APPENDIX I
A STUDY ON THE SURVIVAL PROBABILITY AND RISK FACTORS FOR MORTALITY OF WOMEN WHO WHERE OR HAD BEEN ON DIRECTLY OBSERVED TREATMENT SHORT COURSE (DOTS)

QUESTIONNAIRE A: SURVIVAL STATUS EIGHTEEN MONTHS POST TREATMENT

Date of interview: _______/_______/___________

Place of interview: _____________________________

Name of patient: _________________________________________________

Name of the respondent: (in case patient and responder are different):
_________________________________________________________________

Contact no:
_________________________________________________________________

Address of erstwhile patient/ responden:____________________________________________

Relationship with the patient:______________________________________________

Name of data collector :_______________________________________________________

Signature of data collector:
_________________________________________________________________
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</table>
| 1. | Is the patient alive when contacted? | 1. Yes  
2. No  
3. Don’t know |
| 2. | Data of contact | _____/_______/________ |
| 3. | If the answer to question 1 is No, date of death | _____/_______/________ |
| 4. | Has the patient migrated somewhere else? | 1. Yes  
2. No  
3. Don’t know |
| 5. | If answer to question 4 is Yes, date of migration | _____/_______/________ |
| 6. | Were/was you/s/he irregular while on treatment or stop medicine before completion of treatment? | 1. Yes  
2. No  
3. Don’t know |
| 7. | Was there any co-morbidity? | 1. Yes  
2. No  
3. Don’t know |
| 8. | If yes, which? | 1. ___________________  
2. Don’t know |
| 9. | Was any surgery performed in the recent past? | 1. Yes  
2. No  
3. Don’t know |
| 10. | Did you/s/he have any of these following disease/disorder? | 1. Diabetes mellitus  
2. Cancer  
3. Hyper tension (HBP)  
4. HIV/AIDS  
5. Malaria  
6. Alcoholism  
7. Sudden weight loss  
9. Frequent fever  
10. Fever in night  
11. Chronic cough  
12. Blood stains in cough  
13. Frequent diarrhea  
14. Oral thrush  
15. Other (please specify)  
16. Nothing  
17. Don’t know |
| 11. | Were/was you/she pregnant at the time diagnosis of tuberculosis? | 1. Yes  
2. No  
3. Don’t know |
| 12. | Did you/she deliver just prior to her diagnosis? | 1. Yes  
2. No  
3. Don’t know |
REMARKS

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

_____________________________________________________________________________________

THANK YOU

I appreciate your patient co-operation and answering all the questions. I assure you that all answers provided you will not be disclosed to any one and will be used for research purpose only.
### Medical record from treatment cards/ DOTS registers:

<p>| | | |</p>
<table>
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<tr>
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</thead>
</table>
| **1. Age** |   | 1. <20 years  
2. 20 – 29 years  
3. 30 – 39 years  
4. 40 – 49 years  
5. 50 – 59 years  
6. >/= 60 years |
|   |   |   |
| **2. Sex** | 1. Male  
2. Female |
|   |   |   |
| **3. Date of diagnosis** |   |   |
| **4. Date of initiation of treatment** |   |   |
| **5. Date of completion of treatment/last contact by the TBHV** |   |   |
| **6. Date of death** |   |   |
| **7. Base line sputum smear status** | 1. Positive  
2. Scanty  
3. Negative |
| **8. Type of case** | 1. NSP  
2. NSN  
3. Relapse  
4. TAD  
5. Others  
6. Treatment failure |
| **9. Treatment category** | 1. Category I  
2. Category II  
3. Category III  
4. Category IV |
| **10. Defaulter at any time of the treatment?** | 1. Yes  
2. No |
| **11. Drug regularity** | 1. Yes  
2. No |
| **12. HIV status** | 1. Positive  
2. Negative  
3. Unknwon |
| **13. Drug composition** | 1. DOTS  
2. DOTS/CPT  
3. DOTS/ART  
4. DOTS/CPT/ART |
IF SURVIVING WHEN CONTACTED:

Date of diagnosis                          ________ ___/________/________
Date of initiation of treatment       ___________/_ _______/________
Date of completion of treatment
/ last contact with the DOTS center _________/___ ____ /_________

Calculate the time survived since initiation of treatment/completion of treatment/ last contact with the DOTS center and the contact by the data collector

IF DEATH OCCURRED :

During treatment:

Date of diagnosis                       ___________ /________/________
Date of initiation of treatment    ___________/____ ____/________
***Date of death                        ___________ /________/________

Calculate time between initiation of treatment and death

After treatment:

Date of diagnosis                           _______ ____/________/______
Date of initiation of treatment       __________/ _ _______/_______
Date of completion of treatment   _________/_______  /_________
***Date of death                           ________ _/___________/_________

Calculate time between initiation of treatment / completion of treatment and death:
A STUDY TO DETERMINE THE RISK FACTORS FOR MORTALITY AMONG WOMEN PATIENTS WHO ARE OR HAD BEEN ON DIRECTLY OBSERVED TREATMENT SHORT COURSE (DOTS)

