2011

Need Assessment Report:

Baseling Survey and Need Assessment to understand the circumstances and growing needs of Bhutanese living with HIV/AIDS

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Abbreviations

AIDS	Acute Immono Deficiency Syndrome
ANC	Anti-natal Clinic
ART	Antiretroviral Therapy
CSO	Civil Society Organization
HIV	Human immunodeficiency virus
IDU	Injecting Drug Users
PLHIV	People living with HIV

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Acknowledgement

Lhak-sam would like to thank all the Peoples living with HIV who participated in this study. Without their voluntary participation, this study would not be possible. We would also like to thank the Ministry of Health for all their support and assistance in conducting the study.

This study is our first step towards understanding the problems and issues faced by PLHIV and we hope to disseminate the findings to all relevant agencies and organizations for their concerted effort to improve the quality of life of the people living with HIV.

Executive Director

Lhak-sam

1. Introduction

Bhutan was one of the last countries in the region to report HIV infection when the first case was detected in 1993[1] through routine medical screening. The Royal Government of Bhutan has accorded a high priority to addressing the issue of the epidemic. Since then various strategies and programs to control and prevent the spread of HIV/AIDS have been made by the Ministry of Health. Voluntary counseling and testing centers has been established and since 2009 the treatment for HIV/AIDS were also provide free by the health services. As of July 2010, a total of 217 HIV cases have been detected in the country. Out of this, 43 have died and this leaves 164 known cases of people living with the HIV/AIDS in the country.

However, inclusion of PLHIV in decision making has been lacking and the challenges faced by them have not been addressed appropriately. Therefore when government legalized the formation of CSO in 2009, a group of people living with HIV decided to come together and form a CSO to address the issues and challenges faced by PLHIV and also to raise awareness on HIV/AIDS.

Thus Lhak-sam was formed in September 2009 by a group of positive people in Thimphu with the objective of supporting each other. Encouraged by the ministry of Health, the group expanded to other districts and set its mission to create and promote a strong support system based on solidarity, social networking and people's participation for addressing and taking collective responses to HIV/AIDS and its impact. Lhaks-sam aspires to play the lead role in slowing down the spread of HIV in the county.

Though the HIV cases have been increasing over the years, no comprehensive study has been conducted to assess the growing needs of Bhutanese people living with HIV except a small study of nine people living with HIV through telephonic interview in 2004. Therefore, in order to develop appropriate intervention strategies, Lhak-sam administered this study to explore the issues and challenges faced by people living with HIV.

2. Objectives of the study

2.1. Broad objective

The purpose of the study was to assess the growing needs of Bhutanese living with HIV and to develop the capacity of Lhak-sam on research methodology, data collection and management.

2.2. Specific objectives

1. To develop profile of People living with HIV/AIDS.
2. To study the issues and growing needs of Bhutanese living with HIV/AIDS.
3. To build the capacity of Lhak-sam in research methodology and data collection and management.

[1] Ministry of Health and Armed forces, HIV/AIDS and STIs curriculum for Armed forces;

3. Methodology

3.1. Study Design

Sample size:

This is a study involving PLHIVs and identifying their challenges and issues. Given the sensitivity and the confidentiality of the study and subjects involved, the study was carefully coordinated and administered through Lhak-sam and Ministry of Health.

This is a qualitative study and sample size was intended to be determined by data saturation and redundancy. However, it is also not known how many people living with HIV can be traced and how many will consent to be interviewed. It is proposed that one third of the people living with HIV (55) can be traced and will consent.

Sampling:

The respective district health HIV focal persons contacted the people living with HIV and sought their consent to be interviewed for the study. Also Lhak-sam already had 13 members who are HIV positive, in total 74 people living with HIV voluntarily agreed to participate in the study from various districts.

Tools for the study:

A semi-structured open-ended questionnaire and focus group discussion were the main data collection tools. The questionnaire was developed by the consultant together with the Lhak-sam members and it was pretested before administering in the real study. Indicators were developed in line with the set of what Lhak-sam members wanted to measure keeping in mind their current activities.

Modalities of the data collection:

Lhak-sam the network for people living with HIV was trained on data collection, interview technique and confidentiality issues. The stakeholders were informed about the study for their necessary support to administer the study. All the questions were asked on voluntary basis and interviewees did not necessarily had to answer all the questions, however efforts were made to cover all the questions. Questionnaires do not contain any information with respect to the respondents' identity.

