

The People Living with HIV Stigma Index Nepal 2011



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Foreword

It is our pleasure to share with you the first-ever National Stigma Index Study Report in Nepal. The report will provide additional evidences to inform the national response to HIV and AIDS.

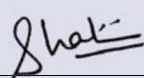
Although stigma and discrimination against people living with HIV (PLHIV) is a gross violation of their human rights, it also acts as a major barrier in providing them access to care, treatment and support services. Stigma and discrimination against PLHIV is also a violation of the “Declaration of Commitment on HIV/AIDS,” which was ratified by the United Nations General Assembly, and to which Nepal is a signatory.

The present study has been designed to ensure representation of Nepalis living with HIV across the development regions, genders, including the third gender, and various sub-groups of key affected populations, such as FSWs, IDUs and MSM/TG people. The report of the National Stigma Index Study comes at an opportune time when the National Strategic Plan (NSP) 2011-2016 for Nepal is under formulation, and it will definitely be useful in providing a necessary evidence base for informing the development of the National Action Plan on HIV and AIDS and the next NSP.

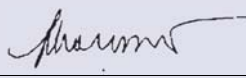
As highlighted by the findings of the report, stigmatization of and discrimination against PLHIV continues to exist in various forms: at the individual (self) level, from their families and/or society as well as in different spheres of life, such as whilst applying for employment, at the workplace, in accessing healthcare services and during religious ceremonies. These prejudices and social injustices against PLHIV call for an integrated programme to eliminate any form of stigma and discrimination. The vision of three zeros—zero new infections, zero discrimination and zero AIDS-related deaths—cannot be achieved without addressing this critical issue.

This report is a collaborative study by FPAN, UNAIDS and NAP+N. We congratulate all those involved in the study and commend their contribution in compiling this report and generating the evidences that will strengthen the national response to HIV/AIDS and enable the creation of an environment in Nepal where the human rights of PLHIV are honoured.

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We extend our heartfelt gratitude to International Planned Parenthood Federation/Department for International Development (IPPF/UKAid) for entrusting us with this important study. We are particularly grateful to Ms. Sangita Khatri, HIV Program Manager, FPAN for leading and coordinating the study under a challenging environment and for the substantive support provided by her throughout the study. We also acknowledge the support of Liz Tremlett from IPPF Central Office and the HIV unit of IPPF's South Asia Regional Office.

This research would have been impossible without support from the Center for Research on Environment Health and Population Activities (CREHPA), particularly that of Mr. Dinesh Dhungel and his team, Ms. Pragya Shrestha and Mr. Bishnu Prasad Dulal. We are grateful to NAP+N, an umbrella organization of people living with HIV (PLHIV) in Nepal for conducting the fieldwork for this study and in particular to Basanta Chhetri, who coordinated the entire fieldwork.

We extend our heartfelt gratitude to the researchers who gave up their time and energy to participate in the study as well as the study participants who received the study team with understanding and patience and devoted time to share their insights and the challenges that they face everyday due to their HIV status. The study would not have been possible without their voluntary participation.

Finally, we would like to acknowledge the contribution of Tanya Sarin for editing this report.

Abbreviations and Acronyms

ADRA	Adventist Development Relief Agency
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral treatment
BDS	Blue Diamond Society
CABA	Children Affected by AIDS
CREHPA	Center for Research on Environment Health and Population Activities
DFID	Department for International Development
FHI	Family Health International
FPAN	Family Planning Association of Nepal
GNP+	The Global Network of People living with HIV/AIDS
HIV	Human Immunodeficiency Virus
ICW	International Community of Women with HIV/AIDS
IEC	Information, Education and Communication
IDU	Injecting Drug User
IPPF	International Planned Parenthood Federation
FSGMN	Federation of Sexual and Gender Minorities Network
FSW	Female Sex Worker
JMMS	Jagriti Mahila Maha Sangh
KP	Key Populations
MoHP	Ministry of Health and Population
MSM	Men who have Sex with Men
NAP+N	National Association of Peoples Living with HIV/AIDS in Nepal
NCASC	National Center for AIDS and STD Control
NFE	Non-formal education
NFWLHA	National Federation of Women Living with HIV/AIDS
NHRC	Nepal Health Research Council
NSP	National Strategic Plan
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
SCN	Save the Children-Norway
SITWG	Strategic Information Technical Working Group
SLC	School Leaving Certificate
SRH	Sexual and Reproductive Health
TG	Transgender
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDP	United Nations Development Program
VCT	Voluntary Counselling and Testing

Executive Summary

This People Living with HIV Stigma Index study is the first study of this kind that has been conducted on such a comprehensive scale among people living with HIV (PLHIV) in Nepal. HIV and AIDS-related stigma and discrimination exists worldwide and varies only in intensity across countries, communities and individuals. HIV stigma and discrimination together have long been recognized as one of the main obstacles to the prevention, care and treatment of HIV and AIDS. Stigma remains the primary barrier to public action; on a personal level, it can make individuals reluctant to access HIV testing, treatment and care. The PLHIV stigma index aims to collect information regarding the experiences of PLHIV related to stigma, discrimination, knowledge of their rights and violation of those rights. Currently, over 40 countries across the world, including Nepal, have joined this research.

The PLHIV Stigma Index is a community research and advocacy initiative that has jointly been developed by the International Planned Parenthood Federation (IPPF), Joint United Nations Program on HIV/AIDS (UNAIDS), The Global Network of People living with HIV/AIDS (GNP+) and The International Community of Women living with HIV/AIDS (ICW).

Family Planning Association of Nepal (FPAN)—a member association of IPPF—was responsible for the implementation of the PLHIV Stigma Index in Nepal. The National Association of People Living with HIV/AIDS in Nepal (NAP+N), an umbrella organization of PLHIV in Nepal, conducted the interviews, and the Center for Research on Environmental Health and Population Activities (CREHPA), a national research organization, was responsible for the research design, determining the sample size, data processing of the completed interviews and report writing.

METHODOLOGY

PLHIV conducted the stigma index interviews wherein information regarding the experiences of PLHIV in relation to stigma and discrimination in and variety of settings including health, social and work and violation of rights was obtained. The data was collected through one-on-one interviews. The targeted sample in each district was selected by applying *systematic random sampling* to the updated list of disclosed PLHIV (sampling frame) maintained by NAP+N for each of the study districts. The study successfully interviewed 848 PLHIV, which included 402 males, 419 females and 27 transgender people. The fieldwork for the study was completed in May–June 2011.

KEY FINDINGS

• *Background Characteristics*

Age: A majority of the PLHIV (65%) participating in this survey belonged to the age group of 25-39 years. Very few respondents (5%) were under the age of 25 years. Thirty per cent of the adult respondents were aged 40 years and above.

Education: Relatively, females had lower levels of education than males and transgender people. A considerable number of female respondents (44%) had never attended school. Approximately 15 per cent of the females, 16 per cent of the transgender people and 40 per cent of the males had completed their lower secondary/secondary education. A significant number of transgender people (64%) had completed their School Leaving Certificate (SLC) course and higher level of education, whereas only a small percentage of males (10%) and females (4%) had completed this course and higher level of education.

Employment status: One-sixth of the respondents (17%) were unemployed. Among the employed respondents, a majority of the males (30%) and females (47%) were engaged in agriculture/animal husbandry, followed by service (jobs at private or non-government organizations) (27% male and 19% female) and business (10% male and 9% female). Among the transgender population, 33 per cent were involved in service and 44 per cent belonged to the other category (i.e. student/working in India/sex worker). Only four per cent of the transgender people were involved in agriculture.

Place of residence: Approximately two-thirds (63%) of the respondents were reportedly residing in rural areas. As compared to males (58%) and transgender people (56%), a higher percentage of females (69%) were residing in rural areas.

Development regions: A greater number of PLHIV were covered from the Western development region, because the highest number of districts were considered from this region, whereas the number of PLHIV was low in the Mid-Western region, because only two districts were covered in this region.

Living status: A total of 76 per cent of the male, 47 per cent of the female and 19 per cent of the transgender respondents were married and living together. Although very few males were separated/divorced (1%) or living alone (2%), 8 per cent and 11 per cent of the females were separated/divorced and living alone, respectively. None of the interviewed transgender people was separated/divorced or living alone. A vast majority of transgender (96%) and male respondents (84%) and approximately half of the female respondents (46%) claimed that they were sexually active.

Less than half of the respondents (44%) were diagnosed with HIV in between 3-5 years prior to survey, one-third of the respondents (33%) were diagnosed with HIV more than 5 years ago and less than one-fourth (21%) had been diagnosed with HIV within the last 1 year. Very few respondents (4%) reported disability besides the HIV infection. Among these, more females than males were suffering from physical disability (47% vs. 39%) and blindness (40% vs. 28%), whereas more males than females were suffering from hearing impairment (33% vs. 13%).

According to the categorization of the respondents by their vulnerability, 23 per cent (195) of the respondents belonged to the migrant group and 20 per cent (165) belonged to the injecting drug user (IDU) group. Thirty-one per cent (260) of the respondents indicated that they had never belonged to any of the key population (KP) groups.

- ***Experience of Stigma and Discrimination due to HIV***

Half of the respondents (50%) had experienced at least one event of stigma and discrimination in the past 12 months, the most frequent event being “gossiping” (as reported by 36% of the respondents). As compared to male and female respondents, a higher number of transgender respondents reported experiencing discrimination and stigma in the form of psychological pressure by wife or partner, sexual rejection, discrimination by other PLHIV and discrimination/hatred by wife or partner or any other household member. Moreover, the results indicate that the society pressurizes PLHIV by barring them from attending religious functions and social gatherings. As compared to male and female respondents, transgender respondents reported slightly fewer experiences of exclusion from social gatherings/activities and religious activities. Approximately one out of ten respondents had experienced discrimination by other PLHIV.

Variation in the proportion of the stigma and discrimination faced by respondents in terms of their occupation, place of residence (urban or rural) and level of education was low. However, the younger population was found to be more prone to stigma and discrimination as compared to older age groups (i.e. people aged over 40 years).

The PLHIV who had been diagnosed less than one year ago (37%) were less likely to experience stigma and discrimination as compared to those who had been diagnosed more than one year ago (>49%). A greater percentage of PLHIV who were IDUs (60%) and female sex workers (FSWs) (68%) had experienced stigma and discrimination than those who were Migrants (50%), men who have sex with men (MSM) (53%) and others (Refugee/Indigenous groups) (50%).

The most common reason cited for HIV-related stigma and discrimination was, “people are afraid of acquiring HIV infection from me” (53%) followed by “ignorance about HIV transmission” (49%). Almost one-fourth of the respondents were uncertain regarding the reason that they experienced HIV-related stigma and discrimination.

Nearly one-third of the respondents who were compelled to change their place of accommodation or were denied rental accommodations and those who were reportedly refused employment during the 12 months prior to the survey said that this was due to their HIV status. The study found that discrimination of PLHIV at educational institutions was low, with only 2.2% of the PLHIV and 2.6% of the children of PLHIV being dismissed, suspended or prevented from attending any educational institution.

The results of the study indicated that health personnel were somewhat involved in discriminating against and stigmatizing PLHIV. Respondents reported instances of denial of health services including dental care (7%) and denial of family planning services (3%) and sexual and reproductive health services (2%) by health workers. A few respondents believed that their medical/health records were not kept confidential.

- ***Self-stigma***

Approximately nine out of ten respondents (87%) had experienced at least one feeling of self-stigma, such as shame, guilt, blaming others, low self-esteem, suicidal thoughts and willingness to be punished. The feelings of self-stigma were slightly lower among female (81%) than male (92%) and transgender (100%) respondents. Moreover, it was found that self-stigma was high among residents of both urban (90%) and rural (87%) areas. Similarly, the results indicated that such feelings were more common among young respondents who were below the age of 25 years (98%) than those belonging to older age groups.

Most of the transgender respondents (93%) and male (87%) respondents blamed themselves for becoming infected, whereas a large number of female respondents (57%) blamed others for acquiring the infection. Guilt, shame and low self-esteem were the most prevalent feelings among transgender and male respondents. Furthermore, a larger percentage of transgender respondents (56%) experienced suicidal feelings, as compared to female (17%) and male (11%) respondents.

Self-stigma had also led respondents to adopt various measures, such as “not having additional children” (males: 60%, females: 62% and transgender people: 52%), “not to get married” (males: 30%, females: 47%, and transgender people: 77%), “becoming celibate” (males: 7%, females: 35%, transgender people: 7%) and “stop attending social gatherings” (13% of the respondents). One out of ten or 11 per cent of the respondents decided not to visit local clinics and 7 per cent decided not to visit hospitals when they needed treatment.

- ***Rights, laws and policies***

The stigma index referred to an international agreement of 2001 called “Declaration of Commitment on HIV/AIDS.” A quarter of the respondents (26%) had heard of this declaration and nearly two-thirds of them had ever read or discussed the content of this document.

Respondents residing in the Far-Western and Western regions were less aware about this declaration (16%).

Some of the violation of rights that were experienced by the respondents were as follows: denial of health/life insurance (12%), forceful testing of their HIV status during medical examination (9%) and disclosure of HIV status to enter another country (6%). As compared to males and transgender people, a higher proportion of females experienced a violation of their rights.

Among those whose rights were abused, 14 per cent (N = 17) attempted to seek legal redress. Of these, the matter of rights violation of 35 per cent of the respondents has been resolved, that of 23 per cent is still in process and 46 per cent have failed to achieve any resolution. One respondent out of ten (11%) attempted to protect their rights with the support of government employees and a similar proportion (10%) sought the help of politicians to protect their rights.

The primary reason provided by those who chose not to take any action against a violation of their rights was a lack of financial resources (29%). Other reasons included long bureaucratic process (5%), fearful of the consequences of taking action (7%) and a lack of faith in the possibility of success (5%).

- ***Effecting change***

One-third of the respondents (36%) encountered situations during the 12 months prior to the survey when they had to educate someone who demonstrated discriminatory behaviour against them. A considerable proportion of transgender respondents (56%) and approximately half of the respondents (47%) of the Eastern region reported such incidences. Most of the PLHIV were also aware of the organizations, such as PLHIV support groups and networks, local non-governmental organizations, and human rights organizations, that they could approach if they experienced discriminatory behaviours. A few PLHIV had sought the help of these organizations to resolve the issue of stigma and discrimination.

It is also common for PLHIV to support other PLHIV. During the 12 months prior to the survey, over half of the respondents (54%) had provided support to other PLHIV. This support was in the form of emotional support (92%), referral to services (42%) and physical support (providing money, food and necessary information) (29%). A number of respondents also felt that they had the power to influence legal matters that affect the lives of people living with HIV (51%).

- ***HIV testing, disclosure and treatment***

The primary reason for HIV testing for PLHIV was to ascertain their status (32%). Males

were much more likely than females to be referred for testing when they exhibited HIV-related symptoms (24% vs. 10%), whereas females were ten times more likely than males to be referred for testing when their partner had tested HIV-positive (41% vs. 4%). The HIV status of a considerable proportion of the transgender people was tested in the course of employment.

A majority of the respondents (81%) voluntarily took the decision to be tested for HIV. Females were more likely than males to be pressured for an HIV test (9% vs. 5%). A higher proportion of the respondents in the Central region were reportedly tested for their HIV status under pressure (17%) and without their knowledge (14%). Approximately half of the respondents (49%) received both pre- and post-counselling. One-sixth (16%) of the respondents received no counselling.

Almost all the respondents had voluntarily disclosed their status. The majority, at 70%, had disclosed their status to other PLHIV, followed by health workers (55%), partners/spouses (50%) and other adult family members (50%). Fourteen per cent felt pressure to disclose their status from other individuals living with HIV, whereas ten per cent felt such pressure from people not living with HIV. Males felt more pressure than females for disclosing their HIV status. One out of every eight respondents (12%) reported that healthcare professionals disclosed their HIV status without their prior consent.

After the disclosure of their status, positive reactions were observed in most cases. It was found that a large majority in the PLHIV community (74%) exhibit supportive behaviour toward people who disclose their HIV status. Although the study found that family members and spouses/partners also extended support on knowing the person's HIV status, a significant number of respondents faced discrimination from their family members, friends/neighbours and partners/spouses. Disclosure of HIV status was an empowering experience for both females (49%) and males (41%).

At the time of the survey, two-thirds (66%) of the respondents were taking antiretroviral treatment (ART), and approximately half (48%) were taking medications to prevent opportunistic infections. Although the percentage of PLHIV respondents taking ART was 50 per cent or higher in all regions, it was highest in the Far-Western (77%) and Western regions (74%). Out of the proportion of respondents who were currently not on ART, 67 per cent were confident that when they would need ART, it would be easily and readily available to them.

- ***Having children***

Most of the respondents (82%) have children and 15 per cent of their children are living with HIV. The children living with HIV is reportedly higher in the Far-Western region (19%). Regarding the reproductive options, approximately half of the respondents (48%) received counselling regarding their reproductive options. One in three (32%) respondents was advised by healthcare providers not to have children. A small proportion of the respondents had

reportedly been coerced into sterilization (2%) and some female respondents had reportedly been coerced into pregnancy termination (2%) by health personnel.

Of the female respondents who were HIV-positive at the time of their pregnancy, only 10 per cent received ART to prevent mother-to-child transmission. Of the others who were not taking ART, 16 per cent were not aware about such treatment, 8 per cent had no access to treatment and 65 per cent were not aware of their HIV status at the time of pregnancy.

- **Recommendations**

The findings highlight the need for **greater awareness** about HIV and its transmission, and the consequent need for awareness raising programs for both children and adults, as well as advocacy programs for reducing HIV-related stigma and discrimination within families and in work/employment settings.

PLHIV support groups and networks are often the first source of information, counselling, treatment and care as well as crucial enablers of status disclosure. Therefore, supporting them and building their capacities is important. Furthermore, at the macro level, the legal environment must be made more conducive for PLHIV through the development of comprehensive laws that improve the legal and policy responses to HIV-related stigma and discrimination.

The report also draws attention to the necessity of strengthening policy and practice for reducing stigma and discrimination against PLHIV in healthcare settings and of ensuring adherence to standards, such as voluntary counselling and testing (VCT), informed consent, and confidentiality, while performing HIV tests. **Training programs for healthcare professionals** need to be conducted regularly in order to sensitize them to the varied needs of PLHIV. Further, there is a need to increase the availability and ease of access to ART and treatment of opportunistic infections.

In terms of reproductive options, gaps in counselling and prevention of transmission, response needs to be strengthened through comprehensive package programs and **prevention of mother-to-child transmission (PMTCT)** services in Nepal. Furthermore, provision for easy access to ART including treatment of all types of opportunistic infections must be made available.

