Report on

Estimating Numbers of People Most Affected by HIV/AIDS in Different Locations to Support Efficient Service Delivery, Capacity Building and Community Mobilization

এইডস সম্পর্কে জানুন, সুস্থ থাকুন

জাতীয় এইডস/এসটিডি প্রোগ্রাম
স্বাস্থ্য অধিদপ্তর, স্বাস্থ্য ও পরিবার কল্যাণ মন্ত্রণালয়

National AIDS/STD Programme
Directorate General of Health Services
Ministry of Health and Family Welfare

Save the Children

Report on

Estimating Numbers of People Most Affected by HIV/AIDS in Different Locations to Support Efficient Service Delivery, Capacity Building and Community Mobilization

A project on 'HIV Prevention and Control among High Risk Population and Vulnerable Young People in Bangladesh'

Strategic direction:

- Dr. Md. Abdul Waheed, Line Director, National AIDS/STD Programme (NASP)
- Dr. S M Idris Ali, Programme Manager, National AIDS/STD Programme (NASP)
- Dr. Hasan Mahmud, Deputy Programme Manager, National AIDS/STD Programme (NASP)
- Dr. Sydur Rahman, Deputy Programme Manager, National AIDS/STD Programme (NASP)
- Dr. Mahmud Hasan, Deputy Programme Manager, National AIDS/STD Programme (NASP)
- Dr. Md. Anisur Rahman, Deputy Programme Manager, National AIDS/STD Programme (NASP)
- Dr. Nizam Uddin Ahmed, Director, HIV/AIDS Sector and South Asia Program Advisor, Save the Children

Report prepared by:

- Dr. Tasnim Azim, Scientist and Head, HIV/AIDS Programme and Virology Laboratory, ICDDR, B
- Ms. Arunthia Zaidi Urmi, Head Counsellor, ICDDR,B
- Dr. Md. Moshtaq Pervez, Medical Officer, ICDDR,B
- Dr. Irona Khandaker, Medical Officer, ICDDR,B

Reviewed by:

- Mr. Scott Mcgill, Asia Regional Advisor, (HIV and AIDS) Save the Children-USA
- Dr. Kazi Belayet Ali, Deputy Director, Performance Measurement, HIV/AIDS Sector, Save the Children
- Dr. Lima Rahman, Program Manager, Young People Prevention, HIV/AIDS Sector, Save the Children
- Dr. Fadia Sultana, Manager Response and Coordination, HIV/AIDS Sector, Save the Children
- Dr. Samina Choudhury, Manager PLHIV
- Dr. Md. Shah Alam, Project Research Manager, ICDDR,B
- Dr. M. Ziya Uddin, Drug User Intervention Specialist and Consultant, National AIDS/STD Programme
- Md. Tahseen Hasan Qadeer, Deputy Program Manager, Monitoring & Evaluation, HIV/AIDS Sector, Save the Children
- Md. Nasir Uddin, Manager, Documentation, HIV/AIDS Sector, Save the Children
- Dr. Shahrear Farid, Manager, Monitoring & Evaluation, HIV/AIDS Sector, Save the Children
- Md. Badruzzaman Khan, Deputy Program Manager, Monitoring & Evaluation and MIS, HIV/AIDS Sector, Save the Children

First Print: October 2011

Design & printing: Printcraft Company Limited

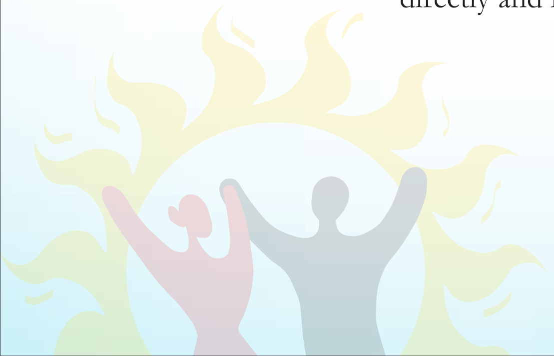
Published by: Save the Children

Acknowledgment

This study titled ‘Estimating Numbers of People Most Affected by HIV/AIDS in Different Locations to Support Efficient Service Delivery, Capacity Building and Community Mobilization’ was funded by The Global Fund to Fight AIDS, Tuberculosis and Malaria (The Global Fund). Save the Children acknowledges with gratitude the commitment of The Global Fund to pave the way towards effective programming by facilitating the application of evidences. This report is a clear reflection of this effort.

The mapping was initiated by the Ministry of Health and Family Welfare (MOHFW), Government of Bangladesh, through the National AIDS/STD Programme (NASP), the implementation and coordination wing for HIV/AIDS-related interventions under the Directorate General of Health Services (DGHS). The stewardship role of the DGHS in supporting the facilitation of all activities under this survey deserves special appreciation, with which NASP officials were able to support the survey. As the Management Agency for The Global Fund supported project, “HIV Prevention and Control among High-Risk Population and Vulnerable Young People in Bangladesh”, Save the Children carried out this survey that has made significant contributions to Bangladesh’s evidence-based knowledge for the improvement of quality HIV/AIDS program implementation especially among the people living with HIV/AIDS and most affected populations in Bangladesh.

Heartfelt thanks to Ashar Alo Society (AAS) and other partners of this consortium for their tremendous support in this study. International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B), as partner of the implementing consortium responsible for the actual research took hard effort to conduct this mapping and they deserve sincere thanks. The data collectors, interviewers and all staff involved in the data processing and report preparation process deserve special gratitude for their hard work in completing field and next level activities. The reviewers of this report have provided valuable inputs in preparing this informative report and they deserve special acknowledgement. Finally all credits and thanks go to the People living with HIV and AIDS (PLHIV) in Bangladesh who are directly and indirectly reached through this program.



ACRONYMS AND ABBREVIATIONS

AAS	Ashar Alo Society
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti Retroviral Therapy
ARV	Anti Retro Viral
BBS	Bangladesh Bureau of Statistics
CAAP	Confidential Approach to AIDS Prevention
FGD	Focus Group Discussion
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GTZ	German Technical Cooperation
HAART	Highly Active Anti Retroviral Therapy
HASAB	HIV/AIDS and STD Alliance Bangladesh
HIV	Human Immunodeficiency Virus
ICDDR,B	International Centre for Diarrhoeal Diseases Research, Bangladesh
IDH	Infectious Diseases Hospital
IDU	Injecting Drug User
MAB	Mukto Akash Bangladesh
MARP	Most At Risk Population
MSCS	Marie Stopes Clinic Society
MSM	Males who have sex with males
MTCT	Mother to Child Transmission
NASP	National AIDS /STD Programme
NGO	Non Government Organization
OI	Opportunistic Infection
OPD	Out Patient Department
OST	Oral Substitution Therapy
PEP	Post Exposure Prophylaxis
PLHIV	People living with HIV
PMTCT	Prevention of Mother to Child Transmission
PPTCT	Prevention of Parent to Child Transmission
SPSS	Statistical Package for Social Sciences
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNODC	United Nations' Office on Drugs and Crime
VCT	Voluntary Counselling and Testing
VD	Venereal Diseases
WHO	World Health Organization

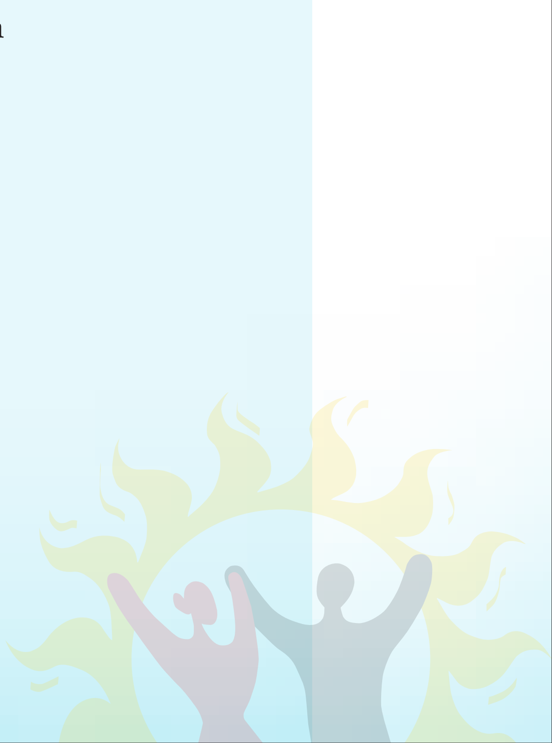


TABLE OF CONTENTS

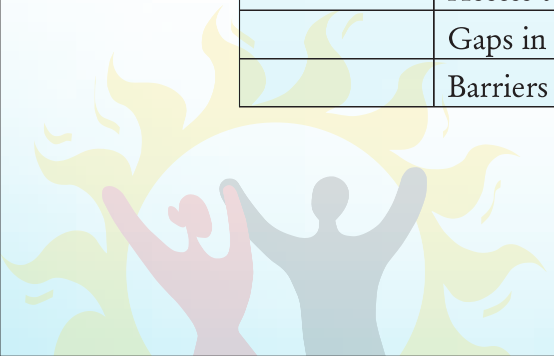
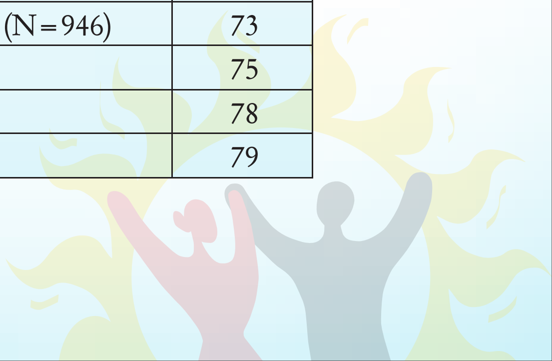


TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

APPENDIXES



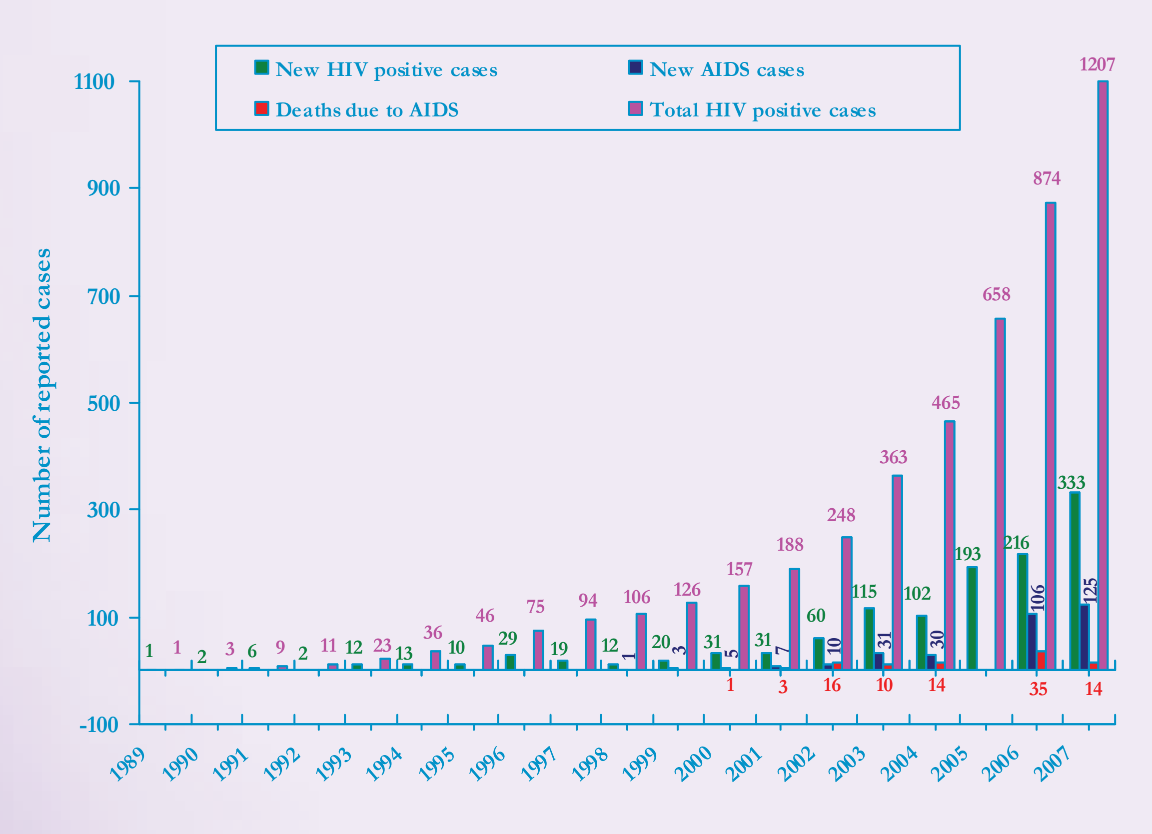
1

BACKGROUND

1. BACKGROUND

In Bangladesh the first case of HIV was detected in 1989, and since then a total of 1207 cumulative cases of HIV have been confirmed and reported by the end of December 2007 (1). During the last two decades the number of newly identified cases and those with AIDS have been rising steadily (Fig 1). It is estimated that there are 7,500 people living with HIV (PLHIV) in the country (2). However, the number of people affected by HIV and AIDS includes not only those infected but also their immediate family members, and others in their social network, and these numbers are not known.

Figure 1. Reported numbers of people with HIV, AIDS and deaths from AIDS, 1st December 2007



The existing self-help groups for PLHIV in Bangladesh have members who have either been referred through testing centres, personal networks, non-governmental organisations (NGOs) or other organizations and institutions. These PLHIV therefore represent passively reported cases, i.e. those who have been identified through testing centres, and it is expected

that there may be many more people in need of services who are not being reached. This remains a difficulty and can only be overcome if more Voluntary Counselling and Testing (VCT) and other services become available and acceptable to the intended recipients. Moreover, the most at risk populations who are highly stigmatized such as injecting drug users (IDUs) and sex workers are often underrepresented. In Bangladesh where the epidemic has just entered a concentrated phase in IDUs (3, 4) it is important to be able to reach out to people who may be affected and infected by HIV in a non-stigmatising fashion and to make services available to them. The needs of different population groups may also vary and it is important to consider these differences.

A major objective of the 910 package under the GFATM Round 6 proposal is to provide care and support services to PLHIV in coordination with other existing programmes so that maximum coverage can be obtained. A consortium of five organisations is working together to deliver the assignments in this package. Partners of this consortium are

- Ashar Alo Society (AAS) – Lead Organisation
- Confidential Approach to AIDS Prevention (CAAP)
- HIV/AIDS and STD Alliance, Bangladesh (HASAB)
- International Centre for Diarrhoeal Diseases Research, Bangladesh (ICDDR,B)
- Mukto Akash Bangladesh (MAB)

In order to be able to provide services to all PLHIV and their affected families, a better understanding of the numbers of people who might be affected by HIV and AIDS, their geographical distribution and the service needs of those infected with HIV is essential. Such an understanding will allow expansion of care and support services in areas that are relevant to the needs of PLHIV. Therefore the first assignment of this package was to estimate the numbers of those most affected by HIV and AIDS in different locations to support efficient service delivery, capacity building and community mobilization.

2

OBJECTIVES OF THE ASSIGNMENT

In order to provide effective services to those who are infected and most affected with HIV, this assignment addressed the following objectives:

1. Assessment of the approximate numbers of people affected by HIV and AIDS
2. Determination of the geographical distribution of those already infected and affected by HIV and AIDS
3. Assessment of the needs of people infected by HIV and of service providers for effective provision of services to PLHIV

This assignment was conducted by ICDDR,B in close collaboration with AAS, MAB, CAAP and HASAB

3

METHODOLOGY

3. METHODOLOGY

Two methods were used to address the three objectives in this assignment:

1. Secondary data was collected from all PLHIV self help groups who are partners of this consortium using a secondary data collection form
2. Focus group discussions (FGDs) were held with PLHIV and service providers from different parts of the country

3.1 Secondary data collection

3.1.1 Development of the form:

Partners of this consortium who provide care and support services (AAS, MAB, CAAP, ICDDR, B) have information from their clients entered in separate data files and forms (counselling and clinical records, etc). The information available in these forms includes demographics, risk behaviour history and clinical profile. Data entered in all these various forms were used to develop a secondary data form which was designed to help understand the profile of patients accessing services including their geographical distribution and the numbers of people affected by HIV and AIDS.

The form was finalised with input from all consortium partners and after incorporation of the feedback from the Management Agency (Save the Children, USA); this form is shown in appendix 1.

3.1.2 Training of staff on secondary data collection:

Prior to data collection, a two day training and orientation was arranged for the staff of the data collection team. Training involved not only instructions on how to complete the questionnaire but also on issues around HIV and AIDS and stigma, emphasising the importance of confidentiality and an open and non-judgemental approach.

3.1.3 Field-testing of secondary data collection:

Field testing of the forms was conducted by the data collection team using data from the VCT Unit of ICDDR,B (Jagori) and AAS. Modifications were made based on the feedback of the field-testing.

3.1.4 Procedure of compilation of secondary data:

Data available in existing registers with four organizations (AAS, MAB, CAAP and ICDDR,B were used to complete the secondary data form. Where there were gaps in information, attempts were made to fill those gaps using counsellors and clinicians' records. Secondary data was collected from 25th February to 10th March 2008.

3.1.5 Data entry and analysis:

Data were entered by EPI/Info Version 3, analyzed by SPSS Version 11.5 and were cleaned by Excel. Before analysis data were further checked for duplications from the corresponding client registers in each organization. Descriptive analyses were conducted by running frequency tables, calculating means, medians and some important categorical variables were compared using the chi-square test.

3.2 Focus group discussions

3.2.1 Elements of FGD:

FGDs were conducted with PLHIV and with service providers working with PLHIV in six Divisional cities (Dhaka, Chittagong, Sylhet, Rajshahi, Khulna and Barisal). The elements that were considered for conducting the FGDs are shown in Table 1.

Table-1. Elements of the Focus Group Discussions

Element	Focus Groups
Format	Group session
Size	6-10 per session (Minimum=4, Maximum=10)
Length	1.5 to 2 hours (Maximum: 2.5 hours)
Number of sessions	13
Selection of Participants	PLHIV were selected by the consortium NGOs (described in more detail below) Service providers were those known to provide services to PLHIV or other HIV related services
Data recording	Audiotape and hand notes
Formats for reporting	Analysis of repeated issues and use of selected quotations
Ethical consideration	Informed written consent was taken from all participants. Data collection form, FGDs notes, audio records and transcripts were kept in a locked cabinet to which only key investigators have access

Each FGD was moderated by a senior VCT counsellor and notes were taken by a clinician.

3.2.2 Numbers and locations of FGDs:

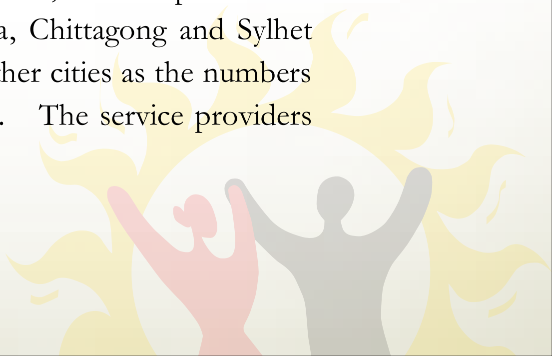
A total of 13 FGDs were conducted, two in each city except in Dhaka where an additional FGD was conducted specifically with HIV positive IDUs. The reason for conducting a separate FGD targeted to IDU was that HIV positive IDUs were known to be receiving services through different organisations and those services were largely harm reduction services and not geared to treatment, care and support. Moreover, their special needs (continuing drug use, homelessness, detoxification, abscess management, etc) suggested that they need to be highlighted as a special category. Table 2 shows the list of FGDs conducted.

Table-2. Numbers of FGDs and participants in different cities

Number of FGDs, (number of participants per FGD) Date of conducting FGD	Service providers	PLHIV	IDU PLHIV
Dhaka	1 (9) 12th March 2008	1 (8) 12th March 2008	1 (6) 27th March 2008
Chittagong	1 (10) 17th March 2008	1 (8) 16th March 2008	
Sylhet	1 (10) 20th March 2008	1 (8) 19th March 2008	
Khulna	1 (9) 24th March 2008	1 (10) 24th March 2008	
Barisal	1 (8) 31st March 2008	1 (4) 31st March 2008	
Rajshahi	1 (7) 3rd April 2008	1 (5) 3rd April 2008	
Total	6 (53) 12th March to 3rd April 2008	6 (43) 12th March to 3rd April 2008	1 (6) 27th March 2008

3.2.3 Participants:

All 49 PLHIV (non-IDU and IDU) who participated in the FGDs were selected by the consortium partner NGOs while the 53 participating service providers were selected directly through personal contacts. A few specific criteria were used for selecting PLHIV which included – age (adult), sex (mandatory to select both male and female representatives), and treatment with antiretroviral (ARV) drugs (both those under treatment and those not receiving treatment). As the selection was done entirely by the NGOs, it is not possible to exclude selection bias but this bias is likely to be more in Dhaka, Chittagong and Sylhet where the numbers of PLHIV available were higher while in the other cities as the numbers were few, all those available and who fit the criteria were selected. The service providers



were selected such that they had experience on working with PLHIV. However, in some places (Rajshahi and Barisal) there were no service providers who had any experience in working with PLHIV while in Khulna there were very few. Selection criteria were therefore expanded in these cities to include to those who had exposure in working on issues around HIV and AIDS. Service providers were from Government, non-Government and private organizations and included

- Peer Support Worker/Peer Counsellor
- VCT Counsellor
- Doctor
- Nurse

An attempt was made to have all the above categories of service providers in each FGD. The affiliation of the service providers is shown in appendix 2.