QUESTIONNAIRE B: FOR EXPIRED PATIENTS

From DOTS Register: Yes No

Date of interview: _______/_______/______________

Place of interview: _______________________________

Name of data collector: __________________________

Signature of data collector: ______________________

Name of deceased: _______________________________

Name of the respondent: _________________________

Contact no: ________________________________

Address of respondent: _________________________

Relationship to deceased: ________________________

1. Did you live with the deceased during the events that lead to his/her death?
   1. Yes
   2. No

2. If NO, then how do you know the details about his death?

1. HISTORY OF TUBERCULOSIS:
I would like to ask a few questions regarding the last episode of illness prior to death.

<p>| | | |</p>
<table>
<thead>
<tr>
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</table>
| 3. | Did the person die due to Tuberculosis? | 1. Yes  
2. No  
9. Don’t know |
|   | Did s/he have the following symptoms | 1. Chronic cough  
2. Fever at night  
3. Blood in cough |
| 4. | How many times did s/he have TB? | 1. _______________  
9. Don’t know |
| 5. | How many times did s/he take treatment for it? | 1. _______________  
9. Don’t know |
| 6. | The last time s/he took treatment, did s/he complete treatment? | 1. Yes  
2. No  
9. Don’t know |
| 7. | The last time she took treatment, was s/he declared cured? | 1. Yes  
2. No  
9. Don’t know |
| 8. | Did s/he fall sick after completion of treatment? | 1. Yes  
2. No  
9. Don’t know |
| 9. | If yes, how many times did s/he fall sick post treatment? | 1. _______________  
9. Don’t know |
| 10. | Did the deceased come in contact with another TB patient just prior to death/illness? | 1. Yes  
2. No  
9. Don’t know |

2. INFORMATION ON DEATH

Now I would like to ask you a few questions on the circumstances during the death.

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<tbody>
<tr>
<td>11.</td>
<td>Date of death</td>
<td><strong>/</strong>/______</td>
</tr>
</tbody>
</table>
| 12. | Did the patients die during or after completion of treatment? | 1. During treatment  
2. Post treatment  
9. Don’t know |
| 13. | Do you have any documents/papers related to his/her death? Can you show them? | 1. Yes  
2. No  
9. Don’t know |

REMARKS:_________________________________________  
_________________________________________________  
_________________________________________________  
_________________________________________________  
_________________________________________________  

<p>| | | |</p>
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</thead>
</table>
| 14. | Place of death | 1. Home  
2. Govt health facility |
### 3. IMMUNOSUPPRESSIVE CONDITIONS

I would like to ask you a few questions on diseases other than TB (if any):

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 18. Was there any co-morbidity?                                          | 1. Yes  
2. No  
9. Don’t know                                                      |
| 19. If yes, please specify                                               | 1. ___________________  
9. Don’t know                                                        |
| 20. Was there any recent surgery prior to death/illness?                 | 1. Yes  
2. No  
9. Don’t know                                                      |
| 21. Did s/he suffer from any of these?                                   | 1. Diabetes mellitus  
2. Cancer  
3. Hypertension (HBP)  
4. HIV/AIDS  
5. Malaria  
6. Alcoholism  
7. Sudden weight loss  
9. Frequent fever  
10. Fever in night  
11. Chronic cough  
12. Blood stains in cough  
13. Frequent diarrhea  
14. Oral thrush  
15. Other (please specify)  
16. Nothing  
17. Don’t know                                                        |

If the deceased is a woman, then ask

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 22. Was the woman pregnant prior to her illness/death?                    | 1. Yes  
2. No  
9. Don’t know                                                      |
| 23. Did she deliver prior to her illness/death                           | 1. Yes  
2. No  
9. Don’t know                                                      |

### 4. SOCIO ECONOMIC STATUS

Thank you for providing such important information. Now I would like to ask a few
questions regarding the persons living in your household.

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<tbody>
<tr>
<td>24.</td>
<td>Place if residence of the deceased</td>
</tr>
</tbody>
</table>
|     | 1. Slum  
|     | 2. Non – slum  
|     | 9. Don’t know  
| 25. | Monthly household income |
|     | 1. \( \leq 2040 \)  
|     | 2. 2041 – 6100  
|     | 3. 6101 – 10160  
|     | 4. \( \geq 10161 \)  
|     | 9. Don’t know  
| 26. | Did/Do your/deceased’s household have a BPL card? |
|     | 1. Yes  
|     | 2. No  
|     | 9. Don’t know  
| 27. | What was the highest level education s/he had attended? |
|     | 1. Illiterate  
|     | 2. Primary (I – V)  
|     | 3. Middle (VI – X)  
|     | 4. High school (XI-XII)  
|     | 5. Graduate and higher  
|     | 6. Other (specify please)  
| 28. | What was the occupation of the deceased? |
| 29. | Was s/he on daily wages or fixed salary? |
|     | 1. Daily wages  
|     | 2. Monthly salary  
|     | 9. Don’t know  
| 30. | Did s/he have to live away from the home? |
|     | 1. Yes  
|     | 2. No  
|     | 9. Don’t know  
| 31. | Did the deceased/spouse own this house? |
|     | 1. Yes  
|     | 2. No  
|     | 9. Don’t know  

I will now ask question about the deceased person’s height and weight. If you know his height tell me, I will note them down as it is. In case, you don’t know, you can show me the approximate height of the person comparing it to the wall or the door. I will measure it using my measuring tape/ruler.