3.2. Data Analysis

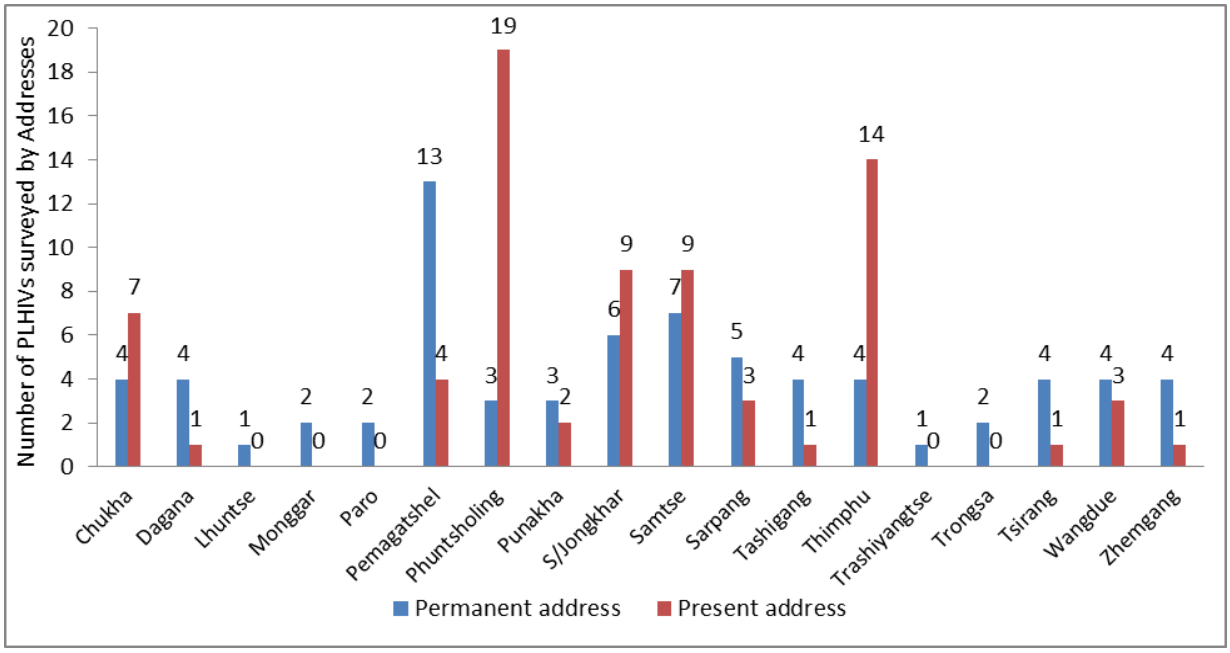
Data was entered directly into SPSS data interface designed specifically for the current study and analyzed using SPSS and Microsoft Excel. As mentioned in the section above, questions that interviewees did not want to answer were left as it is and reported in the same format. All quantitative data were coded and qualitative data were categorized into similar groups. The total frequency counts are calculated and reported using simple percentages.

4. Survey Findings

Place of residence and origin:

A total of 74 PLHIVs were interviewed from 12 districts (Figure 1). 45.9% were female and 54.1% were males. Majority of them are residing in Phuntsholing (Chukha), Thimphu, Samdrupjonkhar and Samtse. Going by permanent address, HIV has infected people from 17 districts with maximum coming from Pemagatshel, Chukha and Samtse (Figure 1)

Figure 1: Permanent address and present addresses of the respondents by District



4.1. Age and Occupation

HIV has infected people from all age groups. In this study 44.6% were between 30-39 years, 23% between 40-49 years, 16.2% between 5-24 years and 12.2% between 25-29 years. Only 4.1% are above the age group of 50 years. Of the interviewed, 12.2% are youths and 5.4% are adolescent[2] (Table 14)

Table 1: Age of the respondents

Age group	Percent (N)
5 to 24 years	16.22 % (12)
25 to 39 years	56.76 % (42)
40 to 49 years	22.97 % (17)
50 years and above	4.05 % (3)
Total	**100.00 % (74)**

[2] Definition of youth and adolescent: ***Youth*** **:** 13-24 years (National Youth Policy of Bhutan) and ***Adolescent*** **:** 10-19 years (WHO, Adolescent Health; Available at: http://www.who.int/topics/adolescent_health/en/

Majority of the respondents are working in the private (24.3%) and government sector (21.6%) followed by Farming (16.2%) and housewives (10.8%). Private sector includes cooperation's, industries and government sector includes the arm force. The occupation includes drivers, babysitter, support staffs, sweepers, gardeners, labourers etc. (Table 2).

Table 2: Occupation of the respondents

Occupation	Percent (N)
Private Sector	24.3 % (18)
Government employee including arm forces	21.6 % (16)
Farmer	16.2 % (12)
House wife	10.8 % (8)
Idle[3]	9.5 % (7)
Business	8.1 % (6)
Student	5.4 % (4)
Monk	1.4 % (1)
Missing	2.7 % (2)
Total	**100.0 % (74)**

4.2. Marital Status and literacy:

62% of all respondents were married. Only 16.2% of the respondents of which three were below the marriage age said they never married. 22% of the respondents were divorced, separated or widowed. 50% of the respondents were literate (Table 3) with 32.4% having studied at least primary and above.

Table 3: Marital status and literacy of the respondents

Marital Status	Percent (N)	Literacy	Percent (N)
Married	62.2 % (46)	Illiterate	50 % (37)
Never married	16.2 % (12)	Monastic	2.7 % (2)
Divorced	12.2 % (9)	Informal	5.4 % (4)
Widow	8.1 % (6)	Below class 6	9.5 % (7)
Separated	1.4 % (1)	Class 6 to 10	27.0 % (20)
Total	**100.0 % (74)**	Class 11 to 12	5.4 % (4)
		Total	**100.0 % (74)**

[3] Idle people are those who are not employed, not married and are not studying.

