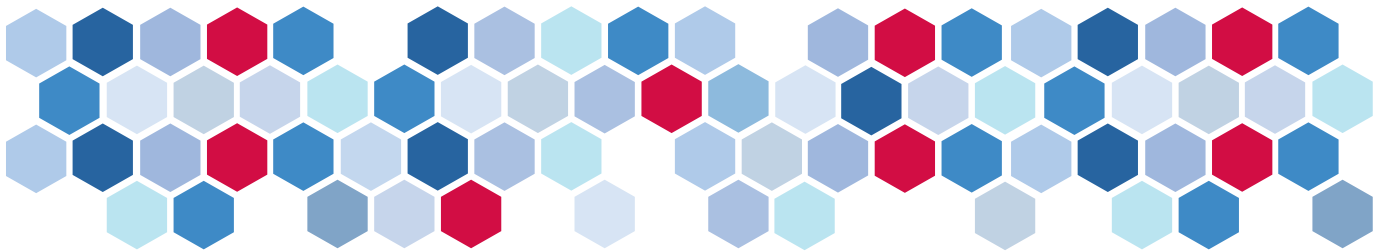




USAID
FROM THE AMERICAN PEOPLE

TB CARE II

Toolkit to Address Timely TB Case Detection and Treatment



University Research CO., LLC
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List of Acronyms

| | |
|--------|--|
| ACSM | Advocacy, communication, social mobilization |
| DHS | Demographic health surveys |
| DOTS | Direct observed treatment, short course |
| EQA | External quality assurance |
| HMIS | Health Management Information System |
| IPC/C | Interpersonal communication and counseling |
| IRV | Internal review board |
| M&E | Monitoring and evaluation |
| MDR-TB | Multi-drug resistant TB |
| MOH | Ministry of Health |
| NGO | Non-governmental organization |
| NTP | National tuberculosis program |
| PPM | Public private mixed activities |
| PVO | Private voluntary organizations |
| TB | Tuberculosis |
| UHC | Universal health coverage |
| USAID | United States Agency for International Development |
| WHO | World Health Organization |

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Background

An effective tuberculosis (TB) control program requires early diagnosis and immediate initiation into treatment to reduce transmission. Most TB transmissions occur between the appearance of coughing and a few weeks after the initiation of treatment. The longer TB patients stay in their communities without being diagnosed and treated, the longer they will be spreading TB bacteria. It is estimated that an untreated smear-positive patient can infect, on average, 10 contacts annually.¹

In many countries, TB cases are found through passive case finding, where patients present themselves to a health facility if they suspect they may have TB. This approach is dependent upon an individual with TB symptoms first recognizing that they have symptoms of tuberculosis, then making a decision to seek health care, and finally seeking care from a provider trained in the DOTS strategy who will follow approved standards for TB diagnosis and treatment.

TB delay occurs when a patient with TB symptoms does not get diagnosed and put onto treatment in a timely manner. Understanding and identifying the causes of delays in diagnosis and treatment initiation are critical for identifying points of intervention to reduce TB delay.

There are many different reasons why patients delay seeking TB care, diagnosis, and treatment initiation. The root causes of these delays are based both in the health system and with patients themselves. For example, some TB infected people are unaware that they have TB symptoms or may not understand how severe the disease can be. Even though TB diagnosis and treatment are free in most countries, many TB infected people delay going to a health care facility because they cannot pay for transport costs to the facility, which may be far away from their home, or take time out of their day to visit a health care provider. Many have repeated consultations with a multitude of healthcare providers without receiving a correct diagnosis. These providers include primary-level government health posts, which may have limited diagnostic facilities and poorly trained personnel; private practitioners with low

awareness of TB; and traditional practitioners or unqualified vendors.² Stigma also plays a critical role in affecting delays and may prompt people with TB symptoms to self medicate and buy drugs directly from drug outlets or use home remedies.^{3,4,5,6} Some providers' disrespectful treatment of poor people, vulnerable groups, or TB infected people may also deter patients from seeking a diagnosis for TB.⁷ Factors affecting delays in initiating appropriate treatment for TB include the inaccessibility of treatment for patients,⁸ lack of provider knowledge about standardized TB treatment protocols,⁹ poor communication of health care workers with patients about the appropriate duration of treatment,¹⁰ difficulty in procuring drugs,¹¹ lack of coordination between multiple health care structures,¹² and non-compliance with TB clinical practice guidelines,¹³ among others.

