1. Patient Unique ID code (write on each page): [__][__] [__][__] [__][__]

Community Based TB DEATH REVIEW – Confidential Inquiry (PART B).

For co-habitants or witnesses to the care of the TB patient.

I am...……………….and this is…………………. who will help me by taking notes during this interview. We want to have this discussion so that we can use your ideas and opinions to improve the care of TB patients so that deaths like this do not happen in the future. Listening to families we can better understand what it was like for [insert name] and your family. We hope that by talking with you, we can learn how to avoid future deaths from TB in this community.

Sometimes it is difficult to be open, especially when you are being asked about how other people do their work or talking about sad times. However I hope you can be open and honest with me because what you have to say can help others. Your information will be combined with the interview of many other families and your names will never be used. If you feel uncomfortable, we can take a break and return later. You may end this interview at any point and no one will be angry with you.

Because there will be a lot of information that I will not be able to remember or write down, I would like to tape record this discussion. If you do not feel comfortable with that, it is OK for me to take notes only.

2. Community code:	[__][__]
3. Date of audit:	[__][__]/[__][__]/[__][__]
4. Field worker code:	[__][__]

5.   Relationship to the patient of respondent:

☐ spouse   ☐ other household member

☐ mother/father   ☐ Other (specify)

☐ brother/sister   _____

☐ son/daughter

SOCIO-DEMOGRAPHIC DATA

6. Date of Birth of deceased TB/HIV patient		[__][__]/[__][__]/[__][__]
7. Gender:		☐ Female ☐ Male ☐ Transgender
8. Age of the deceased patient (in years)		[__][__]
9. Education level of patient:	Include relevant categories	[__][__]
10. Occupation of patient: (adapt as required)	Include relevant categories	[__][__]
11. What was patient's main tribe/ethnicity?	Include relevant categories	[__][__]
12. What was patient's religion (if any)?	Include relevant categories	[__][__]
13. Patient's marital status	If relevant, include categories	[__][__]

14.   What do you think caused the problem that led to [insert name]'s death?

15.   When did this problem start? [__][__]/[__][__]/[__][__]
16.   Why do you think the illness started when it did?

17.   What do you think the sickness does to people who have it? How does it work?

18.   Were there any particular reasons why **[insert name]** got [insert name of sickness]?

Do not read out the list. Just Tick any risk factors if mentioned by the respondent:		
☐ HIV co-infection ☐ diabetes ☐ child under 5 ☐ elderly (>60 yr) ☐ pregnancy/postpartum ☐ mentally ill ☐ alcohol- addicted ☐ drug-addicted ☐ smoking ☐ malnourished ☐ previously treated for TB	☐ miner ☐ factory worker ☐ residence in an urban slum ☐ former prisoner or prison staff ☐ healthcare worker ☐ soldier ☐ refugee or internally displaced (IDP) ☐ contact of a TB case	☐ marginalized man who had sex with men ☐ sex worker ☐ transgender ☐ migrant ☐ indigenous/minority ethnic grp ☐ homeless ☐ orphan or vulnerable child ☐ other (specify) ☐ Not known_____

SYMPTOMS OF TB (and HIV)

19. From the time **[insert name]** started feeling ill, what health complaints did he/she have, and when did those start?

(Interviewer: First ask for the symptoms, then probe for the dates. Tick all options mentioned. DO NOT PROBE for symptoms, only for the dates !! If exact date unknown: beginning of month=07, mid month=15, end of month = 22, if part of the month entirely unknown =99)		
Symptom	**Tick all options mentioned**	**Date symptom started: dd/mm/yy**
20. cough	☐	[__][__]/[__][__]/[__][__]
21. production of sputum	☐	[__][__]/[__][__]/[__][__]
22. chest pain	☐	[__][__]/[__][__]/[__][__]
23. haemoptysis (coughing blood)	☐	[__][__]/[__][__]/[__][__]
24. fever	☐	[__][__]/[__][__]/[__][__]
25. night sweats	☐	[__][__]/[__][__]/[__][__]
26. weight loss	☐	[__][__]/[__][__]/[__][__]
27. breathlessness	☐	[__][__]/[__][__]/[__][__]
28. fatigue	☐	[__][__]/[__][__]/[__][__]
29. loss of appetite	☐	[__][__]/[__][__]/[__][__]
30. headache	☐	[__][__]/[__][__]/[__][__]
31. body pains	☐	[__][__]/[__][__]/[__][__]
32. other, specify …………..........code [__][__]	☐	[__][__]/[__][__]/[__][__]
33. other, specify …………..........code [__][__]	☐	[__][__]/[__][__]/[__][__]