3.2.4 Data collection:

In order to maintain consistency among all FGDs, two guidelines were prepared. The guidelines were finalized following inputs from consortium partners through a consultative workshop and discussions. These guidelines are attached as appendices 3 and 4. Discussions during the FGDs were taped using audiotapes and hand notes were also taken.

3.2.5 Data analysis:

Audiotapes of the discussions were transcribed verbatim and the complete transcripts were then compared with the handwritten notes to fill in the gaps. The data were then thematically analysed on the basis of repeated issues and data from different groups were compared and contrasted. Demographic data were entered into a database and analyzed using the Statistical Package for Social Sciences (SPSS) software (11.5 version).

IDU PLHIV were considered as a special group among the PLHIV in some instances as it was known that there are differences in the treatment, care and support services that the two groups receive and that different organisations are providing services to the IDU PLHIV. Data from this group have been presented separately from the non-IDU PLHIV where there were differences between the two.

4

ETHICAL CONSIDERATIONS

Prior to data collection all staff were trained on issues around HIV and AIDS including stigma and the importance of maintaining confidentiality.

In the secondary data forms, names of PLHIV were used in order to check for duplication. However, no names and addresses have been presented in any report or presentation. To maintain confidentiality, only names of districts and upazillas were used, no detailed address of PLHIV was collected.

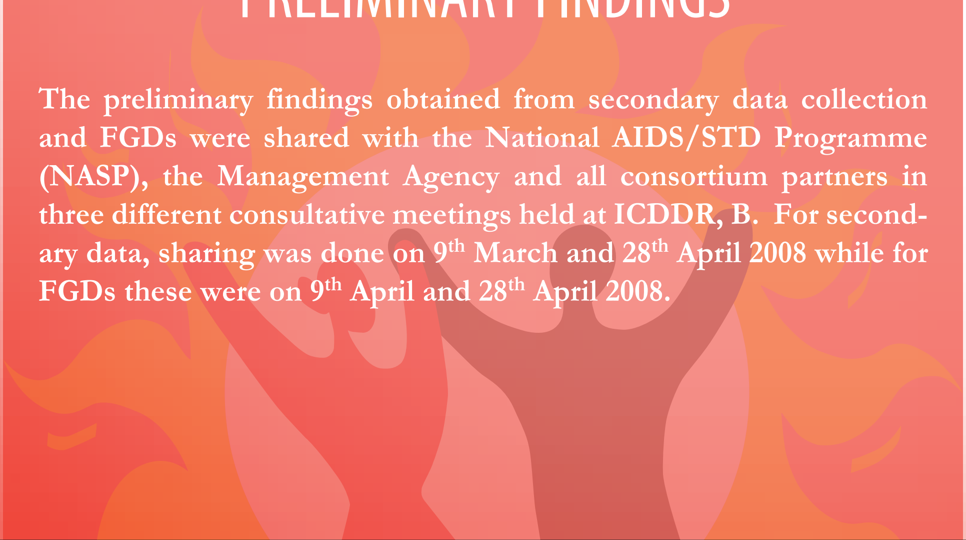
Written consent was taken from all participants in the FGDs using a consent form which is attached to the FGD guidelines in appendices 3 and 4.

All data collection forms, FGDs notes and audio records have been kept in a locked cabinet and are only accessible to the investigators.

5

SHARING OF PRELIMINARY FINDINGS

The preliminary findings obtained from secondary data collection and FGDs were shared with the National AIDS/STD Programme (NASP), the Management Agency and all consortium partners in three different consultative meetings held at ICDDR, B. For secondary data, sharing was done on 9th March and 28th April 2008 while for FGDs these were on 9th April and 28th April 2008.



6

RESULTS

6. RESULTS

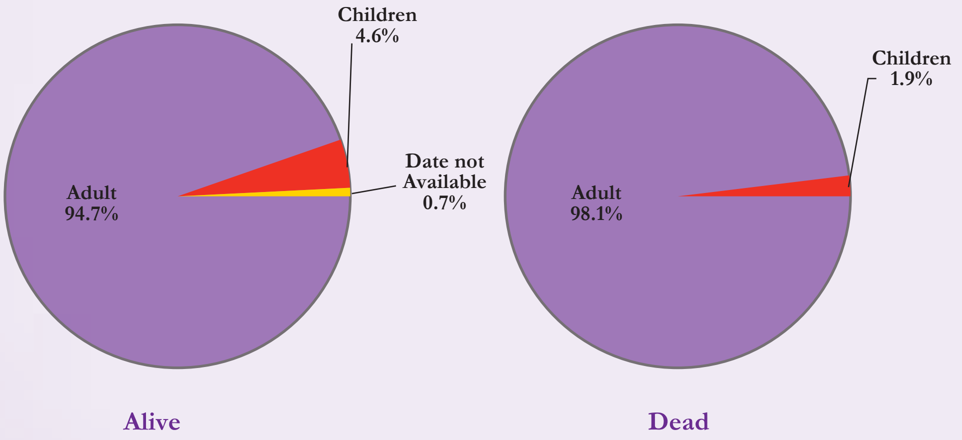
6.1 Secondary Information

Secondary data was available from 1329 PLHIV. After cross checking for duplication, data from 946 PLHIV were accepted and analysed.

6.1.1 Demographic and other characteristics of PLHIV

Out of 946 PLHIV, 736 were alive. Among those who were alive, 94.7% (N=702) were adults (≥15 yrs) and 4.6% (N=34) were children (≤14 yrs). Of the 210 PLHIV who have died, 98.1% (N=206) were adult and 1.9% (N=4) were children (Fig 2).

Figure 2. Proportions of adults and children PLHIV

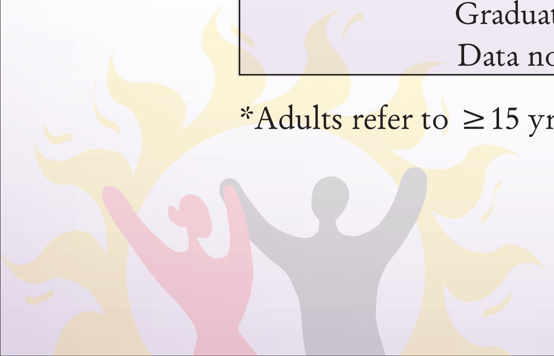


Amongst all 946 PLHIV, most were between 20 to 39 years old and the majority were male (Table 3). Educational status was on average very low with more than half of the PLHIV having either no education or up to the primary level.

Table-3. General characteristics of PLHIV

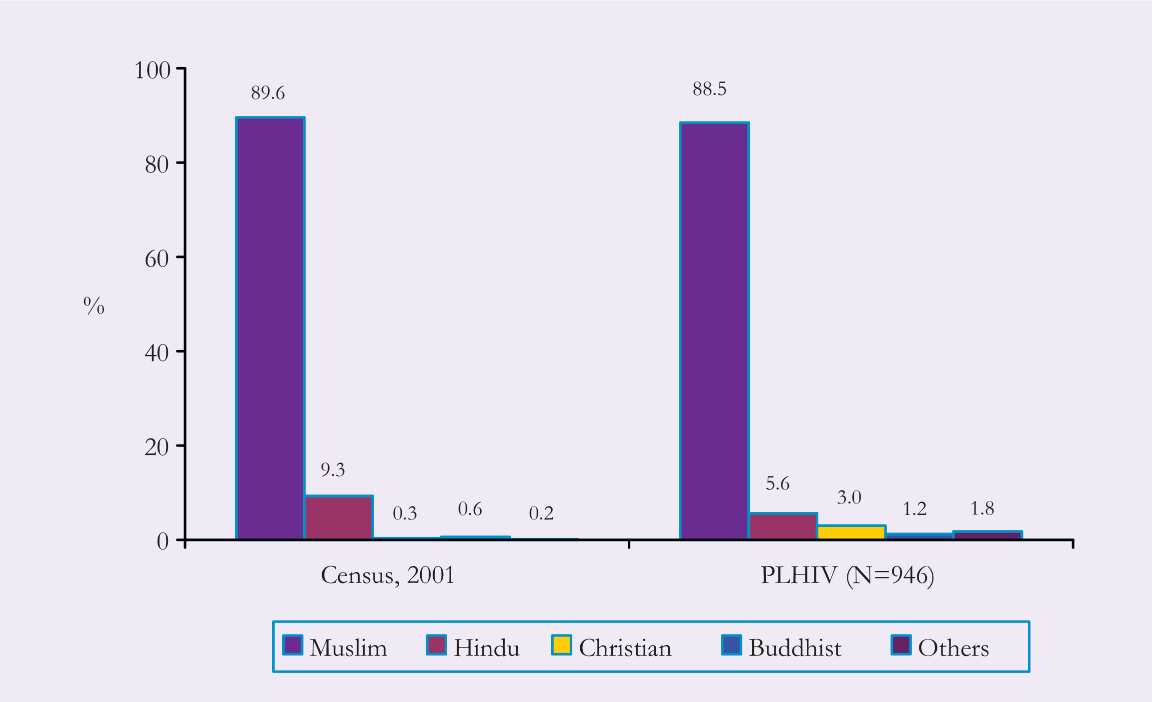
Variable	N= 946 (unless otherwise stated)
Age distribution (in years)	
1-5	42.2 (19)
6-10	37.8 (17)
11-14	4.4 (2)
15-19	1.4 (13)
20-24	6.6 (62)
25-29	16.6 (157)
30-34	20.9 (198)
35-39	26.3 (249)
□40	24.2 (229)
Mean	33.8
Median	35.0
Gender	
Male	70.8 (670)
Female	28.9 (273)
Transgender	0.3 (3)
Marital status (among those who were adults*)	N=908
Married	66.7 (606)
Unmarried	14.1 (128)
Separated	5.5 (50)
Divorced	0.8 (7)
Widow	8.5 (77)
Widower	1.1 (10)
Lives with partner	0.3 (3)
Data not available	3.0 (27)
Educational status (among those who were ≥5 years)	N=927
No education	26.1 (242)
Primary	27.6 (256)
Secondary	32.0 (297)
Higher secondary	7.2 (67)
Graduate or above	3.0 (28
Data not available	4.0 (37)

*Adults refer to ≥15 yrs.



The proportions of PLHIV representing different religions corresponded to the proportions shown in the Bangladesh Bureau of Statistics (BBS), Census 2001, with the exception of Christians (Fig. 3). There were disproportionately more Christians among the PLHIV which is likely to be a reflection of the care and support activities that were conducted by Christian organisations early on in the HIV response in Bangladesh.

Figure 3. Proportions of PLHIV belonging to different religions



Out of 908 adult PLHIV, 71.0% (N=645) had been working previously (Table 4). Of these 645, 64.3 % worked abroad. Amongst the 702 adult PLHIV who were alive, 51.1% (N=359) were currently employed and of these 6.7 % were still working abroad. Among the females, 68.7% were unemployed while amongst males, 35.1 % were unemployed. The common sources of employment are shown in Table 4. This data shows that a large proportion of people who were employed previously became unemployed once they were identified as being HIV positive. The present employment figures show that considerable proportions were farmers and fishermen while very few were in this group prior to becoming HIV positive. The proportions in service also declined after being identified as HIV positive. However, among those presently employed, there was no information from 58.8% on the type of employment.

Table-4. Occupational status and sources of income (previously and at present)

		Previous occupation % (n) N=908	Present occupation % (n) N=702
Status of employment	Employed Unemployed Data not available	71.0 (645) 20.5 (186) 8.5 (77)	51.1 (359) 44.3 (311) 4.6 (32)
Source of income (among those who were/are employed)		N=645	N=359
	Work abroad	64.3 (415)	6.7 (24)
	Service	10.5 (68)	3.9 (14)
	Businessman	8.4 (54)	11.1 (40)
	Farmer/Fisherman	1.7 (11)	14.2 (51)
	Daily labour	4.3 (28)	4.2 (15)
	Sex worker	2.2 (14)	0.8 (3)
	Drug seller	1.4 (9)	0.3 (1)
	Tokai	7.1 (46)	0.0
	Not known	0	58.8 (211)

6.1.2 Geographical distribution of PLHIV

The distribution of 946 PLHIV in different divisions are shown in Fig 4. Dhaka, Chittagong and Sylhet divisions had the most PLHIV. The detailed numbers of PLHIV living in different divisions and districts are shown in appendix 5 and 6. Out of 736 PLHIV who were alive more than half (56.1%) were living in rural areas while 35.2% were in urban areas. The PLHIV identified so far are scattered all over Bangladesh and there are very few districts where there are no known PLHIV (Fig 5).

Figure 4. Divisional distribution of PLHIV (N=946)

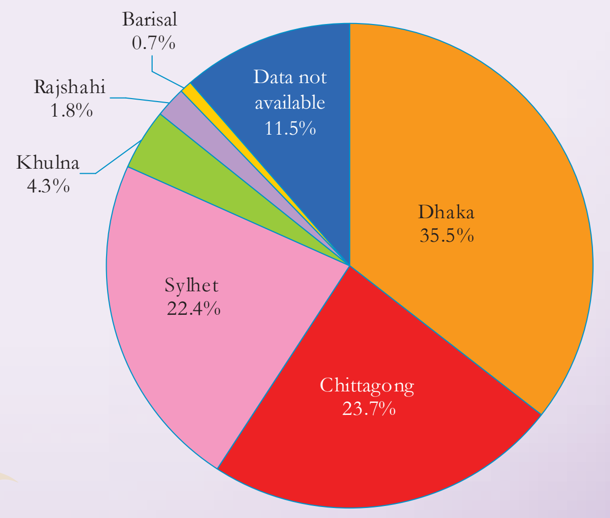
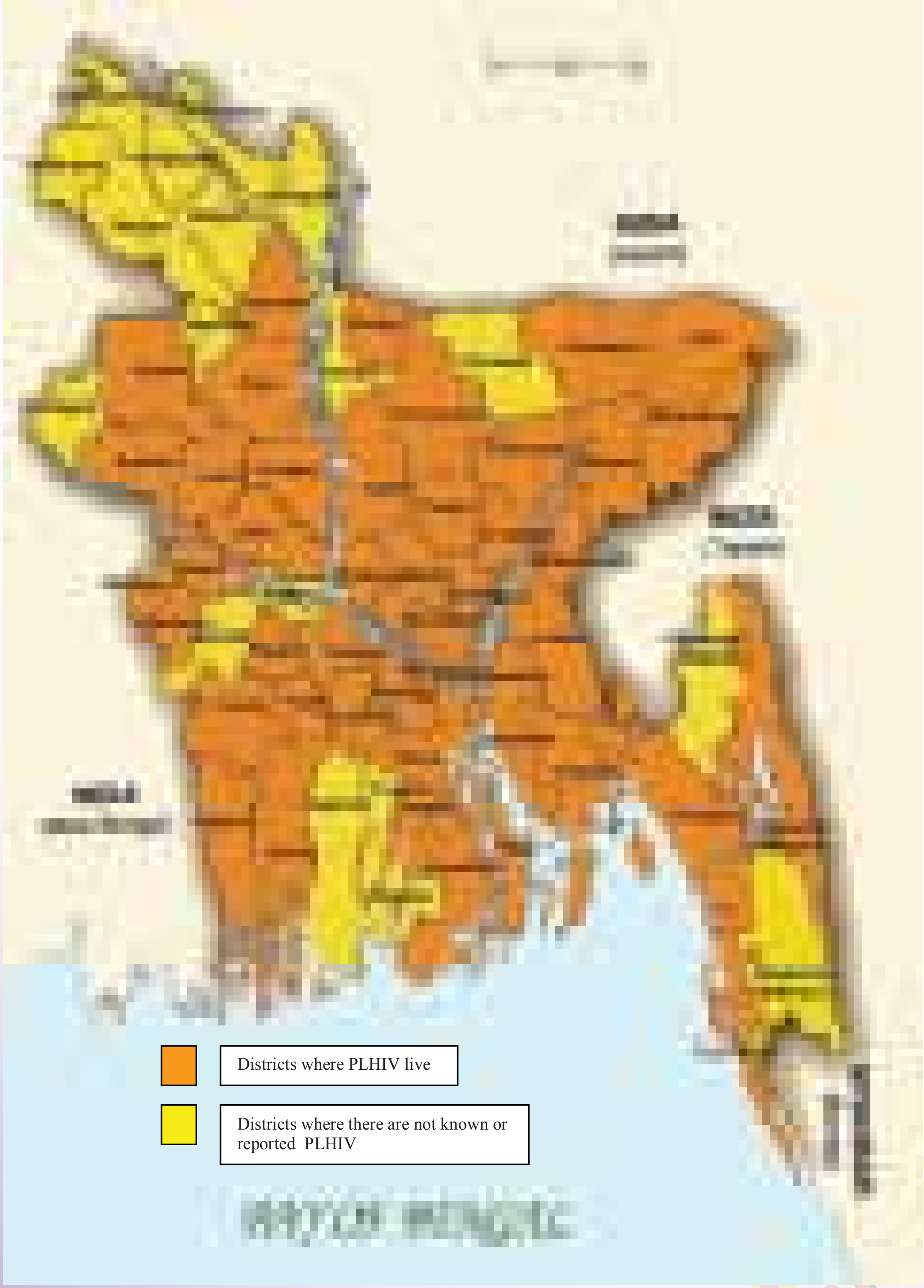


Figure 5. Geographical distribution of PLHIV in Bangladesh



Further analyses showed that the transgender were living in urban areas, in Dhaka (Fig. 6 and 7). In general, there were significantly more males than females in urban areas while the reverse was true for rural areas (Fig 6). As there were more males, it is not surprising to note that in most divisions there were more male than female PLHIV. However, Khulna Division was an exception where there were more female than male PLHIV (Fig 7).

Figure 6. Gender differences in the geographical locations of PLHIV

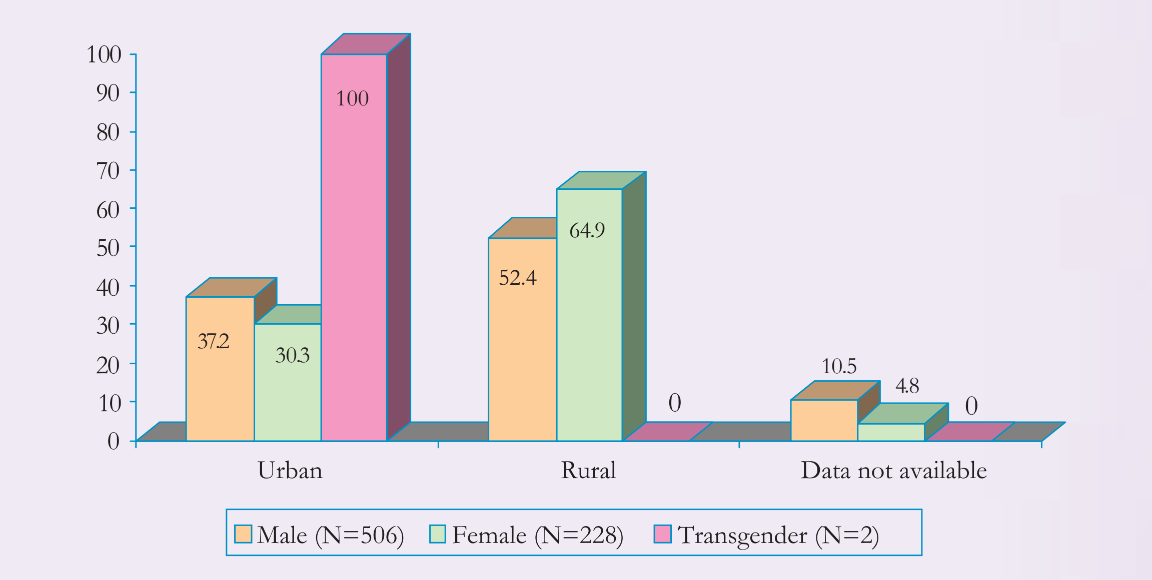
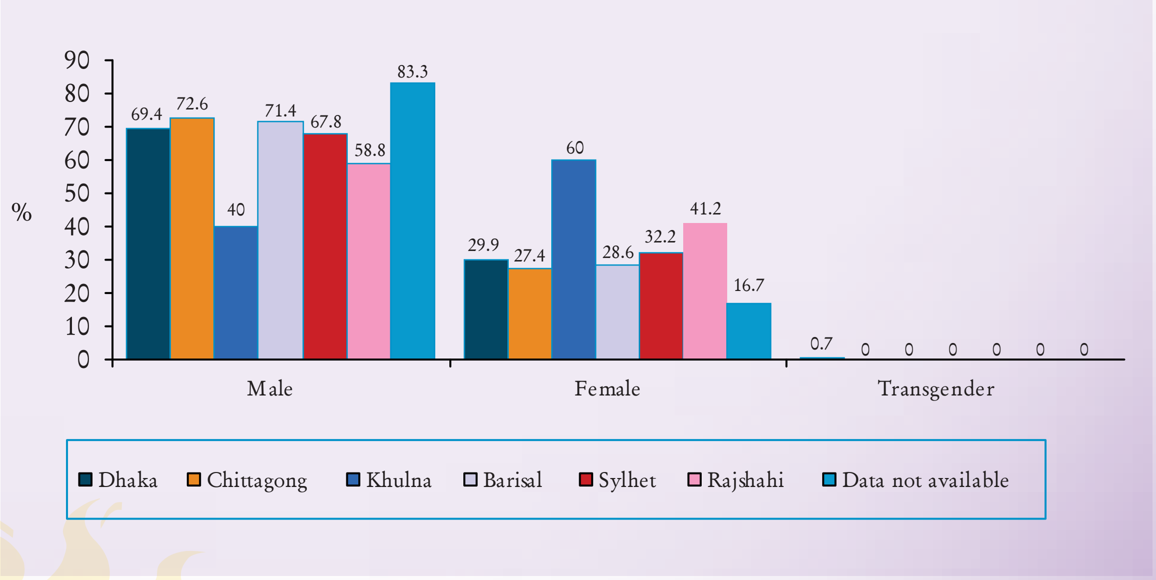