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<tbody>
<tr>
<td>32.</td>
<td>Height of the deceased (approximate)</td>
</tr>
</tbody>
</table>
|     | 1. ________________  
|     | 9. Don’t know  
| 33. | Weight (baseline, from the DOTS cards) |
|     | 1. ________________  
|     | 9. Don’t know  
| 34. | BMI (calculate) |
|     | 1. ________________  
|     | 9. Don’t know  

I will now ask you about the health care facilities where the deceased had taken his/her
35. How long did it take him/her to reach the nearest health facility

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<tbody>
<tr>
<td>1</td>
<td>_________</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

36. What was the form of transport used?

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<table>
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<tbody>
<tr>
<td>1</td>
<td>Walked</td>
</tr>
<tr>
<td>2</td>
<td>Bicycle</td>
</tr>
<tr>
<td>3</td>
<td>PMT bus</td>
</tr>
<tr>
<td>4</td>
<td>Auto rickshaw</td>
</tr>
<tr>
<td>5</td>
<td>Other------------------</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

37. Was there in problem in getting the medicine?

<p>| | |</p>
<table>
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<tbody>
<tr>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

38. If YES, please describe

Now I would like to ask about the behavior of the deceased.

7. BEHAVIOURAL FACTORS

A. TREATMENT SEEKING BEHAVIOUR:

39. How many days/week/months/years after the first appearance of symptoms did s/he approach the doctor/hospital?

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<tbody>
<tr>
<td>1</td>
<td>_________</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know</td>
</tr>
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</table>

40. Who was the first practitioner approached?

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</thead>
<tbody>
<tr>
<td>1</td>
<td>Govt. hospital</td>
</tr>
<tr>
<td>2</td>
<td>Pvt. Practitioner</td>
</tr>
<tr>
<td>3</td>
<td>Traditional healer</td>
</tr>
<tr>
<td>4</td>
<td>Home treatment</td>
</tr>
<tr>
<td>5</td>
<td>Other --------------</td>
</tr>
<tr>
<td>6</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

41. How many days/weeks/months did it take between the first visit to any doctor and diagnosis of TB?

<p>| | |</p>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>_________</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

42. How many days/weeks/months did it take between the diagnosis of TB and initiation of treatment?

<p>| | |</p>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>_________</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

REMARKS:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

B. TREATMENT COMPLIANCE RELATED BEHAVIOUR

I would like to ask you some compliance related questions.

43. Was s/he regular in the first two months of treatment?

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<tbody>
<tr>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>No</td>
</tr>
</tbody>
</table>
### C. TOBACCO CONSUMPTION

I would like to ask you about the tobacco intake habits.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
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</thead>
<tbody>
<tr>
<td>44. Was there in side effect due to the drugs?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>45. If YES, did s/he stop treatment?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>46. If answer to Q 43 is NO, were there any other reasons to stop medicine?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
</tbody>
</table>

**REMARKS:**

___________________________________________________  
___________________________________________________  
___________________________________________________  
___________________________________________________  

**D. ALCOHOL CONSUMPTION**

I would like to ask you some questions regarding the alcohol consumption by the deceased.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>47. Did the deceased consume tobacco?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>If yes, then ask the following questions?</td>
<td></td>
</tr>
<tr>
<td>48. Specify the type of tobacco consumed?</td>
<td>1. Beedi</td>
</tr>
<tr>
<td></td>
<td>2. Cigarettes</td>
</tr>
<tr>
<td></td>
<td>3. Gutkha</td>
</tr>
<tr>
<td></td>
<td>4. Mishri</td>
</tr>
<tr>
<td></td>
<td>5. Other____________</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>49. How many packets/times s/he used to consume?</td>
<td>1. _______________</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>50. Duration of tobacco consumption</td>
<td>1. &lt; 1 year</td>
</tr>
<tr>
<td></td>
<td>2. 1-5 years</td>
</tr>
<tr>
<td></td>
<td>3. 5-10 years</td>
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<td></td>
<td>4. &gt;/=10 years</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>51. Was s/he an ex tobacco user?</td>
<td>1. Yes</td>
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<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>52. If YES, how many years since s/he stopped tobacco intake?</td>
<td>1. _______________</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>53. Did the deceased consume alcohol?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
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<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
</tbody>
</table>
E. PSYCHO SOCIAL SUPPORT

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>58. Did the spouse live away from home?</td>
<td></td>
<td></td>
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<tr>
<td>59. If YES, then for how many months a year?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>60. Did the spouse live with the deceased during the treatment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>61. If NO, then who used to help him/her during the treatment?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>62. Did anyone accompany him/her to the DOTS center?</td>
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<tr>
<td>63. If YES, who?</td>
<td></td>
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REMARKS:
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F. SOCIAL STIGMA