Finally, although the PLHIV Stigma Index showed some evidence of prevalent stigma, additional research to determine the specific areas and its causes is required.

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Chapter 1

Introduction

1.1 Background

Various studies conducted worldwide on Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) suggest that there has been progress in creating awareness about the transmission and prevention of this chronic disease among the general population. Furthermore, with the availability of antiretroviral drugs, the longevity of people living with HIV (PLHIV) has increased. However, the biggest challenge faced by PLHIV, organizations and individuals working towards curbing the adverse effects of the HIV epidemic is combating the rejection and discrimination of PLHIV by the society, that is, dealing with stigma that invariably accompanies HIV.

In simple words, stigma can be defined as a token of disgrace for not adhering to the established societal norms and values. Although HIV -related stigma and discrimination is prevalent worldwide, it varies across countries, within communities and among individuals. The stigma and social prejudice against PLHIV from family and society is prevalent in almost all parts of the world, varying only in terms of the intensity of the injudicious behaviour. In countries where sexuality is a social taboo, prejudice and discrimination towards PLHIV is more intense. HIV-related stigma is usually associated with immoral behaviour and people associated with drug use, sex-work and same-sex and transgender sexual practices usually face additional stigma. The vulnerability towards discrimination is more pronounced among females, children and marginalized and poor communities.

PLHIV often face judgments and criticism from other people. They are deprived of their basic human rights of dignity, respect and involvement in communities. They face discrimination at workplace, education and healthcare facilities, religious, political

and social gatherings, and they are often subjected to verbal abuse and violent physical treatment. Moreover, the partners, children and other family members of PLHIV are under the constant scrutiny of society and face discrimination. All these factors have serious implications on the overall mental and physical well-being of PLHIV.

The dire need to address the emotional, mental and physical trauma faced by PLHIV due to stigma cannot be overlooked. The negative effects of constant depression and the psychological tension owing to the injudicious and discriminatory behaviour of other people and internal stigma can exacerbate their illness. Moreover, other effects of social stigma, such as unwillingness to be tested for HIV, non-disclosure of their HIV status, avoiding the practice of safe sex and not accessing health care, can have serious implications.

It is important to have an indicator that can quantitatively assess the intensity of the social stigma that PLHIV face in the community. An accurate assessment of the social discrimination owing to HIV can effectively enable stakeholders, organizations and policy makers to help lessen and eventually eliminate the social impact of this epidemic.

1.2 HIV-related Stigma and Discrimination in Nepal

Since Nepal's first reported cases of HIV in 1988, the epidemic has evolved from a "low prevalence" to a "concentrated epidemic," especially among the key populations (KP), such as sex workers, IDUs, MSM, and seasonal labour migrants. National estimates (2009) indicate that approximately 63,528 adults and children are infected with HIV in Nepal with an estimated prevalence of approximately 0.39 per cent among the adult population (15-49 years old), a majority of

who are not aware of their infection (National Center for AIDS and STD Control/Ministry of Health and Population (NCASC/MoHP, 2011)). As of March 2011, there were 17,556 officially identified HIV-positive¹ cases in the country, with the reported number of infected males being approximately twice (11,365) as many as infected females (6,191).

In order to assess the disease burden of HIV, the country is geographically divided into four epidemic zones: (1) Kathmandu Valley, (2) Highway districts, (3) Far-Western hills (seven hill districts of the Far-Western development region) and (4) Remaining Hill Districts. A high proportion of migrants in the Far West have added a new dimension to the epidemic. Factors such as the high rate of seasonal labour migration and mobility, unsafe sex practices, poverty, low levels of education and literacy, trafficking of females, increasing sex trade and the low status of females have contributed to the rapid spread of HIV. The growing numbers of PLHIV makes the task of mitigating the spread of HIV challenging, as does denial, stigma and discrimination that surround HIV.

The extent of information on the HIV-related stigma and discrimination in Nepal is rather limited. A 2005 study that evaluated the voluntary counselling and testing (VCT) linkage and the referral project of Adventist Development Relief Agency (ADRA) Nepal revealed that fear of stigma and discrimination and associated problems were the potential barriers to disclosure of their status by PLHIV. In the study, a majority of the youths and their parents strongly believed that only the educated and those who have knowledge about HIV and AIDS support and extend care and affection to HIV-positive¹ people. Several interviewed opinion leaders felt that PLHIV are not readily accepted in society and it will take time for the society to accept the reality about HIV and AIDS. This study narrates

incidences about families or the society maltreating PLHIV in order to demonstrate the persistent stigma and discrimination faced by this vulnerable population in Nepal (CREHPA 2005)².

Another study that assessed the situation of children affected by AIDS (CABA) in Nepal documented the extent of stigma and discrimination faced by children diagnosed with HIV and AIDS. The study showed that stigma and discrimination was highly prevalent among CABA, and more HIV-positive girls (53%) than boys (33%) who were aged 12-18 years had reportedly experienced discrimination. Stigmatization and discrimination often carry over to the children of HIV-positive parents, making their lives much more challenging. Moreover, the study suggested that increasing age was directly proportional to the increase in the experience of discrimination from society (Save the Children-Norway (SCN)/CREHPA, 2009)³.

1.3 The People Living with HIV Stigma Index

The PLHIV stigma index is a community research initiative, which embraced a participatory spirit for all those who were involved in the research. Both the interviewee and interviewers are at the centre of the process of the Stigma Index. This PLHIV Stigma Index study is the first study of its kind and has been conducted on a much larger scale among the PLHIV population in Nepal than other studies.

The PLHIV Stigma Index is developed by and for the PLHIV. It was developed and pioneered as a part of a global initiative between the International Planned Parenthood Federation (IPPF), Joint United Nations Programme on HIV/AIDS (UNAIDS) and two international networks of people living with HIV (The Global Network of

1. *Cumulative HIV Situation of Nepal, MoHP/NCASC, 13 March 2011*

2. *ADRA/CREHPA 2005 "Participatory Evaluation of Nepal Voluntary Counselling Testing Linkage and Referral Project of ADRA Nepal"*

3. *Save the children/CREHPA 2009 "A Situation Assessment of Children Affected by AIDS in Nepal"*

People living with HIV/AIDS (GNP+) and The International Community of Women living with HIV/AIDS (ICW)). The index collects information about the experiences of PLHIV related to stigma, discrimination and human rights. Since the PLHIV conduct the interviews, it becomes a discussion between peers, which encourages openness and confidentiality in the interviewer. Currently, over forty countries across the world, including Nepal, have conducted this research.

The PLHIV Stigma Index provides a mechanism to collect stigma- and discrimination-related information and experiences of PLHIV, with the following objectives:

- Document and broaden the understanding of the stigma- and discrimination-related experiences of PLHIV
- Consider the extent and variables that influence the experience of HIV-related stigma and discrimination in a particular country
- Compare the experiences of HIV-related stigma and discrimination across different national settings
- Measure change over time, particularly the focus, severity and frequency of HIV-related stigma and discrimination
- Provide an evidence base for policy change and programmatic interventions

The results gathered can therefore be used by policy makers and organizations to formulate strategies and the stigma index can be used for advocacy, education and prevention of HIV/AIDS-related stigma.

1.4 Methodology

In Nepal, the information available on the extent and intensity of social stigma and discrimination faced by the PLHIV population is limited. Owing to a lack of

information on stigma and discrimination, and in order to provide a national status to the study, the objective and methodology of the study was presented and approved at the meeting of the Strategic Information Technical Working Group (SITWG) in early 2010. At the time that FPAN was rolling out the Stigma Index in country, two other studies were also measuring stigma, both as a prime objective and as a part of other end-of-project evaluations (UNDP/DFID evaluation). Thus, efforts were made by the SITWG to harmonise duplication and give priority to rolling out the global stigma index.

Since there was a UNDP study on PLHIV to be conducted at the same time as this study, it was agreed that the information on stigma and discrimination of PLHIV will not be included in the UNDP study, as the information regarding this aspect was being collected in this stigma index study. Subsequent discussions with other stakeholders led to an agreement with agencies taking up the stigma issue to consolidate all efforts in this particular study.

At the time of planning the current study, extensive review of similar studies conducted in Pakistan, Sri Lanka, China, Ukraine, Fiji and Asia Pacific region was performed. Learnings from these studies have been taken into account.

1.4.1 Sample Size

The sample size was drawn from a list of PLHIV in contact with local NAP+N representatives from 35 districts. A second criterion based on the presence of 100 or more PLHIV per district was then used to shortlist 18 districts to enable the recruitment of a sufficient number of respondents. These 18 districts represented the five development regions of the country (Table 1.1 and Figure 1.1). The list contained the names, ages, status (living/death) and categories of the PLHIV (IDUs, FSWs, migrants, etc.) residing

in the districts. There were a total of 3,736 PLHIV in these 18 districts. Of these, 426 PLHIV were excluded owing to the non-specification of name, sex and age, and those who were not alive anymore. The study did not include the PLHIV who were aged 17 years and below. Since the target was to sample equal number of male and female populations, two separate samples of 400 Male and Female members each were designed. The PLHIV population of 3,310 was stratified, resulting in 1,696 males and 1,614 females. This stratified list was used as the final sampling frame.

As per the suggestion of the technical committee (formed to provide necessary support for the implementation of the initiatives on a daily basis, led by PLHIV organization/NAP+N, FPAN and UNAIDS), a small-scale rapid assessment survey was conducted in Kathmandu in order to assess the desired information proxy values for use in the sample size calculation. The rapid assessment was conducted by NAP+N among 20 PLHIV in Kathmandu valley. The following indicators were used for the assessment: social exclusion, verbal harassment, refusal of employment opportunity, denial of general health services, denial of Sexual and Reproductive Health (SRH) services and self-stigmatization. Based on the results of the rapid assessment, a sample size of 800 (400 male and 400 female PLHIV) was derived at the 95 per cent confidence level. However, the list did not adequately represent MSM and FSWs. This led the technical committee to seek a booster sample to ensure adequate representation of MSM and FSWs based on the prevalence of HIV among these key population (KP) groups.

The sample size for the study was calculated using following formula:

$$\hat{p} \pm Z_{1-\alpha/2} \sqrt{\frac{p(1-p)}{n}}$$

where $Z_{1-\alpha/2}$ is the $(1 - \alpha/2)\%$ quantile from a standard normal distribution for a 95 per cent confidence interval $Z_{1-\alpha/2} = 1.96$. From this, we note that the precision of the estimate (or size of the half interval) is

$$precision = Z_{1-\alpha/2} \sqrt{\frac{p(1-p)}{n}}$$

The Probability Proportionate to Size (PPS) technique was used to determine the district-wise sample by sex. Finally, a systematic random sample technique was used for the selection of the male and female respondents.

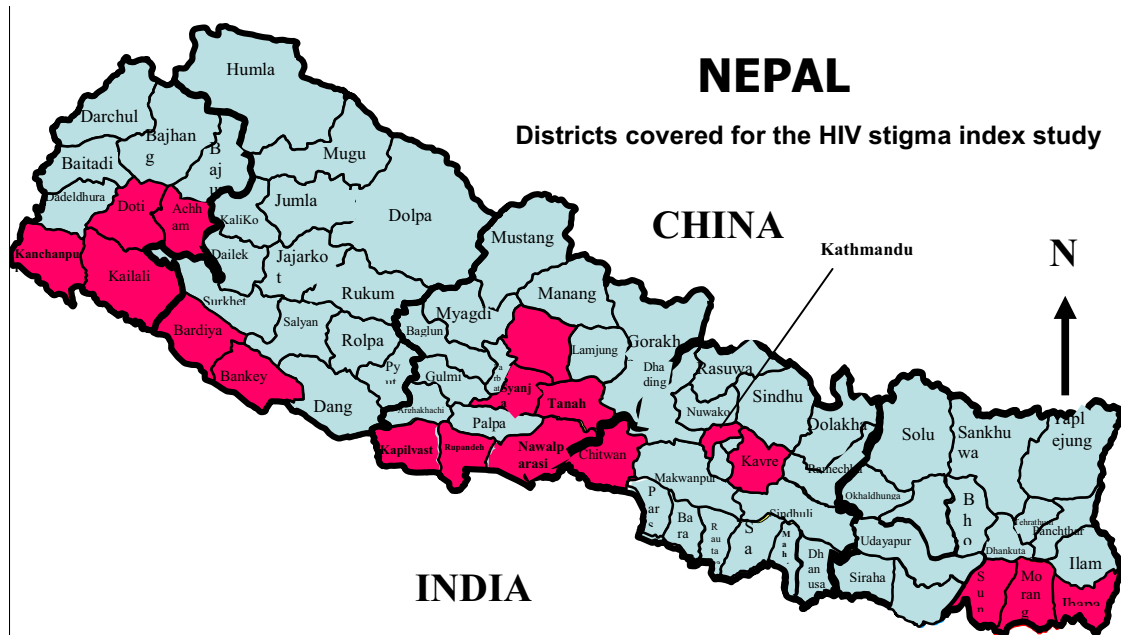
1.4.2 Operation Plan of the Study

Data collection was conducted in two rounds. In the first round of data collection, 399 male and 403 female PLHIV were interviewed. In the second round of data collection, 30 MSM and 16 FSWs were interviewed as a booster sample. MSM were interviewed in Kathmandu and Rupandehi districts with the help of the Blue Diamond Society (BDS), an organization working for MSM and Transgender people and their network, Federation of Sexual and Gender Minorities Network (FSGMN); FSWs from Kathmandu were interviewed with the help of Jagriti Mahila Maha Sangh (JMMS: the network of FSWs). Two male interviewers from BDS and one female interviewer from JMMS were trained to interview MSM and FSWs. Overall, 848 PLHIV (402 male, 419 female and 27 transgender people) aged 18 years and above were interviewed.

Table 1.1 Districts covered for HIV stigma index study

	Eastern	Central	Western	Mid-Western	Far Western
Hill	—	- Kathmandu - Kavre	- Tanahu - Syangja - Kaski	—	- Achham - Doti
Terai	- Sunsari - Morang - Jhapa	- Chitwan	- Nawalparasi - Rupandehi - Kapilvastu	- Banke - Bardiya	- Kailali - Kanchanpur

Figure 1.1 Map of Nepal showing the districts covered for the study



The district-wise target and sample performance are presented below in Table 1.2.

Table 1.2 District-wise targets and sample performance

District	Male		Female		Total	
	Target	Achievement	Target	Achievement	Target	Achievement
Jhapa	24	24	8	8	32	32
Morang	15	15	18	18	33	33
Sunsari	62	62	29	29	91	91
Kathmandu*	18	33	24	40	42	73
Kavre	25	25	17	17	42	42
Chitwan	35	35	40	40	75	75
Nawalparasi	18	18	22	22	40	40
Rupandehi	20	35**	24	24	44	59
Kapilvastu	22	22	23	23	45	45
Syangja	16	16	20	20	36	36
Kaski	26	26	21	21	47	47
Tanahu	18	18	18	18	36	36
Banke	20	20	10	10	30	30
Bardiya	13	13	14	14	27	27
Kailali	24	23	30	31	54	54
Kanchanpur	21	21	26	26	47	47
Doti	15	15	38	40	53	55
Accham	8	8	18	18	26	26
Total	400	429	400	419	800	848

* FSW booster sample covered from Kathmandu

** MSM booster sample covered from Kathmandu and Rupandehi

1.4.3 Quality Assurance Measures

The standard structured questionnaire for PLHIV, which was developed by the joint initiatives of IPPF, GNP+, ICW and UNAIDS and used globally was translated into Nepali for the study; this questionnaire was first translated into Nepali, extensively reviewed by both FPAN and CREHPA and subsequently back-translated into English for ensuring accuracy. Acknowledging the

importance and sensitivity of the study, an intensive training on various aspects of the survey was conducted. This included training 30 PLHIV researchers (16 females and 14 males) in understanding the content of the questionnaire, administering the questionnaire and conducting the interviews. The questionnaire was tested during the training of the interviewers in April 2011. Master facilitators from NAP+N were responsible for the training. In addition,

experts from the various organizations involved in the study and IPPF, Central Office were also present in the training.

The interviews were conducted between 29 May and 20 June 2011 simultaneously in all the study districts. NAP+N was responsible for conducting the interviews. In each district, one team comprising of one male and one female enumerator was responsible for interviewing the PLHIV. The quality of the information collected was ensured by the constant supervision of NAP+N and monitoring visits by the core team members from FPAN, UNAIDS and CREHPA. Random checks on the collected data were conducted during the field visits.

In order to ensure adherence to the ethical aspects of the study, FPAN sought technical and ethical approval from the national ethical body, Nepal Health Research Council (NHRC) (approval reference number 38). The study was also endorsed by SITWG. The participants' rights to information, volunteerism, privacy and confidentiality and adherence to the compliance of both the ethical and human rights standards were maintained throughout the study, including during the fieldwork and data entry.

Data processing was conducted by CREHPA using the recommended program of Epi Info. Before entering data into the system, the completed questionnaires

were manually edited and coded. Double data entry was conducted to control data entry mistakes. After the completion of data entry, errors for inconsistency of responses/ incompleteness of responses to related questions within a questionnaire were checked and corrected. During data coding, 10% of the data was randomly checked. Subsequently, the data was transferred into SPSS for labelling and analysis. The data processing, handling and analysis conducted by CREHPA was monitored by UNAIDS and FPAN.

Due care was taken to maintain respondents' anonymity during the data entry and analysis. The names of individual respondents have not been cited in the report and a system of coding was used in the questionnaire to maintain confidentiality. The electronic data set was password protected and only authorized officials of CREHPA had access to the data files. All completed questionnaires were stored in a locker at the CREHPA office.

A descriptive univariate and bivariate analysis formed the main tools for analysis. Chi-square test was performed to check association for selected indicators. Selection of analytical techniques depended on the descriptive analysis of indicators mentioned before.

Case Study 1. Basanta Chettri

Basanta Chettri from NAP+N was the coordinator in this Stigma Index study. He said, "This has been a great learning experience for me." NAP+N has worked with FPAN before; however, this is the first time that NAP+N was a part of a national level and such an important study. This has enabled NAP+N, for the first time, to create a database of the number of PLHIV in contact with their district staff. Now, they have made a district-wise and district-wide list of the actual number of PLHIV. Basanta says, "Stigma and discrimination has been a part of the HIV epidemic since the beginning; however, we have never been able to categorically say where and in what form stigma and discrimination exist. Although times and attitudes among society have changed, PLHIV continue to be stigmatized. Thankfully, now we are able to record it." Basanta shares that since NAP+N has been involved in the study since the beginning, NAP+N has been able to learn a lot from the entire process. He adds, "Determining the sample size, coordinating the training and fieldwork and actually administering the questionnaire has provided considerable exposure to my colleagues and me. This has been a very scientific process. I think some of our colleagues at the field level would be able to be involved in other HIV-related studies and can therefore find opportunities to contribute to future research as well. We are very grateful to IPPF and FPAN for this opportunity."