Figure 7. Divisions where PLHIV were located according to gender

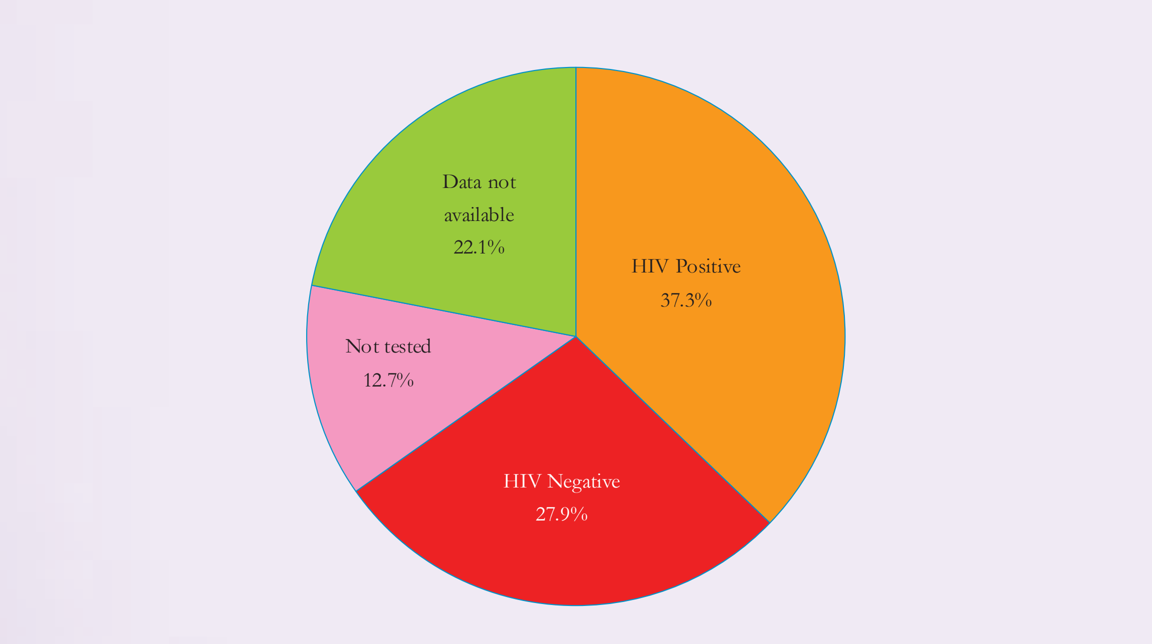


6.1.3 Family members of PLHIV

Spouse

Among all adult PLHIV aged ≥15 years (N=908), 780 were married at one point during their lives while 467 of those adult alive PLHIV were married. Amongst 780, more than one third were HIV infected and 27.9% tested negative for HIV. 12.7% had not yet been tested for HIV (Fig 8).

Figure 8. HIV status of spouse of PLHIV



Among the spouses of married PLHIV (N=780), 21.9% were employed and 55.3% were unemployed. The sources of income of spouses who were employed (N=171) are shown in Table 5.

Table-5. Sources of income of spouses

Sources of income	% (n) N=171
Worked/working abroad	34.5 (59)
In service	24.0 (41)
Businessman	21.6 (37)
Farmer	5.8 (10)
Maid servant	4.1 (7)
Motor mechanic	3.5 (6)
Daily labour	2.9 (5)
Tailor	2.3 (4)
Teacher	1.2 (2)

Children

There were 1,179 children (≤14 years) from 577 PLHIV. Of these 577 PLHIV with children, 19.1% never got their children tested. Children from 51.5% of PLHIV were HIV negative, while those from 7.8% were HIV positive. Most of the children were in Sylhet (31.6) and Chittagong (26.3) followed by Khulna (18.4%) and Dhaka (15.8%) divisions (Fig 9). Most children were in rural areas except in Khulna where there were more children in the city (Fig 10).

Figure 9. Geographical locations of children of PLHIV by division

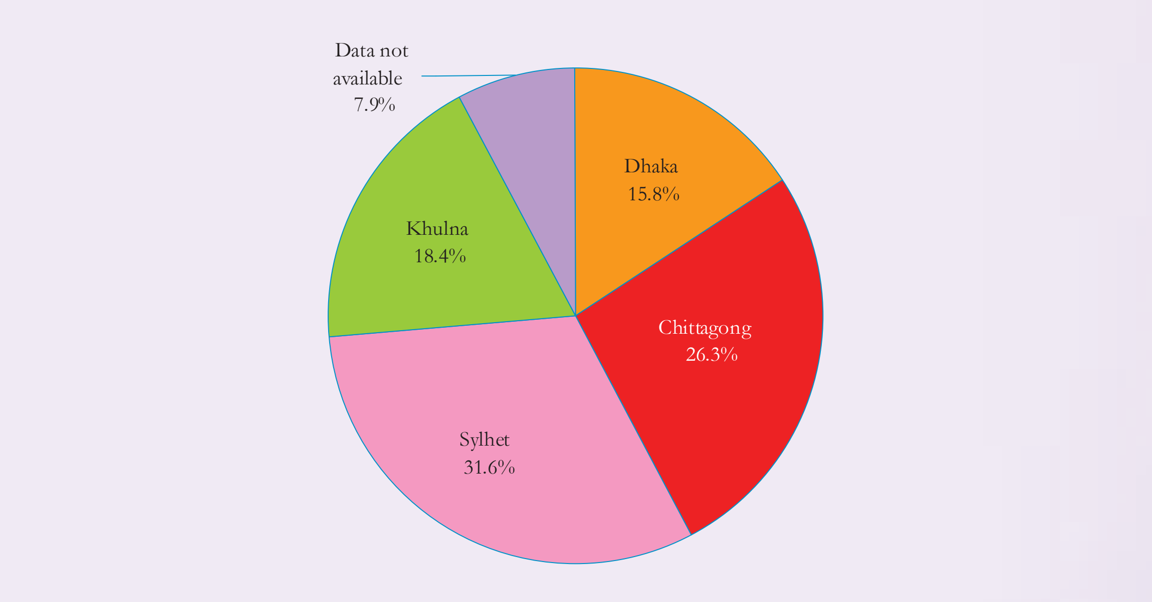
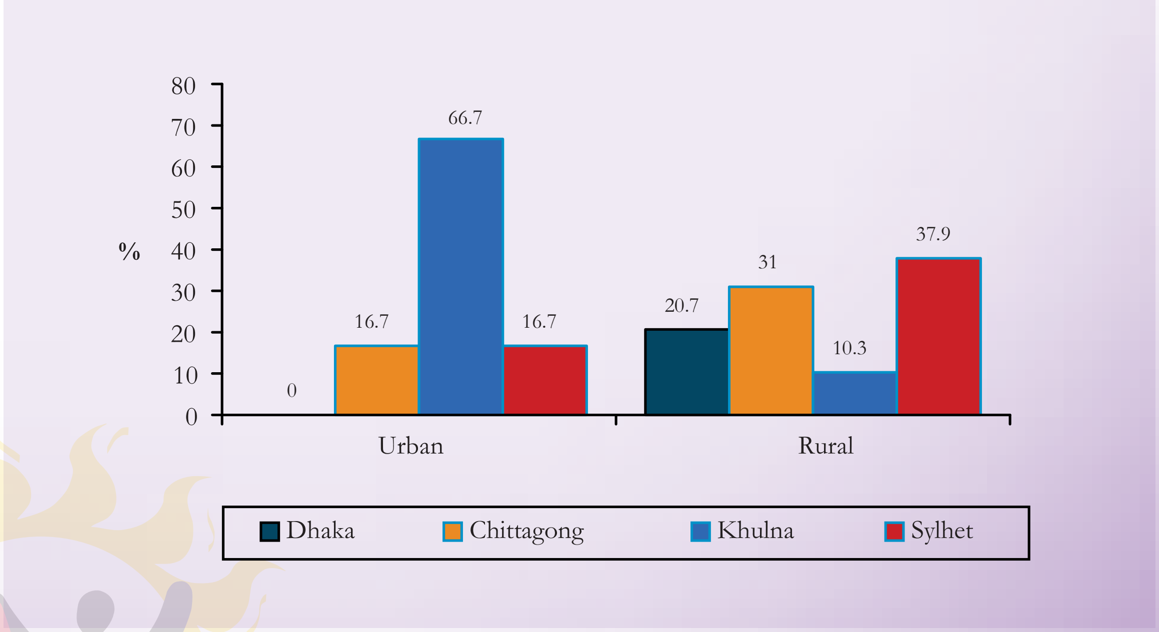


Figure 10. Urban and rural distribution of children of PLHIV



Overall

The number of family members affected by a single person being diagnosed with HIV was assessed indirectly by seeing how many people lived together and assuming that everyone living together would be affected. Out of 946 PLHIV, 807 were living with their families which included different types of relationships. The total number of family members for these 807 PLHIV was 2359 and the numbers of different relationships involved are shown in Table 6; the highest number was for children. These numbers suggest that on average 3-4 people were affected by one PLHIV.

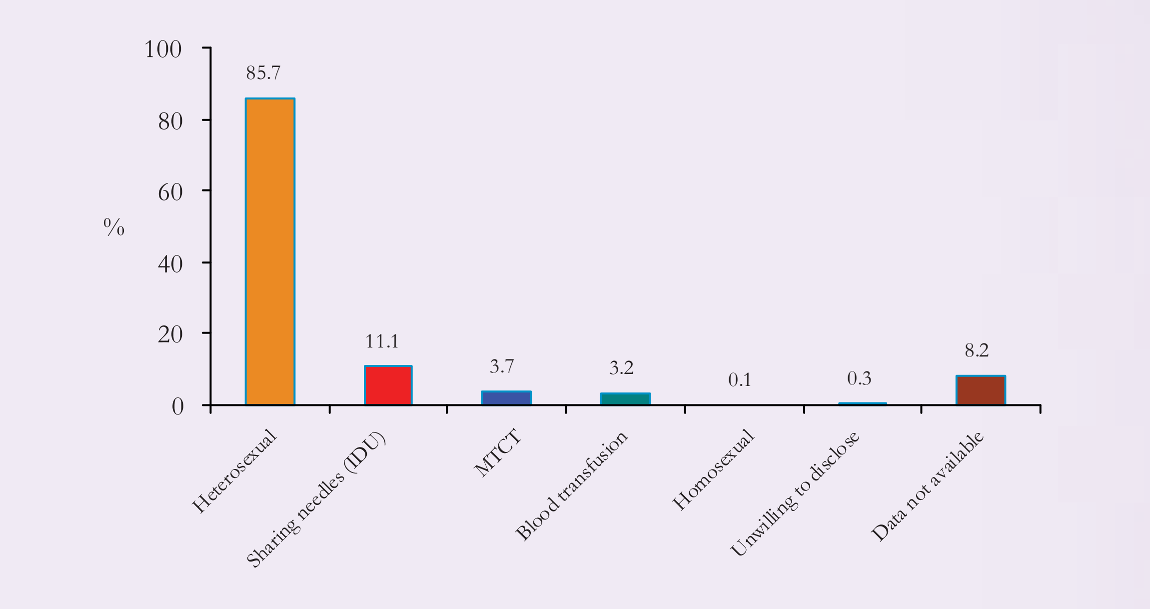
Table-6. Affected family members of PLHIV

Family members	Numbers
Parents	234
Spouse	549
Children	1179
Siblings	140
Brother/Sister-in-law	32
Father/Mother-in-law	14
Nephew/niece	18
Grand parents	18
Regular sex partner (not spouse)	10
Uncle/Aunt	7
Others (son-in-law, daughter-in-law, grand daughter, cousin)	3
Not specified	155
Total	**2359**

6.1.4 Transmission mode or risk factors of HIV infection

Among the 946 PLHIV, the most reported route of acquiring HIV was through heterosexual sex (Fig 11). The transmission mode for 8.2% was unknown (not disclosed by the clients). Of the 38 children identified as being HIV positive, 35 was through mother to child transmission (MTCT), one was from a spouse and two through blood transfusion.

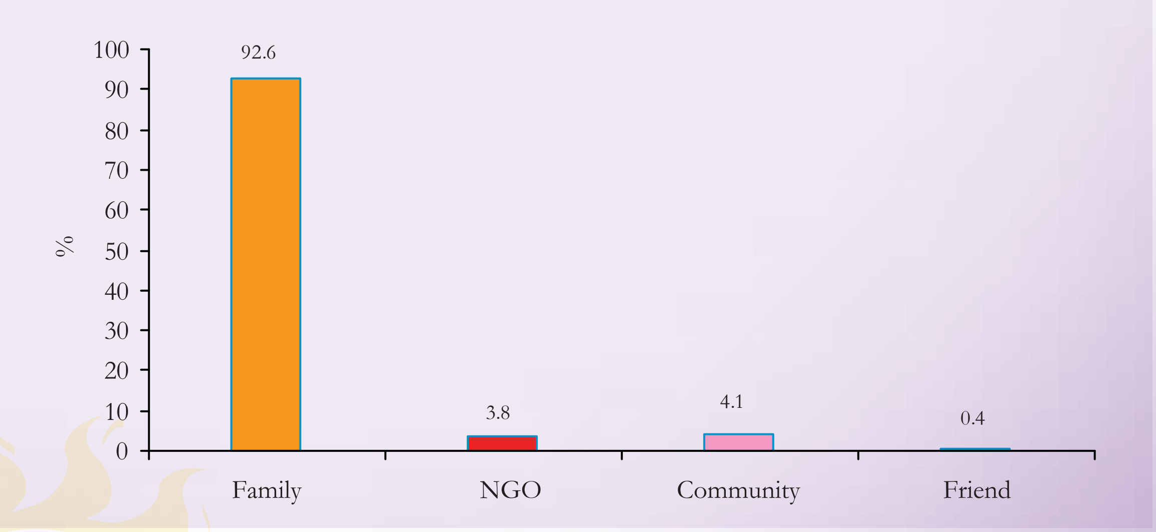
Figure 11. Routes of HIV transmission (multiple responses)



6.1.5 Social support

Out of 946 PLHIV, 48.5% had received social support (which includes primarily emotional, nursing and financial support); only 6.6% did not receive any social support while data was not available from 44.9%. For those who did receive social support, the vast majority was from families (Fig 12). For a large proportion of PLHIV, data was not available because not all organizations recorded this information.

Figure 12. Social support (multiple responses)

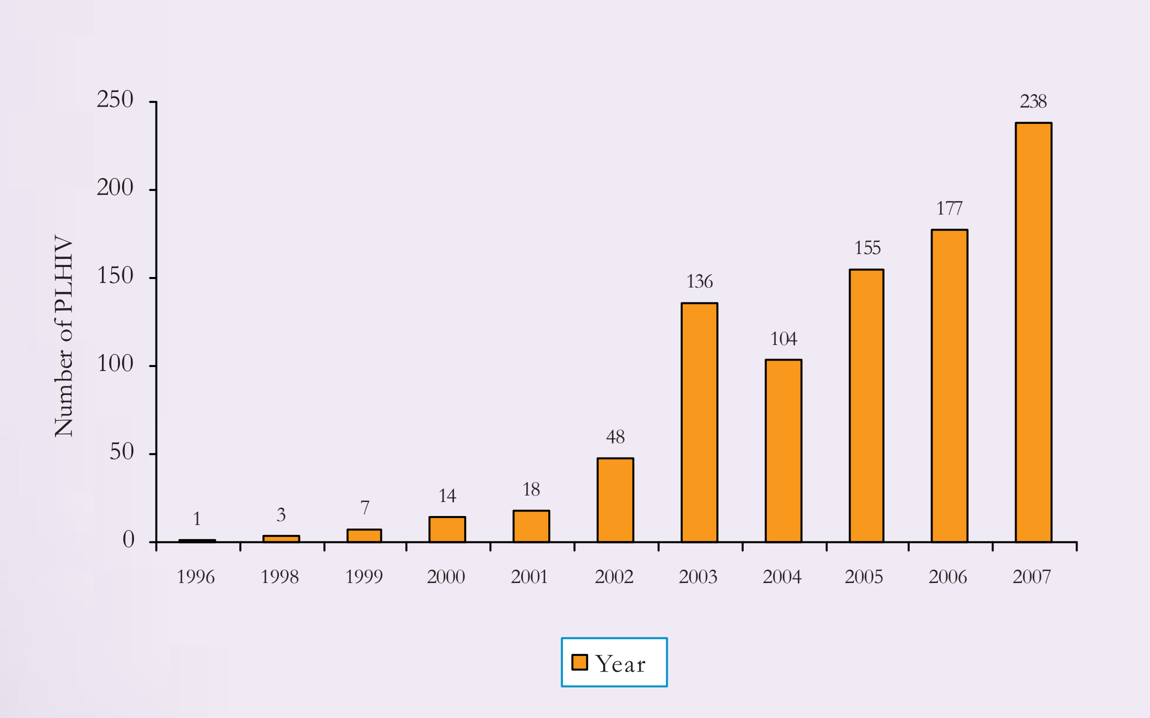


6.1.6 Clinical information

PLHIV health services – access and referrals

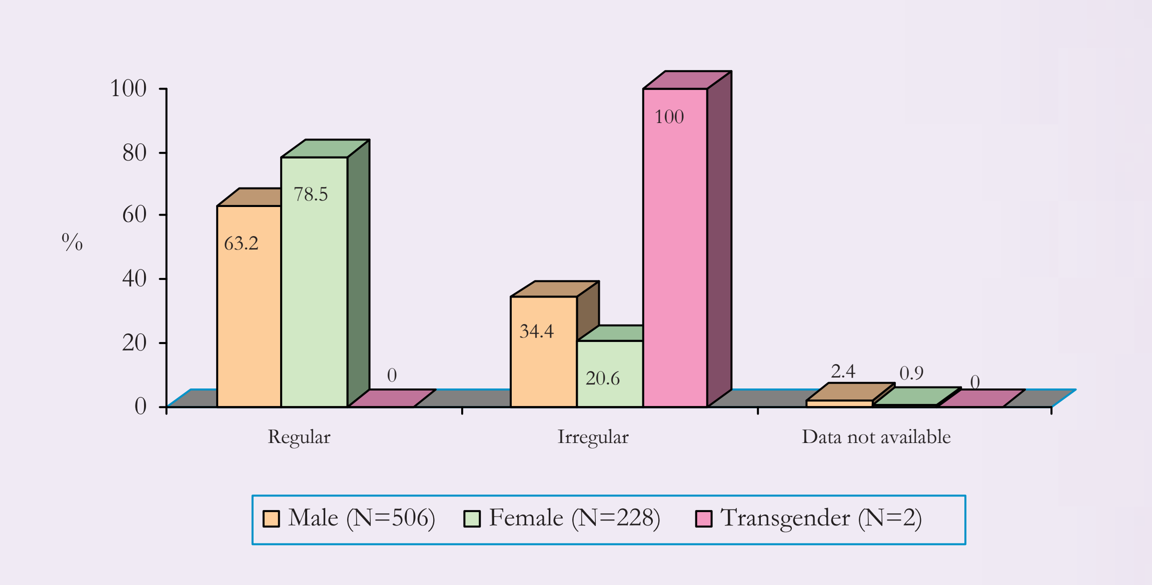
The first HIV related health service was reported to be taken in 1996. Since 2003 the numbers accessing services have risen substantially which could be a result of more services becoming available as well as rising numbers of people being detected with the infection (Fig. 13).

