Patient Support System

Stakeholder Toolkit









A comprehensive approach to link private-sector drug-resistant tuberculosis patients to existing programmatic management of drug-resistant tuberculosis services in the public sector and patient support system creation for enhanced treatment adherence

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Abbreviations

BPL below poverty line

CB-NAAT cartridge-based nucleic acid amplification test

DOTS directly observed therapy, short course

DR-TB drug-resistant Tuberculosis

DST drug-susceptibility testing

DTC District TB Centre
DTO District TB Officer

FL-LPA first-line line probe assay

FO Field Officer

HR human resources

ICT information and communication technology

IGNDPS Indira Gandhi National Disability Pension Scheme
IGNOAPS Indira Gandhi National Old Age Pension Scheme
IGNWPS Indira Gandhi National Widow Pension Scheme
IPAQT Initiative for Promoting Affordable Quality TB Tests

JEET Joint Effort for Elimination of Tuberculosis

M&E monitoring and evaluation

MBPY Madhu Babu Pension Yojana

MDR-TB multidrug-resistant tuberculosis

MGIT™ mycobacterial growth indicator tube

MIS management information system

NFBS National Family Benefit Scheme

NGO nongovernmental organization

NP Nodal Person

OPD out patient department

PHI public health institute

PMDT programmatic management of drug-resistant TB

PMJDY Pradhan Mantri Jan-Dhan Yojana

PMJJBY Pradhan Mantri Jeevan Jyoti Bima Yojana

PMKVY Pradhan Mantri Kaushal Vikas Yojana
PMSBY Pradhan Mantri Suraksha Bima Yojana

PPIA Private Provider Interface Agency

PPM public-private mix

PPSA Patient Provider Support Agency

PTE pretreatment evaluation

RNTCP Revised National TB Control Programme

SDPS Senior DOTS [directly observed treatment, short course] Plus

Supervisor

STCI Standards for TB Care in India

STS Senior Treatment Supervisor

TB Tuberculosis

TC Treatment Coordinator

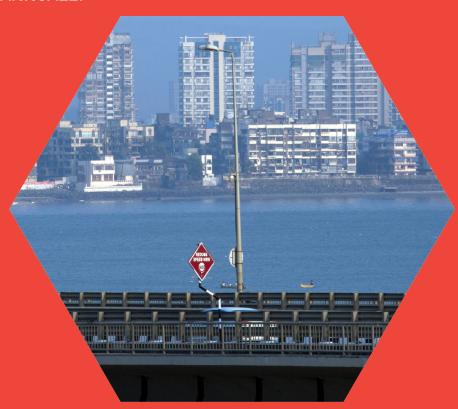
UDST universal drug-susceptibility testing

WHO World Health Organization

2.8 million cases annually



TUBERCULOSIS IN INDIA



147,000 CASES OF MULTIDRUG-RESISTANT TB (MDR-TB)

2.84% DRUG RESISTANCE AMONG NEW CASES

11.62% DRUG RESISTANCE IN THE PREVIOUSLY TREATED CASES

CHAPTER 1 Overview

Introduction

ndia contributes one-quarter of the global burden of tuberculosis (TB), with nearly 2.8 million cases in the country annually. There is evidence to suggest that over half of these cases are detected and treated in the private health care sector in India. Most patients who seek treatment in the private sector are not notified to the national TB surveillance system that is Nikshay; hence, these patients remain unaccounted for in official figures. Estimates by the World Health Organization (WHO) suggest that India accounts for nearly 147,000 cases of multidrug-resistant tuberculosis (MDR-TB). Several prevalence surveys have shown that around 3 to 5 percent of new cases and 11 to 18 percent of retreatment cases have multidrug resistance. The results of the National Anti-Tuberculosis Drug Resistance Survey in India from 2014 to 2016 show that the drug-resistance pattern ranges from 2.84 percent among new cases to 11.62 percent in previously treated cases, which on an average is 6.19 percent of all cases. Several studies suggest that a majority of these patients seek care in the private sector.

Quite often, TB treatment in the private sector is not standardized and is unmonitored, erratic, and costly. O Sometimes, patients do not complete their treatment due to high out-of-pocket expenditure. This is especially true among MDR-TB patients as their treatment is long term and more expensive.

PATH piloted the Private Provider Interface Agency (PPIA) model in Mumbai with the support of the Bill & Melinda Gates Foundation under the guidance of the Revised National TB Control Programme (RNTCP). Its objective was to effectively engage private-sector providers to standardize the diagnosis and treatment of all private-sector TB patients and to provide these services for free. PPIA also highlighted the importance of, and the need for, a patient-centric model of care for drug-resistant tuberculosis (DR-TB) patients in the private sector. Therefore, in 2016, PATH implemented the patient-centric DR-TB model of care in the private sector under the US Agency for International Development's Challenge TB program. The project envisioned linking patients who had been diagnosed with DR-TB in the private sector to public-sector treatment centers for treatment initiation, with the objectives to reduce out-of-pocket expenditure and ensure treatment completion for the patient.

This Patient Support System toolkit is based on PATH's model of care that links private-sector DR-TB patients to the public sector. This toolkit was prepared to support the replicability of the model in similar settings. This toolkit includes learnings from the PATH-US Agency for International Development Challenge TB project. It has several easy-to-follow, evidence-based tools to link DR-TB patients to treatment and extended social support in the public

sector. The toolkit is set on the platform of Patient Provider Support Agency model. Some of the processes to build a PPSA is mentioned in the subsequent pages for a preliminary understanding of the platform.

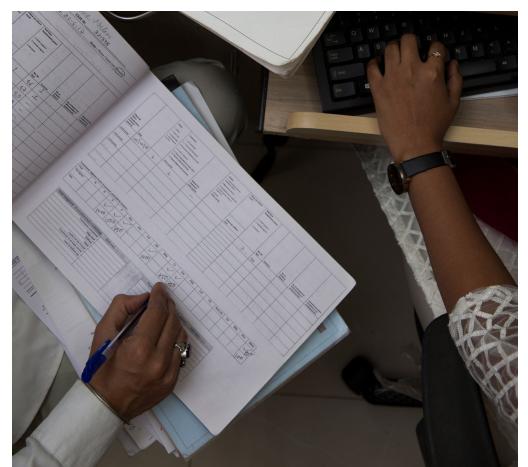
A detailed version of the PPSA toolkit is available on : https://path.org/resources/patient-provider-support-agency-india-toolkit/

"Patient support system" refers to a holistic model of care to ensure that TB patients adhere to and complete treatment. It includes multiple modalities of interventions, a few of which have been listed in this toolkit. Please note that this toolkit does not provide an exhaustive list of patient support system interventions, but only the ones tried and tested through the Challenge TB Project.

Purpose of this toolkit

The Revised National TB Control Programme (RNTCP) envisages free TB care for all patients, including private-sector patients.13 As a result of the success of the PPIA pilot in three different cities, RNTCP extended the PPIA model in the ambitious Joint Effort to Eliminate Tuberculosis (JEET) initiative as a part of the Patient Provider Support Agency (PPSA).

The PSS toolkit paves the way for a uniform and standardized mechanism to layer the DR-TB public private linkages and create a patient centric approach for treatment adherence and completion for the entire country regardless of geography, political context, and other variables.



○ PATH/Ruhani Kaur

Objectives of this toolkit

- Have a standard document to guide all stakeholders in the creation of a patient-centric model of care for DR-TB patients in the private sector.
- Guide stakeholders in establishing a linkage mechanism between the private sector and public sector for DR-TB care services.
- Provide a step-by-step narrative to aid stakeholders in the process.
- Create a baseline patient support system.

Potential users of this toolkit

- All stakeholders who implement a PPSA project and engage private providers for Standards for TB Care in India-guided TB management.
- Nongovernmental organizations (NGOs) that work in TB control activities that diagnose TB patients in the private sector and that involve private providers.
- RNTCP managers and stakeholders can get guidance from this toolkit on effective monitoring of the program.
- Private-sector providers can use this toolkit to help them have a clear vision of the patient pathway and ways in which services will be provided by the public sector.

How to use this toolkit

- The toolkit is divided into sections for ease of use.
- Information regarding manpower and skills can be found in the Human Resources section under the chapter on Resource Requirements.
- Brief information on the platform to build a patient support system is mentioned in the chapter on Prerequisites for using the PSS Toolkit. The detailed PPSA toolkit can be found in the link mentioned in the Introduction section of chapter Overview.
- The chapter on Treatment Linkages elaborates the mechanism of linking the private sector DR-TB patients to public sector, it also mentions a comprehensive model for co morbidity linkages.
- Information regarding different patient support systems created and piloted in the Challenge TB project to ensure adequate treatment adherence for treatment completion is mention in chapter Treatment Adherence.
- Chapter on Monitoring and Evaluation provides a brief on the mechanism of data collection and the indicators that can be used to monitor progress of the toolkit implementation.
- Different scenarios and bottlenecks are elaborated, wherever necessary.

Prerequisites to using this toolkit

- Private-provider mapping and engagement completed
- Established network of referrals and laboratory network available.
- Established mechanism for patient flow and specimen flow available
- Specimen testing with cartridge-based nucleic acid amplification test (CB-NAAT) or first-line line probe assay (FL-LPA) to identify drug resistance should be available to diagnosed Rifampicin resistant.

Scenarios where this toolkit can be used

- For TB patients in the private sector with known drug-resistance pattern [pretesting with FL-LPA/MGIT™ (mycobacterial growth indicator tube)/culture] available.
- For TB patients in the private sector with partially known drug-resistance pattern (pretesting with CB-NAAT) at least Rifampicin resistance status available.

Processes involved in toolkit implementation:

The processes required to implement the toolkit are enumerated below. The details on each of these processes and the subprocesses have been mentioned in chapters 4 and 5.

TREATMENT LINKAGE

- Roles of different stakeholders.
- Linkage process flow.
- Identification of bottlenecks in patient referral from the private sector to the public sector and their solutions.
- Identification of bottlenecks in linkage to the public sector and their solutions.

TREATMENT ADHERENCE

- Factors that affect adherence and ways to address them.
- Tools to enhance adherence:
 - Home visits.
 - Self-monitoring tool.
 - Peer group support meetings.
 - Socioeconomic support.
 - Soft-touch adherence support.
- Management of patient migration from the private sector to the public sector for linkage:
 - Handling migration
 - Inter-stakeholder coordination
 - Information exchange
- Nutritional support:
 - Supporting the patients in getting linked with existing nutritional supplementation schemes.
- Socioeconomic support:
 - Profiling of patients
 - Support to file application for Socio-economic schemes
 - Collaboration with non-governmental sources
 - Community engagement
 - Multi-sectoral co-ordination

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CHAPTER 2 Resource Requirements

The resources required to implement a patient support system can be divided broadly into three pillars: the private sector, PPSA, and RNTCP. The indicative list of stakeholders under each pillar that are required to replicate the PPSA model to replicate the PSS toolkit is shown in Figure 1 below. This structure, which is further detailed in the toolkit, is not rigid and can be modified to fit the local context where the model is implemented.

	Patient Provider Support Agency (PPSA)	Revised National TB Control Programme (RNTCP)
Private providers Private patients Private laboratories	Field Officer (FO) Nodal Person (NP) Treatment Coordinator (TC) City Coordinator (CC) Management Information System (MIS) Officer	Drug-Resistant Tuberculosis Center Public Health Institute (PHI) Senior DOTS Plus Supervisor (SDPS) Medical Officer and Chest Physician District TB Officer (DTO) TB Health Visitor (TB HV) RNTCP Counselor Public-Private Mix (PPM) Coordinator Data Entry Operator

FIGURE 1.
STAKEHOLDERS
REQUIRED TO
IMPLEMENT
A PATIENT
SUPPORT
SYSTEM

Human resources

It is recommended that, wherever possible, the available human resources (HR) in RNTCP should be engaged to facilitate the linkage of private-sector TB patients to the public-sector program. As most of the private providers who detect TB and treat TB patients are likely to be situated at the block level and above, it is recommended that the Senior Treatment Supervisor (STS) of RNTCP undertake this. In places where the STS has a high caseload, TB Health Visitors can undertake this task. States can leverage HR norms of RNTCP, which provide for the appointment of additional TB Health Visitors on a caseload basis. Since this task requires the concerned HR to interact with private providers on a regular basis and to influence private providers to refer patients to the public sector, it is suggested that the terms of reference of these HR reflect the skill sets required for these activities. Existing HR can be trained and appraised for their performances to align them with the required skill sets. Another option is that states can consider employing an NGO under RNTCP private public partnership schemes to carry out this task. If an NGO is hired, the roles and responsibilities below can be shared with them:

■ Field Officer (FO): FOs are responsible for continuous engagement with private-sector providers. FOs meet private providers on a regular basis to update them on the current practices/Standards for TB Care in India, share the next steps after DR-TB diagnosis, and serve as a constant contact with the Nodal Persons (NPs) of the private establishments, among others. They facilitate behavior change among the private providers. This role can be assigned to STS/Public-Private Mix (PPM) Coordinators if RNTCP undertakes the linkage of private-sector TB patients to the public sector without NGO-private public partnership schemes.

Skill set: The FO should have the capacity to seamlessly talk to private providers about the program. He/she should possess marketing skills to sell a product or a service.