[note: if exact date is not known, probe for an estimate. This is information is critical. You can often use community events as a reference for probing, for example, by asking if the patient developed symptoms before or after a commonly observed event/occurrence such as recent elections, harvest time, religious celebrations, rainy season, etc and how many weeks before or after the event.]

Patient Unique ID code (write on each page): [__][__] [__][__] [__][__]

34. In addition to the death of [insert name] has the sickness caused other problems for your family?

HEALTH SEEKING BEHAVIOUR

Now, I would like you to name all the persons, clinics or hospitals that **[insert name]** visited for care about **[insert name]**'s sickness and the investigations done at each if any.

Repeat the below questions until all providers have been mentioned and discussed. Before moving on to other topics, confirm the order of the providers attended. A provider may include any sort of care provider, including: shop, pharmacy, traditional healer, hospital, private clinic, Community Health Volunteer. Note: if the family member has any medical records available and agrees that the interviewer can see those records, they can be used to verify the information (e.g. date of clinic visits, investigations done etc.)

Provider	Date of first visit	Test(s) done	Amount spent (excluding transport)	Date sputum and/or chest X-ray performed
Categories: 1=hospital/health centre/dispensary 2=private clinic, 3=herbalist 4=pharmacy 5=community health volunteer 6=lay person 7=other	If exact date unknown: beginning of month=07, mid month=15, end of month = 22 Part of month completely unknown=99	Tick all answers that apply; Do NOT record Medical History or Physical Examination	A. Cash: exact amount. Can't remember =99999 Free/no cash =00000 B. In-kind 1=yes 2=no 9=don't know	Very important!
35. (full name of provider) _____ 36. Category: [__]	37. [_][_]/[_][_]/[_][_] dd/mm/yy	38. [_]physical exam 39. [_]Sputum 40. [_] Chest X-ray 41. [_]Blood test 42. [_]biopsy 43. [_]Referred for test(s) 44. [_]Other: (specify): …………………..	45. [_][_][_][_][_] 46. B. [_] Code 47. [_], [_]	48. [_][_]/[_][_]/[_][_] dd/mm/yy
49. (full name of provider) _____ 50. Category: [__]	51. [_][_]/[_][_]/[_][_] dd/mm/yy	52. [_] physical exam 53. [_]Sputum 54. [_]X-ray 55. [_]Blood test 56. [_]Referred for test(s) 57. [_]Other: (specify): …………………..	58. [_][_][_][_][_] 59. B. [_] ……………………….. 60. Code[_], [_]	61. [_][_]/[_][_]/[_][_] dd/mm/yy
62. (full name of provider) _____ 63. Category: [__]	64. [_][_]/[_][_]/[_][_] dd/mm/yy	65. [_] physical exam 66. [_]Sputum 67. [_]X-ray 68. [_]Blood test 69. [_]Referred for test(s) 70. [_]Other: (specify): …………………..	71. [_][_][_][_][_] 72. B. [_] ……………………….. 73. Code[_], [_]	74. [_][_]/[_][_]/[_][_] dd/mm/yy

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We are now going to talk about health facilities **[insert name]** *he/she may have visited and how she/he went to the facility. Please give us the exact figures as much as possible.*

A. What are the available transport means from **[insert name]**'s house to the facilities where **[insert name]** went for TB test and/or treatment?