Figure 13. First clinical service accessed



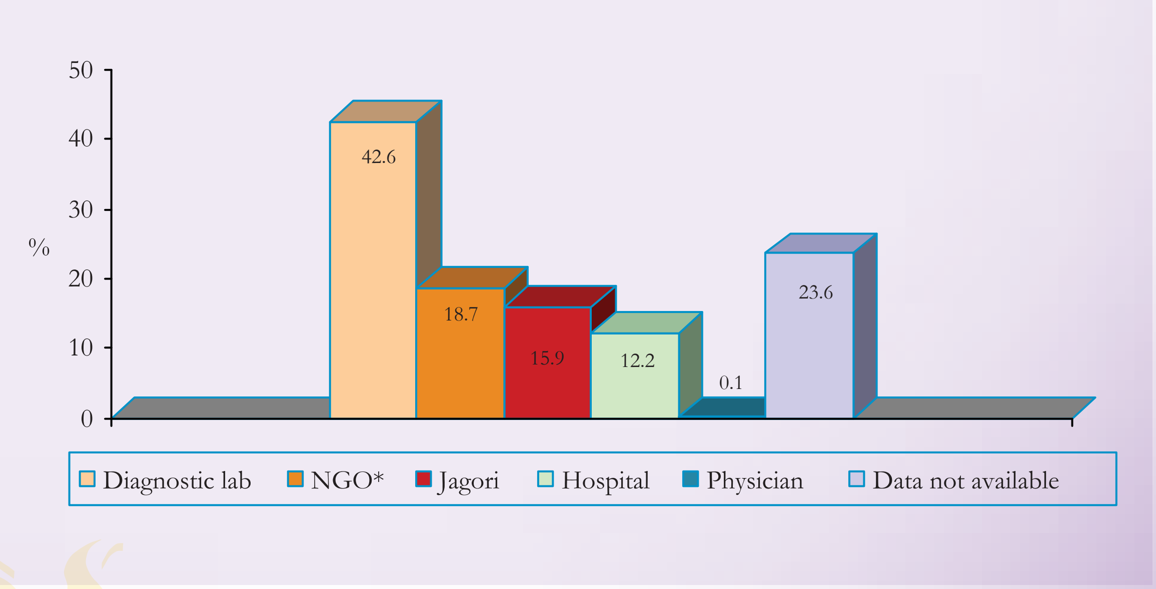
Among those PLHIV who are alive (N=736), 67.8% either regularly accessed services or maintained regular contact with self help groups or service organizations while 30.3% were in irregular contact. PLHIV were categorised as maintaining regular contact if they visited the self help groups at least once in six months. Interestingly, proportionately more female PLHIV than males were regularly taking services or maintaining contact with services ($p < 0.05$) (Fig 14).

Figure 14. Relationship between gender and regularity in accessing care and support services



711 PLHIV had received referral services for laboratory investigations including measurement of CD4 counts, management of Opportunistic Infections (OIs) including hospitalizations, prevention of parent to child transmission (PPTCT) and others. Referrals were made to different places for the different purposes as shown in Fig 15.

Figure 15. Places where referrals were made

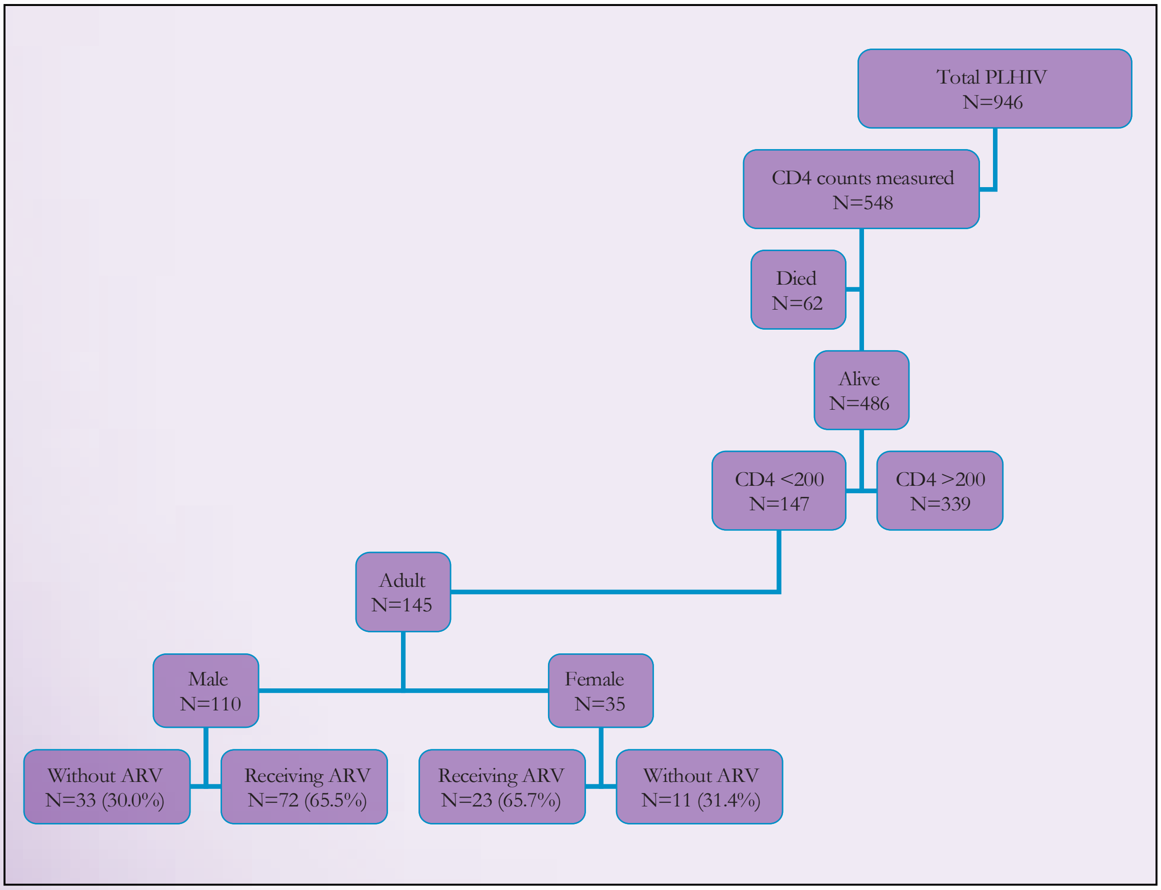


Clinical manifestations

CD4 counts:

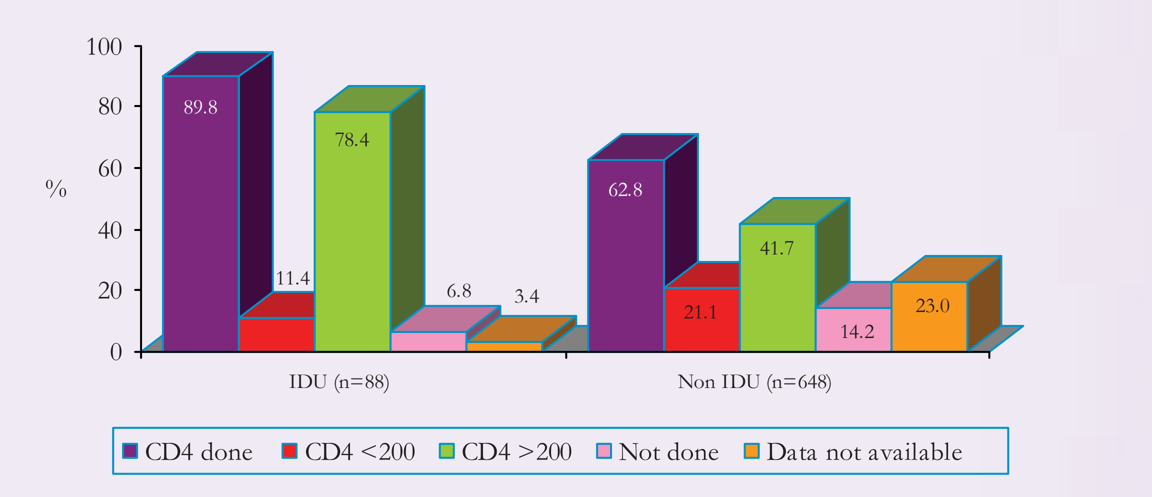
Measurement of CD4 counts was done on 57.9% of the 946 PLHIV, i.e. 548 PLHIV. Among 548 PLHIV in whom CD4 counts were measured, 486 were still alive (flow chart shown in Fig 16). Based on the latest available CD4 count, 147 alive PLHIV had <200 cells/microlitre, 145 of whom were adults. Among the 145 adults, 110 were males and 35 were females. Similar proportions of males and females were receiving ARVs (65.5% and 65.7% respectively). It is to be noted that 30.3% (N=44) adult PLHIV with CD4 count less than 200 cells/microlitre are not under antiretroviral therapy (ART) and need ARVs urgently.

Figure 16. Flow chart showing numbers of PLHIV with low CD4 counts and receiving ARVs



When analyses were done with the PLHIV who were still alive (N=736), to look at differences between IDU (N=88) and non-IDU PLHIV (N=648), more IDU PLHIV had CD4 counts measured than non-IDU PLHIV and this is because the IDU were being followed under a research cohort study aimed at HIV prevention (Fig 17). The proportions of PLHIV with CD4 counts less than 200 cells/microlitre were more for non-IDU than IDU. However, none of the IDU with low CD4 counts were under ART while among the non-IDU PLHIV, who were alive with low CD4 counts, only 25.5% (35) were without ARVs.

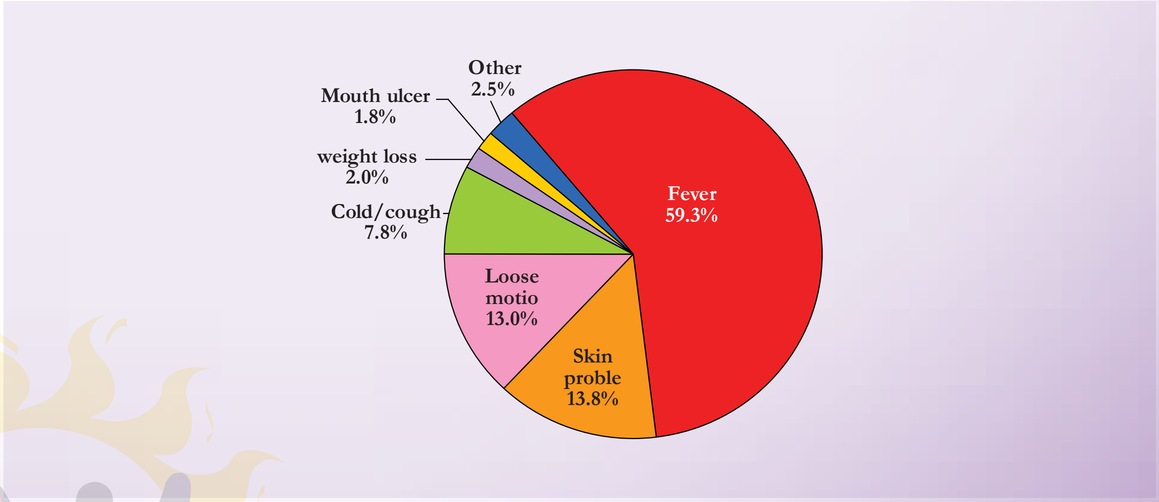
Figure 17. CD4 count of IDU and non-IDU PLHIV



Common Health Problems:

Out of 946 PLHIV, 10.9% never complained of any health problems since joining/attending any one of the service organisations in this consortium. However, 69.6% did seek health services at different times. The most common health problem was fever, followed by skin problems, loose motion, cough and others (weight loss, mouth ulcer, vomiting, loss of appetite) (Fig 18).

Figure 18. Common health problems of PLHIV



Prior to starting ART, the common health problems encountered (among those who had taken ARVs, N=244) were fever, loose motion, thrush, cough and cold, weight loss etc (Table 7). Tuberculosis was diagnosed in 13.1% of the 946 cases.

Table-7. Common health problems immediately prior to initiating ART

Common health problems prior to starting ART N= 244	%
Fever	31.1
Loose motion	18.4
Thrush	16.0
Cold/cough	13.9
Weakness	1.6
Skin problems (rash, itching)	18.4
Mouth ulcer	5.3
Weight loss	6.6

Antiretroviral drugs and cotrimoxazole

Highly active antiretroviral therapy (HAART) became available in Bangladesh in 2003. Out of the 946 PLHIV, 25.8% (N=244) ever received ARVs (Fig 19). The most common reasons stated for taking ARVs was having a CD4 count <200 cells/microlitre (96.3%, N=235); a very small percentage (1.2%, N=3) could only say that they were prescribed this by clinicians; 0.8% (N=2) were given ARVs for PMTCT and data was not available for 1.6% (N=4). However, amongst those currently requiring ARVs (i.e. latest CD4 counts <200 cells/microlitre, N=145), approximately two thirds were under treatment (Table 8 and Fig 16). In Sylhet the proportions not receiving ARVs was higher compared to those receiving ARVs and this was true for both males and females. In Dhaka, among those needing ARVs the proportion was higher for females than for males (Table 8). Of all the children who were HIV positive, ten required ARVs. As paediatric formulation of ARV is not available in the country, most were not under ART. However, two children were receiving ARVs through special arrangements.

Figure 19. PLHIV taking ARVs (N=946)

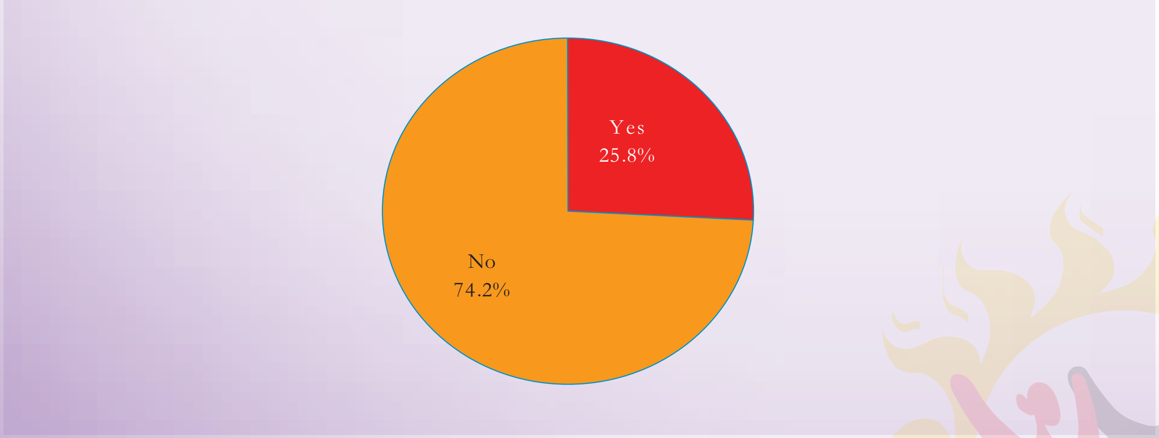
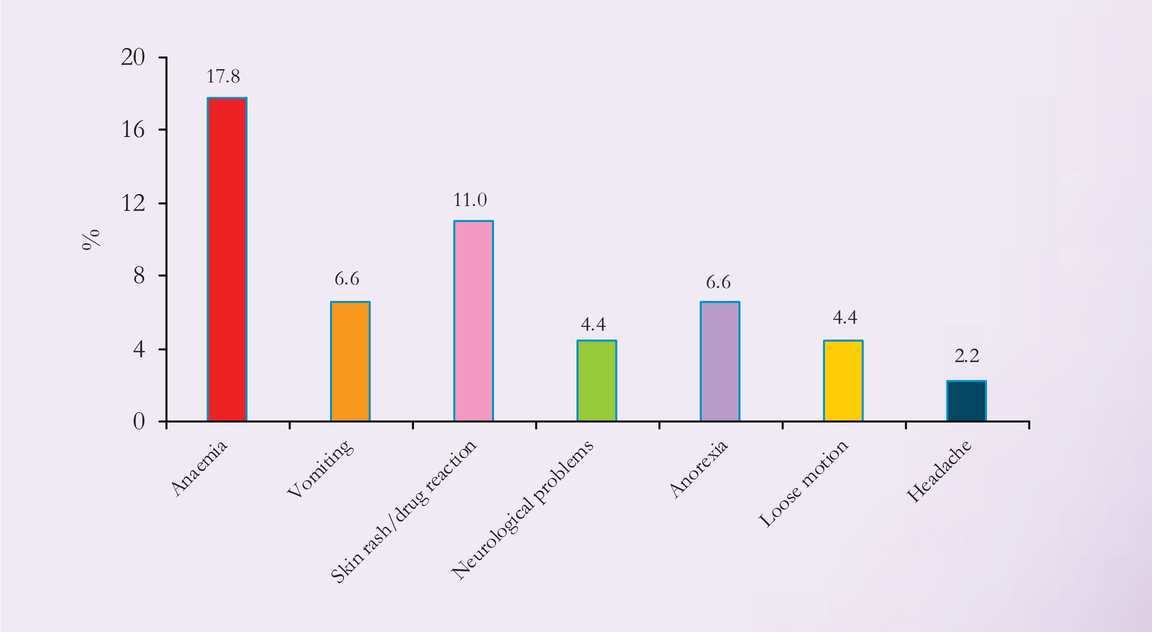


Table-8. ART provision and gaps by gender and geographical location

Adult PLHIV who currently requires ARV (among those whose latest CD4 count is <200), % (n)	Adult Male (N=110)		Adult Female (N=35)	
	With ARV	Without ARV	With ARV	Without ARV
Dhaka	43.1 (31)	39.4 (13)	30.5 (7)	54.5 (6)
Chittagong	27.7 (20)	24.3 (8)	30.5 (7)	9.1 (1)
Sylhet	13.8 (10)	33.3 (11)	13.0 (3)	36.4 (4)
Khulna	2.8 (2)	0	13.0 (3)	0
Rajshahi	5.6 (4)	0	13.0 (3)	0
Barisal	1.4 (1)	3.0 (1)	0	0
Data not available	5.6 (4)	3.0 (1)	0	0
Total	**65.5 (72)**	**30.0 (33)**	**65.7 (23)**	**31.4 (11)**

Side effects to ARVs were reported by 18.4% (45) of those under ART. And the commonest side effect was anaemia, followed by skin rash, vomiting, anorexia and diarrhoea (Fig 20).

Figure 20. Side effects of ARVs



Of all 946 PLHIV, 70.0% (N=662) had taken cotrimoxazole either as prophylaxis for OIs or as an antibiotic to treat other infections while 11.8% (N=112) had never received cotrimoxazole. Data related to cotrimoxazole use were not available for 172 PLHIV.

6.2 Findings From Focus Group Discussions

6.2.1 Characteristics of participating PLHIV and services providers

In total, 13 FGDs were conducted with 102 participants among whom 49 were PLHIV and 53 were service providers (Table 2). The characteristics of participants in the PLHIV and service provider groups are shown in Tables 9 and 10, respectively.

Table-9. Characteristics of PLHIV who participated in the FGDs.

Total number of FGDs	7
Total number of participants	49
Number of participants from different Divisions	
Dhaka	14
Chittagong	8
Sylhet	8
Khulna	10
Barisal	4
Rajshahi	5
Male: Female ratio	31:18
Age in years, mean (range)	34 years, (20–60)
Marital status, % (n)	
Married	75.5 (37)
Unmarried	12.2 (6)
Widow/Widower	8.2 (4)
Separated	4.1 (2)
Occupation, % (n)	
Small Service	30.6 (15)
Unemployed	28.6 (14)
Housewife	22.4 (11)
Small business	8.2 (4)
Others (farmers, tokai, etc)	10.2 (5)

Although most of the PLHIV who participated in the FGDs were diagnosed as being HIV positive two to four years ago, a few of them were diagnosed four to six months back.

Table-10. Characteristics of service providers who participated in the FGDs

Total number of FGDs	6
Total number of participants	53
Male: Female ratio	32: 21
Number of participants from different Divisions	
Dhaka	9
Chittagong	10
Sylhet	10
Khulna	9
Barisal	8
Rajshahi	7
Age in years, mean (range)	36.6 years, (24–62)
Designation of the service providers	
VCT counsellor	14
Peer counsellor cum out reach worker	12
Doctor	19
Nurse	3
Others (Paramedic, Project Coordinator, etc)	5
Type of organization	
Government	10
NGO	35
Others	8

6.2.2 *Thematic Analysis*

Ten principal themes in the context of health service needs of PLHIV were identified by the PLHIV and their service providers. Table 11 provides the list of themes and sub-themes.

Table-11. List of themes and sub themes

Main themes	Sub themes
(i) Access to health care	a) Existing health facilities b) Limited referral linkages
(ii) Gaps in the health care	a) Insufficient medicine supplies b) No support from Government facilities c) Inadequate motivated and trained staff
(iii) Barriers to health services	a) Transport cost and hazards b) Project based support c) Unhealthy competition among care and support NGOs d) Attitudes and behaviours of PLHIV
(iv) Counselling	
(v) Lack of sensitivity in the health care system	
(vi) Satisfaction regarding available health services	a) PLHIV experience b) Service provider experience
(vii) Employment and livelihoods	
(viii)Disclosure	a) Support in disclosing a positive status b) Breach of confidentiality by NGOs in health care
(ix) Stigma and Discrimination	a) Faced by PLHIV b) Faced by service providers
(x) Service providers' dissatisfaction	
(xi) Participants' (providers and recipients) recommendations	a) Government facility b) Treatment including medicine c) Testing d) Training e) Stigma reduction f) Referral linkages g) Employment h) Fund crisis i) Service related

Access to health care

Health services for PLHIV have slowly expanded in Bangladesh however, these are still extremely limited.

Existing health facilities:

All participants more or less agreed that PLHIV have some access to healthcare, although most facilities are available only in Dhaka (Table 12). Only two facilities are available all over the country: VCT services and management of Sexually Transmitted Infections (STIs). However, VCT services in Barisal and Rajshahi are available only for some most at risk populations including sex workers, clients of sex workers and males who have sex with males (MSM); the general population does not have access to VCT in these cities. Most PLHIV receive ongoing counselling, once a month, depending on the need, which mainly focuses on nutrition and family problems. Management of OIs is at present possible only in Dhaka, Chittagong and Sylhet. In Khulna such services were available but have stopped since the last four months due to unavailability of funds. While PLHIV can receive ARVs in Dhaka, Chittagong and Sylhet, all PLHIV need to travel to Dhaka for measurement of CD4 counts. PPTCT is available in Dhaka, Chittagong and Sylhet. Hospitalisation for any condition including emergencies is only possible in Dhaka while in Chittagong and Sylhet this has been possible but in a very limited way. Table 12 summarises the existing health care facilities for PLHIV which clearly shows that services in Bangladesh are centralized in Dhaka.