4.3. Source and level of income

The main source of income is salary followed by agriculture (farming) and 26.7% of the respondents have no source of income. As evident from the occupation, most of the respondents were low income salaried workers.

Table 4: Source of Income of the respondents

Source of income	Percent (N)
Salary	43.7% (31)
Agriculture	12.7% (9)
Weaving	5.6% (4)
Business	8.45% (6)
Husband's salary	2.8% (2)
Remittance from children	1.4% (1)
No source of income	26.7 (19)
Total	**71**

Bhutan's poverty line (Total poverty line) is estimated at an income of Nu. 1096.9 per month[4] and according to this 2.7% of the respondents are living below the poverty line. 37% are earning below Nu. 10,000 per month with 5.4% earning above Nu.15,000 per month.

Table 5: Level of income of the respondents

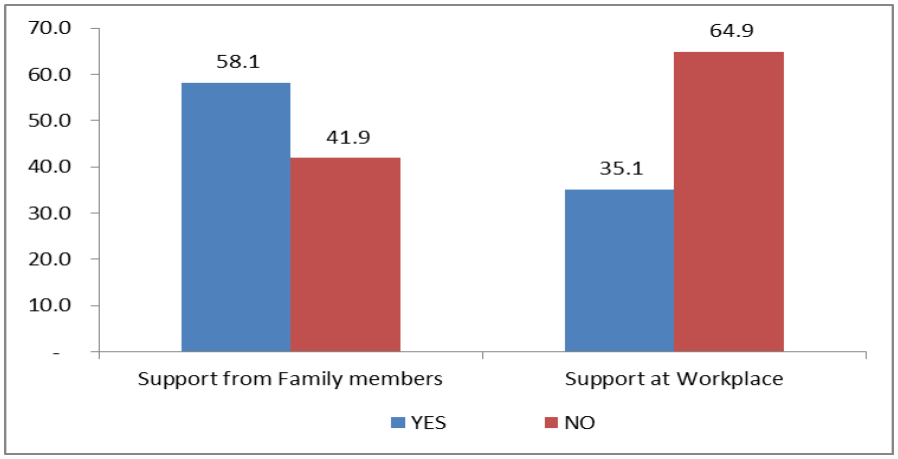
Income level	Percent (N)
Below 1000	2.7% (1)
1001 to 5000	32.4% (12)
5001 to 10000	40.54% (15)
10001 to 15000	18.9% (7)
More than 15000	5.4% (2)
Total	**100% (37)**

[4] National Statistical Bureau, Poverty Analysis Report 2007; December 2007.

4.4. Family and work place support

58.1% of the respondents mentioned that have full support from their immediate family members and only 41.9% don't have support from the family. At the workplace only 35.1% have received the support from the workplace.

Figure 2: Levels of support from Family members and at Workplace



4.5. HIV Testing and status

Probable place of infection

While 10.6% don't know from where they were infected, 78.7% were infected within Bhutan and 10.6% were infected while outside Bhutan. Of those who contacted the disease while outside Bhutan, 85% said they were infected while in India. Within Bhutan, maximum got the infection from Thimphu and Phuntsholing. (Table 15)

Table 6: Place of infection of the respondents

Place	Percent (N)
In country	78.79 % (52)
Out country	10.61 % (7)
Don't know	10.61 % (7)
Total	**100.00 % (66)**

Mode of Transmission

Almost all respondents (81.6%) mentioned that HIV was transmitted to them through sexual route. Unsafe sex still remains one of the major medium through which the virus is transmitted from one person to another. Other modes of transmissions were through blood transfusion, mother to child infection, injection through Injecting Drug Users (IDUs) and tattooing. 3 respondents did not answer the question.

Table 7: Mode of HIV Transmission of the respondents

Mode of Transmission	Percent (N)
Sexual	81.6% (58)
Mother to child	5.6% (4)
Blood transfusion	5.6% (4)
Don't know	2.8% (2)
Intravenous Drug Use	2.8% (2)
Tattoo	1.4% (1)
Total	**71**

Mode of diagnosis:

32.8% are diagnosed as HIV positive through contact tracing and 27% while undergoing routine medical screening. 15.7% are diagnosed while donating blood and 12.8% through ANC. Only 5.7% are diagnosed through voluntary and counseling testing.

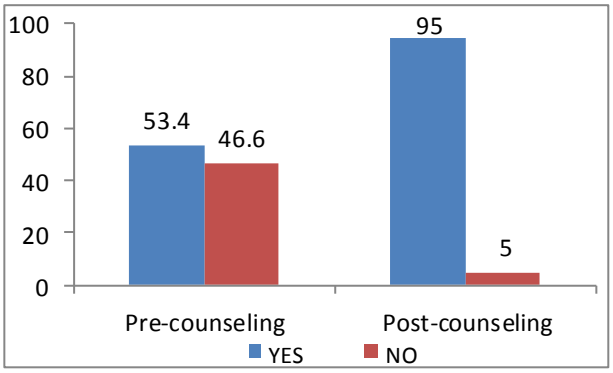
Table 8: Reasons for testing for HIV

Reason for testing for HIV	Percent (N)
Contact tracing	32.8% (23)
Routine medical testing	27.14% (19)
Blood donation	15.7% (11)
ANC	12.8% (9)
Voluntary testing	5.7% (4)
Survey	4.29% (3)
Medical certificate	1.4% (1)
Total	**100% (70)**

Pre and post Counseling received status

Pre and post counseling are important and necessary in HIV testing. 53.4% have received pre counseling before being tested for HIV and 95% have received counseling after being tested positive.

