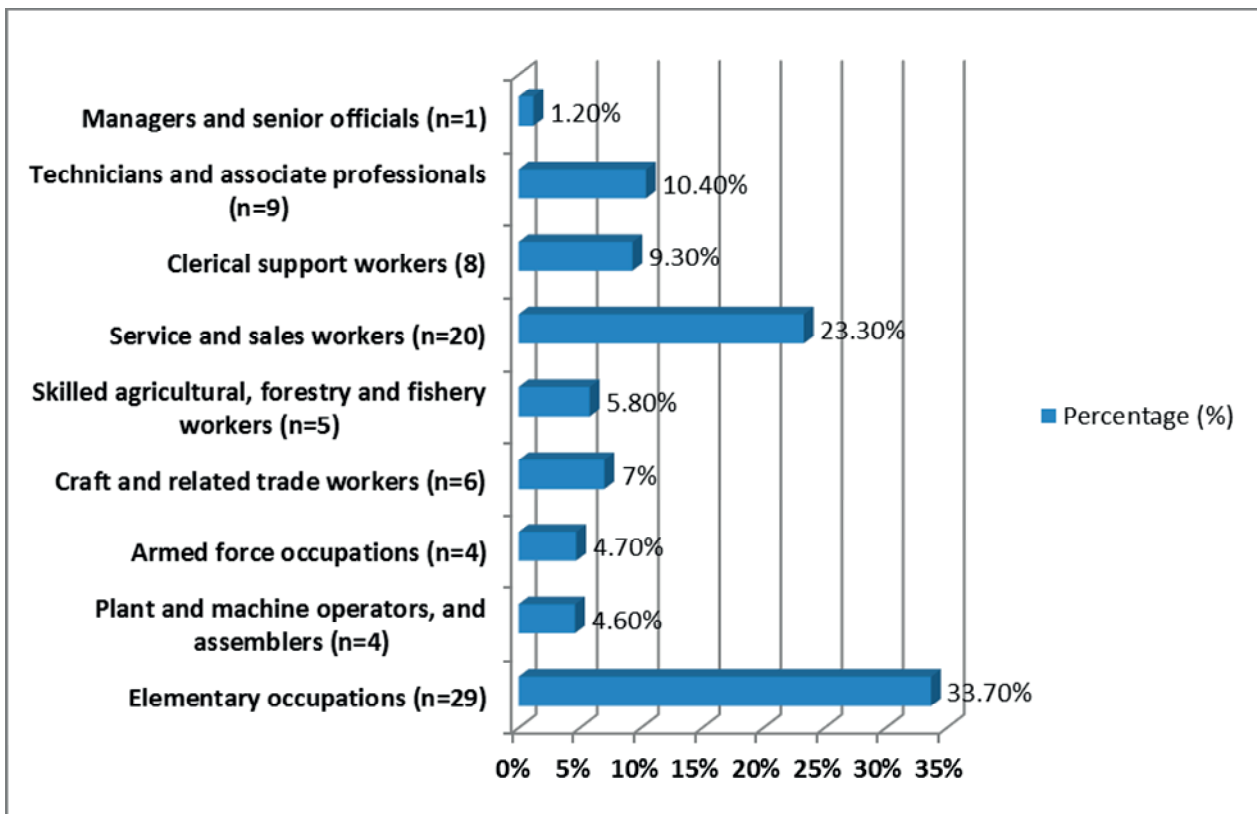
Among the employed persons, only 12% (n=12) were in the government (public) sector, while the rest were in the private sector or self-employed. All public sector employees were entitled to a pension (8%; n=12), while 21 participants (14%) were entitled to EPF/ETF schemes. Only a small proportion (14%; n=14) engaged in an additional income generating job. Thirty two per cent of the employed persons had a permanent employment.



### 3.2.6 The Distribution of the Occupation Category in Study Participants

Out of the currently employed 100 participants, 86 have stated their occupation with the designation. The employment status is categorized according to the International Standard Classification of Occupations (ISCO) (International Labour Office, 2012).

**Figure 3.10: The Distribution of the Occupation Category in the Study Participants according to the ISCO Classification (n=86)**



Most of the participants (66.3%, n=57) were engaged in skilled occupations. The rest of the participants (33.7%, n=29) were performing elementary occupations, which involve unskilled work. Twenty participants (23.3%) were engaged in services and sales work and there were no participants under ‘professionals’ category representing this study population.

**There was only one participant representing the “Managers and senior officials” category. Some professionals were not willing to participate in this research.**

### 3.2.7 The Distribution of the Occupation Category according to the Sex

**Table 3.3: Occupational Categories of those Currently Employed according to the ISCO Classification (n=86)**

Occupational category	Males		Females		Total	
	No.	%	No.	%	No.	%
Managers and senior officials	1	1.7	0	0.0	1	1.2
Technicians and associate professionals	6	10.0	3	11.6	9	10.4
Clerical support workers	7	11.6	1	3.8	8	9.3
Service and sales workers	15	25.0	5	19.2	20	23.3
Skilled agricultural, forestry and fishery workers	1	1.7	4	15.4	5	5.8
Craft and related trade workers	5	8.3	1	3.8	6	7.0
Plant and machine operators, and assemblers	3	5.0	1	3.8	4	4.6
Elementary occupations	18	30.0	11	42.3	29	33.7
Armed force occupations	4	6.7	0	0.0	4	4.7
<b>Total</b>	<b>60</b>	<b>100.0</b>	<b>26</b>	<b>100.0</b>	<b>86</b>	<b>100.0</b>

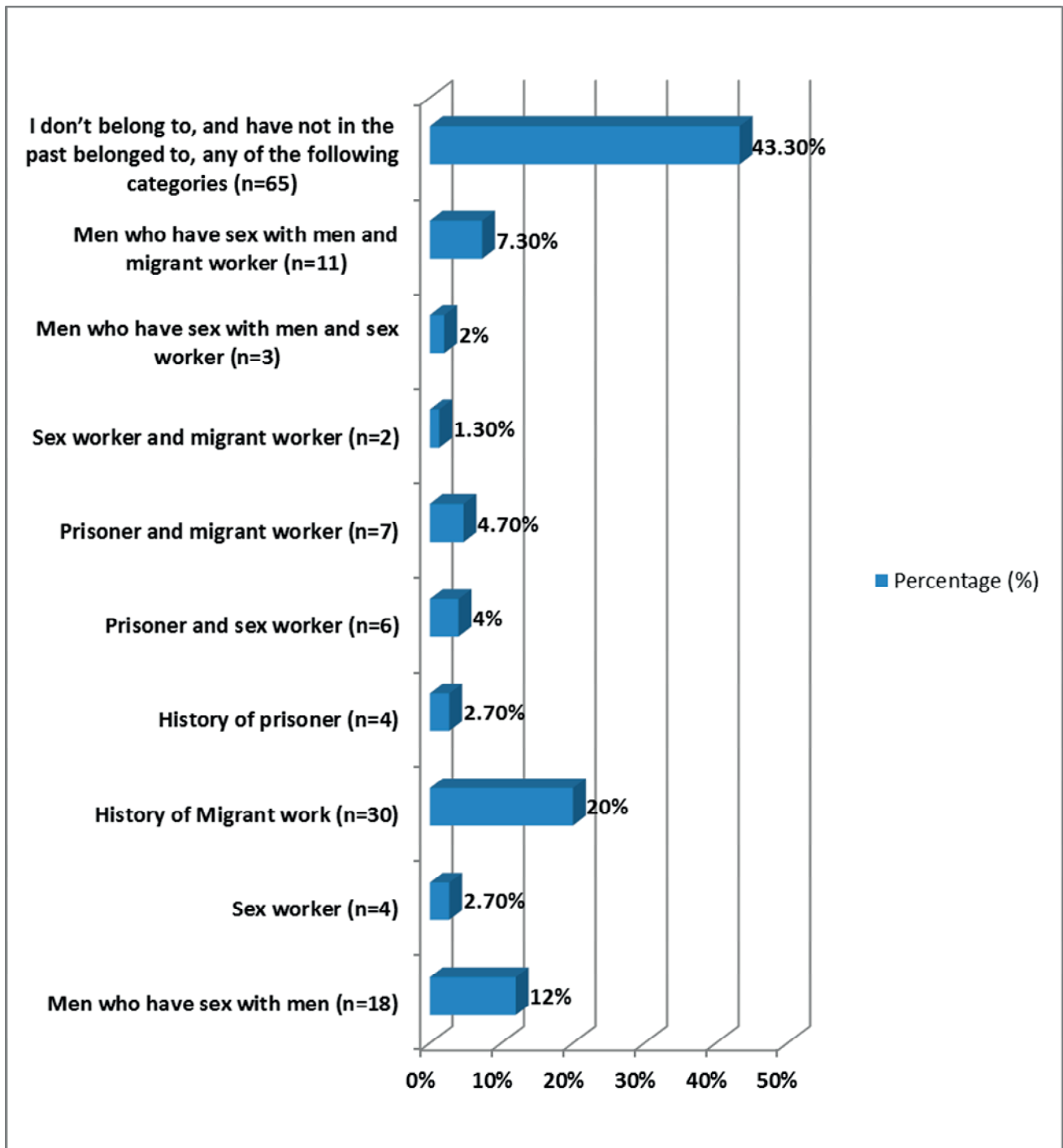
There were 26 female participants (30.2%) who were currently employed, compared to 60 male participants (69.8%). The majority of those employed from both male and female respondents belonged to the “elementary occupations” category, accounting for 30% and 42%, respectively. Elementary occupations include cleaners and helpers, labourers, street related sales and services workers and other unskilled elementary workers. The second highest category is services and sales workers group representing 25% and 19% of male and female respondents, respectively. This category includes personal services workers, sales workers, personal care workers and protective services workers.

### 3.3.Key Populations and Vulnerable Groups

The key populations for HIV in Sri Lanka include sex workers, men who have sex with men, trans gender, intra-venous drug users, and beach boys.

#### 3.3.1 The Distribution of Key Populations and Vulnerable Groups in the Study Population

Figure 3.11: The Distribution of Key Populations and Vulnerable Groups in the Study Participants



Around forty three percent (n=65) did not belong to and have not in the past belonged to any of the key population groups. Vulnerable populations that are HIV positive include participants with a history of migrant work, which represent nearly one-third of the study population (33.3%). Recent data of the NSACP clearly shows that one third of newly reported HIV cases among both males and females had a history of external migration during the past few years. They were either migrant workers themselves or had a spouse or partner who was a migrant worker. Around one fifth of the respondents (21.3%) were identified as belonging to the key population group of men who have sex with men.

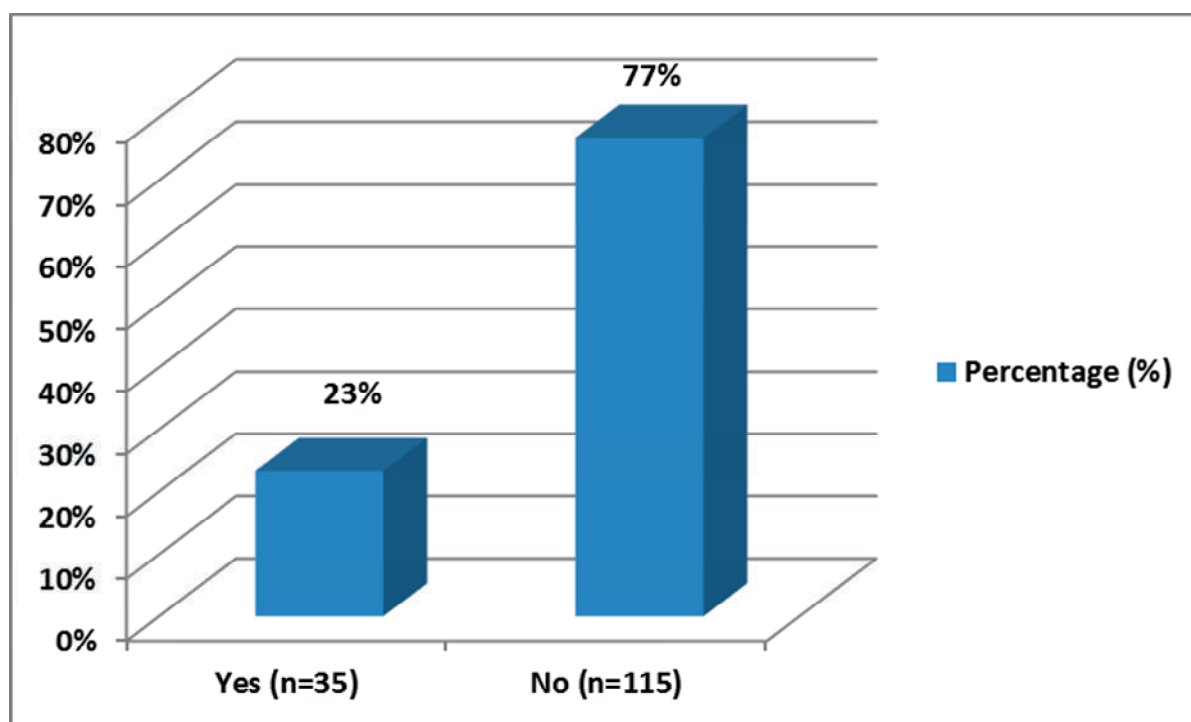
During the last 6 years, it was noted that one third of newly reported HIV cases among both males and females had a history of external migration.

In the current study, nearly one-third of the study population (33.3%) gave a history of migration work.

### 3.4. Chronic Diseases and Health Care Seeking Behaviour

#### 3.4.1 The Distribution of Chronic Disease Status

Figure 3.12: The Distribution of Chronic Disease Status in the Study Participants



Thirty five participants (23.3%) had some form of a history of chronic disease at the time of data collection. Details of the type of chronic medical and psychiatric diseases among the study participants are given in Table 3.4.

### 3.4.2 Distribution of the Study Population by their Chronic Diseases

**Table 3.4: Distribution of the Study Population by their type of Chronic Diseases \*(n=35)**

<b>Chronic diseases</b>	<b>Number</b>	<b>%</b>
Diabetes mellitus	18	12.0
Hypertension	12	8.0
Ischaemic heart disease	6	4.0
Dyslipidaemia	5	3.3
Long standing joint disorders	4	2.8
Kidney disease	2	1.4
Stroke	2	1.4
Malignancy	1	.7
Depression	2	1.3

*\*Some participants had more than one chronic disease, and thus the responses were not mutually exclusive*

Among the chronic diseases, diabetes mellitus and hypertension were the most common, with a prevalence of 12.0 and 8.0 per 100, respectively. Depression was the only psychiatric illness detected, with 2 cases, with a prevalence of 1.3 per 100.

### 3.4.3 The Health Care Seeking Behaviour in the Study Population

**Table 3.5: Health Care Seeking Behaviour in the Study Population (n=150)**

<b>Health care seeking behaviour</b>	<b>Number</b>	<b>%</b>
<b><i>Acute illnesses</i></b>		
<b>Commonly used health institution</b>		
Government Institutions	120	80.0
General Practice	10	6.7
Private hospital	20	13.3
<b>Distance to health institution for acute illness</b>		
< 5 Km	52	34.7
5 – 15 Km	41	27.3
> 15 Km	57	38.0
<b><i>Chronic diseases</i></b>		
<b>Commonly used health institution (n=35)</b>		
Government hospital	27	77.1
Private hospital	5	14.3
General Practice	3	8.6
<b>Distance to health institution (n=35)</b>		
< 5 Km	12	34.3
5 – 15 Km	8	22.9
>15 Km	15	42.8

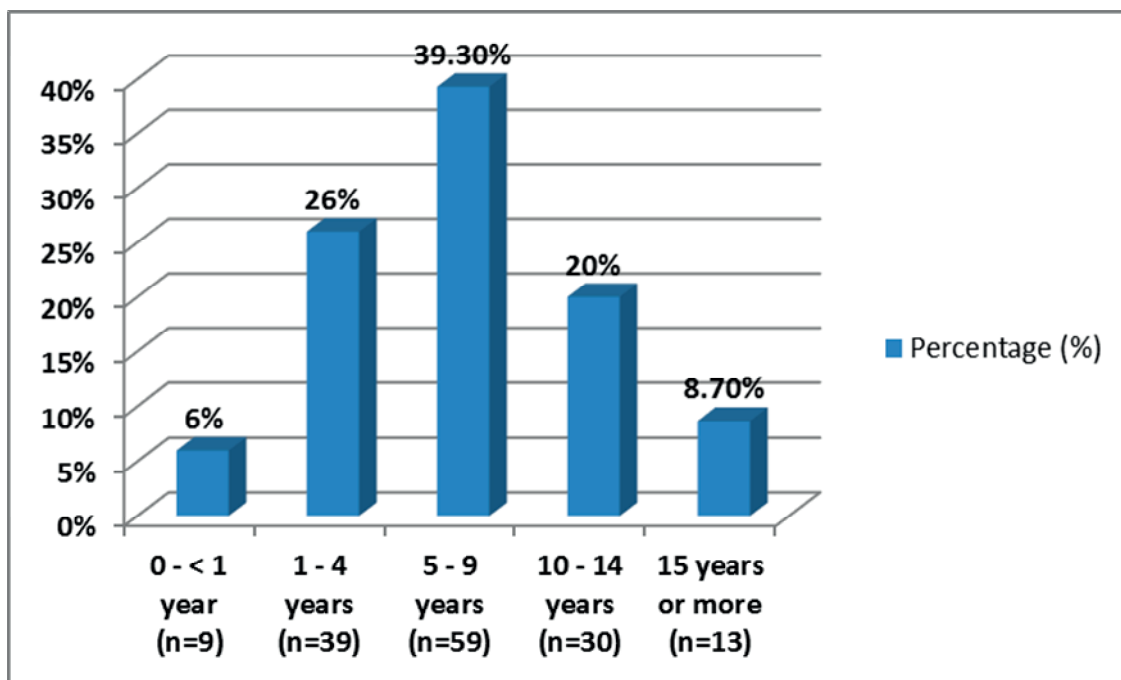
The health institution commonly utilized for acute illnesses was the government hospital (80%). Thirty-five percent had access to a health care institution within 5 km of their residence. However, 38% of the participants were traveling for more than 15Km to reach a health institution for their acute illnesses. For chronic diseases, government hospital was preferred by the most (77.1%), compared to other health care institutions.



### 3.5 Experiences of Stigma and Discrimination

#### 3.5.1 The Distribution of the Duration of Living with HIV after Diagnosis

Figure 3.13: The Distribution of the Duration of Living with HIV after Diagnosis, in the Study Participants



Almost forty percent of the participants (n=59) were living with HIV for 5 – 9 years. Nine participants (6%) have detected their HIV status within the last year.

**In the 2009/2010 Stigma Report, 37% of the participants were living with HIV for more than 5 years.**

**In the current study, almost two-thirds of the participants (68%, n= 102) were living with HIV for more than 5 years**

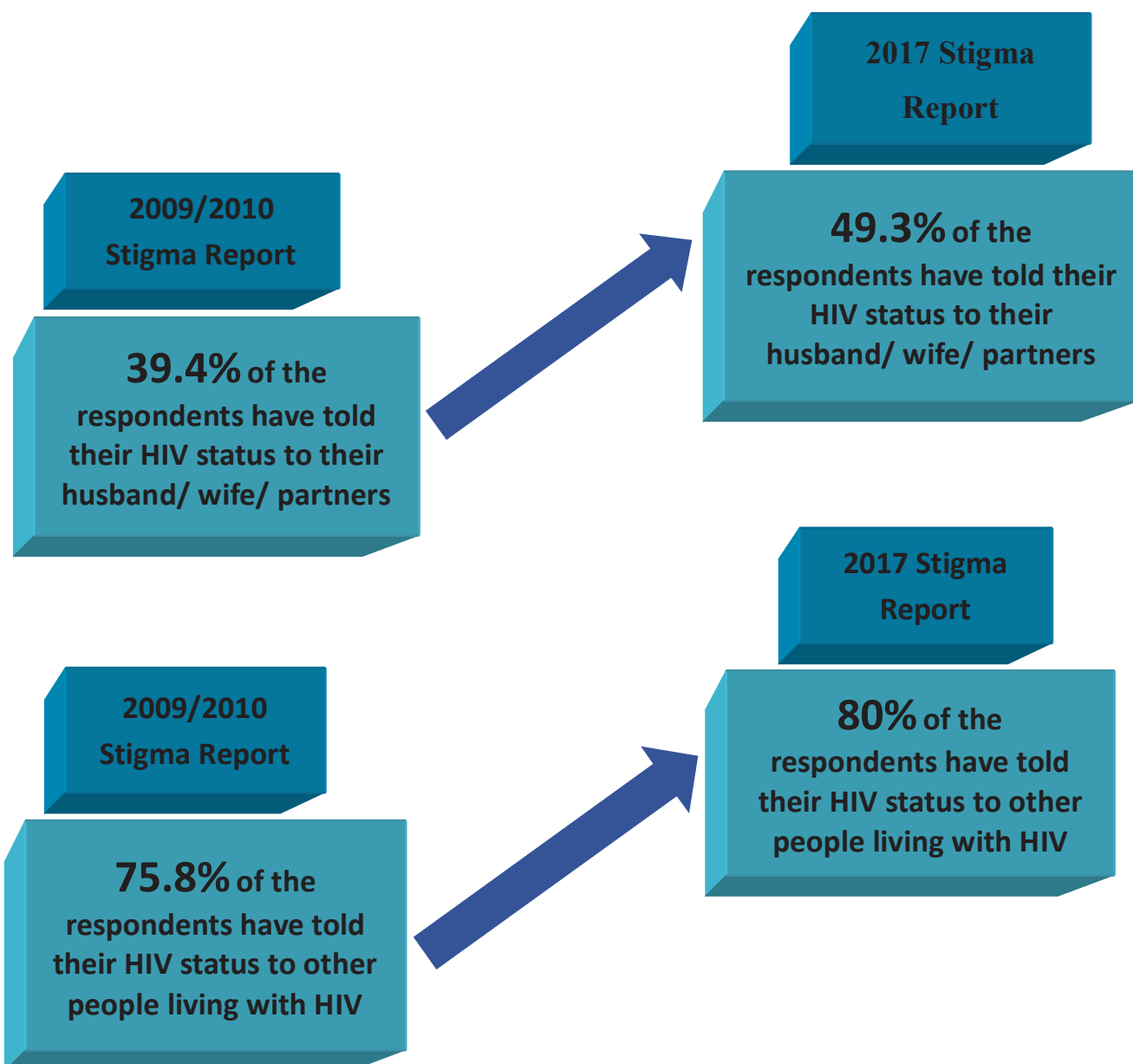
#### 3.5.2 Patterns of Disclosure

Descriptions of how (and if) family and community have learnt the HIV status of the study participants is given in Table 3.6 below.

**Table 3.6: Patterns of Disclosure of the HIV Status among the Study Participants.**

Descriptions of how (and if) family and community learnt about the respondents' HIV status.	I told them	Someone else told them, WITH my consent	Someone else told them, WITHOUT my consent	They don't know my HIV status	Not applicable
	%	%	%	%	%
Your husband/wife/partner	49.3	8.0	2.0	9.3	31.3
Other adult family members	18.7	4.0	5.3	56.7	15.3
Children in your family	16.0	0.7	2.6	46.0	34.7
Your friends	13.3	0.7	1.3	64.7	20.0
Your neighbours	2.7	0	6.0	70.0	21.3
Other people living with HIV	80.0	5.0	4.0	6.0	4.0
People whom you work with	2.0	0	0.7	66.0	31.3
Your employer(s)	0	0	0.7	58.0	41.3
Your clients	0.7	0	0	54.6	44.7
Injecting drug partners	0	0	0	44.0	56.0
Religious leaders	1.3	0.7	0	72.0	26.0
Community leaders	3.3	0.7	0	72.0	24.0
Health care workers (except STD clinics)	3.3	0.7	1.3	73.4	21.3
Social workers	0.7	0.7	0.7	75.3	22.6
Teachers	0	0	1.3	74.0	24.7
Government officials	3.3	0	0.7	73.3	22.7
The media	6.7	0	0.7	70.0	34.0

Fourteen Participants (9.3%) have not declared their HIV status to their husband/wife/partner. It is evident that the respondents were not comfortable with friends, neighbours, co-workers, employers, and children finding out their status. HIV positive people have found it easiest to share their status with other people living with HIV (80%).



### 3.6 General Experiences

The general experience of stigma and discrimination due to HIV status is described in Table 3.7. It assessed exclusion from family activities, religious activities and social gatherings due to HIV status among the study participants.