In 2011, the TB CARE II Project, funded by USAID, developed a framework for analyzing TB delay along with a set of tools to collect data on patient delays. TB CARE II then conducted field assessments using these tools in two high-burden TB countries—Bangladesh and Swaziland—in order to identify specific factors causing delay. Factors identified to play a major role in those countries included: patients' unawareness of the severity of TB symptoms; misinterpretation of the symptoms of TB; distance to the health facility; cost associated with transportation; fear of being diagnosed with TB, and the stigma that might follow such diagnosis; and preference for untrained non-DOTS providers. Additional tools were developed and tested through studies carried out in 2012 by TB CARE II in Bangladesh, Zambia, and Kenya to evaluate why there is the gap between TB standards and guidelines and actual TB health provider performance. These studies pointed out health system shortages that can contribute to delays in TB diagnosis and treatment, including delays in getting TB guidelines from the NTP to health care facilities; TB drug shortages; providers' insufficient knowledge about TB; inadequate supervision; gaps in information health providers communicated to TB patients (e.g., need for contact tracing, not linking all patients to DOT support); and lack of recording systems for contact tracing.

Purpose of toolkit

The purpose of the Toolkit to Address Timely TB Case Detection and Treatment is to provide local TB and health program managers step-by-step assistance in understanding and identifying the possible reasons why people with TB symptoms delay in getting diagnosed and treated for TB. To do so, we provide practical assessment tools to measure causes of delay among different audiences (TB patient, TB health care provider, health facility manager, and NTP/district level manager) from the first signs and symptoms of TB to treatment initiation. In addition, we include a chart assessment tool with which you can measure actual times of TB delay (and assess where most delays within a health system occur) using TB recording and reporting registries from the time a patient enters a health facility with TB symptoms until s/he is diagnosed and put on treatment. Our sample tools are based on TB CARE II's field tested studies in Bangladesh, Swaziland, Kenya, and Zambia and can be adapted to specific country and/or program needs.

This toolkit provides guidance on how to collect data in selected areas, including designing a sampling strategy, pre-testing questionnaires, ensuring quality of the data collected, etc. In addition, it explains how to use the findings from the surveys for decision-making and provides examples of evidence-based interventions to address TB delays. In our document we point out that when designing interventions addressing patient delay it is important to remember that patients, the community, health providers (both public and private), and governments can work as partners in a positive and open relationship to improve TB care and enhance the healthcare process.

In addition, in both our assessment tools and examples for evidence-based interventions, we discuss the need for a shift towards targeted **active case finding**. The purpose of active case finding is to empower front-line health care workers, patients, and communities to be more assertive in recognizing TB symptoms and seeking appropriate care and treatment. Recent studies from high-burden TB countries demonstrate that improving case finding may save 10 times as many lives as the passive case finding approach proposed by the DOTS strategy alone.¹⁴

A Patient-Centered Approach to TB Care:

*In 2006, the World Health Organization (WHO), in partnership with TB patients around the world, created the **Patients' Charter for Tuberculosis Care** which outlines the rights and responsibilities of people with TB. It affirms that the empowerment of individuals living with TB is a major catalyst for effective collaboration with health providers and authorities, and is essential to help end the spread of TB in communities. Annex B provides a list of patients' rights outlined in the charter, which provide basic principles to consider when planning your interventions to address TB delays. (See Appendix C)*

