Appendix I
Case Study of PLWHA

Case Study I
Perminder\(^1\) is a 25 year old girl. She has studied up to class 12. She is a resident of Kurseong and was infected when she came to Darjeeling to write her board examination. After the examination she joined ICICI bank as an executive. Her job involved meeting a lot of people and during the course of this phase, she met her present husband and fell in love.

The love affair soon progressed into marriage. She was happily married and became pregnant. This was the time when everything for Perminder turned upside down. It was known to everybody in the locality that her husband was a drug addict and was a widower. Perminder’s elder sister was somehow made aware of this fact. Perminder was informed by her elder sister about this fact and she became very upset. In such a situation she went to the hospital for regular checkup. Seeing her condition the doctor tried to show empathy and wanted to know why her condition was such when she seemed to be happy during her earlier visits.

Perminder confided on the doctor and told her about everything. Knowing the history of her husband the doctor advised both of them to undergo HIV test. Her husband initially refused to get himself tested but with lot of counseling and pressure by her agreed to do the test. Unfortunately both of them were found to be positive.

With the advice of the doctor she went to Siliguri and aborted the baby. She said that she did not at that time that with proper monitoring and regular medicine the chances of infecting the baby could have been reduced. Had she known this then she would not have taken the decision to abort the baby. It was in March 2007, that she was found to be positive and she underwent abortion in the month of April.

She is very upset with her in-laws for not telling her the truth about their son. She laments, “They could have been a little more responsible and told me about their son’s indulgence in such habits. It is also my fault that I trusted him completely.” Today we are both members of Shanker Foundation. He seldom comes here as he also looks after the shop and I volunteer here.

\(^1\) All the names are changed.
I have not told my parents about my status but my elder sister knows of both of us. My in-laws treats me well may be they are trying to pay for the mistake they have committed.

Case Study II

Rajender is 30 years old, unemployed male. He is a resident of Darjeeling. He has studied upto class 10. He is a former IDU. He had been injecting drugs for the last 5-6 years and now has stopped because of the infection.

He had a very close group of friends with whom he used to ‘fix.’ One of the members was assigned the task of getting the ‘stuff’ from Siliguri. We did not know that he used to share needles there with other IDUs. We did not know about the implications of sharing needle and syringe at that time. HIV/AIDS was not known to us then and even if we had known I do not think it would have made any difference.

I was ill once and was taken to Eden hospital for treatment. The doctors there referred me to ‘Kripa Foundation’ as they found I was a drug dependent person. I joined Kripa at the insistence of my parents. I refused to go there as I did not want to accept that I was a drug dependent person. At that time Kripa was undertaking a programme called “AGE 13” and under this programme the Foundation was encouraging all the inmates there to undertake HIV test. I volunteered to get myself tested. I was tested thrice and was found to be positive.

I was shocked when they said that I was positive. I have still not disclosed my status publicly. I have joined Shanker Foundation to help IDUs to give up their drug addiction. I told some of my friends about my status. Many of my former friends are still scared of me and do not want to have any contact with me. But some who have given up and those who are trying to abdicate drug addiction are friendly.

Still I have not disclosed my status to my parents. I do not want to hurt their sentiments. They want me to get married and dream of having grand children as I am the only son. Still I do not have the courage to tell them about the infection as I am worried about their reactions.

Today my health seems to be fine and I keep myself fit by jogging and I also eat properly. I would like to avoid ARVs till I am 40.'
Case Study III
Ranjita is a 25 year old widow. She was infected by her husband who was a driver. On 28th January, 2006 she was found to be positive. Her husband was admitted to Eden hospital, Darjeeling after a prolonged illness. The doctors could not diagnose his illness and finally asked to do HIV test. On testing he was found to be positive. The doctors also advised me to get tested. I did not know anything about HIV/AIDS at that time. I was also found to be positive. When the result was given to me my sister-in-law was with me so she automatically came to know about the result. Then my in-laws came to know and now my family also knows about it.

She was suffering from tuberculosis at the time of the interview and had started DOTS. She had to incur a lot of expenditure as she needs to eat nutritious food. Since she had to move away from her home and stay in Darjeeling to get her regular treatment she is staying with her sister-in-law. The family members initially thought that HIV/AIDS spread sitting or sleeping together.