### 3.6.1 Distribution of the General Experience of Stigma and Discrimination in the last 12 months in the Study Participants

**Table 3.7: Distribution of the General Experience of Stigma and Discrimination in the Last 12 months among the Study Participants (n=150)**

General experience (in the last 12 months)	Number	%
<b>Excluded from family activities by others due to HIV status</b>		
Often	4	2.7
A few times	10	6.7
Once	3	2.0
Never	113	75.3
Not applicable	20	13.3
<b>Excluded from religious activities by others due to HIV status</b>		
Often	2	1.3
A few times	5	3.3
Never	118	78.7
Not applicable	25	16.7
<b>Excluded from social gatherings and activities due to HIV status</b>		
A few times	3	2.0
Never	122	81.3
Not applicable	25	16.7

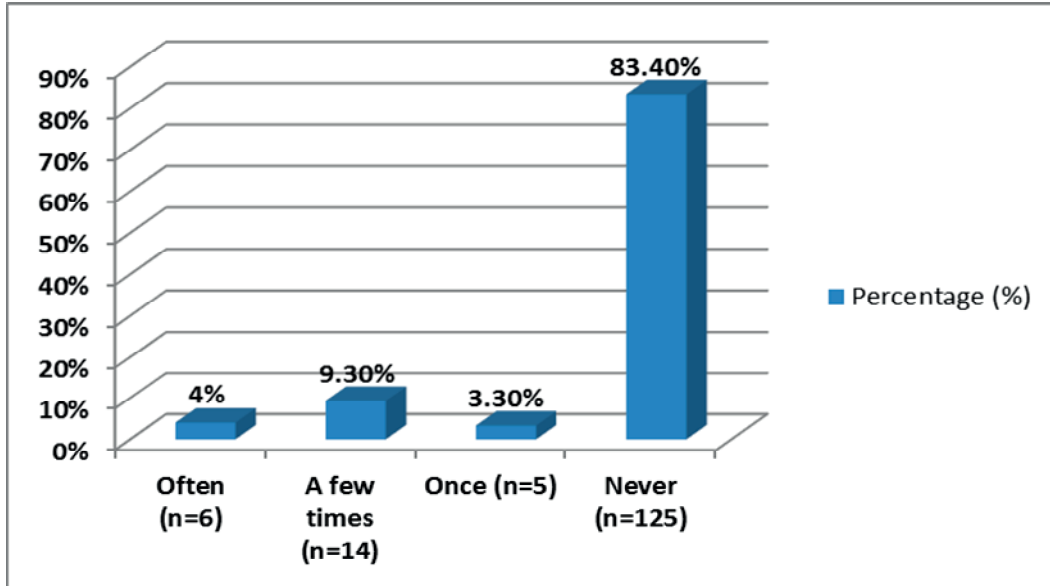
Exclusion from family activities, religious gatherings and social gatherings, due to HIV status was as low as 11.4%, 4.6%, and 2%, respectively.

**A fair percentage of PLHIV stated that the low levels of stigma and discrimination experienced was mainly due to non-disclosure of their HIV status.**

### 3.7 Harassment and Assault

#### 3.7.1 The Distribution of the Frequency of Verbal Insult, Harassment and /or Threat in the Study Participants

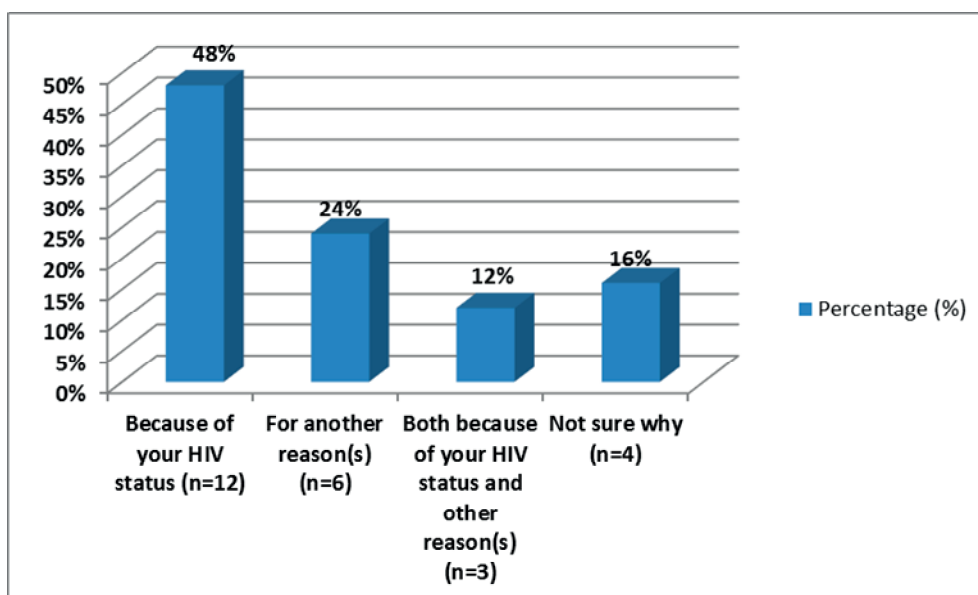
Figure 3.14: The Distribution of the Frequency of Verbal Insult, Harassment and /or Threat in the Study Participants (From all causes including HIV status)



Notably, 16.6% (n=25) felt that they had experienced some form of verbal harassment or threat in the last 12 months.

#### 3.7.2 The Distribution of the Reason for Verbal Insult, Harassment and/ or Threat in the Study Participants

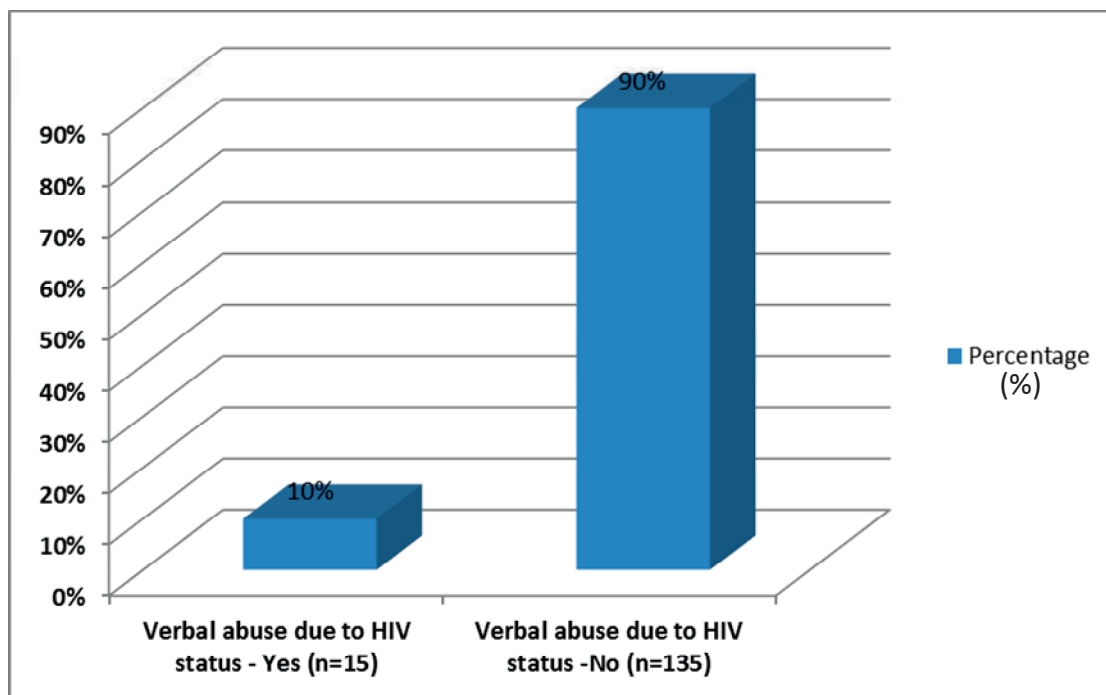
Figure 3.15: The Distribution of the Reason for Verbal Insult, Harassment and/ or Threat in the Study Participants (n=25) (From all causes including HIV status)



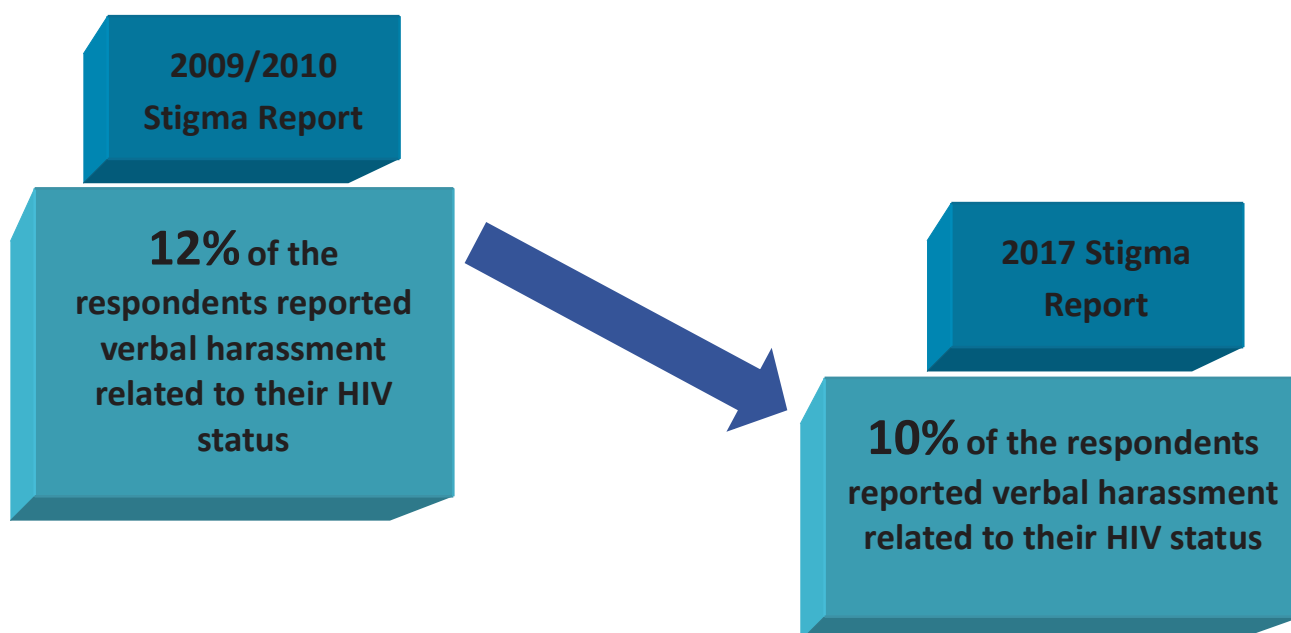
Out of all 25 participants who have faced verbal insult/ harassment, 15 of them (60% ) have felt that the verbal insult, harassment or threat was completely or partially due to their HIV status. Thus, these 15 cases represent 10% of the total study population, whom have met with a verbal insult, harassment and/ or threat based on their HIV status.

### 3.7.3 The Distribution of experiencing Verbal Insult, Harassment or Threat due to HIV status in the total Study Participants

Figure 3.16: The Distribution of experiencing Verbal Insult, Harassment or Threat due to HIV status in the total Study Participants (n=150)

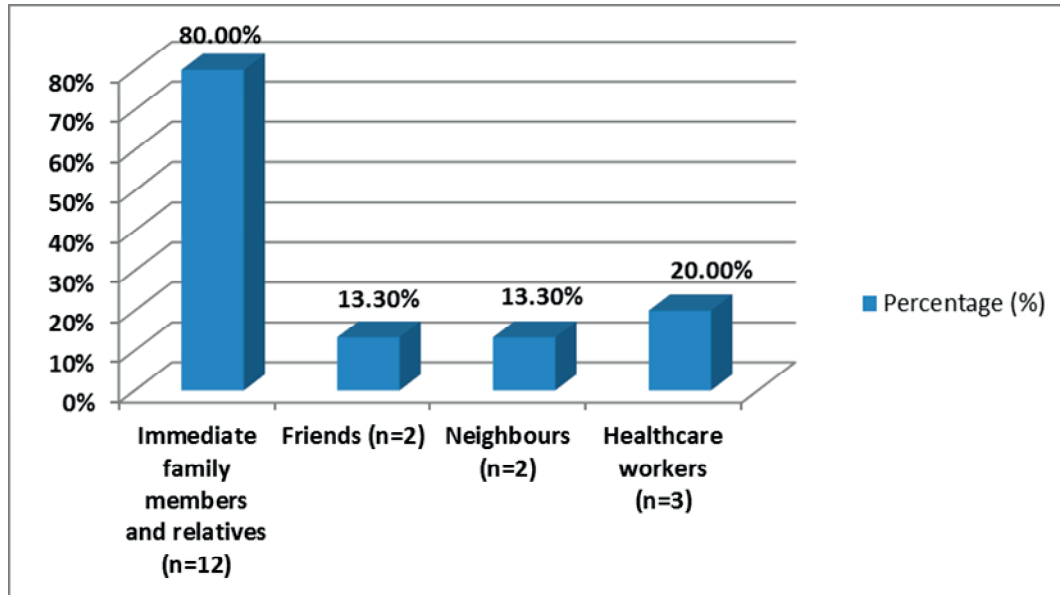


Ten percent of the total study participants (n=15) have faced verbal insult, harassment or threat due to their HIV status.



### 3.7.4 The Distribution of the Person who conducted the Verbal Insult, Harassment or Threat due to their HIV Status

Figure 3.17: The Distribution of the Person who Conducted the Verbal Insult, Harassment or Threat due to their HIV Status (n=15)\*

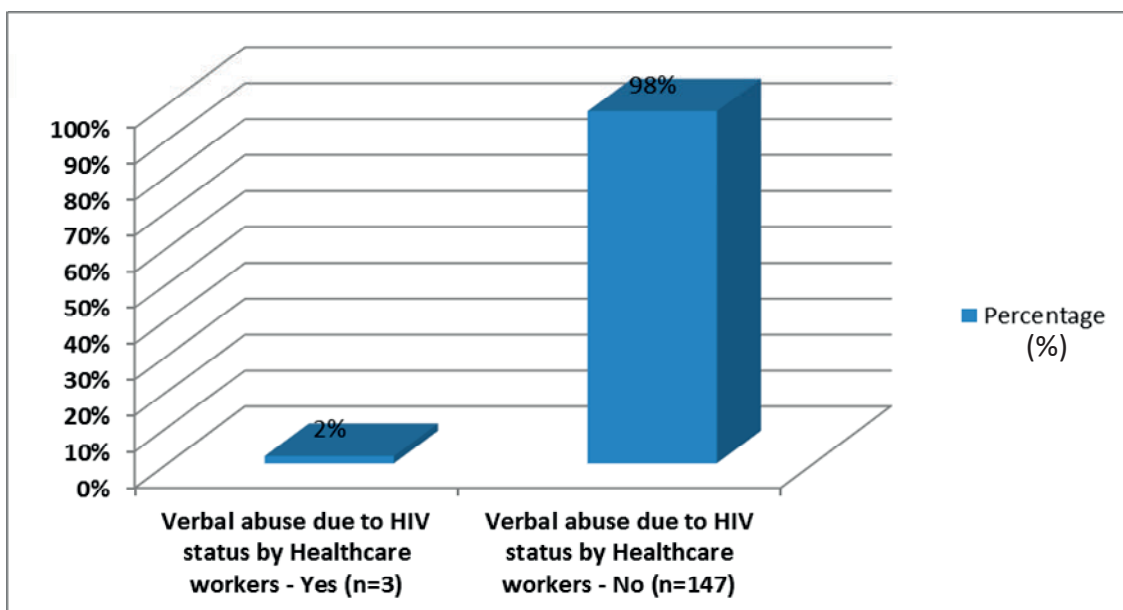


\*More than one person is mentioned by the respondents, and thus not mutually exclusive.

Verbal harassment was commonly committed by the patient's immediate family members and relatives, accounting for 80% (n=12) of verbal harassment. Immediate family members include patient's parents, partners, children and close relatives.

### 3.7.5 The Distribution of experiencing Verbal Insult, Harassment or Threat due to HIV status conducted by Healthcare Workers in the total Study Participants

Figure 3.18: The Distribution of experiencing Verbal Insult, Harassment or Threat due to HIV status conducted by Healthcare Workers in the total Study Participants

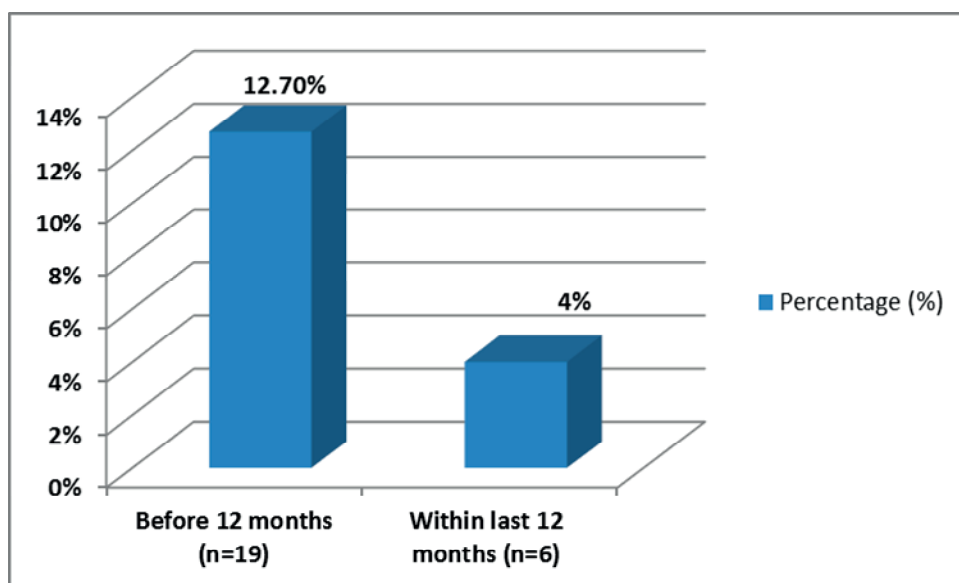


Three study participants (2%) had experienced verbal insult, harassment or threat by healthcare workers due to their HIV status.

**Verbal insult, harassment or threat due to HIV status conducted by healthcare workers accounted for only 2%, in the current study sample.**

### 3.7.6 The Distribution of Verbal Abuse Occurring Within and Before 12 Months in the Study Participants

**Figure 3.19: The Distribution of Verbal Abuse occurring within and before 12 Months in the Study Participants (From all causes including HIV status)**



Out of total participants, 4% (n=6) have experienced verbal abuse within the last 12 months,

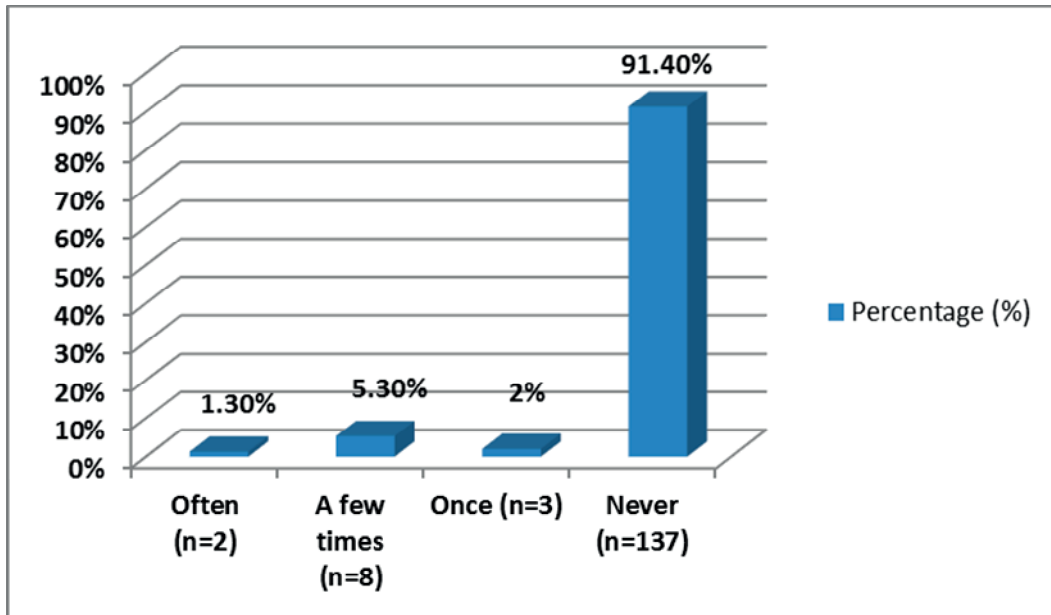
### 3.8 Physical Harassment and Threat

Thirteen (8.7%) people have said that they had experienced some form of physical abuse in the last 12 months.

#### 3.8.1 The Distribution of the Frequency of Physical Harassment and Threat in the Study Participants



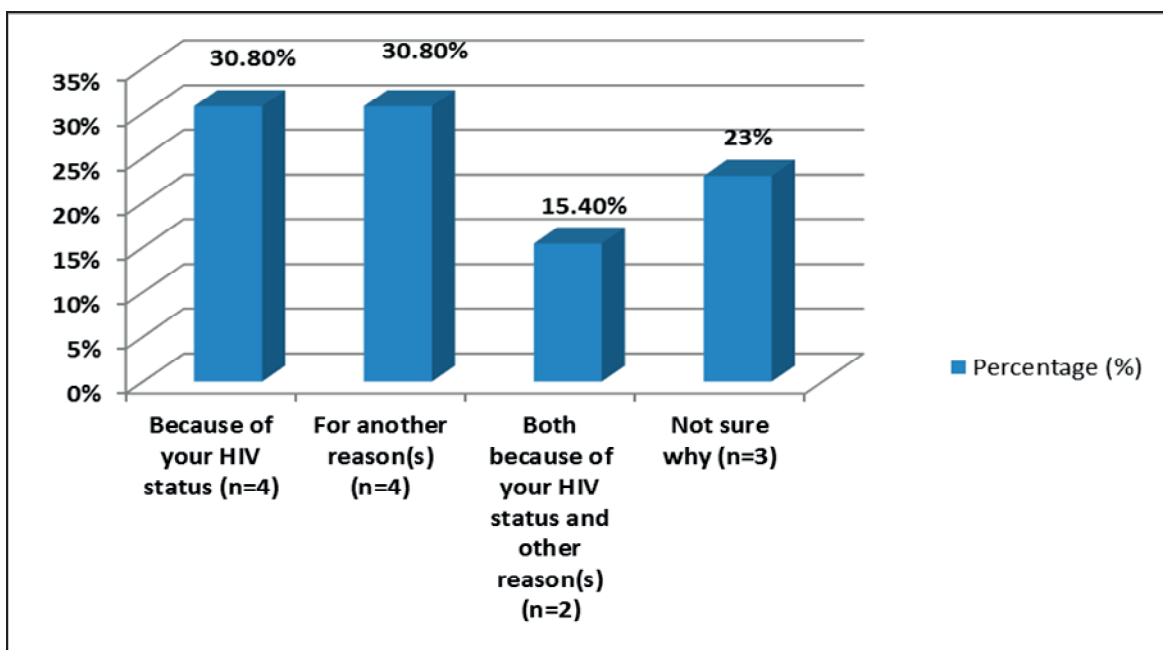
**Figure 3.20: The Distribution of the Frequency of Physical Harassment and Threat in the Study Participants (From all causes including HIV status)**



Thirteen participants (8.6%) had stated that they had experienced some form of physical violence in the last 12 months.