Nodal Person (NP): The NP is responsible for manning the hospital, which serves as the collection point for testing specimen. The NP is one of the employees of the private hospital, usually the receptionist, compounder, or staff nurse. The NP is designated by the FO to be in constant touch with the patient, to refer and counsel the patient, and to document the patient's progress and outcome. The FOs and Treatment Coordinators (TCs) will regularly talk to the NP to get updates on patient tracking.

Skill set: An NP should possess skills to engage with patients.

■ Treatment Coordinator (TC): The TC is responsible for serving as a link between the private-sector patient and the public sector. Primarily, TCs will coordinate with the NPs at the private health centers and the diagnosed DR-TB patients before linking the patient to public-sector programmatic management of drug-resistant TB (PMDT). The TC is responsible for regularly following up with the NP to receive updates on newly detected DR-TB patients, linking the patients to pretreatment evaluation (PTE) labs, tracking the dropouts for PTE, counseling DR-TB patients to undergo further tests, consulting the private provider to generate consensus for public-sector linkage, documenting PTE, coordinating with the Senior DOTS [directly observed therapy, short course] Plus Supervisor (SDPS) for referrals to the public-sector DR-TB centers for treatment initiation, and hand-holding the patient for linkage where necessary. This role can be assigned to the TB Health Visitors/STS if RNTCP undertakes the linkage.

Skill sets: The TC should be fluent in the local language, have vast knowledge about TB and related subjects have documentation skills, and be comfortable to mix with people.

Management Information System (MIS) Officer: The MIS Officer is responsible for overseeing the data management process and ensuring quality.

Skill sets: An MIS Officer should have knowledge about data management, data analysis software, Microsoft Office, and other software packages.

Although this toolkit uses specific designations for the human resource roles for ease of reference, these designations may be changed to best suit the roles in the local context of implementation.

Logistical resources

DR-TB patient linkage with PMDT demands certain logistics. Therefore, a detailed plan of implementation is required to ensure that logistical resources are in place for uninterrupted flow of processes. A few logistical resources are discussed below:

- Molecular laboratories: As discussed in Chapter 1, the objective of this toolkit is to diagnose the DR-TB patient in the private sector and link them to PMDT services in the public sector. Therefore, molecular laboratories are needed to assess the patients' drug-susceptibility testing (DST) status. Regardless of the method used for diagnosis, all confirmed TB patients should be offered universal drug-susceptibility testing (UDST) with the molecular laboratory for assessment of resistance pattern. Hence, it is desirable that every private provider is assigned one laboratory where all the tests-including UDST, PTE, and other collateral screening tests, such as HIV and blood sugar (one-stop shop)—are available or at least the facility to collect and transport the sample to the lab is available. This significantly reduces the time required for treatment initiation, as well the chances of patient attrition. It is preferred that, wherever possible, a public-sector laboratory is engaged. Alternatively, a private-sector laboratory paid either by priavte donors/ CSRs/ organizations/ philanthropists or the public sector, or a private-sector laboratory where patients pay a subsidized amount, can be engaged. A list of the network of these designated laboratories should be periodically updated and given to the private providers and the relevant stakeholders.
- Falcon tubes: Falcon tubes are required to collect sputum specimen for CB-NAAT and UDST. Since morning samples are collected from the patient's home, it is desirable to keep the stock of tubes with the private provider, who can give a tube to the patient and give specific instructions for collecting sputum. Existing PMDT stocking norms can be used to ensure seamless supply of stock.
- at which the CB-NAAT is adopted in the pathway for TB diagnosis. If all presumptive TB patients are evaluated using CB-NAAT for diagnosis, a higher quantity of cartridges are required as compared to situations in which cartridges are used to detect rifampicin resistance in diagnosed TB patients. Thorough planning and forecasting are important to determine the average number of cartridges needed. If the laboratory is in the public sector, the test may be free for the patient. These cartridges may be supplied by the government, along with some incentives to the private network laboratories; in this case, the test will be free for the patient. Alternatively, the government may provide cartridges without incentives for contingencies; in this case, the laboratory may charge the patient nominally. Lastly, the lab may also use subsidized prices for the patients to take up large volumes to make the cost similar to that under the Initiative for Promoting Affordable Quality TB Tests (IPAQT) mechanism.

- Registers and forms: Various referral forms—such as the CB-NAAT/UDST referral form, PTE referral forms, and PMDT center referral form, among others—are required. Additionally, registers are to be provided to each private provider and laboratory to collect information on the patients. These registers and referral forms should be in line with the RNTCP referral forms, wherever possible. If there is a need to capture additional information, RNTCP may be requested to add additional columns/cells.
- Reporting forms: Periodic reporting forms should be provided to the person responsible for the linkage process. It is desirable to have the same reporting form as the RNTCP reporting form. Any additional columns/cells/indicators that are required specifically for the private sector may be shared with RNTCP so that they can be included in the national forms for standardization.
- Forecasting logistics: The DR-TB centers in the toolkit implementation area need to account for the additional patient load from the private sector and ensure seamless management of logistics for patient testing and treatment. The patient load can be estimated using different variables as standalone or in totality; for example, notifications from the private sector, spread of the private sector in the program geography, a comparison of total notifications against expected total notifications, etc.
- Additional DR-TB regimen drugs: It is expected that when private-sector DR-TB patients are linked to PMDT, the number of patients to be treated will increase twofold. Therefore, robust planning to procure drugs for DR-TB is required. The patient flow from the private sector should be assessed periodically to forecast the drug requirement.
- Preparedness of information and communication technology (ICT) platforms: ICT platforms, such as call centers for PPSA and Nikshay, need to be refined to accommodate information on the linking processes. Details of this information are discussed in subsequent section of Monitoring and Evaluation..
- Miscellaneous requirements: Miscellaneous requirements include flip charts for regular pitching to private providers; patient charters to inform patients of their roles and responsibilities; equipment for electronic data entry, such as smartphones/tablets/computers; information, education, and communication materials for patients and the community; and transportation for the HR who are responsible for linkages.

Financial requirements

The processes involved in linking private-sector DR-TB patients to PMDT has some recurrent costs; these include:

- Logistics-related expenses.
- Reimbursements for PTE.
- ICT maintenance cost.
- HR cost.

The toolkit implementation plan needs to consider these recurrent expenditures while preparing the annual program implementation plan. It also should adequately budget for these expenditures to ensure services are uninterrupted.





CHAPTER 3

Prerequisites to using the *Patient Support*System toolkit

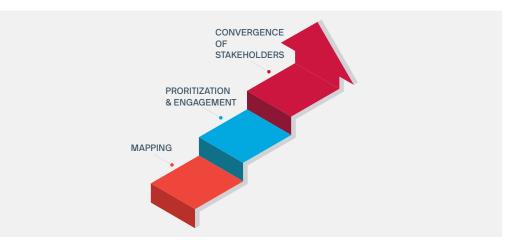
This toolkit aims to facilitate the linkage of DR-TB patients who are diagnosed in the private sector to existing public-sector PMDT services. The objectives of the model of care stated in this toolkit are to reduce the out-of-pocket expenditure of private-sector patients diagnosed with DR-TB, counsel them on treatment adherence, support them with social welfare schemes, and thus ensure they complete treatment.

There are some prerequisites to using this toolkit. The most important of them is the creation of a Patient Provider Support Agency. A toolkit for creating a PPSA can be found in https://path.org/resources/patient-provider-support-agency-india-toolkit/. While the list of prerequisites is dynamic and will differ according to the scenario of implementation, some important ones are noted below:

- Private-provider mapping and engagement: Mapping is done by trained staff (designated NGO staff or program staff). They map the entire universe of service providers, which includes all practicing doctors (all specialties), hospitals, laboratories, and chemists in the public health institute (PHI) area. A PHI is the last level of institutional structure in the RNTCP structural organogram. The PHI area map can be used to define the services that are provided to the private-sector patients who reside in the PHI area. The information collected for mapping includes geographic coordinates, addresses, Out Patient Department (OPD) load, OPD timings, and load of coughing patients. The data are validated by an FO.
- Prioritization and engagement: Once mapping is complete, the private providers (doctors and hospitals) and laboratories are prioritized based on multiple variables, such as monthly OPD load, number of cough patients seen by the doctor, prescriptions at the nearby chemists, and knowledge of TB treatment services by the doctor. This leads to a very specific list of providers who cater to potential TB cases. Thereafter, a service contract is executed between the PPSA and all the providers who are willing to offer their patients the services provided as a result of toolkit implementation.

Convergence of stakeholders: This refers to the pathway created for communication, support, and monitoring and evaluation (M&E) between the various stakeholders involved in the implementation model. The staff responsible for linkage activities under the PPSA (refer to Human Resources section in Chapter 2) are assigned areas/wards. The staff are also assigned specific tasks to ensure that all the services are provided seamlessly to all private-sector DR-TB patients. The staff should coordinate with the local RNTCP stakeholders, as well as the private-sector providers, to ensure seamless services for the patients. Essentially, the linkage staff form a crucial point of convergence between all stakeholders involved.

FIGURE 2. PREPARATORY
ACTIVITIES AND
PREREQUISITES FOR
CREATING A PPSA
FOR FURTHER LINKING
PRIVATE-SECTOR
DRUG-RESISTANT
TUBERCULOSIS
PATIENTS TO
PROGRAMMATIC
MANAGEMENT OF
DRUG-RESISTANT
TUBERCULOSIS.



- Established network of referrals and laboratory network: The detection of TB requires an effective interprovider referral mechanism. However, this prerequisite for linking private and public services goes beyond just the diagnosis of TB; the DR-TB patient, once diagnosed, also needs to be referred to an assigned laboratory where his/her second-line line probe assay, culture drug-susceptibility testing, and PTE can be done. Each private provider needs to be linked to a specific private laboratory where all of the above-mentioned tests and tests for other co-morbidity linkages, such as HIV and diabetes, are available or where the samples for all these tests can be collected for transportation. An alternative mechanism that could be explored is using a public-sector laboratory to further reduce costs. However, if public labs cannot be found for such an engagement, any of the private labs can be engaged, which can be paid through either private funds such as donors, CSRs, philanthropists, trusts and organizations or public-sector funds under PPSA. It is also important to have a blueprint of the network that indicates to which laboratory the provider is networked. While it is desirable to have each provider assigned a specific laboratory, the patient's convenience and opinion should be considered when referring them to a lab for these investigations. Hence, it is imperative that a network of patient referrals (doctor to doctor or doctor to laboratory), which includes the laboratory to which such referrals should be made, should already be established when implementing the guidance in this toolkit.
- Established mechanism for patient flow and specimen flow: Once the network of referrals and laboratories is established, there is a need to develop a mechanism for patient flow and specimen collection. A defined pathway of patient movement is necessary for hassle-free and smooth review of the linkage processes. As discussed in Chapter 2, it is preferred that laboratory and human resources are from the existing public-sector resources wherever possible. In case of unavailability of resources in the public sector, a parallel mechanism to adopt the private-sector laboratories, which would require the creation and contracting of a PPSA NGO for specific task management, can be explored. Patient flow mainly depends on this arrangement. The private providers and the NPs in the private health establishments who refer these patients to the public sector to avail various services need to be aware of these linkages and the persons responsible. The providers or the NPs then counsel the patient to approach the networked laboratory or the concerned linkage staff to avail these services. An indicative model of patient flow is shown in Figure 3.

Link patient to public sector for treatment Facilitates Provide one-to-one and family guidance for linkage in ARTC treatment in coordination 3. Linking to social schemes counterparts 4. Peer group meetings ADR refferals Contact tracing (verbal) Adherence supported till treatment competition 8. FU for DST modified treatment after 6 weeks Supports the DR-TB centre ensure patient compliance in private-sector engagements C/STS/TBHV Confirms patient Facilitates filling of Appendix 5 and address and counsels patient communicates the Diagnosis: Private case to SDPS/DTO about next steps sector TB patient diagnosed by either CB-NAAT or Sputum Knowing Laboratory: All smear microscopy Rifampicin investigations like All test resistance UDST/HIV/PTE/ results DR-TB Treatn UDST/DST for with or DM are available available without INH knowing RR with under one roof or or without other resistance collection point for all tests resistance pattern Counselling and PTE along with HIV and DM testing in linked laboratory Rifampicinsensitive TB patient Continue treatment with the same Private Doctor private provider

FIGURE 3.
FLOW CHART
DEPICTING THE
PATIENT PATHWAY
AND LINKAGE
PROCESS.

Abbreviations: ADR, adverse drug reaction; ART, anti-retroviral therapy; ARTC, anti-retroviral therapy centre; CB-NAAT, cartridge-based nucleic acid amplification test; DM, diabetes mellitus; DR-TB, drug-resistant tuberculosis; DST, drug-susceptibility testing; FU, follow up; INH, isoniazid; NACO, national AIDS control organization; PTE, pretreatment evaluation; RR, rifampicin reistance; STS, Senior Treatment Supervisor; TB HV, Tuberculosis Health Visitor; TB, tuberculosis; TC, Treatment Coordinator; UDST, universal drug-susceptibility testing.