Table-12. Existing health care facilities for PLHIV in Bangladesh

Type of service	Dhaka	Chittagong	Sylhet	Khulna	Barisal	Rajshahi
VCT	Yes	Yes	Yes	Yes	For most at risk populations	For most at risk populations
Management of OIs	Yes	Yes	Yes	Stopped	No	No
CD4 counts	Yes	No	No	No	No	No
ARVs	Yes	Yes	Yes	No	No	No
STI management	Yes	Yes	Yes	Yes	Yes	Yes
PPTCT	Yes	Yes	Yes	No	No	No
Ongoing Counselling	Yes	Yes	Yes	Yes	No	No
Hospitalisation	Yes	Limited	Limited	No	No	No

Limited referral linkages:

For most PLHIV (IDU and non-IDU), the only health care facility available is the NGOs providing care and support. The NGOs are based in the Divisional cities so that most PLHIV have to travel from different districts to the Divisional cities. PLHIV residing in rural areas have to use more than one mode of transport for each visit, e.g. they have to use a boat or van rickshaw to reach the urban areas from where they can catch a bus or train that takes them to the Divisional city to receive service. The care and support NGOs provide counselling, outdoor consultation by physicians, ARVs and medicines to manage OIs. However, they have to refer the PLHIV to other health facilities for CD4 counts, emergency care for acutely ill patients, hospitalisations due to any cause.

The referral linkage is limited to a few organizations shown in appendix 7. There are no services available in Barisal and Rajshahi, the PLHIV from those regions travel to Dhaka for services. In Barisal however, the physician from Barisal Medical College Hospital expressed interest in providing services to the PLHIV but no one is aware of this and he has not been contacted by anyone to provide such services.

It is obvious that the referral linkage is not very well developed yet; in some places the service providers are not even aware of the existing health services for PLHIV.

Gaps in health care services

Three major gaps were identified in the current health facilities for PLHIV:

Insufficient medicine supplies:

Almost all non-IDU PLHIV and service providers said that the supply of ARVs is limited. A large number of PLHIV in Sylhet are still on the waiting list for ARVs and some have died without receiving treatment. Those on ARVs are at present not getting their drugs regularly. Previously they would receive their ARVs on a monthly basis but because there are not enough ARVs in stock they now have to collect their dose of ARVs every two weeks. As a result they travel from their residence to Dhaka, Chittagong or Sylhet twice per month, but they are reimbursed their transport cost only for one visit per month. The HIV positive IDUs are not being treated with ARVs and most do not know the term "ARV" but they have heard about ARVs from other non IDU PLHIV during detoxification in a treatment centre. They strongly expressed their need for ARVs. This is exemplified by a statement from an HIV positive IDU:

"X organisation gives a capsule that costs 4200 taka which controls the virus, if we were given that capsule; we would become physically healthy and would not fear death"

In addition to ARVs, IDU PLHIV, complained that many of the medicines for management of OIs are not available with the care and support NGOs and they usually have to buy these medicines themselves. According to PLHIV, the quality of the medicines given in recent days is questionable, as they do not recover after taking these medicines which was not the case before.

Both PLHIV and service provides expressed concern that second line ARVs are not available in Bangladesh because it is felt that drug resistance may have become a problem in Bangladesh.

Service providers also expressed great concern about the lack of availability of paediatric formulations of ARVs and this was especially mentioned in Khulna where there are many children who are HIV positive.

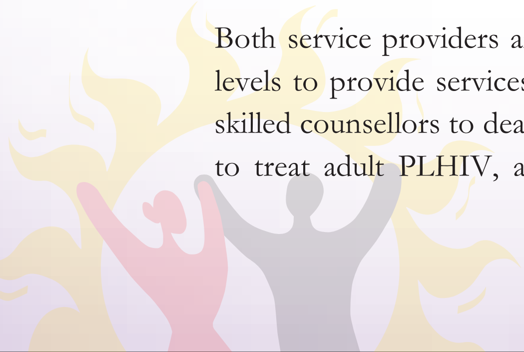
No support from Government facilities:

There was a general consensus among PLHIV and service providers that the health care services are mostly NGO based; there is very limited Government facility available for PLHIV in Bangladesh. Many PLHIV participants reported that previously services for PLHIV at government facilities were not provided properly and reported "horror stories" in this regard; some confirmed that the situation has changed after some NGOs trained the staff of a government facility and renovated the concerned HIV unit. Despite the recent improvements, there remain limitations in terms of resources and stigmatisation. Care and support NGOs have to provide certain basic supplies such as gloves, saline, medicine, and help with a phlebotomist when PLHIV are admitted in government facility. Moreover, there is only one clinician who provides services to PLHIV; during his absence no other doctor is available even if there is an emergency.

A number of participants, especially the service providers, said that there is no VCT centre within the Government facility, although some participants argued that HIV testing in Government laboratories would be less expensive but they would also be less reliable. Many PLHIV also doubted that confidentiality can be maintained in the out patient departments of Government hospitals. From among the service providers who previously worked or are presently working with the Government, there had complaints of not receiving acknowledgment and/or encouragement from the Government for providing services to PLHIV.

Inadequately motivated and trained staff:

Both service providers and PLHIV said that there are not enough trained staff at different levels to provide services to PLHIV e.g. female physicians especially for STI management, skilled counsellors to deal with complicated issues, inadequate numbers of trained physicians to treat adult PLHIV, almost no paediatricians trained on HIV and AIDS management.



Although training has been provided to care providers at different levels, trained staff are not always available for management of PLHIV or those chosen for training are not adequately motivated in providing services to PLHIV. The possible reasons stated for why trained staff are not always available are that NGO staff move from one organisation to another as better job opportunities emerge, while in the Government setting personnel are frequently transferred from one department or one location to another. In addition, service providers think there is a huge gap between knowledge and practice. No training has been provided to laboratory personnel in testing procedures.

Almost all participants mentioned that a negative attitude prevails against PLHIV among nurses in clinics and hospitals. This is not only true for nurses but also for surgeons and dentists. The service providers need to request and personally pursue admission for PLHIV in hospitals and clinics; surgeons in general are not willing to perform any surgery if they are informed of a positive HIV status. This has led to a tendency of not disclosing a HIV positive status to clinics in cases of surgery. Dental care for PLHIV is not available.

Barriers to health services

Several barriers to accessing health care services were identified and these are discussed below:

Costs and hazards related to journeys:

As most PLHIV live in rural areas or in cities outside the main Divisional cities, and as health services are based in Dhaka and to some extent in Chittagong and Sylhet, PLHIV have to travel long distances using multiple modes of transport on a regular basis to access services and also stay overnight in those cities. According to most PLHIV, they have to spend two to three days for this purpose, two days on the journey and one day in the city. Though the NGOs providing care and support services also provide transport cost (at a rate of Taka 250 to 300 per person[1]), the actual cost for travel usually exceeds that amount considerably. Female PLHIV often bring attendants with them as they do not find it safe to travel alone but transport costs for attendants are not covered. This is also true for those PLHIV who are very ill and need to be supported. Taking such long and difficult journeys is especially hard for emergency cases and those with diarrhoea.

In addition to the physical hardship of the journey and the associated costs, other issues such as anxiety about travelling to an unknown big city, especially for females and not having somewhere to stay, are major obstacles. For example, if the journey is undertaken at night they reach Dhaka very early in the morning around 4 a.m. and the NGOs open at 9:00 a.m.,

---

[1] 1 US$ = ~ Taka 68

so they have to wait on the streets. A similar situation occurs when they return home; NGOs close at approximately 6:00 p.m. and their bus departs at ~ 10:00 p.m.

Moreover, they are not given any allowance for food and lodging. And recently, since the shortage of supply of ARVs, they are provided drugs for 15 days so that they have to travel every 15 days to collect their doses, whereas they are given transport cost for only one journey a month.

As a consequence of all these transport related problems, PLHIV cannot maintain regular appointments leading to a lack of adherence to the ART regimen through running out of medication.

Project based support:

At present health services for PLHIV are dependent on funds from donors. Both PLHIV and service providers said that interruption in the funding of NGOs is a major impediment for receiving and providing effective health services. This is particularly hazardous for ARVs as PLHIV who are on ARVs have to buy their own drugs but as most are poor and many unemployed, they simply stop their treatment. A PLHIV raised a question asking how this can be allowed:

"When there is a project there is support, when there is no project there is no support. Do we become HIV negative then?"

At present there appears to be a funding crunch. Because of this all investigations and provision of ARVs is delayed creates an ethical dilemma for the service providers. According to PLHIV there was once a time when they received support for all health related costs including actual transport cost, allowance for food and lodging and nutrition from the NGOs. Many PLHIV are so poor that they cannot clothe or feed themselves let alone buy medicines for treatment.

PLHIV believe that one of the reasons for the reduction in funding may be because the number of PLHIV has increased so that each PLHIV gets less support. A few PLHIV also feel that the NGOs are receiving funds but are depriving PLHIV from the services that are due to them.

"…they are getting funds because of us but we are deprived."

A number of the service providers felt that the funds are not being utilized properly so that considerable amounts are being spent on education materials such as posters but there is a shortage of medicines for PLHIV.

There was a general agreement among PLHIV and service providers that current health services for PLHIV is project based, not need based. One of the service providers said that services provided are often conditional - “if you do this you will get that”. The situation cited below elucidates this sentiment:

“Recently, a study was conducted by some organisations which required CD4 counts to be measured in PLHIV. Through the study, those identified as requiring ARVs, would be treated. However, it was necessary for all those interested in participating in the study to travel to Dhaka and get their CD4 counts measured within a certain time period. For many travelling is difficult, especially if they are ill and then when conditions are placed that only if they can come to Dhaka at that particular time, they will be enrolled in the study and have access to treatment – this is unethical. The PLHIV have no choice – they want treatment and they can get it only under specific conditions that do not take into consideration their own difficulties and needs”.

Unhealthy competition among care and support NGOs:

Services provided by the NGOs are not uniform with some services being available at some NGOs and not in others so that some PLHIV tend to seek services from multiple organizations. If the NGO personnel become aware of this, PLHIV are refused services. This is exemplified by the following two quotes from PLHIV:

“I asked for referral because they could not provide the service that was needed then. They got very angry and told me, you want to go, ok, we will not refer you, neither will we provide service to you, you will die.”

“If we go to X, they say we are getting medicine from Y, and if we go to Y they say we are getting from X. This way we are deprived from every organization. …What should we do?”

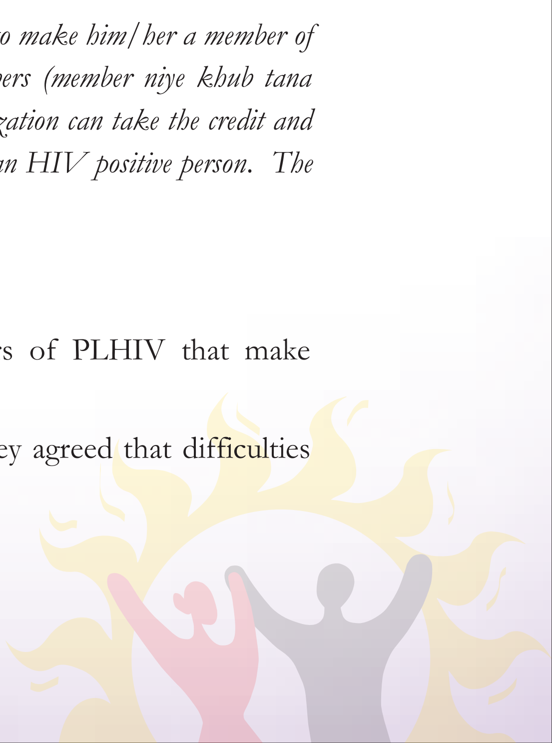
Some of the service providers have confirmed this by saying that PLHIV take services from multiple NGOs for medicine and other support. However, the PLHIV argue that the NGOs are competing amongst themselves for PLHIV as they need the numbers to show to the donors for funding support. Following is another quote from PLHIV:

“A person tested HIV positive and then different organizations came running to make him/her a member of their organisation (hoomri dia porse). These NGOs are fighting over members (member niye khub tana hechra) and this is very common in Bangladesh, everywhere, because the organization can take the credit and next day there will be news in the newspaper that this organization has found an HIV positive person. The name of their organization will be in the news headlines.”

Attitudes and behaviours of PLHIV:

Service providers highlighted certain issues related to behaviours of PLHIV that make service provision difficult. These are listed below:

- lack of adherence to counselling and treatment, though they agreed that difficulties related to transport cost could be responsible for this



- no change in adopting protective behaviours by some PLHIV; e.g. marriage without disclosure, pregnancy without consulting the service provider. This lack of behaviour change has led to burn out or stress of some service providers which they have not been trained to handle
- some service providers think that PLHIV are too dependent on the NGOs
- demand of employment from PLHIV is seen as a problem by some service providers which they feel ill-equipped to deal with
- PLHIV often conceal their risk history from service providers which can mislead the doctors who then carry out many investigations before suggesting a HIV test

Counselling

All participants mentioned that they received HIV counselling, some of them received pre and post test counselling, some did not. Those who did not receive counselling during HIV testing received it later as ongoing counselling once a month. According to the non –IDU PLHIV participants, counselling is very effective. It helps them not to worry, not to be scared, helps to cope with HIV, and provides hope and courage. Some of them said, they would have had suicidal thoughts if they had not received such counselling which is shown by the quote below:

"counselling is very useful, it helped to reduce my mental pressure, refreshed my mind, and provided courage."

There were differences in the counselling provided to IDU and non-IDU PLHIV. Non-IDU PLHIV stated that counselling helped them decide to be tested for HIV and to live positively with the virus, while the IDU PLHIV said that their counselling is more geared to prevention of risk behaviour rather than positive living. IDU PLHIV also said that one of their main issues is their addiction which is their primary concern, not their HIV status.

"When we are undergoing withdrawal, we do not even remember that we are HIV positive."

There appears to be a gap between the IDU PLHIV and the counsellors because the IDU do not think it important to take the counsellors words very seriously as exemplified by the quote below:

"Actually it is our fault, we do not give it [counselling] importance. We think, let them [health worker/counsellor] say what they have to say, we will do our work [take drugs]".

(v) Lack of sensitivity in the health care system

Most PLHIV said that some providers have a negative attitude towards PLHIV such that it deters them from seeking services. The IDU PLHIV complained that many staff lack genuineness and warmth, they are detached, "simply doing their job".

"They provide service but they don't do it with love, previously they used to care; now they don't do it with affection. See, if you give me medicine, but do not monitor whether I am taking it or throwing it, all you care about is that you are supposed to give the medicine and you have given this".

Negligence of some of the staff of all care and support NGOs is another issue that the PLHIV raised about service providers. The staff are apparently busy with the increased patient load and sometimes with meetings and seminars; there is usually a long queue on member's day; staff are sometimes not available over the telephone, either they do not respond to their calls or switch off their mobiles.

A few of the non IDU PLHIV felt that there is favouritism so that some PLHIV receive better services than others. One PLHIV felt that this discrimination was due to differences in the social status of PLHIV.

PLHIV participants felt that they cannot complain of these negative aspects of service provision to the heads of the NGOs as they were worried that such complaints may lead to negative repercussions such as withdrawal of life-saving medicines.

Satisfaction regarding available health services

PLHIV experience:

Despite the problems that were mentioned by the participants, the overall feeling expressed by PLHIV is gratitude. Several positive aspects were highlighted:

- both IDU and non-IDU PLHIV feel that it is because they have HIV they have some services being provided to them and that they would not have received any service if they had any illness other than HIV. Non-IDU PLHIV mentioned that some physicians give them special attention so that they do not have to wait in long queues.
- non-IDU PLHIV have been trained on different issues such as life skills, care giver training etc.
- for non-IDU PLHIV counselling has helped them to cope with their positive status.
- for non-IDU PLHIV home visits and community sensitization meetings by different NGOs has in some cases helped PLHIV in receiving family and community support. However, not all PLHIV agree; few think such meetings make people suspicious about their HIV status.

- for IDU and non-IDU PLHIV some professionals along with care and support NGOs have taken the initiative to address stigma and discrimination within the government and private health care settings, particularly in Dhaka and Sylhet.
- some referral services are very effective (although this is not true for all) for both IDU and non-IDU PLHIV
- both IDU and non-IDU PLHIV are receiving free treatment and medicine, and ARVs (in the case of non-IDU only) from the care and support organizations for PLHIV. Almost all PLHIV appreciated the free service from different organizations; they would not have survived if the organizations were not helping, especially the IDU PLHIV as shown by the quote below:

"They [organizations] have picked us up from the streets and are providing services. They are doing things for us that even our family and relatives don't do for us."

Service provider experience:

The main source of satisfaction for service providers of PLHIV was the feeling of being able to help a marginalised, stigmatised and neglected group of patients. They felt that although they could not do everything that is needed for PLHIV, at least they are providing something. There were other different reasons for satisfaction:

- fulfilling a personal motivation of providing free services
- being able to utilize their training and education on HIV
- achieving international recognition through providing services to PLHIV
- developing a service system for PLHIV and being a pioneer in the field
- being able to successfully build up rapport with clients and observing successes such as when the PLHIV are accepted in the family after family counselling

Employment and livelihoods

Although the guidelines for the FGDs did not have employment as a specific issue to be addressed, it came up repeatedly during the FGDs and was discussed at length in all of the sessions. Employment is therefore being presented here as a distinct thematic issue.

All said that employment of PLHIV is a key issue especially as most PLHIV lost their job after being diagnosed as HIV positive. Employment is necessary not only to survive but there are major expenses related to health services that have to be borne. The monthly out of pocket expense is on average Taka 3000-5000 and the breakdown was shown as:

* Medicine and tests: Taka 1000 to 1500
* Transport: Taka per trip 700/800, more than once a month.
* Nutrition (fruit, milk etc): Monthly Taka 1000 to 2000

Although most PLHIV are unemployed, some are employed but their salary is small and not enough to cover health related costs.

The majority of the PLHIV objected to the employment of people who are HIV negative in NGOs providing care and support to PLHIV especially as it is not easy for PLHIV to find jobs in other organizations because of their HIV positive status. A PLHIV said:

"we are only 1207 and there are many NGOs working in the HIV field, if each NGO employs one HIV positive person, all of us would have survived."

PLHIV said that jobs will not only help them pay for their health services but will keep them busy and distract them from their worries, prevent depression and build their self esteem. The PLHIV are often refused employment because they are not educated enough for most of the jobs.

"They say we do not have education, but we have experiences and skills in different fields. We are not asking for a big post, we are only asking for the jobs that we can do, even a job of peon or guard will do…………"

Disclosure

Support:

Most PLHIV said that they had initially not disclosed their HIV status but eventually they did disclose to their spouse, other family members or close relatives. Some of them have not yet disclosed due to shame, guilt or fear of stigma and discrimination. A few of the participants felt disclosure depends on the family and their own responsibility in the family. According to them it is much easier for a single person and one who has less family responsibilities to disclose their HIV positive status while it is difficult for married PLHIV who have children or for those who have to care for others in the family such as siblings. A reason for this argument is that an HIV positive status jeopardises the marriage prospects of the children or siblings.

Most of the PLHIV said they receive support from their family members which may not have been the case in the initial stages but gradually over the course of time, most families provide support. Support from family includes reminder to take ARVs (adherence), accompanying them while seeking health services, emotional support, financial support in a few cases, taking care of the PLHIV, etc. A few PLHIV said they received community support after community sensitization meetings that were held by different NGOs as exemplified by the quote below:

"I did not disclose my status initially because I heard at the tea stall that no one should sit next to an AIDS patient (AIDS rogir pashe bosa jay na). After my HIV status was disclosed, nobody in the village sat beside me. Then I told the support NGO about my problem. Then they had a meeting with the members, chairman, and other elite people in the village. Now everyone, including chairman member, accepts me in the village."

In order to obtain services, most of the PLHIV do not disclose their status to the health care providers, unless they were referred by the NGOs. However, a few health care professionals are supportive to PLHIV after disclosure and give them special attention.

Breach of confidentiality:by NGOs

Disclosure of their HIV status has had some negative effects as well, especially in health care settings. Because of this PLHIV are wary about disclosure and they expressed their dissatisfaction with some NGOs who have taken the liberty of introducing them to others in different meetings and seminars. Their information has been given to the newspapers in the past. There are some NGOs who as part of the documentation of their work, photograph all the services provided to PLHIV in such a way that PLHIV feel threatened. According to PLHIV, even though they are repeatedly assured that their information will be kept confidential such confidentiality is often not maintained.

