# Form-2: Demand-side – Assessment of TB patients

# Form-2.1: Baseline semi-structured interview guide for the TB patients

*[NB: Administer this tool to all the sampled smear +/- pulmonary TB patients, representation of all types/sectors/regimen of patients, representation of IP/CP patients, in case of pediatric TB then consider interviewing parents]*

Section-1: Introduction

1. Brief introduction about the project and the intention of the interview
2. Patient’s consent for the participation
3. Please note the geography of the patient such as DOT centre, PHI etc, patient belongs to normal area or vulnerable etc.
4. Brief family history to understand the social background and family history of TB, phase of treatment (IP/CP), comorbid conditions (HIV, DM, HTN, COVID19 etc.)

Section-2: Care seeking pathways

1. Please tell about yourself and your experiences during the course of the disease?

*Probe:* How it was detected, what were the symptoms you developed in this current episode of TB that made you first seek care, when did it first start? what you did, any other co-morbidity

1. Please tell us your experience on how you have diagnosed with TB?

*Probe:* What happened first and where you went, then where? What motivated you to get tested for TB, type of TB, place of diagnosis, type of tests you have undergone, pre-treatment evaluation at district centre (for DR-TB), any delays in diagnosis, no of visit conducted to health facility before being diagnosed at TB, If not initiated treatment; Why? What were the challenges? Availability /Accessibility /Cultural /Religious/ Traditional Healers/Psychological/ Migration/ transfer between facilities-providers reasons etc.

1. Can you please briefly tell us about your journey so far in the TB treatment?

*Probe:* how the treatment was continued (public-private transition), any support from health workers, what are your major challenges, issues/ Timely response in solving those, first contact for your TB treatment, Any delays in initiation of treatment, Issues related to accessibility of treatment, Issues related to availability of drugs or health care professionals, experiences in DOTS center, difference in quality of care in public/private, ask patient’s perspective about door-step delivery of drug, and if received any challenges

1. Can you tell us about the different health care workers you came into contact with during the course of treatment?

*Probe:* Whom you contacted first, how was the experience, who comes to you or how you approach them

Section-3: TB medications

1. Can you tell us about the medication you are taking/have taken during the course of your treatment?

Probe: Duration of treatment, Name of medicines (if knowing), Number of tablet, Frequency of tablets, Place from where you were receiving/ purchasing medicines, explore for those who were treated for TB more than two times

1. What are your experiences on TB drugs and its acceptance in the view of adherence?

Probe: Taste, any side-effects you experiencing, any psychological disturbance, Role of health care providers in minimizing the side effects, their availability and responses

1. Have you taken any medications apart from DOTS treatment? If yes, can you describe about that?

*Probe:* Self-medication, Faith healing/traditional healing methods, Place, Preference to use NTEP medicines or FDC for the first line patients, motivating factors to opt for other modes of medications, any benefits/aggravation experienced because of that, Is it still continued or not (reasons for both)

Section-4: Motivation and Counselling

1. Can you tell us about the advice and counselling related to TB that you have received?

Probe: Prior to start of the treatment/during the treatment course? (For each provider who diagnosed and/or treated TB and MDR-TB), What kind of information was given to you/your family by the provider/ compounder/ field officer on the following? a) importance of adherence b) adverse drug reactions c) dietary advice d) precautions to avoid transmission – cough etiquette, Did the provider/ compounder/ field officer give you any specific advice regarding (if any) children under 6 in your household? If Yes, then what was it? Did the provider advise a chest x-ray as a follow-up test? If Yes, then how often was it advised? Did the provider advise a sputum microscopy as a follow-up test? If Yes, then how often was it advised?

Section-5: Exclusively for the drop-out cases/refused to treatment

1. Can you discuss about your concern for drop out/ refusal for the treatment?

Probe: When did you drop out (IP/CP), Probable date (NIKSHAY or treatment card), Reasons for drop out, What motivated you to drop out, Cost of treatment, Distance, Aggravation of disease, Adverse drug reactions, Co-morbidity, Behaviour of health care professionals, Adopting any other mode of treatment, Stigma/discrimination, Availability/ accessibility/ cultural/ religious/ traditional healers/ psychological/ migration/ transfers between facilities-providers reason