### 3.8.2 The Distribution of the Reason for Physical Harassment and Threat in the Study Participants

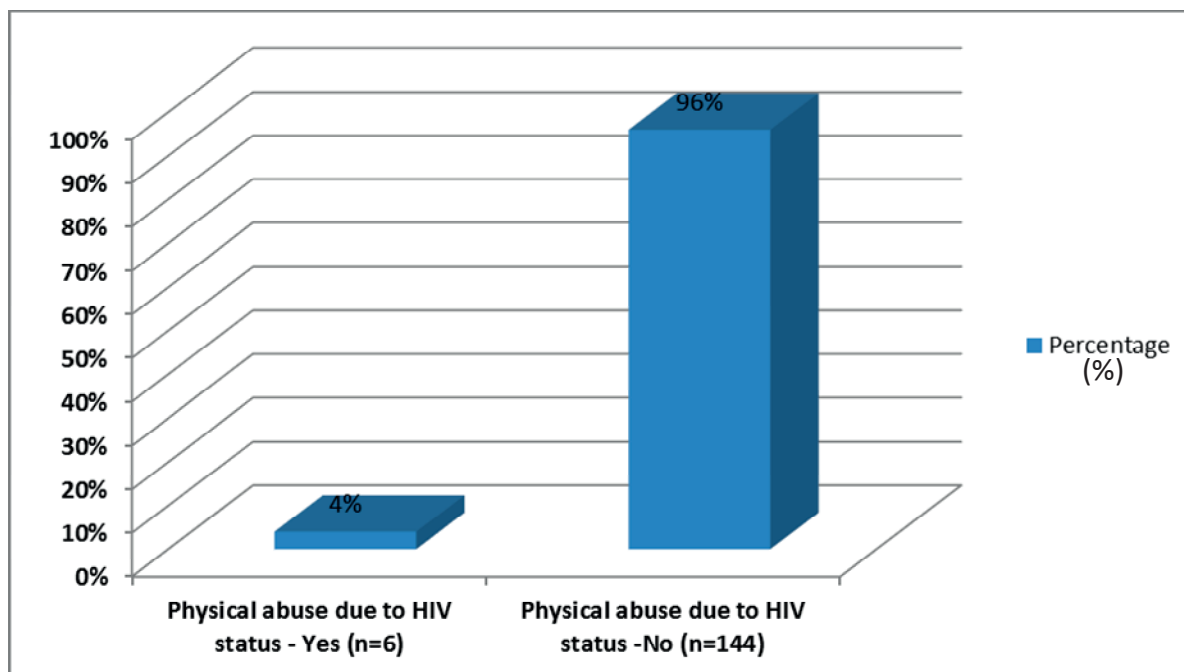
**Figure 3.21: The Distribution of the Reason for Physical Harassment and Threat in the Study Participants (n=13) (From all causes including HIV status)**



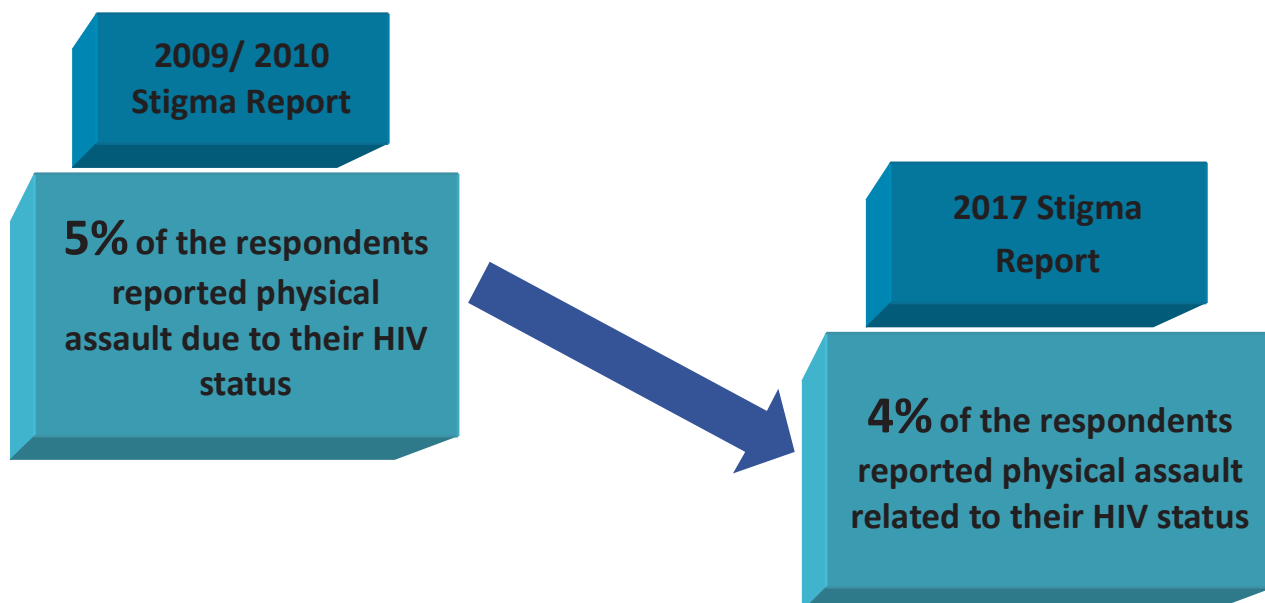
Accordingly, the physical harassment or threat experienced by six participants was directly related to their HIV status. When considering the total study population, this accounts for 4% (n=6) of physical harassment or threat being directly related to their HIV status.

### 3.8.3 The Distribution of experiencing Physical Harassment and Threat due to HIV status in the total Study Participants

Figure 3.22: The Distribution of experiencing Physical Harassment and Threat due to HIV status in the total Study Participants

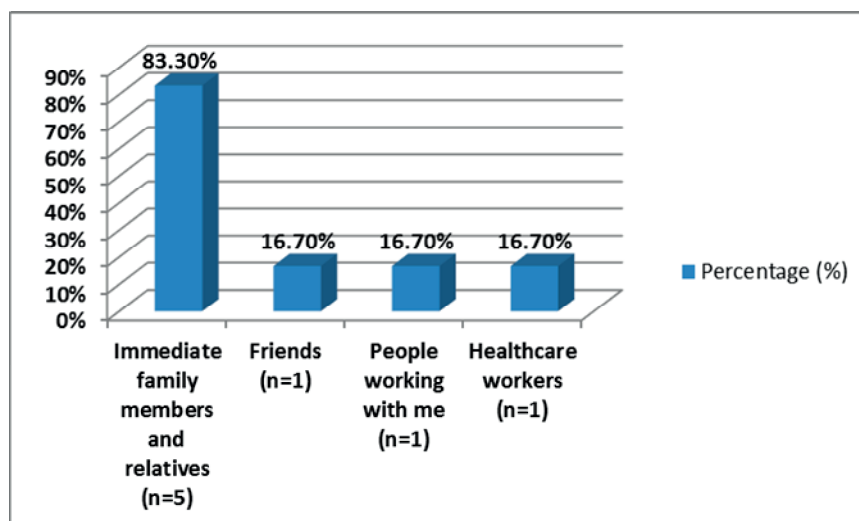


Six study participants (4%) had experienced physical harassment and threat due to their HIV status.



### 3.8.4 The Distribution of the Person who had committed the Physical Harassment and Threat

Figure 3.23: The Distribution of the Person who had Committed the Physical Harassment and Threat (n= 6)\*



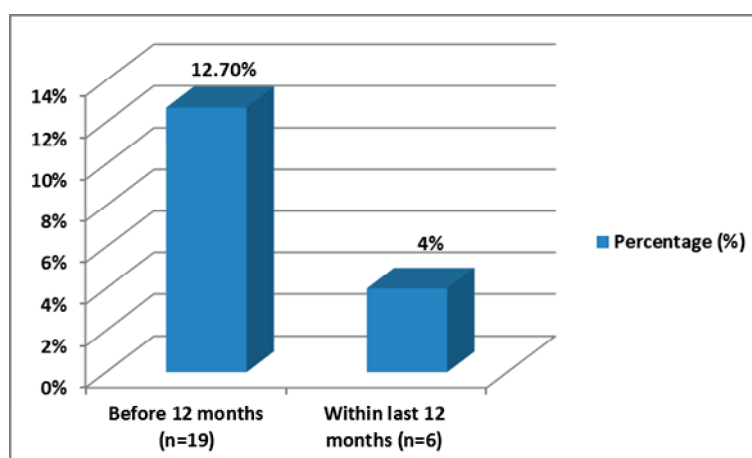
\*More than one person is mentioned by the respondents, and thus not mutually exclusive.

Physical harassment and threat occurring due to the HIV status committed by healthcare workers accounts for only 0.67% (n=1) of current study sample. This incident was related to a physical threat by a minor staff category (attendant) healthcare worker at a medical clinic.

Physical harassment was commonly caused by their immediate family members and close relatives including partners, parents, and children. Neighbours have not been involved in any such physical harassment.

### 3.8.5 The Distribution of Physical Abuse Occurring Within and Before 12 Months in the Study Participants

Figure 3.24: The Distribution of Physical Abuse Occurring Within and Before 12 Months in the Study Participants



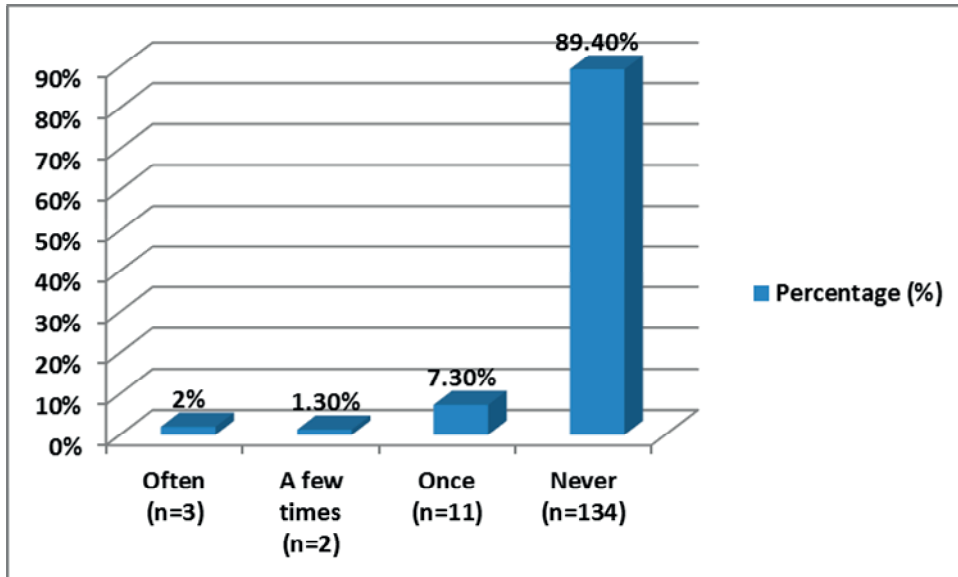
There were more physical abuse incidents (12.7%; n= 19) before 12 months of data collection, than within the past 12 months.

### 3.9 Stigma and Discrimination during Employment and Education

This section describes how the employment and education have been affected in the PLHIV within the last 12 months.

#### 3.9.1 The Distribution of the Frequency of Losing the Job or Income in the Study Participants

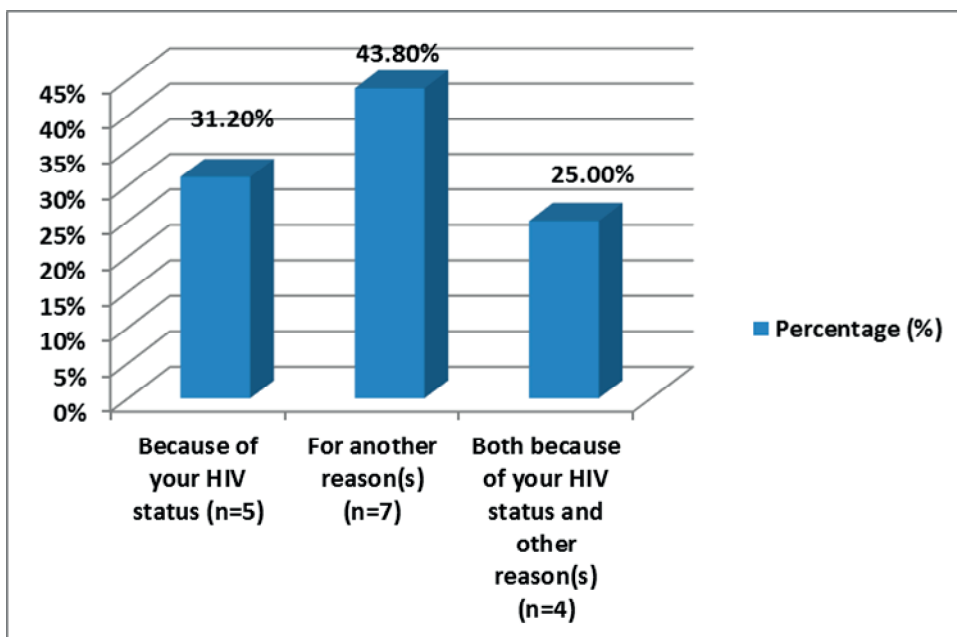
Figure 3.25: The Distribution of the Frequency of Losing the Job or Income in the Study Participants (From all causes including HIV status)



Sixteen participants (10.7%; n= 16) had some form of negative influence towards their job or income in the last 12 months.

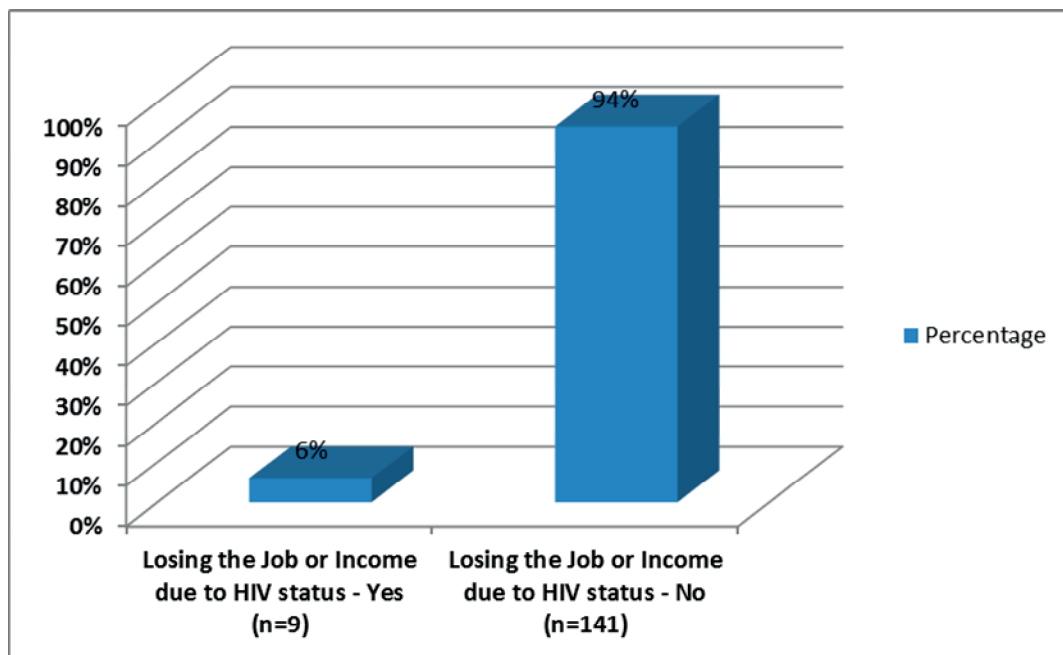
#### 3.9.2 The Distribution of the Reasons for Losing the Job or Income in the Study Population

Figure 3.26: The Distribution of the Reasons for Losing the Job or Income in the Study Population (n=16) (From all causes including HIV status)



### 3.9.3 The Distribution of Losing the Job or Income due to HIV status in the total Study Participants

Figure 3.27: The Distribution of Losing the Job or Income due to HIV status in the total Study Participants



Out of the total study participants, nine (6%) had lost their job or income due to their HIV status.

**In the 2009/2010 Stigma Report, 11% of the participants indicated loss of job or another source of income due to their HIV status.**

**In the current study, only 6% (n=9) of the study population indicated that the loss of job or another source of income was due to their HIV status**

### 3.9.4 Educational Missed Opportunities

Only three participants (2%) have stated that they have been dismissed, suspended or prevented from attending educational institutions in the last 12 months. All of them have declared that educational missed opportunities were not due to their HIV status. However, one respondent (0.67%) has indicated that his/her child had been dismissed, suspended or prevented from attending educational institutions purely due to the HIV status.

**The Majority of the study participants stated that the reported low levels of stigma and discrimination in the Stigma Index are due to non-disclosure of the HIV status.**

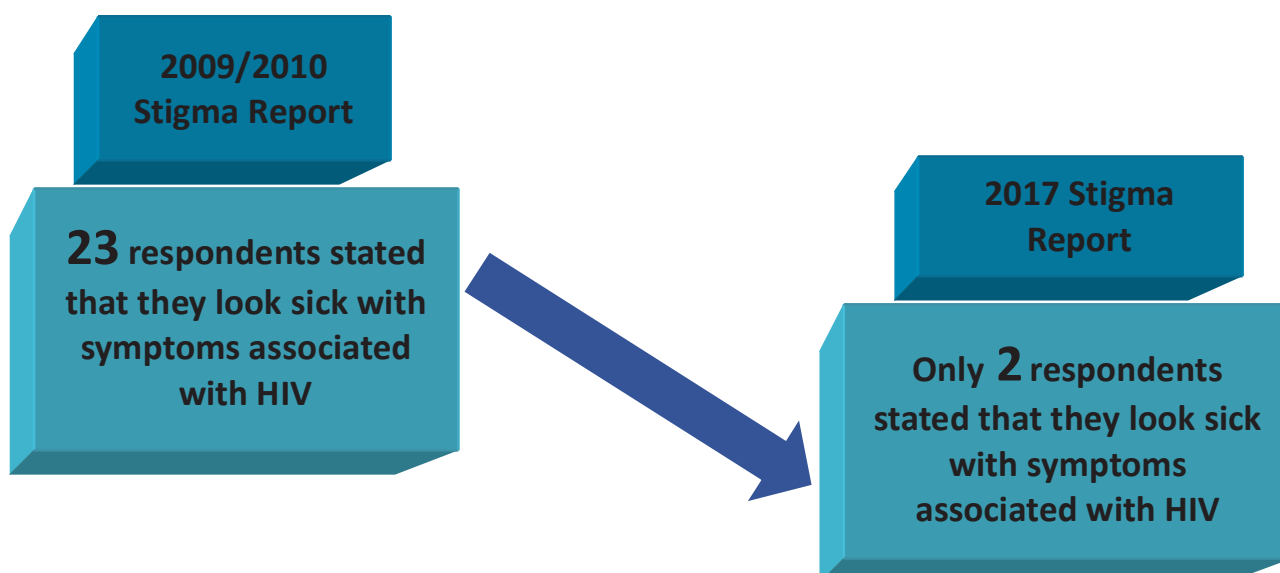
If HIV positive people are reluctant or afraid to disclose their status, it is still an indication of the high levels of stigma and discrimination they perceive or anticipate. Therefore, it is important to ask why they think people stigmatized or discriminated them.

### 3.9.5 Perceived Reasons for Experiencing Some Form of HIV Related Stigma and Discrimination in the Last 12 Months

**Table 3.8: Perceived reasons for experiencing some form of HIV related stigma and discrimination in the last 12 months**

Reasons for stigma and discrimination	Number	%
People are afraid of getting infected with HIV from me	27	18.0
People do not understand how HIV is transmitted and are afraid I will infect them with HIV through casual contact	16	10.7
People think that having HIV is shameful and they should not be associating with me	14	9.3
People disapprove my lifestyle or behaviour	5	3.3
I look sick with symptoms associated with HIV	2	1.3
I don't know/ I am not sure of the reasons	3	2.0

Some of the participants (18%; n= 27) have thought that “People are afraid of getting infected with HIV from me” as the main reason for stigma and discrimination. It is further supported by the ideas that the public do not have accurate and comprehensive knowledge of HIV transmission (10.7%; n=16). Fourteen percent of people living with HIV feel that ‘having HIV is shameful’, while two participants sense that they look sick with symptoms associated with HIV.



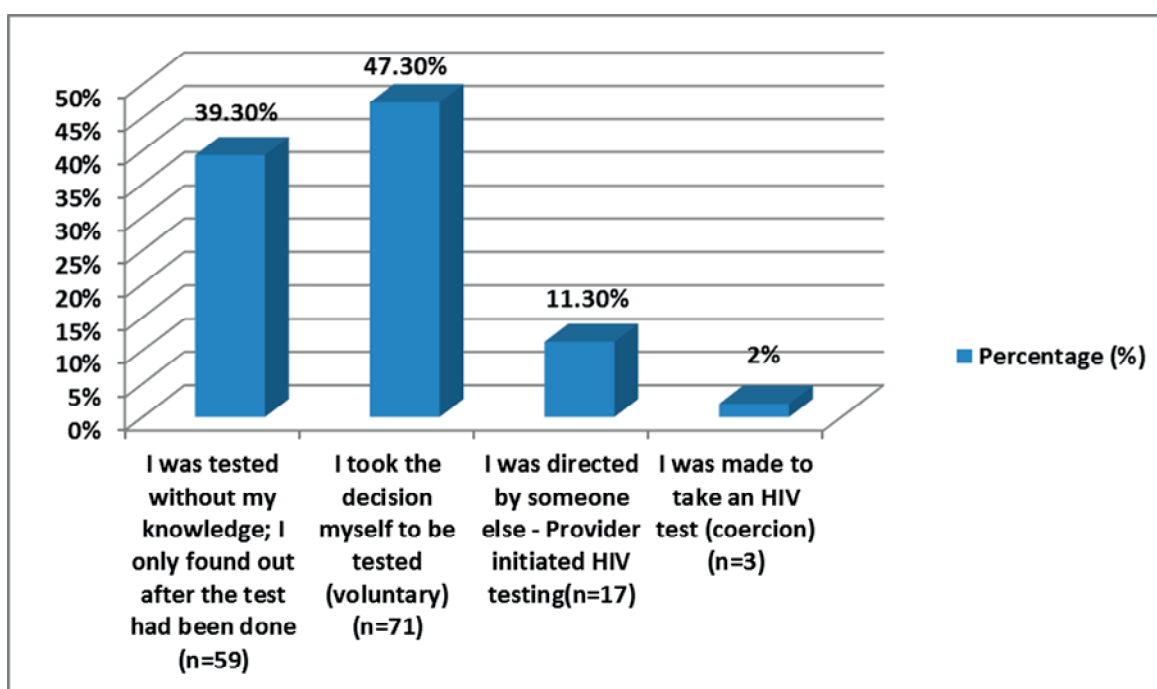
This clearly shows that people living with HIV have correctly perceived that HIV is a chronic and a manageable disease and they have received good care, counselling and support for a positive living (how to live positive, productive and fruitful lives with HIV). The assistance provided for positive living by PLHIV organizations, healthcare workers, and all other relevant stakeholders should be strengthened further.

### 3.10 Stigma in Healthcare Settings

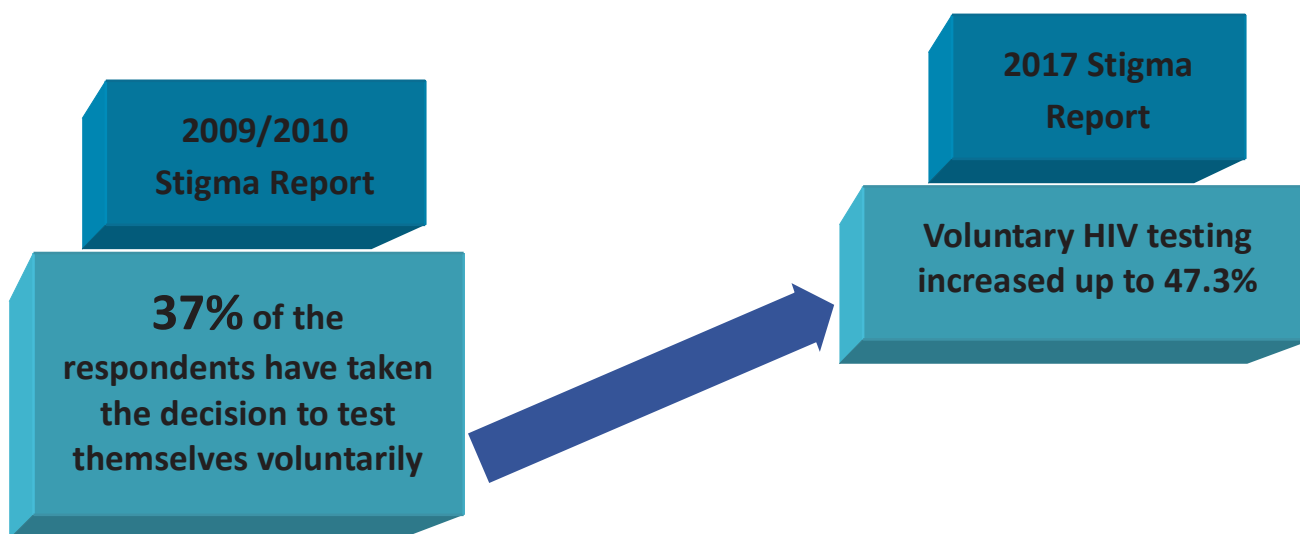
This section consisted of three key components. They are Testing & Diagnosis, Confidentiality & Disclosure, and Care & Support (including Reproductive Options).

#### 3.10.1 Testing and Diagnosis

**Figure 3.28: The Distribution of the Decision to Get Tested for HIV in the Study Population**



Nearly half of the respondents (47.3%; n= 71) took the decision to test themselves voluntarily.



The reasons that prompted the study participants to get tested for HIV are given in Table 3.9.