Figure 3: Prevalence of pre-counseling and post-counseling for HIV.



HIV status

64% of the respondents have revealed their status and 21% have not revealed their status to anyone yet. The main reason for not revealing their status were fear of stigma and discrimination by the family members, friends and at workplace.

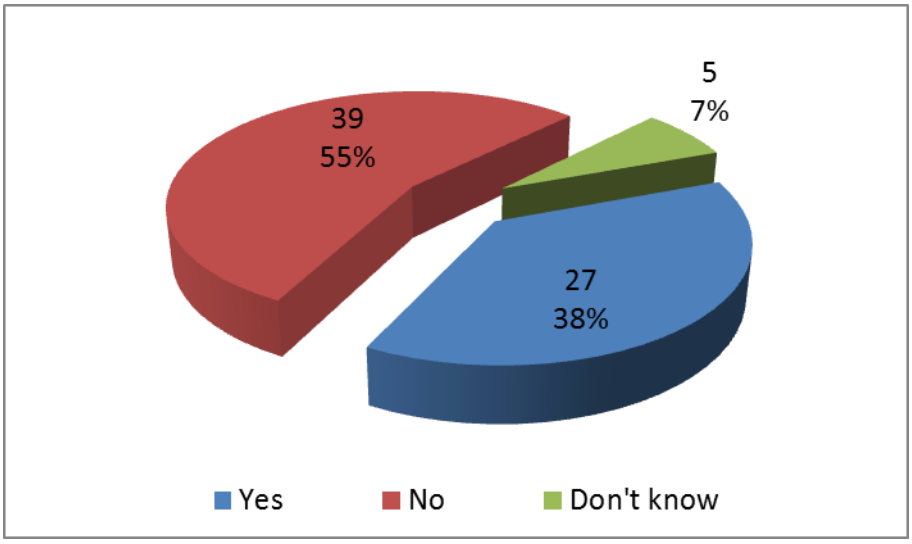
Of those who have revealed their status, it was only within very close family members and friends. 48.9% have revealed it to their immediate spouse, 12.7% to their children and 6.3% to their close friends and 9% have revealed it to other family members.

Table 9: HIV status and disclosure to others

Have you revealed your status to anyone?		**To whom have you revealed your status?**	
Yes	69.1% (47)	Spouse	48.9% (23)
No	30.8% (21)	Children	12.7% (6)
Total	**100% (68)**	Parents	12.7% (6)
		Friends	6.38% (3)
		Other family members	19.1% (9)

38% of the respondents mentioned that they had family members who were also infected by HIV. 7 % of the respondents did not know about the status of their family members.

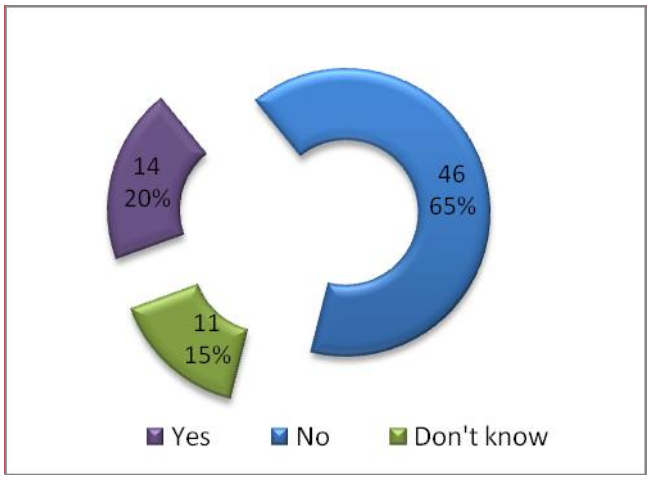
Figure 4: Status of other positive members in the family of respondents



4.6. Stigma and discrimination

65% of the respondents said they did not experience any form of stigma and discrimination and 15% said they don't know whether they were stigmatized or discriminated. However 20% of respondents said that they were stigmatized and discriminated.

Figure 5: Experienced stigma and discrimination



Following tables shows the most common forms of discrimination faced by the respondents:-

- Doctors and nurses treating them differently after knowing their status.
- In the arm force, asked to resigned and told that HIV is a disease of the unfaithful. Not allowed to enter the army kitchen.
- Asked to deregister from the central monastic body.
- Asked to leave the village.
- At the family level, property rights were not given. Plates, mugs, blankets, mattress and pillows were separated. Asked not to use the common toilet.