Now I would like to ask a few questions regarding the social support of the deceased person.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>64. Was s/he afraid of going to the TB clinic /DOTS center because many people might see him/her there?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Question</td>
<td>Options</td>
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<td>----------------------------------</td>
<td></td>
</tr>
<tr>
<td>65.</td>
<td>Was s/he afraid to tell his/her family members that s/he had TB?</td>
<td>1. Yes 2. No 9. Don’t know</td>
<td></td>
</tr>
<tr>
<td>66.</td>
<td>Did s/he worry or feel guilty/sense of burden to the family members due to illness?</td>
<td>1. Yes 2. No 9. Don’t know</td>
<td></td>
</tr>
<tr>
<td>67.</td>
<td>Was s/he asked to stay away from the work/social groups?</td>
<td>1. Yes 2. No 9. Don’t know</td>
<td></td>
</tr>
<tr>
<td>68.</td>
<td>Did s/he himself/herself keep away from social group?</td>
<td>1. Yes 2. No 9. Don’t know</td>
<td></td>
</tr>
</tbody>
</table>

**REMARKS:**
___________________________________________________
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**G. GENDER ISSUES:**

Ask if the deceased is a woman

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Options</th>
</tr>
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<tbody>
<tr>
<td>71.</td>
<td>Was there any incidents known to you about abuse (scolding/beating/abandoned/forced to move back to natal home/divorce/deserted/remarriage) by the husband/in laws or any other family member/relatives owing to TB?</td>
<td>1. Yes 2. No 9. Don’t know</td>
</tr>
</tbody>
</table>

**REMARKS:**
___________________________________________________
___________________________________________________
___________________________________________________
___________________________________________________
___________________________________________________
THANK YOU
I appreciate your patient cooperation and answering all the questions. I assure you that all the answers provided by you will not be disclosed to any one and will be used for research purpose only.
**NOT TO BE FILLED BY THE DATA COLLECTOR:**

Medical record from treatment cards/ DOTS registers:

<p>| | | |</p>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td><strong>Age</strong></td>
<td></td>
</tr>
</tbody>
</table>
|   |   | 1. <20 years  
2. 20 – 29 years  
3. 30 – 39 years  
4. 40 – 49 years  
5. 50 – 59 years  
6. >/= 60 years |
| 2. | **Sex** |   |
|   |   | 1. Male  
2. Female |
| 3. | **Date of diagnosis** | / /   |
| 4. | **Date of initiation of treatment** | / /   |
| 5. | **Date of completion of treatment/last contact by the TBHV** | / /   |
| 6. | **Date of death** | / /   |
| 7. | **Base line sputum smear status** |   |
|   |   | 1. Positive  
2. Scanty  
3. Negative |
| 8. | **Type of case** |   |
|   |   | 1. NSP  
2. NSN  
3. Relaspe  
4. TAD  
5. Others  
6. Treatment failure |
| 9. | **Treatment category** |   |
|   |   | 1. Category I  
2. Category II  
3. Category III  
4. Category IV |
| 10. | **Defaulter at any time of the treatment?** |   |
|   |   | 1. Yes  
2. No |
| 11. | **Drug regularity** |   |
|   |   | 1. Yes  
2. No |
| 12. | **Phase at the time of death ( if died during treatment)** |   |
|   |   | 1. Intensive phase  
2. Continuous phase |
| 13. | **HIV status** |   |
|   |   | 1. Positive  
2. Negative  
3. Unkwon |
| 14. | **Drug composition** |   |
|   |   | 1. DOTS  
2. DOTS/CPT  
3. DOTS/ART  
4. DOTS/CPT/ART |
IF DEATH OCCURED:

**During treatment:**

Date of diagnosis                        __________/________/________
Date of initiation of treatment         __________/________/________
***Date of death                         __________/________/________

Calculate time between initiation of treatment and death

**After treatment:**

Date of diagnosis                        __________/________/________
Date of initiation of treatment         __________/________/________
Date of completion of treatment         __________/________/________
***Date of death                         __________/________/________

Calculate time between initiation of treatment and

completion of treatment and death:

**CALCULATE DELAY IN DIAGNOSIS (IF ANY)**

Patient delay:

(Time between appearances of symptoms

and visit to doctor/health care facility)

Doctors’ delay:

(Time between first visit to the doctor and diagnosis)

Health system’s delay:

(Time between diagnosis and initiation of treatment)
If the patient is not the respondent, then ask Q 1-2