### 3.10.2 The Perceived Reasons for HIV Testing among the Study Participants

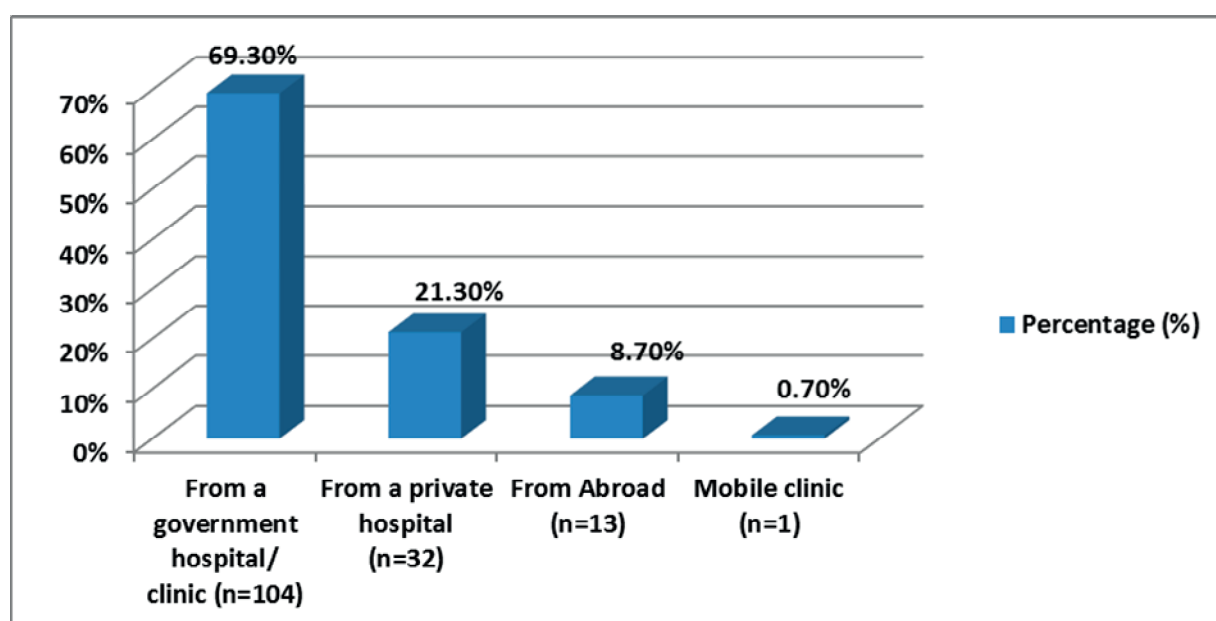
**Table 3.9: The Perceived Reasons for HIV Testing among the Study Participants**

Reasons for HIV testing	Number	%
Employment	42	28.0
Pregnancy	8	5.3
Referred due to suspected HIV related symptoms	31	20.7
Referred by a clinic for sexual transmitted diseases	14	9.3
Husband/ wife/ partner/ family member tested positive	29	19.3
Illness or the death of husband/ wife/ partner/ family member	7	4.7
I just wanted to know	10	6.7
Blood donation	9	6.0
<b>Total</b>	<b>150</b>	<b>100.0</b>

The most common reason for HIV testing is for employment (28%; n=42). Other reasons include referral due to suspected HIV related symptoms (20.7%; n=31) and family member being tested positive (19.3%; n=29).

### 3.10.3 The Distribution of the Place of HIV Testing in the Study Participants

**Figure 3.29: The Distribution of the Place of HIV Testing in the Study Participants**

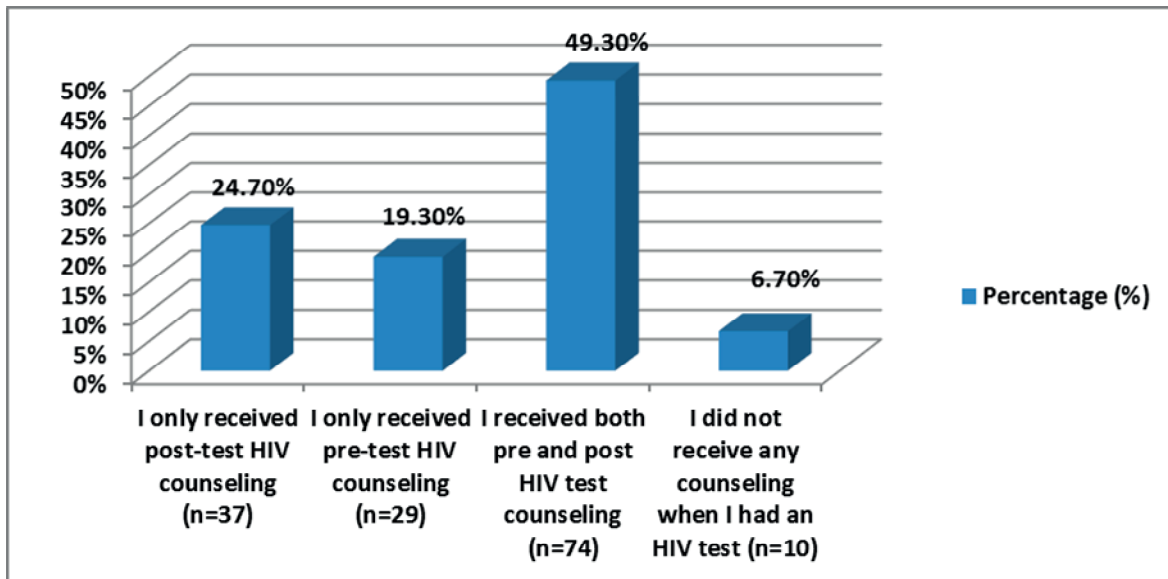


Many of the respondents (69.3%; n=104) have done their HIV testing from a government hospital or clinic.

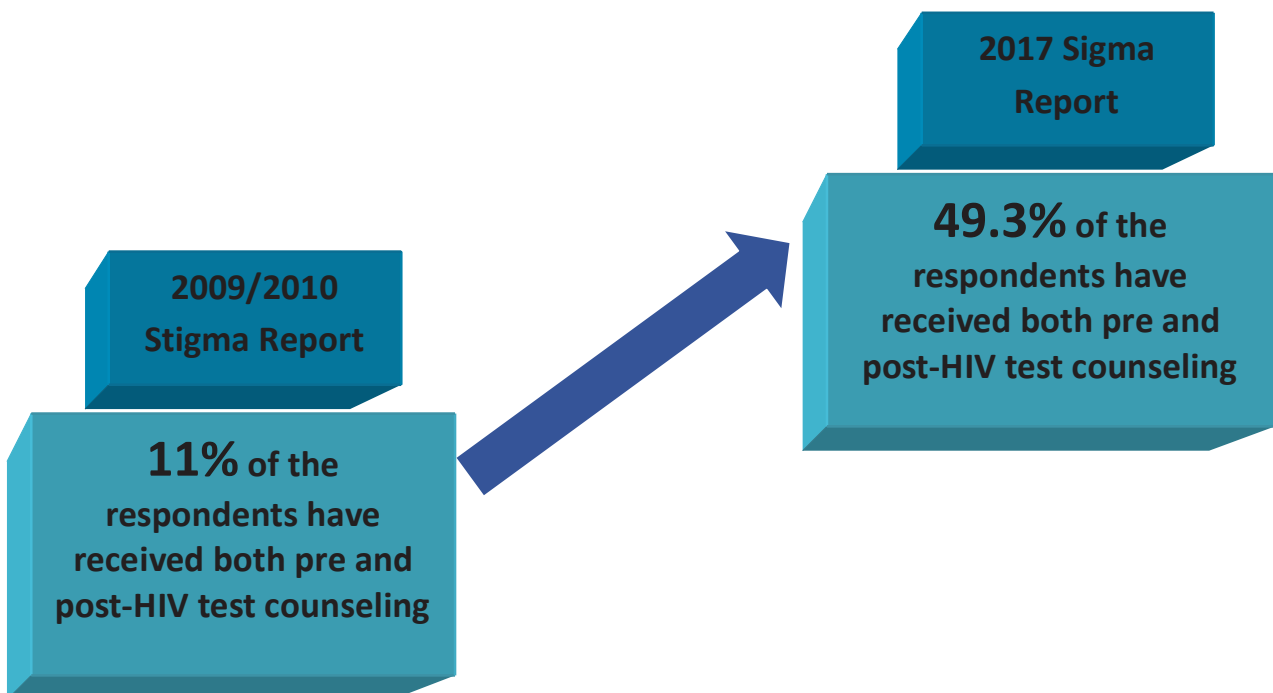


### 3.10.4 The Distribution of the Type of Counseling Received During HIV Testing, in the Study Participants

Figure 3.30: The Distribution of the Type of Counseling Received During HIV Testing, in the Study Participants



Nearly half (n=74) of the participants have received both pre and post-HIV testing counseling.



In 2016, a total number of 455,260 HIV tests were carried out from Government institutions.\* In 2016, the number of HIV testing conducted by Private Hospitals and laboratories were 225,047.\*

\*Annual Report NSACP, 2016

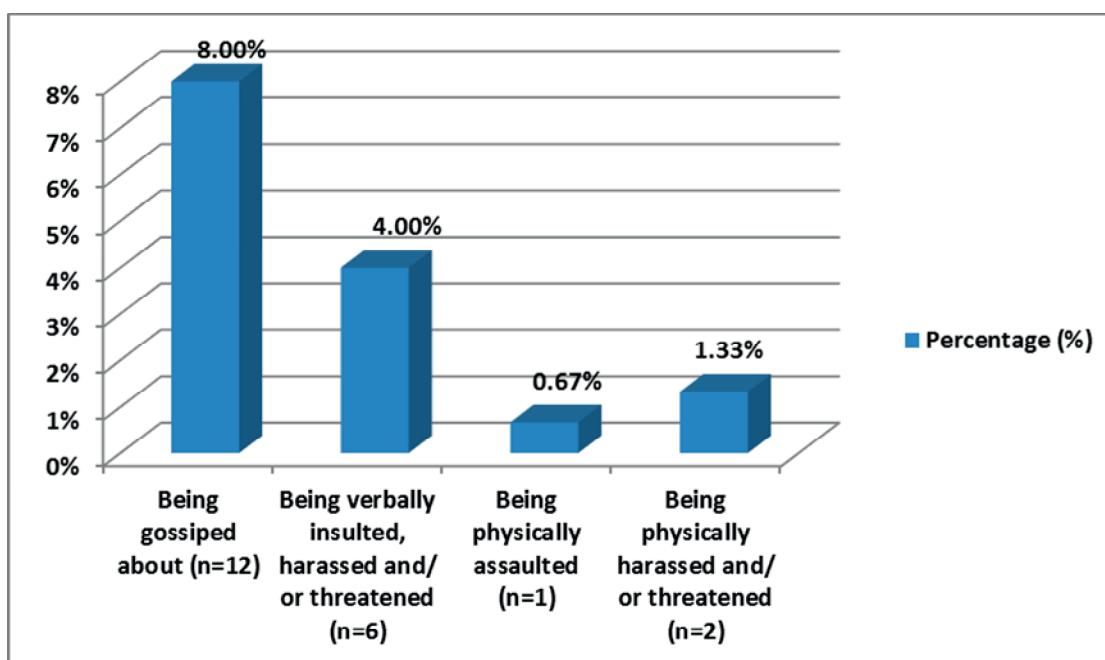
This shows the improvement in adhering to the National STD/AIDS Control Programme guidelines by providing both pre and post-test counseling services. However, ten participants (6.7%) have not received any counseling either before or after HIV testing. These 10 participants could have undergone the HIV testing in the private sector. These participants had to cope up with the result of the HIV testing with their limited knowledge on the disease status.

Pre-test counselling prepares an individual for the HIV test. It allows for discussion of fears and doubts related to the test, and also mitigates the fear of receiving a poor prognosis. If correctly administered with discussions on lifestyle changes (regardless of the result), it can be an effective prevention tool and an opportunity for the test candidate to receive accurate and comprehensive information on living with HIV. Pre-test and post-test counselling are the first steps in the continuum of care for a person living with HIV. Ignoring these first steps are a violation of human rights and a lost opportunity for both prevention and positive living.

### 3.11 Confidentiality and Disclosure within Healthcare Setting

#### 3.11.1 The Distribution of Perceived Fearful Incidents Happened in Healthcare Settings, in the Study Participants

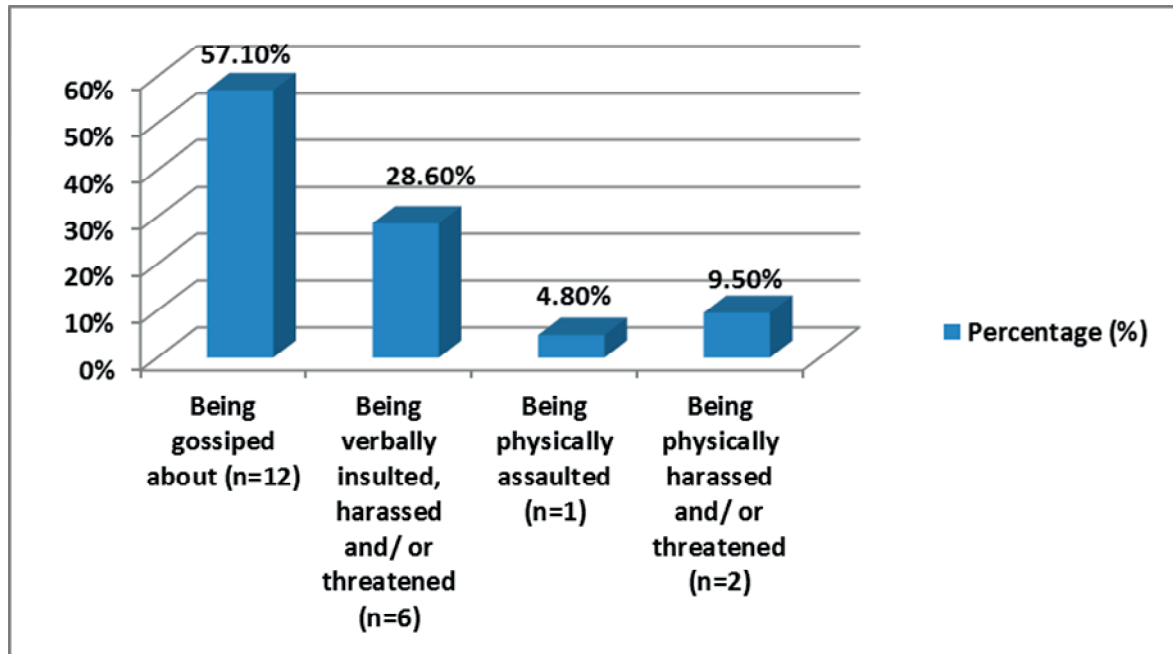
**Figure 3.31: The Distribution of Perceived Fearful Incidents Happened in Healthcare Settings, in the Study Participants**



Out of the total sample, twelve participants (8%) had the fear of being gossiped about. It is obvious that the fear would intensify when associated with healthcare workers who have accurate knowledge of their HIV status. There was one incident where the participant's status was communicated by hospital workers to their family members or close relatives, resulting in verbal harassment, physical assault, and physical threat/ harassment.

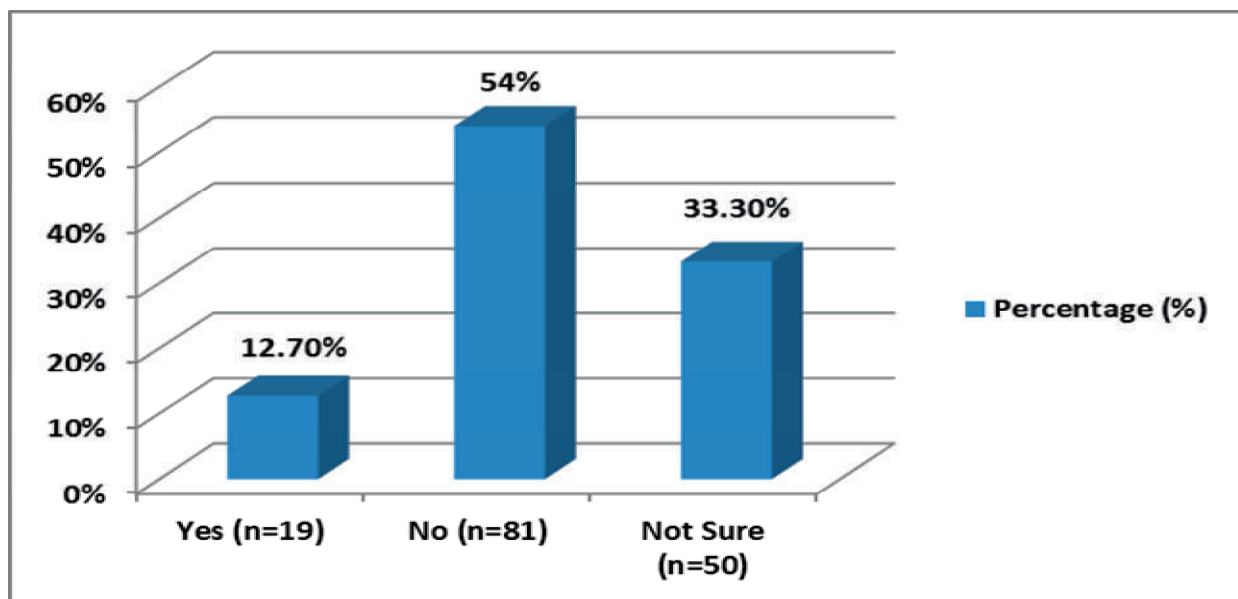
There were only 21 participants out of the study population who have perceived fearful incidents within healthcare settings. Most of them were related to gossips (57.1%; n=12) and verbal harassments (28.6%; n=6).

**Figure 3.32: The Distribution of Perceived Fearful Incidents Happened in Healthcare Settings, among those who have Faced such Incidents (n=21)**

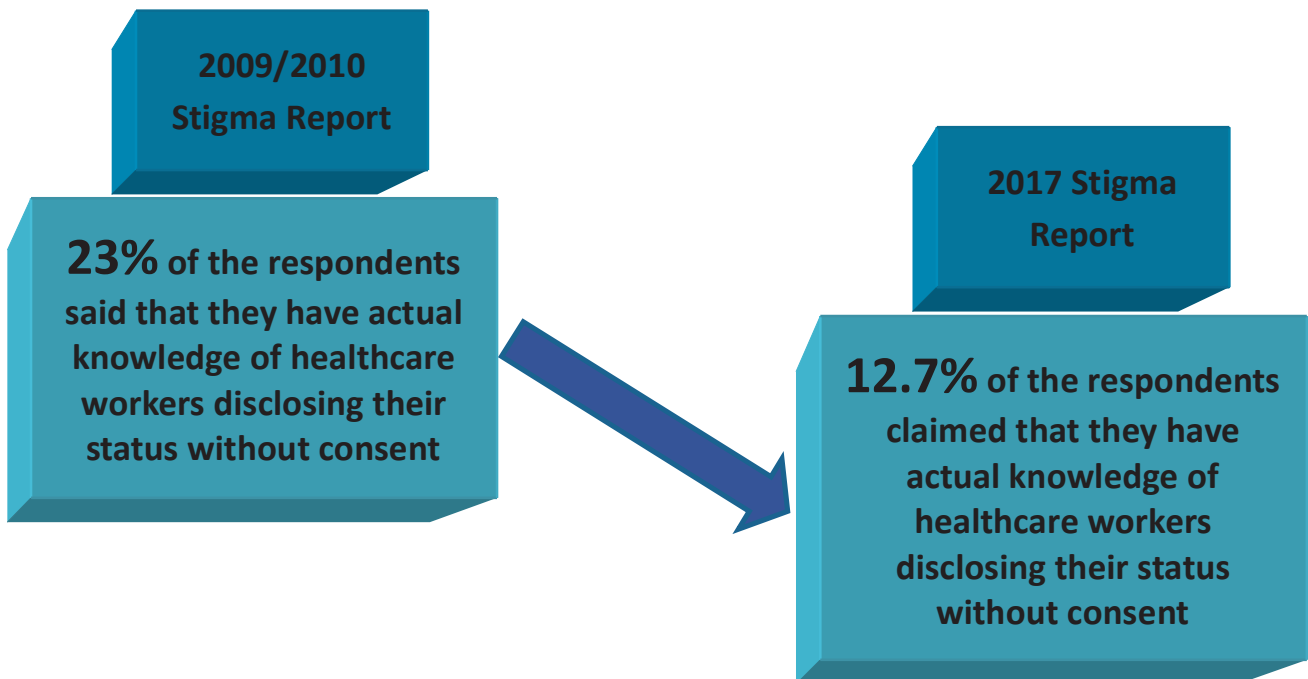


### 3.11.2 The Distribution of Perceived Disclosure of HIV Status by Healthcare Workers without their Consent, in the Study Participants

**Figure 3.33: The Distribution of Perceived Disclosure of HIV Status by Healthcare Workers without their Consent, in the Study Participants**

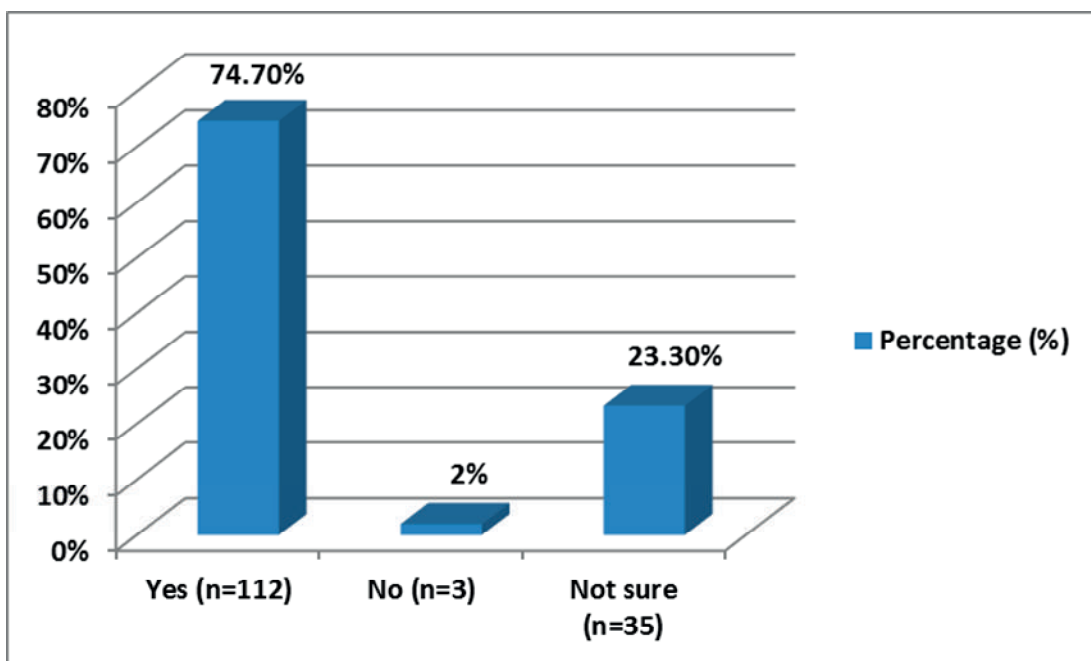


Nineteen participants (12.7%) claimed that they have actual knowledge of healthcare workers disclosing their HIV status without consent, while 33% (n=50) indicated that they are not sure whether healthcare workers have disclosed their status.

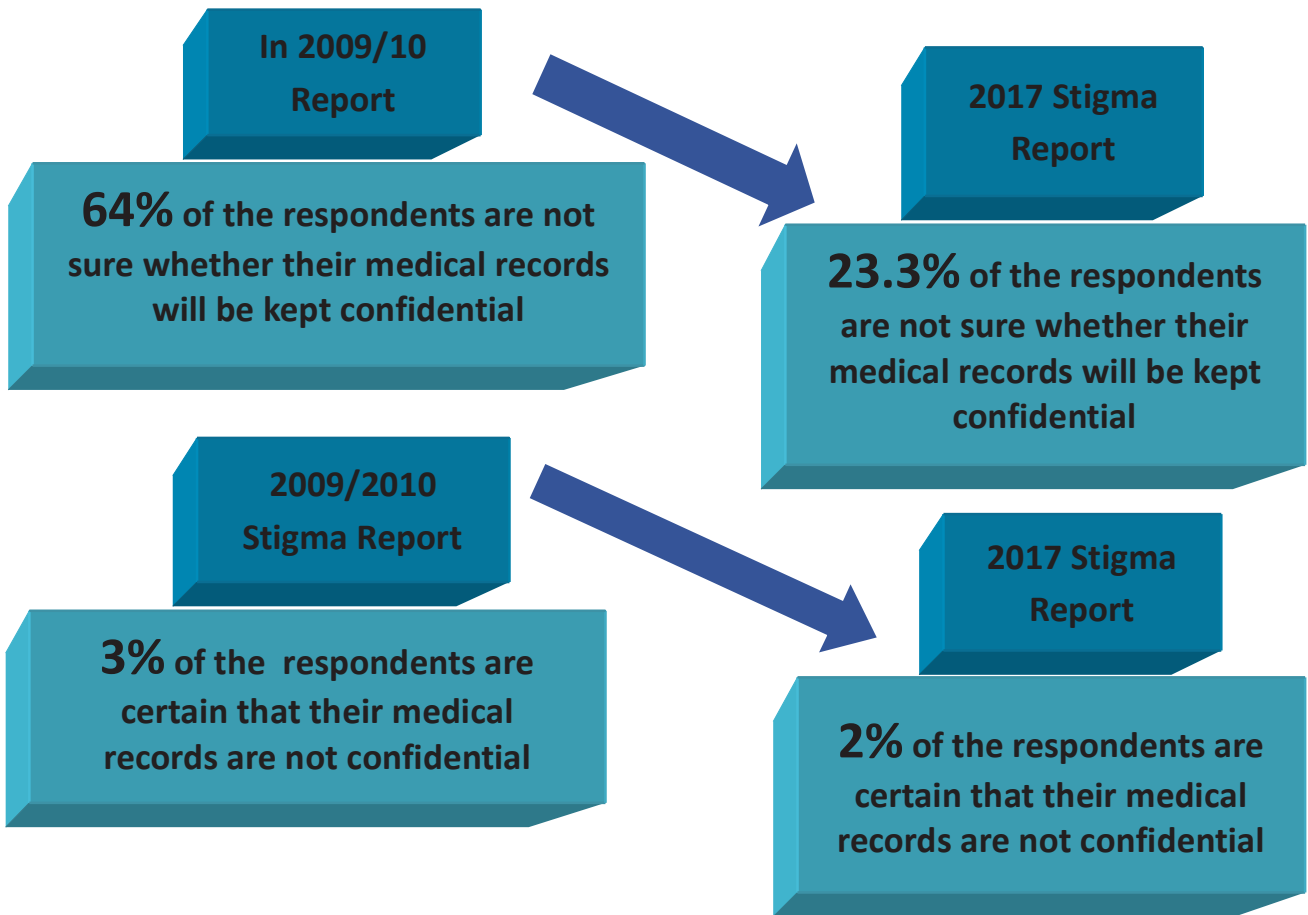


### 3.11.3 Confidentiality of Medical Records in Healthcare Institutions

Figure 3.34: The Distribution of Perceived Confidentiality of Medical Records in Healthcare Institutions Related to HIV Status, in the Study Participants



This clearly shows that 23% of the respondents are not sure as to how confidential their medical records related to the HIV status remain.