"Soon after my diagnosis I was referred by the hospital to Shanker Foundation. I used to come often and stay there. But now I stay here in Darjeeling and am always there at Shanker Foundation, as I work as a peer counsellor. Here I feel good as I get to meet people who share the same problem as I do and we can relate to each other well. The understanding amongst us is good and everybody is helping each other. I do not want to go home as there the people do not understand what I am going through.

As my husband was a driver at times he would not come home for days. I do not know what he did during those days and I am facing a lot of problems alone. Initially I wished he was alive and helping me to coup with this life taking disease. Now I know everything about this disease and think that had he been alive I would have taken care of him. Today I am not afraid about the infection as I was earlier. But I am very scared the last couple of weeks as I am also infected with tuberculosis which can easily kill a PLWHA. I do not understand why he did this as we had a very happy married life."

Case Study IV
Sangeeta is a 28 year old widow. She is unemployed and has a child who is also positive. She was tested in 2003 but believed that she was negative and did not bother
to collect her test report. After a year she was ill again and this time she was tested again. She collected her report this time and was found to be positive. The doctor on seeing her report did not maintain the confidentiality and declared her report in front of the people around. She was referred to Shanker Foundation.

Though her husband was never tested she says that she was infected by her husband as he was a drug addict and died of overdose. She was staying with her parents who are very old. They know about her status and are taking care of her. She is apprehensive about life after them. She is illiterate and does not have any source of income. She has not told her son about his status and whenever he falls sick she is very afraid. She is also afraid about the treatment he receives from his friends if they come to know about his positive status.

She is receiving ART and has to go to NBMCH to get her medicines. She says that she has to really make an effort to arrange the money required to go to Siliguri. Though she is helped by Shanker Foundation in arranging the money she says that she cannot rely on them every time.

She has not disclosed her status publicly and only the members of Shanker Foundation and her parents know about it. She cries every time her parents ask her what she will do when they will not be there. She always thinks about her husband and sometimes she curses him but most of the time she wants him to be beside her.

**Case Study V**

Rabina is a 23 year old widow. She has studied upto class 8. She was also infected by her husband who was a person dependent on drug. He was advised by the doctors to get HIV test done long time before we got married but he refused. We were very happy and I also gave birth to a child. After some years he fell ill and this time he was asked to get himself tested. He was found to be positive. The doctors also advised me to get tested. I was counseled at the VCCTC and I was finally prepared to get myself tested. I was also found to be positive. I did not know what to do about it and cried a lot. I was advised to go to Shanker Foundation. Today I am am a member of the Foundation. I lost my husband soon.

My health at present is good and not suffering from any OI. But I am afraid what will happen if I fall ill. There is no one to take care of me and my baby. My in-laws are not
concerned about us. I am afraid what will happen if my child also turns out to be positive. Because of this I have not yet got my child tested. Only members of Shanker Foundation looks after me when I am not well. Today I knit sweaters and sell for my living."

**Some Case Studies of Community Members**

Mahendra is a 29 year old male, resident of Kurseong. He is educated and his income is also relatively high. He is married and has two daughters. "I have completed BA. After the completion of BA I was unemployed so started working with my father in his projects. Today I am a recognized contractor.

Prior to being a contractor I had very few friends and all of us had similar likings. But once I started doing contracts I started meeting other people whose likes and dislike were not similar to mine. But me being new in the profession had to adjust to almost everything. At first I started staying away from home till late as there was lot of get togethers. All these parties were all about drinking. I gradually started to drink.

Now I do lot of business and I have to interact with lot of new people, especially engineers. These engineers have to be pleased at all cost and we have to make sure that they are happy and so not cause any problem regarding the work. To keep them happy we have to spend a lot of money and providing booze is the best way of keeping them happy. I along with my friends entertain them and we also drink.

We had gone to Kolkata once. There as usual we went out to drink and went to a bar. There were lot of people and music was also loud. There we met with a group of girls and treated them with drinks. As the drinking became heavier we started touching each other and ended having sex. This was my first sexual experience outside here. Since then I have been having sex anytime I go out of station for work. Even here we have girls who come when we give them a call. We drink together and have sex. Some of my friends are not married and they even take these girls when they go out of station alone.