Specimen testing with CB-NAAT, line probe assay, or culture for identification of drug resistance: Currently, in the public sector in India, a presumptive case of TB is diagnosed using a sputum smear for acid-fast bacillus and a chest X-ray. In the private sector, TB is diagnosed largely by using X-rays and sometimes sputum smear microscopy. The PPIA model in Mumbai offered up-front CB-NAAT examination for the diagnosis of microbiologically confirmed TB. This led to the diagnosis of DR-TB as well. FL-LPA also can be used for diagnosing drug resistance, though this is uncommon. However, regardless of the diagnostic criteria to detect TB, the resistance pattern needs to be evaluated once TB is confirmed, which is mostly done using line probe assay and culture DST. To apply this toolkit, it is imperative to have the patient's rifampicin susceptibility known (at the least). In places where TB is diagnosed using CB-NAAT, a patient who is rifampicin resistant is eligible for linkage to the public-sector DR-TB center right away. Alternatively, if TB diagnosis is done using sputum microscopy or X-ray, then CB-NAAT testing needs to be done to detect DR-TB before the patient is eligible for linkage. Hence, specimen testing using CB-NAAT, FL-LPA, or culture DST to determine the DR-TB status is a prerequisite to using this toolkit.



CHAPTER 4 Treatment linkage

RNTCP includes preset PMDT in the public sector, which ensures high-quality diagnostic and treatment services.¹ While the private sector continues to diagnose and treat DR-TB, most patients in this sector do not complete the treatment due to its high cost.¹¹ PPIA, which was implemented in Mumbai, showed that most private providers were willing to connect these patients to public PMDT services for various reasons, including reducing treatment interruption, infectiousness, cost, and mortality. However, private providers tend to refer patients to the private-sector labs for PTE because of various concerns. For example, in the public sector, PTE takes a longer time, which delays treatment initiation; certain tests are unavailable; and a high volume of patients leads to a longer waiting period. In addition, unavailability of all tests at a single point or unavailability of a few tests in the public sector leads to patient distress, as well as out-of-pocket expenditure.

THINGS TO CONSIDER FOR DELIVERING QUALITY SERVICES:

- Provide pretreatment evaluation (one-time cost) in the private laboratories (reimburse-ment model), which:
 - Provides a one-stop shop for all tests.
 - Decreases the delay in treatment initiation.
 - Minimizes patient travel and expenditure.
 - Reduces patient attrition.
- Link the patient to existing programmatic management of drug-resistant TB services, which provides the patient:
 - Quality-assured treatment.
 - Free services, thus reducing out-of-pocket expenditure.
 - Extensive network of Revised National TB Control Programme facilities, which brings services near the patient's home and thus increases convenience.
 - Availability of monitoring staff next to the patient's residence.

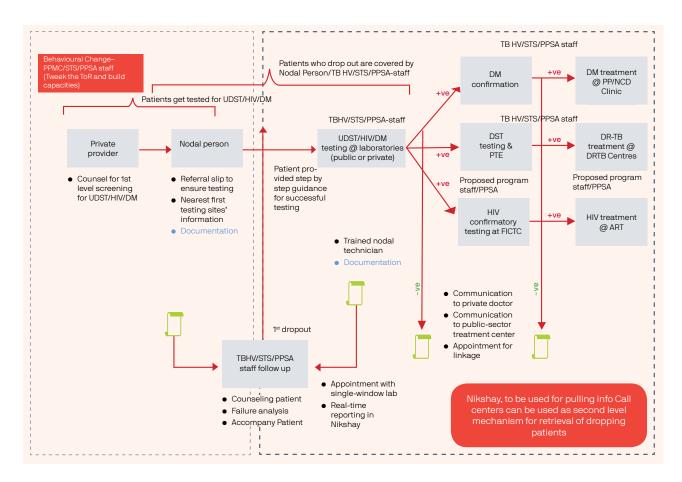


FIGURE 4. GENERIC MODEL OF LINKAGE OF PRIVATE-SECTOR TUBERCULOSIS PATIENTS FOR COLLABORATIVE AND HIGHER RATE OF TREATMENT INITIATION IN THE PUBLIC SECTOR.

Abbreviations: +ve, positive; ART, anti-retroviral therapy; DM, diabetes mellitus; DR-TB, drug-resistant tuberculosis; DST, drug-susceptibility testing; FICTC, facility based integrated counseling and testing centre; ICTC, integrated counseling and testing centre; NCD, non-communicable diseases; PP, private provider; PPMC, Private Public Mix coordinator; PPSA, Patient Provider Support Agency; PTE, pretreatment evaluation; STS, Senior Treatment Supervisor; TB HV, Tuberculosis Health Visitor; ToR, terms of reference; UDST, universal drug-susceptibility testing.

The treatment linkage model

Once a DR-TB patient is diagnosed by a private provider, the following steps are recommended for linkage to PMDT services:

- All molecular laboratories should enter the results of TB diagnosis in Nikshay, the online portal.
- The results should automatically be communicated to the provider, the linkage staff, and to the District TB Officer (DTO) for public health action and accountability.
- The TC (or the staff responsible for linkage) should prepare a list of each provider's DR-TB patients periodically based on the CBNAAT results available from the engaged laboratories..
- After sharing the results with the patient, the provider (or the NP on his/her behalf) should guide the patient on further tests and linkage processes.
- At the provider's clinic, the provider should fill a referral slip and advise the patient to attend the networked laboratory where all the necessary tests (PTE, UDST, HIV, and Diabetes Mellitus (DM)) will be conducted. The results of the relevant tests at these laboratories also should be captured in Nikshay.
- Patients who undergo prescribed tests at these networked laboratories should be tracked regularly by the linkage personnel (TC or equivalent). This can be done by validating the list from Nikshay with the available patient data at the networked laboratory.

- The TC (or the staff responsible for linkage) also should note the dropouts and track them for a second round of follow-up and guidance to motivate them to get tested before linkage.
- Alternatively, call-center staff can also look at the laboratory data for periodical tallying of DR-TB patients and call the dropout patients for counseling. The information can then be shared with the TC (or the staff responsible for linkage).
- Once the prelinkage investigations are complete, the patient should consult the private provider for prelinkage documentation (referral slip). The patient then would be referred to the public-sector DR-TB center for treatment initiation.
- Patients who are referred to the DR-TB center should be tracked regularly by TCs (or other relevant linkage staff). The TC then provides information on the disease condition and guidance on next steps to the dropout patients to link as many private sector DR-TB patients to PMDT services.
- FOs should regularly reach out to private providers (or the concerned staff for private-provider engagement) to motivate them, as well as to provide information on linking patients to the public sector.

Checklists to follow before treatment linkage:

CHECKLIST TO AID DOCTORS AND/OR NODAL PERSONS IN COUNSELING PATIENTS FOR		
PUBLIC-SECTOR INTEGRATION:		
	Explain the diagnosis and pathophysiology of the disease.	
	Explain routes of transmission.	
	Explain risk of transmission to immediate contacts.	
	Explain the need for early treatment initiation.	
	Explain the cost implications of private-sector treatment.	
	Outline the processes to be followed before initiation of treatment.	
	Inform the patient where to go for further testing, if required.	
	Explain the duration of the treatment.	
	Notify the patient of adverse drug reactions that could be anticipated.	
	Inform the patient of the need for treatment adherence.	

Private practitioners tend to get inactive. Continuous visits and coordination are necessary to keep the private practitioners active.

COUNSELING POINTS FOR THE TUBERCULOSIS HEALTH VISITOR/SENIOR TREATMENT SUPERVISOR/SENIOR DOTS [DIRECTLY OBSERVED THERAPY, SHORT COURSE] PLUS SUPERVISOR AFTER A PATIENT HAS BEEN DIAGNOSED:

- Ask the patient if he/she has planned to initiate treatment.
- If not, then explain the need for early treatment initiation.
- Explain the health risk if the patient refuses treatment.
- Explain the health risk to the immediate contacts of the patient.
- Give details on further testing.
- Give contact details of the person/call center that can be contacted during an emergency.
- Explain the duration of treatment.
- Share what to anticipate once treatment has been initiated.
- Explain about DOTS and the support system that will be provided to the patient during the course of the treatment.

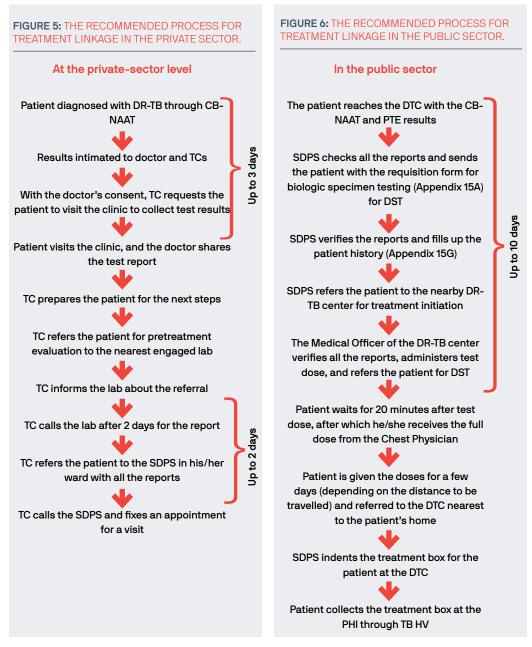
 ECKLIST FOR FIELD OFFICER DURING THEIR REGULAR VISITS TO THE PRIVATE OVIDER:		
Interact with the Nodal Person at the provider's clinic to know about the availability of the doctor.		
Always wait till the provider finds time for you. Do not hurry; hurried entry into the doctor's cabin may irritate him/her.		
Visit the doctor with a positive attitude. Greet the doctor with a smile.		
Introduce yourself, your organization, and the project. Tell them about the purpose of your visit.		
Briefly discuss the importance of linking the drug-resistant tuberculosis (DR-TB) patients to the public-sector programmatic management of drug-resistant TB services:		
o Highlight the out-of-pocket expenditure.		
o Highlight the communicability of tuberculosis when treatment initiation is delayed.		
o Highlight the DR-TB patients who drop out from treatment in the private sector.		
o Assure the provider that the patient will not be lost to follow-up.		
Discuss the option of becoming a provider of directly observed therapy for DR-TB.		
Discuss the linkage protocol and the investigations before linkage.		
Remind them of the laboratory to which the clinic is assigned for prelinkage investigations.		

Before initiation of treatment, the TC should collect the general information of the DR-TB patient from the private provider's records. During the initial visit at the doctor's clinic (for CB-NAAT test result delivery), the TC should obtain the sociodemographic information, contact information, and address of the patient. The patient then can be sent for PTE.

The integrated referral form for all the tests after TB diagnosis (RNTCP Appendix 15A, available in the Technical and Operational guidelines of RNTCP) should be filled at the private provider's clinic. Refer to Appendix 1 for the integrated form. The private provider should keep the private-provider notification register, which will include details of the patient for notification in Nikshay. Refer to Appendix 2 to access the form for this register. If the patient is resistant to rifampicin, then a separate form needs to be filled for other tests. Refer to Appendix 3 for this form.

	LIST FOR TREATMENT COORDINATOR (OR LINKAGE STAFF) TO FOLLOW BEFORE BENT LINKAGE:	
☐ Collect general information of the patient from the private provider in the registration form: Yes/No.		
Collect sociodemographic information of the patient: Yes/No.		
☐ Correctly fill the pretreatment evaluation form of the patient: Yes/No.		
After the documentation has been completed, ensure the following:		
0	Registration form is with the private doctor: Yes/No.	
0	Presumptive tuberculosis register is filled by the Nodal Person: Yes/No.	
0	Linkage register is filled by the Treatment Coordinator, including pretreatment evaluation results: Yes/No.	
0	Referral form is filled by the Treatment Coordinator: Yes/No.	

The recommended processes for treatment linkage between the private sector and public sector are given in Figure 5 and Figure 6.



Abbreviations: CB-NAAT, cartridge based nucleic acid amplification test; DR-TB, drug-resistant tuberculosis; DST, drug-susceptibility testing; DTC, District TB Centre (district level administrative and infrastructure unit of RNTCP organogram); PHI, public health institute; PTE, pretreatment evaluation; SDPS, Senior DOTS [directly observed treatment, short course] Plus Supervisor; TB HV, TB Health Visitor; TC, Treatment Coordinator.

Management of patient migration

In the event that a patient migrates to a different area, the patient should be encouraged to inform their TC of their plan prior to migrating. The information then should be passed on to the SDPS of the patient's origin geography. This allows enough time for the SDPS to send communication to the concerned RNTCP staff in the patient's destination geography. This also helps the RNTCP to furnish the patient with enough drug supply to last until he/ she resumes in the destination geography. The TC can then telephonically follow up with the patient and guide him/her until treatment initiation/resumption happens in the new geography.

Analysis of bottlenecks in treatment linkages in the public sector:

The following are a few bottlenecks that were identified during the implementation of the Challenge TB project which affected the quality of implementation and patient services.

- When PTE forms are unavailable at the District TB Centre (DTC), the SDPS instructs the patient to go elsewhere for the form, which delays the initiation of treatment.
- The high volume of patients in the public sector delays PTE.
- Unavailability of tests increases out-of-pocket expenditure for the patients.
- Usually, there is no single point of testing for all the tests recommended in PTE; hence, patients need to go to different laboratories.
- Unavailability of laboratory staff on the day of the patient visit can also delay the process.