4.7. Expectations from Lhak-sam

Respondents were happy to know the Lhak-sam, a network for people living with HIV is formed and that it is managed and coordinated by people living with HIV. They feel more comfortable and confident in becoming the member and hopes that the Lhak-sam will represent their issues and challenges at appropriate level.

Expectations:

- To provide employment, financial incentive/loans and scholarships for their children.
- Providing emotional support and counseling services to PLHIV.
- Providing ART medicine and CD4 count facilities.
- To raise awareness on prevention and treatment of HIV.
- To raise awareness on discrimination and stigmatization.
- Networking among the PLHIV, representing their views and challenges in public forums for appropriate rights and policies.

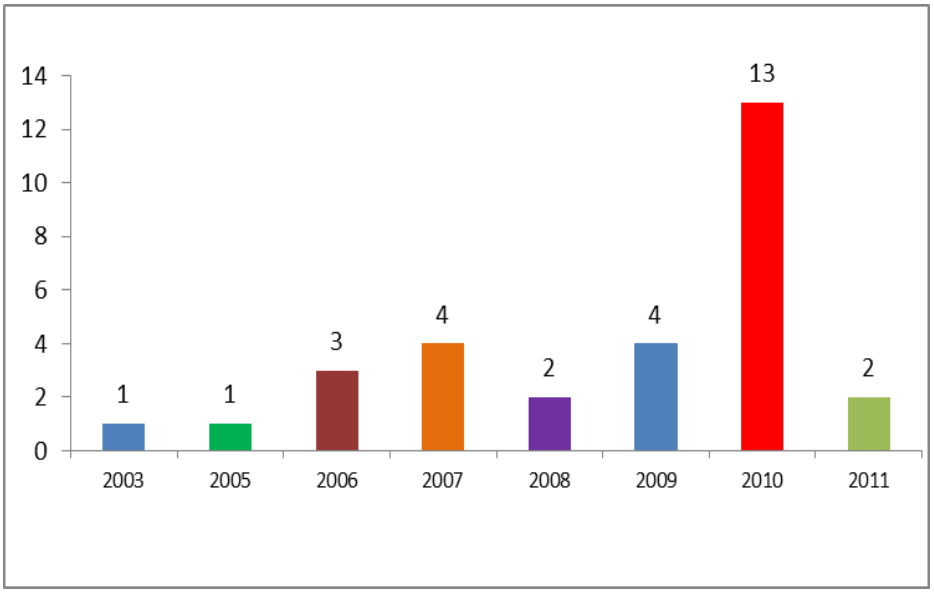
It must also be noted that majority of the respondents were not aware of the following:

- The definition of Civil Society Organization, its mandate and regulations.
- Mission and vision of Lhak-sam

4.8. ART Treatment and side effects

49% of respondents are on Antiretroviral therapy (ART) and 51% have not yet started the treatment. Who should be on ART is being decided by the treating medical specialist. Majority of them were assigned for ART in 2010 (Figure 5). Of those on treatment only 38% reported to have experienced side effects like vomiting, giddiness, weight loss, loss of appetite, headache, skin allergy, rashes, hallucinations and reduced hemoglobin counts.

Figure 6: Year in which ART was started by the respondents.



4.9. CD4 count at the time of first diagnosis

The CD4 cell count and HIV viral load (RNA level) are closely linked to HIV-related illness and mortality. They give prognostic information on HIV progression and on response to therapy[5]. Normal CD4 counts range from 500 to 1300 cells per cubic microliter of blood. Treatments can be based on the consistent CD4 counts trends[5] and it can also indicate the duration of infection.

98.4% (64) of the respondents had their CD4 count tested after their HIV diagnosis and only 1.6% did not have their CD4 counted. Of those who had their CD4 counted, only 46.8% remembered their CD4 count level.

Table 10: CD4 Count at the time of first diagnosis

	Yes	No	Total
Tested for CD4 count	98.4% (64)	1.6% (1)	100% (65)
Do you remember the CD4 reading	46.8% (30)	53.2% (34)	100% (64)

The average CD4 count of the respondents is 385.13 per ccm of blood and the national average is 356[6]. Both the figures indicated late detection of the virus[6]. Therefore it is estimated that a PLHIV on average lived with HIV for six to seven years before detection.

5. Conclusion

Bhutanese affected with HIV came from lower income groups and majority of the respondents were uneducated and even those considered educated are lowly educated. Majority of the cases were detected by contact tracing and through routine medical screening. Only few were detected through Voluntarily Counseling and Testing. Many have not revealed their status and choose not to for fear of stigma and discrimination. And those that have revealed their status have done so to their family members and to their very close friends.

People living with HIV and having disclosed their status had faced stigmatization at homes, in workplaces and in accessing health services.

The knowledge on HIV prevention and transmission is good but many are not aware of the treatment, CD4 count, confections and their right to be treated equally in workplaces and that they cannot be fired from the jobs.

In conclusion, this study helped build the capacity of Lhak-sam in conducting small scale studies, knowing the challenges of people living with HIV and through the process Lhak-sam was also able to build more contacts and establish networking with people living with HIV in other districts.