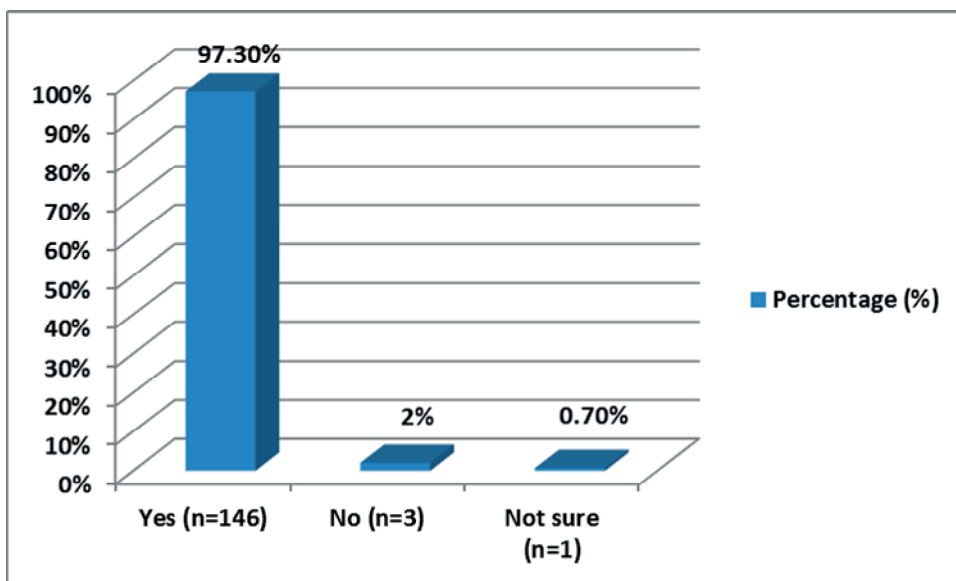


The data showed that PLHIV have more confidence in confidentiality of their status among healthcare providers compared to the 2009/10 assessment.

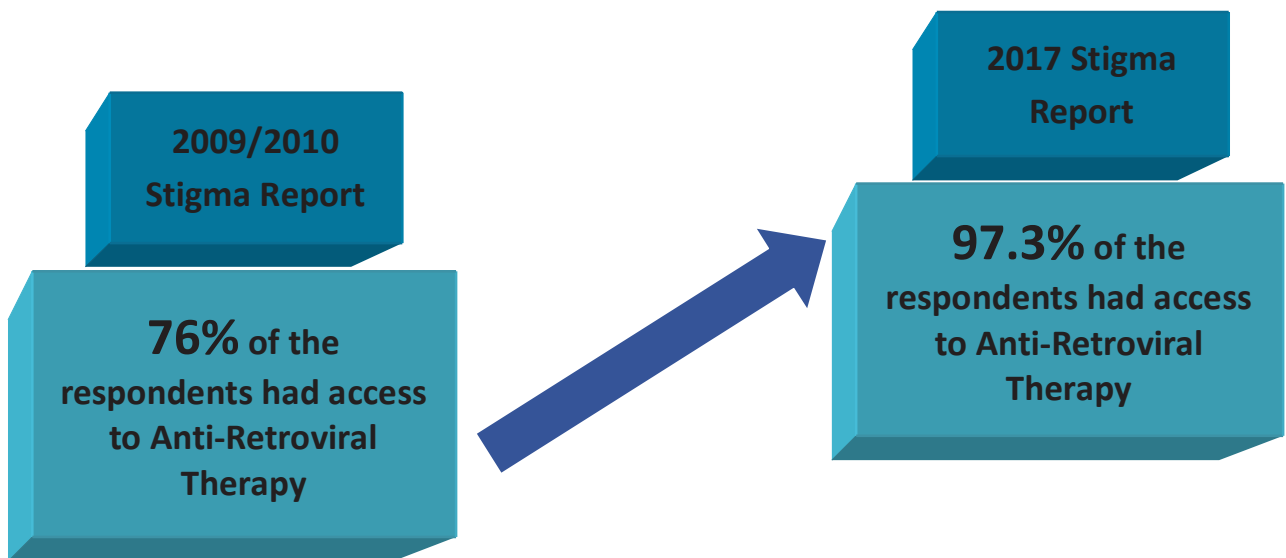
### 3.12 Care and Support

#### 3.12.1 Access to Anti-Retroviral Therapy (ART)

Figure 3.35: The Distribution of Access to Anti-Retroviral Therapy (ART) in the Study Population

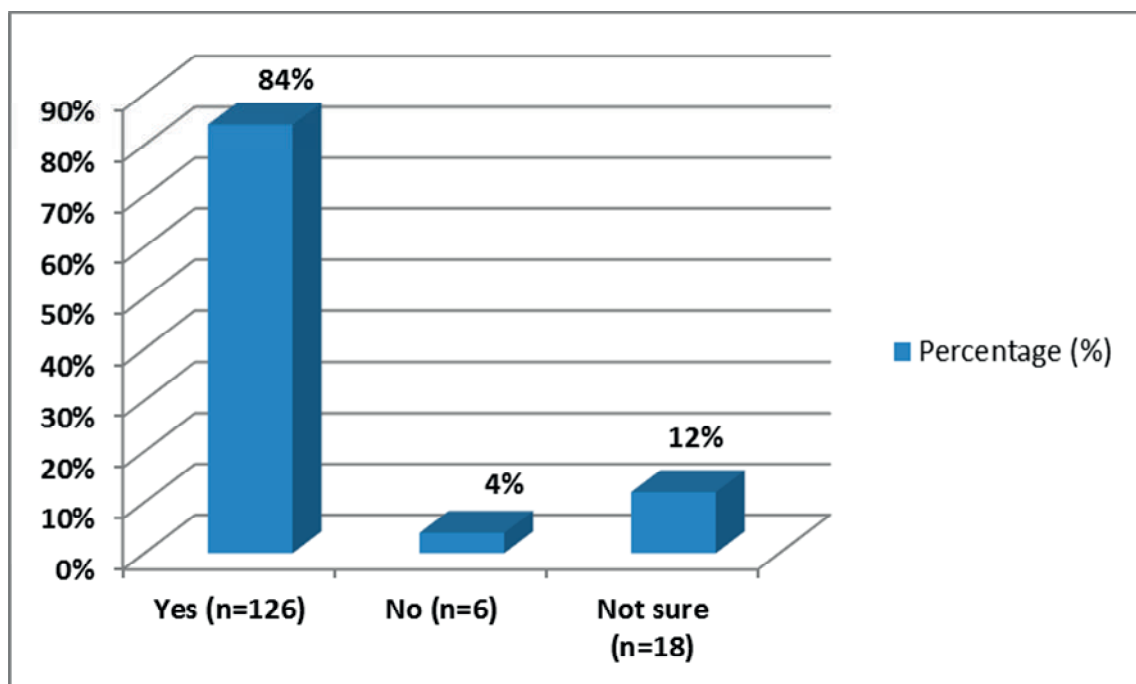


The majority (97.3%; n=146) of the respondents have access to Anti-Retroviral therapy. Rest of the participants (n=4) have said that they are still in the process of investigations prior to the initiation of the ART schedule.



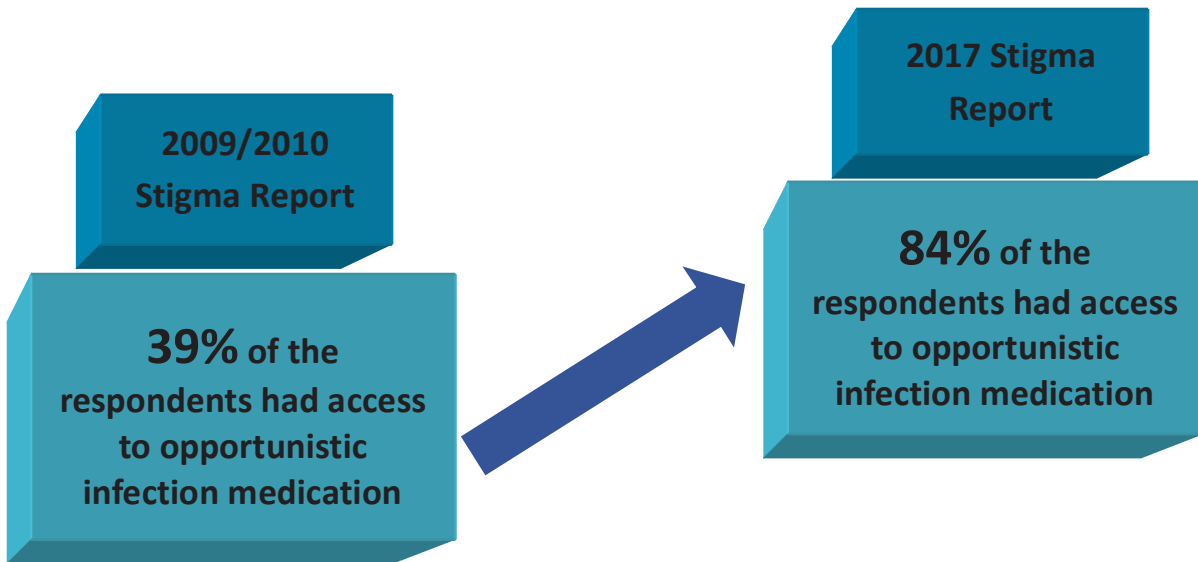
### 3.12.2 Access to Opportunistic Infection (OI) Medication

Figure 3.36: The Distribution of Access to Opportunistic Infection (OI) Medication in the Study Population



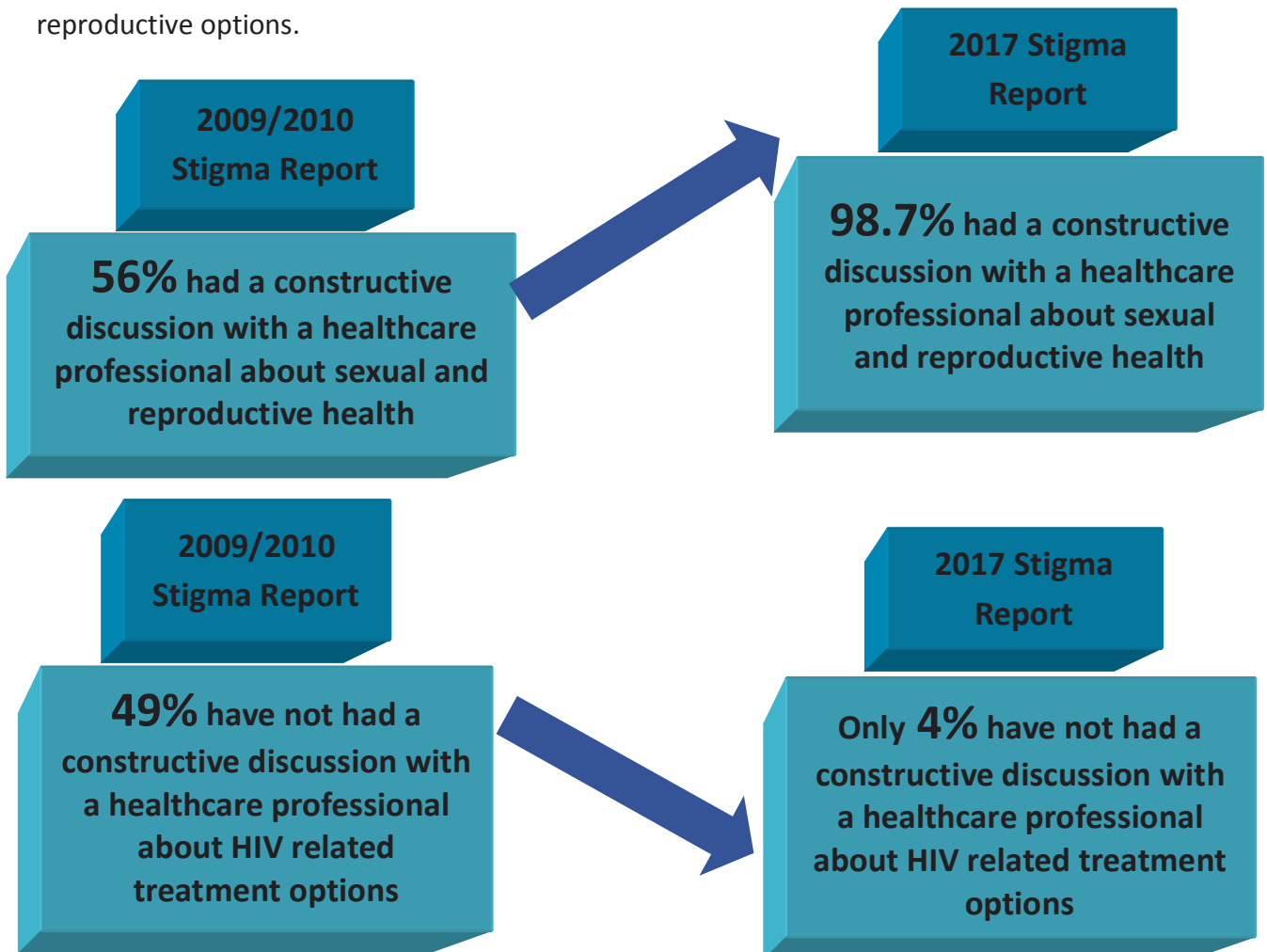
Eighty four percent (n=126) of the participants had access to opportunistic infection medication.

Throughout the history, the NSACP has taken maximum effort to provide opportunistic infection medication for all patients. But, only 84% had responded 'yes' to that question. The rest of the participants could not have understood the real '*Sinhala*' meaning of the term "Opportunistic Infection" during the data collection process.



### 3.12.3 Provision of Counselling Services

Almost all the participants (98.7%; n=148) had received the opportunity to discuss issues of sexual and reproductive health, sexual relationships and emotional well-being with appropriate healthcare professionals. The majority of the participants (95.3%; n=143) had the chance to have a constructive discussion with a healthcare professional about HIV related treatment options. Most of them (89.3%; n=134) have received specific counseling from healthcare professionals on their reproductive options.

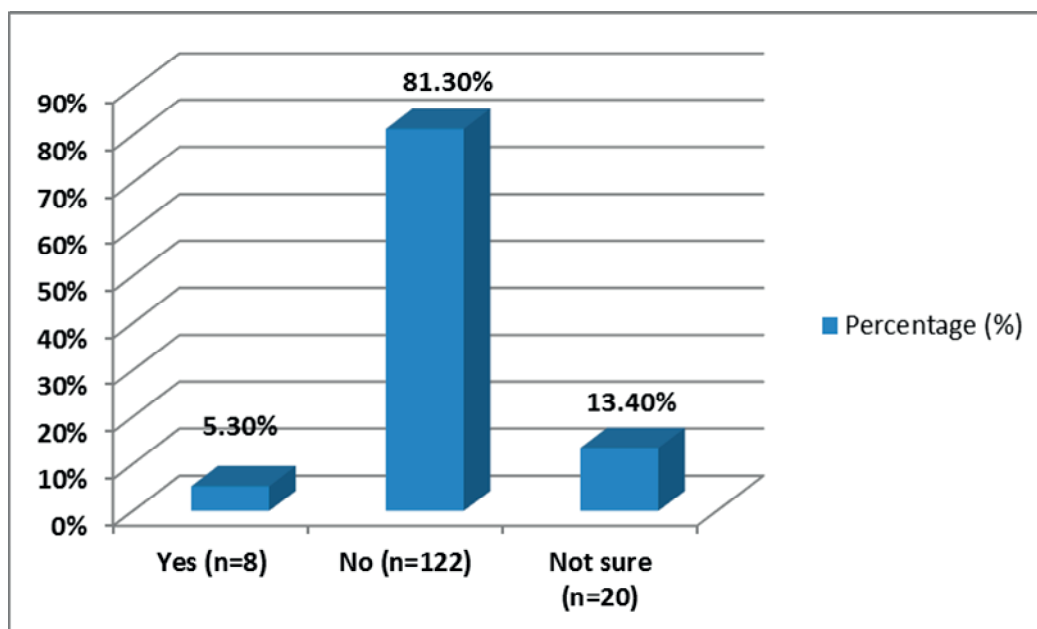


Thirty-three respondents (22%) have stated that ‘healthcare professionals have advised not to have a child after being diagnosed HIV positive’. Only two participants (1.3%) have mentioned that healthcare professionals have forced them not to have children. Three participants (2%) reported that obtaining ART was conditionally based on the use of some form of contraception, and one participant (0.7%) indicated that the healthcare professionals forced to terminate the pregnancy.

### 3.12.4 Experiencing Stigma and Discrimination in Specific Procedures at Healthcare Institutions

Experiencing any kind of stigma and discrimination when admitted to a hospital for other specific procedures including surgeries, eye procedures, wound dressings, etc., is assessed here.

**Figure 3.37: The Distribution of Experiencing Stigma and Discrimination in Specific Procedures at Healthcare Institutions**



Only eight participants (5.3%) have experienced any kind of stigma and discrimination when admitted to a hospital for other specific procedures (e.g. – surgery, eye procedures, wound dressings, etc) in the last 12 months.

### 3.13 Stigma Internalized: Feelings and Decisions of HIV Positive People

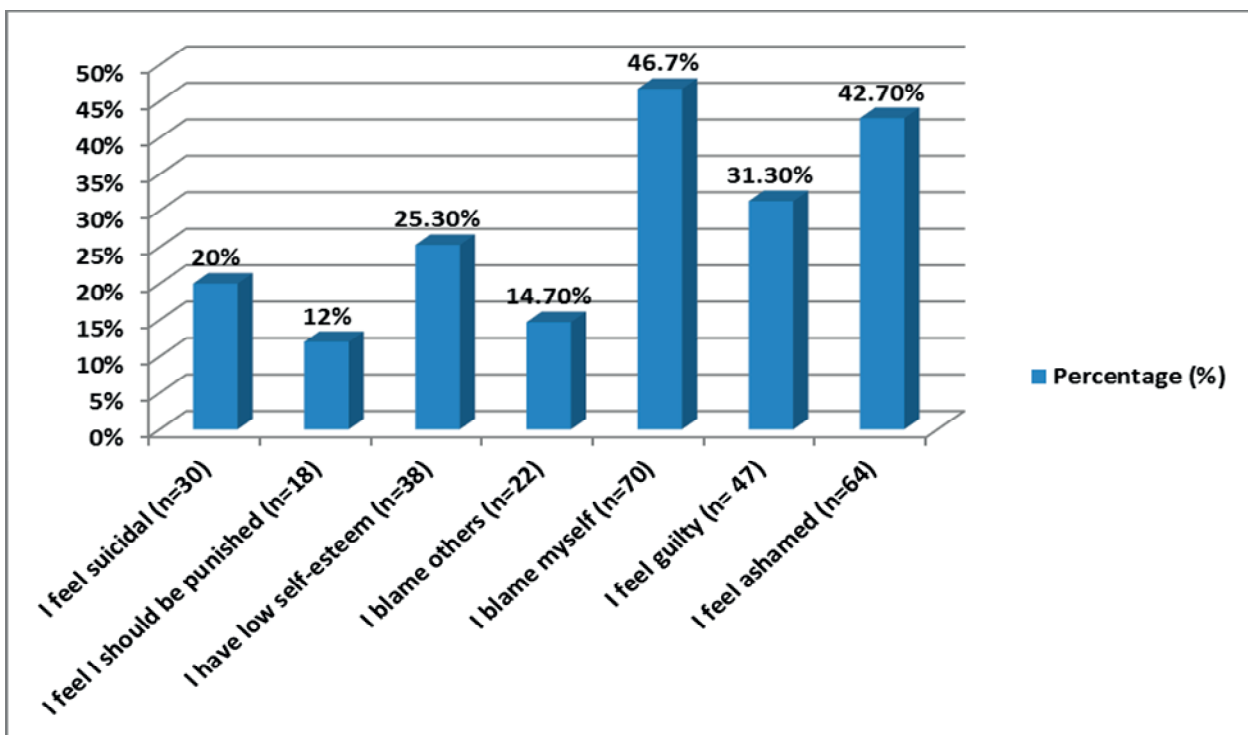
Internalized stigma is assessed using experienced feelings and decisions taken by the people living with HIV.



Exploration of internal stigma is one main aspect of identifying stigma and discrimination pertaining to HIV. Internalized stigma is closely related with conventional behaviours that can result in HIV infection, such as extramarital affairs and sex with sex workers.