1.5 Assumptions and Limitations

- It is assumed that the frequency of the observed parameters between PLHIV who are members of NAP+N is similar to that of the non-members of NAP+N, because the observed parameter based on the interviews of NAP+N members has been projected to the entire PLHIV population in that district.
- It is assumed that the distribution of the observed parameter is uniform across the districts having more than 100 PLHIV as compared to those that have less than 100 PLHIV.
- It is assumed that the observed parameters are uniformly distributed between those who refused to respond or responded "don't know," because only the valid responses have been analyzed and assumed to be applicable for the entire PLHIV population.
- The sample for this study was limited only to those PLHIV who were openly living with HIV and were in contact with the PLHIV organization/network.
- The study used predesigned data collection tools developed through global partnership. Therefore, the tools permit the data collection of only the situations and do not answer questions in detail.
- A booster sample was taken purposively to ensure adequate representation of MSM and FSWs based on the prevalence of HIV among these key population groups.
- In order to provide a national level estimate, weights have been applied in proportion to the male, female and various KP groups sampled. The percentage from NCASC 2010 was taken as a reference to calculate the weights, because it was the best available data.

- A relative weightage of 0.65, 0.29 and 0.06 was applied on the findings of the studied parameters for male, female and transgender respondents, respectively (since the proportion of IDUs and labour migrants is not given by gender in the NCASC data). In the present study, while calculating weights for males, the proportion of IDUs (0.04) and labour migrants/clients of FSWs/remaining low risk males (0.61) have been added. For females, the proportion of FSWs (0.01) and remaining low risk females/female IDUs (0.28) have been used. Moreover, since there is no available proportion of transgender people alone, the NCASC

percentage of MSM has been used as weights for the transgender population.

- Due to the small number of transgender people in the study, they have been included in the MSM category while performing analysis based on KP groups. In addition, the analyses by gender (male, female and transgender person) have been performed only in key tables.

However, there is no reason to believe that these limitations have any major negative impact on the quality of the data in this study.



Chapter 2

Background Characteristics

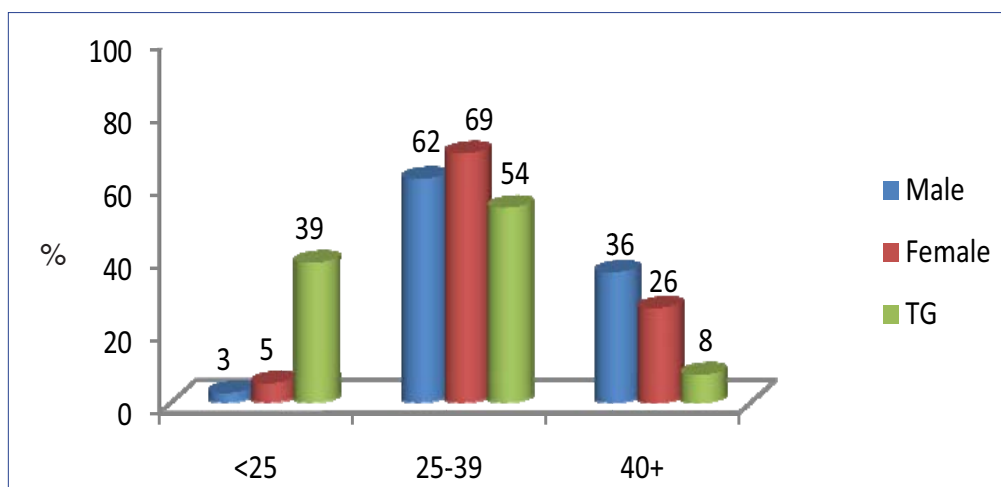
This section provides information on the socio-demographic characteristics of the 848 respondents (402 males, 419 females and 27 transgender people) covered in the survey. In addition, information on relationship status, whether they belong to any KP group and physical disability status are presented.

2.1 Socio-Demographic Characteristics

Age: The age group of 25-39 years

comprised the largest group for PLHIV. Within this age group, females formed the largest group (69%), followed by males (62%) and transgender people (54%). Very few respondents (5%) were below 25 years of age, whereas one-third of the male respondents (36%), a quarter of the female respondents (26%) and less than one-tenth (8%) of the transgender respondents belonged to the older age group (>40 years). The ages of the respondents ranged from 18 to 62 years (Figure 2.1).

Figure 2.1 Age group of the respondents (N=829)



Case Study 2. Tara Bahadur Thapa (name changed to protect privacy)

“The poor and the lower castes should also get the same service”

Tara Bahadur Thapa began using drugs when he was 12 and was injecting drugs by the time he was 18. Tara Bahadur was aware about HIV and took precautions. He never shared his syringe; however, he was still at risk because he stored his needle in a crevice in the wall of a building, and someone else could find it and use it. Therefore, between 1990 and 1999, Tara Bahadur underwent testing approximately twenty times and the result was always negative.

%

Tara Bahadur designed carpets that he sold independently and was a cabin attendant with a reputed airline. By 1996, however, his drug habit had spun out of control and he became a full-time drug user for three years. Subsequently, Tara Bahadur attempted to quit and tried methadone. An HIV test was a precondition for enrolling in the methadone program, and this time, Tara Bahadur tested positive. After three years, the methadone program was discontinued, and he relapsed.

Following this, Tara Bahadur checked into Youth Vision rehabilitation. “Youth Vision taught me that to quit, the most important thing is changing attitudes and behaviours.” On his release from the centre, he opted to volunteer at a VCT centre. Before beginning his work, he voluntarily decided to check his HIV status, as he did not believe that he was actually

HIV-positive. On learning his status, he was devastated and felt the urge to start taking drugs again. Fortunately, his counsellor and friends from the VCT centre prevented him from relapsing. After twelve anxious days, Tara Bahadur disclosed his status to his wife and following his counsellor’s advice, took his wife for counselling.

Tara Bahadur began providing counselling and community support to others as a corollary to needing them himself. He also founded a care home to provide comprehensive services to PLHIV. Over his six years of helping other PLHIV, Tara Bahadur is proudest of having saved many people’s lives by enabling despondent families access care and treatment services for their HIV-positive family members, thereby helping them live.

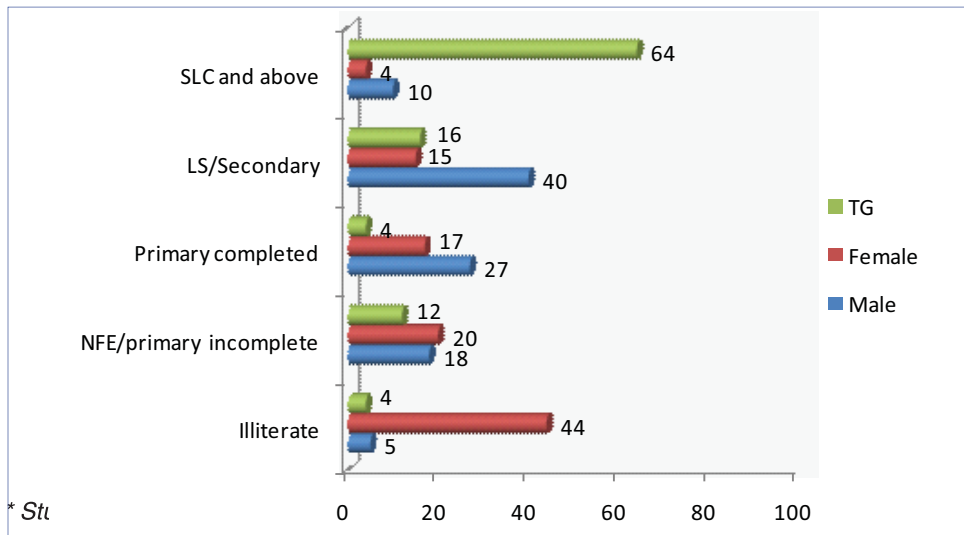
Tara Bahadur’s overarching concerns about treatment and care relate to the imbalance of services provided across the country and different communities and he recognizes that his current success eases his own experience of living with HIV. As an advocate, however, he is dissatisfied with this situation and believes that everyone should get equal treatment. Tara Bahadur adds that caste- and class-based discrimination also prevents impoverished patients from receiving equal treatment.

To help alleviate some of these imbalances, Tara Bahadur recommends better availability of services, including more antiretroviral therapy clinics and viral load machines. He adds that free follow-up testing for HIV would be a useful measure to equalize service regardless of class.

Education: Relatively, female respondents had lower levels of education compared to the male respondents and transgender people. A considerable proportion of the female respondents, that is, 44 per cent, had never attended school, whereas this percentage was only 5 per cent and 4 per cent for males and transgender people, respectively. A significant number of respondents (females: 20%, males: 18% and transgender people: 12%) had attended either non-formal education (NFE) or had

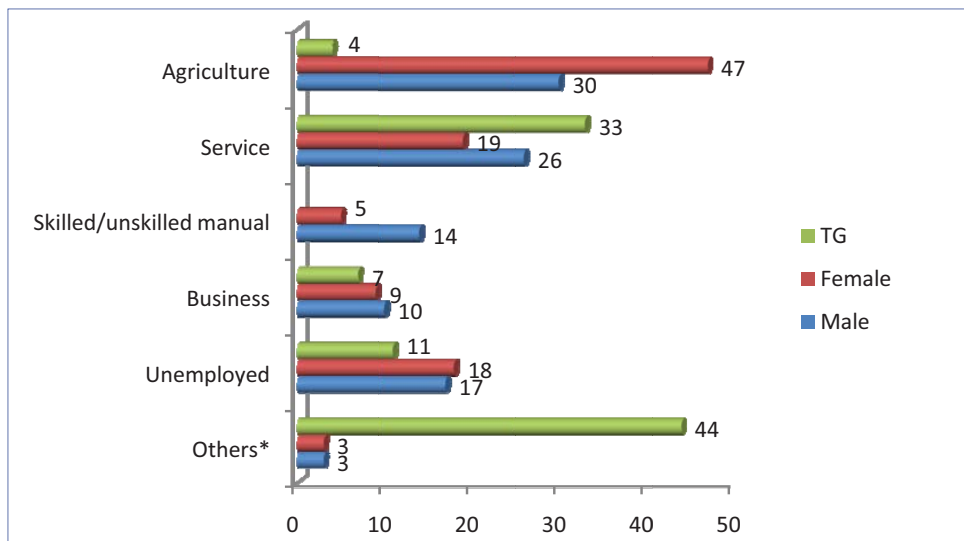
joined school, but not completed their primary level of education. Approximately 15 per cent of the females, 16 per cent of the transgender people and 40 per cent of the males had completed their lower secondary/secondary education. Although the School Leaving Certificate (SLC) course and higher education had been completed by 64 per cent of the transgender respondents, this percentage was only 10 per cent for the male respondents and 4 per cent for the female respondents. (Figure 2.2).

Figure 2.2 Educational attainment (N = 810)



Employment status: One-sixth of the respondents (17%) reported that they were unemployed. Of the remaining respondents who were employed, a quarter of the males (27%), one-fifth of females (19%) and one-third of the transgender people (33%) were employed in the service sector. Being an agricultural country, a majority of the male (30%) and female (47%) respondents were engaged in agriculture/animal husbandry; however, only 4 per cent of the transgender respondents were employed in this sector. Although only 5 per cent of the female respondents were labourers, nearly thrice of this percentage or 14 per cent of the male respondents were labourers (Figure 2.3).

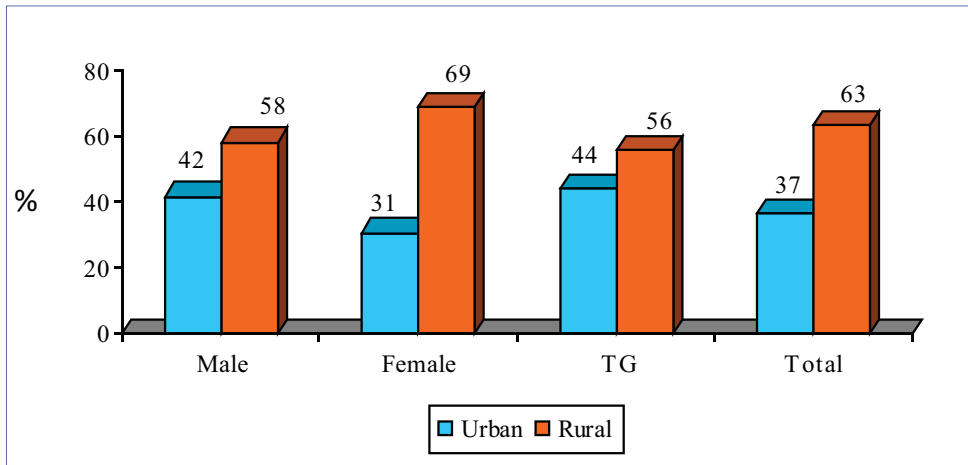
Figure 2.3 Employment status (N = 838)



* Student, sex worker, working in India

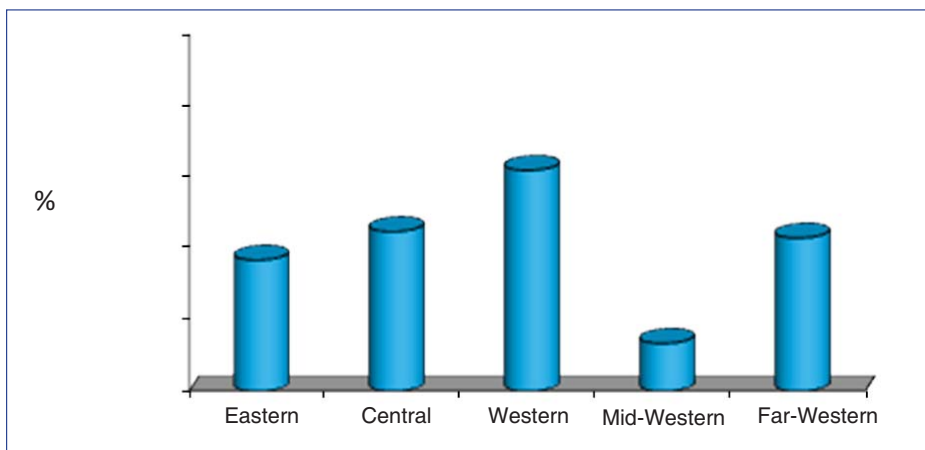
Place of residence: Approximately two-thirds of the respondents (63%) were from rural areas. The proportion of female respondents (69%) residing in rural areas was higher than that of male (58%) and transgender (56%) respondents as shown in Figure 2.4.

Figure 2.4 Place of residence (N = 781)



Development regions: The proportion of the PLHIV interviewed according to development regions are presented in the chart below (Figure 2.5). In this study, a greater number of PLHIV were considered from the Western region, because the highest number of districts were covered from this region, whereas the share of PLHIV was low in the Mid-Western region, because only two districts were covered in this region.

Figure 2.5 Development regions (N = 848)



Living Status: A total of 76 per cent male, 47 per cent female and 19 per cent transgender respondents were married and living together. Although none of the transgender respondents was separated/divorced or living alone, 11 per cent of the female and 2 per cent of the male respondents were reportedly living alone and 8 per cent of the female and 1 per cent of the male were separated/divorced (Table 2.1).

A majority of the transgender (96%) and male (84%) respondents and approximately half of the female respondents (46%) were reportedly sexually active during the 12 months prior to the survey (Table 2.1).

Table 2.1 Relationship status and sexual activity

Relationship Status	Male	Female	TG person	Total
Currently married or cohabiting and living together (%)	75.8	46.5	18.5	60.8
Cohabiting but not living together (%)	9.8	11.2	74.1	12.8
Currently married or cohabiting but living separately owing to job (%)	6.4	11.9	7.4	8.9
Living with parents or family members and institutional members (HIV networks, rehabilitation centres, etc.) (%)	5.4	11.9	—	8.1
Living alone (%)	1.5	10.9	—	5.6
Widow/er and separated (%)	1.0	7.6	—	3.9
Sexually active during the past 12 months				
Yes (%)	83.8	45.9	96.3	66.0
No (%)	16.2	54.1	3.7	34.0
N	395	392	27	814

2.2 Time Elapsed since HIV Diagnosis

Analysis of the time elapsed since diagnosis of respondents shows that the majority of respondents, that is, 43 per cent of the male, 46 per cent of the female and 42 per cent of the transgender respondents had been diagnosed with HIV in between 3 to 5 years prior to survey. Approximately a quarter of the female (26%) and transgender (27%) respondents and two-fifths of the male (41%) respondents had reportedly been diagnosed with HIV over five years ago. Moreover, less than one-third of the transgender (31%), approximately one-fourth of the female (26%) and approximately one-sixth of the male (16%) respondents had been diagnosed as HIV-positive within the last two years (Table 2.2).

Table 2.2 Time elapsed since diagnosis of HIV

Time elapsed since diagnosis	Male	Female	TG person	Total
Within last one year (%)	1.3	2.7	—	1.9
1–2 years (%)	15.8	25.6	30.8	21.1
3–5 years (%)	42.5	45.9	42.3	44.2
>5 years (%)	40.5	25.8	26.9	32.8
N	393	407	26	826

2.3 HIV and Disability

Very few respondents (4%) reported disability besides HIV infection. None of the transgender people in the study was disabled. Among those who reported disability besides the HIV infection, a majority suffered from physical disability, followed by blindness and impaired hearing. Among the disabled PLHIV, physical disability (47% vs. 39%) and blindness (40% vs. 28%) were more prevalent in females as compared to males, whereas a greater proportion of males than females were reportedly suffering from hearing impairment (33% vs. 13%) (Table 2.3).