[5] AETC National resource center, Supporting HIV Education for Health Care Professionals; Available at http://www.aids-ed.org/aidsetc?page=cg-206_cd4_monitoring, Viewed on October 25, 2011
[6] Ministry of Health, An update on HIV/AIDS; 1st July 2011

6. Recommendations

1. **Communication strategy for HIV requires to incorporate the following aspects apart from prevention messages:**
    a. How to living in harmony (at homes and workplaces) with people living with HIV. Messages like; HIV is not transmitted through sharing of blankets, toilets, mattress, etc.
    b. HIV messages should avoid illustration containing sexual connotations (couple in bed) and depicting death (Skulls, etc.). These messages are stigmatizing and discourages people from coming out and seeking help. Treat it like any other diseases. (E.g. messages on prevention of cervical cancer are not depicted with skulls and a couple in beds).
    c. Service rules of the government, CSO, corporations and institutions should incorporate Clause 15, Article 7 of the constitution of Bhutan. Which prohibits any kind of discrimination?

2. **Timely networking and information sharing amongst the PLHIVs**
    There is a strong need for networking and information sharing within the PLHIVs and this task is best done by Lhak-sam. Lhak-sam needs to encourage PLHIVs to register with them and also raise awareness about their visions and services in all available media.

3. **Livelihood program**
    Ministry of Labour and Human resources needs to be approached to impart tailored made technical and vocation training courses for PLHIV in order to improve the livelihood of the PLHIV. Establishment of endowment fund may need to be explored for sustenance of Lhak-sam as a CSO.

4. **Follow up research**
    Lhak-sam needs to develop a simple database of the PLHIV which can serve as baseline information and also for tracking disease trends and other indicators related to HIV (prevention, transmission, ART, stigma and discrimination).

Annexure:

Figure 7: Gender of the respondents

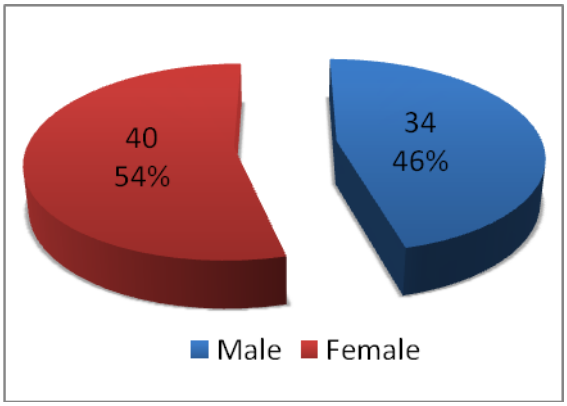


Table 11: Categorized age of respondents in years

Age	Percent
5 to 14 years	5.4 % (4)
15 to 19 years	1.4 % (1)
20 to 24 years	9.5 % (7)
25 to 29 years	12.2 % (9)
30 to 39 years	44.6 % (33)
40 to 49 years	23.0 % (17)
50 years and above	4.1 % (3)
Total	**100.0** % (**74**)

Figure 8: Monthly Income of the respondents in Ngultrums.