1. Did you live with the erstwhile patient during his/her

   1. Yes
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. HISTORY OF TUBERCULOSIS:</td>
<td></td>
</tr>
<tr>
<td>I would like to ask a few questions regarding the last episode of illness</td>
<td></td>
</tr>
<tr>
<td>3. How many times did you/s/he have TB?</td>
<td>1. _______</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>4. How many times did you/s/he take treatment for it?</td>
<td>1. __________________</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>5. The last time you/s/he took treatment, did you/s/he complete treatment?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>6. The last time you/s/he took treatment, were/was you/s/he declared cured?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>7. Did you/s/he fall sick after completion of treatment?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>8. If yes, how many times did you/s/he fall sick post treatment?</td>
<td>1. ______________</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>9. Did you/s/he come in contact with another TB patient just prior to illness?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>2. INFORMATION ON TREATMENT</td>
<td></td>
</tr>
<tr>
<td>Now I would like to ask you a few questions on the last episode of TB</td>
<td></td>
</tr>
<tr>
<td>10. Where did you/s/he take the last treatment from?</td>
<td>1. DOTS center</td>
</tr>
<tr>
<td></td>
<td>2. Pvt. facility</td>
</tr>
<tr>
<td>11. When did you/s/he last take your/his/her treatment?</td>
<td>1. ______________</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>12. When did you/s/he last take your/his/her doses?</td>
<td>1. ______________</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>3. IMMUNOSUPPRESSIVE CONDITIONS</td>
<td></td>
</tr>
<tr>
<td>I would like to ask you a few questions on diseases other than TB (if any):</td>
<td></td>
</tr>
<tr>
<td>13. Was there any co-morbidity?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>14. If yes, please specify</td>
<td>1. ______________</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>15. Was there any recent surgery prior to illness?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>9. Don’t know</td>
</tr>
<tr>
<td>16. Did you/s/he suffer from any of these?</td>
<td>1. Diabetes mellitus</td>
</tr>
<tr>
<td></td>
<td>2. Cancer</td>
</tr>
<tr>
<td></td>
<td>3. Hyper tension (HBP)</td>
</tr>
<tr>
<td></td>
<td>4. HIV/AIDS</td>
</tr>
</tbody>
</table>
5. Malaria
6. Alcoholism
7. Sudden weight loss
8. Frequent diarrhea
9. Frequent fever
10. Oral thrush
11. Nothing
99. Don’t know

If the patient is a woman, then ask

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
| 17. | 1. Yes  
|     | 2. No  
|     | 9. Don’t know  |
| 18. | 1. Yes  
|     | 2. No  
|     | 9. Don’t know  |

4. SOCIO ECONOMIC STATUS
Thank you for providing such important information. Now I would like to ask a few questions regarding the persons living in your household.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
| 19. | 1. Slum  
|     | 2. Non – slum  
|     | 9. Don’t know  |
| 20. | 1. </= 2040  
|     | 2. 2041 – 6100  
|     | 3. 6101 – 10160  
|     | 4. >/= 10161  
|     | 9. Don’t know  |
| 21. | 1. Yes  
|     | 2. No  
|     | 9. Don’t know  |
| 22. | 1. Illiterate  
|     | 2. Primary (I – V)  
|     | 3. Middle (VI – X)  
|     | 4. High school (XI- XII)  
|     | 5. Graduate and higher  
|     | 6. Other (specify please)  |
| 23. |   |
| 24. | 1. Daily wages  
|     | 2. Monthly salary  
|     | 9. Don’t know  |
| 25. | 1. Yes  
|     | 2. No  
|     | 9. Don’t know  |
26. Did the deceased/spouse own this house?  
1. Yes  
2. No  
9. Don’t know

I will now ask question about your/erstwhile patient’s height and weight. If you know your/his/her height; tell me, I will note them down as it is. In case, you don’t know, I ask for your permission to measure your height/ you can show me the approximate height of the person comparing it to the wall or the door. I will measure it using my measuring tape/ruler.

27. Height of the erstwhile patients (approximate)  
1. _______________  
9. Don’t know

28. Weight (baseline, from the DOTS cards)  
1. _______________  
9. Don’t know

29. BMI (calculate)  
1. _______________  
9. Don’t know

I will now ask you about the health care facilities where you/she had taken his/her treatment.

30. How long did it take you/ him/her to reach the nearest health facility  
1. _______________  
9. Don’t know

31. What was the form of transport used?  
1. Walked  
2. Bicycle  
3. PMT bus  
4. Auto rickshaw  
5. Other------------------  
9. Don’t know

32. Was there in problem in getting the medicine?  
1. Yes  
2. No  
9. Don’t know

33. If YES, please describe

Now I would like to ask some questions regarding some habits/behaviour  

7. BEHAVIOURAL FACTORS

A. TREATMENT SEEKING BEHAVIOUR:

34. How many days/week/months/years after the first appearance of symptoms did you/s/he approach the doctor/hospital?  
1. _______________  
9. Don’t know

35. Who was the first practitioner approached?  
1. Govt. hospital  
2. Pvt. Practitioner  
3. Traditional healer  
4. Home treatment  
5. Other------------------  
6. Don’t know

36. How many days/weeks/months did it take between the first visit to any doctor and diagnosis of TB?  
1. _______________  
9. Don’t know

37. How many days/weeks/months did it take between the
diagnosis of TB and initiation of treatment?  9. Don’t know

REMARKS:
___________________________________________________
___________________________________________________
___________________________________________________
___________________________________________________