I have till now not suffered from any kind of STI/STD. I have heard about HIV/AIDS and at times am scared of getting infected. But in the intoxicated state do not think much beyond sex. I have had lot of sex in many places. I think I need to get myself tested but am afraid."
Case Study of a FSW

Seema is a married girl and is 29 years old. She has studied upto class 10. She says that she did not turn to this profession because she wanted to but circumstances led her to it. She was in school when she had a boyfriend. Their relationship was long and both of them were seriously thinking about marriage. She became pregnant. Her boyfriend wanted time to convince his parents for marriage. She was ready and even a month he did not showed up. So one day she decided to go to his home and meet him. When she reached there he refused to meet her. She was insulted by his family and a big fight broke out. They started abusing her and her boyfriend did not say a single word. She went to Siliguri and aborted the baby. My family was very supportive of me. Slowly I over came the trauma. But my life took a new turn.

I met another boy and fell in love with him. He too exploited me sexually and left me. as this is a small town everybody seemed to know about our physical relation. Since then a lot of boys started sending advances. I rejected all of them. My father then had become old and the canteen we had in one of the schools was not doing well. One of my brothers got married and separated and the other got into drugs. In such a circumstance I went to Delhi to work. I wanted to earn a lot of money. I became friends with girls from the North East. I went for a party and some of the boys started to ill behave with me after they were drunk. I told my friend about it but she did not seem to understand my predicament. She infact encouraged me. I thought I will change at this moment. Since then I have started selling myself. To be in the profession I also went to the parlours. After two and half years I returned.

At home I was a totally different girl. I met a guy again. He was from Sikkim. He wanted to marry me. I told him everything about myself. He was still interested to marry. So we got married. I gave birth to a girl. Everything was fine and all of a sudden he started accusing me of adultery. It became too much as we used to fight everyday. I left him and went back to Delhi again. I met a girl whom I knew. She had come with one of the contractors and she invited me to join them. There were four of them. I helped them to arrange two more girls and we had very good time. They were all very good and caring.
They returned after about a month and they paid me handsomely. I was very happy. I stayed for another year and returned. On return I met the contractor again here and he invited me for a party. There I met a lot of his friends and they call me whenever they require my service. I go at anytime of the day if they call as they help me financially even when I do not give them my service. They have helped me build this house. They provided cements and iron rods sometimes free of cost."
Appendix II

SET I

Interview Schedule for Community Members

1. Age 2. Gender
3. Marital Status 4. Religion
5. Education 6. Place of residence
7. Occupation 8. Income

9. Have you heard of HIV/AIDS?
1. Yes 2. No

10. From where have you heard about HIV/AIDS?

11. What is the difference between HIV and AIDS?

12. Can it be transmitted by?
1. Touching a positive person
2. By having food from the same plate
3. By kissing
4. None of the above

13. Then how is HIV/AIDS transmitted?

14. How long will it take for HIV to be full blown AIDS?

15. Is HIV/AIDS a socio-economic or medical issue?

16. Why do you think so?

17. Is HIV/AIDS a curable disease?
1. Yes 2. No

18. Is there any medicine available for it?
1. Yes 2. No

19. Who are the most vulnerable group?

20. Are you vulnerable to HIV/AIDS?
1. Yes 2. No

21. What are ways to protect oneself from it?

22. Have you heard about the ‘ABC’ concept?
1. Yes 2. No
23. If yes, what does ‘ABC’ mean?
24. Have you heard about VCCTC?
   1. Yes  2. No
25. Is there any VCCTC in the District?
   1. Yes  2. No
26. If yes, since when is it functioning?
27. Would you like to sit and talk with a HIV positive person?
   1. Yes  2. No
28. Why?
29. Should a HIV positive person be allowed to stay within the community?
   1. Yes  2. No
30. Why?
31. Should a HIV positive person be allowed to walk around freely?
   1. Yes  2. No
32. Why?
33. Should the children of HIV positive parents be allowed to go to the same school where other children go?
   1. Yes  2. No
34. Why?
35. Would you allow a positive teacher to teach in a school?
   1. Yes  2. No
36 Why?
37. Will you touch a positive person?
   1. Yes  2. No
38 Why?
39. Will you provide care to a positive person?
   1. Yes  2. No
40. Why?
41. If the positive person is from your family will you provide care to him/her?
   1. Yes  2. No
42. Why?
43. Is the medical infrastructure adequate for the prevention and treatment of HIV/AIDS?
   1. Yes  2. No