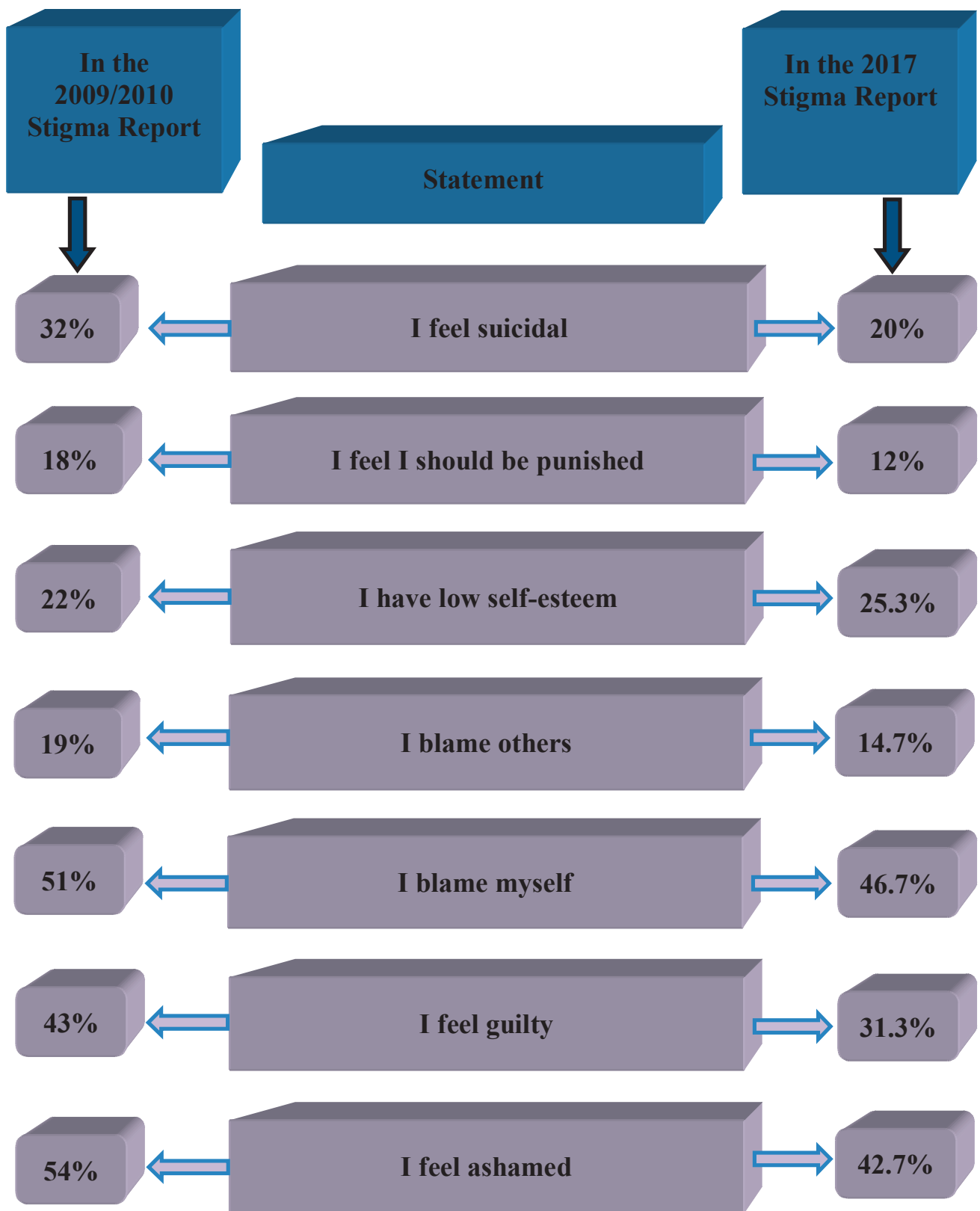
### 3.13.1 The Distribution of the Type of Internal Feeling which is Experienced due to HIV Status, in the Study Participants

Figure 3.38: The Distribution of the Type of Perceived Feelings Experienced due to HIV Status, in the Study Participants\*



\* Some participants have answered to more than one response, and thus the responses were not mutually exclusive

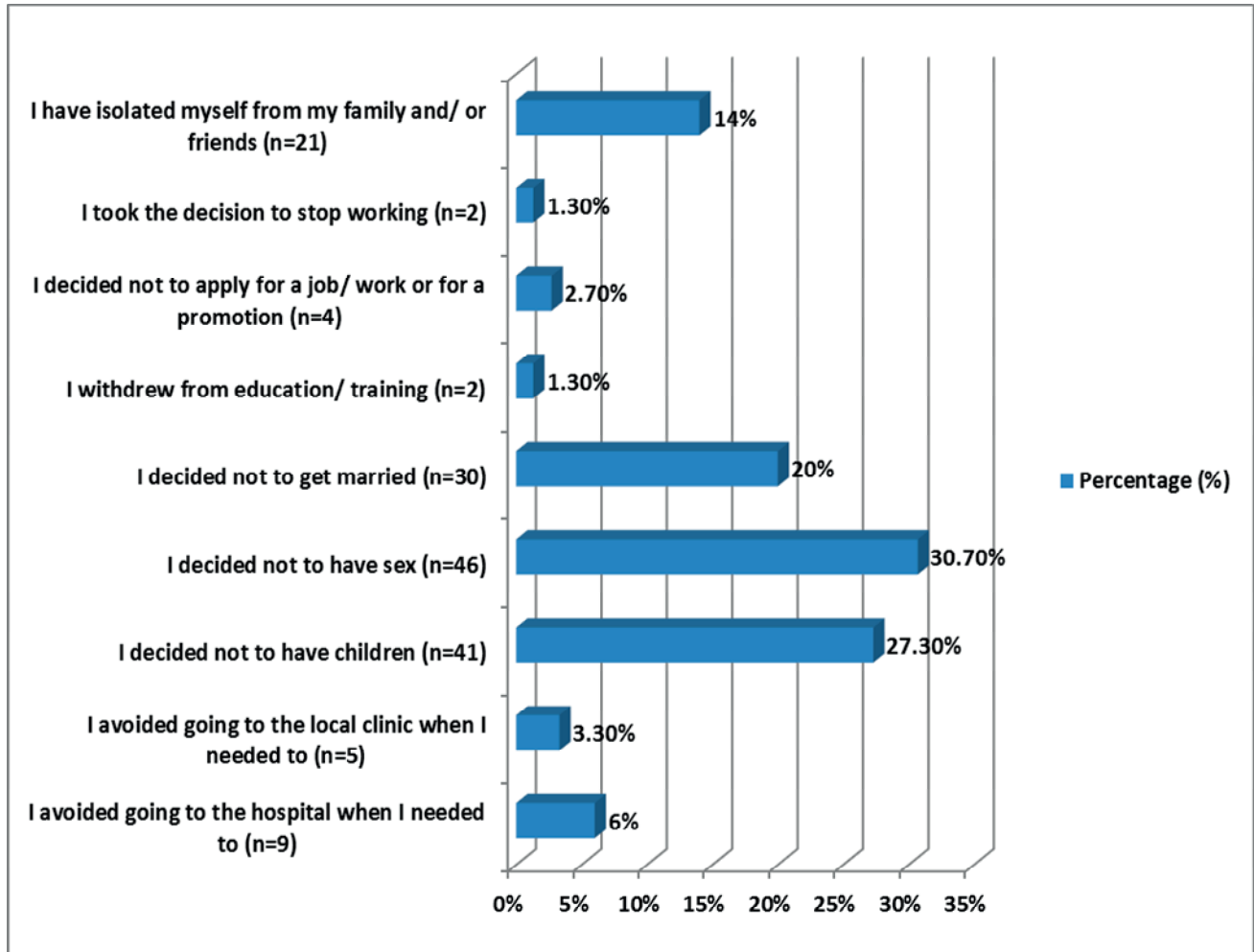
The results show that self-blame (46.7%) and shame (42.7%) are the most prevalent feelings, followed by guilt (31.3%). Some respondents stated that they had low self-esteem (25.3%; n=38), while 20% (n=30) of the respondents had suicidal thoughts. These feelings could be influenced by the cultural values and norms within the context of the country.



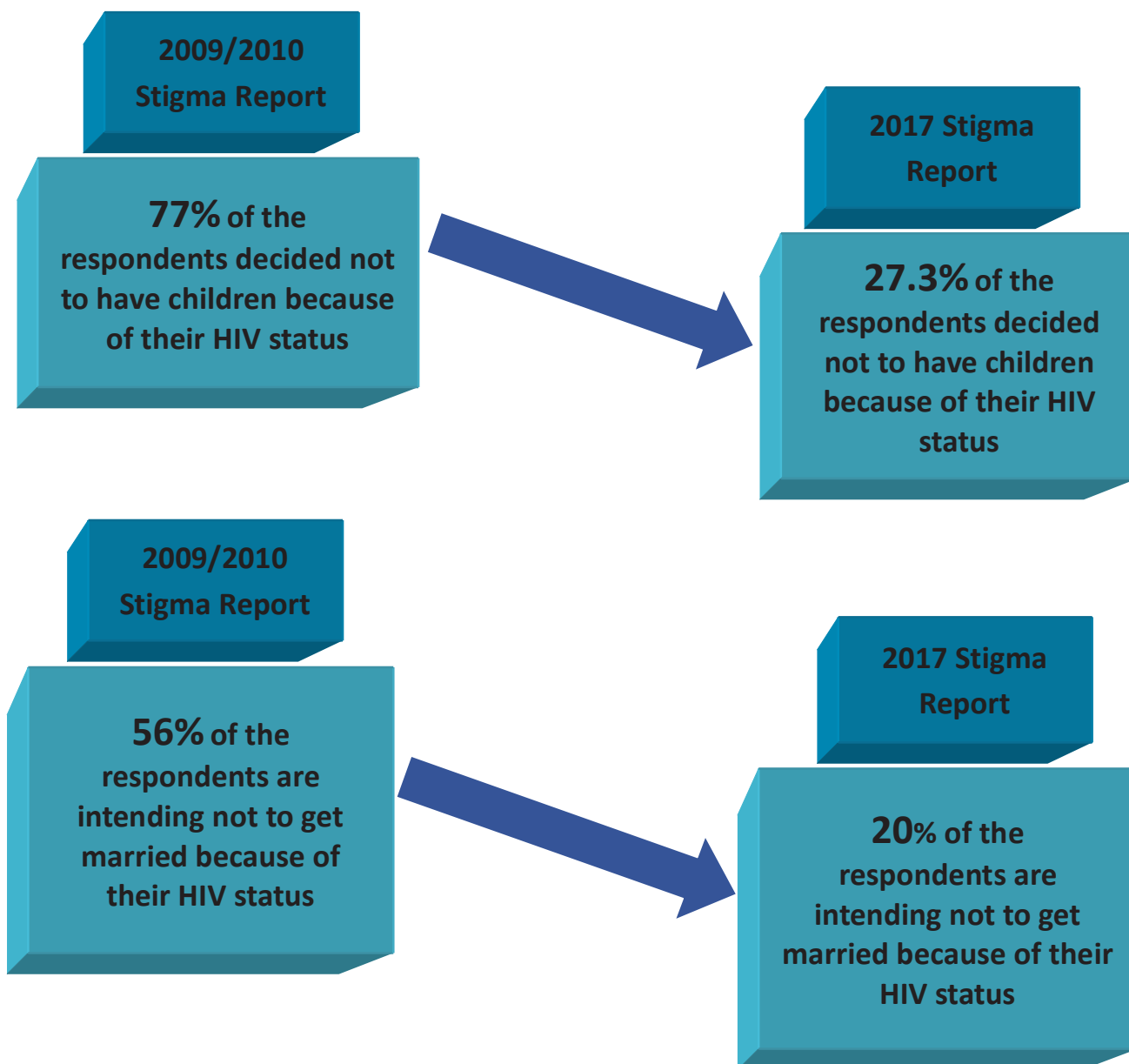
The above comparison shows that there was some reduction of internal stigma among PLHIV, when compared to the previous 2010 stigma assessment. But, almost one third to half of the PLHIV have internal stigma.

### 3.13.2 Perceived Decisions taken by People Living with HIV

Figure 3.39: The Distribution of the Perceived Decisions Taken due to the HIV Status by the Study Participants



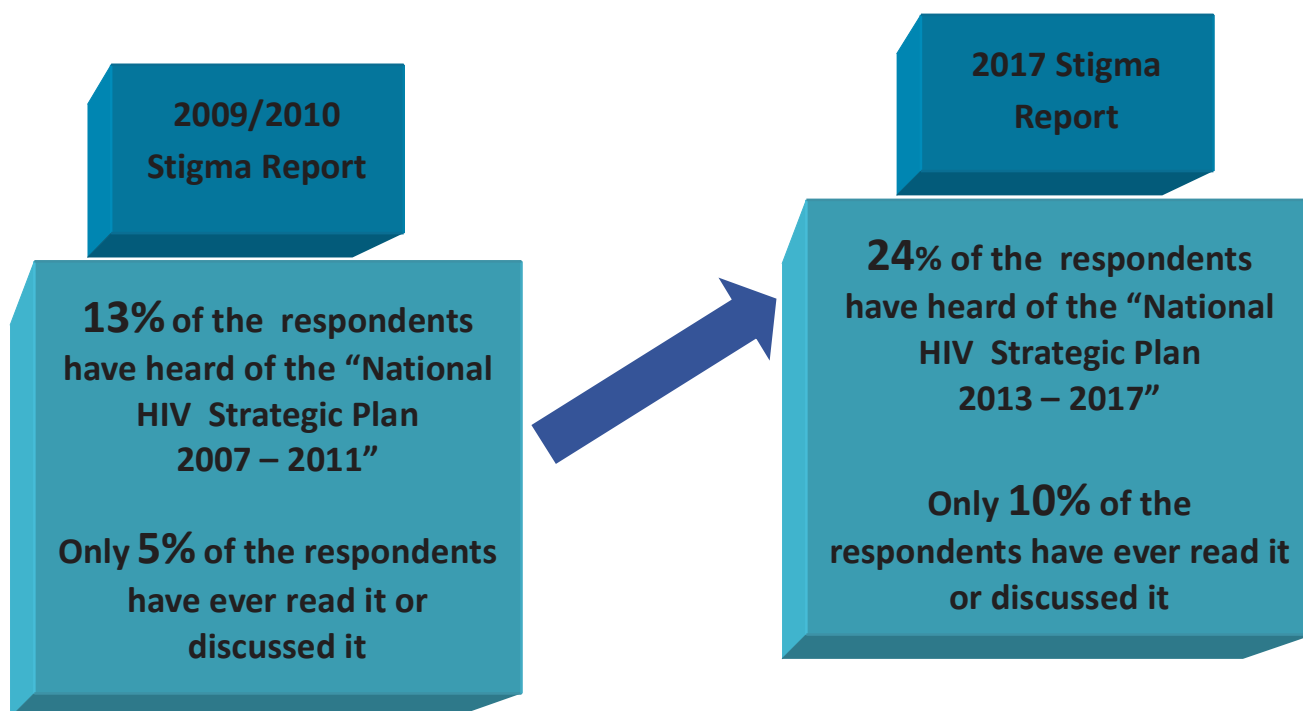
Decisions around sexual and reproductive health are the most distinct, with 30.7% (n=46) deciding not to have sex again; 27.3% (n=41) deciding against having children and 20% (n=30) not intending to get married.



### 3.14 Rights, Laws, and Policies

In this section, the knowledge of people living with HIV on laws and policies was assessed. Thirty six participants (24%) have heard about the “National HIV Strategic Plan 2013 – 2017” prepared by the National STD/AIDS Control Programme, and only 15 respondents (10%) claimed to have read or discussed it.

Nearly one-quarter of the respondents (25.3%; n=38) have heard about the “National HIV/AIDS policy for Sri Lanka” prepared by the National STD/AIDS Control Programme and other relevant stakeholders, out of which 20 respondents (13.3%) have read or discussed it. Twenty three respondents (15.3%) have heard about the “Declaration of Commitment on HIV/AIDS” made by the General Assembly of the United Nations.



Twenty four respondents (16%) claimed that they had their rights abused, but only 25% of them (6 respondents) attempted to get legal redress, of which 4 respondents indicated that nothing happened and 2 claimed that the matter was still being dealt with.

Only 10 participants (6.7%) have confidence in seeking legal redress for violating human rights of people living with HIV, while 24.7% (n=37) believed that PLHIV's will be subjected to further stigma and discrimination through seeking legal redress for violation of their human rights.

### 3.15 Perceived Obstacles Identified by PLHIV to Prevent Stigma and Discrimination

This section discusses how HIV positive people can participate in effecting change in their communities.

#### 3.15.1 Perceived Obstacles Identified by PLHIV to Prevent Stigma and Discrimination

**Table 3.10: Perceived Obstacles Identified by PLHIV to Prevent Stigma and Discrimination\***

Perceived Obstacles for effecting change	Number	%
Fear of disclosure	106	70.7
Fears of stigma and discrimination	115	76.7
Poor attitudes towards PLHIV	84	56.0
Cultural barriers	64	42.7
Lack of power to influence any decision related to the community	64	42.7
Lack of power to influence any decision related to the policy	61	40.7

\*some respondents have marked multiple responses, and thus responses are not mutually exclusive.

In Sri Lanka, the main obstacles to effecting change are the fears of stigma and discrimination (76.7%; n=115) and fear of disclosure (70.7%; n=106). This clearly shows that people are not willing to come forward and be identified as HIV positive. Only certain leaders of the networks do. Almost 40.7% of the respondents would like to be silent as they think that they do not have the power to influence any decision related to the policy.

### 3.15.2 Perceived Factors that Prevent People from Seeking HIV/AIDS Care Services

**Table 3.11: Perceived Factors that Prevent People from Seeking HIV/AIDS Care Services\***

<b>Factors preventing people from seeking HIV/AIDS care services</b>	<b>Number</b>	<b>%</b>
People are unaware of the services available	85	56.7
Services are not available in a client friendly manner	25	16.7
The feeling of 'people may reject me'	95	63.3
Feeling afraid/ shy to go to a treatment centre	96	64.0
Advice by a family member saying it is harmful/ shameful to the family	59	39.3
They may resolve spontaneously	27	18.0
Not thinking it as a health problem	18	12.0
Due to financial difficulties	55	36.7
People do not have signs and symptoms for a long time	74	49.3

*\*some respondents have marked multiple responses, and thus responses are not mutually exclusive.*

### 3.15.3 Support Received from PLHIV Organizations

**Table 3.12: Support provided by PLHIV Organizations to their Membership\* (n=140)**

<b>Supportive Service</b>	<b>Number</b>	<b>%</b>
Provide of counseling services	112	80.0%
Provide appropriate referrals	97	69.3%
Financial assistance	108	77.1%
Support for treatment	102	72.9%
Conduct home visits if necessary	99	70.7%
Provide care during hospitalizations	45	32.1%
Provide food and shelter	40	28.6%
Provide legal support	13	9.3%

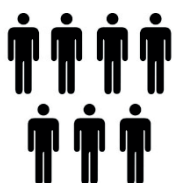
*\*some respondents have marked multiple responses, and thus responses are not mutually exclusive*

## Recommendations from people living with HIV to Minimise the Stigma and Discrimination

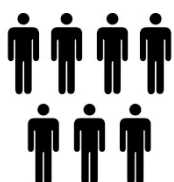
People living with HIV recommended the following, to prevent stigma and discrimination:

- a. Advocate government officials for rights of all people living with HIV
- b. Raise public knowledge and awareness about HIV and AIDS by providing accurate and comprehensive knowledge to prevent stigma and discrimination
- c. Educate people living with HIV for positive living and provide support to increase self-reliance
- d. Educate rights of PLHIV and key population groups
- e. Involve PLHIV for policy making and effective implementation processes

### Some Views Collected During Data Collection



**“As long as I am hiding my HIV status, I can live a normal life. But, I really do not know what will happen to me, if I express my HIV status to the society”**

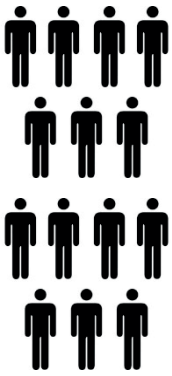


**“The work done by the STD clinic staff is amazing. Really appreciate their work”**



**“I really wanted to commit suicide, but PLHIV organization helped me a lot. They hold me, how important I am for this society. Now I have a hope and a new life.”**





PLHIV organizations are really good. They help us to overcome many challenges in our lives



“Before developing HIV, I worked abroad and saved a lot of money. I spent all of them for my children’s needs. But now they do not take care of me, because of my HIV status. I feel ashamed. I have very strong feelings to commit suicide”



“I was slowly recovering from a stroke when my brother in laws and father in law came to my home and assaulted me. I went to police and they handled the case in a biased manner after knowing my HIV status. Police humiliated me in front of others. I have a divorce case at a magistrate court in the central province. During the court proceedings, lawyers always ask questions related to my HIV status and discriminate me in front of all others. I feel ashamed, and more importantly, it affects my child’s education. I don’t have any faith regarding Sri Lankan police and our current legal system”

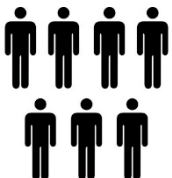




“I was admitted to a government hospital for a routine surgery. I did not declare my HIV status to them. If I tell my real situation they will discriminate me. So I kept silent. Everything went smoothly and my surgery was successful.”



I am 31-year-old and I was admitted to the one of the main District Hospitals following a generalized illness. During this hospital stay, I was diagnosed as having HIV. The medical doctors who were performing their routine ward rounds have discussed this in English in front of the bystander (My uncle is fluent in English). After I was discharged, my uncle has spread it and I could not stay in my village and came to Colombo for my own survival.



Appreciated the services given by all STD clinics and IDH Hospital. But satisfaction of services given by other medical setups are questionable, especially TB clinics



**“I still think that PLHIV organizations have much more space for improvement”**

**“By improving PLHIV organizations, you directly improve the PLHIV community”**



**“I am living with HIV for 11 years. All STD clinic staff is kind and helpful. The services given by IDH clinic are excellent. When I go to other hospitals for other services and tests, I feel very helpless”**



**“I would like to receive all health services under one roof. It is my dream to have the STD clinic, dental clinic and Tuberculosis clinic at the same place. This will attract more patients and certainly, we will benefit from this”**

## Part 2

### Conducive Environment for People Living with HIV

#### Desk Review

The desk review involved a systematic literature search, review of policies, laws and papers, and finally synthesis of all relevant documents related to stigma and discrimination. The desk review was organized in several principal sections corresponding to the following themes: Laws, Policies, Plans, Programmes and Committees, Management and Governance, Government and Non-Government support for People Living with HIV and contribution from people Living with HIV, and role of Positive Community Organizations.

#### Legal and Policy Frameworks for People Living with HIV in Sri Lanka

The objective is to describe the available laws, policies, programmes, plans and institutional structures and practical problems related to prevention of stigma and discrimination towards PLHIV.

The Government of Sri Lanka recognizes that HIV/AIDS is not only a public health concern but also a social and a developmental challenge, hence the importance of strengthening and scaling up preventive interventions including prevention of stigma and discrimination aimed at behavior development and behaviour change to maintain a low prevalence of HIV infection in keeping with the Sustainable Development Goals and also providing care and support for those infected and affected.

Although there is no specific law related to HIV in Sri Lanka, there are a number of supportive laws, policies, plans, guidelines, strategies and programmes in Sri Lanka which oversee and provide a supportive and conducive environment for the people living with HIV/AIDS.

#### Laws, Policies, Plans and Programmes

##### Sri Lankan Constitution

The Constitution of the Democratic Socialist Republic of Sri Lanka 1978, recognizes equal fundamental human rights for all. Article 12 indicates, that all persons are equal before the law and are entitled to equal protection of the law, and no citizen shall be discriminated against on the grounds of race, religion, language, caste, sex, political opinion, place of birth or any one of such grounds. Also, it recognizes that no person shall, on the grounds of race, religion, language, caste, sex or any one of such grounds, be subjected to any disability, liability, restriction or condition with regard to access to shops, public restaurants, hotels, places of public entertainment and places of public worship of his own religion.

Therefore, the Sri Lankan constitution permits accessibility of every person for Reproductive and Sexual Health services, irrespective of the marital status, age, sex or religion.

### **International Human Rights Instruments**

Sri Lanka is a signatory to international human rights instruments and that facilitates the human rights of citizens of Sri Lanka. Those are: Convention on the Elimination of All Forms of Discrimination Against Women in 1981, International Covenant on Civil and Political Rights in 1980, International Covenant on Economic, Social and Cultural Rights in 1980, Convention on the Rights of the Child in 1991, Convention on the Elimination of All Forms of Racial Discrimination in 1982 and Convention on the Rights of Persons with Disabilities in 2016. These international instruments have provisions for access to health services and education for all human beings without discrimination.

### **Health Policy**

The present health policy was available for the public with a vision of a healthier nation that contributes to its economic, social, mental and spiritual development and with guiding principles for a People Centred Health System in Sri Lanka. The Health policy was not available to the public till the early part of 2017. The present Health Policy of Sri Lanka was prepared in 1996 and now, after 20 years it has been replaced with an updated policy. This new health policy has been designed accordingly, in a systematic process carried out over three years (2014 - 2016) and has been approved by the cabinet on the 18<sup>th</sup> of July 2017. It addressed the five board strategic directions: Appropriate and accessible high quality curative care for all Sri Lankan citizens, Promotion of equitable access to quality rehabilitative care, Develop strategic partnership with all providers of health care, Ensure a comprehensive health system through better re-structuring , including HRM, and Strengthen service delivery to achieve preventive health goals.

Although, health issues and strategies related to specific diseases including HIV are not addressed in the policy, it ensures the need of a multi-sectoral approach to minimize the transmission of STI including HIV through its broader statements.

### **National AIDS Policy**

The National HIV/AIDS Policy was developed by the Ministry of Health in 2011 and was approved by the cabinet. The objectives of the policy were to prevent HIV and other sexually transmitted infections in Sri Lanka through effective strategies aimed at reducing sexual transmission, transmission through blood and blood products, and mother to child transmission, and to improve the quality of life of people infected and/or affected by HIV/AIDS through minimizing stigma and discrimination, and providing quality care and support. The policy has identified twelve strategic

areas for implementation in the country to achieve the expected objectives. These strategies are implemented at central, provincial and regional level, with close monitoring and evaluation of the central NSACP.

These strategies emphasize the importance of human rights of people living with HIV/AIDS. It includes promotion, protection, respect and measures taken to eliminate discrimination and combat stigma which provide an enabling environment to seek relevant services. These include the rights of everyone to life, liberty and security of the person, freedom from inhuman or degrading treatment or punishment, equality before law, absence of discrimination, freedom from arbitrary interference with privacy or family life, freedom of movement, the right to work (rights of the people living with HIV in the work places) and to a standard of living adequate for health and well-being including housing, food and clothing, the right to the highest attainable standard of physical and mental health, the right to education, the right to information which includes the right to knowledge about HIV/AIDS/STI related issues and safer sexual practices, the right to capacity building of the individual in dealing with this condition, the right to participate in the cultural life of the community and to share in scientific advancement and its benefit. However, steps shall be taken to prevent persons from wilfully and knowingly infecting other persons with HIV.

### **National Policy on HIV and AIDS in the World of Work in Sri Lanka (2011)**

The National Policy on HIV and AIDS in the World of Work in Sri Lanka has been developed by the Ministry of Labour and Labour Relations, with the help of the ILO in June 2010, for the safety of the workforce in Sri Lanka from HIV and AIDS, access for treatment and care, prevention of stigma and discrimination of PLHIV and protection of human rights of PLHIV who are in the work force. Sri Lanka has a workforce of nearly 7.6 million men and women in the formal and informal sectors. The workforce constitutes of a large group of people in the reproductive age group, who are sexually active, including the migrant workforce. The policy incorporates the 10 key principles of the ILO Code of Practice on HIV/AIDS and the world of work.