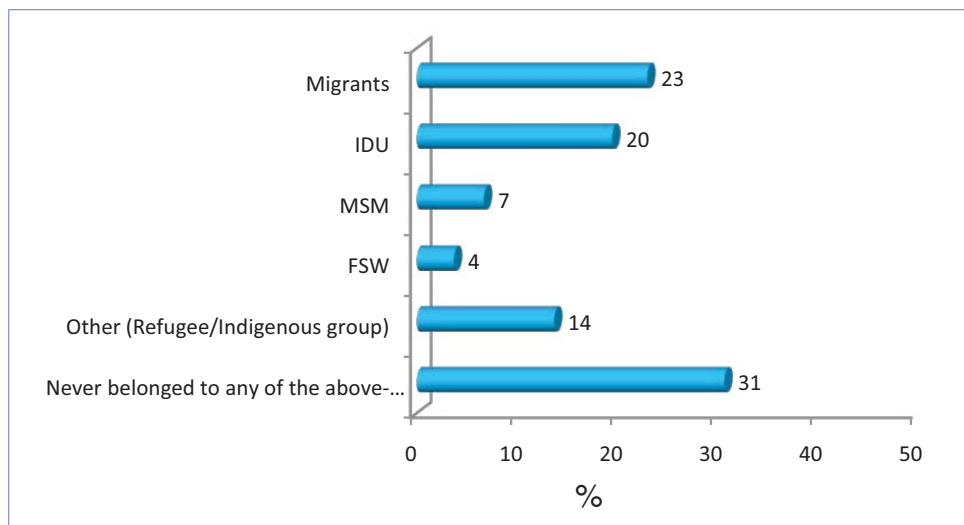
Table 2.3 Disability status

	Male	Female	TG person	Total
Disability status				
Yes (%)	4.5	3.6	—	3.9
No (%)	95.5	96.4	100.0	96.1
N	402	419	27	848
Disability				
Blindness (%)	27.8	40.0	—	33.3
Physically disability (%)	38.9	46.7	—	42.4
Hearing Impairment (%)	33.3	13.3	—	24.2
N	18	15	-	33

2.4 Membership of the Risk Groups

Thirty-one per cent of the respondents reported that they had never belonged to any risk group as shown in Figure 2.6, which is presented below. [Note: Transgender people are included in the MSM population group (4% MSM and 3% TG people)].

Figure 2.6 Respondents belonging to any risk groups (N = 848)





Chapter 3

Experiences of Stigma and Discrimination

Case Study 3. Raj Kumar Chettri (name changed to protect privacy)

Raj Kumar Chettri started using drugs in 1995-1996 and became addicted. During the process of applying to travel overseas in 2000-2001, he learned that he was HIV-positive.

His family and friends are aware of his status. According to Raj, his mother is the only family member who does not discriminate against him because of his status, probably because she does not know much about HIV. Besides his family, which has practically disowned him, his friends, who were close to him before, hesitate to talk to him now. Even the medical staff at the hospital where he learned about his HIV status ill-treated and discouraged him about his chances of survival, saying, "You will die soon."

His addiction had separated him from his family and relatives. After acquiring HIV, he became severely ill and suffered from illnesses like abscess. He became extremely weak and had to be hospitalized. There, the doctors told him that he had a very low chance of survival and the healthcare staff ill-treated him. He had hoped that in his extremely poor condition, his family would be by his side; however, this did not happen. No one from his family supported or even visited him. He became extremely despondent and lost all hope of living.

Fortunately, some persons from organizations working in the HIV sector visited him and referred him to Nava Kiran Plus, a rehabilitation center in Kathmandu; they also took responsibility for his treatment. After undergoing surgery and further treatment, he began working for NAP+N, which gave him the opportunity to interact with several other people fighting to overcome similar problems. He worked hard and was eventually sent to another district to handle office responsibilities. At the new location, he met old friends who gossiped about him behind his back, giving him immense mental stress. As a result, he returned to his hometown, and relapsed into drugs.

He eventually got married to an HIV-positive woman. Both of them have been taking ARV since the last six years. He says that he has faced discrimination at the ARV centres and their staff has not shown much concern about his condition. Although he has completely stopped using drugs now, he is compelled to work as a physical labourer. He searched for a job in many organizations; however, was not offered even a sweeper's job. He says that he knows that working as a labourer is detrimental for his health; however, he has to do it because he is the sole earner in his family and needs the money to feed his family.

3.1 Experiences of Stigma and Discrimination due to HIV

In the present survey, a series of questions were asked to the respondents to measure their level of stigma and discrimination, including questions on the types/kinds of discrimination faced by them and the occurrence of such stigma and discrimination as experienced by them because of their HIV status.

As is evident from Table 3.1, half of the PLHIV respondents (50%) reported that they had experienced at least one event of stigma and discrimination from the society that they live in or from their workplace during the 12 months prior to the survey. Among the various forms of stigma and/or discrimination faced by them, 36 per cent of the respondents reported that “gossiping” was the most frequent form of stigma and/or discrimination faced by them and a majority of these respondents (28%) reported that

they had experienced this kind of stigma a few times over the past 12 months. In addition, a little less than 18 per cent of the respondents had reportedly experienced discrimination/rejection by their spouses or partners or any other household member with a majority (13%) facing such stigma and discrimination at least a few times. Other forms of stigma and/or discriminatory behaviour experienced by the respondents included being subjected to psychological pressure by spouse or partner (reported by approximately 12% of the respondents) and verbal insult, harassment and/or threat (reported by 12% of the respondents). The results also indicated that society puts pressure on PLHIV by barring them from religious participation and attending social gatherings. Moreover, among the respondents who were sexually active during the 12 months prior to the survey, 18 per cent had reportedly experienced sexual rejection. Further, almost 10 per cent of the respondents reportedly experienced discrimination by other PLHIV (Table 3.1).

Table 3.1 Level of experience of stigma and discrimination due to HIV

	Once (%)	A few times (%)	Often (%)	Never (%)	N (unweighted)
Gossiping	4.5	27.5	4	63.9	804
Discriminated/rejection by spouse or partner or any other household members	4	12.8	1.5	81.7	837
Psychological pressure by spouses or partner	1.3	9.4	1.7	87.7	828
Verbally insulted, harassed and/or threatened	2.4	8.2	1.4	88.0	828
Experienced sexual rejection	2.4	14.6	0.7	82.2	535
Ignored/isolated by other PLHIV	2.7	6.7	0.8	89.8	829
Excluded from social gatherings or activities	2.1	6.3	1	90.6	848
Excluded from family activities	1.8	3.1	1.5	93.6	847
Physically harassed and/or threatened	1.9	3.6	0.6	94.0	839
Excluded from religious gatherings or activities	0.9	2.5	0.5	96.1	848
Physically assaulted	1	2.1	0.3	96.6	843
Experienced at least one event (listed above) of stigma and discrimination	49.7%				848

A gender-analysis of the levels of stigma and discrimination experienced by the respondents clearly indicates that discrimination is faced by males, females and transgender people, and varies only in terms of the frequency of the injudicious behaviour. As compared to males and females, a greater number of transgender people have reportedly experienced discrimination and stigma in the form of psychological pressure by spouse/partner, sexual rejection and discrimination/rejection by other PLHIV,

spouse/partner or other household members. Male and female respondents reported slightly higher number of instances of exclusion from social gatherings or activities and religious activities than transgender respondents. Reportedly, none of the transgender people had experienced physical assault; however, both male and female respondents reportedly experienced physical assault with females reporting such experiences more often than males.

Table 3.2 Level of experience of stigma and discrimination due to HIV according to gender

	Once (%)	A few times (%)	Often (%)	Never (%)	N (unweighted)
Excluded from social gatherings or activities					
Male	1.9	7.1	1	90.1	402
Female	2.3	5.4	1	91.2	419
Transgender person	3.7	—		96.3	27
Excluded from religious gatherings or activities					
Male	0.4	2.9	0.4	96.2	402
Female	1.6	2.1	0.5	95.8	419
Transgender person	—	—	—	100	27
Excluded from family activities					
Male	1.4	3.0	0.4	95.2	401
Female	2.3	3.1	2.8	91.7	419
Transgender person	3.7	3.7	—	92.6	27
Gossiping					
Male	2	28.8	2.4	66.7	381
Female	7.9	26.1	6	60.1	397
Transgender person	—	15.4	3.8	80.8	26
Verbally insulted, harassed and/or threatened					
Male	2	7.2	0.1	90.8	392
Female	2.9	9.5	3.2	84.5	410
Transgender person	7.7	3.8		88.5	26

	Once (%)	A few times (%)	Often (%)	Never (%)	N (unweighted)
Physically harassed and/or threatened					
Male	2.3	4.1	—	93.6	400
Female	1.3	2.9	1.3	94.5	412
Transgender person	3.7	3.7		92.6	27
Physically assaulted					
Male	0.5	1.6	—	97.9	401
Female	1.6	2.9	0.8	94.8	415
Transgender person	—	—	—	100	27
Psychological pressure by spouse or partner					
Male	1.2	9.3	1.5	88	386
Female	1.3	8.9	1.8	88	415
Transgender person	7.4	44.4	3.7	44.4	27
Experienced sexual rejection					
Male	1.4	10.8	1.1	86.7	330
Female	1.3	10.5	0.6	87.5	179
Transgender person	3.8	50.0	—	46.2	26
Ignored/isolated by other PLHIV					
Male	2.8	6.8	0.6	89.8	398
Female	2.4	5.9	1.1	90.6	404
Transgender person	7.4	44.4	—	48.1	27
Discriminated/hatred by spouse or partner or any other household members					
Male	3.9	12.8	0.1	83.2	401
Female	4.2	12.2	3.2	80.4	410
Transgender person	7.7	50	—	42.3	26

3.2 Experience of Stigma and/or Discrimination by Background Characteristics

Data on experience of at least one event of stigma and discrimination during the 12 months prior to the survey according to the background characteristics of the respondents is shown in Table 3.2.

The findings suggest that the level of discrimination is almost similar for respondents residing in both urban and rural areas. Moreover, the results indicate that the population aged less than 40 years was more prone to stigma and discrimination as compared to that in the older age groups. No considerable difference was seen in the extent of stigma and/or discrimination

reportedly faced by respondents belonging to different professions. In addition, the results did not indicate significant differences between the percentages of literate and illiterate respondents who experienced stigmatization and/or discrimination.

PLHIV who were diagnosed less than one year (24%) prior to the survey were found to be less likely to report experiences of stigma and discrimination compared to those who had had been found to be HIV-positive over one year ago (>49%).

In terms of risk categories, IDUs (60%) and FSWs (68%) reported to have experienced

more stigma and discrimination than respondents from migrant (50%), MSM (53%) and other (Refugee/Indigenous group) (50%) population groups (Table 3.3).

Across epidemic regions, Central region had the highest percentage of PLHIV (66%) who experienced at least one event of HIV-related stigma during the 12 months prior to the survey. Except for the Far-Western region (37%), all other regions had 50 per cent or more respondents who had experienced at least one event of stigma due to HIV during the 12 months prior to the survey.

Table 3.3 Experience of at least one event of stigma and discrimination due to HIV during the past 12 months according to background characteristics

Characteristics	Percentage (%)	N (Unweighted)
Age*		
<25	51.5	41
25–39	53.2	538
40+	43.8	250
Sex		
Male	49.1	402
Female	50.1	419
Transgender person	66.7	27
Education		
Illiterate	43.7	192
NFE/Primary incomplete	53.7	153
Primary	54.2	172
Lower sec/secondary	47.4	220
SLC and above	48.0	73
Occupation		
Unemployed	56.2	143
Service	47.8	191

Characteristics	Percentage (%)	N (Unweighted)
Business	50.5	81
Agriculture/animal husbandry	45.6	312
Skilled/Unskilled manual	61.4	75
Others (student/working in India/sex worker)	56.4	36
Time elapsed since diagnosis of HIV		
Within the last one year	24.1	16
1-2 years	55.1	174
3-5 years	51.0	365
>5 years	48.6	271
Place of residence		
Urban	50.2	286
Rural	50.7	495
Disability status**		
Yes	67.1	33
No	48.8	815
Development region		
Eastern	54.9	156
Central	65.9	190
Western	47.8	263
Mid-Western	58.8	57
Far-Western	37.1	182
Type of respondents		
IDU	60.2	165
FSW	67.7	31
Migrant	50.4	195
MSM	52.6	57
Never belonged to any the above-mentioned groups	49.9	260
Other (Refugee/Indigenous group)	49.9	116
Total	49.7	848

** $p < 0.01$; * $p < 0.05$

3.3 Reasons for HIV-related Stigma and/or Discrimination

The survey gathered information on the reasons for stigma and discrimination as perceived by PLHIV. The most common reason cited was “people are afraid of acquiring HIV infection from me” (53%). Moreover, ignorance about HIV transmission among population (49%) was the second most common reason cited for such behaviour. Other reasons for stigma and discrimination were “People perceive that having HIV is shameful” (22%) and “I look sick with symptoms associated with HIV” (22%). Almost one-fourth of the respondents did not know or were uncertain about the reasons for HIV-related stigma and discrimination. Discrimination due to religious beliefs or moral judgments was relatively less cited (5%) than other reasons. The various reasons mentioned by the interviewees clearly indicate that in their opinion, there is a lack of accurate knowledge about HIV/AIDS transmission and prevention among the general population (Table 3.4).

Table 3.4 Reasons for HIV-related stigma and/or discrimination according to the types of respondents

Reasons for HIV-related stigma and/or discrimination	IDU	FSW	Migrant	MSM	Never belonged to the mentioned group	Other (Refugee/ Indigenous group)	Total
People are afraid of acquiring HIV infection from me (%)	42.6	42.9	62.1	66.7	50.8	54.4	53.1
People are ignorant regarding how HIV is transmitted and are afraid (%)	46.8	42.9	56.3	76.7	39.7	47.4	48.7
People perceive that having HIV is shameful (%)	34.0	9.5	26.2	40.0	10.3	14.0	21.8
Religious beliefs or “moral” judgements (%)	7.4	4.8	8.7	3.3	1.6	3.5	5.1
People disapprove of my lifestyle or behaviour (%)	30.9	28.6	14.6	13.3	7.9	8.8	16.1
I look sick with symptoms associated with HIV (%)	16.0	33.3	27.2	26.7	17.5	24.6	22.1
I don't know/ I am not sure of the reason(s) (%)	25.5	23.8	16.5	6.7	34.1	17.5	23.2
N	94	21	103	30	126	57	435

Note: Percentage total exceeds 100 owing to multiple responses (441 respondents had experienced at least one event of stigma and discrimination and only 435 respondents had indicated the reasons).

3.4 Effect of HIV Status on Place of Accommodation

The study also gathered information to determine whether the HIV status of the respondents played a role in compelling them to change their place of residence or influenced their ability to rent an accommodation. Approximately one-third of the respondents who were compelled to change their place of residence or were denied rental accommodation said that it was owing to their HIV status.

Although almost 59 per cent of the respondents of the Mid-Western region had reportedly experienced at least one event of stigma and/or discrimination, only approximately 4 per cent were reportedly compelled to change their place of residence or were unable to rent an accommodation. Wide disparity was observed in the discrimination faced by respondents of different regions at the place of accommodation, as indicated in the table below.

Table 3.5 Discrimination at the place of accommodation according to development regions

Compelled to change your place of residence or have been unable to rent accommodation	Eastern	Central	Western	Mid-Western	Far-Western	Total
Yes (%)	17.9	23.7	8.7	3.5	3.8	12.4
No (%)	82.1	76.3	91.3	96.5	96.2	87.6
N	156	190	263	57	182	848

3.5 Experiences of Stigma and/or Social Discrimination at Workplace

Approximately one-tenth of the respondents who were reportedly refused employment opportunities during the 12 months prior to the survey said that this was due to their HIV status.

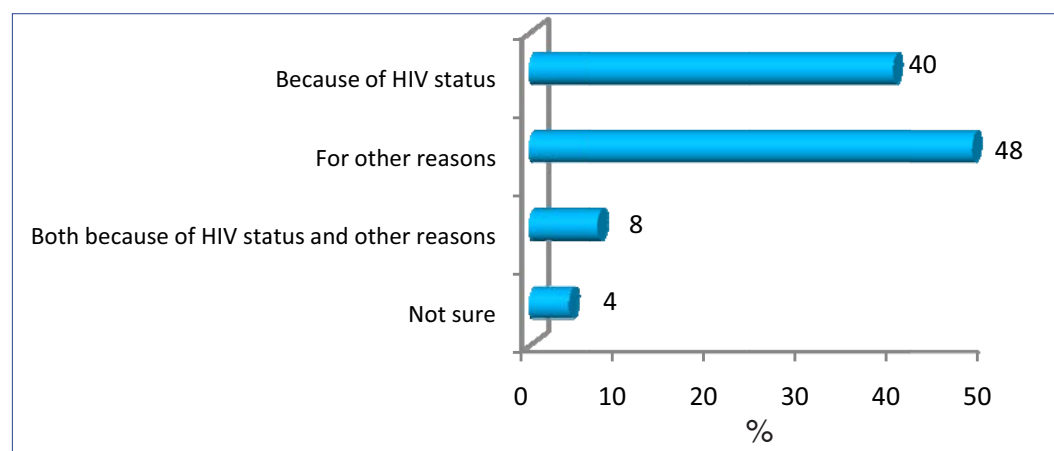
Over one-tenth of the respondents belonging to the Western region had reportedly been refused employment or job opportunity owing to their HIV status. Approximately the same percentages (6%) of respondents in the Central and Far-Western regions had reportedly faced such discrimination. Respondents belonging to the Mid-Western regions had reportedly faced lesser discrimination than those in the other regions.

Table 3.6 Discrimination at the work place according to development regions

Refused employment or a work opportunity	Eastern	Central	Western	Mid-Western	Far-Western	Total
Yes (%)	7.6	6.5	10.7	3.5	6.3	7.7
No (%)	92.4	93.5	89.3	96.5	93.8	92.3
N	132	168	244	57	176	777

Further, results indicate that two-fifths of the respondents who had lost a job or other source of income during the 12 months prior to the survey reported that it was due to their HIV status (Figure 3.1).