According to one PLHIV - "*they usually say they will keep it secret, but actually they don't (maintain confidentiality)"*

According to another PLHIV - *"They would take bags (during visits to the PLHIV), the bag was labelled with AIDS (statements about AIDS). The NGO provided me (financial support for) a shop. What shop….just a bench and few materials, and for that one shop they made a video recording, they had the AIDS bags with them; the community people were suspicious because of that. Then the community misbehaved with me, they said I must have AIDS otherwise why should they have bags with AIDS written and why are they recording? As a result of this, the neighbours from 5/6 houses in my village do not talk to me."*

Some service providers believe that some PLHIV do not seek service from NGOs as they fear that confidentiality will not be maintained.

Stigma and discrimination

Stigma and discrimination faced by PLHIV:

Stigma and discrimination against PLHIV still exists and has been experienced in different forms:

- derogatory remarks
- anger, avoidance, gossip, etc.
- not allowed to mix with others, including family and friends
- not allowed to bathe in a common pond
- blamed for infecting the partner

PLHIV sometimes feel that others in their community are very curious about their activities and are questioned about why they travel to Dhaka or other cities every month, why do they take so many medicine, what is the illness, etc. This curiosity is even greater in case of widows; people are more suspicious when a widow goes out so often. And when there is suspicion, there is also harassment by journalists.

Many PLHIV have been refused services from health care providers especially doctors because of the negative reaction that is invoked by a positive HIV test result. In some health care facilities the HIV test report is given in such a manner that the PLHIV regret having had a test. More often than not they face inappropriate questions from health care staffs, i.e. how did you get it, were you abroad etc.

Having a separate HIV unit in a health care setting can further stigmatise PLHIV which was reported by PLHIV, because their attendants have often had to deal with a negative reaction because their patient was in the HIV unit.

Stigma and discrimination faced by service providers:

PLHIV are not the only people who face stigma and discrimination. Stigma against HIV is so strong that the service providers dealing with PLHIV are also subject to stigma and discrimination from community members and other health care workers. Several issues were highlighted by the service providers in this regard:

- Difficulty in renting space for their offices
- Some service providers face difficulty in getting married
- Others think that they may be HIV infected as they are working with PLHIV. If the service provider's health is not good and s/he looks weak, it is often assumed that they are HIV positive

- Other patients avoid physicians who provide services to PLHIV because they do not want to use the same waiting area as the PLHIV
- Support staff have quit their jobs once they realised that PLHIV are provided health services at the clinic
- Sometimes journalists pester health professionals for information on their (health professional's) HIV status
- Other health professionals, who are not involved in providing services to PLHIV, discriminate against them. Other health providers recommend that they should also get their HIV status checked as they are likely to become infected from their patients. Also, other health care professionals assume that all patients receiving services from the clinicians providing services to PLHIV must be HIV positive.

Service providers' dissatisfaction

Service providers expressed dissatisfaction mainly about the Government set up. These include:

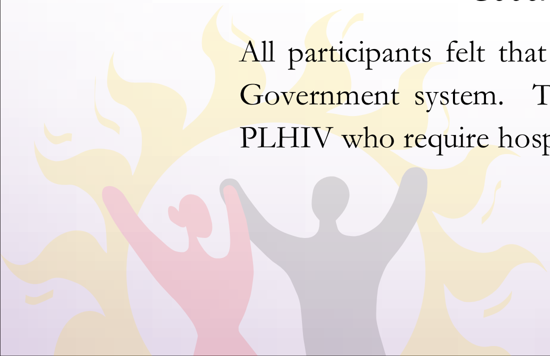
- In the Government medical college hospitals, it is often thought that the treatment of patients with AIDS is the responsibility of the Skin and Venereal Diseases (VD) Department. The Medicine Department is often not involved so that admission in the Medicine ward is difficult. In the Skin and VD Department, there are limited beds, which make it difficult to admit PLHIV. Perceived political affiliation of health professionals affect posting of experienced professionals and their ability to provide quality services.
- Although most of the service providers are happy about providing free services to PLHIV, they are dissatisfied with the existing Government health system for not providing enough incentive in the form of remuneration or national recognition.

Participants' Suggestions/ Recommendations

There were several recommendations that were made repeatedly by both PLHIV and service providers. These are categorized under nine heads as follows:

Government health facilities:

All participants felt that health services for PLHIV need to be made available under the Government system. There were some suggestions as to how this should be done for PLHIV who require hospitalisation:



- establishment of a Government Hospital for PLHIV in Dhaka
- having one HIV Unit in each District Government Hospital
- allocating two beds in the District Hospitals;

However, as mentioned in section 2B, ix (a), stigmatisation of PLHIV may be enhanced by allocating separate facilities for PLHIV. Some PLHIV, expressed doubts whether the Government systems would provide standard care and maintain confidentiality as shown in the quote below:

"Government service is not good because Government job holders think, we have our job, and we will still have this job even if we do not provide service"

Service providers suggested that VCT, measurement of CD4 counts, out patient care could be provided through Government Medical College Hospitals in different Divisions and that advocacy and sensitization in the Government hospitals has to be continued.

Medicines:

The demand for ARVs and drugs for the treatment of OIs was universal. Recommendations include:

- ensuring regular supply of ARVs and drugs for the management of OIs
- availability of second line ARVs
- availability of ARVs for children
- provision of ART to IDUs

Local ARV production is an option suggested by the service providers.

Testing for HIV and CD4 counts:

Khulna participants want confirmatory HIV test to be available in Khulna. There were several concerns regarding existing facilities for the measurement of CD4 counts – facilities for measuring CD4 count outside Dhaka need to be established, there are variations in the CD4 counts being provided by the different organisations and there needs to be better standardisation of this test so that reliable results are obtained.

Training:

Several suggestions were made regarding training of different categories of care providers:

- training of health professionals e.g. doctor and nurses is essential in order to provide effective services

- counselling and training for the care givers such as family members is very important, as they are the main people who provide support
- during internship, placement of doctors and nurses in any HIV Unit must be included

Stigma reduction:

It is apparent that stigma in the health system is a major barrier to providing services. Suggestions to reduce stigma and discrimination include awareness raising in the family and community though community sensitization meetings and mass media. To combat discrimination, the service providers recommend that legal support be made available for PLHIV, especially for widows and children.

Duplication of services by the NGOs:

Service providers suggested more coordination among the NGOs to minimize duplication of health services especially in the same locality.

Employment:

Costs related to receiving regular health services needs to be covered and in order to do that some suggested that the actual transport cost, per diem and nutrition support is provided while others felt that securing employment of PLHIV will help them to cover those health related costs. The service providers suggested income-generating work or micro credit system for PLHIV.

Sustained funding for NGOs

A common recommendation from PLHIV and service providers was that NGOs need to be better able to plan their budgets so that periods of funding gap do not create gaps in provision of services. The service providers recommended that donors should fund according to the needs of PLHIV and not according to their own policies.

Improvement of existing services:

Several suggestions were made on how to improve existing services -

- doctors should be available daily including female doctors
- have a one stop service

- counselling on HIV before migrating to another country must be established
- set up VCT services for the general population in Barisal and Rajshahi
- start telemedicine to deal with the critical patients where a doctor in the periphery would consult with the expert HIV physician in the Divisional cities through video conference

6.3 Differences between IDU and non-IDU PLHIV

As among the most at risk populations, IDUs were the one group that have substantial numbers who are HIV positive, HIV positive IDUs were addressed as a special group. There were several differences between IDU and non-IDU PLHIV that was highlighted through both the secondary data and the FGDs. These differences reflect the unique situation of IDUs, services that are available to them and the ability to manage the special needs of IDUs by the service providers, which are summarised in Table 13.

Table-13. Differences between IDU and non-IDU PLHIV

	IDU PLHIV	Non IDU PLHIV
Homelessness and social support	Most IDUs are street based and mobile; hence it is difficult to reach them to provide services. Most of them do not have family support and the only support available is through the NGOs and other organisations.	Non IDU PLHIV are home based which makes it easier to reach them for care and support services. Most have family support, along with support from other PLHIV and care and support NGOs
Drug withdrawal, detoxification and oral substitution therapy (OST)	Health service providers need to know how to manage drug withdrawal of IDUs and most general health care providers and clinics are unable to manage this. Drug detoxification services that can help stabilise IDUs have become more available but mainly in Dhaka. OST has not yet been started in Bangladesh although a pilot in Dhaka has been planned which will help stabilise IDUs to bring then under care and support services.	Not applicable
CD4 counts, ARVs and OIs management	Because of an ongoing research study aimed at monitoring HIV positive IDUs and to prepare the ground for ART and OST in IDUs, most have had CD4 counts measured. ARVs have not yet	More than a quarter of the PLHIV are receiving 1st line ARVs. Their main concern is the regular supply of ARVs and also that 2nd line ARVs should become available. They are also

	IDU PLHIV	Non IDU PLHIV
	become available to IDUs but will be provided through GFATM in the very near future. Though IDUs do not know the term “ARV” but they have heard that there is medicine that controls HIV and they want it. They are less worried about the management of OIs as they are less aware of this.	concerned about the limited stock of ARVs and quality of medicine for OIs management.
Knowledge about health care services available for PLHIV	They know very little about the care and support services that are available in the country for PLHIV, e.g. CD4 counts, counselling for positive living, ARVs etc. Although most have had their CD4 counts measured, they do not fully comprehend the significance of this possibly because they are not being treated with ARVs. The only thing they know is that they receive treatment for their problems (iron and vitamins but not with HIV medicines).	They have very good knowledge about the services that they are provided and that are available for them, including the terminology.
Counselling	Counselling for IDU PLHIV is mainly prevention focused and the IDUs are not really interested in such counselling as they are more concerned about dealing with their craving for drugs. No counselling on positive living is being provided although training of some NGOs working on IDUs has been conducted on this aspect.	Counselling for PLHIV is mainly focused on positive living, nutrition education, life skill training etc. All of them said that counselling was very helpful.
Satisfaction with referral services	IDU PLHIV are more or less satisfied with the referral service	Most of them are not satisfied with the referral service (especially the ones in the Govt. setting)

There were also some similarities in the two groups:

- neither was happy with the behaviour of some staffs of the care and support organizations.
- both groups felt the need for jobs to cover the cost of living, health services and good mental health.

7

LIMITATIONS

There are a few limitations in the data presented here and these are listed below:

i) The secondary data provides information primarily on those who are already members of PLHIV self help groups. Information on individuals who are not members of self help groups or who are not covered by any of the service providers is not available and therefore has not been analysed.

ii) The information recorded by the organisations in this consortium has not always been updated. As a result some data reflect those at the time that PLHIV were first seen by the service organisations, while others have been updated and are real time. Although this has been considered in the analysis, it has not always been possible to check this.

iii) All service organisations in this consortium do not collect data in a similar format. Although the secondary data form was developed through a consultative process so that information that would most likely be available with most organisations was included, this could not be ensured in all cases. Where data was not available, it has been recorded and analysed accordingly.

iv) It is possible that all cases of duplication may not have been detected

v) Selection of PLHIV for FGDs was done by the PLHIV self help organisations which may have created a selection bias. However, discussions were open and frank.

vi) In some cities there were very few or no service providers who had any experience of working with PLHIV. In these areas discussion on service provision for PLHIV therefore was therefore very limited.

8

SUMMARY OF FINDINGS AND DISCUSSION

8. SUMMARY OF FINDINGS AND DISCUSSION

In Bangladesh, services for PLHIV have been gradually developing and evolving ever since the first case was identified in 1989 and the first HAART provided in 2003. The services that have been and are being provided have been very *ad hoc* and without any real understanding of the existing situation of PLHIV. Developing and delivering appropriate and effective health services for PLHIV requires an understanding of the perceptions, attitudes and behaviours of the PLHIV and the service providers as well as the actual demographics of PLHIV in a country. With availability of funds for care and support for PLHIV through package 910, round 6 of GFATM, a concerted effort to provide effective health related services to PLHIV is being made. Accordingly the first assignment of the 910 package is to provide an understanding of the needs of PLHIV as well as the service providers and to assess the approximate numbers of people affected by HIV and AIDS to allow appropriate planning for service provision.

An important finding from this assignment is that most PLHIV are living in rural areas, across Bangladesh while most services are centralised primarily in Dhaka with some services also being available in Chittagong and Sylhet. In order to avail health services, their (PLHIV) journey to the cities can be long and arduous and PLHIV are not provided full support (financial and security) for their journey. This is particularly pertinent in the case of females many of whom reside in rural areas and have to be accompanied for security reasons. Making services available in rural areas is a challenge that must be addressed. Trials of different models to provide decentralized services to rural communities in Africa may provide insights into how to meet this challenge (5).

Poverty is an overwhelming issue; a large proportion of the PLHIV were migrants who have returned home; many PLHIV are not employed, those who had jobs before do not have jobs now, many have gone back to their rural homes to farm and fish. Because of their low level of education and skill, finding suitable jobs that will cover their health related expenses is difficult.

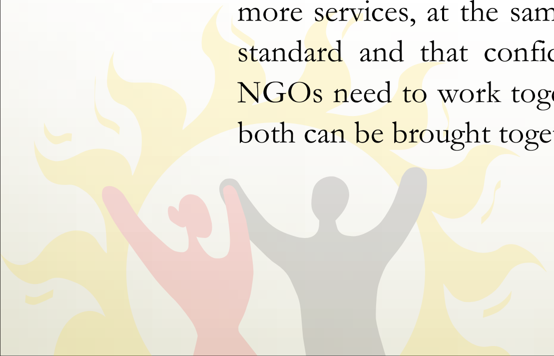
Families constitute the major source of support for PLHIV – they have been the care givers and provide emotional support. From the secondary data available it is estimated that for each PLHIV, three to four family members are affected and most of these are children. However, family support, other than counselling, has not been considered in the planning for the care and support of PLHIV. As an example, when family members accompany PLHIV for accessing health services, their travel and lodging cost is not covered.

Although it is encouraging to see that a proportion of spouses and children are still HIV negative, it is alarming that some have not yet been tested. Possible reasons could be issues around disclosure, access and availability of testing centres. Counselling around partner notification and disclosure needs strengthening as does setting up more reliable and accessible VCT centres.

Shortage of ARVs, no ARV formulations for children and disbursement of ARVs only through some central service sites are all factors that interfere with adherence to ART. ARVs are being provided through individual donors funding an NGO and through private sources – none of these have long-term agendas and the amount supplied is limited. GTZ has recently undertaken a study to assess the future needs of ARVs and other medicines in the country and along with the needs assessment conducted through this assignment, it is hoped that a long term planning for ARVs along with the medicines required for the management of OIs will soon be possible. It is extremely important that planning should be a Government activity that could allow better coordination among the service providers and other potential donors. With possible availability of funds for care and support for PLHIV through round 6 GFATM, such planning is crucial for proper utilisation of funds and appropriate distribution between advocacy efforts and clinical care.

Unhealthy competition between NGOs and other services providers is a major barrier to service provision. The beneficiaries themselves have felt the need to conceal where they access services from fear of reprisal in the form of receiving no support from the NGOs. Such competition usually stems from the need of funds. Funds have been limited so far and there have been many disruptions in the funding mechanism so that services have had to be curtailed resulting in many problems for the beneficiaries as well as the service providers. Beneficiaries note a change in the attitude of service providers with many not being as supportive as required which may or may not be related to funding restrictions. There is also a lack of adequately trained staff that are sensitive to the situation of PLHIV. Not having adequately trained and motivated staff is a problem that is prevalent in many resource constrained settings even where HIV and AIDS has been prevalent for some time such as in Uganda (6). Training of service providers at all levels – from the outreach worker to the physician - is an urgent requirement. Training restricted to theoretical courses does not suffice, hands on training is essential. Retention of trained staff is another challenge and in the Government set up, frequent transfers interfere with developing a cadre of trained personnel who will continue to provide services to PLHIV and who could potentially train new health service providers.

Government facilities providing clinical care as well as laboratory services are almost non-existent. The improvements in IDH, a recent occurrence, have been well appreciated. However, that the service is dependent on one particular physician is very restrictive and does not work well for emergencies. Although PLHIV all want Government to provide more services, at the same time, they are wary that Government services are not of a high standard and that confidentiality may not be maintained. Therefore, Government and NGOs need to work together to see how best to develop a linkage so that the strengths of both can be brought together.



PLHIV also need to be responsive to the limitations of services available and the constraints under which the service providers are working. PLHIV need to be better consulted on services regularly (as well as represented within NGOs) and a collaborative approach to expectations management developed.

A major barrier to services for PLHIV remains stigma and discrimination and this is a global issue (7) which is magnified in cases of marginalized populations such as sex workers, IDUs, etc. It is not just PLHIV but service providers also face stigma. Although many efforts are being made in the country to overcome stigma and there are many awareness campaigns which are not only geared towards knowledge on HIV prevention but also in dealing with misconceptions, this continues to be a problem. However, strides have been made and families have come forward to support most PLHIV, in some cases community support has been gained, and many service providers have also come forward as individuals interested in working for the "neglected". To have a greater impact is likely a matter of continued effort and time.

In many countries IDUs tend to be excluded from ART, and often even from basic primary care (8, 9). The situation is similar in Bangladesh; none of the IDUs are under ART. However the service providers who are providing services to the IDUs in Bangladesh think that it is important to assess the readiness for ART in IDUs because most are homeless and mobile and do not have any caregiver to monitor adherence. More clinical services need to become available for IDUs including longer term rehabilitation and OST which have shown to increase adherence to ART. Counselling services related to positive living is not being provided to IDUs unlike other PLHIV. Such support is essential and needs to be made available to IDUs. It is hoped that a recent training on positive living for IDUs which was conducted by UNODC will be utilised by the NGOs providing services to IDUs.

Several gender differences were highlighted in this assignment. Women who are in contact with PLHIV self help organisations, tend to be in more regular contact than their counterpart men. This happened despite the fact that more women PLHIV were residing in rural areas than in urban areas. Women pointed out their need for female physicians especially for the management of STIs. It is well known that women are the main care givers for families and reaching out to women who are providing support to spouses who are HIV positive is essential. It is however, very encouraging that similar proportions of male and female PLHIV who require ARVs are under ART.

In conclusion, there is much to be done to provide effective health care services to PLHIV. The challenges are immense, however, some issues can be dealt with relatively easily and quickly and require coordinated planning.

9

RECOMMENDATIONS

9. RECOMMENDATIONS

Although it may not be possible to address all the needs that have been identified through this assignment, it is essential that efforts are made to address some key issues that have emerged. In order to do this a set of recommendations at different levels are being proposed here that are based on the findings from the assignment:

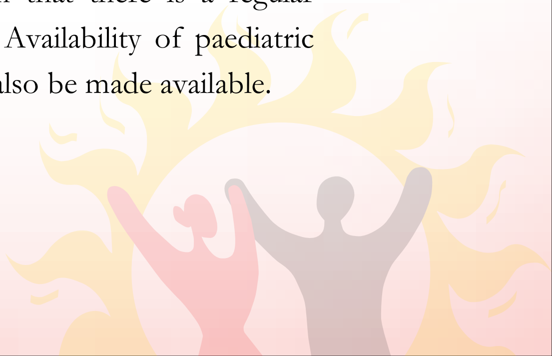
9.1 Government:

1. A uniform recording system needs to be developed so that all organisations providing care and support maintain key information from PLHIV receiving services from them. These data can be entered at regular intervals in a central data base where information will be collated and analysed at regular intervals using a system that will minimise duplication. The purpose of collecting such information will be several fold:
    - analysis of the key determinants of PLHIV in Bangladesh, as has been done in the secondary data analyses for this assignment, helps understanding the demographics of PLHIV, including their geographical distribution.
    - early identification of changes in demographics or geographical locations, can allow quick and timely action such as making relevant services available.
    - such a recording system will facilitate coordination of services among the service providers

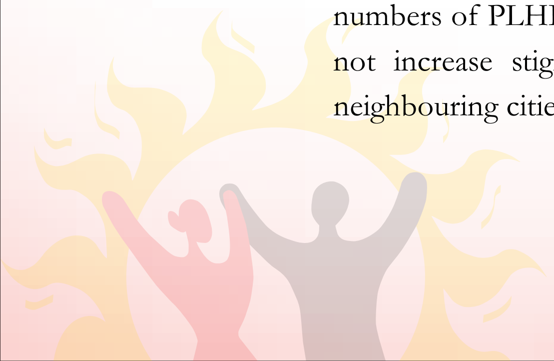
    However, ethical concerns, such as maintaining confidentiality and obtaining consent prior to collecting information is essential.

2. Based on information collected a long-term plan should be developed for programming for the care and support of PLHIV. This plan needs to have clear requirements for advocacy, clinical care (including ARVs, drugs for OIs, laboratory investigations, etc), counselling and other support demarcated. While designing programmes for PLHIV, Government must involve the community based HIV prevention organizations and peer support NGOs who are currently working in this field with their limited resources.

3. Government has to ensure provision of free ARVs such that there is a regular supply. Local production of ARVs will minimize cost. Availability of paediatric formulations has to be ensured. Second line ARVs should also be made available.