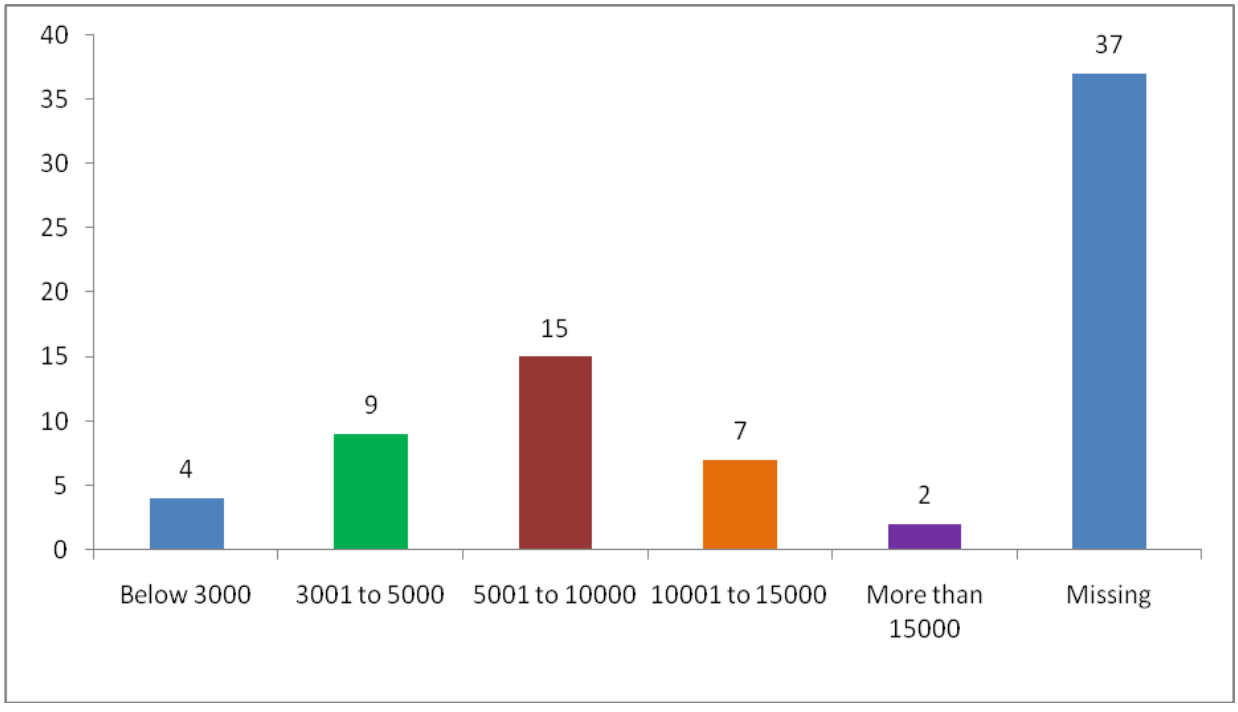


Figure 9: Support from family members

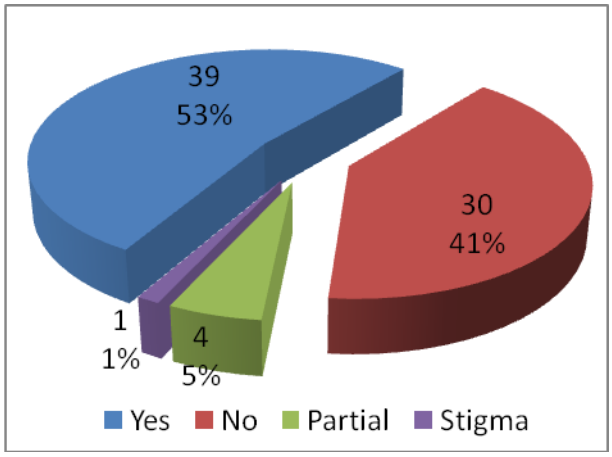


Figure 10: Support at workplace

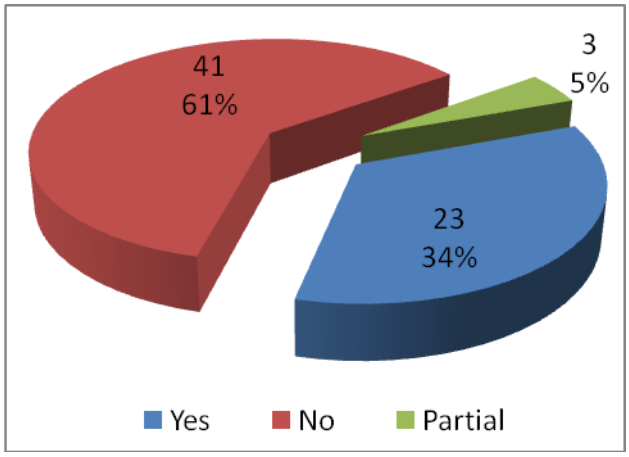


Figure 11: Pre-counseling status

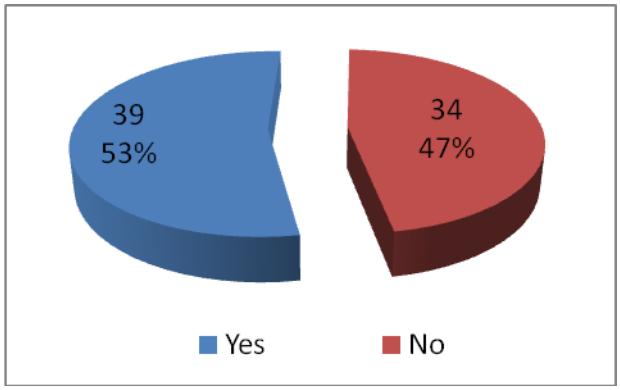


Figure 12: Post-counseling status

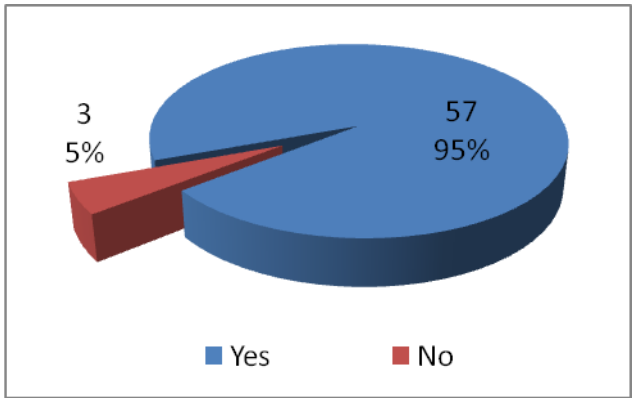


Figure 13: Status revealed to anyone

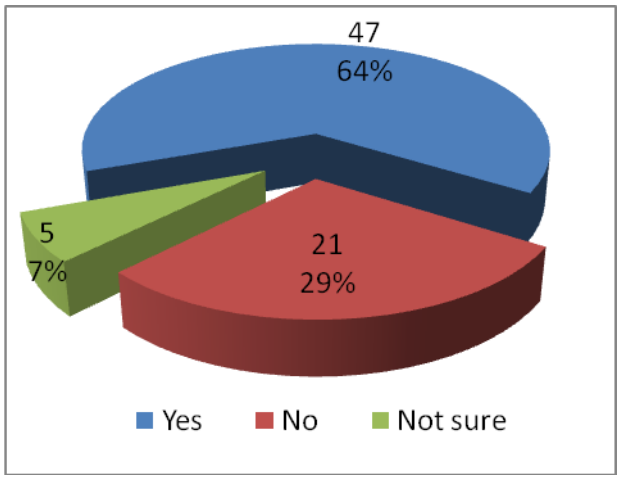


Figure 14: Other medical co-infections

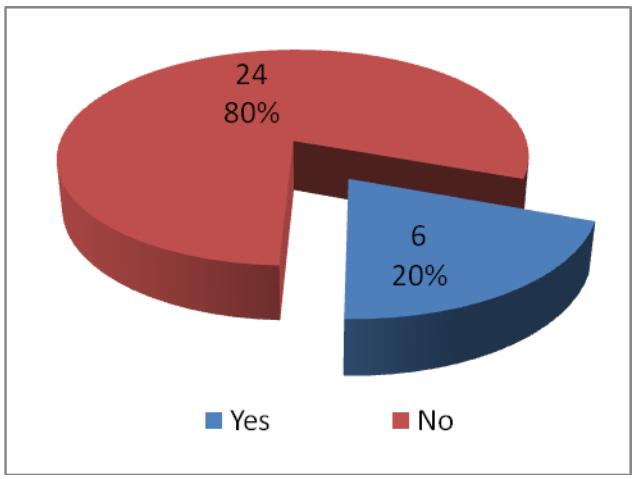


Table 12: Aims, Objectives and future plans

Aims/Objectives/Plans	Frequency
Agriculture	7
Aspires to become a Doctor	1
Auto-mechanic workshop	2
Business	16
Contractor	1
Educate my children and build them a house	2
Practice religion	2
Shopkeeper and to help Lhak-sam	1
Tailoring and Carpentry	1
Weaving and Marketing	6
Work in Lhak-sam and help other PLHIV friends through capacity building	13
Lottery draw	1
No plan	14
Missing	6