Solutions to address bottlenecks

Some of the solutions identified during the Challenge TB project implementation to the above mentioned bottlenecks are mentioned below:

- Forecast and indent required papers and registers to avoid stockout.
- Identify replacement staff a day prior to the staff leave to avoid inconvenience for the patients.
- Avoid admitting the patient for PTE if it is unnecessary and treat the case on an ambulatory basis.
- Provide all tests at the network laboratory or arrange for specimen collection in the same laboratory to reduce the time taken for each patient.
- Incentivize the private sector laboratory and/or supply test kits to decrease out-of-pocket expenditure for the patients.
- Introduce a single-window system for PTE testing for TB patients that would ensure either specimen collection or testing at a single window rather than different laboratories in the same facility or different facilities

Analysis of bottlenecks in patient referral from the private sector to the public sector

Some of the bottlenecks identified in referral and linking of private sector patients to the public sector PMDT as well as in the subsequent follow up by public sector staff are mentioned below:

- Poor attitude and behavior of public sector staff toward patients discourage privatesector doctors from referring patients to the public sector.
- Public-sector field staff's poor patient-handling skills lead to patient's unwillingness to go to the public sector.
- Unavailability or erratic supply of drugs in the public sector discourage patients from continuing treatment in the public sector.
- The health care providers of the public sector are overburdened and unable to spend high-quality time with patients during visits.

Solutions to address bottlenecks

The solutions proposed to the bottlenecks mentioned above can be found below:

- Public-sector staff who deal with patients should be trained in counseling and respectful care to improve the patient and health care staff relationship.
- Prevent stockout of drugs by proper forecasting and robust logistics and supply chain management.
- Conduct repeated sensitization of staff on patient handling and supervise them from time to time.
- Optimize resources in the public sector, especially HR, to improve the quality of care provided to patients.

SALIENT POINTS TO KEEP IN MIND TO IMPROVE THE IMPACT OF THE INTERVENTION:

- Rapport should be established with the patients during the first visit.
- High-quality time spent with the patient should be at least 30 minutes during the first home visit.
- Public-sector staff behavior toward patients should be moderated to reduce stigma and the feeling of discrimination.
- The patient load per linkage staff should be calculated practically to operate efficiently. Hence, resources should be optimized to maintain quality.
- Linkage staff should be available over the phone for patient support during an emergency.
- Regular visits to the patients are important, irrespective of patient adherence. Visits should be prioritized in case of non-adherence



Chapter 5 Treatment Adherence

Definition of adherence

WHO defines adherence as the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed recommendations from a health care provider.

Factors affecting adherence

WHO states that adherence is a multidimensional phenomenon that is determined by the interplay of five sets of factors, hereafter referred to as "dimensions," of which patient-related dimensions is just one determinant (Figure 7). The common belief that patients are solely responsible for continuing their treatment is misleading and most often reflects a misunderstanding of how other dimensions affect people's behavior and capacity to adhere to their treatment. A detailed enumeration of the factors affecting adherence and interventions to improve adherence is mentioned in Table 1.

The five dimensions are briefly discussed below:

- Socioeconomic dimensions: Lack of effective social support networks and unstable living conditions, cultural and lay beliefs about illness and treatment, ethnicity, gender, age, high cost of medication, high cost of transport, criminal justice involvement, long distance from the treatment setting and patient homes, low socioeconomic status, illiteracy, high cost of medication.1,2
- Health system dimensions: Poorly developed health services; inadequate/poor relationship between health care provider and patient; health care providers who are untrained, overworked, inadequately supervised, or unsupported in their tasks; inability to predict potentially non-adherent patients; lack of knowledge and training of health professionals about treatment management and/or an inadequate understanding of the disease; short consultations; poor implementation of educational interventions.1,3-6

- Condition-related dimensions: Asymptomatic patients, drug use, altered mental states caused by substance abuse, depression and psychological stress, poor understanding of the disease and its "side effects," other psychiatric co-morbidities, long duration of the disease.1,7
- Therapy-related dimensions: Complex treatment regimen, adverse effects of treatment, toxicity, long duration of treatment, frequent doses, lack of clear instructions about how to take the medications.1
- Patient-related dimensions: Forgetfulness, drug abuse, depression, psychological stress, misunderstanding instructions about how to take medications, inadequate knowledge and skill in managing the disease symptoms and treatment, anxieties about possible adverse effects, lack of self-perceived need for treatment, psychosocial stress, low motivation.

FIGURE 7: FIVE DIMENSIONS THAT AFFECT TREATMENT ADHERENCE

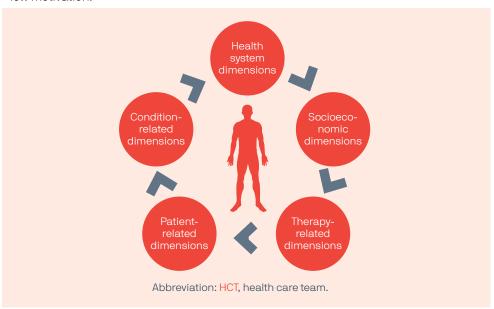


TABLE 1. FACTORS AFFECTING ADHERENCE TO TREATMENT FOR TUBERCULOSIS AND INTERVENTIONS FOR IMPROVING IT, LISTED BY THE FIVE DIMENSIONS AND THE INTERVENTIONS TO IMPROVE ADHERENCE.

Tuberculosis	Factors affecting adherence	Interventions to improve adherence
Socioeconomic-related factors	(-) Lack of effective social support networks and unstable living circumstances ^{14;} culture and lay beliefs about illness and treatment ^{15,16} ; ethnicity, gender and age ^{17;} high cost of medication; high cost of transport; criminal justice involvement; involvement in drug dealing	Assessment of social needs, social support, housing, food tokens and legal measures ^{18–20} ; providing transport to treatment setting; peer assistance; mobilization of community-based organizations; optimizing the cooperation between services
Health care team/health system-related factors	(-) Poorly developed health services; inadequate relationship between health care provider and patient; health care providers who are untrained, overworked, inadequately supervised or unsupported in their tasks ²¹ ; inability to predict potentially nonadherent patients ²² (+) Good relationship between patient and physician ²³ ; availability of expertise; links with patient support systems; flexibility in the hours of operation of treatment centers	Uninterrupted ready availability of information; flexibility in available treatment; training and management processes that aim to improve the way providers care for patients with tuberculosis; management of disease and treatment in conjunction with the patients; multidisciplinary care; intensive staff supervision ²⁴ ; training in adherence monitoring; DOTS strategy ²⁵

Tuberculosis	Factors affecting adherence	Interventions to improve adherence
Condition-related factors	 (-) Asymptomatic patients; drug use; altered mental states caused by substance abuse; depression and psychological stress (+) Knowledge about TB²⁶ 	Education on use of medications ²⁷ ; provision of information about tuberculosis and the need to attend treatment
Therapy-related factors	(-) Complex treatment regimen; adverse effects of treatment; toxicity ²⁸	Education on use of medications; adherence education; tailor treatment to needs of patients at risk of nonadherence; agreements (written or verbal) to return for an appointment or course of treatment; continuous monitoring and reassessment of treatment
Patient-related factors	 (-) Forgetfulness; drug abuse; depression; psychological stress (+) Belief in the efficacy of treatment²⁶; motivation²⁹ 	Therapeutic relationship; mutual goal- setting; memory aids and reminders; incentives and/or reinforcements ^{30,31} ; reminder letters ³² , telephone reminders ³³ or home visits ³⁴ for patients who default on clinic attendance

Source: World Health Organization. (2003). Adherence to long-term therapies: evidence for action / [edited by Eduardo Sabaté]. World Health Organization. http://www.who.int/iris/handle/10665/42682 Table 10.

Abbreviations: DOTS, directly observed therapy, short course; TB, tuberculosis.

Note: +, factors having a positive effect on adherence; -, factors having a negative effect on adherence.

Tools for adherence support

Since multiple dimensions affect treatment adherence, a multipronged approach is required to assess individual patients to identify factors affecting adherence and support them according to their assessment result. Figure 8 gives an overview of the tools that can be used for adherence support in particular cases. However, the staff who provide adherence support should analyze the patient needs, as well as consult the treating doctor and the program officers, to identify the best methods of adherence for each patient.



FIGURE 8. ADHERENCE SUPPORT TOOLS FOR TUBERCULOSIS PATIENTS

Home visits

Home visits by the TCs or the linkage staff are crucial to interact with the patient, counsel the patient and their family, as well as monitor for any possible adverse drug reactions. This opportunity should also be utilized on educating the patient and family on airborne infection control. Appendix 9 outlines the cough etiquette the patient has to follow. Home visit is recommended as a high-priority activity on a regular basis. A recommended schedule of visits and the activities during each visit are outlined in Appendix 4. Below are a few vital activities:

- Two initial fortnightly visits are important to assess the patient's adherence dimensions and to build rapport.
 - Use the home visits to holistically study the patient's sociodemographic profile, surroundings, and likelihood to adopt infection prevention practices; to counsel the patient; and to impart information on social welfare schemes.
 - Be open to listen to the patient's opinions, concerns, beliefs, feelings, and difficulties to assess their adherence tendencies.
 - Answer all queries of the patients and their family. If you do not know the answer
 to a query, inform the patient that you would enquire from relevant resources and
 share the answer during the next visit or telephonically

Self-monitoring tool

This tool is given to patients so that they may actively participate in their treatment adherence. The tool contains three parts in its four-page/two-leaf folder. The front and back pages contain a patient charter, which details the roles, responsibilities, and the rights of TB patients in availing the treatment. The second page (i.e., the first of the inner two pages) contains details about the patient, registration, DR-TB center, important phone numbers, among other information; this page also can be used as a DR-TB "ID card." The second of the inner two pages contains a small guide on nutritional requirements and a daily tally sheet, which can be used as a checklist for daily doses. An addendum with responses to simple adverse drug reactions, presented as a separate leaflet in the local language, can be included in the folder to improve patient compliance. The patients are required to indicate their adherence in the given form daily. This helps the patient to visualize and internalize the adherence pattern.

- The self monitoring tool requires minimum literacy.
- This tool also gives the patient some important information that they need to know.
- Home visits provide an opportunity to evaluate the patient's ability to fill the form and teach them how to fill it.
- If the patient is a minor, mentally or physically not capable of filling the form, or old, the task of marking can be done by one of the family members.

DR-TB counselors in the public sector should talk about this tool and its use in detail when they counsel the patient on treatment adherence. This effort will then be facilitated by the TCs. On the TCs first visit, they should explore the possibility of the patient adopting this tool after assessing the capabilities of the patient/family members. They also should teach the patients and family members how to use the tool if they adopt it. Subsequent visits should be made to check if they are using the tool

correctly and to address any concerns or queries. Refer to Appendix 5 for the format of the self-monitoring tool.

Daily reminder messages:

Messages using commercial platforms can be sent to patients which reminds the patient to take the medications, some of them can also depart from this structure to be motivational quotes to ensure minimal psychological support. ICT platforms like the call centre has the function of sending messages, but if the need be separate messaging systems can be explored.

Peer group support meetings

Peer group support meetings, as the name suggests, provides a platform for patients to come together to encourage one another to adhere to and complete treatment. It is different from adherence counseling in that it allows the patients to play an active role. These meetings serve as a forum for like-minded people, which reassures the patient that he/she is not alone. The meetings are attended by patients who are sputum negative, by virtue of either sputum conversion on treatment or extrapulmonary TB.

The SDPS of the district collaborates with health workers and accredited social health activists to convene the meeting on a predecided date in consultation with the DTO and the Medical Officer -Public Health Institution. DR-TB patients from the private sector and the public sector who are availing PMDT services may be involved in this activity.

The peer-group meetings should have the following characteristics for effective implementation:

- The meetings are to be conducted every month in every ward/district/block.
- The ideal number of participants is eight to ten.
- The meeting should be led by a tuberculosis survivor/champion.
- The participating patients should be sputum negative by culture at the time of attending (to avoid infectivity).
- The family members of the patient are encouraged to attend the meeting.
- The objective of the meeting is to improve motivation levels of patients and create patient support systems to encourage better adherence.

The agenda for the meeting is shared in Appendix 6. The first session is an introduction and ice-breaker session, with some motivational videos and breathing exercises. In the second session, all the peers discuss and share their experiences and motivate each other to continue treatment. The third session is used for patient education. The entire meeting should not exceed two hours to keep participants focused; it can end with a high tea.

Socioeconomic support

TB patients, especially when drug resistant, have huge socioeconomic impact and require socioeconomic support to complete the treatment successfully.35,36 Most TB patients often battle extreme poverty, hunger, loss of employment, and social stigma; they also are unfortunately away from government's social security net.37 It has been observed that socioeconomic support interventions can add significant value to TB control; they improve treatment success rates and reduce patient suffering. Delivery of social support to TB patients requires collaboration among multidisciplinary teams. Quite often, these teams work in close collaboration with or are organized by people outside of the National TB Programme. Clear procedures to identify patients' needs through patient-centered approaches are likely to ensure effective targeting of social support resources and promote accountability. A holistic socioeconomic model is represented in Figure 9.

The objectives of linking TB patients to social welfare support are to:

- Improve treatment adherence and outcome, lower out-of-pocket expenditures, and improve the overall quality of a patient's life through:
 - Financial assistance.
 - Nutritional support.
 - Skill-development courses.
 - Livelihood opportunities
- Reduce social stigma and build communities that support TB patients.
- Forge collaborations within existing national programs.

Multipronged approach

The following socioeconomic support can be provided for holistic care of TB patients.