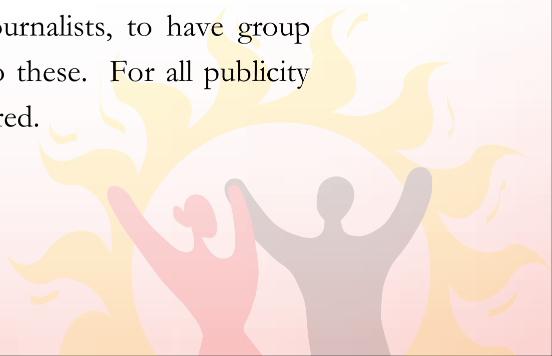
4. Government needs to play a coordination role in order to ensure that services for PLHIV are not duplicated and that NGOs and other services organisations work together.
5. Government should help to build the capacity of PLHIV self help organisations.
6. Provision of services by Government health facilities – existing facilities in Government hospitals need to be made available to PLHIV either as integrated services, as a separate Government hospital, or separate units or beds within existing hospitals. The services should not only be restricted to hospitalisations but should be extended to other required clinical care, VCT and laboratory tests such as measurement of CD4 counts. However, the services provided must be of good quality with trained personnel – physicians, nurses, laboratory staff, etc.
7. In laboratories that will conduct CD4 counts, it is essential that there are trained engineers available who can maintain equipment and overshoot problems that may arise. Laboratory staff who will measure the CD4 counts will need to be adequately trained and supervised. Ongoing quality control systems need to be in place with external quality control through recognised overseas reference laboratories.
8. The barriers to provision of services by Government facilities must be addressed. The barriers are mainly stigma against PLHIV, fear of HIV which often arises from incomplete knowledge and misconceptions and lack of implementation of Universal Precautions. Some of the ways suggested for increasing knowledge were not only through mass communication and inclusion in school curricula regarding HIV prevention but HIV and AIDS should also be included in the curricula of doctors and nurses with emphasis on practical, hands-on training during internship. When training of medical personnel and other care providers are offered, personnel should be selected carefully so that relevant personnel are trained, i.e. those who will provide services. Frequent transfers of trained personnel needs to be avoided and a system should be developed that will allow retention of trained staff. Universal Precautions has to be implemented without which it is often difficult for surgeons and dentists to provide services required.
9. A system of delivering services in rural areas needs to be explored. Experiences from other countries may be taken into consideration keeping in mind that the numbers of PLHIV in a specific location are very few and that such services should not increase stigmatisation. Alternatives, such as making services available in neighbouring cities, may be an option.



10. Recognition of service providers for their role in providing services to PLHIV would attract more Government health providers to enter this field.
11. IDUs may be considered as a special group who have special requirements. They require additional support that will help stabilise them for ensuring better adherence to ART. Some of these measures include detoxification and rehabilitation as well as provision of OST.
12. The current policy on disclosure of a HIV positive status to health care providers and family members should be clearer as different NGOs follow different strategies. The benefits and risks related to disclosure without consent need to be more closely analysed.

9.2 NGOs and other service organisations:

1. It is important that NGOs provide the essential services required for PLHIV and that there is no interruption in these services. In order to identify those essential services, NGOs need to develop their own strategic plans, so that donors provide funds to meet the needs of NGOs according to the strategic plans. Development of strategic plans will require technical assistance. All NGOs providing services to PLHIV could do this in a coordinated manner to avoid duplication of services.
2. NGOs need to conduct an exercise looking at costs (including the breakdown) that a PLHIV from different parts of Bangladesh has to incur in order to avail health care services. This would enable designing of a program for health service delivery which however, needs to be done in consultation with PLHIV such that maximum service can be provided within a reasonable budget that is sustainable.
3. PLHIV should not feel constrained in taking services from more than one organisation however, at the same time duplication of services need to be avoided. In order for this to happen, NGOs need to be more coordinated in the services they provide, there should be less competition and more cooperation among the NGOs. A possible way to address this would be to develop a functioning network of self-help groups of PLHIV.
4. NGOs must have a system in place to ensure the confidentiality that is assured to their beneficiaries. PLHIV who are not ready to face journalists, to have group photographs taken in meetings, should not be subjected to these. For all publicity activities a system of taking written consent may be considered.



5. Decentralization of the services provided by NGOs is essential and efforts to expand to rural areas in ways that do not stigmatise communities must be explored.

6. The clinicians appointed by NGOs should be regular staff who provide services daily, better trained to deal with the needs of different PLHIV, and there needs to be both male and female doctors available for services. In order that services provided meet the needs of PLHIV, NGOs need to develop a system of monitoring the performance of their own staff and assessing satisfaction/dissatisfaction of the beneficiaries (PLHIV). NGOs need to be more open to such monitoring which could follow a participatory and constructive approach.

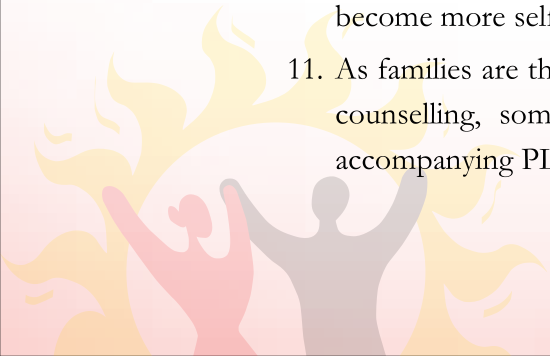
7. NGO staff who are interacting directly with PLHIV, such as outreach workers, counsellors, other health professionals need further training on issues of sensitivity. They need to learn how to ask questions, which questions may be asked and which not and where there is a need to ask questions, they should explain the reason for asking those specific questions. Such training will also help them to explain to PLHIV what the reality is in terms of services available in order not to raise the expectations of PLHIV. Supportive supervision should be made available for such staff.

8. NGOs need to improve the support systems for the staff of their own organizations, e.g. to deal with issues of burn out.

9. Stigma and discrimination continue to remain major barriers for service provision even within the NGO setting. This needs to be tackled through two ends –
    - NGO staff - intensive training of the newly recruited staff and ongoing training of old staff is required to deal with stigma and discrimination
    - PLHIV - training to recognize stigma in all its forms, to understand how it works, how it is structured; so that they can help themselves, and can develop skills to protect themselves

10. Ensuring employment of more PLHIV in central roles within NGOs will empower PLHIV and as will help to look for alternate income sources for PLHIV. Also, PLHIV need to reduce their dependency on NGOs and NGOs need to ensure that while imparting services including counselling of PLHIV, measures on how to become more self-reliant need to be discussed.

11. As families are the main caregivers of most PLHIV, therefore support for families – counselling, some financial support such as transport costs and lodging when accompanying PLHIV for services – is essential.



12. Testing of all spouses and children of PLHIV has to be encouraged. This however, depends on disclosure by PLHIV and therefore must follow ethical norms.
13. Ideally location of VCT services should not be restricted to peer support NGOs providing services to PLHIV as this often discourages many who would rather attend a centre that is open to all.
14. Testing for HIV needs to be improved. Most existing laboratories and VCT centres conducting rapid tests do not maintain quality control and there is no central facility that is recognised as a national reference laboratory. A system needs to be developed that ensures that HIV tests conducted at different VCT sites are reliable. Staffs conducting HIV tests need to be adequately trained and monitored. Universal Precautions including safe waste disposal has to be addressed at all these sites.
15. IDUs should receive counselling on positive living. All efforts to reach out to their families need to be made. Strong referral mechanisms need to be developed for the treatment, care and support of HIV positive IDUs.

9.3 Service Providers:

1. PLHIV also feel discriminated against by some service providers who are providing services to PLHIV. There needs to be more acknowledgment of this by the service providers, they need to be more open-minded and undergo regular follow up training to avoid such occurrences.
2. Support staff such as receptionists, etc. need special training on stigma and discrimination.
3. A referral network of service provides needs to be developed so that PLHIV can be referred to appropriate institutions or individuals when the need arises.
4. Service providers from different organizations could form a network of their own to deal with issues of burn out, to discuss difficult cases and problems, to ensure cooperation, etc.
5. Service providers need to be trained to better understand the needs of marginalized population groups such as IDUs, sex workers, males having sex with males.

10

REFERENCES

10. REFERENCES

1. National AIDS/STD Program. World AIDS Day, Souvenir: Take the lead; stop AIDS: keep the promise. Dhaka: National AIDS/STD Program, Directorate General of Health Services, MOHFW, Govt. of Bangladesh; 2007.

2. National AIDS Committee. UNGASS indicators country report. Dhaka: Ministry of Health and Family Welfare, Govt. of Bangladesh.; 2006.

3. Azim T, Rahman M, Alam MS, Chowdhury IA, Khan R, Reza M, et al. Bangladesh moves from being a low prevalence nation for HIV to one with a concentrated epidemic in injecting drug users. Int J STD AIDS. 2008 19:327-31.

4. Govt. of Bangladesh. National HIV Serological Surveillance, 7th Round Technical Report, 2006 Bangladesh. Dhaka: National AIDS/STD Programme, Directorate General of Health Services, Ministry of Health and Family Welfare, Govt. of Bangladesh.; 2007.

5. Bedelu M, Ford N, Hilderbrand K, Reuter H. Implementing antiretroviral therapy in rural communities: the Lusikisiki model of decentralized HIV/AIDS care. J Infect Dis. 2007;196, Suppl 3:S464-8.

6. Dieleman M, Bwete V, Maniple E, Bakker M, Namaganda G, Odaga J, et al. 'I believe that the staff have reduced their closeness to patients': an exploratory study on the impact of HIV/AIDS on staff in four rural hospitals in Uganda. BMC Health Serv Res. 2007;18:205.

7. Elford J, Ibrahim F, Bukutu C, Anderson J. HIV-related discrimination reported by people living with HIV in London, UK. AIDS Behav. 2008;12:255-64.

8. World Health Organisation, UNAIDS, UNODC. Advocacy guide: HIV/AIDS prevention among injecting users. Geneva; 2004.

9. Aceijas C, Oppenheimer E, Stimson GV, Ashcroft RE, Matic S, Hickman M, et al. Antiretroviral treatment for injecting drug users in developing and transitional countries 1 year before the end of the 'Treating 3 million by 2005. Making it happen. The WHO strategy' ('3by5'). Addiction. 2006;101:1246-53.

APPENDIX

APPENDIX

Appendix-1

Data collection form for assessing the numbers of people affected by HIV/AIDS, ICDDR, B, Mohakhali, Dhaka, Bangladesh

Name of the organization: Date:

1. Name*:
2. Regular member /irregular member/expired
3. Date of first service taken/ membership:
4. Present address: Upazila: District:
5. Permanent address: Upazila: District:
6. Sex: Male / female / Transgender
7. Age (in years):
8. Education: Illiterate / Primary / Secondary / Higher secondary / Graduate and above
9. Marital status: married / unmarried / separated / divorced / currently living with partner / Widow / Widower
10. Religion: Muslim/ Hindu/ Christian/ Buddhist/ Other _______________
11. Present occupation: employed / unemployed / not applicable
12. Previous occupation:
13. Spouse occupation:
14. Spouse HIV status: Not tested / positive / negative / unknown/ Not applicable
15. Total number of family members:
16. Who are those family members (number of children, spouse and others)? :
17. HIV status of children: Not tested / positive / negative / unknown/ Not applicable
18. Referred to:
19. Referred by:

20. Risk factors/ possible source of infection:

21. Last CD4 count: Not done / more than 200/ less than 200 / Not known

22. Opportunistic infections: Yes / No/ Not known

If yes, ____

23. History of taking ARV: Yes / No / Not known

24. Why were ARVs taken?

25. If ARVs taken, were any side effects noted? : Yes / No.

If yes, what are those side effects?:

26. History of taking cotrimoxazole: Yes / No / Not known

27. History of TB: Yes / No / Not known

28. Nearest health care facility for HIV/AIDS: Yes / No/ Not known

If yes, ____

29. Nearest harm reduction services for IDU: Yes / No/ Not known

If yes, ____

30. Nearest STI service facility: Yes / No/ Not known
If yes, ____

31. Any social support received from the community or family? If yes, what is the support received? Yes / No/ Not known
If yes, ____

* This will be shared amongst consortium members only

______________________	______________________	____________
Data collector's Name	Data collector's Signature	Date

Appendix –2

Service providers and the organisations that they represented

Government Organizations	NGO	Others
Chittagong Medical College Hospital	Ashar Alo Society (AAS)	ICDDR, B
American Hospital, Chittagong	Mukto Akash Bangladesh (MAB)	Sylhet Women's Medical College
Rangamati Sadar Hospital	Confidential Approach to AIDS Prevention (CAAP)	Ragib Rabeya Medical College
Comilla Medical College	HIV/AIDS and STD Alliance Bangladesh (HASAB)	Private practitioners
Sylhet MAG Osmani Medical College	Health and Education for the Less Privileged (HELP)	
Khulna Medical College Hospital	Marie Stopes Clinic Society (MSCS)	
Rajshahi City Corporation	Social Marketing Company (SMC) Suraksha	
Shere-E-Bangla Medical College, Barisal	Khulna Mukti Seba Sangstha (KMSS)	
	Family Planning Association of Bangladesh (FPAB)	
	Social Advancement Society (SAS)	
	Avash	
	Light House	
	Urban Primary Health Care Project (UPHCP)	
	Population Services and Training Center (PSTC)	

Appendix 3:

Estimating number of those most affected by HIV/AIDS in different locations to support efficient service delivery, capacity building and community mobilization for PLHIV
(GFATM package # 910)

Focus Group Discussion (FGD) for PLHIV

(Consent form, Guideline and Checklist)

সম্মতি পত্র

আমরা (নিজেদের নাম বলুন ও পরিচয় দিন) আশার আলো সোসাইটি, মুক্ত আকাশ বাংলাদেশ, হাসাব এবং ক্যাপ এর সহায়তায় GFATM, Round-6 এর অর্থায়নে আইসিডিডিআর’বি র পক্ষ থেকে এইচ আইভি পজিটিভ দের সম্পর্কে বিভিন্ন তথ্যাবলী জানার জন্য একটি জরীপ প্রকল্পে কাজ করছি। এইচআইভি পজিটিভদের জন্য কি ধরনের সেবা আছে এবং আরো কি কি প্রয়োজন, আমরা তা জানার চেষ্টা করছি। এ ব্যপারে আপনাদের কিছু প্রশ্ন জিজ্ঞাসা করা প্রয়োজন। কারন আমরা আন্তরিক ভাবে চাই, আপনারা যারা এইচআইভি পজিটিভ তারা যেন সঠিক স্বাস্থ্য সেবা পান। আপনারা আমাদের যা বলবেন তা সম্পূর্ণভাবে গোপন রাখা হবে। আলোচনা শুরু করার পর আপনারা যে কোন সময়ে আলোচনা প্রদান বন্ধ করে দিতে পারবেন। আপনারা যদি আলোচনা করতে রাজী থাকেন, তা হলে সম্পূর্ণ সঠিক তথ্য দেয়া অত্যন্ত গুরুত্বপূর্ন। আপনাদের অনুমতি সাপেক্ষে আলোচনাটি আমরা অডিও ক্যাসেটের মাধ্যমে রেকর্ড করতে চাই। আপনারা কি এই আলোচনায় অংশ গ্রহনে সম্মত আছেন ? আপনারা যদি অংশ গ্রহনে সম্মত থাকেন তবে নিম্নে স্বাক্ষর করুন অথবা বাম হাতের বৃদ্ধাঙ্গুঁলীর ছাপ দিন।

অংশগ্রহণকারীদের সম্পর্কিত প্রাথমিক তথ্যাবলী

নং	বয়স	লিঙ্গ	বৈবাহিক অবস্থা	বর্তমান পেশা	কতদিন আগে এইচআইভি ধরা পড়েছে?	স্বাক্ষর অথবা বাম হাতের বৃদ্ধাঙ্গুঁলীর ছাপ
১						
২						
৩						
৪						

৫						
৬						
৭						
৮						
৯						
১০						

FGD পরিচালনাস্থলের নাম -----------------------------

FGD পরিচালনার (তারিখ এবং সময়):

FGD পরিচালনাকারীর নাম এবং স্বাক্ষর:

নোট গ্রহনকারীর নাম এবং স্বাক্ষর:

Guideline

- নিজেদের নাম, পরিচয় ও উদ্দেশ্য অংশগ্রহনকারীদেরকে বুঝিয়ে শুরু করুন।
- এফজিডি করতে সবসময়ই অন্ততঃ দুজনের প্রয়োজন হবে। একজন আলোচনা করবেন এবং অপরজন তা লিপিবদ্ধ/রেকর্ড করবেন।
- এফজিডি এর অংশগ্রহনকারীর সংখ্যা ৬-৮ এর মধ্যে হলে ভাল হয়।
- দলটি যাতে (বয়স, লিঙ্গ, ARV নিচ্ছে অথবা নিচ্ছে না ইত্যাদির পরিপ্রেক্ষিতে) সমগোত্রীয় হয়।
- অংশগ্রহনকারীদের তাদের দেয় তথ্যের ব্যাপারে সম্পূর্ন গোপনীয়তার নিশ্চয়তা দিন।
- দলীয় আলোচনার প্রতি গুরুত্ব দিন, ফেসিলিটেটর পার্টিসিপেন্টকে নিয়ন্ত্রন করুন (আই কনটাক্ট কমিয়ে দিন), চুপচাপ থাকা পার্টিসিপেন্টকে আলোচনায় অংশগ্রহন করতে উৎসাহিত করুন। সবাই যেন সমানভাবে অংশগ্রহন করতে পারেন এরকম পরিবেশ বজায় রাখুন।
- অংশগ্রহনকারীদের প্রতি সম্মান রেখে এফজিডি পরিচালনা করুন।
- কখনই কোন মিথ্যা আশ্বাস দেবেন না।
- নিশ্চিত করুন আশেপাশের অন্য কেউ আপনাদের আলোচনা শুনছে না।
- আলোচনার সময় চা/হালকা খাবারের ব্যবস্থা রাখুন।
- সময়ের ব্যাপারে সতর্ক হোন, এফজিডি পরিচালনা ৪০-৬০ মিনিটের মাঝে সীমাবদ্ধ রাখার চেষ্টা করুন কিন্তু তাই বলে ঘনঘন ঘড়ির দিকে তাকিয়ে অংশগ্রহনকারীদের নিরুৎসাহিত করবেন না।
- এফজিডি পরিচালনা শেষ হলে সকল অংশগ্রহণকারীকে ধন্যবাদ দিয়ে শেষ করুন।

Checklist

১. বর্তমানে আপনারা কি কি স্বাস্থ্য সেবা পাচ্ছেন? (কাউন্সেলিং, OIs, ARV, CD4, STI, সাধারন স্বাস্থ্য সেবা, এইচআইভি সম্পর্কিত বিশেষায়িত স্বাস্থ্য সেবা ইত্যাদি)

২. স্বাস্থ্য সেবা নিতে গিয়ে কি কোন অসুবিধার সন্মুখীন হচ্ছেন? যদি অসুবিধার সন্মুখীন হন তাহলে কি কি অসুবিধার সম্মূখীন হয়েছেন?

৩. এইচআইভি পরীক্ষার আগে ও পরে প্রি-টেষ্ট ও পোস্ট টেস্ট কাউন্সেলিং পেয়েছিলেন কি?

যদি পেয়ে থাকেন তাহলে সেখানে কি কি বিষয়ে আলোচনা করা হয়েছিল?

কাউন্সেলিং এর পরে কেমন বোধ করেছিলেন?

অনগোয়িং বা নিয়মিত ফলো আপ কাউন্সেলিং পাচ্ছেন কি?

পেয়ে থাকলে কত দিন পর পর পাচ্ছেন?

অনগোয়িং কাউন্সেলিং এর সুবিধা ও অসুবিধা গুলো কি কি?

৪. আপনার বাসস্থানের কাছাকাছি এইচআইভি এবং যৌনরোগ এর জন্য স্বাস্থ্য সেবা আছে কি? যদি থাকে তাহলে কতদূরে আছে? যদি না থাকে তাহলে আপনাকে এই স্বাস্থ্য সেবা পাওয়ার জন্য কোথায় যেতে হয় ?

৫. আপনাদের স্বাস্থ্য সেবার জন্য কোথাও কি রেফার করা হয়েছিল । যদি রেফার করা হয়ে থাকে তাহলে কোথায় রেফার করা হয়েছিল এবং কি কারনে?

৬. শারীরিকভাবে অসুস্থ হলে চিকিৎসার জন্য আপনি কোথায় যান?

আপনি একজন এইচআইভি পজিটিভ একথা স্বাস্থ্যসেবা প্রদানকারীদের কাছে প্রকাশ করেছেন কি?

প্রকাশ করার আগে ও পরে ঐ সমস্ত সেবাদান কারীদের আচরনের কোন পরিবর্তন লক্ষ্য করেছেন?

পরিবর্তন হলে কি কি ধরনের পরিবর্তন লক্ষ্য করেছেন?

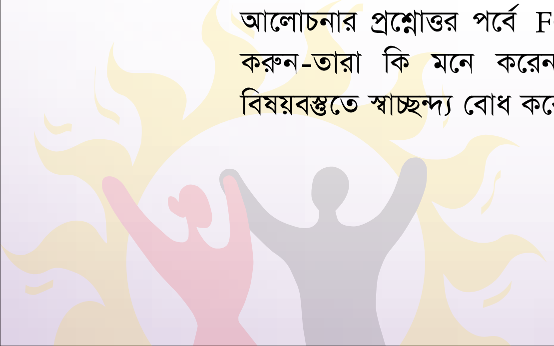
৭. স্বাস্থ্যসেবা প্রদানকারীরা আপনার সংঙ্গে কি ধরনের ব্যবহার করে থাকে? সেবা প্রদানকারীদের ব্যবহার এবং প্রাপ্ত চিকিৎসার সন্তুষ্টির বিষয়ে আপনার অনুভুতি কি?