Figure 3.1 Reasons perceived by PLHIV for losing their jobs (N = 93)



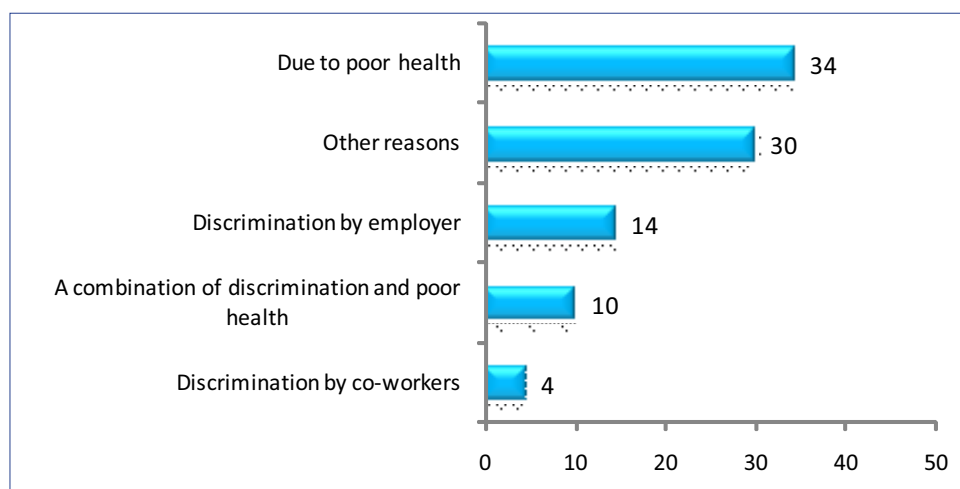
In terms of geographical location, approximately one-fifth or 19 per cent of the respondents in the Eastern region had reportedly lost their jobs or other sources of income owing to their HIV status. Moreover, 16 per cent of the respondents from the Central region reported the same reason.

Table 3.7 Loss of job due to HIV according to development regions

Lost a job (if employed) or another source of income	Eastern	Central	Western	Mid-Western	Far-Western	Total
Yes (%)	18.8	16.2	9.1	10.5	6.2	11.7
No (%)	81.2	83.8	90.9	89.5	93.8	88.3
N	133	167	243	57	177	777

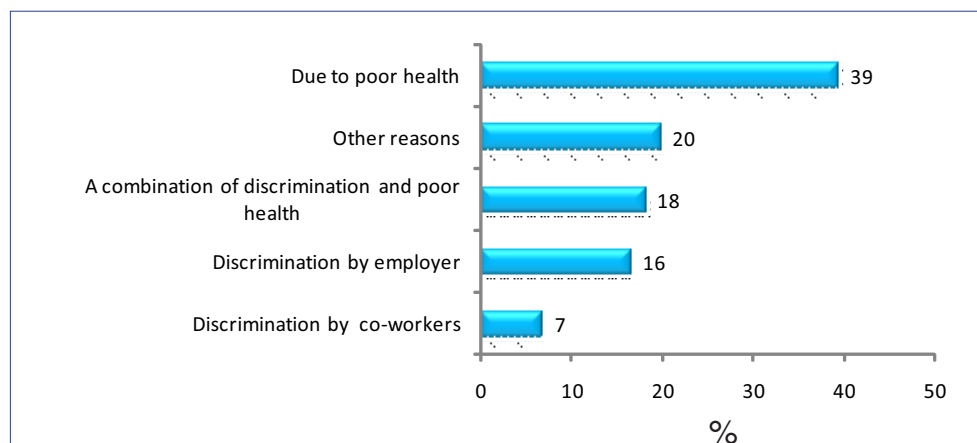
The respondents who had lost their jobs (if employed) or other sources of income (if self-employed or informal/casual workers) owing to their HIV status were also asked about the type of stigma and discrimination that they faced at the workplace and the reasons that compelled them to quit their jobs. The primary reason that was cited by these respondents was poor health (34%). Other reasons included discrimination by employer (14%) and co-workers (4%). Furthermore, a combination of discrimination and poor health (10%) was another perceived reason for respondents losing their jobs (Figure 3.2).

Figure 3.2 HIV-related reasons for loss of jobs by PLHIV (N = 91)



In addition, the respondents who had experienced a change in their job description/nature of work, or had been refused a promotion owing to their HIV status during the last 12 months were also asked about the reasons for such changes at their workplace, which are indicated in the figure below (Figure 3.3).

Figure 3.3 Perceived reasons for PLHIV facing changes in job description/nature of work or refusal of promotion (N = 61)



Almost a similar proportion of the respondents from the Central and Eastern regions (approximately 11%) experienced changes in their job descriptions/nature of work or were refused promotions owing to their HIV status. Less than 2 per cent of the respondents belonging to the Mid-Western region reported likewise.

Table 3.8 Change in job description/nature of work due to HIV according to development regions

Change in job description or nature of your work, or have been refused promotion	Eastern	Central	Western	Mid-Western	Far-Western	Total
Yes (%)	10.6	11.7	6.6	1.8	3.4	7.3
No (%)	89.4	88.3	93.4	98.2	96.6	92.7
N	132	171	244	56	177	780

3.6 Experience of Stigma and Discrimination at Educational Institutions

The study found that the discrimination of PLHIV at educational institutions was low. However, instances of children of PLHIV being dismissed, suspended or prevented from attending an educational institution because of their parents' HIV status were reported in the study. Table 3.9 indicates the percentages by region.

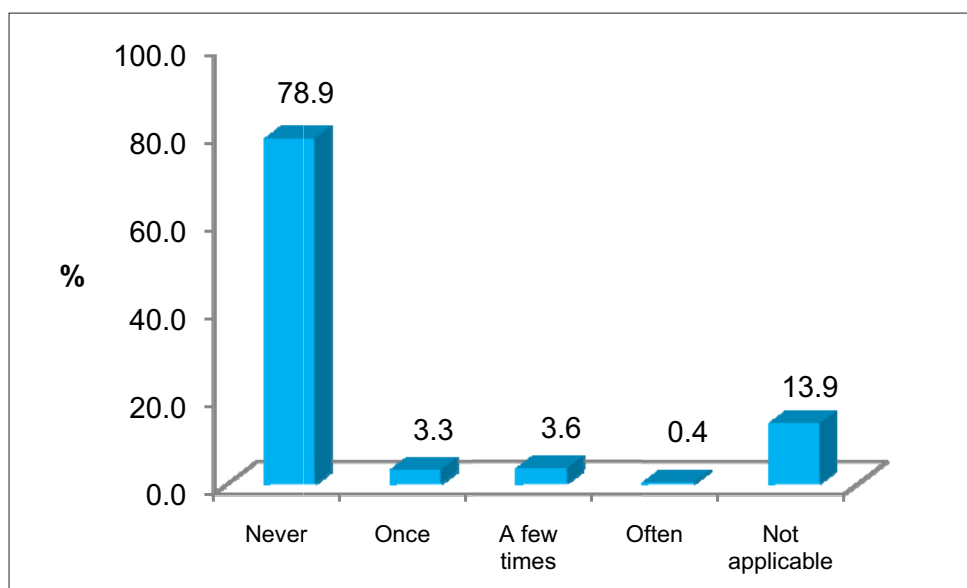
Table 3.9 Experience of stigma and discrimination at educational institutions according to development regions

	Eastern	Central	Western	Mid-Western	Far-Western	Total
Dismissed, suspended or prevented from attending an educational institution						
Yes (%)	2.6	4.2	2.7	—	—	2.2
No/Not applicable (%)	97.4	95.8	97.3	100.0	100.0	97.8
N	156	190	263	57	182	848
Your child/children been dismissed, suspended or prevented from attending an educational institution						
Yes (%)	4.0	4.8	1.1	3.5	1.1	2.6
No/Not applicable (%)	96.0	95.2	98.9	96.5	98.9	97.4
N	151	186	263	57	180	837

3.7 Experience of Stigma and Discrimination at Health Facilities

A total of seven per cent of the respondents had reportedly been denied health services, including dental care, because of their HIV status (Figure 3.4).

Figure 3.4 Denial of health services, including dental care, to PLHIV (N = 837)



As compared to other risk groups, a higher proportion of FSWs and IDUs had reportedly experienced denial of health services. The percentages for the denial of health services, including dental care, according to risk groups are shown in Table 3.10.

Table 3.10 Denial of health services, including dental care, according to risk groups

	Once (%)	A few times (%)	Often (%)	Never (%)	N
IDUs	7.3	8.5	—	75	164
FSWs	3.2	—	3.2	51.6	31
Migrants	1.5	3.1	—	78.4	194
MSM	—	—	—	77.2	57
Never belonged to the above-mentioned groups	3.1	3.5	0.8	84	256
Other (Refugee/Indigenous group)	3.5	0.9	—	85.1	114
Total	3.3	3.6	0.4	78.9	837

There is a wide variation among the respondents belonging to different geographical locations in terms of the denial of health services, including dental care. As compared to other regions, respondents from the Eastern and Central regions had reported a higher percentage of such instances.

Table 3.11 Denial of health services, including dental care, according to development regions

Denied health services, including dental care	Eastern	Central	Western	Mid-Western	Far-Western	Total
Yes (%)	12.4	14.7	4.3	1.8	1.1	7.3
No/Not applicable (%)	87.6	85.3	95.7	98.2	98.9	92.7
N	153	190	258	57	179	837

The study found that respondents have reportedly been denied family planning services (3%) and SRH services (2%) because of their HIV status (Table 3.12).

Table 3.12 Denial of family planning and reproductive health services

	Male	Female	TG person	Total
Denial of family planning services				
Yes (%)	2.3	2.9	7.4	2.7
No/Not applicable (%)	97.7	97.1	92.6	97.3
N	400	412	27	839
Denial of sexual and reproductive health services				
Yes (%)	2.8	1.0	7.4	2.0
No (%)	97.2	99.0	92.6	98.0
N	399	404	27	830

The following table (Table 3.13) illustrates the percentages of PLHIV who had been denied family planning services and SRH services by region.

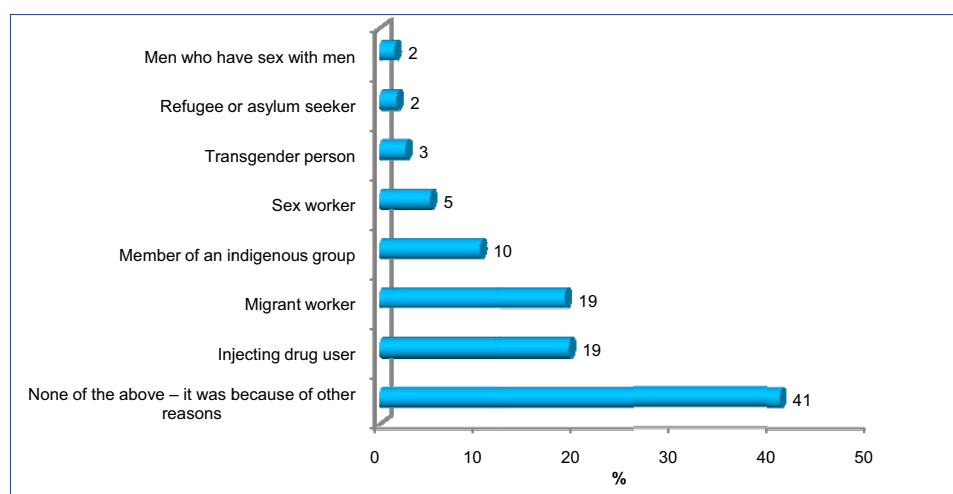
Table 3.13 Denial of family planning and reproductive health services according to development regions

	Eastern	Central	Western	Mid-Western	Far-Western	Total
Denied family planning services						
Yes (%)	3.2	2.1	1.5	1.8	5.0	2.7
No/Not applicable (%)	96.8	97.9	98.5	98.2	95.0	97.3
N	154	187	260	57	181	839
Denied sexual and reproductive health services						
Yes (%)	4.5	1.6	2.3	—	0.6	2.0
No (%)	95.5	98.4	97.7	100.0	99.4	98.0
N	154	190	262	57	167	830

3.8 Experienced Stigma and Discrimination for Reasons other than HIV Status

Certain groups face discrimination because of their categorization into particular communities of the society; this is reflected in the figure below. This suggests that stigma and discrimination to these groups are prevalent irrespective of their HIV status. Stigma and discrimination was reported to be the highest for IDUs (19%) and migrant workers (19%) as compared to other groups (Figure 3.5).

Figure 3.5 Experienced stigma and/or discrimination for reasons other than HIV status (N = 758)



The results from the current study clearly indicate that PLHIV are facing stigma and discrimination at various levels of the society and this stigma and discrimination varies only in terms of their intensity. Unfortunately, the PLHIV, irrespective of their gender, age, occupation, etc., face stigma and/or discrimination on a daily basis by other people at the family level, community level, workplace, educational institutional and unfortunately even at health facilities.



Chapter 4

Self-Stigma

4.1 Feeling of Self-Stigma

Self-stigma is common among PLHIV, which is clearly reflected in the survey results. During the survey, respondents presented a number of instances related to self-stigma that PLHIV generally face owing to their HIV status. They were asked to indicate whether they had experienced any instances of self-stigma during the 12 months prior to the survey. Approximately nine out of ten respondents (87%) stated that they had experienced at least one feeling, such as shame, blaming themselves, guilt, blaming others, low self-esteem, suicidal thoughts and willingness to be punished. Feelings of self-stigma were found to be slightly lesser among female (81%) than among male (92%) respondents, and it was 100 per cent for transgender respondents. Moreover, the feelings of self-stigma were slightly higher among respondents residing in urban areas (90%) rather than those residing in rural areas (87%). All the PLHIV respondents residing in the Mid-Western development regions expressed internal feelings of stigma, whereas 81 per cent of PLHIV belonging to the Far-Western development regions expressed feelings of self-stigma. Moreover, the results indicated that such internal feelings commonly arose among respondents below the age of 25 years (98%) compared to those in the 25-39 (88%) and older (40 years and above) age groups (86%). Only slight variation was found in the feelings of self-stigma among the respondents living with HIV for different lengths of time.

Table 4.1 Feeling of self-stigma according to selected background characteristics

	Percentage (%)	N (unweighted)
Age		
<25	97.2	41
25-39	87.3	538
40+	86.9	250
Sex***		
Male	91.9	402
Female	81.0	419
Transgender person	100.0	27
Place of residence		
Urban	89.5	286
Rural	87.3	495
Development region		
Eastern	96.5	156
Central	90.6	190
Western	84.9	263
Mid-Western	100.0	57

	Percentage (%)	N (unweighted)
Far-Western	80.6	182
Duration of HIV infection		
Within one year	90.4	16
1-2 years	91.1	174
3-5 years	87.0	365
>5 years	86.7	271
Total	87.2	848

*** $p < 0.001$; ** $p < 0.01$

4.2 Types of Feelings Experienced

A majority of the male respondents (87%) and transgender respondents (93%) blamed themselves for acquiring HIV. Twenty-three per cent of the female respondents, that is, approximately four times lesser than the percentage of male and transgender respondents, blamed themselves for acquiring the infection. However, as compared to the male (3%) and transgender (4%) respondents, a large number of female respondents (57%) blamed others for acquiring the infection. The survey results showed that guilt (86%), shame (53%) and low self-esteem (48%) were the other most prevalent feelings of male respondents, whereas the corresponding percentages for transgender respondents were guilt (89%), shame (100%) and low self-esteem (74%). It was found that as compared to female (17%) and male (11%) respondents, a greater proportion of transgender (56%) respondents experienced suicidal feelings associated with HIV (Table 4.2).

Table 4.2 Feelings of Self-stigma

Situations of feeling	Male	Female	TG person	Total
I blame myself (%)	86.8	22.9	92.6	55.4
I feel guilty (%)	85.6	18.6	88.9	52.6
I feel ashamed (%)	52.7	41.5	100.0	48.7
I have low self-esteem (%)	47.8	34.4	74.1	42.0
I blame others (%)	3.2	56.8	3.7	29.7
I feel suicidal (%)	11.2	16.7	55.6	15.3
I feel I should be punished (%)	18.2	2.4	22.2	10.5
N	402	419	27	848

Case Study 4. Ram Sharma (name changed to protect privacy)

“If I had not disclosed my status, I would have succumbed to my suicidal thoughts and died long ago.”

Ram Sharma and his wife had four children together. Today, only their nine-year-old daughter is alive. His wife discovered that both she and her daughter were HIV-positive after having lost two other children. She had just given birth to her fourth child, her daughter, who also died when she was only 27 days old.

On getting the news of the death of their youngest born, Ram hurried home. Going through his medical records, Ram found a record of an HIV test that his doctor in Mumbai had conducted when he had been hospitalized for a suspected case of typhoid. The doctor had conducted the test without telling him. The record showed that he was HIV-positive. The doctor had informed Ram’s employer of his status, who in turn notified Ram’s father. However, no one shared this information with Ram.

Ram was furious with the doctor in India. “Two of my children died. Had I known, my third child wouldn’t have died. My children died before my eyes, it makes me so depressed.”

Ram underwent testing once again, which confirmed his positive status. He felt depressed, despondent and had suicidal thoughts. “When I learned my status, I was tempted to jump off the bridge over a river,” says Ram.

Ram stayed at a community-based residential care and treatment center, Navajivan, for about four months, where he saw other similar people and found the strength to recover and live. After returning home, Ram continued working, first with Navajivan and then with Transcultural Psychosocial Organization (TPO) Nepal. Today, he works as a psychosocial counsellor in three Village Development Committees. He visits the homes of the 92 people in these villages who have been diagnosed as HIV-positive, and provides social support and counselling. Now, Ram also takes care to have safer sex with his wife.

Ram has overcome the profound loss of three of his children, his sense of betrayal by his doctor in India, and his suicidal impulses upon learning his status. Now he accepts himself as being HIV-positive. “If I had not disclosed my status, I would have succumbed to my suicidal thoughts and died long ago,” he reflects.

4.3 Measures Adopted

Self-stigma had also led respondents to either take or avoid taking various types of actions in their lives. The most prominent action that was taken by the male, female and transgender respondents (60%, 62% and 52%, respectively) was to refrain from having (any more) children as a result of being HIV-positive, followed by not getting married (30% male, 47% female and 77% transgender respondents). More than one-third of the female respondents

(35%) stated that they had decided not to have sex again as compared to a small proportion of the male (7%) and transgender (7%) respondents. Thirteen per cent of the respondents had decided to stop attending social gatherings and over 10 per cent had decided not to visit local clinics or had isolated themselves from family and friends. In addition, 7 per cent had decided not to visit hospitals when they needed medical care (Table 4.3). The decision of not visiting clinics or hospitals even when in need indicates the experiences of stigma and discrimination within healthcare settings.

Table 4.3 Measures adopted

Measures	Male	Female	TG person	Total
Decided not to have (more) children (%)	59.7	61.6	51.9	60.4
Decided not to get married (%)	29.4	46.8	76.9	39.4
Decided to become celibate (%)	6.7	35.3	7.4	20.9
Chosen not to attend social gathering(s) (%)	13.2	10.7	40.7	12.9
Isolated from family and/or friends (%)	7.5	11.9	63.0	11.4
Avoided visiting a local clinic for medical care (%)	10.4	9.1	40.7	10.7
Avoided visiting a hospital for medical care (%)	6.7	6.2	22.2	7.0
Withdrew from education/training or did not take up an opportunity for education/training (%)	8.2	4.1	7.4	6.1
Decided to stop working (%)	6.2	3.1	—	4.5
Decided not to apply for a job/work or for a promotion (%)	2.0	1.9	7.4	2.1
N	402	419	27	848



Chapter 5

Rights, Laws and Policies

Case Study 5. Chandra Biswakarma (name changed to protect privacy)

“People in the villages used to call it the disease from Mumbai.”