B. TREATMENT COMPLIANCE RELATED BEHAVIOUR

I would like to ask you some compliance related questions.

| 38. Were/Was you/s/he regular in the first two months of treatment? | 1. Yes  
2. No  
9. Don’t know |
| --- | --- |
| 39. Was there in side effect due to the drugs? | 1. Yes  
2. No  
9. Don’t know |
| 40. If YES, did you/s/he stop treatment? | 1. Yes  
2. No  
9. Don’t know |
| 41. If answer to Q 38 is NO, were there any other reasons to stop medicine? | 1. Yes  
2. No  
9. Don’t know |

REMARKS:
___________________________________________________
___________________________________________________
___________________________________________________
___________________________________________________

C. TOBACCO CONSUMPTION
I would like to ask you about your/his/her tobacco intake habits.

| 42. Did you/s/he consume tobacco? | 1. Yes  
2. No  
9. Don’t know |
| --- | --- |
If yes, then ask the following questions?
| 43. Specify the type of tobacco consumed? | 1. Beedi  
2. Cigarettes  
3. Gutkha  
4. Mishri  
5. Other  
9. Don’t know |
| 44. How many packets/times you/s/he used to consume? | 1. ___________  
9. Don’t know |
45. Duration of tobacco consumption

1. < 1 year
2. 1-5 years
3. 5-10 years
4. >/=< 10 years
5. Don’t know

46. Were/Was you/s/he an ex tobacco user?

1. Yes
2. No
3. Don’t know

47. If YES, how many years since you/s/he stopped tobacco intake?

1. ___________
2. Don’t know

D. ALCOHOL CONSUMPTION

I would like to ask you some questions regarding the alcohol consumption.

48. Did you/s/he consume alcohol?

1. Yes
2. No
3. Don’t know

If YES then ask the following questions

49. How many times you/s/he used to take alcohol

1. ___________
2. Don’t know

50. Duration of alcohol consumption

1. ___________
2. Don’t know

51. Were/was you/s/he an ex alcoholic?

1. Yes
2. No
3. Don’t know

52. If YES, how many years since you/s/he stopped alcohol intake?

1. ___________
2. Don’t know

Now I would like to ask you some questions regarding a few important aspects of your/the erstwhile patients’ life. I understand that some of these questions are very personal. However, your answers are crucial for helping to understand the conditions of patients suffering from TB in India. Let me assure you that your answers are completely confidential and will not be told to anyone and no one else will know that you had answered these questions.

E. PSYCHO SOCIAL SUPPORT

53. Did the spouse live away from home

1. Yes
2. No
3. Don’t know

54. If YES, then for how many months a year?

1. ___________
2. Don’t know

55. Did the spouse live with you/his/her during the treatment?

1. Yes
2. No
3. Don’t know

56. If NO, then who used to help you/him/her during the treatment?

1. ___________
2. Don’t know
57. Did anyone accompany you/him/her to the DOTS center?
1. Yes
2. No
9. Don’t know

58. If YES, who?
1. ____________
9. Don’t know

REMARKS:
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

F. SOCIAL STIGMA

Now I would like to ask a few questions regarding the social support.

59. Were/was you/s/he afraid of going to the TB clinic /DOTS center because many people might see you/him/her there?
1. Yes
2. No
9. Don’t know

60. Were/was you/s/he afraid to tell your/ his/her family members that you/s/he had TB?
1. Yes
2. No
9. Don’t know

61. Did you/s/he worry or feel guilty/sense of burden to the family members due to illness
1. Yes
2. No
9. Don’t know

62. Were/was you/s/he asked to stay away from the work/social groups?
1. Yes
2. No
9. Don’t know

63. Did you/s/he yourself/himself/herself keep away from social group?
1. Yes
2. No
9. Don’t know

64. Was there any problem in getting yourself/relative married due to the illness?
1. Yes
2. No
9. Don’t know

REMARKS:
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

G. GENDER ISSUES:
Ask if the patient is a woman

65. What is your/the lady’s marital status?
1. Currently married
2. Widowed
3. Divorced/Separated /
| 66. | Was there any incidents known to you about abuse (scolding/beating/abandoned/forced to move back to natal home/divorce/deserted/remarriage) by the husband/in laws or any other family member/relatives owing to TB? | Deserted  
4. Never married  
5. Live in relationship  
9. Don’t know |

1. Yes  
2. No  
9. Don’t know

REMARKS:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

THANK YOU
I appreciate your patient co – operation and answering all the questions. I assure you that all the answers provided by you will not be disclosed to any one and will be used for research purpose only.
Medical record from treatment cards/ DOTS registers:

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>
| 1. | Age | 1. <20 years  
2. 20 – 29 years  
3. 30 – 39 years  
4. 40 – 49 years  
5. 50 – 59 years  
6. >/= 60 years |
| 2. | Sex | 1. Male  
2. Female |
| 3. | Date of diagnosis | _____/_______/_______ |
| 4. | Date of initiation of treatment | _____/_______/_______ |
| 5. | Date of completion of treatment/last contact by the TBHV | _____/_______/_______ |
| 6. | Date of contact by data collector | _____/_______/_______ |
| 7. | Base line sputum smear status | 1. Positive  
2. Scanty  
3. Negative |
| 8. | Type of case | 1. NSP  
2. NSN  
3. Relaspe  
4. TAD  
5. Others  
6. Treatment failure |
| 9. | Treatment category | 1. Category I  
2. Category II  
3. Category III  
4. Category IV |
| 10. | Defaulter at any time of the treatment? | 1. Yes  
2. No |
| 11. | Drug regularity | 1. Yes  
2. No |
| 13. | HIV status | 1. Positive  
2. Negative  
3. Unknown |
| 14. | Drug composition | 1. DOTS  
2. DOTS/CPT  
3. DOTS/ART  
4. DOTS/CPT/ART |
Date of diagnosis

Date of initiation of treatment

Date of completion of treatment

Date of contact by data collector

Calculate time between initiation of treatment and contact by data collector

Calculate time between the completion of treatment/last contact and contact by data collector

**CALCULATE DELAY IN DIAGNOSIS (IF ANY)**

Patient delay:
(Time between appearances of symptoms and visit to doctor/health care facility)

Doctors’ delay:
(Time between first visit to the doctor and diagnosis)

Health system’s delay:
(Time between diagnosis and initiation of treatment)
Instructions Manual for interviewer

GENERAL INSTRUCTIONS:

1. Introduce yourself politely:

   “Namaste... is this ......................... (listed person’s name)’s house? Are you --------
   his/her family member (in case person answering the door is not the listed person)?
   Introduce yourself

   “I am ___________. I am working on a health related research on behalf of a phd
   student from University of Pune.

   (produce the introduction letter...if required)

   “Do you have some time say a half an hour? Can I ask you some question?”

   If the person approves, proceed further.

   “The research work deals with individuals who had taken DOTS treatment, thus
   would like to have information regarding the same. If you permit me, I would like to
   ask a few questions. It would take some 15-20 minutes of your time.”

   If the person approves, produce the INFORMED CONSENT, HELP IN
   EXPLAINING THE CONTENT. Ask the respondent to sign the consent form with
   repeated assurance that all data will be kept confidential and there will not be any
   consequence if the person signs. Encourage the respondent to get it read by a trusted
   person, if s/he insists.

   Ask for permission once again

   “Thank you................, Can I start the interview?”

   Express empathy and condolence, when you interview family member of an expired
   case. Then proceed further.

2. Throughout the interview, maintain politeness. Also note that the respondent
   remains comfortable throughout the process. Do not probe the respondent too much if
   s/he appears to hide some information, uncomfortable or non -cooperative. It can
   affect negatively to subsequent questions. Stop the interview, the moment respondent
   wishes to. Respect the wish to privacy.

   Throughout the interview, be sensitive to the respondent keeping in mind that the
   person had suffered tuberculosis or had expired and might have left a lot of grievances,
   the family might have lost bread earner or have faced a lot of social discrimination.

   address book
QUESTIONNAIRE B: MORTALITY QUESTIONNAIRE: Interview the spouse/closest kin/caregiver/confidant of the person registered in RED in the address book provided.

Page 1
1. Fill the details of interview
   a) Date
   b) Place
   c) Name of interviewer with signature
   d) Name of deceased
   e) Name of responder
   f) Contact details

Page 2
1 Clinical data:
   Do not fill page 2, information will be filled by investigator from TB cards.

Fill questionnaire from page 3 onwards

Page 3
2.1 respondent’s characteristics
   a) Relation of the respondent to the deceased person
   b) Confirm the presence of respondent during the death of the patient and if not, then probe politely about the authenticity of the information about the deceased to be provided by the respondent.
   c) Ask for any document that confirms the death due to tuberculosis eg death certificate

2.2 demographic characteristics:
   a) Age: Document the age as it is, as reported by the respondent at the time of death
      Do not categorize the age in the second column.
   b) Place of residence: document the place of residence as slum if it is designated as a slum in a census.
   c) Ask the respondent in order to collect information on question no 8 to 12.
      confirm question no 11 and 12 by re-probing in order to collect authentic information.
3.1. Socio – economic status:

a) Ask respondent about question no 13 to 19

b) Be sensitive and ask carefully about question no 20 (marital status at the time of death)

c) Ask respondent about question 21 to 22

d) Follow the definition to decide question no 23 (type of house) i.e. pucca = both wall and roof made of brick and cement, semi pucca = only wall made of brick and cement but roof made of corrugated tin or asbestos or tiles or thatch, kuchha = both wall and roof made of temporary structures like corrugated tin, asbestos, mud etc but not brick and cement.

Page 6/7

a) Ask the respondent about question no 24 to 29

b) Ask the respondent about question no 30 to 33, with a polite probing to have the best possible answer

c) Question no 31 = ask the respondent about the height of the deceased person and write the approximate height as provided by the respondent, eg, the respondent might show the height just above the window pane, middle of a door or might even state as “five and half feet” or “little more than five feet” etc.