৮. মাসে আপনার স্বাস্থ্যসেবার পিছনে কত টাকা খরচ হয় এবং কিসে খরচ হয় ? এই খরচ কি আপনি নিজে দিচ্ছেন নাকি কোন সংগঠন / সংস্থা দিচ্ছে ?

৯. আপনার মত এইচআইভি পজিটিভদের জন্য ভবিষ্যতে আরো কি কি ধরনের স্বাস্থ্য সেবার ব্যবস্থা করা প্রয়োজন বলে আপনি মনে করেন ?

১০. আপনি যে একজন এইচআইভি পজিটিভ একথা আপনার পরিবার,আত্নীয়-স্বজন এবং প্রতিবেশীদের কেউ জানে কি? যদি জেনে থাকে তাহলে আত্নীয়-স্বজন এবং প্রতিবেশীরা আপনার সাথে কি ধরনের ব্যবহার করে?

আলোচনার প্রশ্নোত্তর পর্বে FGD সদস্যদের আলোচনার তথ্য, বিষয়সমূহ লিপিবদ্ধ করুন । (জিজ্ঞাসা করুন-তারা কি মনে করেন যে, তারা আলোচনায় ভালভাবে অংশ নিয়েছেন? এই আলোচনার বিষয়বস্তুতে স্বাচ্ছন্দ্য বোধ করেছেন? কিছু কি বাদ পড়েছে যা আলোচনা করার দরকার ছিল?



Appendix 4:

Estimating number of those most affected by HIV/AIDS in different locations to support efficient service delivery, capacity building and community mobilization for PLHIV (GFATM package # 910)

Focus Group Discussion (FGD) for PLHIV service provider

(Consent Form, Guideline and Checklist)

সম্মতি পত্র

আমরা (FGD পরিচালনাকারীরা নিজেদের নাম বলুন ও পরিচয় দিন) আশার আলো সোসাইটি, মুক্ত আকাশ বাংলাদেশ, হাসাব এবং ক্যাপ এর সহায়তায় GFATM, Round-6 এর অর্থায়নে আইসিডিডিআর’বি র পক্ষ থেকে এইচ আইভি পজিটিভদের সম্পর্কে বিভিন্ন তথ্যাবলী জানার জন্য একটি জরীপ প্রকল্পে কাজ করছি। এইচআইভি পজিটিভদের জন্য কি ধরনের সেবা আছে এবং আরো কি কি প্রয়োজন, আমরা তা জানার চেষ্টা করছি ।এ ব্যপারে আপনাদের কিছু প্রশ্ন জিজ্ঞাসা করা প্রয়োজন। কারন আমরা আন্তরিক ভাবে চাই, আপনারা যারা এইচআইভি পজিটিভ দের সেবায় নিয়োজিত, তারা যেন সঠিক সেবা প্রদান করতে পারেন। আপনারা আমাদের যা বলবেন তা সম্পূর্ণভাবে গোপন রাখা হবে।আলোচনা শুরু করার পর আপনারা যে কোন সময়ে আলোচনা বন্ধ করে দিতে পারবেন। আপনারা যদি আলোচনা করতে রাজী থাকেন, তা হলে সম্পূর্ণ সঠিক তথ্য দেয়া অত্যন্ত গুরুত্বপূর্ন। আপনাদের অনুমতি সাপেক্ষে আলোচনাটি আমরা অডিও ক্যাসেটের মাধ্যমে রেকর্ড করতে চাই। আপনারা কি এই আলোচনায় অংশ গ্রহনে সম্মত আছেন ?

আপনারা যদি অংশ গ্রহনে সম্মত থাকেন তবে নিম্নে স্বাক্ষর করুন।

অংশগ্রহণকারীদের সম্পর্কিত প্রাথমিক তথ্যাবলী

নং	বয়স	লিঙ্গ	পদবী	কত দিন ধরে PLHIV দের সেবা প্রদান করছেন	কর্মরত প্রতিষ্ঠানের নাম	স্বাক্ষর
১						
২						
৩						
৪						
৫						
৬						
৭						
৮						
৯						
১০						

FGD পরিচালনাস্থলের নাম -----------------------------

FGD পরিচালনার (তারিখ এবং সময়):

FGD পরিচালনাকারীর নাম এবং স্বাক্ষর::

নোট গ্রহনকারীর নাম এবং স্বাক্ষর:

Guideline

- নিজেদের নাম, পরিচয় ও উদ্দেশ্য অংশগ্রহনকারীদেরকে বুঝিয়ে শুরু করুন ।
- এফজিডি করতে সবসময়ই অন্ততঃ দুজনের প্রয়োজন হবে । একজন আলোচনা করবেন এবং অপরজন তা লিপিবদ্ধ/রেকর্ড করবেন ।
- এফজিডি এর অংশগ্রহনকারীর সংখ্যা ৬-৮ এর মধ্যে হলে ভাল হয় ।
- দলটি যাতে (বয়স, লিঙ্গ, পেশা ইত্যাদির পরিপ্রেক্ষিতে) সমগোত্রীয় হয় ।
- অংশগ্রহনকারীদের তাদের দেয় তথ্যের ব্যাপারে সম্পূর্ন গোপনীয়তার নিশ্চয়তা দিন ।
- দলীয় আলোচনার প্রতি গুরুত্ব দিন, ফেসিলিটেটর পার্টিসিপেন্টকে নিয়ন্ত্রন করুন (আই কনটাক্ট কমিয়ে দিন), চুপচাপ থাকা পার্টিসিপেন্টকে আলোচনায় অংশগ্রহন করতে উৎসাহিত করুন । সবাই যেন সমানভাবে অংশগ্রহন করতে পারেন এরকম পরিবেশ বজায় রাখুন ।
- অংশগ্রহনকারীদের প্রতি সম্মান রেখে এফজিডি পরিচালনা করুন ।
- কখনই কোন মিথ্যা আশ্বাস দেবেন না ।
- নিশ্চিত করুন আশেপাশের অন্য কেউ আপনাদের আলোচনা শুনছে না ।
- আলোচনার সময় চা/হালকা খাবারের ব্যবস্থা রাখুন ।
- সময়ের ব্যাপারে সতর্ক হোন, এফজিডি পরিচালনা ৪০-৬০ মিনিটের মাঝে সীমাবদ্ধ রাখার চেষ্টা করুন কিন্তু তাই বলে ঘনঘন ঘড়ির দিকে তাকিয়ে অংশগ্রহনকারীদের নিরুৎসাহিত করবেন না ।
- এফজিডি পরিচালনা শেষে সবাইকে ধন্যবাদ দিয়ে শেষ করুন ।

Checklist

১. আপনার এখানে কি কি স্বাস্থ্য সেবা প্রদান করা হয় (VCT, ARV, CD4, OIs, PEP, PPTCT etc) ? PLHIV দের সেবা প্রদান করতে গিয়ে আপনি কি কি সমস্যার সন্মুখীন হয়েছেন?

২. PLHIV রা সেবা গ্রহনের ক্ষেত্রে কি কোন অসুবিধার সন্মুখীন হচ্ছে বলে আপনারা মনে করেন? যদি অসুবিধার সন্মুখীন হচ্ছে বলে আপনারা মনে করেন তাহলে কি কি?

৩. PLHIV দের আপনি কি কোথাও রেফার করেন? যদি করেন তাহলে কোথায় এবং কি কারনে রেফার করেন? সেবা প্রদান করার জন্য যদি প্রচলিত রেফারেল সার্ভিস থাকে তাহলে সে সম্পর্কে আপনার ধারনা কি ?

- ☐ মান
- ☐ সুযোগ- সুবিধা
- ☐ সীমাবদ্ধতা

৪. PLHIV দের স্বাস্থ্য সেবা প্রদান করে আপনি কেমন বোধ করেন ? সেবা প্রদান করে আপনি কি সন্তুষ্ট৩ না অসন্তুষ্ট? সন্তষ্ট বা অসন্তষ্ট হলে কেন?

৫. PLHIV দের সেবার মান উন্নত করার জন্য কি কি করা উচিত বলে মনে করেন?

৬. PLHIV দের আত্মীয় বা প্রতিবেশীরা কি তাদেরকে স্বাস্থ্য সেবা গ্রহনের ব্যাপারে প্রয়োজনীয় সাহায্য করে থাকেন? যদি সাহায্য করে থাকেন তাহলে কি ধরনের সাহায্য করে থাকেন ? আর যদি না করে থাকেন তাহলে কি কারনে?

৭. PLHIV দের সেবা প্রদানকারী হিসাবে আপনি কি কোন বৈষম্যের শিকার হয়েছেন ? যদি হয়ে থাকেন তাহলে কোথা থেকে এবং কি ভাবে ?

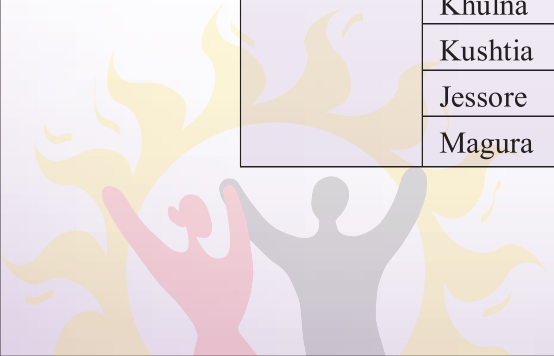
- ☐ পরিবার হতে
- ☐ সামাজিকভাবে
- ☐ অন্যান্য স্বাস্থ্য সেবা কেন্দ্র থেকে

আলোচনার প্রশ্নোত্তর পর্বে FGD সদস্যদের আলোচনার তথ্য, বিষয়সমূহ লিপিবদ্ধ করুন। (জিজ্ঞাসা করুন তারা কি মনে করেন যে তারা আলোচনায় ভালভাবে অংশ নিয়েছেন? এই আলোচনার বিষয়বস্তুতে স্বাচ্ছন্দ্য বোধ করেছেন? কিছু কি বাদ পড়েছে যা আলোচনা করার দরকার ছিল?

Appendix –5

Geographical distribution of PLHIV, urban vs. rural (N=946)

Division	Districts	Urban	Rural	Information not available	Total
Dhaka	Mymensingh	1	9	0	10
	Narayangaonj	11	20	0	31
	Dhaka	159	19	12	190
	Madaripur	3	3	0	6
	Gazipur	2	29	0	31
	Munshigong	5	29	2	36
	Gopalganj	1	2	0	3
	Faridpur	1	5	1	7
	Tangail	4	6	0	10
	Manikganj	0	4	0	4
	Kishoreganj	0	1	0	1
	Shariatpur	1	1	0	2
	Sherpur	0	1	0	1
	Norsingdi	1	2	1	4
	Sub-total	**189**	**131**	**16**	**336**
Chittagong	Cox's Bazar	5	19	1	25
	Comilla	6	21	3	30
	B. Baria	2	16	4	22
	Chittagong	10	74	2	86
	Chandpur	5	10	1	16
	Noakhali	3	12	7	22
	Lakhipur	5	3	0	8
	Fani	2	6	5	13
	Rangamati	2	0	0	2
	Sub-total	**40**	**161**	**23**	**224**
Khulna	Narail	1	0	0	1
	Khulna	19	8	0	27
	Kushtia	0	2	0	2
	Jessore	0	5	0	5
	Magura	0	1	1	2



Division	Districts	Urban	Rural	Information not available	Total
	Satkhira	0	0	1	1
	Meherpur	0	3	0	3
	Sub-total	**20**	**19**	**2**	**41**
Barisal	Barisal	0	1	0	1
	Patuakhali	0	3	1	4
	Jhalokathi	0	1	0	1
	Bhola	1	0	0	1
	Sub-total	**1**	**5**	**1**	**7**
Sylhet	Sunamgonj	2	23	0	25
	Sylhet	24	126	7	157
	Moulovibazar	4	20	1	25
	Hobigonj	0	5	0	5
	Sub-total	**30**	**174**	**8**	**212**
Rajshahi	Pabna	0	5	0	5
	Gaibandha	0	0	1	1
	Bogra	2	0	1	3
	Rajshahi	2	0	0	2
	Chuadanga	2	0	0	2
	Sirajgonj	0	1	0	1
	Natore	0	2	0	2
	Nagaon	0	1	0	1
	Sub-total	**6**	**9**	**2**	**17**
Grand total	**All divisions**	**286**	**499**	**161**	**946**

Appendix –6

Geographical distribution of PLHIV based on sex (N=946)

Division	District	Adult		Children		Transgender	Total
		Male	Female	Male	Female		
Dhaka	Mymensingh	7	3	0	0	0	10
	Narayangaonj	18	13	0	0	0	31
	Dhaka	149	39	0	0	2	190
	Madaripur	4	2	0	0	0	6
	Gazipur	19	9	1	2	0	31
	Munshigong	22	13	0	1	0	36
	Gopalganj	3	0	0	0	0	3
	Faridpur	2	3	0	2	0	7
	Tangail	8	2	0	0	0	10
	Manikganj	2	2	0	0	0	4
	Kishoreganj	1	0	0	0	0	1
	Shariatpur	1	1	0	0	0	2
	Sherpur	0	1	0	0	0	1
	Norsingdi	3	1	0	0	0	4
	Sub-total	239	89	1	5	2	336
Chittagong	Cox's Bazar	16	7	0	2	0	25
	Comilla	22	8	0	0	0	30
	B. Baria	16	6	0	0	0	22
	Chittagong	60	19	4	3	0	86
	Chandpur	13	3	0	0	0	16
	Noakhali	15	6	0	0	1	22
	Lakhipur	7	1	0	0	0	8
	Fani	10	3	0	0	0	13
	Rangamati	0	1	1	0	0	2
	Sub-total	159	54	5	5	1	224
Khulna	Narail	0	1	0	0	0	1
	Khulna	6	14	4	3	0	27
	Kushtia	1	1	0	0	0	2
	Jessore	1	4	0	0	0	5
	Magura	1	1	0	0	0	2
	Satkhira	0	1	0	0	0	1
	Meherpur	2	1	0	0	0	3
	Sub-total	11	23	4	3	0	41

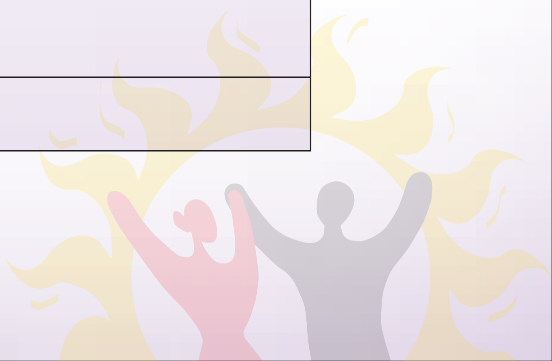
Division	District	Adult		Children		Transgender	Total
		Male	Female	Male	Female		
Barisal	Barisal	1	0	0	0	0	1
	Patuakhali	2	2	0	0	0	4
	Jhalokathi	1	0	0	0	0	1
	Bhola	1	0	0	0	0	1
	Sub-total	5	2	0	0	0	7
Sylhet	Sunamgonj	12	10	2	1	0	25
	Sylhet	109	40	4	4	0	157
	Moulovibazar	17	7	0	1	0	25
	Hobigonj	5	0	0	0	0	5
	Sub-total	143	57	6	6	0	212
Rajshahi	Pabna	3	2	0	0	0	5
	Gaibandha	0	1	0	0	0	1
	Bogra	3	0	0	0	0	3
	Rajshahi	0	2	0	0	0	2
	Chuadanga	1	1	0	0	0	2
	Sirajgonj	1	0	0	0	0	1
	Natore	1	1	0	0	0	2
	Nagaon	1	0	0	0	0	1
	Sub-total	10	7	0	0	0	17
Data not available		83	23	3	0	0	109
Grand total		650	255	19	19	3	946

Appendix –7

Referral linkages

Division	Where	Why
Dhaka	Jagori- ICDDR, B, Armed Forces Pathology Laboratory (AFPL)	Measurement of CD4 counts
	IDH, AITAM welfare organization	Hospitalisation
	Ibn Sina Diagnostic & Imaging Center	X ray, other laboratory tests
	Marie Stopes Clinic Society (MSCS)	Antenatal care and delivery
	Dhaka Medical College Hospital (DMCH), National Institute of Traumatology, Orthopaedic and Rehabilitation (NITOR)	Surgery
	Dhaka Ahsania Mission (DAM), Centre for Rehabilitation of drug Addiction (CREA)	Detoxification and rehabilitation
	Mitford hospital	Abscess management
	Crisis Care Shelter Home (CCSH) CARE, Bangladesh (closed 2 years back)	Hospitalisation of IDUs
Chittagong	Chittagong Medical College Hospital (CMCH)	Ear, Nose and Throat (ENT), Outdoor medical consultation in skin and veneral disease department, blood transfusion

Division	Where	Why
	Jagori-ICDDR, B, Dhaka	Post Exposure Prophylaxis (PEP)
	Private practitioners (personal contact)	Gynaecology, dental, eye, diabetes, skin disease, TB, surgical procedure
	Jagori-ICDDR, B, Dhaka and AFPL, Dhaka	Measurement of CD4 counts
Sylhet	Sylhet Osmani Medical College Hospital (SOMCH)	Outdoor medical consultation
	Royal Clinic	Hospitalization
	Marie Stopes Clinic Society	Antenatal care and delivery
	Private practitioners (personal contact)	Medical consultation
	Jagori-ICDDR, B, Dhaka and AFPL, Dhaka	Measurement of CD4 counts
Khulna	Ashar Alo Society refers to Social Marketing Company (SMC), Benapole	VCT
	Mukto Akash Bangladesh refers to Dhaka Bangabandhu Sheikh Mujib Medical University (BSMMU)	HIV Confirmatory test
	Mukto Akash Bangladesh refers to CAAP, Dhaka and AFPL, Dhaka	ARV treatment, measurement of CD4 counts
	IDH and AITAM, Dhaka	Hospitalization



Division	Where	Why
	One private clinic, Khulna	Hospitalization
	World Vision, Khulna	Nutrition, medicine, physical check up
	Khulna Shishu Hospital	Paediatric treatment
	Dr. Al Amin (private practitioner)	Physical check up
Barisal	IDH, Dhaka	Hospitalization
	Jagori-ICDDR,B and BSMMU, Dhaka	HIV test and measurement of CD4 counts
	AITAM, Dhaka	Surgery, TB
	Ibne Sina Diagnostic Centre and Bangladesh Institute of Research in Diabetic Endocrine Metabolic (BIRDEM), Dhaka	Ultra sono graphy, X ray
Rajshahi	SMC, Rajshahi	VCT
	Dhaka	All other service

Appendix –8

List of people interviewed/consulted

NAME	DESIGNATION	ORGANIZATION
Partner NGOs		
Ms. Habiba Akter	Executive Director	Ashar Alo Society
Mr. Zilhas Azam Chowdhury	Project Coordinator	Ashar Alo Society
Dr. Nilufar Begum	Medical Consultant	Ashar Alo Society
Mohammad Ali	Counsellor Cum Out Reach Worker	Ashar Alo Society
Ms. Flora Jesmin Deepa	VCT Counsellor	Ashar Alo Society
Ms.Nomita Rani Baroi	Nurse	Ashar Alo Society
Ms. Mukti	Executive Director	Mukto Akash Bangladesh
Mr. Nazrul Islam	Assistant Programme Officer	Mukto Akash Bangladesh
Ms. Maksuda Akter Sumi	Counsellor Cum Out Reach Worker	Mukto Akash Bangladesh
Ms. Rehana Begum	Counsellor	Mukto Akash Bangladesh
Dr. Halida Hanum Khandoker	Executive Director	CAAP
Dr. Md.Shahidul Islam	Senior Medical Officer	CAAP
Ms. Suriya Islam	Adherence Counselor	CAAP
Ms.Tinku Costa	Nurse	CAAP
Ms. Mahfuza Rahman Shikha	VCT Counsellor	Jagori-ICDDR,B
Mr. Mahfujul Haque	VCT Counsellor	Jagori-ICDDR,B
Md. Mizanur Rahman Khan	VCT Counsellor	Jagori-ICDDR,B

Appendix –9

Core group members for the project

1.	Dr. Tasnim Azim, Scientist and Head, HIV/AIDS Programme and Virology Laboratory, ICDDR, B
2.	Dr. Md. Moshtaq Pervez, Medical Officer, ICDDR,B
3.	Ms. Arunthia Zaidi Urmi, Head Counselor, ICDDR,B
4.	Dr. Irona Khandaker, Medical Officer, ICDDR,B
5.	Dr. Chandra Nath Roy, Medical Officer, ICDDR,B
6.	Mr. Masud Reza, Statistician, ICDDR,B
7.	Ms. Habiba Akhter , Executive Director, Ashar Alo Society
8.	Ms. Mukti, Executive Director, Mukto Akash Bangladesh
9.	Dr. Halida Hanum Khandoker, Executive Director, CAAP
10.	Dr. Nazneen Akhter, Executive Director , HASAB
11.	Dr. Fadia Sultana, Manager Response and Coordination, Save the Children- USA
12.	Dr. Samina Choudhury, Manager PLHIV, Save the Children- USA

এইডস কী?

বাঁচতে হলে জানতে হবে

জানাতে হবে

icddr,b
KNOWLEDGE FOR
GLOBAL LIFESAVING SOLUTIONS

ASHAR ALO SOCIETY