B. What is the cost one way

C. How long did it take him/her?

A. Transport Means	B. Cost (one way)	C. Duration
Insert relevant categories [e.g. bus =1 , bike= 2]	currency	1=≤10 minutes 2=10-30 minutes 3=31-59 minutes; 4=1-2 hours 5=> 2 hours; 99=don't know
73. [__]	74. [__][__][__]	75. [__][__]
76. [__]	77. [__][__][__]	78. [__][__]
79. [__]	80. [__][__][__]	81. [__][__]

82. Is this facility where **[insert name]** was getting TB treatment the nearest to his/her residence?

1=yes, 2=no, 9=don't know	[__]

83. *If no*, why did **[insert name]** attend this facility but not the one nearest to him/her?

84. Did **[insert name]** consider going to the hospital earlier than he/she did?

1=yes, 2=no, 9=don't know	[__]

85. *If Yes*, what were reasons that **[insert name]** didn't go earlier?

Verbatim: ………………………………………………………………………………………………………
……
……
………………………………………………………………

Do not read the options to the participant. Only probe by asking : "Were there any other reasons?" Tick all mentioned options (9=don't know)	
86. money factor, (Specify) e. g:	[__]
87. no money for transport to facility	[__]
88. no money to pay at the hospital	[__]
89. illness did not seem serious	[__]
90. he/she did not know what illness s/he had	[__]
91. self treatment effective	[__]
92. TB thought to be without cure	[__]
93. natural/environmental issue- rains, snow, harvest, earthquake	[__]
94. sought traditional/herbal remedies	[__]
95. fear of VCT/HIV testing	[__]
96. fear of hospital overnight admission	[__]

97. fear of injection	[__]
98. cause of problem was non-medical (witchcraft, curse, fate)	[__]
99. distance to health facility	[__]
100. long waiting on queues	[__]
101. no one to assist in family	[__]
102. co-morbidity (e.g. drug-use, alcoholism, mental illness, etc),	[__]
103. bad experience with health care system ………………………………………	[__]
104. family opposition	[__]
105. child care responsibilities	[__]
106. fear of loss of employment	[__]
107. religious prohibition	[__]
108. civil strife, war, danger, crime	[__]

109.   How many visits to the formal health care system were made before TB was diagnosed?

For each provider, what kind of treatment was given?

Provider (See question 30 and record names in the same order)	Type of treatment
110.	111.
112.	113.
114.	116.

116.   What kind of treatment do you think **[insert name]** should have received?

117.   If TB treatment was provided, did **[insert name]** take the TB treatment every day?

1=yes, 2=no, 9=don't know		[__]

118. Probe: Why not? (verbatim)

119. feared side effects	1=yes, 0=no 7=n/a	[__]
120. couldn't afford	1=yes, 0=no 7=n/a	[__]
121. didn't want to go to clinic for DOT	1=yes, 0=no 7=n/a	[__]

122. What do you think [insert name] hoped would happen after taking this treatment?

COMMUNITY CARE AND SUPPORT

123. Did the [insert name] receive any kind of extra support from the TB program or the community to help get better?	1=yes, 0=no , 9=I don't know(skip to #)	
What treatment support did the patient receive?		
124. Food support?	1=yes, 0=no 7=n/a	[__]
125. Financial support?	1=yes, 0=no 7=n/a	[__]
126. Home-visits by health care provider?	1=yes, 0=no 7=n/a	[__]
127. Counseling?	1=yes, 0=no 7=n/a	[__]
128. Treatment reminders (SMS)?	1=yes, 0=no 7=n/a	[__]
129 Transport reimbursement?	1=yes, 0=no 7=n/a	[__]

Treatment supporter?	1=yes, 0=no 7=n/a	[__]
Other (specify)	1=yes, 0=no 7=n/a	[__]