Chandra Biswakarma was working as a driver in India when he developed severe diarrhoea. His boss referred him to a doctor, who tested Chandra for HIV without informing him, and then sent the results to Chandra’s boss. Chandra’s boss began to mock him for being HIV-positive, and this made Chandra feel very frustrated. When Chandra realized that his doctor had notified his boss rather than Chandra about the results of his HIV test, he became upset and quit his job. At the time, however, he found another job.

Later, when he contracted herpes zoster, he was advised to undergo HIV testing and discovered that he was HIV-positive. Chandra had no awareness about the modes of transmission of HIV. He continued to engage in unsafe sex in India, and with his wife when in Nepal. He says, “If I had known that having unsafe sex could transmit the virus, I would not have done it.” Further, he was unaware about the available services and thought that treating HIV cost a lot of money.

He eventually disclosed his status to his wife suggesting separation as he thought he would not live very long; however, his wife accepted him despite his status. She also tested positive, but fortunately, his children tested negative. Chandra took ART and now his health has improved. In 2006, Chandra thought of helping people like him, and started working in the HIV sector. Today, he is a counsellor for an NGO and by his efforts, contributes to creating a conducive environment for the hidden population of PLHIV to disclose their status.

5.1 Awareness of PLHIV regarding the Rights, Laws and Policies

Currently, Nepal has no specific laws or policies related to HIV; therefore, information was sought only on an international agreement of 2001 called “Declaration of Commitment on HIV/AIDS.” The declaration affirmed that the realization of human rights and fundamental freedom for all is essential for reducing vulnerability to HIV and protecting the rights of the PLHIV.

Only one in four PLHIV (26%) had heard of the “Declaration of Commitment on HIV/AIDS.” The proportion of respondents demonstrating awareness of the declaration was the lowest among transgender respondents (7%), followed by female (20%) and male (32%) respondents. Of those who had heard of the declaration, 63 per cent reported having ever read or discussed the content of this declaration. Among the transgender respondents, only two of those who had heard about the declaration had ever read or discussed the content of the document (Table 5.1).

Table 5.1 Awareness of the “Declaration of Commitment on HIV/AIDS” that protects the rights of PLHIV

	Male	Female	TG person	Total
Heard of the “Declaration of Commitment on HIV/AIDS,” which protects the rights of people living with HIV				
Yes (%)	33.9	20.2	7.4	26.3
No (%)	66.1	79.8	92.6	73.7
N	401	416	27	844
Ever read or discussed the content of this declaration				
Yes (%)	63.2	63.1	50.0	63.1
No (%)	36.8	36.9	50.0	36.9
N	136	84	2	222

Analysis by region indicates that the respondents of the Eastern region were the most knowledgeable (56%) about the declaration, followed by the respondents of the Mid-Western region (37%). The respondents belonging to the Western and Far-Western regions were least knowledgeable regarding the declaration (16% each) (Table 5.2).

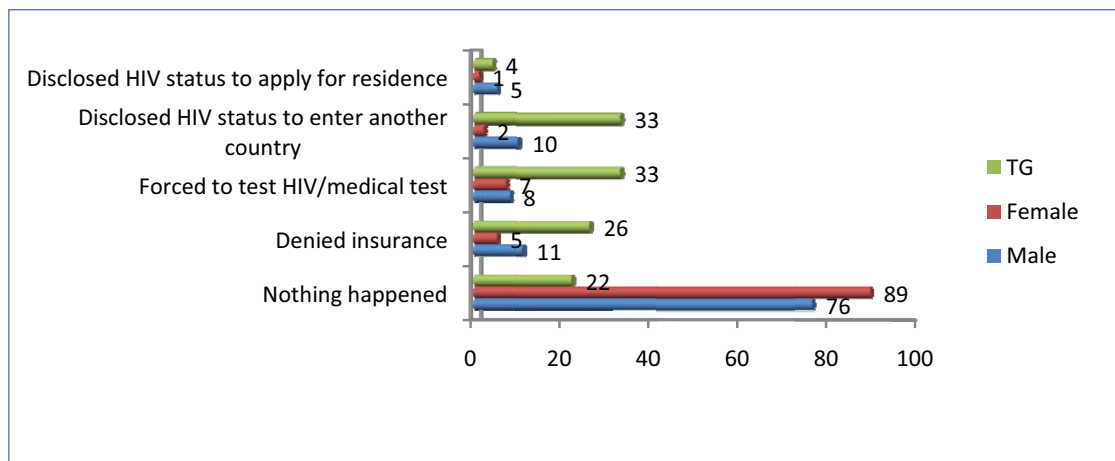
Table 5.2 Awareness of the “Declaration of Commitment on HIV/AIDS” that protects the rights of the PLHIV by region

	Development region					Total
	Eastern	Central	Western	Mid-Western	Far-Western	
Have you heard of the “Declaration of Commitment on HIV/AIDS,” which protects the rights of the PLHIV?						
Yes (%)	56.4	22.1	16.1	36.8	16.1	26.3
No (%)	43.6	77.9	83.9	63.2	83.9	73.7
N	156	190	261	57	180	844

5.2 Violation of Rights

Respondents were presented with a number of situations regarding the violation of their rights arising owing to their HIV status (Figure 5.1). They were asked to indicate whether any of the situations were experienced by them in the 12 months prior to the survey. Denial of health/life insurance (9%), followed by forceful testing for HIV during medical procedure (8%) were the violations of rights that were reportedly experienced by the respondents during the 12 month period prior to this survey. A significant number of respondents (6%) were compelled to disclose their HIV status to enter another country.

Figure 5.1 Violation of rights



Percentage total exceeds 100 due to multiple responses

The violation of right that was experienced most often by the respondents of the Mid-Western region was denial of insurance (28%), and none of the respondents experienced any forceful testing for HIV during medical examination. In the Eastern region, the most experienced rights violation was forceful testing of their HIV status during medical examination, as reported by 18 per cent of respondents. In contrast, the respondents of the Far-Western region reported the least number of experiences of rights violation across regions (Table 5.3)

Table 5.3 Region-wise violations of rights

During the last 12 months, have you experienced any of the following situations because of your HIV status?	Development region					Total
	Eastern	Central	Western	Mid-Western	Far-Western	
Denied health/life insurance (%)	7.1	12.1	7.6	28.1	2.2	8.7
Forced to test for HIV/medical examination (%)	17.9	9.5	6.1	—	3.3	8.0
Asked to disclose HIV status to enter another country (%)	10.3	12.1	4.6	1.8	1.1	6.4
Asked to disclose HIV status to apply for residence (%)	5.1	3.7	2.3	1.8	0.5	2.7
None of these things happened to me/No Response (%)	69.2	73.2	85.2	70.2	94.5	80.5
N	156	190	263	57	182	848

Percentage total exceeds 100 due to multiple responses

Data indicates that respondents were subjected to a range of rights violations due to their HIV status. One out of eight respondents (14%) had reported that their rights violations had occurred during the 12 months prior to the survey. The proportion of females who had experienced rights violations during the 12 months prior to survey was higher (20%) than that of males (9%) during the same period. Out of the respondents who experienced rights violations during the previous 12 months, one out of eight (14%) attempted to seek legal redress. The legal process yielded mixed results. Approximately 35 per cent of the respondents stated that the matters of rights violation had been resolved, 24 per cent had stated that the matter was still in process and 41 per cent of the respondents failed to achieve any result through the legal process. In order to protect their rights, approximately one respondent out of ten respondents (11%) sought the support of government employees, whereas a similar proportion (10%) of respondents approached politicians (Table 5.4).

Table 5.4 Violation of human rights and effort to seek legal redress

	Male (%)	Female (%)	Total (%)
Violation of human rights and effort to seek legal redress			
Violation of the rights of a person living with HIV (N = 845)	8.2	20.0	14.0
Attempted to seek legal redress for any violation of rights (N = 117)	17.1	13.4	14.5
The outcome of legal redress (N = 17)			
The matter has been dealt with	33.3	36.4	35.3
The matter is still in process	33.3	18.2	23.5
Nothing happened/the matter was not dealt with	33.3	45.5	41.2
Attempted to seek support from a government employee (N = 8)	14.7	9.6	11.0
Attempted to seek support from a politician (N = 7)	11.8	9.6	10.2

5.3 Reasons for Not Taking Action against Violation of Rights

Amongst the respondents who did not take any action against a violation of their rights, the highest proportion of respondents (29%)—including two-fifths of the male (38%) and a quarter of the female (25%) respondents—cited lack of financial resources as the primary reason for not taking any action. The other reasons mentioned for not seeking legal redress are as follows: received advice to not take action (9%), fear of consequences (7%), lengthy bureaucratic processes (5%) and no/little confidence in the possibility of success (5%) (Table 5.5).

Table 5.5 Reasons for not seeking legal redress

Reasons for not seeking legal redress	Male	Female	Total
Insufficient financial resources to take action (%)	37.9	25.0	28.7
Was advised to not take action (%)	13.8	6.9	8.9
Felt intimidated or scared to take action (%)	3.4	8.3	6.9
Process of addressing the problem appeared too bureaucratic (%)	10.3	2.8	5.0
No/little confidence that the outcome would be successful (%)	3.4	5.6	5.0
None of the above (%)	31.0	51.4	45.5
N	28	72	101*

** Only one TG person mentioned that someone advised against taking action, which is not shown in the table*

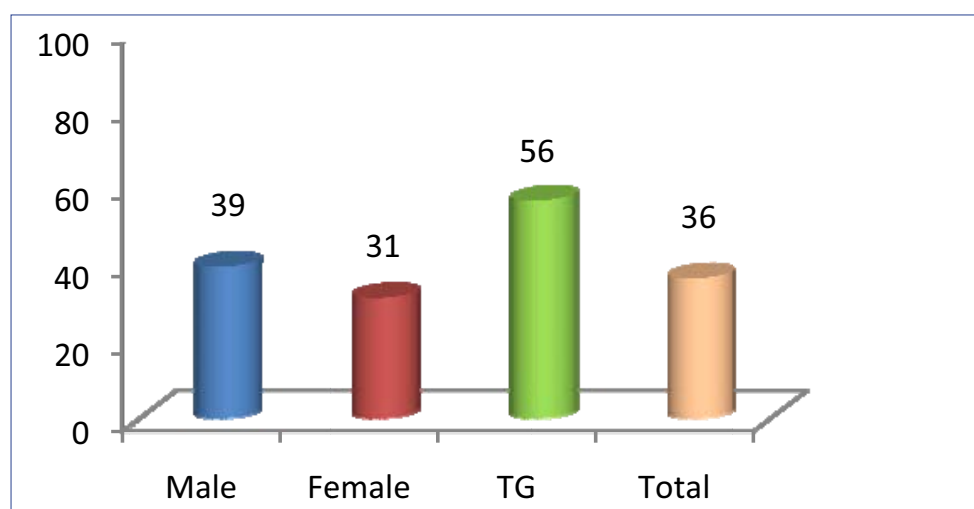


Chapter 6

Effecting Change

HIV-positive people can play an important role in effecting change in their communities. However, the main obstacle to participation and contribution in this process is the fear of disclosure and related fears of stigma and discrimination. Very few HIV-positive people are willing to voluntarily and publicly disclose their HIV status. Out of these HIV-positive people, some are able to confront, challenge and educate those who discriminate against and stigmatize them. It must be noted that one-third of the respondents (36%) encountered situations during the 12 months prior to the survey wherein they had to educate (inform, confront or challenge) someone who discriminated against or stigmatized them. The transgender respondents were much more likely than the male and female respondents to educate (56%) someone who discriminated against or stigmatized them.

Figure 6.1 Confronted, challenged or educated someone who was stigmatizing PLHIV



Approximately half of the respondents from the Eastern region and approximately two-fifths of the respondents from the Mid-Western (44%) and Central regions (42%) had reportedly experienced situations wherein they had to educate someone who demonstrated discriminatory behaviour/attitude against them. Respondents belonging to the Western region reported such incidences (discriminatory behaviour of the people) less frequently (26%) than respondents of other regions (Table 6.1).

Table 6.1 Confronted, challenged or educated someone who was discriminating against the PLHIV by regions

During the last 12 months, have you confronted, challenged or educated someone who was discriminating against and/or stigmatizing you?	Development region					Total
	Eastern	Central	Western	Mid-Western	Far-Western	
Yes (%)	46.8	41.6	26.2	43.9	30.9	35.7
No (%)	53.2	58.4	73.8	56.1	69.1	64.3
N	156	190	263	57	178	844

It is important for the PLHIV to be aware of who they can seek support from for addressing discriminatory behaviour against them and for taking action against those who violate their rights. Most of the PLHIV were aware of the organizations that they could approach if they experienced stigma and or discrimination. PLHIV support groups (95%) and networks (70%) were the most well-known organizations that they could approach, followed by local non-governmental organizations (38%), district AIDS coordination committee (25%), legal practitioners (20%) and human rights organizations (19%), if they experienced stigma and/or discrimination. A few respondents (7%) had sought the help of these organizations/groups to resolve the issues of stigma and discrimination (Table 6.2).

Table 6.2 Awareness of the PLHIV regarding the types of organizations or groups that can help them fight against stigma and/or discrimination

	Male (%)	Female (%)	Total (%)
Knowledge about organizations/groups that can help them if they experience stigma or discrimination (N = 847)			
Yes	85.5	86.1	85.8
No	14.5	13.9	14.2
Types of organizations/groups they know** (N = 727)			
People living with HIV support group	94.6	95.6	95.0
Network of people living with HIV	66.8	73.1	69.9
Local non-governmental organization	38.1	38.0	38.1
District AIDS Coordination Committee	30.2	18.9	24.6
A legal practitioner	21.5	18.3	19.9
A human rights organization	24.0	13.1	18.6
National non-governmental organization	15.0	11.7	13.3
National AIDS council or committee	14.2	11.9	13.1
UN organization	8.4	8.6	8.5
Have sought help from any of the above organizations/groups to resolve an issue of stigma or discrimination (N = 840)			
Yes	6.5	6.6	6.5
No	93.5	93.4	93.5

***Percentage totals exceed 100 due to multiple responses*

It is rather common for people living with HIV to support other people living with HIV. During the 12 months prior to the survey, over half of the respondents (54%) reportedly provided support to other people living with HIV. Out of those providing support, a vast majority provided emotional support (92%), followed by referral to services (42%) and physical support (29%) (Table 6.3).

A majority of the respondents (65%) were also currently members of an HIV support group/network. The proportion of females who were found to be a part of this support group/network was higher (72%) than that of males (51%) (Table 6.3).

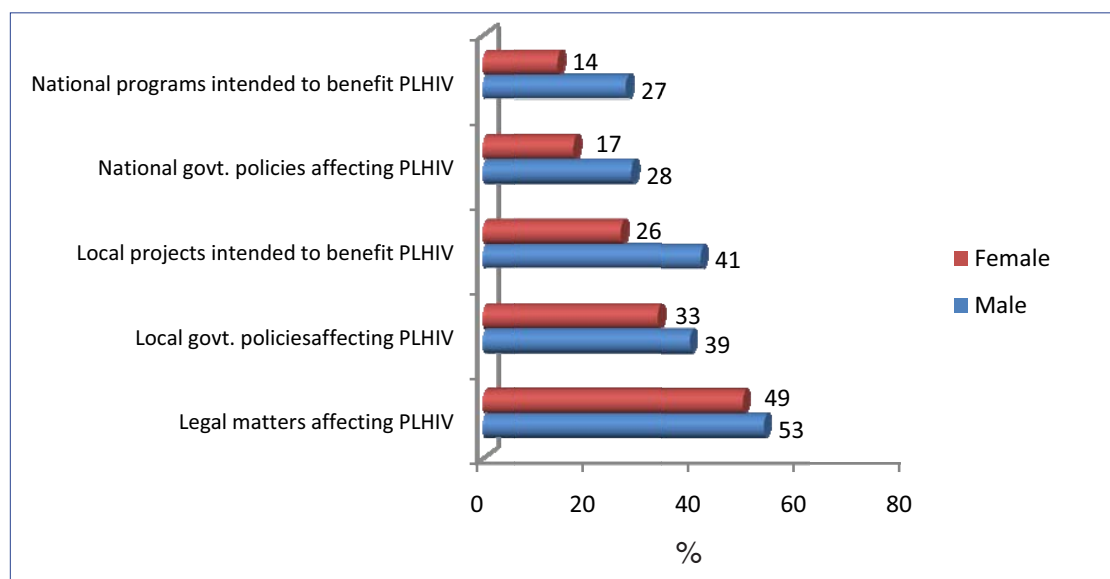
Table 6.3 Support/types of support provided to other PLHIV and members of a PLHIV network currently

	Male (%)	Female (%)	Total (%)
Support provided to other people living with HIV (N = 839)	61.8	45.9	54.0
Types of support provided** (N = 453)			
Emotional support (e.g. counselling, sharing personal stories, etc.)	91.3	92.6	91.8
Referral to other services	49.6	32.3	42.4
Physical support (e.g. providing money or food and necessary information)	34.5	22.2	29.4
Currently a member of a PLHIV support group and/or network (N = 825)	59.3	71.8	65.3

**Percentage totals exceed 100 due to multiple responses

Overall, half of the respondents (51%) strongly felt that they had the power to influence any legal matters that affect the lives of people living with HIV (Figure 6.2).

Figure 6.2 Feeling of power to influence policies



The percent total exceeds 100 due to multiple responses. The percentage of transgender people is too low to be presented.

A number of suggestions were offered by PLHIV in order to address stigma and discrimination by organizations involved. They allocated the highest priority to advocacy for the rights of PLHIV (40%), followed by the provision of emotional support (23%) to them. A vast majority of the transgender respondents (89%) had suggested the involvement of organizations to advocate for the rights of and/or provide support to particularly marginalized groups including MSM, IDUs, FSWs, etc. (Table 6.4).