4.3 Behavioural --- Page 7/8

a) Ask the respondent about question 34 to 41 with polite probing to obtain the details

b) Be sensitive and careful when the deceased in question is woman. Do not ask directly if the woman smoked and used alcohol, instead ask, if the lady used to use tobacco in any form eg mishri etc, then wait till the respondent talks more about behavioural aspect of the woman deceased. If not, then ask confidentially and very politely with extreme sensitivity about the alcohol consumption. If the respondent had been non – cooperative since initiation of the interview, then do not ask the question so that the subsequent questions are affected.

Page no 9/10

a) Ask respondent about questions no 50 to 61

b) Listen patiently to the stories/incidents if any, and you are free to take a note.
Gender issues and stigma:
Be extremely sensitive while dealing with questions on gender issues and stigma issues. Probe politely with sensitivity to get answer for these questions. Note down the case stories/incidents that the respondent might share,
Page 12 – 15
a) ask the respondent about question no 79 to 106, with polite probing.
b) If possible, try to confirm the authenticity of the information from any available documents associated with death (if any).

Instructions for interviewers - 2

QUESTIONNAIRE C: SURVIVAL : Interview every second living person registered in the address book provided.

GENERAL INSTRUCTIONS:
Please, be sensitive and polite while asking the questions while keeping in mind that the person is question had been a patient on anti tuberculosis treatment with a possibility that the person might have been subjected to social discrimination. Ask politely for permission to carry out interview.
Stop interview the moment respondent wants to, don’t probe too much if the respondent appears uncomfortable and non – co operative, which might affect negatively on the subsequent questions.
Try that the patient is the respondent. In case, the patient is not well or is out of station for a longer duration, give a second visit to the house. Even if in the second visit, the situation doesn’t change, consider the spouse/nearest kin/ care giver/ confidant as the respondent.

Page 1
2. Fill the details of interview
   g) Date
   h) Place
   i) Name of interviewer with signature
   j) Name of patient
   k) Name of responder (if the patient is not the respondent)
   l) Contact details

Page 2
1 Clinical data:
Do not fill page 2, information will be filled by investigator from TB cards.

Fill questionnaire from page 3 onwards

Page 3/4
In case, the patient is not the respondent:
2.1 respondent’s characteristics
a) Relation of the respondent to the deceased person
b) Confirm the presence of respondent during the episode of illness.
2.2 demographic characteristics:
d) Age: Document the age as it is, as reported by the respondent at the time of illness
   Do not categorize the age in the second column.
e) Place of residence: document the place of residence as slum if it is designated as a slum in a census.
f) Ask the patient/respondent in order to collect information on question no 8 to 12. Confirm question no 11 and 12 by re probing in order to collect authentic information.

Page 5/6
3.1. Socio – economic status:
a) Ask respondent about question no 13 to 19
b) Be sensitive and ask carefully about question no 20 (marital status at the time of illness)
c) ask respondent about question 21 to 22
d) follow the definition to decide question no 23 (type of house) i.e. pucca = both wall and roof made of brick and cement, semi pucca = only wall made of brick and cement but roof made of corrugated tin or asbestos or tiles or thatch, kuchha = both wall and roof made of temporary structures like corrugated tin, asbestos, mud etc but not brick and cement.

Page 7/8
a) ask the respondent about question no 24 to 29
b) ask the respondent about question no 30 to 33, with a polite probing to have the best possible answer
c) question no 31 = note down the approximate height of the patient

4.3 Behavioural --- Page 8/9
a) Ask the respondent about question 34 to 41 with polite probing to obtain the details

b) Be sensitive and careful when the patient is woman. Do not ask directly if the woman smoked and used alcohol, instead ask, if the lady used to use tobacco in any form eg mishri etc, then wait till the respondent talks more about behavioural aspect of the woman deceased. if not, then ask confidentially and very politely with extreme sensitivity about the alcohol consumption. If the patient/respondent had been non – cooperative since initiation of the interview, then do not ask the question so that the subsequent questions are affected.

Page no 10

(c) Ask respondent about questions no 50 to 61

d) Listen patiently to the stories/ incidents if any, and you are free to take a note.

Page 11 / 13

Gender issues and stigma :

Be extremely sensitive while dealing with questions on gender issues and stigma issues. Probe politely with sensitivity to get answer for these questions. Note down the case stories/ incidents that the respondent might share,

Page 13 – 15

(c) ask the respondent about question no 79 to 95, with polite probing.

Instructions for interviewers - 3

QUESTIONNAIRE A: SURVIVAL PROBABILITY : Interview all person registered in the address book provided.

General instruction:

All person in the address book to be contacted irrespective of living status. If the person has died when contacted, note down the incident with date, if the person had permanently shifted/ transferred out, note down the incident and ask neighbours for probable date of transfer/shifting.

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4. Fill the details of interview

s) Date

t) Place

u) Name of interviewer with signature
5. Fill the details of the patient
   a) Name
   b) Age (at the time of the illness)
   c) Sex

3. Do not fill question no 5, 10, 11, 13 and 16, they are to filled form the treatment card/DOTS register.