It ensures that all workers are entitled to statutory benefits, irrespective of their HIV status and continuity of employment, as long as they are medically fit to carry out present work or available alternative work. It also ensures relevant HIV and AIDS workplace policies, enabling environment, free of stigma and discrimination, care and support for PLHIV, maintain confidentiality, activities using evidence-based strategies, in order to reduce stigma and discrimination and no screening for HIV infection for job applicants or at job recruitment.

### **Prison HIV Prevention, Treatment and Care Policy**

National STD/AIDS Control Programme, together with Department of Prisons and other stakeholders, developed the Policy on prison HIV prevention, treatment and care. The activity has

been completed and it is ready to be sent for the cabinet approval. The main objectives of the Prison HIV Prevention, Treatment and Care Policy are as follows:

1. Prevent HIV among all prisoners and prison staff to ensure no new HIV transmissions occur in prison settings.
2. Enable prisoners to know their HIV status by promoting voluntary, confidential HIV counselling and testing and follow up.
3. Provide access to treatment, care and support for HIV, Hepatitis, Tuberculosis and STI.
4. Preserve and protect the rights of people living with and affected by HIV.
5. Ensure that the prison environment is conducive to promote and preserve the health of the prisoners and prison staff.
6. Conduct regular assessments to ensure the policy and programmes are effective.

This policy ensures the prison environment to be conducive to promote and preserve the health of the prisoners and prison staff, while protecting the rights of people living with and affected by HIV.

### **Other Supportive Policies**

The following policies ensure reproductive and health services for all and different target groups including PLHIV.

These are: National Maternal and Child Health Policy (2009), National Youth Policy (2014), National Policy and Strategy on Health of Young Persons, Sri Lanka National Migration Health Policy (2012). These policies support the provision of comprehensive, sustainable, equitable and quality services with gender equity basis.

### **National Health Strategic Master Plan - 2016-2025**

National Health Strategic Master Plan 2016 - 2025 consisted of Vol I - Preventive Health, Vol II - Curative Services , Vol III - Rehabilitative Services , and Vol IV - Health Administration & HRH. The Sustainable Development Goals relevant to the health sub-sectors are also indicated in this document. This master plan ensures the concept of universal health coverage (Equitable access to services by all clients, Equitable distribution of services to all clients, Quality service to all clients and Financial protection of all clients), assuring the clients' rights and social justice including sexual and reproductive health for all, in an equitable basis, in a safe and effective manner. This has been issued under the general circular of Ministry of Health under the number of 01-66-/2016.

### **National HIV Strategic Plan 2013-2017**

The National HIV Strategic Plan 2013 -2017 (NSP) has been developed based on the most recent epidemic data on HIV/AIDS and evidence based findings. These findings were put in to strategies, in consultation and partnership with all the sectors involved in the HIV response such as: various communities, civil society organizations, ministries and development partners.

The plan has five strategic directions contributing to the development of a healthy nation through Sexual Health promotion, emphasizing the importance of prevention, control and provision of quality services for sexually transmitted infections including HIV. Strategic direction five directly addresses the development of a conducive environment for PLHIV to reduce stigma and discrimination with several strategic activities. Other four strategies are directly or indirectly related to reduce stigma and discrimination of PLHIV. Currently, the NSACP is conducting stakeholder meetings to gather information to develop the new National HIV strategic plan.

### **National Condom Strategy 2016-2020**

The National STD/AIDS Control Programme developed a national condom strategy based on the key outcomes of the situation assessment of condom programming conducted during 2015. This was developed in line with the National AIDS Policy (2011) and other relevant policies: the Population and Reproductive Health Policy (1995), the National Maternal and Child Health Policy (2009), the National HIV Strategic Plan (2013-2017) and the National Strategic Plan on Maternal and Newborn Health (2012- 2016). The main aim of the national condom strategy is to ensure the availability of quality condoms of choice, either free of charge or at an affordable price, through an effective and responsive service delivery system, in order to provide quality sexual health services to the entire country. The priority of the national condom strategy is to ensure the availability of quality condoms throughout the country and to enhance the use of condoms among the key populations, vulnerable groups and PLHIV. It was developed under five thematic areas: Leadership and coordination, Supply and commodity security, Support systems (programming), Demand, and Access and utilization.

### **Gender Recognition Certificate for Transgender Community**

The Ministry of Health has recognized the importance of health of the transgender community. The Ministry of Health has established services in every hospital where there is a consultant Psychiatrist. When a transgender person requests services, the responsible Psychiatrists will provide the care which includes, assessment, counselling and issuing the gender Recognition Certificate. This certificate will be able to facilitate the obtaining of the birth certificate by changing the biological sex which is given at birth. This certificate could be issued only to those above 16 years of age and it will indicate the desired gender to be shown in the birth certificate. This certificate has to be certified by a consultant Psychiatrist and the head of the institution

working under the Ministry of Health. This has been further confirmed by the Ministry of Health General Circular Number- 01 - 34/ 2016 under the topic of 'Gender recognition certificate for transgender community'.

### **Global AIDS Monitoring**

The 2016 United Nations Political Declaration on HIV and AIDS includes the Fast-Track to Accelerate the Fight against HIV and to End the AIDS Epidemic by 2030, adopted at the United Nations General Assembly High-Level Meeting on AIDS in June 2016 and mandated UNAIDS to support countries in reporting on the commitments in the Political Declaration. This Political Declaration was built on three previous political declarations: the 2001 Declaration of Commitment on HIV/ AIDS, the 2006 Political Declaration on HIV/AIDS and the 2011 Political Declaration on HIV and AIDS.

The 2017 Global AIDS Monitoring is the first year after the transition from the Millennium Development Goals to the Sustainable Development Goals and also the first year of reporting for the HIV monitoring framework for 2016–2021. These guidelines reflect a review of the set of indicators used for global reporting in previous years and integrate indicators that monitor the treatment cascade. The WHO, UNAIDS and partners collaborated to compile the consolidated strategic information guidelines for HIV in the health sector, which have informed the Global AIDS Monitoring guidelines. These guidelines are designed to improve the quality and consistency of the data collected at the country level, enhancing the accuracy of the conclusions drawn at the national, regional and global levels. It identified several indicators including PLHIV treatment data and treatment facilities.

### **Sustainable Development Goals and End the HIV Epidemic by 2025**

The world is committed to end the AIDS epidemic by 2030, as a part of the Sustainable Development Goals (SDGs), with the support of all global partners by achieving zero new HIV infections, zero discrimination and zero AIDS-related deaths. Ending of the AIDS epidemic by 2030 requires all countries to fulfill Fast-Track indicators by year 2020. It is targeted to identify 90% of new HIV infections by year 2020. Sri Lankan National health authorities have taken initial steps to achieve zero HIV infections by year 2025, before the Global targets, with a five year advance of the global target. This was confirmed by the Director General's circular number 01-51/ 2016 of the Ministry of Health.

### **Favourable Supreme Court Judgement for People Living with HIV**

The Supreme court judgment given on SC.FR.No.77/2016 on 14.03.2016 states "The court also wishes to place on record that the state should ensure that the human rights of the people living



with HIV/AIDS are promoted, protected and respected and measures to be taken to eliminate discrimination against them". Further, the Supreme court placed on, recorded that the terms of Article 27 (2)(h) of the constitution states that it is one the directive principles of state policy to ensure the right to universal and equal access to education at all levels. This judgment was given in a court case against educational authorities, following refusal of admission of a grade one HIV affected child to a government school by education authorities.

### **Labour Tribunal Judgment for People Living with HIV**

In 2010, Wattala Labour tribunal has given a judgment to the owners of a company to pay two years' salary for one PLHIV who was dismissed from his company. This judgement further confirmed the right for employment of PLHIV.

### **Partnership with Human Rights Commission**

A 7-year-old affected child of a HIV positive woman went to a school in the 'Gampaha' district without any problem. The mother had them declared her HIV status and that her child is also living with HIV in a HIV preventive programme. Other parents had negative attitudes towards that child, and forced school officials not to take this child to school premises for education. The Human Rights Commission noticed this incident from media reports and intervened in this case. They initiated fruitful discussions with zonal education directors, the principal, teachers, parents and affected parties and solved this issue. The Human Rights Commission has taken the correct decision to protect the educational rights of the affected child. This child is currently attending the same school without any incidents of stigma and discrimination.

### **Legal Status of Condoms in Sri Lanka**

There are no restrictions for accessibility of condoms in Sri Lanka, and they could be purchased over the counter. Condoms are not manufactured in Sri Lanka. Condoms are listed under the medical device category in the essential drug list of the Ministry of Health. The Cosmetics, Devices and Drugs Act No. 27 of 1980 regulates (National Medicines Regulatory Authority ACT, No. 5 of 2015) and controls the manufacture, importation, sale and distribution of cosmetics, devices and drugs in Sri Lanka. Any person can keep condoms without any problem.

In 2015, the first ever condom situation assessment revealed that there is still a considerable amount of stigma behind condom users.

The Ministry of Health, Sri Lanka provides free condoms for both family planning and HIV prevention through health care service providers. The NSACP is responsible for the distribution of free condoms for STD clinic clients, in order to achieve the objectives of dual protection and prevention of developing ART resistance occurring from exchanging different virus strains among

positive people during sex. Clinic clients include people who seek treatment from the island-wide network and PLHIV. Further, the NSACP provides free condoms for KPs through principal recipient 2 under the GFATM. The Family Health Bureau is the national focal point of the family health programme and supplies free condoms to the community for family planning through 1800 island wide family planning clinics and through grass root level Public Health Midwives, based on the cafeteria method. The two NGOs in Sri Lanka (FPASL & Population Services Lanka) offer Sexual and Reproductive Health services, contraceptives and condoms free of charge through a limited number of centres. The commercial sector supplies condoms to the pharmacies, supermarkets, grocery shops, private hospitals and other retail places at a varying price range based on the quality of the condoms.

In the past, there was an instance of arrest of a woman with condoms in a public place. But, possession of a condom does not illustrate commission of any offence. Condoms are considered as medical devices and not as a proof of sex work. Condoms are listed as medical devices in the essential drug list in the Ministry of Health. However, some officers misinterpret the Vagrants' ordinance and 365 A laws and believe that condoms should not be distributed as they promote homosexuality which is illegal.

Another example is where, a few years ago, the police often considered condoms as a proxy for sex work, and used condoms as evidence to arrest FSWs or venue owners who distributed condoms. These unlawful arrests were reduced by continuous advocacy and through conducting master training programmes by the NSACP for Police officers island-wide, on prevention of HIV infection among KPs. However, sex workers who were arrested under the vagrants' ordinance often claim that they got caught because of condoms. Recent evidence showed that this type of arrests have been reduced after advocacy and master training programmes conducted by the NSACP.

Recently, Police Department has issued an internal circular to all police stations clarifying that condoms are a medical device and keeping condoms should not be produced as evidence to the courts when they produced sex workers under Vagrance Ordinance. Same circular highlighted that condoms are useful to protect against STI.

### **Restrictive Environment in the Legal Framework in the Sri Lankan Penal Code Vagrants Ordinance (1841)**

According to the Sri Lankan Law, sex exchanged for monetary or other benefits by an individual on his/her own will is not an offence, as far as a third party is not involved or benefited in that transaction. Adultery is also not a criminal offence, whereas, it is a marital offence. Adultery

means that the spouse practices sexual activities with another person besides his or her legal partner. There is no specific legal offence for sex work in private. However, many facets of sex work are prohibited under three ordinances, which were introduced during the British colonial rule: the Vagrants Ordinance, the Brothels Ordinance and the Houses of Detention Ordinance.

The section 7 of the vagrants ordinance which was introduced in 1841, indicates that any person in or about any public place soliciting any person for the purpose of the commission of any act of illicit sexual intercourse or indecency, whether with the person soliciting or with any other person, whether specified or not, shall be guilty of an offence, and shall be liable on summary conviction to imprisonment of either description for a period not exceeding six months, or to a fine not exceeding one hundred rupees, or to both .

### **Penal Code 365 and 365 A (1995)**

Same-sex sexual activity is criminalized under the article 365 of the Penal Code. This was first introduced during the British colonial rule, in tandem with the introduction of the British family law system of marriage, divorce, property and inheritance laws. The Penal Code (Amendment) Act No. 22 of 1995 changed the rape and sexual harassment laws, introduced incest, child sexual exploitation and trafficking into the Penal Code and raised the age of sexual consent. It also changed the language in the article 365 A, making “gross indecency between male persons” gender neutral, thus extending the law against same-sex sexual activity to women.

## **Management and Governance**

### **The National AIDS Council**

The National AIDS Council is the highest governing body and guides and monitors the inter-ministerial support extended to the national response to fight HIV/AIDS, under the chairmanship of His Excellency the President of Sri Lanka. This council has met once in the recent past.

### **The National AIDS Committee**

The National AIDS Committee is chaired by the Secretary of Health and includes representation from all the relevant stakeholders, and guides and monitors the national response to HIV/AIDS. The National AIDS Committee (NAC) co-ordinates activities on HIV/AIDS at the national level. The NAC comprises of several other ministry representatives, including Finance, Education, Justice, Social Services, Labour, Women’s Affairs, Tourism, Youth Affairs, Defence and Sports. It also has the representation from the Chamber of Commerce, UN Theme Group, non-governmental organizations, community-based organizations and people infected with HIV.

The NAC is supported by four technical subcommittees, namely; 1. HIV care, treatment, counseling, and laboratory services, 2. Policy, legal and ethical 3. Multi-sectoral (prevention) 4. Strategic information management 5. Information, education and Communication. Each subcommittee has separate terms of references, and provides necessary recommendations to the NAC. All these subcommittees represent the PLHIV community and it is a forum to voice out stigma and discrimination issues. This leads to solving problems without delay.

### **Country Coordinating Mechanism (CCM) - Sri Lanka**

Country Coordinating Mechanism, Sri Lanka (CCMSL) is the governing body for the use of Global Fund to Fight AIDS, Tuberculosis and Malaria for the HIV/AIDS prevention programme in Sri Lanka, and was established in year 2002. The CCMSL comprises of 25 members, with the Secretary to the Ministry of Health as the Chairperson, and meet once in two months to uphold the principles of national ownership and participatory decision making on HIV/AIDS prevention. The CCMSL is responsible for the coordination and development of suitable proposals through a public- private partnership, for the submission to the GFATM in order to obtain funds, and to oversee the proper utilization of such resources to mitigate the impact caused by HIV/AIDS, Tuberculosis and Malaria in Sri Lanka. The CCMSL is a National level multi sectoral organization comprising of the Government Sector, Private Sector, Academic/Education Sector, NGOs, Faith Based Organizations, Multilateral and Bilateral Development Partners, People living with diseases and Key Affected Populations.

### **National HIV Monitoring & Evaluation Framework 2017 – 2021**

The National M & E framework 2015 - 2017 includes several indicators based on the output, outcome and the impact levels. Indicators of monitoring and evaluation (M&E) framework provide the data needed to monitor progress and evaluate results to inform programme decisions and policy formulation. The plan spells out by programme areas, details of what information is needed including: indicators, data sources, collection methods, analysis, use and reporting, and feedback as well as the responsibilities of implementing partners and stakeholders.

This will be able to provide data to achieve the 2020 target on zero discrimination.

## **Government and Non-Government support for People Living with HIV**

### **National STD/AIDS Control Programme, Ministry of Health**

The National STD/AIDS Control Programme (NSACP) of the Ministry of Health, Sri Lanka is the focal point for the prevention and control of sexually transmitted infections (STI) including HIV. As a specialized public health programme under the Ministry of Health, the NSACP is responsible for coordinating, planning, implementation, monitoring and evaluation of the national response to

the control and prevention of STI including HIV. The National STD/AIDS Control Programme is responsible for coordinating, planning and implementation of the HIV National Strategic Plan in line with the AIDS Policy in the country, together with other stakeholders. There are 31 full-time STD clinics and 23 branch STD clinics in Sri Lanka as at the end of 2016. Of these STD clinics, 21 have the capacity to provide antiretroviral treatment (ART) services.

The headquarters of the NSACP including the central clinic is situated at 29, De Saram Place, Colombo 10, Sri Lanka. The Reference laboratory is also situated in the central clinic.

#### **NSACP together with peripheral STD clinics, is responsible for the following activities:**

- Screening and diagnosis of STI and HIV
- Comprehensive care , treatment and management for STI and HIV
- Treatment and management of opportunistic infections among PLHIV
- Counselling
- Family Planning services for clinic attendees including PLHIV
- Condom promotion and distribution
- Preventive services and necessary capacity building

#### **Screening, Diagnosis and Monitoring of HIV**

A public health and human rights-based approach is used for HIV testing along with counselling, correct results, quality assurance and linkage to care. Focused and strategic approaches are used for HIV testing. Provider initiated HIV testing is offered at STD clinics, Antenatal clinics, in the prison setup and in outreach programmes for key populations and other vulnerable groups by the government sector. In addition, a fair percentage of persons come to the STD clinics to uptake HIV tests on a voluntary basis. Every time, pre-test and post-test counselling are provided.

The laboratory services of the NSACP are provided by the National reference laboratory (NRL) and the peripheral laboratories for HIV and other sexually transmitted infections. The NRL is the apex body of the laboratory network. It provides technical guidance for diagnostic laboratory services of the country on HIV and STI and it is the reference centre for those services. One of the primary roles of the laboratory is to screen, diagnose and monitor the patients with sexually transmitted infections. The range of tests provided covers mainly the bacterial and the viral STIs. The private sector also provides a range of STI and HIV screening tests.

Screening tests are carried out in various levels by approaching the community with different strategies. This can be referral and self-referral to the STI clinics, antenatal screening, blood transfusion screening and outreach programmes. In addition, the private sector carries out

screening tests, based on the referral and the three Armed forces carry out HIV screening among service personnel. The screening tests used for screening of HIV (ELISA, particle agglutination and rapid strip tests) are performed on a routine basis in the NRL as well as in most of the peripheral STD clinic laboratories. The confirmatory test for HIV is performed only in the reference laboratory. In order to improve the case detection and diagnosis of HIV in the country, the NRL provides HIV confirmation services to the National Blood Transfusion Service and to private sector laboratories free of charge. The NRL is the only laboratory in the government sector, which performs the HIV viral load testing and CD4 testing for the management of people living with HIV. In addition, the haematological and biochemical investigations are carried out in the Colombo HIV clinic.

### **Treatment and Care for People Living with HIV**

The Sri Lankan government provides free of charge health services for all citizens. Twenty one clinics have the capacity to provide antiretroviral treatment (ART) services out of these 31 STD clinics. All service delivery points are equipped with specially trained staff who provide curative and preventive services. The central level of the NSACP networks with all these clinics to provide necessary guidelines and technical support.

National STD/AIDS Control Programme of the Ministry of Health is the sole provider of ART in Sri Lanka. Except for the National Infectious Diseases Hospital, Angoda, all other ART centres are situated within the STD clinics.

### **Services for People Living with HIV through the National STD/AIDS Control Programme**

#### **ART Treatment**

##### **Key Milestones in ART Supply and Services in Sri Lanka**

- The Ministry of Health started to provide free of charge ART for PLHIV in late 2004. The ART programme was initiated with the financial support of the World Bank in 2004 and was continued with the support of the Global Fund until 2015. The Ministry of Health has initiated the process to procure ARV drugs from 2016 through government funds. Treating all HIV infected persons with ART will lead to viral suppression and will halt the transmission. The NSACP took a decision to start ART for all diagnosed PLHIV irrespective of their CD4 count from 2016 to achieve zero new infections by 2030. **Treating all HIV infected persons with ART from government funds can be considered as a major milestone.**

The NSACP developed guidelines on the use of ART in 2016 and developed the guidelines on HIV care services and Opportunistic Infections management in 2017. Eligibility criteria for ART have been changed over the years, and since 2016, the country adheres to the “Test and Treat” policy (Treat all PLHIV) where everyone diagnosed with HIV is eligible for treatment irrespective of the CD4 count, viral load or the HIV clinical stage.

### **Other Services for People Living with HIV through the National STD/AIDS Control Programme**

- Treatment and management of opportunistic infections of PLHIV with necessary investigations
- Individual counselling
- Consultant psychiatrist from the Mental Hospital, Angoda visits once in two weeks to conduct a mental health clinic at the central HIV clinic for managing the PLHIV who need support
- The NSACP has good partnership with the National Programme for Tuberculosis Control and Chest Diseases (NPTCCD) in Sri Lanka. All newly diagnosed PLHIV and PLHIV with symptoms are referred to NPTCCD for screening to exclude TB.
- Family planning services are supplied for people who need them. All PLHIV who are sexually active are given free condoms from STD clinics for dual protection. The objectives are to prevent the STIs and HIV infection through sexual transmission, family planning measures and to prevent the exchanging of different virus stains among HIV positive people when they have sex with positive partners, to avoid ART drug resistance.
- The NSACP encourages consistent condom use, in conjunction with the additional contraceptive methods among PLHIV women who need family planning services. The objective of giving an additional family planning method is to avoid accidental unplanned pregnancies among women who have not achieved undetectable viral load. This will prevent the mother to child transmission of HIV. All these steps are taken following a series of counseling sessions.
- Fertility plan development for PLHIV. This will be done based on the couple’s requirement.
- Referral of PLHIV for other health services when necessary by assuring shared confidentiality
- Vaccination of Hepatitis B when necessary, for those who practice high risk behaviours
- Pap smear for female PLHIV at diagnosis, at six months and annually
- Nutritional counseling
- Linking with social services, when necessary
- Linking with child protection authorities, when necessary
- Arrange and refer PLHIV who need Isoniazid Preventive Therapy to Chest clinics

It is the policy of the ministry of health that all PLHIV requiring institutional care are to be managed at general wards. Based on this policy decision, the following procedures should be adopted. All PLHIV who need inward care facilities should be managed appropriately in the general wards (medical, surgical or any other specialty) in Colombo and in out-stations without stigma and discrimination. (General Circular No. 02/125/98)

### **Elimination of Mother to Child Transmission of Syphilis and HIV**

Almost all paediatric HIV infections were vertically transmitted in Sri Lanka. Currently, the existing integration of prevention of mother to child transmission (PMTCT) and maternal and child health services in Sri Lanka provide an opportunity to reach the pregnant mothers and thereby, early identification of HIV infection in pregnant women, provision of ART treatment delivery management and breastfeeding counselling, which are proven and evidence based strategies to reduce the risk of transmission. The comprehensive HIV component of the antenatal package in Sri Lanka consists of providing information on HIV and AIDS and its prevention, promoting and providing condoms, counselling on safer sex, referral for treatment of sexually transmitted infections, promoting HIV testing with pre and post-test information and counselling, referral to ART centers and male partner involvement. All Pregnant HIV positive women receive optimal care from a multidisciplinary team including an obstetrician, venereologist, paediatrician, anaesthetist, theatre sister, medical officer of health, midwife and a counsellor. Good coordination, confidential communication and shared responsibility are maintained. Guidelines on Management of HIV Infection in Pregnancy in Sri Lanka have been developed in year 2011.

All pregnant women with Syphilis or HIV should be provided appropriate services including institutional care, without stigma or discrimination. HIV screening of all pregnant mothers, based on the provider initiated method, has been adopted from 2014 island-wide. It was instructed by the circular on “The Programme for Elimination of Mother to Child transmission of Syphilis and HIV” (EMTCT of Syphilis and HIV) in Sri Lanka - No. 02 - 02/2014.

Currently, Sri Lanka has taken all steps to eliminate mother to child transmission of syphilis and HIV infection. It has been arranged and planned to achieve the required target by the end of 2017. The NSACP together with other stakeholders has taken steps and is working hard to achieve the targets. This has been further confirmed by Ministry of Health **General Circular Number- 01 - 59/ 2016** under the elimination of mother to child transmission of HIV.

Of the pregnant women attending government ANC clinics (349,259), 92.6 % (323,518) were tested for HIV by the government system (STD clinics). A total of 23 pregnant women were given care in 2016, and of these, 16 women delivered during the year. Services have been given to all 16 HIV exposed infants and none of the new-borns were infected with HIV.



All children diagnosed with HIV are registered at the STD clinics and are managed in collaboration with the paediatricians. According to the latest ART guidelines of the WHO, all children were offered ART from 2016.

### **Contact Tracing Process in HIV Clinics**

People can attend STD clinics by: self referral, referral by a health care personnel, referral by NGOs or any other referral methods.

A comprehensive sexual history including other relevant history will be obtained from the person who attends the STD clinic. It includes the number of partners, the frequency and type of sexual intercourse, etc. A detailed contact history will be obtained such as marital partner, regular partners, and non-regular partners, etc.