44. Are there any trained doctors in the hospitals for the prevention and treatment of HIV/AIDS?
   1. Yes  2. No

45. Do you think it is necessary to have trained doctors for treating a person living with HIV/AIDS?
   1. Yes  2. No

46. Why?

47. Do you think mandatory testing should be implemented?
   1. Yes  2. No

48. Why?

49. Have you ever had sex?
   1. Yes  2. No

50. Have you had sex before marriage?
   1. Yes  2. No

51. Have you had sex after marriage with others?
   1. Yes  2. No

52. Have you had sex when you have travelled to other places?
   1. Yes  2. No

53. Can you say why you had sex while travelling?

54. With whom did you have sex?

55. Did you use a condom?
   1. Yes  2. No

56. Do you talk about sex with others?
   1. Yes  2. No

57. With whom do you talk about sex?

58. What do you talk about?
59. Do you drink while having sex?
   1. Yes  2. No

60. When you have sex with your wife do you drink?
   1. Yes  2. No  3. Sometimes

61. Have you ever used the services of CSWs?
   1. Yes  2. No

62. Where have you used their services and how do you contact them?

63. Have you ever suffered from STI/STD?
   1. Yes  2. No

64. If yes, where did you treat yourself?

65. What are the reasons for the spread of HIV/AIDS in the hills?

66. Have you ever met or seen a PLWHA?
   1. Yes  2. No

67. What will you do if you come to know that one of your friends is a PLWHA?

68. Have you heard that someone in the locality is a PLWHA?
   1. Yes  2. No

69. If yes, what did you do then?

70. Have you ever attended any awareness programme organized by the NGOs?
   1. Yes  2. No

71. What message did they give?

72. Have you ever spoken about HIV/AIDS with other people?
   1. Yes  2. No

73. Why?

74. Do you want to get tested for HIV/AIDS?
   1. Yes  2. No

75. Why

76. Do you want the schools to give sex education?
   1. Yes  2. No

77. Why

78. When you think about HIV/AIDS what is the first thought that comes to your mind?

79. Do you have a boy/girl friend?
1. Yes 2. No
80. Have you ever had sex with Him/her?
1. Yes 2. No
81. Do you trust him/her?
1. Yes 2. No
82. Why?
83. Does he/she has any other relations?
1. Yes 2. No
84. If Yes, how do you know,
85. Do you want to share anything more?
Appendix III

SET II

Interview Schedule for FSW

1. Since when have you been doing this business?
2. Why have you opted for this work?
3. Where do you work?
4. What is the reaction of your family members?
5. What are the occupational problems faced by you?
6. What has been the reaction of your family members?
7. How do the people who know about your occupation treat you?
8. Do your clients force you to do things you do not want to do?
9. Who are your clients?
10. Do your clients drink?
   1. Yes 2. No
11. Do you drink as well?
   1. Yes 2. No
12. How do the clients behave after drinking?
13. How are you contacted?
14. Do you ever discuss about HIV/AIDS among your peers?
   1. Yes 2. No
15. Why?
16. Do you ever talk about HIV/AIDS with your clients?
   1. Yes 2. No
17. Why?
18. Do you ask your clients to use condoms?
   1. Yes 2. No
19. How do you think can HIV/AIDS be prevented?
Appendix IV