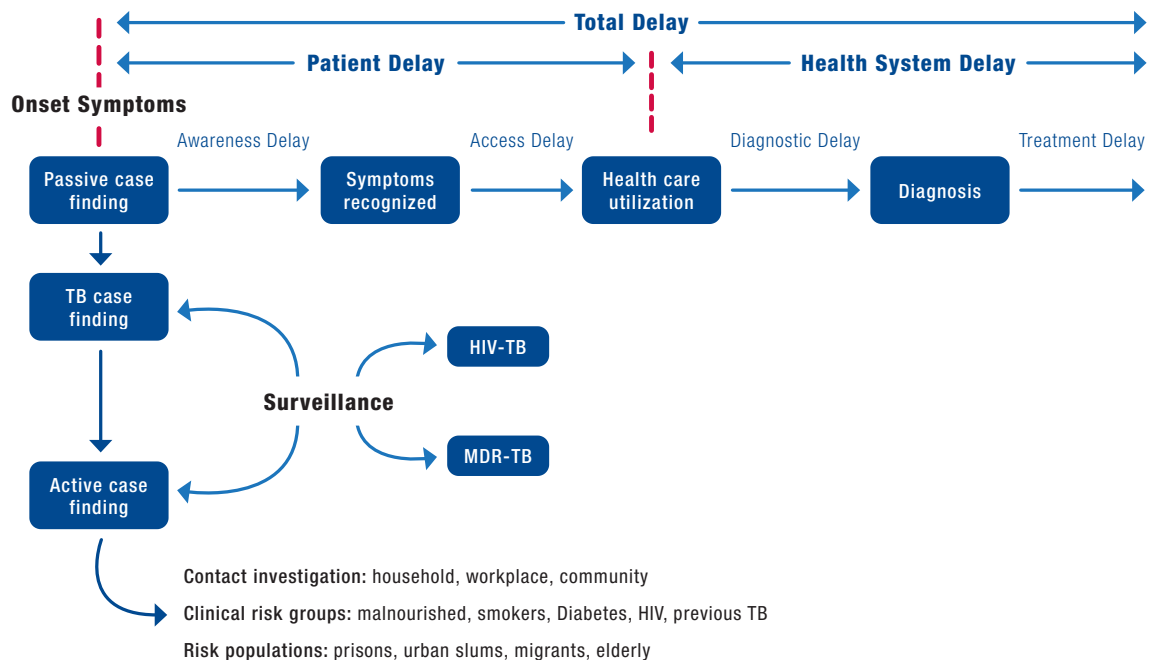
Why do people with TB symptoms delay in getting TB care?

Over the years, various studies have analyzed the causal factors for TB delays. Many of these studies define and measure delay differently.¹⁵ Based on much of the research that has been done to date, TB CARE II developed an “Analysis Pathway of Delay” that divides “TB delay” into distinct phases: “total delay,” “patient delay,” and “health systems delay” (see Figure 1).

- **TB total delay** is the time between the onset of TB symptoms and the patient initiating appropriate TB treatment.
- **TB patient delay** is the time between the onset of symptoms and the first contact with any health care service (formal or informal). Patient delay is comprised of:

1. **Awareness delay** – the time between the onset of the symptoms and the recognition of those symptoms as a disease that needs health care, and
 2. **Access delay** – the time from symptoms recognition to the first contact with a health care system (formal or informal)
- **Health systems delay** is the time between the first care-seeking behavior and receiving appropriate TB treatment. It also has two phases:
 1. **Diagnostic delay** – the interval between a patient arriving at any type of provider (public, private, traditional healers) and the patient receiving a TB diagnosis, and
 2. **treatment delay** – the interval between TB diagnosis and initiation of correct TB treatment.

Figure 1. Pathway for delays in TB diagnosis and treatment*



* Based on Knut Loennroth. Framework for improved, early case detection. DEWG meeting October 2009.

What do you want to assess?

How can you identify the root causes of TB delay? Several years ago the “Cough to Cure Pathway” was developed as an analytical and planning tool to map out ideal TB patients’ behaviors from the first sign of symptoms (cough) to treatment completion (cure) (see Figure 2).¹⁷ The Cough-to-Cure Pathway is an effective framework to identify and organize obstacles to TB diagnosis and treatment that are related to patient factors, provider factors, community behaviors, and the health system itself.

For this toolkit we have developed a framework (see Figure 3) that combines and expands both the “Cough to Cure Pathway” and the “Pathways to Delay”. Our framework shows that patients, communities, and health systems affect TB delay in appropriate care seeking (i.e., patient delay) as well as delay in diagnosis (i.e., health system delay).