FIGURE 9: HOLISTIC SOCIO ECONOMIC SUPPORT MODEL





Mapping of government schemes

The Government of India announces welfare/social security schemes for a cross section of the society from time to time. These schemes are either national or state specific, or they are a joint collaboration between the center and the states. It is observed that not all the declared government schemes are functional in the states. Therefore, information on functional government schemes (i.e., schemes with beneficiaries in the previous financial year) can be obtained from the Department of Social Welfare/Social Justice Department/Department of Social Security and Development of the respective states.

The Central TB Division periodically circulates to the states a list of the government social welfare/security schemes that are announced by and available from the different central ministries. There are two ways to update the list to encompass state-specific/functional schemes. First, the state PPM Coordinator, in consultation with the State TB Officer, needs to list the state-level active government social security schemes and the state-specific schemes. The District PPM Coordinator, in consultation with the DTO, then shares this list with all of the districts to map the schemes that are active in each district. This list can then be shared with the different stakeholders and the staff responsible for handling TB patients.

The information that should be compiled and provided to the staff who are responsible for linking patients to socioeconomic support is as follows:

- Name of the scheme.
- Summary information.
- Benefits.
- Required criteria for eligibility and conditions.
- Documents required for application.
- Application procedure.
- Contact details: Which departments/institutions applicants can contact for further assistance [e.g., Gram Panchayat (Village council), Anganwadi (The last mile structure of the Integrated Child Development Services Programme which caters to both child development services like nutrition, education, immunization as well as some maternal health services.)].
- References (official links for further information).

Refer to Appendix 7 for an indicative list of government schemes for patient linkages.

Patient profiling

Patient profiling is important to know the patient's eligibility to avail a particular government social welfare scheme. It is important to collect detailed information on the patient to know which schemes are appropriate.

Information will be broadly based on the following criteria:

- Demographic: age, gender, patient's education, patient's occupation, type of residential locality, patient's domicile status, whether the family has any member who is a senior citizen/differently abled person/widow/diagnosed with a major illness, whether the patient or any other family member is already receiving socioeconomic support, etc.
- **Economic:** yearly family income (as per ration card), current yearly family income (reported by the patient), number of earning members in the family, number of dependent family members, type of income source, etc.
- Social: religion, caste, etc.

Patient consent should be obtained prior to collection of the information. The TCs will use their initial home visits to collect this information. This information will then be given to the PPSA MIS Officer, and the patient profile will be prepared by the MIS Officer. In cases where the RNTCP staff are implementing the linkage directly, the linkage person responsible would collect the data and the profile would be prepared by the District PPM Coordinator with assistance from the Data Entry Operator.

An indicative patient profiling and assessment tool is provided in Appendix 8. Patients who are eligible for functional government schemes are identified based on the information collected from patient profiling. Additionally, a list can be prepared of patients who do not meet eligibility criteria due to various reasons but, upon profiling, are found to be indigent. Such patients can be supported through nongovernmental sources. The criteria that define "indigent patients" can be determined by the respective State TB Cell or District TB Office.

Support for filing application

The TC should inform the patients who are eligible for government social welfare/security scheme support about the scheme details and benefits. For patients who are willing to receive the support, the TC should check if they have the documents required for the application. In case the patient does not have the required documents or bank account, the TC should inform the patient about the procedure to obtain the documents. If needed, support to obtain these documents may be extended. Local accredited social health activists, health workers, or RNTCP staff can be assigned this responsibility of hand-holding patients if needed.

Community engagement

Community engagement is the process of working collaboratively with and through communities to address issues that affect the well-being of patients. Community engagement is critical to improving the reach and sustainability of TB interventions. The WHO End TB Strategy includes engagement of communities and civil society organizations as one of the core components. The goal of community engagement is to build an empowered community that supports its TB patients.

Patient support services should be carried out through community-based TB activities, depending on the state, district, and local context. Community groups can be involved in:

- Generating awareness and reducing stigma: Raising awareness about TB, using behavior change communication, dispelling myths about TB to reduce stigma.
- **Early case finding:** Explaining the main symptoms of TB in community meetings and encouraging people to seek care if they experience the symptoms.
- Making and facilitating referrals: Referring for diagnosis of TB and related diseases; linking with clinics; providing transport support and facilitation, and accompaniment; using referral forms.
- Providing treatment adherence support: Conducting home visits, providing adherence support, pill counting, giving home-based care, performing family directly observed therapy.
- Preventing the transmission of TB: Providing information on simple behavior to prevent TB, such as covering the mouth and nose when coughing and sneezing.
- Providing social support: Providing nutrition support and supplementation, implementing voluntary savings and loans programs, supporting linkages with existing social welfare schemes

The following approaches can be used for community engagement to provide patients support services:

- Creating linkages between existing community structures: Existing community structures—such as Mahila Arogya Samiti, women's self-help groups, Anganwadi, Public Distribution System shops, and health posts, among others—can be leveraged for pooling resources and participatory efforts to support TB patients. This also ensures sustainability in the long term. Mahila Arogya Samiti is a local women's collective under the National Urban Mission. They are expected to take collective action on issues related to Health, Nutrition, Water Sanitation and its social determinants at Slum/Ward level.
 - For establishing such linkages, it is important to assess the community structure's mandate, activities the community has undertaken, and the target population. The objectives and activities of the patient support system can be aligned with these.
 - RNTCP needs to define the support that it will provide to these structures; for example, training of community group leaders or members on TB, payments or incentives for community health workers or volunteers, etc.

To effectively engage the existing community structures, the following steps may be undertaken:

- Identifying the existing community groups by obtaining a list of all registered groups from the concerned national programs: For example, a National Urban Livelihoods Mission Project Officer can be approached to get a list of self-help groups in the implementation area. This also will contain information about the group leader's name, address, and contact number.
- Identifying the functioning groups: At times, groups stop being operational due to various reasons; it is important to approach only functioning groups. This can be done by contacting the group leaders on their registered mobile numbers.
- Approaching the groups: The project staff should conduct a face-to-face meeting with the group leader and members and provide them preliminary information about TB and the initiative.
- Training: Training should be conducted for all group leaders and their members on TB awareness, fighting social stigma, and actions to support TB patients.
- Conducting community meetings: A community meeting focused on TB awareness should be conducted on a periodic basis. The meeting can be used to plan activities to support TB patients.
- Tracking actions taken: Actions taken by the group should be tracked and support should be provided to the group, if needed.
- Facilitating coordination between district officials: A coordination mechanism between the District TB Officer and officials from the National Urban Health Mission/National Urban Livelihoods Mission should be set up to advance TB patient support services in the community.

- The national, state, or district officials of the programs under which these community structures function can be involved during the planning and implementation processes. A mechanism for coordination and collaboration at all the levels needs to be established.
- A system for sharing data and regular monitoring also needs to be created
- **Establishing new structures:** Areas that do not have structures at the community level for effective mobilization of resources can be identified. New structures can be created to advance the patient support services.

Multisectoral coordination

WHO has promoted the concept of intersectoral action for health as "a recognized relationship between part or parts of the health sector with parts of another sector which has been formed to take action on an issue to achieve health outcomes (or intermediate health outcomes) in a way that is more effective, efficient or sustainable than could be achieved by the health sector acting alone."38 Being a recognized relationship suggests that intersectoral action for health is a managed process. The involvement of parts of sectors point to the structural and functional nature of the relationship, not just a conceptual one. Improved effectiveness, efficiency, and sustainability are the benefits expected from the relationship based on specified roles and responsibilities played.

Multisectoral coordination is crucial to address social determinants of health, which play a significant role in a disease like TB.³⁸ A TB patient battles with various challenges, such as poverty, hunger and malnutrition, illiteracy, lack of vocational skills and/or livelihood opportunities, among others.^{35,36} A multisectoral approach to health care addresses these issues; in doing so, it builds on strong evidence that the benefits to communities of improvements in living conditions and in quality of life can extend to the control of diseases like TB in those communities.³⁹ For example, a community development program in Indonesia aimed to raise people's living standard on a broad level by strengthening community institutions, raising income levels through providing assets, giving capital and vocational skills to the neediest groups, and initiating community-based health services

NATIONAL STATE DISTRICT National-level State-level consultation Linkages for the TB consultation for to plan for collaborative patients and families consensus-building for structures between for socioeconomic collaborative framework line ministries (Ministry support (nutrition between line ministries of Women and support, vocational Child Development, courses, livelihood Forge coordination Ministry of Labour and opportunities, etc.) mechanisms between Employment, Ministry of RNTCP and other health Tribal Affairs, etc.) programs such as NUHM, NRHM, etc.

FIGURE 10. LEVELS
OF MULTISECTORAL
COORDINATION AND
ACTIVITIES ENVISAGED
AT EACH LEVEL

of a curative, disease-preventative, and health-promotional nature in all villages. 40,41 Multisectoral coordination can be facilitated at all levels, as in Figure 10. Abbreviations: NRHM, National Rural Health Mission; NUHM, National Urban Health Mission; RNTCP, Revised National TB Control Programme; TB, tuberculosis.

Collaboration with nongovernmental sources

For universal coverage of TB patients who are under the social safety net, it is important

to pool available resources by forging collaborations between the government and nongovernmental entities. As a result of The Companies Act, 2013, a substantial number of corporate social responsibility initiatives are currently underway in the spirit of the social good. Similarly, local and international NGOs have been playing an important role in developing the society, improving communities, and promoting citizen participation. Therefore, it is crucial to involve nongovernment or private organizations to either design new initiatives in support of TB patients or to extend benefits of existing initiatives to TB patients.

Some important nongovernmental resources are:

- Corporate social responsibility.
- International or local NGOs.

FIGURE 11: STEPS TP LEVERAGES NONGOVERNMENTAL RESOURCES FOR TUBERCULOSIS PATIENT SUPPORT

Landscaping nongovernmental resources

Identifying and approaching organizations for smart partnerships

Designing the initiative

Ensuring effective implementation

Conducting monitoring and evaluation

Fostering consistency and commitment

■ Listing the existing NGOs or CSR initiatives that have initiatives to support TB patients/TB elimination efforts. These will be high-priority resources.

- Listing potential corporations/citizens' clubs/NGOs that work in health or hygiene, but not necessarily on TB. These will be medium-priority resources.
- Listing potential corporations/citizens' clubs/NGOs that do not work on health or hygiene. These will be low-priority resources.
- Geography plays an important role in determining which NGOs would be willing to lend support. For example, manufacturing companies usually want to serve the communities around their factories, whereas serviceoriented companies can be more geographically flexible.

Organizations will be approached based on priority.

- Smart partnerships create value for both the business and society; therefore, proposing initiatives that are gainful for the business is an important aspect of the proposal/briefing stage.
- A clear understanding of available resources with stakeholders is required to design mechanisms for their use.
- Instead of expecting the private organization to take complete onus of the implementation, it is important to adopt a collaborative approach wherever necessary. For example, if a corporation is ready to offer commodities but cannot offer logistics support, a local NGO can be hired to provide it.
- An ongoing procedure to monitor the performance of initiatives and an assessment to identify gaps should be established.
- Instead of looking at initiatives as one-time collaborations, efforts should be made to make sustainable and long-term partnerships. This can include forging partnerships with corporations or NGOs at the national or state level.
- Identifying new areas for collaboration and going beyond TB or health can also encourage such partnerships.

Abbreviations: CSR, corporate social responsibility; NGO, nongovernmental organization; TB, tuberculosis.

■ Citizens' groups, such as Rotary Club and Lions Club.

Since partnerships at the national level (for initiatives across multiple states) or at the state level (for initiatives across multiple districts) are more effective in mobilizing resources than collaborative efforts that are limited to districts, a national- or state-level task force can be established to encourage more such efforts. Steps can be taken to leverage nongovernmental resources for TB patient support, as shown in Figure 11.

Way forward

Table 2 lists some potential challenges that TB patients may face in obtaining support from government social welfare/security schemes, along with probable solutions to these challenges.

TABLE 2. CHALLENGES AND POSSIBLE SOLUTIONS FOR SOCIOECONOMIC LINKAGES.

Challenges	Solutions
Nonfunctional govern- ment welfare schemes	Classifying respiratory disability and onboarding TB as a possible cause of respiratory disability. If respiratory disability due to TB can be quantified, this can be linked to the disability pension schemes, which can be availed independently.
Dated eligibility criteria, which can exclude vulnerable people from the social security net	A periodic review of the eligibility criteria of each scheme and appropriate revisions are the needs of the hour. RNTCP will continue to advocate this at all available interdepartmental coordination platforms.
Similar income criteria for eligibility between the rural and urban populations adversely impact the urban poor	Social welfare schemes should be linked to income and the local live-lihood expenditure index rather than solely to income. While RNTCP will talk about it at intersectoral coordination meetings, every attempt should be made at the state and district levels to convince the appropriate authorities on all platforms.

Nutritional support

Nutrition plays an important role in maintaining immune levels and in responses to TB treatment, especially for DR-TB.⁴² It is believed that a poorly nourished patient responds poorly to treatment, and the treatment outcome is better in a properly nourished patient.^{43–45} RNTCP recently initiated a nutritional support scheme for TB patients. The support is offered in two forms: It can be a monthly payment of 500 rupees for nutrition expenses to each TB patient on treatment; this support is disbursed through the Direct Benefit Transfer program. Alternatively, the support can be offered as nutritional packets. Advocacy and patient education on the proper use of this support are required to boost the nutritional level of TB patients. Monthly peer-support meetings and similar platforms should be used to share this information and to encourage patients to use the cash transfer as intended. In addition, education on proper nutritional alternatives and combinations should be shared with the patients. Existing mechanisms of ration provision under various government social welfare schemes can also be explored.