SET III

Interview Schedule For IDUs

1. When did you start drugs?
2. Do you inject drugs?
   1. Yes  2. No
3. When was the first time you injected drugs?
4. How often do you inject drugs?
5. With whom do you inject drugs?
6. When you go away from this place do you inject drugs?
   1. Yes  2. No
7. Whose equipment do you use?
8. Have you ever shared a needle with anybody?
9. Do you want to have sex after doing drugs?
   1. Yes  2. No
10. If yes how do you satisfy your desire?
11. Do the people in your locality know that you do drugs?
   1. Yes  2. No
12. If yes how do they treat you?
13. Have you heard of Shankar Foundation?
   1. Yes  2. No
14. If yes how did you hear about it?
15. Are you a member of SF?
   1. Yes  2. No
16. Are you enrolled in needle exchange programme?
   1. Yes  2. No
17. If yes, why are you enrolled in the programme?
18. How useful or beneficial is the programme for you?
19. How do the police treat you?
20. From where do you get the drugs?
Appendix V

SET IV

Interview Schedule For The PLWHAs

1. How did you get infected?
2. Where did you do the test?
3. Did anyone advice you to do the test?
4. Did you take any help from the VCCTC?
   1. Yes  2. No
5. If yes, what help did the VCCTC provide you?
6. To whom did you disclose the result for the first time?
7. What was the person’s reaction?
8. Has your CD4 cell been counted?
   1. Yes  2. No
9. Where did you get them counted?
10. At present are you suffering from any OI?
    1. Yes  2. No
11. What kind of discrimination have you had to face?
12. Is there any discrimination from the medical staff?
    1. Yes  2. No
13. If yes, how do they discriminate you?
14. Do you have to face any problem when you access health services?
    1. Yes  2. No
15. If yes, what kind of problems do you face?
16. Have you disclosed your status in public?
    1. Yes  2. No
17. How do the people who know your status treat you?
18. Who was the first person to whom you disclosed your status?
19. How was the person’s reaction?
20. How has been your relation with that person since then?
21. What do you think about the general public’s knowledge about HIV/AIDS?
22. Have you ever faced any discrimination?
    1. Yes  2. No
23. If yes, how were you discriminated?
24. Where were you discriminated?
25. What did you do then?
26. Did you tell your friends about this?
27. What are the facilities available in the hospital?
28. How do the hospital staffs behave with you?
29. Are there any help coming to you from other organizations?
   1. Yes 2. No
30. If yes, who helps your organization and what kind of help do they provide?
31. Have you ever asked for help from the DGHC?
   1. Yes 2. No
32. If yes, what has the DGHC done?
33. Has the formation of DACC been beneficial to you?
   1. Yes 2. No
34. How does the DACC help you?
35. Did you have any knowledge about HIV/AIDS prior to your infection?
   1. Yes 2. No
36. If yes, what did you know about HIV/AIDS?
37. Did you know all the modes of transmission of HIV/AIDS before infection?
   1. Yes 2. No
38. How do you feel now that you are infected with HIV/AIDS?
39. What do you think about HIV/AIDS as a disease?
40. Have you disclosed your HIV positive status to your family members?
   1. Yes 2. No.
41. If no, why?
42. If yes how has their reaction to the news been?
43. How do you perceive the general population?
Appendix VI

SET V

Interview Schedule For Bisexuals

1. Have you ever heard about HIV/AIDS?
   1. Yes  2. No
2. How did you hear about it?
3. What are the modes of transmission of HIV/AIDS?
4. Who do you think are vulnerable to HIV/AIDS?
5. How can one protect oneself from HIV/AIDS?
6. Do you have a sexual partner?
   1. Yes  2. No
7. Do you change your partner?
   1. Yes  2. No
8. Why do you/ don’t you change your partner?
9. Do you use condom?
   1. Yes  2. No
10. Why do you/ don’t you use a condom?
11. Do you think you can be vulnerable to HIV/AIDS?
    1. Yes  2. No
12. Why do you think so?
13. Are you a member of any organization?
    1. Yes  2. No
14. How do being/ not being a member help you?
15. How do the members of the community treat you?
16. Are you harassed by anybody?
    1. Yes  2. No
17. If yes, why were you harassed?
18. Do the community members discriminate you?
    1. Yes  2. No
19. Why do you think they do so?
20. Do you know of any other person who also has your sexual preference?
    1. Yes  2. No
21. If yes, where and how did you meet him?
22. Do you have partners outside Darjeeling?
   1. Yes  2. No
23. If yes, where do you have?
24. How do you contact him?
25. Were you ever infected with STD/STI?
   1. Yes  2. No
26. If yes, where did you get it treated?
27. Do you drink before sex?
   1. Yes  2. No
28. If yes, why do you drink?
29. Are there anyone who charges fees for the service?
   1. Yes  2. No
30. If yes, why do they charge a fee?
Appendix VII