Obstacles affecting delay include:

Patients/Communities

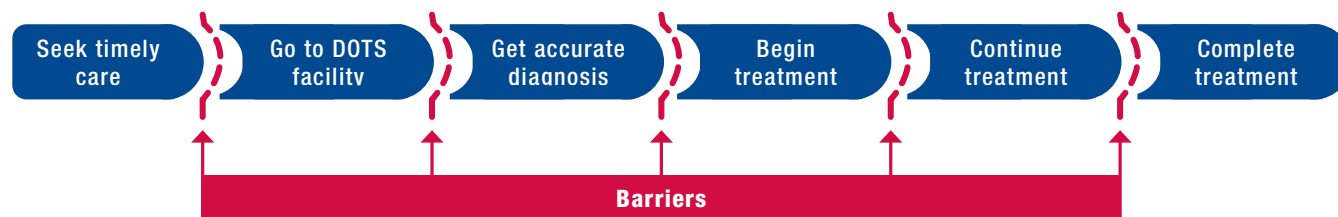
- **Patient access** – Time, cost, distance to DOTS facilities. Misperceptions of cost for diagnosis and treatment (patients not aware of TB services being covered in NTP facilities).
- **Patient knowledge** – Poor knowledge of TB symptoms, TB care and cure; low perception of TB risk.
- **Patient risk perceptions** – Perception of risk associated with the TB symptoms.
- **Patient attitudes toward health system/perception of services** – Patient’s previous experiences with government health facilities (e.g., inconvenient hours, long waiting time, dirty and crowded facilities); treatment by health staff; preference for non-DOTS health services.
- **Patient receiving care from multiple providers** – Patients receiving care for TB symptoms from multiple providers within the same or in different facilities.
- **Self medication** – Patient’s self-medication with homeopathic or unprescribed TB drugs.

- **Stigma/gender norms** – Community norms regarding whether women need to be accompanied by men to health clinics; decision-making powers of women regarding their health; how people with TB are treated/perceived in their communities.
- **Passive case finding** – Availability/lack of availability of systematic active case finding outside of health care facilities (e.g., among current and former workers in workplaces with silica exposure; TB screening in prisons; vulnerable sub-populations with very poor health access—urban slum dwellers, homeless people, people living in remote areas, indigenous populations, migrants)

Health Care System

- **Provider knowledge** – Provider knowledge of correct diagnostic, referral, and treatment procedures. Poor knowledge and/or compliance with TB diagnostic and treatment protocols as well as lack of experience with TB patients can result in patients needing to make multiple visits to obtain the TB diagnosis. Private providers’ lack of knowledge of TB services being provided free of cost in NTP facilities.
- **Provider interpersonal communication and counseling** – Quality of interpersonal communication and counseling between a provider and his/her client. Provider gives patient unclear, incomplete, incorrect, or delayed messages about TB diagnosis or treatment.
- **Provider stigma** – Providers’ (including health care workers) negative attitudes toward TB patients. Sometimes this is related to their perception of TB as a disease of the socially marginalized and the perceived danger of becoming infected by treating TB patients.
- **TB strategies and guidelines** – Availability of TB strategies and guidelines at national and local levels; provider compliance with guidelines.
- **TB training and supervisory system** – Availability of a functioning TB training and supervisory management system. Insufficient training of providers (public, private,

Figure 2. Cough to cure pathway



and informal) in TB diagnosis and treatment protocols. High rotation of personnel resulting in new personnel not being trained. Existence of a functional TB supervisory system. Supervision being conducted as often as often as stipulated by TB guidelines. Adequate follow-up being provided.

- **Referral mechanisms** – Functioning referral mechanisms between non-DOT providers and DOT providers. Private providers and informal providers’ failure to refer patients to DOT services. Insufficient public private mix (PPM) activities for referral of TB suspects, including the informal sector.
- **Passive case finding** – Availability/lack of availability of active case finding within health facilities (e.g., systematic screening of household contacts and other close contacts of people with TB; screening of people living with HIV).
- **Drug/diagnostic kit management** – Procurement and forecasting, storage and distribution of TB drugs.
- **Health management information system** – Availability of functioning Health Management Information System (HMIS) for TB
- **Laboratory systems** – Participation of laboratories in external quality assurance (EQA); coordination between laboratories and health clinics to report test results; sufficient human resources in labs.
- **Insurance mechanisms covering TB services** – To what degree people with TB symptoms are covered by a health insurance scheme that covers TB services. To what degree adequate coverage for TB diagnosis and treatment is provided at chosen health facilities. Whether perceived quality of TB care (i.e., long wait times at clinics, etc.), despite the fact that this care is free, is a disincentive for service utilization.