Soft-touch adherence support

As discussed in the earlier section of home visits, the TCs can conduct a higher number of visits than prescribed in the schedule, if the need arises. In addition to in-person visits, the TCs can also be contacted telephonically whenever the patient requires immediate assistance.

Daily SMS messages are another form of soft-touch adherence support for the patients. SMS messages serve as motivation, as well as reminders for medication adherence. Various ICT platforms, as well as the call centers, can be used to generate and send periodic SMS messages to the patients. In addition, encouraging and enabling video clips in local languages can be circulated to patients with smartphones. These videos are not limited to TB, but generic motivational videos with a positive message or moral.

Soft-touch support can go a long way to ensure treatment adherence. This supplements the in-person visits and prevents the patient from discontinuing medication by providing psychological support and daily motivation.

Factors strengthening adherence:

- Compulsory home visits to the patient immediately after they initiate treatment.
- Patient education on the disease condition, treatment duration, and treatment effects.
- Patient education on the need for adherence.
- Family education on patient condition and necessary support to be provided.
- Access to the health care worker over the phone.
- Excellent relationship with the treatment support staff.

Factors responsible for non-adherence:

- Inadequate information provided regarding the disease.
- Inadequate information provided regarding the need for treatment, treatment duration, and adverse drug reactions.
- Lack of family support.
- Low socioeconomic status.
- Poor nutrition.
- Poor relationship between the patient and the health care provider.
- · Lack of support to patients.

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Chapter 6 Monitoring and Evaluation

A robust M&E system is necessary for every intervention to provide insights into where it stands in achieving its objectives and goals. It also helps in identifying roadblocks and making timely course correction.

An M&E system includes the following:

- Tools for data collection and reporting.
- Indicators to understand the progress of the intervention.

The M&E structure for a PPSA to implement the toolkit is depicted in Figure 12.

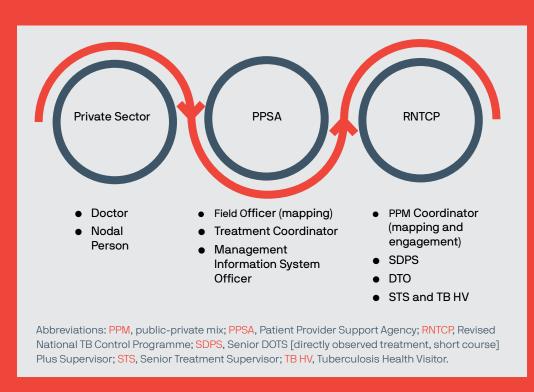


FIGURE 12. DATA
STRUCTURE FOR THE
IMPLEMENTATION
OF THE PATIENT
SUPPORT SYSTEM
FOR DRUG-RESISTANT
TUBERCULOSIS PATIENTS.

The data workflow between stakeholders in the PPSA structure to implement the linkages is depicted in Figure 13.

FIGURE 13. DATA FLOW BETWEEN THE STAKEHOLDERS

RNTCP

- PPM Coordinator receives the list of providers from PPSA
- SDPS receives the data of DR-TB patients to be linked
- DTO is given the details of the patients diagnosed and linked in his/her respective wards
- STS and TB HV receive information regarding the patients in their respective PHI

PPSA

- FO maintains the details on private provider mapping and engagement
- TC collates the diagnosis details along with the sociodemographic details
- MIS officers then collate the information from all TCs
- Notification of patients done if not done by NP

Private sector

- NP collects presumptive preliminary data
- Issues tests with appropriate forms
- After confirmation of TB diagnosis, doctor/ NP notifies the patient

Abbreviations: DR-TB, drug-resistant tuberculosis; DTO, District TB Officer; FO, Field Officer; MIS, management information system; NP, Nodal Person; PHI, public health institute; PPM, public-private mix; PPSA, Patient Provider Support Agency; RNTCP, Revised National TB Control Programme; SDPS, Senior DOTS [directly observed treatment, short course] Plus Supervisor; STS, Senior Treatment Supervisor; TB HV, Tuberculosis Health Visitor; TC, Treatment Coordinator.

The major tools used for data collection have been included in the appendices.

- Registration form (Appendix 1): This is the form that provides the detailed patient information. It should be filled when a private provider identifies a person with presumptive TB.
- Biological requisition form (Appendix 2): This form is used to order tests for confirmation of TB, as well as for further evaluation once the diagnosis is confirmed.
- PTE investigation form (Appendix 3): As the name suggests, this form is used to order the PTE tests, as well as to communicate the results before treatment initiation.
- The above data are collated into a single Excel sheet and updated on a periodic basis.

The major indicators that can be used to monitor progress are outlined in Table 3.

TABLE 3. MAJOR INDICATORS USED TO MONITOR THE IMPLEMENTATION OF THE TOOLKIT.

Indicator	Description
Total number of presumptive TB cases tested on CB-NAAT	Number of presumptive TB cases who were offered CB-NAAT testing for microbiological confirmation of TB
Total number diagnosed with TB	Number of presumptive TB cases who were diagnosed with TB both clinically and microbiologically
Total number notified	Total number of TB-diagnosed patients who were notified in Nikshay. Nikshay ID generated can be used as proxy for identification
Total number of patients diagnosed with DR-TB	Number of presumptive TB cases diagnosed with DR-TB through CB-NAAT testing

Indicator	Description								
Total number of patients who received PTE	Number of patients who received PTE								
Percentage of PTE done	The percentage of patients who completed PTE among those diagnosed with DR-TB								
Total number of patients who received DST	Number of patients who received DST								
Percentage of DST done	The percentage of patients who received DST among those diagnosed with DR-TB								
Number of patients initiated on treatment	The total number of patients who had been diagnosed with DR-TB who were initiated on DR-TB regimen								
Percentage of treatment initiation	The percentage of patients who were initiated on DR-TB regimen among those diagnosed with DR-TB								
Percentage of patients completed treatment	The percentage of patients who completed the treatment (RNTCP regimen) among those who had been initiated on DR-TB regimen								
Number of patients linked to socioeconomic schemes	The total number of patients who were linked to at least one socioeconomic scheme								

Abbreviations: CB-NAAT, cartridge-based nucleic acid amplification test; DR-TB, drug-resistant tuberculosis; DST, drug-susceptibility testing; PTE, pretreatment evaluation; RNTCP, Revised National TB Control Programme; TB, tuberculosis.

Appendix 1. Integrated referral form for Diagnosis Tuberculosis

			(Required for Diagnos	is of TB, Drug susci	publ	iity lestilig allu	TOIIOW	up)							
			Pati	ient Informati	on										
Patient name	е			Age (in				Gender:							
Patient mobi	ile no. d	or		Specim	en c	date of		☐ Sputu	ım						
other contac				collecti	on (DD/MM/YY)			(specify)						
Aadhaar no.	(If available)													
B-111-1-				HIV Sta	HIV Status: □Reactive □Non-Reactive □Unknown Key populations: □Contact of known TB Patient □Diabetes										
Patient addr	ess witi	ו ו													
landmark						lPrison ⊔Min worker □Ot			Refugee 🗆 Urban	slum					
				ППССССС	care	WOIREI LIO	tilei (3)								
DTC/ICTC/ART/I specify): Health Facilit	Medical (College/DR			NIKSHAY ID:										
State:			District:	Tub	ercu	ılosis Unit (TU): _								
Reason for T	esting														
			Diagno	osis and follov											
Diagnosis				Follow	up (Smear and	cultu	re)							
H/O anti TB F	Rx for >	1 month	: □ Yes □ No												
☐ Presumpti	ive TB	Pre	dominant symptom	Regime	n:	☐ Nev	N	☐ Previo	usly Treated						
☐ Repeat Exa	am			Reason	:	☐ End	IP	☐ End CF							
☐ Private ref	ferral			Post tre	eatm	nent: 🗆 6n	n 🗆 :	12m 🗆 1	.8m 🛮 24m						
☐ Presumpti	ive NTN	1 Dur	ration days												
			Diagnosis and	d fo ll ow up [)ruç	g-resistant	ТВ								
Drug Suscer	ptibi li ty	Testing	(DST)			Follow up	(Cul	ture)							
			☐ New ☐ Previou	ıs l y treated	reated PMDT TB No DR TB NIKSHAY ID:										
☐ Presumpt	tive		agnosis			DR TB NI	IKSH.	AY ID: _							
MDR TB		25-233 common (1/2) com	act of MDR/RR TB ow up Sm+ve			Regimen:									
			ate referra l		☐Regimenfor INH mono/poly resistant TB										
			ordance resolution		□Regimenfor MDR/RR TB □ Regimenfor MDR/RR-TB + FQ/SLI resistance										
□ Presumpt	ive H n	nono/pol	ly		□Regimenfor XDR TB										
□Presumpti XDR TB		□ ≥ 4 m □ 3 mo (treatmo □ Cultu □ Failu □ Recu	N/RR TB at Diagnosis nonths culture positive onthly for persistent culturent month) ure reversion are of MDR/RR-TB regime urrent case of second line ordance resolution	en		□Regimer FQ/SLI res □Regimer □Regimer for MDR-T	nwith sistand nwith n with B n with B	Bedaquilir ce Bedaquilir Bedaquili Bedaquili	ed pattern resist ne for MDR-TB ne for XDR-TB ine for failures of the	Regimen +					
Universal [DST:														
Test request	ted:														
		T □IGR	A □Chest X-ray □Cyto	pathology 🗆	Histo	opathology	□с	BNAAT E	Culture DS	T FL -LPA					
			ng □Other (Please Spe												
Requested b	y (Nam	e, Design	ation and Signature):												
Contact Nun	mber:		Ema	il ID:			_		102						
Results:	NIK	SHAY ID	Generated:		_										
			Microsc	opy (ZN	Flo	rescent)									
	Lab	Sr. No	Visual appearance				R€	sult							
	Lab .		- isaai appearance	Negative		Scanty		1+	2+	3+					
Sample A					-		_								
Sample B					_										
Date tested:			Date Reported:		Repo										
Laboratory N	Name: _					1)	Name	and Sign	ature)						

Appendix 2. Form for tuberculosis notification register to be kept at private clinic

		С	artridge Based	l Nucleic Acid	Amplification Test	(CBNAAT)	Lab. sr. No
Sample		ΠA		□В			
M. Tuberculo	osis	☐ Detec	ted	☐ Not Detect	ted □ N/A		
Rif Resistance	е	☐ Detec	ted	☐ Not Detect	ted 🔲 Indeterr	minate [□ N/A
Test		☐ No Re	sult 🔲 Inva	alid 🗆 Err	or – Error Code	(Please arr	range for fresh sample)
Date tested:			Date Reported:		Reported by:		
Laboratory N	lame: _				(Name and Sig	gnature)
				Culture (□	LJ 🗆 LC)		
Lab Sr. No	Nega	tive Pos	sitive for M.tb.		NTM (write species)		Contamination
					, , ,		
Date Result:			Date Reported:		Reported by:		
Laboratory N	lame: _				(Na	ame and Signa	ature)
				Line Probe	Assay (LPA)		
			□ Dire	ect 🗆 Indirect			
				First lir		-	
RpoB: locus co	ontrol: 🗆 p	resent 🗆 abse	ent				
WT1: 🗆 present 🗆	absent	WT	2: □ present □ abse	nt	WT3: ☐ present ☐ absent	WT4:	□ present □ absent
WT5: 🗆 present 🗆	absent	WT	6: □ present □ abse	ent	WT7: ☐ present ☐ absent	WT8:	□ present □ absent
MUT1 (D516V): 🗆	present 🗆	absent MU 1	Г 2A (H526Y): □ pres	ent □ absent	MUT2B (H526D): ☐ present	□ absent MUT3	(S531L): ☐ present ☐ absent
Kat G: locus co	ontrol: 🗆 p	resent 🗆 abse	ent		Inh A: locus control:	present 🗆 absent	
WT1 (315):	present [absent			WT1 (-15, -16): □ present	absent WT2 (-8): present absent
MUT1 (S315T1): 🗆	present [absent MUT2 (A	\16G): □ present □ absent				
MUT2 (S315T2):	present [absent				absent MUT3B	(T8A): ☐ present ☐ absent
συ π Δ.			gyrB:	Second	rrs:		is:
gyrA:							
locus control: Dep	resent 🗌 ab	sent	locus control:	present absent	locus control: prese	nt 🗆 absent 📗 lo	ocus control: present absent
WT1 (85-90): pre			WT1 (536-541):	present absent	WT1 (1401-02): prese	iii ambeiii	VT1 (37): □ present □ absent
WT2 (89-93): □ pre WT3 (92-97): □ pre					WT2 (1484): prese	VT2 (14, 12, 10): ☐ present ☐ absent VT3 (2): ☐ present ☐ absent	
MUT1 (A90V): □ p			MUT1 (N538D):	nresent - chaont	MUT1 (A1401G):		NUT1 (C-14T): present absent
MUT2 (S91P): □ pr			MUT2 (E540V):		MUT2 (G1484T): prese		noti (C-141).
MUT3A (D94A): 🗆							
MUT3B (D94N/Y): MUT3C (D94G): □							
MUT3D (D94H):							
Final LPA Inte	erpreta	tion:					
MTB result	□ N	1TB detect	ed 🗆 MTB not d	etected 🗆 Inva	alid		
RIF Resi rpoB		etected	□ Not detect		Resi		
FQ Resi gyrA			□ Not detect Date Reported:		Resi = eis Detected	□ rrs Detect	ed Not detected
Date Result: Laboratory N			Date Reported.			lame and Sigr	nature)
Laworatory							Turker 57
L					OST) results (□ ⊔		
Lak Cabla	1	st line dru	gs S	LI F	Q	0	ther
Lab Sr.No		(0.1) H (0.4) S	W Z E 8	Mfx Fx B	(0.5) Mfx (2) Eto PAS	B	Azi Dlm
	<u>~ I</u>	y I y s	M N X C) 4 3 2			4 00 0 1
Date Result:			Date Reported		Reported by:		
Laboratory N			Date Reported	•		e and Signatu	ure)
R: Resistant; S: Su		C: Contamina	ted; Not done		(ivaii	ic and signate	ui c j
				Other tests fo	r TB diagnosis		
Test (Please :	Specify):					
Result:							
Date reporte					Reported by:		
Laboratory N	lame: _				(Na	ame and Signa	ature)