Guidelines for Focus Group Discussion (Community Members)

1. Introduction
2. Declare the purpose of the study
3. Ask if they need any clarifications
4. Knowledge about HIV/AIDS
   a. Modes of transmission
   b. Prevention methods
   c. ABC concept
   d. VCCTC
5. Exposure to sex
6. Exposure with FSW or partner
7. No. of partners
8. Condom use
9. Why should one use or not use condoms
10. Discrimination of PLWHAs
11. Should people treat PLWHAs as any one of them
12. Should people talk, eat, sit and play with them
13. Alcohol consumption before sex
14. Do you know any FSW
15. Is the medical infrastructure sufficient to control and prevent HIV/AIDS
16. What are the NGOs doing
17. Who are the most vulnerable population
18. Why are they vulnerable
19. How are the young people different from the earlier generation
20. Should sex education be provided by schools
21. What is Shanker Foundation
22. Have they heard about Shanker Foundation
23. What role does it play
24. Do you have a boy/girl friend?
   - Yes
   - No
25. Have you ever had sex with Him/her?
27. Yes  no
28. Do you trust him/her?
29. Yes  no
30. Why?
31. Does he/she has any other relations?
32. Yes  no
33. If Yes, how do you know,
Thanks Giving
Collect all belongings
Appendix VIII

Guidelines for Focus Group Discussion (FSWs)

Introduction
Explain the purpose of the discussion
Clarify that they can leave if they want
Encourage them to ask questions if they have any

Introduction of the participants
1. Why are they in this profession?
2. Since when they are in this profession?
3. What is the reaction of their family members?
4. Where do they work?
5. How do they work?
6. Who are their clients?
7. Have they ever suffered from STI/STD?
8. When is there peak time for earning more money?
9. How much do they earn?
10. Heard about HIV/AIDS?
11. What are the modes of transmission?
12. How can they prevent it?
13. Where have they heard from?
14. Do they know anyone who is infected by it?
15. Have they thought of getting themselves tested for HIV/AIDS?
16. Do they know that there is a VCCTC at the Darjeeling District Hospital?
17. Do they ask their clients to use condoms?
18. Do they use?
19. How do the clients behave with them?
20. Do they avail the reproductive health services?
21. How do the community members treat them?
22. Do you have a boy/girl friend?
   Yes  No
23. Have you ever had sex with Him/her?
   Yes  no

25
26. Do you trust him/her?
27. Yes no
28. Why?
29. Does he/she has any other relations?
30. Yes no
31. If Yes, how do you know,

Thanks Giving
Collect Belongings
Appendix IX

Guidelines for Focus Group Discussion (IDUs)

Introduction

Explain the purpose of the discussion
Clarify that they can leave if they want
Encourage them to ask questions if they have any

Introduction of the participants
1. Since when are they into drugs?
2. Why have they started using drugs?
3. How did they start using it?
4. Do they share needles and syringes?
5. Do they know that needle and syringe sharing is dangerous for them?
6. How did they know?
7. Are they aware that they are the most vulnerable and susceptible sub group?
8. Have they heard about HIV/AIDS?
9. From where have they heard it?
10. What are the modes of transmission?
11. Do they think that they can be vulnerable to it?
12. Have they ever thought of getting themselves tested for HIV/AIDS?
13. How do the community members perceive them?
14. Have they ever being to rehabilitation center?
15. How do the police treat them?
16. From where do they get the drugs?
17. Do they have sexual partners?
18. What are the ways in which they satisfy their sexual urges?
19. Do they use condoms while having sex?
20. Are there any females who are also dependent on drugs like them?
21. Do you have a boy/girl friend?
22. Yes No
23. Have you ever had sex with Him/her?
24. Yes no
25. Do you trust him/her?
26. Yes  no
27. Why?
28. Does he/she has any other relations?
29. Yes  no
30. If Yes, how do you know, 
Thanks Giving
Collect belongings