Table 6.4 Suggestions provided to address the issue of stigma and discrimination by organizations involved

	Male	Female	TG person	Total
Advocating for the rights of all PLHIV (%)	36.4	46.0	7.4	40.2
Providing emotional support to PLHIV (%)	30.2	17.8	3.7	23.2
Raising awareness and knowledge of the public about AIDS (%)	18.0	23.1	—	19.9
Educating the PLHIV about living with HIV (%)	12.2	9.7	—	10.6
Advocating for the rights and/or providing support to particularly marginalized groups (MSM, IDUs, FSWs) (%)	3.2	1.7	88.9	5.2
Don't know (%)	—	1.7	—	0.8
N	428	411	27	839

Case Study 6. Binita Gurung (name changed to protect privacy)

“Now I am out of the house and the founder of an NGO.”

Binita Gurung learned that she had acquired HIV from her injecting drug user husband when he fell sick in 2004. Unclear about the difference between HIV and AIDS, Binita felt terrified that she would die, and that her children would be orphans with no support. Then, her husband disappeared. Six months pregnant, with two children already, Binita found a job at a family planning clinic where she met Shyam, an HIV activist. He told her that he was HIV-positive and helped her gain knowledge on HIV. Shyam introduced her to Nava Kiran Plus, a community-based care and treatment center in East Nepal.

Binita realized that treatment and care services specific to women were scarce and organized a group of nine women affected by HIV and AIDS to provide help, support and assistance to HIV-positive women and children. Her group received a challenge

fund grant given by NAP+N. Subsequently, Binita registered her NGO. Today, her NGO's membership has grown to more than 200 women and children. Married to Shyam now, and raising their children from both their first marriages, she advises women who do not know their HIV status, "Get tested. Don't rely on your husband alone. Protect yourself."

She is happy about this transformation in her life. "Before I knew that I was HIV-positive, I was purely a housewife," she says. "Now I am out of the house, and the founder of an NGO that provides services to women relating to reproductive health and HIV and AIDS. I was ignorant before. But now I can advocate, raise awareness and help others."

Binita has seen the power of organizing the community and that of collective voice. Her organization reaches its target audience through outreach and awareness programmes as well as through referral cards that are left at public places by women who have accessed the NGO's services. Binita emphasizes that disclosing her status publicly was critical to her success. Her example has galvanized other women to emerge from the "hidden" population of people living with HIV and AIDS. Her example has galvanized other women to emerge from the "hidden" population of people living with HIV and AIDS.



Chapter 7

HIV Testing, Disclosure and Treatment

7.1 Reasons for HIV Testing

The reasons for HIV testing vary by gender. Approximately two-fifths of the transgender (41%) and male respondents (39%), as against a quarter of female respondents (26%), stated that the reason for being tested for HIV was their desire to ascertain their status. Male respondents (24%) were more likely than transgender (22%) and female (10%) respondents to be referred by healthcare centres for HIV testing due to the manifestation of HIV-related symptoms, whereas females were ten times more likely than males to be tested because their partner had tested positive (41% vs. 5%). Although 44 per cent of the transgender respondents reported employment as the primary reason for HIV testing, a very small proportion of the female respondents, that is, 3 per cent had stated that it was the primary reason for HIV testing. The other reasons for testing HIV status reportedly included illness, illness/death of partner/family member, employment, etc. A negligible proportion of the respondents underwent HIV testing as a part of the preparation for their wedding or sexual relationship (Table 7.1).

Table 7.1 Reasons for HIV testing

Reasons	Male	Female	TG person	Total
Just wanted to know (%)	38.6	25.5	40.7	32.3
Partner/family members tested positive (%)	4.5	40.6	—	22.1
Illness or death of a partner/family members (%)	8.3	34.5	20.9	20.8
Referred due to suspected HIV-related symptoms (%)	24.3	9.7	22.2	17.1
Employment (%)	19.8	2.4	44.4	12.1
Due to illness (%)	10.6	7.8	11.1	9.2
Referred by a clinic for sexually transmitted infections (%)	3.8	3.6	33.3	4.7
Drug User (%)	4.0	—	—	1.9
To prepare for a marriage/sexual relationship (%)	1.3	0.7	3.7	1.1
Pregnancy (%)	.5	3.4	—	1.9
N	426	411	27	837

Percentage totals exceed 100 due to multiple responses

7.2 Extent of Decision-making Freedom for HIV Testing

A majority of the respondents (81%) voluntarily took the decision to be tested for HIV, whereas one-fifth of the respondents (19%) stated that they were pressured to undergo testing or were tested without their knowledge. Out of the latter group of respondents, seven per cent

reportedly took the decision to be tested under pressure from others, six per cent were coerced into taking an HIV test, whereas a similar proportion (6%) of respondents were tested without their knowledge. Females were more likely than males to be pressured into taking an HIV test (9% vs. 5%). All transgender respondents reportedly took the decision to be tested for HIV voluntarily (Table 7.2).

Table 7.2 Decision to be tested for HIV

Decision to be tested for HIV	Male	Female	TG person	Total
I took the decision myself to be tested (%)	80.7	80.0	100.0	81.0
I took the decision to be tested, but under pressure (%)	4.8	9.1	—	6.8
I was coerced to test for HIV (%)	6.6	5.4	—	5.8
I was tested without my knowledge (%)	7.9	5.4	—	6.4
N	420	406	27	826

The region-wise data on the reasons for respondents to undergo testing voluntarily/involuntarily indicates that the proportion of respondents who voluntarily took the decision to be tested for HIV was the highest in the Eastern region (93%), followed by the Mid-Western region (90%) and the Far-Western region (84%). The proportion of respondents who were pressurized to take the decision to undergo HIV testing was the highest in the Central region (17%), 14 per cent of whom also claimed that they were tested for HIV without their knowledge, whereas the proportion of respondents who were reportedly coerced to undergo HIV testing was the highest in the Far-Western region (12%) (Table 7.3).

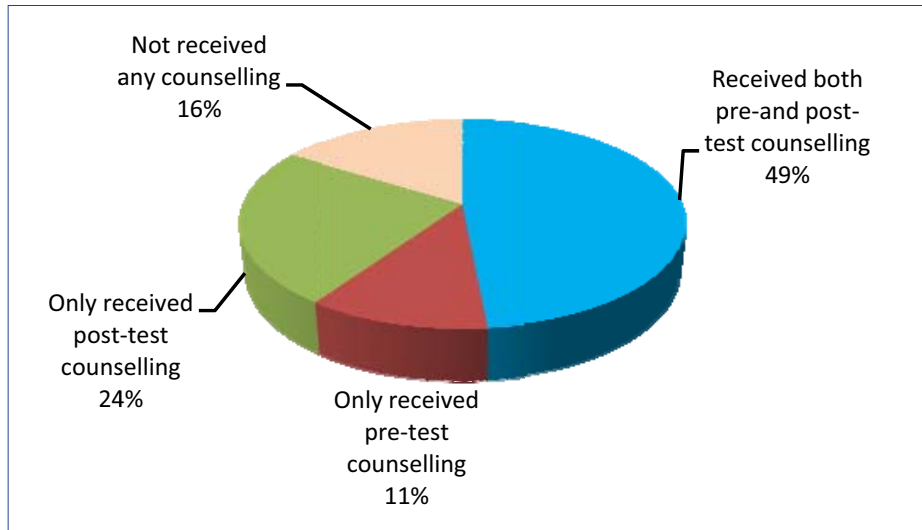
Table 7.3 Decision to be tested for HIV by regions

Was the decision to be tested for HIV up to you?	Development region					Total
	Eastern	Central	Western	Mid-Western	Far-Western	
I took the decision myself to be tested (%)	92.8	65.1	81.8	89.5	83.9	81.0
I took the decision to be tested, but under the pressure (%)	1.3	16.9	6.7	3.5	1.7	6.8
I was coerced to test for HIV (%)	5.2	4.2	3.6	5.3	11.5	5.8
I was tested without my knowledge (%)	0.7	13.8	7.9	1.8	2.9	6.4
N	153	189	253	57	174	826

7.3 Counselling for HIV Testing

Although almost half of the respondents stated that they had received both pre- and post-test counselling, 11 per cent had reportedly received only pre-test counselling and 24 per cent had received only post-test counselling. A significant number of respondents (16%) had reportedly received no counselling of any sort (Figure 7.1)

Figure 7.1 Counselling for HIV testing (N = 839)



7.4 Disclosure

In this survey, PLHIV respondents were enquired if they had disclosed their HIV status to anyone or if any other person, with or without their consent, had disclosed their status. It was encouraging to find that almost all the respondents (90%) had disclosed their status to others voluntarily and only 10 per cent stated that another person had disclosed their status, with or without their consent (Figure 7.2).

The data indicates that a large majority of respondents, across regions, voluntarily disclosed their HIV status to others. However, 15 per cent of the respondents in the Western region, 12 per cent in the Far-Western region and 11 per cent in the Mid-Western region stated that their HIV status was disclosed by someone else, with or without their consent (Table 7.4).

Figure 7.2 Ways of HIV status disclosure (N = 848)

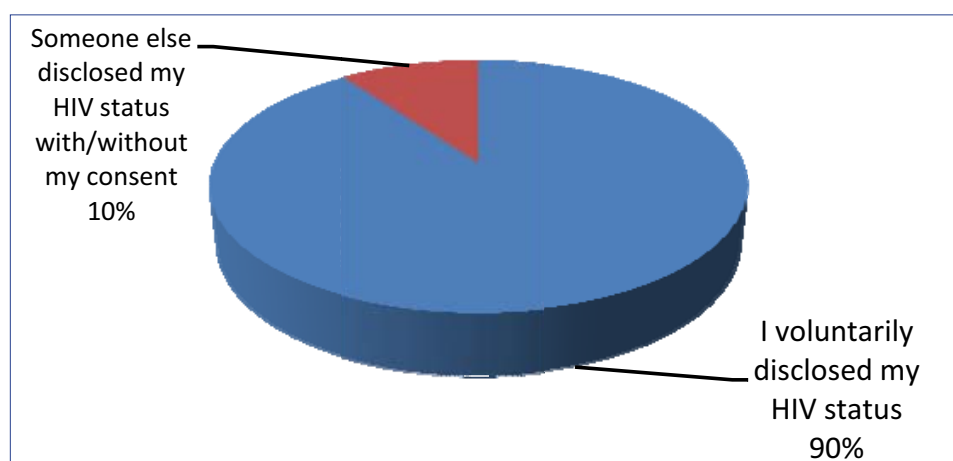


Table 7.4 Ways of HIV disclosure by regions

Ways of HIV status disclosure	Development region					Total
	Eastern	Central	Western	Mid-Western	Far-Western	
I voluntarily disclosed my HIV status (%)	96.2	92.1	84.8	89.5	88.5	89.6
Someone else disclosed my HIV status with/without my consent (%)	3.8	7.9	15.2	10.5	11.5	10.4
N	156	190	263	57	182	848

Table 7.5 provides the analysis of the type of persons to whom the PLHIV respondents disclosed their status, themselves or through someone else, with or without their consent. As this table indicates, a large majority of the PLHIV (70%) had voluntarily disclosed their status to other PLHIV whom they had encountered. The other types of persons to whom they had voluntarily disclosed their status included health workers (55%), spouses/partners (50%) and other adult family members (50%). Respondents were not found to be as comfortable in sharing their HIV-status-related information with co-workers, friends/neighbours, employers, and their own children, directly or indirectly. Approximately one-third of the respondents reported that they had disclosed their status voluntarily to co-workers (33%), friends/neighbours (31%) and children in the family (29%) (Table 7.5).

Table 7.5 Ways of HIV status disclosure to various categories of population

	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/ NR (%)
Other people living with HIV	70.0	5.8	7.3	3.2	13.7
Healthcare workers	55.9	5.9	5.8	4.4	28.1
Spouses/partner	50.4	5.7	8.5	7.5	28.0
Other adult family members	50.4	8.0	12.6	9.9	19.1
Social workers/counsellors	46.3	7.4	6.0	6.8	33.4
People who you work with (co-workers)	33.0	3.2	4.2	13.6	46.0
Friends/neighbours	31.0	4.6	17.5	18.6	28.3
Children in family	29.5	3.1	6.3	19.5	41.7
Employer(s)/boss(es)	18.6	1.3	2.1	11.9	66.0
Community leaders	12.9	3.8	6.5	16.7	60.1
Injecting drug partners	12.6	0.7	3.2	8.1	75.4
The media	10.1	1.1	1.8	17.2	69.8
Teachers	9.8	2.0	4.0	17.2	67.0
Government officials	7.8	1.8	1.5	16.4	72.5
Clients	4.3	0.9	0.6	10.0	84.2
Religious leaders	4.2	0.8	1.7	16.2	77.1
N	848				

When asked if the respondents had felt pressurized to disclose their HIV status, 14 per cent of the respondents expressed that they were pressurized either from other individuals living with HIV or groups/networks of PLHIV. Of these, 2 per cent of the respondents experienced this often and 10 per cent experienced this a few times. On the other hand, 10 per cent felt such pressure from people not living with HIV (including 2% who experienced this often and 7% who experienced this a few times). Males felt more pressure than females from both types of individuals—those with and without HIV—and networks of PLHIV to disclose their status (Table 7.6).

Table 7.6 Felt pressure to disclose HIV status

Felt pressure to disclose HIV status	Male	Female	Total
Felt pressure from other individuals living with HIV or from groups/networks of PLHIV			
Often (%)	0.7	3.4	2.1
A few times (%)	15.5	5.4	10.5
Once (%)	2.4	1.0	1.7
Never (%)	81.4	90.2	85.7
N	419	408	827
Felt pressure from other individuals not living with HIV			
Often (%)	1.4	3.2	2.3
A few times (%)	10.1	4.4	7.3
Once (%)	.9	.7	.8
Never (%)	87.5	91.7	89.6
N	424	411	835

Analysis by region indicates that a majority of the respondents across regions did not feel any pressure from PLHIV, their network or other individuals not living with HIV to disclose their HIV status. On an average, 86 per cent of the PLHIV reported that they did not feel any pressure from individuals living with HIV or their networks to disclose their HIV status. Similarly, 90 per cent of the PLHIV reported that they did not feel any pressure from individuals not living with HIV to disclose their HIV status. However, the proportion of respondents who were reportedly pressurized to disclose their status a few times, either by individuals living with HIV/networks of PLHIV (19%) or by persons not living with HIV (12%) was the highest in the Central region (Table 7.7).

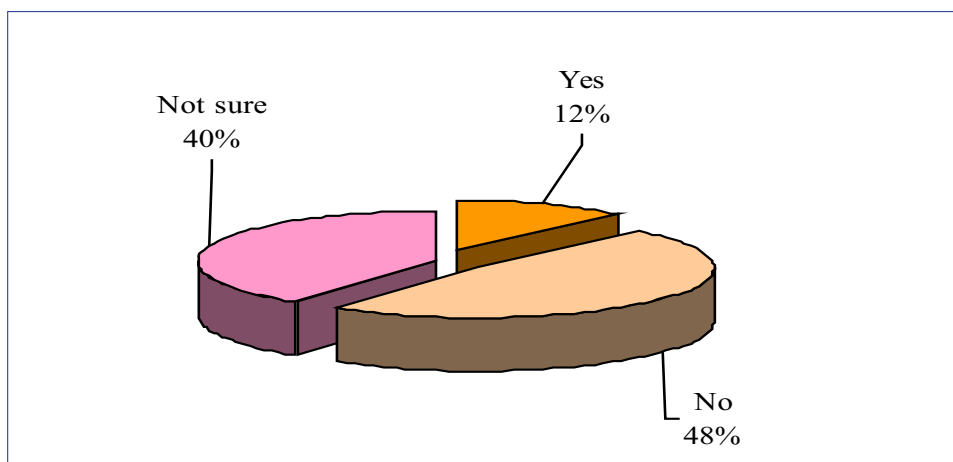
Table 7.7 Felt pressure to disclose HIV status by region

Felt pressure to disclose HIV status	Development region					Total
	Eastern	Central	Western	Mid-Western	Far-Western	
Felt pressure from other individuals living with HIV or from groups/networks of PLHIV						
Often (%)	2.7	1.1	4.3	—	—	2.1
A few times (%)	12.1	18.8	10.5	—	4.0	10.5
Once (%)	—	2.2	2.3	1.8	1.7	1.7
Never (%)	85.2	78.0	82.9	98.2	94.4	85.7
N	149	186	258	57	177	827

Felt pressure to disclose HIV status	Development region					Total
	Eastern	Central	Western	Mid-Western	Far-Western	
Felt pressure from other individuals not living with HIV						
Often (%)	0.7	2.2	5.0	—	0.6	2.3
A few times (%)	5.3	11.8	8.9	3.5	3.3	7.3
Once (%)	—	0.5	0.8	3.5	1.1	.8
Never (%)	94.1	85.5	85.3	93.0	95.0	89.6
N	152	186	259	57	181	835

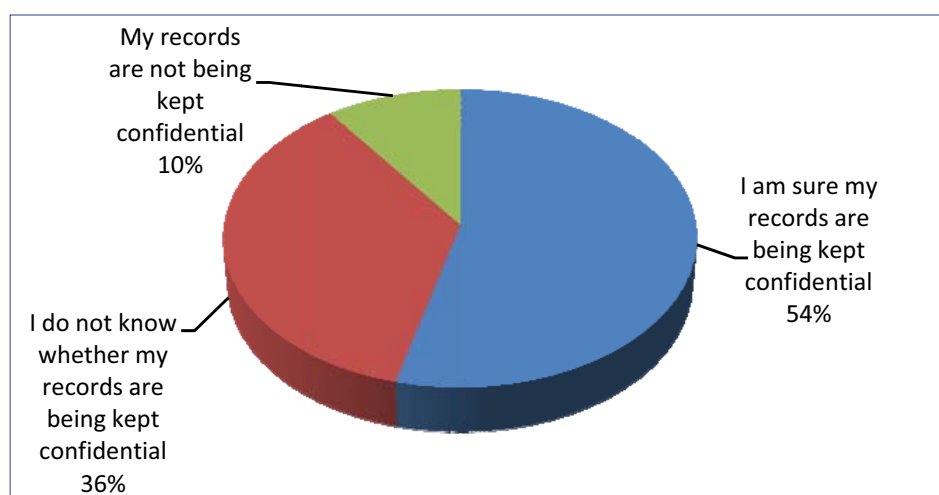
When asked whether they were aware of any incident wherein a health worker had disclosed their HIV status to others, 12% of the respondents reported at least once such incident wherein their status was disclosed without their permission. Two-fifths of the respondents (40%) reported that they were unsure if their status had been disclosed by a healthcare worker. These figures demonstrate that confidentiality is a major concern for PLHIV.