Appendix 3. Pretreatment Evaluation Investigation form

Patient's	1	Nam	ne, c	desig	gnat	ion	of :	treat	mer	ıt su	por	ter:								_					
Age:	yrs Gender: ☐ Male ☐ Female ☐ Transgender	-																			_				
Address:		C	Cont	tact	no:																				
		S	State: District:																						
Marital st	atus:	Т	B U	Jnit:									PHI:												
Occupation												_													
Contact N	lo:	li	nitia	al h	ome	vis	it: [Date					B	y:							-				
Aadhar ID	[OR T	В С	entr	re:_				_ D	istric	t				_Sta	ate _			_						
		— Г)rug	Su	scen	ntibi	litv	Tes	t (DS	T) re	esult	s at l	Diag	nosi	s			Spe	ec. co	oll. D	ate:				
Reason for Testing							,		1	,,,,			5)			SS									
□ New	☐ Previously Treated	71.	2	H (inhA/0.1)	H (katG/0.4)				.E.	Ę	Am	¥	Mfx (0.	Mfx (2)	FQ class	LI clas	LI (eis	Eto	PAS	pz¬	Cfz	능	Azi	Bdq	Dlm
☐ Presumptive	TB ☐ Private Referral ☐ Presumptive NTM	7	-	_	_	S	Ш		Ť		4		2	2		S		ш		_	0	0	_ ₹	B	
Presumptive	☐ At diagnosis ☐ Contact of MDR/RR TB		lam	ie of	f the	e lab		_					La	b.sr.	No.			Res	ult r	epor	t dat	te			
MDR TB	☐ Follow up Sm+ve at end IP	F	R: R	esis	stant	t; S:	Sus	sce	otible	e; C:	Cor	tam	inat	e d ; -	- No	t do	ne/a	vaila	able						
	☐ Private referral		_														- г								
☐ Presumptive	H mono/poly		Η.						onta					_			41'	T VII	estir	ng: D	ate:				
	☐ MDR/RR TB at diagnosis	┪	No of members screened									Von i	react	ive [UN										
	☐ ≥ 4 months culture positive							No of presumptive TB cases identified No of presumptive TB cases evaluated PID number:																	
	Presumptive XDR TB Don't like the state of t							No diagnosed with TB									:			_					
ADRIB		_		_				osed	1				+			11,	ART s	start	date	:					
	☐ Failure of MDR/RR-TB regimen ☐ Recurrent case of second line treatment		Ľ														_ [_								
	_																								
Pre-treatment	investigation																								

Pre-treatment inve	estigation				
Test	Date	Result (units)	Test	Date	Result (units)
ALT (SGPT)			Chest X-Ray findings		
AST (SGOT)			Cavities (Y/N)		
Bilirubin- Direct -Indirect					
S. Albumin					
WBC (TC/DC)			ECG (QTc & other findings)		
Haemoglobin			Creatinine		
ESR			Creatinine Clearance		
Platelet count			Blood Urea		
Lactic acid			Visual acuity		
Amylase			Audiogram		
Lipase					
CD4 Count			Psychiatric evaluation		Yes/ No
Hepatitis markers			Surgical evaluation		Yes/ No
TSH			Ophthalmic evaluation		Yes/ No
Urine (R/M)			HIV I & II		
UPT			Random Blood Sugar		
Potassium			Fasting Blood Sugar		
Magnesium			Post Prandial Blood Suga	r	
Calcium			HbA1C (if indicated)		

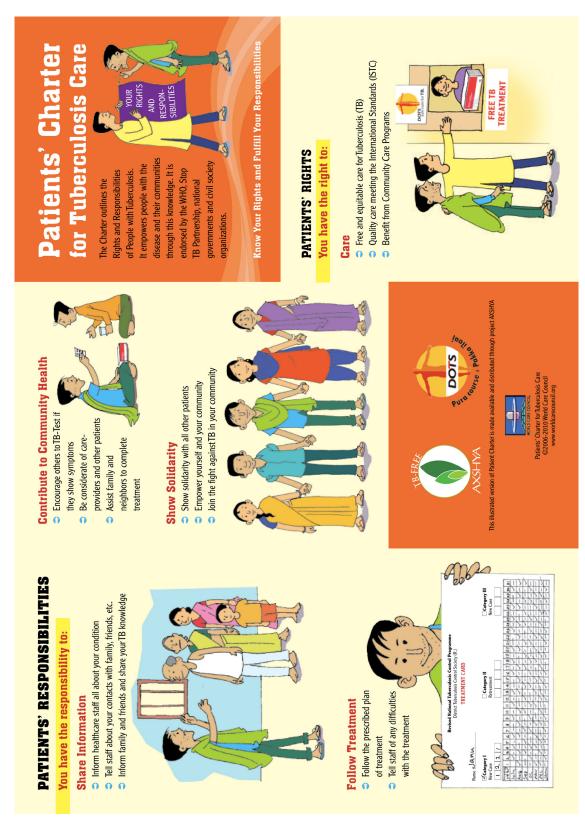
Appendix 4. Schedule for patient visit and activities

										during t					
during the visit	1st FU				5 th FU	6 th FU	7 th FU			10 th FU					
	15 days	days	45 days	60 days	3 mos.	4 mos.	5 mos.	6 mos.	6-9 mos.	10-12 mos.	13-15 mos.	16–18 mos.	19-21 mos.	22-24 mos.	End Rx
Verify address															
Collect sociodemo- graphic details															
Provide patient education on TB															
Counsel patient and family															
Provide nutrition education															
Conduct contact tracing															
Administer self- adherence tool															
Do need assessment for socioeconomic linkages															
Follow up treatment adherence															
Check self- adherence tool															
Repeat the points of IB education															
Answer queries															
Refer if ADR or new suspect identified															
Check documents for social linkages															
Check DST report and record treat- ment modification															
Provide information on peer group sup- port meetings															
Record treatment outcome															

Abbreviations: \overline{ADR} (adverse drug reaction); \overline{DST} (drug susceptibility testing); \overline{FU} (follow-up); mos. (months); \overline{Rx} (treatment); \overline{TB} (tuberculosis).

^{*}These number of visits are mandatory, but visits are not limited to these. The Treatment Coordinator can visit the patient on demand even if more than the prescribed number of visits.

Appendix 5. Self-monitoring tool



		Annexure 15F
RNTCP PMDT TB identity card	resistant TB □ Regimen for H mono/poly resistant TB	ppointment dates
lame:	☐ Regimen for MDR/RR-TB + FQ/SLI resistance ☐ ☐ Regimen for XDR TB	
ddress:	☐ Regimen with Bedaquiline for MDR-TB + ☐ ☐ FQ/SLI resistance	
	Regimen with Bedaquiline for XDR-TB	
	□ Regimen with Bedaquiline for failures of	
	regimen for MDR-TB ± FQ/SLI resistance ☐ Regimen with Bedaquiline for failures of	
ontact No:	regimen for XDR-TB	
MDT TB number:	Regimen for mixed pattern resistance	
MDT NIKSHAY ID:	CPT ART Diabetic Smoker	
R TB Centre:	Date of starting treatment: (DD/MM/YYYY)	
istrict:	Date of starting treatment. (DD/MIN/1111)	
B Unit:	Culture follow-up results	
	Month Month	
OT Centre:	Month Month Month	
ame of Treatment Supporter:	Month Mont	
	Month Month	
contact Number of Treatment Supporter:	Month Month In case of sign	de effects or queries please
	Date: contact	to enterto or queries pieces
		entact number:
टीबी 100% ठीक होती है, पर उसका ईलाज पूरा क	रना जरुरी हैं।	
अपनी दवाईयों का रेकॉर्ड खुद रखें, दवाई का नियमित सेवन करें	, , , , , ,	
दवाई के सेवन का शुरवाती माहिना और तारिख:		
TITE 2 2 3 X 4 E 6 C 9 20 22 23 2X 24 2E	50 58 56 50 38 53 53 5X	
TE CONTRACTOR OF THE CONTRACTO		
3	्रमेटिन जूबन आसर आपकी रोग प्रतिकार समित बढाईमा तथा आपको स्थ्य रखेगा	
X	्रमाध्या पूचा जाहार से राजेता । प्राचित्र पूचा जाहार से राजेता ।	A
ξ.		
0		

दवाई	के से	वन व	न शु	रवार्त	मा	हिना	और	तारि	ख :	_												
ma 8	?	3	Х	4	Ę	ю	۷	٩	१०	११	१२	3 8	४ १५	१६	१७	16	१९ २	0 2	2 22	?	3 27	
8										_	_		-		_	_	_	-		L		
3					_					_			-			_	4	-		L		
3										_			_				4	_		L		.मोटिज युक्त आसर आपकी रोज प्रतिकार सवित बढारेगा तथा आपको स्थ्य रखेगा .पोटिज युक्त आसर के स्थोत :
8	ļ.,				_					_			_		_	_	4	_		L	4	प्राटम वृक्त आहर के लात :
4																		1				
Ę																	_	_		L		
19					_				_	4	1		-			4	1	1		1	1	
۷																				1		
9		Ш								_							_	1		L		विद्यामिन सी युक्त फल आहार आपकी रोग प्रतिकार शक्ति बळाऐमा और आपको रोक्रमण से बवाएमा. ऑयला, निंबु, संबा, अंनूर आदि सालें फलों का सेवन करें.
१०																						ऑवला, निंबु, संत्रा, अंगूर आदि तार्ने फलों का सेवन करें.
११					_												_	_		L		
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\$8										_							4	1		L		
१५																						
१६																				L		
१७										_							_	1		L		
१८																						
28																1						
२०																				L		
78																						
२२																						
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58																						
34																						
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- Be treated with respect and dignity
- Social support of family, community and national programs

opinion, with access A second medical

to records

0

drug treatment is Refuse surgery if

at all possible

Refuse to



research studies

participate in

Information

- available care services Information about
- condition and treatment Be informed about
 - dosage and side effects Know drug names,
 - Access to your medical records in local language
- Have peer-support and voluntary counseling



- File a complaint about care, and to have a response
 - Appeal unjust decisions to a higher authority
- local, national patient Vote for accountable representatives



Organization

Care in facilities that practice effective infection control

Have privacy, culture, religious beliefs respected

Confidence

Keep your health condition confidential

- Join or organize peer support groups, clubs and NGOs
 - Participate in policy making in TB programs



Security

- Job security, from diagnosis through to cure
- Access to Quality Assured drugs and diagnostics Food coupons or supplements if required





Appendix 6. Peer Group Support Meeting Agenda

Session	Торіс	Responsible					
1 st session:	Participant introduction	Moderator /STS					
	Orientation to the meeting	Moderator/STS					
	Breathing exercises	Moderator /TB Champion					
	Sharing of motivational videos/stories	Moderator					
2 nd session	Experience sharing: Journey with TB	All patients					
	Personal hurdles in adherence and solution	All patients					
	Self-motivation techniques	All patients					
	Family support: How to contribute	Moderator to family members					
3 rd session	General information on TB disease	SDPS/DTO					
	Treatment and follow up	SDPS/DTO					

Abbreviations: DTO, District TB Officer; SDPS, Senior DOTS [directly observed treatment, short course] Plus Supervisor; STS, Senior Treatment Supervisor; TB, tuberculosis.

Name and details of the scheme	Introduced by	Ministry	Eligibility criteria	Documents required	Benefits offered
Pradhan Mantri Jan-Dhan Yojana (PMJDY) Details: PMJDY is national mission for financial inclusion to ensure access to financial services—namely, banking/savings and deposit accounts, remittance, credit, insurance, and pension in an affordable manner. Reference link: www.pmjdy.gov.in	Central government	Ministry of Finance	All adults (age 18 years or above). A minor (age above 10 years and below 18 years).	An account can be opened by presenting an officially valid document: Passport. Driving license. Permanent Account Number card. Voter's Identity Card issued by the Election Commission of India. Job card issued by National Rural Employment Guarantee Act, duly signed by an officer of the state government. Letter issued by the Unique Identification Authority of India containing details of name, address, and Aadhaar number; alternatively, any other document as notified by the Central Government in consultation with the Regulator, provided that, where simplified measures are applied for verifying the identity of the clients, the following documents shall be deemed to be officially valid documents: Identity card with applicant's photograph, issued by central/state government departments, statutory/ regulatory authorities, public-sector undertakings, scheduled commercial banks, and public financial institutions. Letter issued by a gazetted officer, with a duly attested photograph of the person.	 Interest on deposit. Accidental insurance cover of 1 lakh rupees. No minimum balance required (0 balance). The scheme provides life cover of 30,000 rupees payable on death of the beneficiary, subject to fulfillment of the eligibility condition. Easy transfer of money across India. Beneficiaries of government schemes will get Direct Benefit Transfer in these accounts. After satisfactory operation of the account for 6 months, an overdraft facility will be permitted. Access to pension and insurance products. The claim under personal accidental insurance under PMJDY shall be payable if the rupay card holder has performed a minimum of one successful financial or nonfinancial customer-induced transaction at any bank branch, Bank Mitra, ATM, Point Of Sale, etc. Channel both intra- and interbank customers (i.e. bank customer/rupay card holder transacting at same bank channels and bank customer/rupay card holder transacting at other bank channels) within 90 days prior to date of accident including accident date will be included as eligible transactions under the Rupay Insurance Program 2016-2017. Overdraft facility up to 5,000 rupees is available in only 1 account per household, preferably the lady of the household.