Note: Please fill the below mentioned-table with the help of patient inputs

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Care cascade   |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | |  | mm/yy | Duration (in mm/yy) | Whom | Reasons | Challenges faced | | Onset of symptoms |  |  |  |  |  | | First consultation with healthcare provider (HCP) |  |  |  |  |  | | Diagnosis |  |  |  |  |  | | Treatment initiation |  |  |  |  |  | | Treatment completion |  |  |  |  |  |   Codes  Whom: 0. Frontline worker (ASHA/FHW/MPHW), 1. Informal providers (Quacks/ Faith healers), 2. Private practitioner, 3. Private chemist, 4. PHI (Peripheral Health Institute), 5. DMC (Designated Microscopy Centre), 6. DOT Centre, 7. Govt. chemist  Reason: 0. Accessible, 1. Advised by relatives/neighbours, 2. Cost, 3. Lack of time, 4. Referred by HCP |

*Anything else you want to tell or discuss? Any other suggestions?*

# Form-2.2: Baseline structured tool for the demand-side assessment of TB patients

*[NB: Administer this tool to all the sampled smear +/- pulmonary TB patients, in case of paediatric TB then consider interviewing parents]*

|  |  |
| --- | --- |
| UID | CONFIDENTIAL  (For research purpose only) |

|  |  |  |
| --- | --- | --- |
| **1.TB registration number**  **(as per NIKSHAY)** | **2.Tuberculosis unit number/name** | **3.Diagnosing Facility -** |
| **4.Patient Status** | **5.Phase of Care Cascade** | **6.Phase of Treatment** |
| **7. Basis of Diagnosis** | **8. On Treatment** | **9. If retreatment Category:** |
| **10. If retreatment: last dose of previous treatment (mm/yyyy)** | **11. Number of Events of TB**  **1st/2nd/3rd/4th/ > 4th** | **12. Site of TB**  (please mention site if Extrapulmonary) |
| **13 Respondents** | Date/month of first consultation (dd/mm/yyyy) | Date/month of diagnosis  (dd/mm/yyyy) |
| **Code for Q3:** 0. PHI, 1. PVTHF, 2. PVTLAB  **Code for Q4:** 0. Diagnosed but not on treatment, 1. Diagnosed and on treatment, 2. Diagnosed and outcome assigned.  **Code for Q5:** 0. Diagnosed to treatment initiation 1. Ongoing Treatment, 2. Treatment completed.  **Code for Q6:** 0.Intensive Phase (IP), 1. Continuation Phase (CP) **Code for Q7:** 0. Chest X-Ray, 1. Sputum Test, 2. CBNAAT, 3. TruNat, 4. Others; specify.  **Code for Q8:** 0. New 1. Retreatment, 2. PMDT-Mono H poly, 3. PMDT-Shorter Regimen, 4. PMDT- Oral Regimen conventional, 5. PMDT-MDR-FQ  **Code for Q9:** 0. Recurrent 1. Treatment after failure 2. Treatment after lost to follow up 3. Others  **Code for Q12:** 0 Pulmonary 1. Extrapulmonary  **Code for Q13:** 0. Self – Patient 1. Relatives 2. Friends 3. Health worker | | |