You can use **Figure 3** as a visual planning tool for assessing where the barriers causing delay are in the pathway and for selecting appropriate interventions. In the next sections, we will discuss how to collect information on TB delays according to individual, group, and health systems factors. To

Phases of data collection

Identify factors causing delayed diagnosis and treatment for TB by conducting surveys in-country, we have divided data collection into 3 phases:

1. **Pre-implementation Phase:** involves activities such as meeting with project stakeholders and local experts, assessing data needs, designing a sampling strategy, adapting the survey instruments, and training supervisors and interviewers.
2. **Field Implementation Phase:** involves actual collection of data in selected sample sites.
3. **Post Implementation Phase:** involves entering and analyzing the data, disseminating findings, and using the data for decision-making.

The steps required for each of these phases are outlined in **Box 1**. Details for some of the steps are described further under each phase.

Pre-Implementation Phase

Adapt Survey Instruments

Review existing data to see what information already exists in your country about TB and the causes of TB delay. Useful information may be found in Demographic Health Surveys (DHS) or other national TB-related surveys, health service statistics, other qualitative or quantitative studies from research and/or non-governmental organizations (NGOs) or private voluntary organizations (PVOs) conducted in your country. In addition, engage local partners and stakeholders (e.g., Department of Health, local universities, NGOs, community leaders, etc.) to not only build consensus regarding your study but also to listen to their concerns and priorities.

You may want to conduct formative research that reflects the local context for your survey. Through formative research you

can investigate the why and how of decision-making affecting TB delay from the patient and community points of view as well as from the health care system. There are many different approaches for collecting formative data. The more common include observations (i.e., provider observations; patient observations), focus groups, and in-depth interviews. You may also want to consider using qualitative research after you conduct your TB delay surveys to provide a more in-depth understanding of the reasons for TB delay—from the individual level to the systems level.

What should we include in the survey?

In Appendix A, we provide different sample surveys that measure delay. However, based on your research findings, these surveys may need to be adapted to your local context. Before adapting the survey instruments, decide what you want the purpose of your surveys to be and what you plan to do with the results. For example, do you want the surveys to be mainly:

- **Exploratory:** The purpose of these types of studies is to collect information on TB delays to help prioritize interventions to address those delays.

- **Provide baseline/endline information:** The purpose of these types of studies is to assess changes by first collecting information before any interventions are carried out and later repeating the same data collection after interventions have been implemented. If you plan this type of survey, you will need to pay particular attention to sample size. Also, you will need to make sure that your questions are relevant to the activities you will be implementing.

Depending on the purpose of your survey, you may want to add or delete certain questions to the sample survey questionnaires.