Name and details of the scheme	Introduced by	Ministry	Eligibility criteria	Documents required	Benefits offered
Pradhan Mantri Jeevan Jyoti Bima Yojana (PMJJ-BY) Details: PMJJBY is an insurance scheme backed by the Government of India that is a one year life insurance scheme, renewable from year to year, offering coverage for death due to any reason. Reference: www.jansuraksha.gov.in	Central government	Ministry of Finance	Age: 18 – 50 years.	 A bank account—single or joint (Aadhar would be the primary Know Your Client for the bank account). Payment of 330 rupees as premium for the year (renewable yearly). Submission of self-certificate of good health. 	Risk coverage under this scheme is for 2 lakh rupees in case of death of the insured, due to any reason.
Pradhan Mantri Suraksha Bima Yojana (PMSBY) Details: PMSBY is an insurance scheme backed by the Government of India that is aimed at bridging the coverage gap of unaffordability by providing accidental death and disability insurance to uninsured poor adults. Reference: www.jansuraksha.gov.in	Central government	Ministry of Finance	Age: 18-70 years.	A bank account—single or joint (Aadhar would be the primary Know Your Client for the bank account) Payment of 12 rupees for the annual premium (renewable yearly).	Risk coverage is 2 lakh rupees for accidental death and permanent total disability and 1 lakh rupees for permanent partial disability. Permanent total disability is defined as total and irrecover- able loss of both eyes, or loss of use of both hands or feet, or loss of eyesight and loss of use of a hand or a foot. Permanent partial disability is defined as total and irrecov- erable loss of an eyesight or loss of use of a hand or foot.
Atal Pension Yojana Details: Atal Pension Yojana is a government-backed pension scheme in India targeted at the unorganised sector. Reference: www.jansuraksha.gov.in	Central government	Ministry of Finance	Age: 18-40 years. Unorganized sector worker not associated with any statutory social security scheme. Persons who work in the private sector or are employed in occupations that do not give them the benefit of a pension. Exclusion criterion: Applicant should not be a tax payer.	 A duly filled registration form. Bank passbook. Aadhar and mobile number (required if subscriber wants updates via mobile, but not mandatory). 	 Fixed pension for the subscribers, ranging between 1,000 to 5,000 rupees, if he/she joins and contributes between the ages of 18 years and 40 years. The contribution levels would vary and would be low if subscriber joins early and higher if he/she joins late. 50% of total contribution co-contributed by the Central government for each subscriber for the period of 5 years.

Name and details of the scheme	Introduced by	Ministry	Eligibility criteria	Documents required	Benefits offered
Indira Gandhi National Old Age Pension Scheme (IGNOAPS) Details: IGNOAPS is administered under the National Social Assistance Programme, a welfare program that is implemented in both rural and urban areas. This scheme aims to ensure a respectful life for elderly persons who live below the poverty line by providing them financial assistance. Reference link: http://nsap.nic.in/	Central government	Ministry of Rural De- velopment	Age: 65 years or above. An applicant from the category of below poverty line (BPL).	 Aadhar card. BPL ration card. Bank details. Proof of address. Proof of age. A duly filled application form. 	Central government's contribution: • Monthly pension of 300 rupees to beneficiary in the age group of 60–79 years. • Monthly pension of 500 rupees to beneficiary in the age group of 80 years and above, States can increase the pension amount by adding state contribution.
Indira Gandhi National Widow Pension Scheme (IGNWPS) Details: IGNWPS is administered under the National Social Assistance Programme, a welfare program that is implemented in both rural and urban areas. This scheme aims to ensure a respectful life to widows who live below the poverty line by providing them financial assistance. Reference link: http://nsap.nic.in/	Central government	Ministry of Rural De- velopment	Age: 65 years or above. An applicant from the BPL category.	 Aadhar card. BPL ration card. Bank details. Proof of address. Death certificate of the husband. Proof of age (e.g., voter ID). A duly filled application form. 	Central government's contribution: • Monthly pension of 300 rupees. States can increase the pension amount by adding state contribution.
Indira Gandhi National Disability Pension Scheme (IGNDPS) Details: IGNDPS is administered under the National Social Assistance Programme, a welfare program that is implemented in both rural and urban areas. This scheme aims to ensure a respectful life to severely and multidisabled per- sons who live below the poverty line by providing them financial assistance. Reference link: http://nsap.nic.in/	Central government	Ministry of Rural De- velopment	Severely (disability categorized as 80% and above) and multidisabled persons— physical or mental disability. Age: 18-79 years. An ap- plicant from BPL category.	 Aadhar card. Certificate of disability. BPL ration card. Bank details. Proof of address. Proof of age. A duly filled application form. 	Central government's contribution: • Monthly pension of 300 rupees. States can increase the pension amount by adding state contribution.

Name and details of the scheme	Introduced by	Ministry	Eligibility criteria	Documents required	Benefits offered
National Family Benefit Scheme (NFBS) Details: NFBS is administered under the National Social Assistance Programme, a welfare program that is implemented in both rural and urban areas. NFBS aims to provide financial assistance to households below the poverty line in the case of death of the primary breadwinner. Reference link: http://nsap.nic.in/	Central government	Ministry of Rural De- velopment	 BPL house-hold. Age of the primary breadwinner between 18-59 years. Death of primary breadwinner due to natural or accidental causes. 	 Aadhar card. BPL ration card. Bank details Proof of address. Death certificate of primary breadwinner. A duly filled application form. 	20,000 rupees to the immediate family of the primary breadwinner.
Pradhan Mantri Kaushal Vikas Yojana (PMKVY) Details: The objective of this PMKVY is to encourage skill development among youth by providing monetary rewards for successful completion of approved training programs. National Skill Development Corporation is the implementing agency of this scheme. Reference link: www.pmkvyofficial.org	Central government	Ministry for Skill Develop- ment and Entrepre- neurship	Any candidate of Indian nationality who: Undergoes a skill-development training in an eligible sector by an eligible training provider. Is certified by approved assessment agencies during the span of 1 year from the date of launch of the scheme. Is availing of the monetary award for the first and only time during the operation of this scheme.	 Proof of identity. Bank details. Proof of address. School and college certificates. 	 All beneficiaries will receive skill education. Certification by the training partner at the end of successful completion of training. A monetary incentive to trainees (Direct Benefit Transfer) who have completed the training and have received the certification. Mentoring program in the post-training phase to support and guide trainees seeking employment opportunities.

Name and details of the scheme	Introduced by	Ministry	Eligibility criteria	Documents required	Benefits offered
Sanjay Gandhi Niradhar Anudan Yojana Details: The objective of this scheme is to provide social security to the marginalized population through financial assistance. Reference link: www.sjsa.maharashtra.gov.in	Maharash- tra state government	Social Justice & Special Assistance Depart- ment	Persons suffering from a critical illness such as tuberculosis, cancer, AIDS, and leprosy; destitute persons; or- phaned chil- dren; disabled persons; destitute widows; des- titute divorced women and women in process of divorce; wom- en freed from prostitution; outraged women; transgender. A person with minimum 40% of disability. Age: Below 65 years. Annual family income of the household up to 21,000 rupees. A person who is a resident of Maharashtra.	 Application form. Certificate of residence. Certificate of age. Certificate of income. Domicile certificate. Proof of the household belonging to the category of BPL. Certificate of incapacity (if applicable). Certificate of disease issued by the Civil Surgeon or Medical Superintendent of a Government hospital (if applicable). 	600 rupees per month for a single beneficiary. 900 rupees per month if there are 2 or more beneficiaries.
Madhu Babu Pension Yojana (MBPY) Details: The objective of MBPY is to provide social security to marginalized populations through financial assistance. Reference link: www.ssepd.gov.in	Odisha state gov- ernment	Social Security & Empow- erment of Persons With Disabilities Depart- ment	The applicant: Is of 60 years of age and above. Or is a widow (irrespective of age). Or is a leprosy patient with visible signs of deformity (irrespective of age). Or is a person of 5 years of age or above and unable to do normal work due to his/her deformity or disability or multiple disabilities. Or is a widow of an AIDS patient (irrespective of age and income criteria).	 Application form. Certificate of residence. Certificate of age Certificate of income. Domicile certificate. Proof of belonging to a BPL household. Any other documents based on applicant's eligibility (disability certificate, death certificate of husband for widows, etc.). 	 300 rupees per month per beneficiary, up to the age of 79 years. 500 rupees per month per beneficiary for the ages of 80 years and above.

Name and details of the scheme	Introduced by	Ministry	Eligibility criteria	Documents required	Benefits offered
			Or is an AIDS patient identified by the state/district AIDS Control Society or District AIDS Prevention Control Unit (irrespective of income). Or is an unmarried woman above 30 years of age belonging to a BPL family or has an individual income from all sources not exceeding 24,000/-rupees per annum, irrespective of the family income. Has family income from all sources not exceeding 24,000/-rupees per annum or is included on the BPL list (as certified by the concerned Tahsildar). Is a permanent resident/domicile of Odisha. Has not been convicted of any criminal offense involving moral turpitude. Is not in receipt of any other pension from the Central Government, or any organization aided by either Government		

Appendix 8. Indicative Patient Profiling and Assessment Tool

TB Patient and Family Need Assessment Form: Full Name of the Patient):______,

TB No.: ,Nikshay ID,

Sr no	Relation	First name	Age	Educa- tion	Occupa- tion	Income	Other Health Problems	Addic- tion, Specify	Remarks
1	Self								
2									
3									
4									
5									
6									
7									
8									

List of Social Schemes:

LIST OF SOCIAL			1		
	List of Social Schemes	Concerned members name	Priority as identified by Family	Priority as identified by TC	Remarks / Details (by Family or by TC)
	Immunisation				
H E					
A	ANC/PNC				
L	Family planning / Spacing				
T					
Н					
E	Pre-Primary Education				
D	Formal Education				
U	Halt School Drop-Out				
C	Non - Formal Education				
A T	Adult Education				
· 1	Vocational Training				
0					
N					
ECONOMIC	Employment				
STATUS	Savings & Budgeting				
	Loan Facilities				
	Birth Certificate (BC)				
DOC. /	Ration Card (RC)				
Legalisation	PAN Card / Aadhar Card				
	Housing Documents				
	Other Legal Doc.:				
FAMILY	Child Care / Child Development				
, aviil	Addiction Control				
ATMOSPHERE					
	Psychological Balance *				
	Settlement of Domestic Issues **				
SOCIAL	Non-Discrimination of Gender				
ICCLIEC	Alternatives to Child Labour				
ISSUES	Settlement of Neighbourhood conflicts				
	Healthier Environmental Hygiene				
Environment	Better Housing Conditions				
	Detter Flousing Conditions				

Further information or Comments:

Observation Monitoring

No	Visit Dates	Selected Schemes Agreed with family	Discussion	Outcome	Points for next follow up
1					
2					
3					
4					
5					
6					
7					

Appendix 9. Household precautions for tuberculosis patients (*Guidelines on Airborne Infection Control)

Patients with respiratory infections are potentially infectious. Patients and their family members should be educated on the importance and proper practice of handwashing, cough etiquette, and respiratory hygiene. Cough etiquette and sputum disposal should be discussed as important general hygiene issues for anyone with respiratory symptoms, not just the tuberculosis (TB) patient.

Specific measures to reduce exposure in households include:

- Houses should be ventilated adequately, particularly the rooms where people with infectious TB spend the most time. Natural ventilation is generally sufficient to provide adequate ventilation. Windows should be open for as long as possible.
- Smear-positive TB patients should spend as little time as possible in enclosed, crowded settings or in public transport till they are smear negative.

Patients and family members should be educated on collection and disposal of sputum. Simple options for safe sputum disposal that patients can be counseled on include:

- Dispose the sputum in paper (tissue or any other paper), and burn or bury it in the evening.
- Dispose the sputum in a pot with ash or lime, and bury the contents in the evening.





Summary

This toolkit has been developed based on the experiences of PATH's Challenge TB project implemented in three states of India. It is a compilation of the best practices and intends to provide guidance to you so that you can launch a Patient Provider Support Agency model with Drug Resistant Tuberculosis linkages as well as design patient support systems in your region. It is completely customizable as long as all the services provided are under the purview of the Standards of TB Care in India and Revised National TB Control Programme. It can be easily combined with models that are already implemented in your region.

To know more, please write to india@path.org