Don't know	1
Total	**74**

Table 13: Categories of Ages7

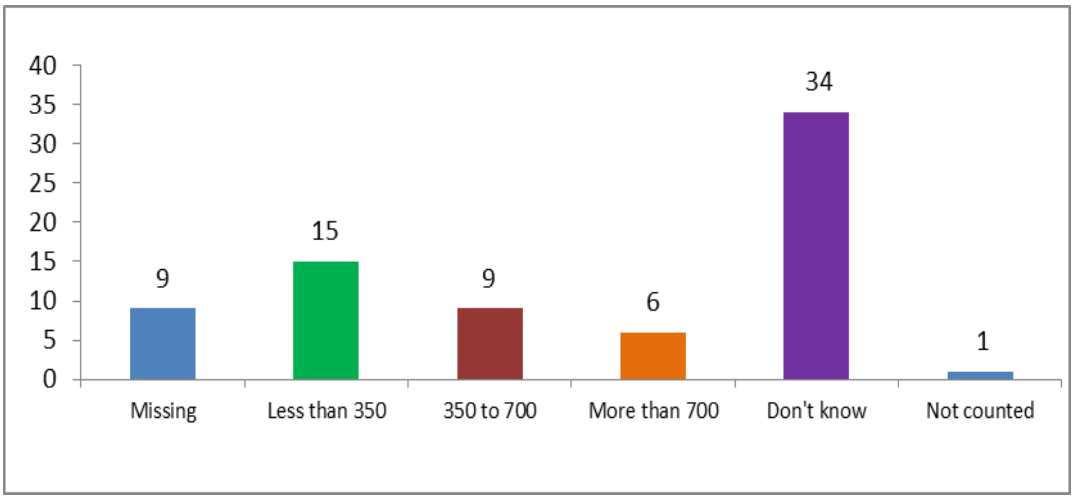
Age Categories	Percent (N)
Youth	12.2 % (9)
Adolescent	5.4 % (4)
Economically productive population	94.6 % (70)

Table 14: Table showing probable place of infection

Probable place of Infection	Percent (N)
Dagapela	1.5 % (1)
Dewathang	3.1 % (2)
Gelephu	3.1 % (2)
Gomtu	6.2 % (4)
Home	1.5 % (1)
Husband	4.6 % (3)
India	9.2 % (6)
Jail (Prison)	1.5 % (1)
Mother to child	1.5 % (1)
Out of country	1.5 % (1)
Pasakha	3.1 % (2)
Pemagatshel	4.6 % (3)
Phuntsholing	18.5 % (12)
S/Jongkhar	7.7 % (5)
Samtse	1.5 % (1)
Thimphu	20.0 % (13)
Don't know	10.8 % (7)
Total	**100.0 % (65)**

[7] Definition of youth and adolescent: ***Youth*** **:** 13-24 years (National Youth Policy of Bhutan) and ***Adolescent*** **:** 10-19 years (WHO, Adolescent Health; Available at:

Figure 15: CD4 count at the time of first diagnosis



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