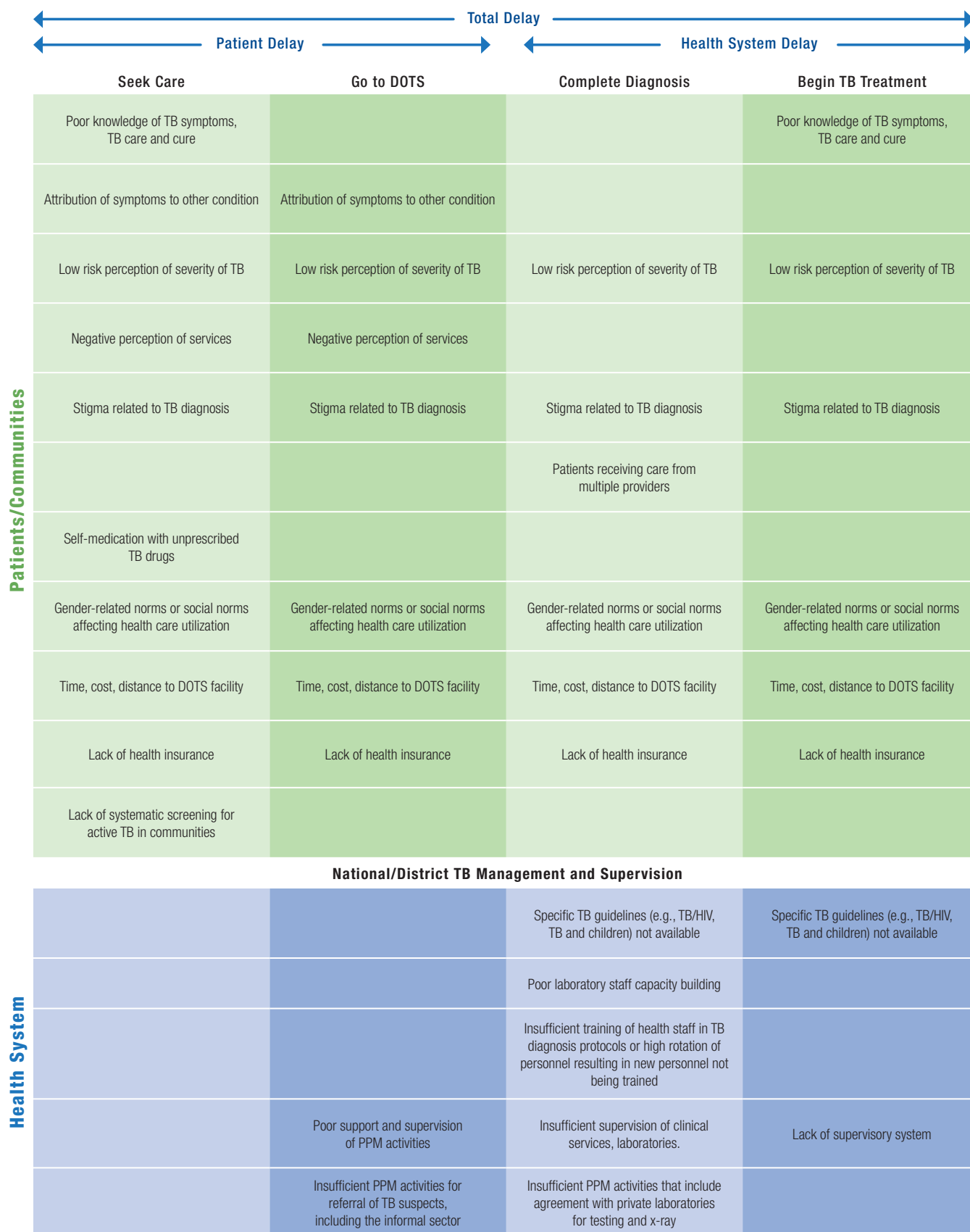
Identify survey population

Decide who will be included in your survey. This will depend on your study objectives as well as logistics and practicalities. Given that TB delay is influenced by patient and health system factors, to get a holistic picture of the causes of TB delay, you may want to include all of the populations suggested in Table 1.

Table 1. Survey populations, type of assessment, and selection method

| Population | Type of Assessment | Selection Method |
|--|---------------------------------------|--|
| TB cases | Patient questionnaire | Exit interviews at district or provincial public TB facilities (ages x to x) |
| TB Patients | Patient questionnaire | Exit interviews at district or provincial public TB facilities (ages x to x) |
| TB health provider (trained and untrained) | TB health provider questionnaire | In-person interview |
| Health facility manager | Health facility manager questionnaire | In-person interview |
| NTP manager | NTP manager questionnaire | In-person interview |
| Chart assessments (e.g., TB suspect register, TB laboratory register, TB treatment register, TB patient treatment form, case finding form) | Chart assessment tool | Chart audits |

Figure 3. Framework for Causes of TB Care Seeking and Treatment Delays*



| | Seek Care | Go to DOTS | Complete Diagnosis | Begin TB Treatment |
|--|---|--|--|---|
| | | | | Drug management and supply chain delays |
| | Lack of insurance mechanisms covering TB for poor | Lack of insurance mechanisms covering TB for poor | Lack of insurance mechanisms covering TB for poor | Lack of insurance mechanisms covering TB for poor |
| | Health Providers | | | |
| | | | Poor provider communication with patient regarding need for timely treatment | Provider interpersonal communication and counseling. Delay in communicating results to the patient. |
| | | | Health provider stigma | Health provider stigma |
| | | | Poor provider knowledge and compliance with TB diagnostic and treatment protocols | Poor provider knowledge and compliance with TB diagnostic and treatment protocols |
| | Health Facilities | | | |
| | | Referral mechanism between non DOT providers and DOT providers | | |
| | | | High rotation of staff resulting in a patient being seeing by multiple health workers "vicious circle of care" | |
| | | | Poor quality of patient management (hours, wait-time); poor physical environment (dirty; crowded) | Poor quality of patient management (hours, wait-time); poor physical environment (dirty; crowded) |
| | | TB drugs being sold in retail pharmacies without prescription | | Stockouts due to poor drug/diagnostic kit management |
| | | Lack of functioning HMIS system | Lack of functioning HMIS system | Lack of functioning HMIS system to understand date of treatment initiation |
| | Laboratories | | | |
| | | | Stocks out of lab supplies (sputum containers, lab reagents, etc) | |
| | | | Inadequate lab performance (sample processing and smear reading, samples lost or cross contamination, etc) | |
| | | | Diagnostic laboratories not participant in an external quality assurance (EQA) program | |
| | | | Poor coordination between lab and health clinics to report test results | |
| | Pharmacies | | | |
| | | | | Stock out due to poor drug management |
| | | | | Drugs being sold in retail pharmacies without prescription |