The patient referral method will be as follows, for contact tracing of HIV cases. The importance of screening the partner for sexually transmitted infections including HIV is emphasized and encourages the partners to bring their partners to the STD clinic. Health workers do not go to patients' houses for contact tracing and it is the responsibility of the patients to bring their partners to the clinic for screening and investigation. If the partner has not declared his/her HIV status to the partner, the medical officer divulges this information to the partner after taking informed verbal consent from the patient.

### **Condom Promotion and Family Planning Services for PLHIV**

The NSACP is responsible for the distribution of free condoms for all the STD clinics, in order to supply condoms for the clients including HIV positive people attending the island-wide network.

### **The Objectives of the Condom Programming of NSACP are as follows:**

- Prevent the STIs and HIV infection through sexual transmission
- As a family planning measure for the clients attending the STD clinics
- Prevent the exchanging of different virus stains among HIV positive people when they have sex with positive partners, to avoid ART drug resistance

The NSACP encourages consistent condom use, in conjunction with the additional contraceptive methods among PLHIV women who need family planning services. The objective of giving an additional family planning method is to avoid accidental unplanned pregnancies among women who have not achieved and undetectable viral load. This will prevent the mother to child transmission of HIV. All these steps are taken following a series of counseling sessions. Some of the family planning methods will be offered to PLHIV women who need family planning services. This will be further strengthened by the National Condom Strategy from 2016-2020. Further, the condom programme was strengthened by the Ministry of Health by issuing the guideline on condom education and demonstrations of condoms (**General Circular Number- 01 - 31/ 2017**).

## **Partnership of Multi-sectoral Government Agencies**

The NSACP is closely working with multi-sectoral agencies having the objective of prevention and control of HIV/AIDS and STIs among people who are working in non-health sectors and their respective target populations.

The Multi-sectoral unit of the NSACP oversees, coordinates and provides technical support for advocacy, capacity building, awareness and internalization of STI and HIV prevention activities of the multi-sectoral non health government institutions. The Multi-sectoral agencies provide technical support for advocacy, capacity building, awareness and internalization of STI and HIV prevention activities to multi-sectoral institutions. In addition to that, policy development and guideline development for relevant institutions is done by the national programme. The NSACP closely works with the Prison Department, Department of Police, Sri Lanka Air Force, Sri Lanka Army, Sri Lanka Navy, National Youth Services Council, Youth Corps, Ministry of Education, Ministry of Labour, Sri Lanka Foreign Employment Bureau, and Road Development Authority, in relation to the HIV/AIDS prevention. Each institution has different objectives under the National HIV strategic plan which tally with the National AIDS policy. The main objective is prevention and control of HIV/AIDS and STIs among people who are working in institutions and their respective target populations. All these training objectives are based on the development of capacity building in each respective institution through training of trainers. These trainings are based on training modules which include life skill based participatory training. The objective of the trainings for the Sri Lanka police is to develop a conducive environment for key populations to access preventive and curative health services.

## **Post Exposure Treatment for HIV**

Antiretroviral drugs for post exposure prophylaxis (PEP) are now available in all STD clinics island wide. In addition, measures have been taken to make PEP drugs available outside working hours by keeping a stock of drugs in a place that is functioning round the clock. PEP is prescribed to reduce the risk if somebody has been exposed to HIV. Accidental exposure to HIV can occur in the healthcare setting due to:

1. Accidental needle prick injury
2. Cut injuries during surgeries
3. Splashing of infected material to mucous membranes such as eyes, mouth, etc.
4. Exposure to infected material through non-intact skin

## **Supportive Circulars issued by the Director General of Health Services, Ministry of Health for People living with HIV**

The following circulars have been issued by the Director General of Health Services, Ministry of Health to all relevant authorities of the Ministry of Health. These circulars and guidelines directly and indirectly promote the wellbeing of PLHIV and prevention of HIV transmission. The following are some of the circulars issued by the Ministry of Health:

- Guideline for Education and Demonstration of Condoms - No. 01 - 31/2017
- Management of Healthcare workers following occupational exposure to blood and other body fluids and post exposure prophylaxis for HIV - No. 01 - 19/2017
- Programme for Elimination of Mother to child transmission of syphilis and HIV - No. 01 - 59/2016
- The Programme for Elimination of Mother to Child transmission of Syphilis and HIV (EMTCT of Syphilis and HIV) in Sri Lanka - No. 02 - 02/2014
- Providing Sexual & Reproductive Health (SRH) Services to Adolescents- No. 01 - 25/2015
- Change of Treatment for Gonococcal Infection - No. 02 - 173/2013
- Instructions on how to inform the HIV antibody test results to hospital wards/ clinics 2011
- Protocol for HIV testing for central STD clinics patients without a clinic file but only a OPD number (People who came for a voluntary test)
- Guideline for HIV testing among prison inmates
- Internal Circular- The strategic use of anti-retroviral drugs 2012
- Proper use of disposable sterile surgical gloves 2008 - No. MS - 01102008
- Guideline for the disposal of dead bodies - No. 02 - 130. 2008
- Management of health care worker exposures to HIV and recommendations for the post exposure prophylaxis - No. 02 - 36. 2001
- Management of patients infected with HIV - No. 02 - 125. 1998
- Surveillance and clinical case definitions for advanced HIV disease (AIDS) in adults and adolescents in Sri Lanka - No. 4521 – 1995
- Gender certificate
- Ministry of Health General Circular Number- 01 - 34/2016 under the topic of gender recognition certificate for transgender community

## **Prevention of HIV Transmission through Blood Transfusion**

The National Blood transfusion bill has been passed by the parliament in 2007 to provide an effective safe blood supply throughout the country. (*Gazette* of the democratic socialist republic of Sri Lanka, part 11. 21 September 2007, Supplement- issued on 24<sup>th</sup> Sept. 2007).

The National Blood transfusion services under the Ministry of health consists of 90 hospital based blood banks affiliated to 17 cluster centers based on their geographic location. In addition, the Defense Ministry and the private medical institutions provided the services. All blood samples are screened for transfusion diseases, including those at HIV government clinics as well as private hospitals. An important policy decision was made in 1988 to educate all blood donors on STI/ HIV/ AIDS, provide counseling for blood donors and screening all donated blood for HIV infection. As a result, since year 2000, no transfusion transmitted infections have been reported. However, gaps have been identified in the monitoring system of private sector blood transfusion services by the government.

## **Support Provided by Non-Governmental Organizations**

### **GFATM Programmes for Comprehensive Sexual Health Care Package for Key Affected Populations**

Prevention of HIV infection and STIs among key populations, and capacity building of PLHIV, had been recognized in the Round Nine (09) of the GFATM project (2011-2015). Presently, the new funding model of the GFATM Project (2016-2018) carries out the same interventions and it includes the same interventions of GFATM Round nine with more capacity building programmes. The NSACP is the Principal Recipient 1 (PR1) of the project grant, while the Family Planning Association of Sri Lanka is the Principal Recipient 2 (PR2). The FPASL is responsible for designing, implementing and monitoring the interventions for KPs, in technical partnership with PR 1. The principal recipient 2 carries out interventions for the key population groups. It is linked to the Sub-recipients and Sub-sub recipients to reach the key population groups and the majority of the interventions are targeted for them. Interventions for Key populations are received through the peer leader intervention model. All the key affected population groups receive an equal sexual health service package and the number of peers to be reached is different for each group. The FPASL has produced a procedure manual for the implementation, and this includes guidelines for providing sexual health services for MSM, sex workers and their clients, beach boys, and drug users. Therefore, guiding principles have been developed to carry out their efforts according to the standard procedures spelt out at the outset to minimize misunderstandings and performance gaps. These interventions also give special emphasis on overcoming self-stigma among the GFATM targeted groups.

### **The comprehensive sexual health package includes the following:**

- Identify and register FSW, MSM, DU and beach boys
- Conduct pocket meetings/support group meetings to provide basic information on HIV/STI
- Provide information on HIV prevention services
- Provide information on HIV testing services
- Provide information about HIV treatment services
- Condom demonstration
- Condom distribution
- Escort to the STD clinics

In addition, it supports three drop-in centers in Colombo for MSM, drug users and female sex workers.

### **Services for PLHIV under the GFATM Programme**

- GFATM supports to run three drop-in centers for three PLHIV networks.
- PLHIV are supported by an encouragement fee to attend the ART clinic at a monthly basis.
- Support is given to PLHIV networks to find the defaulters and to provide encouragement for escorting to the ART clinic.
- Capacity building programmes for PLHIV on legal awareness, health and well-being, and overcoming of self-stigma

### **Multi Country South Asia Global Fund HIV Project**

The Family Planning Association of Sri Lanka is the Sub Recipient for the Multi Country South Asia Global Fund project on HIV. Save the Children International in Nepal is the Principal Recipient of MSA Global Fund HIV Programme.

The overall goal of the programme is to reduce the impact of and vulnerability to HIV of men who have sex with men (MSM), and transgender people. The expected outcomes of the grant is to promote and protect the rights of Key Populations and to build a foundation to ensure that regional and country level networks continue to be an essential part of the HIV response and strengthen community systems to improve coordination with local governments and healthcare providers, deliver concentrated and quality capacity development support and provide technical assistance to ensure high intervention impact and sustainability. The MSA Global Fund HIV Programme was rolled out in October 2014 and is being implemented in Sri Lanka until the end of 2017.

## **Other Supportive Environment for People living with HIV**

### **Partnership of Media**

Both electronic and print media play a good role to prevent stigma and discrimination against PLHIV. The Ministry of Health conducts capacity building and sensitization programmes for media personnel. But, negative discriminative messages published indirectly were seen in some media during the past few years.

The responsibility and behavior of the media as stated in Article 28 of the constitution of Sri Lanka which casts a duty to respect the rights of others on reporting on matters related to HIV/AIDS, is emphasized.

### **Role of Positive Community Organizations and People Living with HIV**

#### **Involvement of People Living with HIV with Government Programmes**

The national programme is closely working with PLHIV in the formulation and implementation of the AIDS policy. The PLHIV represent themselves in many committees: National AIDS committee and five sub committees of the National AIDS committee. The PLHIV are involved in developing National HIV Strategic Plan, external reviews, etc. In addition, they support to find loss to follow up cases who are in the positive networks, and very closely support the preventive sector capacity building under the theme of positive telling for a productive life.

The PLHIV are engaged with some of the national events such as World AIDS Day events, and support the research team in national level relevant research projects.

There are three main positive organizations which are working for PLHIV and have a good partnership with the National STD/AIDS Control Programme.

### **Community Based Positive Organizations**

There are three positive organizations actively working for PLHIV in Sri Lanka. All three organizations have a common goal to provide welfare of PLHIV. Following are the key details of these organizations:

## Lanka Plus - Community Based Organization

<b>Name</b>	: Lanka Plus
<b>Category</b>	: PLHIV Organization
<b>Current membership</b>	: All island 350 representing all ethnic groups including key population groups and all age groups.
<b>Year Founded</b>	: 1997
<b>Founder</b>	: Deshamanya Dr. Kamalika Abeyrathna
<b>Address</b>	: No 55, Abhayarama Mawatha, Narahenpita, Colombo 05.
<b>Contact</b>	: 0112369069
<b>Hotline</b>	: 0770806666
<b>Email</b>	: <a href="mailto:lankaplus2001@yahoo.com">lankaplus2001@yahoo.com</a>
<b>Website</b>	: <a href="http://www.lankaplus.org.lk">www.lankaplus.org.lk</a>
<b>Facebook</b>	: <a href="https://www.facebook.com/lankaplus.official/">https://www.facebook.com/lankaplus.official/</a>

**Vision:** To enable those living with HIV/AIDS and the members of their families (i.e. mother, father, spouse, children, brothers and sisters) enjoy the rights and privileges of a normal citizen and transform their lives to a satisfactory standard.

**Mission:** Guiding and encouraging members through awareness improvement and consultations. Help them entertain their rights. Developing leadership skills through professional qualifications. Working towards changing government policies.

### Objectives:

- (a) Prevent the spread of HIV
- (b) Work towards making the HIV/AIDS community a force to be reckoned with
  - i. Enable those persons (living with HIV/AIDS) to have the human rights protection of the Human rights provisions of the national constitution.
  - ii. To lobby in respect of GIPA
  - iii. To establish a working relationship between the association (Lanka Plus) and other organizations and committees who plan and implement projects regarding those living with HIV/AIDS
- (c) Work towards continually sustaining and improving welfare and medical services for those affected.

(d) To strengthen the self-confidence of those living with HIV/AIDS and raise a voice against social stigma and discrimination.

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- i. To improve the image of those living with HIV/AIDS
- ii. To encourage those living with HIV/AIDS to lead socially productive and responsible livelihoods
- iii. To strengthen the relationships between those living with HIV/AIDS by providing for the exchange of information, attitudes and experiences among them
- iv. To provide opportunities for those living with HIV/AIDS to strengthen their inherent skills by obtaining training facilities.

**Description of services:** The organization is committed for the welfare of PLHIVs (People Living with HIV) in Sri Lanka. The organization is the premier HIV/AIDS organization in Sri Lanka and conducts activities at country level which includes awareness campaigns, positive speaking and provides medical advice, counseling, hospital visits, home visits, care and support and financial aid to its members and their children who are a part of the PLHIV community in Sri Lanka. The organization is funded by benefactions made by individual benefactors and donor organizations such as the Global Fund, Hope for Children, Family Planning Association of Sri Lanka (FPASL), AIDS foundation of Lanka, etc. The organization also maintains a drop-in centre to provide accommodation, meals and refreshments for members.

## Positive Hopes Alliance - Community Based Organization

<b>Name</b>	: Positive Hopes Alliance
<b>Category</b>	: PLHIV Organization
<b>Current Membership</b>	: 85 members
<b>Year founded</b>	: 2009
<b>Founder</b>	: Seven members collectively formed this organization
<b>Address</b>	: No. 479/2 Madawaththa road, Veyangoda
<b>Contact number</b>	: 0713586712 / 0771816674
<b>Hotline</b>	: Not available
<b>Email</b>	: <a href="mailto:su.pha2009@yahoo.com">su.pha2009@yahoo.com</a>
<b>Website</b>	: Not available
<b>Facebook</b>	: <a href="https://www.facebook.com/Positive-Hopes-Alliance-770080019772214/">https://www.facebook.com/Positive-Hopes-Alliance-770080019772214/</a>

### Vision:

To create an enabling environment for People and all other marginalized groups to live within society without fear of discrimination and stigma. To build capacity and sense of self-esteem especially for PLHIV.



## **Mission:**

## **Objectives:**

To promote manfully involvement of PLHIV in government, non-government and international programmes to eradicate the HIV and AIDS from Sri Lanka ensuring better service for the PLHIV for a dignified life with equal rights with other citizens.

To provide overall support for the PLHIV members of the alliance in the areas of physical, mental, livelihood and legal for a positive living through friendship, mediation referrals through development of linkages and networking, in a rights based programme approach.

## **Description of Services:**

Positive Hopes Alliance is a community Based organization working with and for People living with HIV in Sri Lanka. Positive Hopes Alliance (PHA) was established in 2009 with a total of 07 members. Currently, there's an approximate membership of 60 families and the numbers have been increasing. The PHA stands as a voice for all PLHIV in Sri Lanka and support their care, treatment literacy, positive living and counseling. It also assists in campaigning for national HIV prevention, skill development and economic empowerment of PLHIV. Also it focuses on sensitization workshops for the general public in order to create a society free of stigma and discrimination.

### Key Activities -

1. conducting a drop in center
2. Economic empowerment - Support self-employment (financial and training) for PLHIV
3. Counseling how to live positively (including treatment literacy, mental health, Nutrition)
4. Family visit (create self-help group) to PLHIV members
5. Hospital visit (to see the hospitalized persons with HIV and care and support for them)
6. Contribute to the national HIV prevention programme
7. Referral to job opportunities and social protection opportunities
8. Appear as an organization for PLHIV who got their human rights violated

## **Positive Women's Network**

<b>Name</b>	: Positive Women's Network
<b>Category</b>	: PLHIV Organization
<b>Current Membership</b>	: 513 members island wide, representing all ethnic groups
<b>Year founded</b>	: 2009
<b>Founder</b>	: Mrs. Princy Mangalika
<b>Address</b>	: 864/6, Thalagaha Junction, Gothatuwa New Town, Sri Lanka
<b>Contact number</b>	: 0114 54624/ 0719 184196
<b>Hotline</b>	: Not available
<b>Email</b>	: pwnprincy@gmail.com
<b>Website</b>	: <a href="http://www.pwnsrilanka.org/">http://www.pwnsrilanka.org/</a>
<b>Facebook</b>	: <a href="https://www.facebook.com/Positive-Womens-Network-Sri-Lanka-1627212434234322/">https://www.facebook.com/Positive-Womens-Network-Sri-Lanka-1627212434234322/</a>

**Vision:**

To be the organization with the best support and services for people living with HIV in the entire South Asia Region as well as in Sri Lanka.

**Mission:**

In order to uplift the lives of the people living with HIV, aim to better the living standards of PLHIV and their families by introducing them to sustainable methods of income generation, while protecting their human rights and caring for their physical and mental well-being. Also aim to increase the knowledge of HIV/AIDS among all sectors and thereby work towards reducing the prevalence of HIV in society.

**Description of Services:**

- Counselling
- Visiting families (need-based)
- Caring for those who have been stigmatized and separated from society until re-integration
- Forwarding to tests and obtaining medicine
- Providing medicine and tests not offered by hospitals
- Providing medicine and tests for side effects and opportunistic infections
- Programmes to raise awareness on reducing stigma and discrimination
- Media appearances (with photos)
- Training for self-employment
- Lending money for self-employment
- Providing resource training
- Need-based support at funerals
- Monthly awareness raising programmes
  - ◇ On Nourishment
  - ◇ On Sexual and Reproductive Health and ARV

**In-depth Interviews of Main Focal Points of Three Positive Networks****Views of the President of Positive Hopes Alliance**

It is a timely requirement to quantify the stigma level among PLHIV after the first stigma research was conducted way back in 2009. As a person who was directly involved in the previous stigma research, I am very happy that our members have actively participated in this important research project. It is highly beneficial for our community.

I personally feel that the stigma and discrimination have come down drastically when compared with the situation in 2009/10. I still feel that stigma and discrimination are common among “Men who have sex with men” group. They are facing challenges to seek medical care.

We as an organization, are always willing to help PLHIV and improve their status. Provision of self-employment opportunities and soft loan schemes will be used to empower them. Discrimination from family members can be minimized with proper counseling services. It is important to enhance the psychological support to uplift their standard of living. The relationship with the police sector has also improved a lot compared to the past experiences.

Dealing with media is a sensitive issue and I personally believe that we should adhere to a strict protocol/guideline before appearing in front of media. Media provides a good resource to convey our message to the general public, but it should safeguard our community rights, as well. Recent incidents reported from the education sector are a bit disappointing. But we should make use of these opportunities to convey our message to the public in a more effective way.

### **Views from the President of Positive Women's Network**

The situation on stigma and discrimination towards PLHIV has improved by leaps and bounds compared to the 2009/10 period. This was mainly due to increased awareness campaigns, island wide enhanced distribution of STD clinics and capacity building of the clinic staff. Although STD clinics have rapidly improved to provide services without stigma and discrimination, there is still more room for improvement for other sections of the hospitals. This includes in ward patients, clinic procedures, surgical procedures, etc. Patients get stigmatized in clinic queues and during the inward treatment process. This mainly occurs from nursing officers and minor staff members. Therefore, I would urge the government to conduct more awareness programmes for hospital staff members and sensitize them on HIV.

More attention should be made towards the private sector as the HIV testing conducted through the private sector is enhancing rapidly. A few of my organization members have experienced stigma and discrimination from people working in lab counters in leading private hospitals.

There are around 2000 identified people living with HIV in Sri Lanka and we should really appreciate the care provided for them by the government sector. On the other hand, PLHIV also should identify their social responsibility and act accordingly rather than going behind their rights only. Everybody should be responsible for themselves and it is the only way to minimize the spread of this infection. We cannot point out fingers to other sectors and institutions for discrimination. It is also the responsibility of us to create the conducive environment to minimize discrimination. It is disappointing to hear the incidents that are occurring at schools for children whose parents are HIV positive. I feel that these issues should be addressed at a higher level through national inter-ministerial discussions and appropriate policies should be implemented to stop harassments to innocent school children.

### **Views from the President of Lanka Plus**

People living with HIV are still not willing to expose themselves to the public due to stigma and discrimination in the society. They like to keep quiet and live a normal life. They strongly believe that problems may arise if they disclose their HIV status openly. I personally think that the society is not mature enough to understand the feelings from the standpoint of people living with HIV. It is relatively less within the health sector, but there is no guarantee of the reaction/ response from other sectors towards PLHIV.

Comprehensive attitudinal change is necessary within the society to move forward. The responsibility should be taken by everyone including health sector and PLHIV organizations. Awareness should be raised with a special emphasis on modes of transmission and non-modes of transmission of HIV targeting the general public. The situation has improved very much compared to past 10 years and I am very much optimistic to drive our community towards a society with zero discrimination in the near future.

## Conclusions and Recommendations

The following conclusions were drawn from the study.

1. 74% of the respondents have obtained secondary school education and 66.7% of the respondents were currently employed, while 21.3% of the respondents are engaged in full time employment and many of the participants (66.3%, n=57) were engaged in skilled occupations.
2. One fifth of the respondents (21.3%) were identified as belonging to the key population group of men who have sex with men and one-third of the study population (33.3%) has a history of migration work, which is also identified as a vulnerable group.
3. Thirty five participants (23.3%) had a history of a chronic disease except HIV and most of them prefer to go to a government hospital for treatment.
4. Considerable number of respondents (9.3%; n=14) have not declared their HIV status to their husband/wife/partner. HIV positive people have found it easiest to share their status with other people living with HIV (80%). Very few participants (3.3%) have disclosed their HIV status to healthcare workers who do not belong to STD clinics.
5. 10% of the respondents reported verbal harassment related to their HIV status out of the total study sample during the last 12 months. Verbal harassment was commonly committed by the respondents' immediate family members and relatives during the last 12 months.
6. 4% of the respondents reported physical assault related to their HIV status during the last 12 months. Physical harassment commonly occurred from their immediate family members and close relatives including partners, parents, and children during the last 12 months.
7. Only 6% (n=9) of the study population indicated that the loss of job or loss of another source of income during the last 12 months was due to their HIV status.
8. The Majority of the study participants stated that the reported low levels of stigma and discrimination for HIV status are due to non-disclosure of their status.
9. Almost half of the study participants (47.3%) have undergone voluntary HIV testing and 49.3% of the respondents have received both pre and post-HIV test counseling.
10. 12.7% of the respondents claimed that they have actual knowledge of healthcare workers disclosing their status without consent and 23% of the respondents were not sure as to how confidential their medical records related to the HIV status remain.
11. 97.3% of the respondents had access to Anti-Retroviral Therapy and the rest (2.7%) were currently undergoing investigations prior to initiation of ART.

12. 98.7% had a constructive discussion with a healthcare professional about sexual and reproductive health during their consultations.
13. Access to opportunistic infection medication was seen among 84% of the study participants.
14. Almost half of the participants have experienced internal stigma: self-blame (46.7%) and shame (42.7%) are the most prevalent feelings, followed by guilt (31.3%).
15. Only 10 participants (6.7%) have confidence in seeking legal redress for violating human rights of people living with HIV, while 37 (24.7%) believed that PLHIV's will be subjected to further stigma and discrimination through seeking legal redress for violation of their human rights.

### **Recommendations for the Multi-Sectoral Agencies Including Health Sector**

1. Conduct advocacy meetings to relevant stakeholders to disseminate results of the stigma report.
2. Raise public knowledge and awareness about HIV/AIDS by providing accurate and comprehensive knowledge to prevent and eliminate stigma and discrimination against PLHIV
3. Educate people living with HIV for positive living and provide support to increase self-reliance
4. Arrange psychological/ psychiatric counselling facilities for all PLHIV to minimize their internalized stigma levels.
5. Educate and empower PLHIV and key population groups regarding their rights and responsibilities with special emphasis on reporting human rights violations.
6. Further capacity building should be implemented to all healthcare providers attached to the STD clinics.
7. Capacity building should be done to all healthcare providers on disclosure concerns, stigma prevention and human rights of PLHIV. Further trainings should be arranged to healthcare workers at STD clinics.
8. Advocate political leaders regarding the rights of people living with HIV to enhance a supportive environment.

## Policy Level Recommendations

1. Empowerment and strengthening of legal system officials (judiciary, law enforcement officers) regarding human rights of the PLHIV.
2. Involvement of PLHIV for the policy making process and effective implementation procedures.
3. National AIDS committee and the legal subcommittee at NSACP should forward their suggestions to prevent and eliminate stigma and discrimination and to initiate necessary policy implementations.
4. The existing law in the country should be further strengthened to ensure educational rights for children living with HIV by facilitating internal circulars within the educational sector.
5. HIV testing and management protocols should be enforced within private hospitals to ensure quality care by maintaining the confidentiality of PLHIV.

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