|  |  |  |  |
| --- | --- | --- | --- |
| Section 1.1: Socio-demographic details | | | |
| Date of interview (dd/mm/yyyy) | | | Name of interviewer |
| Name of patient | | | Mobile |
| Address (with village block) | | | Location (GPS) |
| Age | Weight | | Gender   1. Male 2. Female |
| Religion | | | Caste |
| Education | | | Occupation |
| Marital status | | | BPL Card |
| Total family members:……..   |  |  |  |  |  | | --- | --- | --- | --- | --- | |  | Children (0-5 years) | On IPT  0. No 1. Yes | Adolescent (6-19 years) | Adult  (>19 years) | | Male |  |  |  |  | | Female |  |  |  |  |   Remarks if any: | | | Total family income per year |
| Codes  Religion (0. Hindu, 1. Muslim, 2. Others, 3. Prefer not to disclose)  Education (0. Illiterate, 1. Never been to school but Able to read and write, 2. Primary, 3. Secondary, 4. Higher Secondary, 5. Graduate and above)  Marital status (0. Single, 1. Married, 2. Divorced/separated/widow) | | | Codes  Gender (0. Male, 1. Female)  Caste (0. SC/ST, 1. OBC, 2. General, 3. Prefer not to disclose)  Occupation (0. Farmer/Cultivator, 1. Daily Labourer, 2. Self-employed, 3. Employed (Govt./Private), 4. Student, 5. Housewife, 6. Other-specify)  BPL Card (0. No, 1. Yes) |
| Section-1.2 History of Addiction (Smoking) & Co- morbidities 0. No 1. Yes | | | |
| Addiction history (Mark 0. No 1. Yes)   |  |  |  |  | | --- | --- | --- | --- | | Habits | Past | Present | Frequency | | 1. Smoking |  |  |  | | 1. Chewing tobacco |  |  |  | | 1. Alcohol |  |  |  | | 1. Other (specify) |  |  |  |   Pre-treatment Evaluation (psychological) (DR-TB)  0. No  1. Yes | | Co-morbidities   |  |  |  |  | | --- | --- | --- | --- | | Condition | Duration  (mm/yyyy) | On Medication | If Yes  From where? | | 1. Hypertension |  |  |  | | 1. Diabetes |  |  |  | | 1. HIV |  |  |  | | 1. COVID-19 |  |  |  | | 1. Mental Health Disorder (Any) |  |  |  | | |
| Codes  Past/Present: 0. No, 1. Yes  Frequency: Number of cigarettes or bidi or packet of tobacco or glass of alcohol/day for how many years  E.g., xx nos./day (xx years) | | Codes  On medication: 0. No, 1. Yes  Place: 0. Informal provider, 1. Govt. provider, 2. Private provider  For HIV-TB patient, CPT received.  0. No  1. Yes | |

|  |  |  |  |
| --- | --- | --- | --- |
| Section 2. Drug Acceptance and reactions details | | | Remarks |
| Date of Initiation of Treatment: (dd/mm/yyyy)  Date of Treatment Completion or Lost to follow up: (dd/mm/yyyy) | | |  |
| 1. | Is there any change in number of tablets during the treatment? | 1. No 2. Yes |  |
| 2. | Is there any change in regimen during your treatment? | 1. No 2. Yes |  |
| 3. | Have you experienced any side effect of the drugs (adverse drug reactions)? | 1. No 2. Yes, Mild. 3. Yes, Moderate.   Yes, Severe |  |
| 4. | If yes, when (at which month of the treatment) | 1. Mm/yyyy |  |
| 5 | When you experienced ADR | 0. IP  1. CP  2. Both |  |
| 6. | What side effects have you experienced?   |  |  |  |  | | --- | --- | --- | --- | | Side effect experienced | When?  (in which month) | Duration/Frequency | Actions Taken (open-ended) | |  |  |  |  | |  |  |  |  | |  |  |  |  | |  |  |  |  | |  |  |  |  | | | Side effect-   1. Nausea/Vomiting/Gastric discomfort 2. Itching/ Rashes 3. Tingling/burning/numbness in the hands and feet. 4. Joint pains 5. Impaired vision 6. Psychological disturbance 7. Other (Specify) |
| 7. | Have you have ever missed any dose during the treatment | 1. No 2. Yes |  |
| 8. | If yes, how many times |  |  |
| 9. | What was your immediate retrieval actions? | 0. Self-retrieval  1. Contacted to the HCP.  2. Re-started the drugs with Govt PHI consultation.  3. Re-started the drugs with PVHF consultation.  4. Stopped the medication.  5. Others (Specify) |  |
| 9. | Have you stopped taking TB drugs because of the adverse effects? | 1. No 2. Didn’t stop but modify the dosage. 3. Yes, temporarily. 4. Yes, permanently |  |
| 10. | Are you aware, if you do not comply with the treatment, what may happen to you? | 1. Restart the treatment. 2. I may get drug-resistant Tuberculosis 3. Others in the family may get 4. Nothing will happen. 5. Other (Specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_   5. Don’t Know |  |

Start after Section - 1

DRAW THE PATHWAY

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Intervals  Events  Detection of symptoms  Seeking healthcare  First consultation with Formal HCP  Diagnosis  Treatment initiation  Treatment completion | Onset of Symptoms to first informal consultation (if any) | First informal Consultation to first formal consultation | Formal Consultation to Diagnosis | Diagnosis to Treatment Initiation | During treatment |
| Duration (in days) |  |  |  |  |  |
| Information of facility | Name of the doctor who diagnosed | Name of the health facility who suspected TB | Name of the health facility diagnosed | Name of the health facility / DOT center | Name of the health facility / DOT center |
| Challenges |  |  |  |  |  |