AWARENESS OF TB

How can a person prevent getting infected with TB? (Do not read answers out loud) Tick all mentioned options	*Verbatim:*	
132. Opening the windows at home		[__]
133. Covering mouth and nose when coughing or sneezing		[__]
134. Avoid sharing dishes/utensils		[__]
135. Purify water		[__]
136. Washing hands		[__]
137. Closing windows		[__]
138. Abstaining from sexual contact		[__]
139. Pray regularly		[__]
140. Other (please explain):		[__]
141. Do all people who get infected with TB eventually develop TB disease?	1=yes, 2=no, 9=don't know	[__]
142. Why do some develop the disease and some do not develop the disease?	*Verbatim:*	
How can a person who is already infected with TB reduce their risk of developing TB disease? *(Do not read answers out loud)*		
143. Prayer		[__]
144. Avoid alcohol, drugs and/or smoking		[__]
145. Use a bed net		[__]
146. Eat healthy food		[__]
147. Avoid infection with HIV		[__]
148. Take antiretroviral medicines if they have HIV		[__]
149. Take medicines that prevent development of TB disease (IPT)		[__]
150. Avoid people who are sick		[__]
151. Other (specify)		[__]
What are the signs and symptoms of TB? *(Do not read answers out loud)*		
152. Rash		[__]
153. Cough that lasts longer than 2 weeks		[__]
154. Coughing up blood		[__]
155. Severe headache		[__]
156. Nausea		[__]
157. Weight loss		[__]
158. Fever without clear cause that lasts longer than 2 weeks		[__]
159. Chest pain		[__]
160. Shortness of breath		[__]
161. Night sweats that lasts longer than 2 weeks		[__]
162. Ongoing fatigue		[__]
163. Other (specify)		[__]

164. In [insert name]'s case survival was not possible, but in other cases, can TB be cured?	1=yes, 2=no, 9=don't know	[__]
165. What is needed to cure someone of TB?	*Verbatim*	
166. How long does it usually take to cure TB?	1= Between 1-5 months 2=Between 6-12 months 3=Between 13-24 months 9= Do not know 7=TB has no cure	[__]
168. Do you think you personally could get TB?	1. Yes 2. No 9. Do not know 4. Has (had) TB now	[__]

Where are the places you might go for care if you had symptoms of TB? *(Please tick all mentioned, but do not read)*	
169. Go to a public health clinic or hospital	[__]
170. Go to a pharmacy	[__]
171. Go to a traditional healer	[__]
172. Go to a chemical seller	[__]
173. Go to a private clinic	[__]
174. Go to a pastor or religious leader	[__]
175. Other	[__]
If you would not go to the public health clinic, what is the reason? *(Please Tick all that apply)*	
176. Not sure where to go	[__]
177. Cost	[__]
178. Difficulties with transportation/distance to clinic	[__]
179. Do not trust medical workers (confidentiality)	[__]
180. Do not like attitude of medical workers	[__]
181. Cannot leave work (overlapping work hours with medical facility working hours)	[__]
182. Do not want to find out that something is really wrong	[__]
183. Other (please explain)	[__]

Now we would like you to think about the community where you live. I will read aloud some statements, and ask you to judge how much you agree or disagree.

	Strongly agree	Agree	Disagree	Strongly disagree
184. Some people may not want to eat or drink with friends who have TB				
185. Some people feel uncomfortable about being near a person who has had TB				
186. Some community members will behave differently towards that person for the rest of his / her life				
187. Some people do not want those with TB playing with their children				

188. Some people keep their distance from people with TB				
189. Some people think that those with TB are disgusting				
190. Some people do not want to talk to others with TB				
191. Some people are afraid of those with TB				
192. Some people try not to touch others with TB				

193. In your opinion, what should be done to solve the TB problem in this community?

194. (if not specified)Who should be doing that?

195. What role can the community play?

Thank the participant and tell her/him that their contribution has been very valuable. Emphasize that this information will be kept confidential and will only used to improve the care for future patients.

Make sure to give extra time to go over some of the misconceptions that were discussed. A TB factsheet could be handed out, but where literacy is an issue, talking with the people further would be more effective.

Remember that the household members of a TB case who has passed away are probably in need of TB screening themselves.

Consider bringing screening tools and equipment to offer free diagnosis and treatment.