Figure 7.3 Disclosure of status by healthcare worker without consent (N = 814)



The chart below depicts the awareness levels of respondents regarding the confidentiality of their HIV-related medical records. Approximately half of the respondents (54%) believed that their records were kept confidential. Over 36 per cent of the respondents were not sure whether their HIV records were kept confidential and 10 per cent claimed that their HIV records were not being kept confidential (Figure 7.4).

Figure 7.4 Confidentiality of records relating to HIV (N = 805)



7.4.1 Attitudes and reactions to disclosure of HIV status

Table 7.8 presents the analysis of the general reactions of various individuals to the disclosure of respondent's HIV status. Positive reactions were observed in most cases after disclosure. A large majority of the PLHIV community showed their support (74% including 56% supportive and 18% very supportive) after the HIV status disclosure. The attitudes of co-workers, friends and relatives towards PLHIV also did not change after their status disclosure and they were found to be supportive. The study found that overall, the attitudes of family members and spouses/partners were either supportive or remained unchanged after they were informed about the respondent's HIV status; however, 17 per cent of the respondents faced discrimination from adult family members and 9 per cent faced discrimination from their spouses/partners.

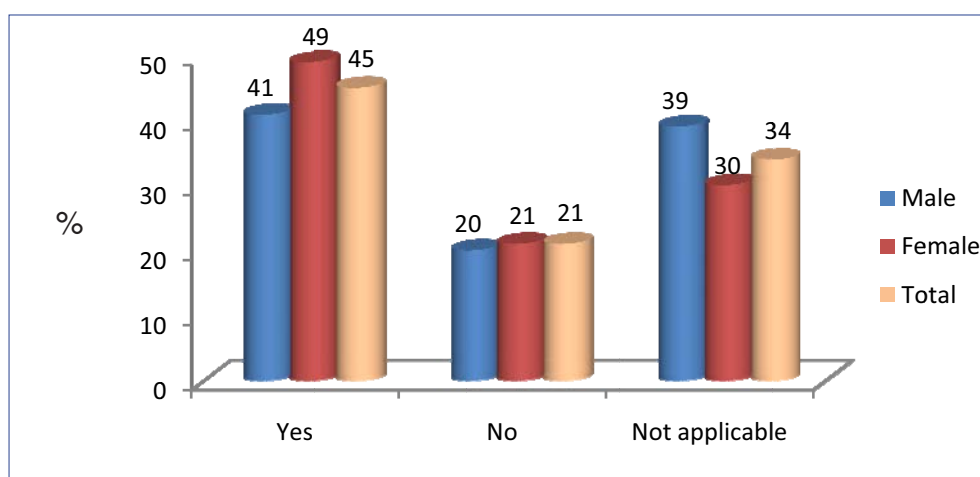
Table 7.8 Attitudes and reactions to disclosure of HIV status

	Very discriminatory (%)	Discriminatory (%)	No different (%)	Supportive (%)	Very supportive (%)	Not applicable/ NR (%)
Spouses/partner	3.4	6.1	20.0	21.2	16.2	33.0
Adult family members	8.1	9.1	22.8	24.8	8.8	26.4
Children in your family	1.1	1.3	18.6	17.7	6.3	55.1
Your friends/neighbours	7.4	8.0	22.4	19.7	1.9	40.6
Other PLHIV	0.6	0.9	9.7	56.1	17.9	14.7
Your co-workers	0.7	1.9	10.4	25.8	3.7	57.5
Your employer/boss	0.9	0.8	4.5	13.1	4.5	76.2
Your clients	0.2	0.1	2.4	2.1	0.6	94.6
Injecting drug partners	0.6	2.5	6.1	6.4	0.2	84.2
Religious leaders	0.1	0.4	4.1	3.7	0.7	91.0

	Very discriminatory (%)	Discriminatory (%)	No different (%)	Supportive (%)	Very supportive (%)	Not applicable/ NR (%)
Community leaders	1.2	1.5	8.0	12.6	0.7	75.9
Health care workers	2.7	3.2	15.6	44.8	4.1	29.6
Social workers/ counsellors	0.8	0.7	12.7	42.6	3.8	39.4
Teachers	0.7	0.7	8.3	7.4	0.6	82.3
Government officials	0.4	0.4	4.6	7.7	0.7	86.3
The media	0.1	0.2	5.8	8.3	0.8	84.8
N	848					

More than two-fifths of the respondents (45%) stated that the disclosure of their HIV status was an empowering experience for them. A higher proportion of females found disclosure to be an empowering experience as compared to males (49% vs. 41%) (Figure 7.5).

Figure 7.5 Disclosure of HIV status: An empowering experience (N = 781)



Case Study 7. Kedar Bahadur Gharti (name changed to protect privacy)

“HIV isn’t a big deal these days.”

Kedar Bahadur Gharti, a migrant worker in India at the time, had never heard of HIV when he had tested positive in 1996; he had undergone an HIV test only because it was mandatory for applying for the visa to Dubai.

Kedar did not understand the implications of the results and thought he would die. Kedar began drinking heavily. “I experienced different feelings, and I didn’t want to return home. I was afraid that if I told my family or neighbours, they

would discriminate against me.” Kedar lost confidence in himself and avoided social engagements. “I felt uncomfortable with my friends and with myself.”

After having learnt his status, Kedar tried using condoms with his wife whenever he returned to Nepal. However, Kedar’s wife wanted babies; therefore, he disregarded the advice against impregnating his wife and risked the transmission of the virus to the child. Kedar resumed the use of condoms after the birth of his two children—a son and a daughter.

In 2000, Kedar confided in his brother about his HIV-positive status. He introduced Kedar to a friend who had founded a support group for PLHIV. Kedar began attending the support group meetings. His brother also helped Kedar disclose his status to family members. Learning that Kedar was HIV-positive, his wife responded with resignation: “If you have HIV, I must, too. If you are going to die, so am I.” However, luckily, Kedar’s wife tested negative, as did his two children. Subsequently, Kedar became an outreach worker at the support group and gained knowledge of HIV awareness raising and community organizing.

Kedar emphasizes that the key to reaching the “hidden” population is a village-level campaign and persistence. Having seen many village-level interventions, members of the “hidden” population of PLHIV have also voluntarily started coming forward. Kedar has disclosed his status to his children and they feel comfortable questioning him about it, for example, they ask him, “Father, if we eat together, will we get HIV?” He uses the act of answering such questions as opportunities to teach them about transmission methods; the family, of course, eats meals together.

7.5 Antiretroviral Treatment

At the time of the survey, 66 per cent of the respondents (68% males, 64% females and 41% transgender people) were taking ART, and 48 per cent of the respondents (43% males, 53% females and 59% transgender people) were taking medications for preventing or treating opportunistic infections. In addition, 67 per cent of the respondents currently not on ART were confident that ART would be easily and readily available to them whenever they needed it in the future (Table 7.9).

Table 7.9 Access to antiretroviral treatment

	Male (N = 424) (%)	Female (N = 404) (%)	TG person (N = 27) (%)	Total (N = 428) (%)
Currently taking antiretroviral treatment				
Yes	70.0	63.6	40.7	65.9
No	30.0	36.4	59.3	34.1
Treating opportunistic infections currently	Male (N = 421) (%)	Female (N = 401) (%)	TG person (N = 27) (%)	Total (N = 822) (%)

	Male (N = 424) (%)	Female (N = 404) (%)	TG person (N = 27) (%)	Total (N = 428) (%)
Yes	41.4	52.9	59.3	47.6
No	58.6	47.1	40.7	52.4
Access to antiretroviral treatment, even if not taking currently	Male (N = 134) (%)	Female (N = 144) (%)	TG person (N = 16) (%)	Total (N = 278) (%)
Yes	68.6	72.9	6.3	67.3
No	20.3	13.9	81.3	20.5
Don't know	11.0	13.2	12.5	12.2

Most of the respondents in the Far-Western (77%) and Western regions (74%), and a majority in the Mid-Western (61%), Central (60%) and Eastern (50%) regions were reportedly taking ART at the time of survey (Table 7.10).

Table 7.10 Current use of antiretroviral treatment by regions

Are you currently taking antiretroviral treatment?	Development region					Total
	Eastern	Central	Western	Mid- Western	Far- Western	
Yes (%)	49.7	60.1	73.9	60.7	76.7	65.9
No (%)	50.3	39.9	26.1	39.3	23.3	34.1
N	155	188	253	56	176	828

The proportion of respondents who were confident of getting access to ART, currently or in the future was reported to be highest in the Mid-Western and Far-Western regions, that is, 91% and 88%, respectively. In contrast, the respondents in the Central region (where the capital city of Kathmandu is located) were less confident about the availability of ART (43%). A significant proportion of the respondents in this region (28%) stated that they did not know about the availability of ART (Table 7.11).

Table 7.11 Region-wise access to antiretroviral treatment

Do you have access to antiretroviral treatment, even if you are not currently taking it?	Development region					Total
	Eastern	Central	Western	Mid- Western	Far- Western	
Yes (%)	75.3	43.2	64.6	90.9	87.5	67.3
No (%)	18.2	28.4	29.2	—	7.5	20.5
Don't know (%)	6.5	28.4	6.2	9.1	5.0	12.2
N	77	74	65	22	40	278



Chapter 8

Having Children

Case Study 8. Sushila KC (name changed to protect privacy)

Sushila KC was married off to her sister's brother-in-law when she was in the tenth grade. Her family did not know much about his background and she discontinued her studies after passing her School Leaving Certificate (SLC) exams.

Sushila became pregnant soon after getting married. At the medical college where she was taken for her delivery, the doctors tested Sushila for HIV. She tested positive, and doctors discharged her from the hospital. When their landlord came to know about her status, he threw them out of their rented accommodation. Despite having come to know of his wife's HIV status, Sushila's husband hid the news from her. She was taken to another hospital for her delivery. Sushila says, "I gave birth to a baby boy, who died five days after he was born." Both Sushila and her husband were tested again for HIV, and both were positive. "I learned then, that I had been infected by my husband, who been a truck driver before marriage."

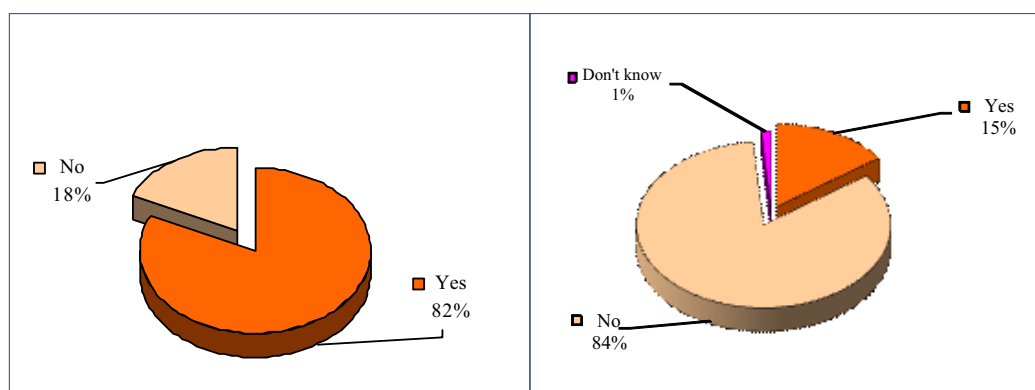
Sushila's husband became severely ill. After being taken to various hospitals, he was referred to a rehabilitation center in Kathmandu where he underwent treatment. After his recovery, the couple started working in the HIV sector in their hometown. Sushila now works as a volunteer in the ARV center. Talking about children, Sushila says, "I do not have any plans to give birth. I know I am only 28 years old, and it is possible to prevent transmission of HIV to my child while I am pregnant. I am scared however, that I may still pass it on, and I do not want to see another child of mine die from this disease."

"I would like to advise PLHIV not to carry the pain but go for treatment. Do not put your health at risk," Sushila says. "Awareness should be spread among people regarding HIV. I feel happy when I sit in front of PLHIV and give them advice/suggestions. Even the people with sad faces cheer up when I tell them that although I acquired this disease at the age of seventeen and lost a five-day-old child to this disease, today I am happy."

The stigma index study also investigated the situations related to children and health care options. The chart below shows that most of the respondents (82%) had children, and of these, 15 per cent of the children were living with HIV.

Figure 8.1 Have children (N = 819)

Figure 8.2 Children living with HIV (N = 673)



Data by region shows that 91 per cent of the respondents in the Far-Western region and 89 per cent in the Western region had children and a higher percentage of children from these regions were living with HIV. Although one-fifth of the respondents in the Far-Western (19%) and one-sixth in Western regions (16%) reported that their children were living with HIV, only one in fifteen children (6%) of the respondents in the Mid-Western region reported their children to be HIV-positive (Table 8.1).

Table 8.1 Having children and children living with HIV by regions

Do you have a child/children?	Development region					Total
	Eastern	Central	Western	Mid-Western	Far-Western	
Yes (%)	67.8	75.6	89.1	82.5	90.6	82.2
No (%)	32.2	24.4	10.9	17.5	9.4	17.8
N	152	172	258	57	180	819
If Yes, are any of these children known to be HIV-positive ?						
Yes (%)	13.6	16.2	14.3	6.4	19.0	15.2
No (%)	85.4	83.8	83.9	91.5	79.1	83.5
Don't know/NR (%)	1.0	—	1.7	2.1	1.8	1.3
N	103	130	230	47	163	673

Regarding the reproductive options, almost half of the respondents (48%) (55% male and 42% female respondents) reportedly received counselling regarding their reproductive options after being diagnosed as HIV-positive. One in three (32%) respondents reported being advised against having children at least once by healthcare providers (39% male and 26% female respondents). Two per cent of the respondents (2% female and 1.3% male respondents) stated that they were coerced into being sterilized.

Table 8.2 Received counselling about reproductive options, advised to not have children, coerced into sterilization

Ever received counselling about reproductive options	Male (N = 388) (%)	Female (N = 397) (%)	Total (N = 785) (%)
Yes	54.6	42.3	48.4
No	45.4	57.7	51.6
Advice from a health care personnel to not have children	Male (N = 387) (%)	Female (N = 396) (%)	Total (N = 783) (%)
Yes	38.8	25.8	32.2
No	61.2	74.2	67.8
Coerced into sterilization	Male (N = 388) (%)	Female (N = 394) (%)	Total (N = 782) (%)
Yes	1.3	2.0	1.7
No	98.7	98.0	98.3

The questions related to coerced abortion, childbirth, feeding practices and prevention of mother-to-child transmission were posed only to female respondents. Although a majority of the respondents did not report being coerced by healthcare providers, a few instances of coercion were reported. Approximately two per cent of the female respondents reportedly experienced coercion from healthcare workers to terminate their pregnancy, four per cent experienced coercion in choosing the method of delivery and four per cent experienced coercion over infant feeding practices.

Table 8.3 Coerced by a healthcare professional in relation to any of the following because of HIV status

Coercion in termination of pregnancy (abortion)	Female
Yes (%)	1.6
No (%)	51.5
Not applicable (%)	46.9
N	369
Coercion in method of giving birth	
Yes (%)	3.6
No (%)	48.3
Not applicable (%)	48.0
N	358
Coercion in infant feeding practices	
Yes (%)	4.2
No (%)	43.6
Not applicable (%)	52.2
N	358

Only 10 per cent of the female respondents who were HIV-positive at the time of their pregnancy received ART to prevent mother-to-child transmission. Out of those who did not receive ART, the majority (65%) stated that they were not aware that they were HIV-positive at the time of pregnancy, whereas others stated that they were either not aware of such type of treatment (16%), refused treatment (0.3%), or did not have access to treatment (8%). Four in five females (83%) said that at the time of receiving ART, they were advised regarding the prevention of mother-to-child transmission and having a healthy pregnancy and maternity.

Table 8.4 Ever taken antiretroviral treatment to prevent mother-to-child transmission

Ever taken antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy (N = 348)	Female (%)
I have received such treatment	9.8
I did not know that such treatment existed	15.8
I was refused such treatment	0.3
I did not have access to such treatment	8.0
I was not HIV-positive when pregnant	65.8
Not applicable	0.3
Given information about healthy pregnancy and motherhood (N = 34)	
Yes	82.4
No	17.6



Chapter 9

Recommendations

The following recommendations have emerged from the present study:

- 1 The study reveals that overall, most of the PLHIV have low levels of education attainment and females have still lower levels of educational attainment. Therefore, it is imperative to introduce an awareness-raising program focusing on the issues related to HIV from the school level. This would facilitate the reduction of HIV risk and vulnerability.
- 2 Public awareness programs targeting adult members of the community for eliminating the common myths regarding the routes of HIV transmission and consequent fear of acquiring HIV through casual contact among general population must be conducted in order to reduce the stigma and discrimination related to HIV. An effort must be made to increase initiatives to reduce HIV-related stigma and discrimination within families in work/ employment settings.
- 3 Advocacy to mitigate stigma and discrimination should also be part of HIV programming at the national level. Active involvement of PLHIV in designing and planning of programs is necessary to create a more enabling environment in the health and social sector
- 4 Continued support must be provided to PLHIV support groups and networks, since they constitute a very important source of support for PLHIV. Efforts must be made to build the capacities of such groups and networks and the capacities of individuals living with HIV to deal with stigma, discrimination and human right violations.
- 5 There are no laws for preventing the violation of rights of the PLHIV in Nepal. Therefore, the government should develop a comprehensive law that improves legal and policy responses to HIV-related stigma and discrimination. The involvement of PLHIV must be ensured at every step from policy to operational level.
- 6 There are instances wherein health personnel have been involved in discriminating against and stigmatizing PLHIV and disclosing their HIV status without their prior consent. Policy and practice must be strengthened for reducing HIV-related stigma and discrimination in healthcare settings and ensuring confidentiality. Moreover, it must be ensured that all HIV tests are performed by adhering to standards, such as voluntary testing, informed consent, pre- and post-test counselling and confidentiality. It is important to organize training programs for healthcare professionals on a regular basis in order to cater to the complex medical, physical, emotional and psychological needs of the PLHIV. This should form part of the training of all healthcare workers.
- 7 The study shows that there continues to be a lack of counselling regarding reproductive options for PLHIV. Therefore, a comprehensive package program needs to be developed in order to address their reproductive health issues, especially that of female PLHIV.
- 8 There is a need to strengthen the PMTCT in Nepal. Although the service has expanded, it needs to be strengthened in terms of quality.
- 9 Although a majority of the respondents were on ART at the time of survey, a significant number of PLHIV had no access to this treatment. Therefore, provision for easy access to ART including treatment of all types of opportunistic infections must be made available.
- 10 More research on stigma is also required. The PLHIV Stigma Index showed some evidence of prevalent stigma. However, more research is required in terms of the specific areas and its causes.

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