Health System (Continued)

**Adapted from "Cough to Cure: A Path of Ideal Behaviors in Tuberculosis Control"*

Box 1: Survey Phases*

Pre-Implementation Phase

Assess Information Needs and Incorporate Stakeholders and Local Experts

- Consult existing data sources and review existing project documents (e.g., NTP, existing quantitative and qualitative surveys, data from PVOs, NGOs working in the same project areas)
- Meet/collaborate with project stakeholders

Make Administrative and Logistical Preparations

- Determine survey dates/timelines
- Develop logistics and budget plan for all phases of survey

Determine What/From Whom/How Information Will Be Collected

- Identify survey indicators and develop analysis plan
- Conduct formative research to identify local information needs, terms/concepts to be included in survey
- Identify survey targets (e.g., TB patients, persons presumptive of TB, TB health care providers, etc.)
- Design sampling strategy
- Select sample areas
- Adapt/translate/back-translate questionnaire(s)
- Pretest questionnaires; revise as necessary based on pretest

Maximize Quality of Data Collected

- Develop/adapt training materials for supervisors/interviewers
- Develop procedures for quality control during data collection/data entry
- Recruit and train field personnel (supervisors, interviewers, etc.)
- Field-test questionnaires with interviewers/supervisors; make final revisions

Data Management

- Develop data entry, error-checking, and data analysis programs
- Plan tabulation, analysis, and feedback sessions (post-data collection)

Survey Implementation Phase

- Conduct interviews
- “Clean” questionnaires in the field before tabulation and analysis
- Enter data electronically as questionnaires are reviewed and submitted by field supervisors
- Refine analysis programs (if needed)

Post-Implementation Phase

- Complete data entry/data cleaning
- Tabulate/analyze survey data
- Identify and prioritize problems
- Match interventions to root causes
- Draft survey report
- Hold community feedback session(s)
- Share preliminary findings with NTP, and other stakeholders
- Develop action plans to address problems identified by survey

* Adapted from CORE. *Knowledge, practices, and coverage survey 2000+ field guide*. Calverton, Child Survival Technical Support Project, 2003.

Design a Sampling Strategy

To design your sampling strategy you will first want to choose your **sampling frame**. This is the list of target population from which you will draw your sample. For example, you may want to choose a sampling frame according to lower TB case notification rates or higher number of TB cases, or areas where certain interventions have/have not been implemented (e.g., PPM). Next, you will want to decide what **sample design** you want to use. There are two types of sample designs: probability and non-probability. Probability designs depend on the laws of chance to be included in the sample (e.g., through simple random sampling). Non-probability designs rely on human judgments. The advantage of probability designs is that you can more confidently generalize the findings to a larger population. The disadvantages are that these types of sampling often require much larger numbers of populations and tend to be more time consuming and costly to carry out. Try to seek the help of a statistician to provide guidance on the type of sampling best suited for your survey and the sample size required.

In practice, most survey designs involve combinations of different sampling methods. For example, the TB CARE II study assessing provider adherence to TB guidelines in Bangladesh used following sampling strategy:

A cross-sectional design was used to collect data from NTP managers at the national and district levels; facility managers at public and private facilities at district and sub-district levels; public, NGO, and private health care providers who screen and treat TB patients/ persons with presumptive TB; and TB patients/ person with presumptive TB. The national level TB managers were selected purposively to ensure adequate representation from those in charge of TB decision-making and supervision. Purposive sampling was used to select 10 of Bangladesh's 64 districts, based on their lower TB case notification rate. Sub-districts/ upazilas, unions and villages were selected by random sampling to reduce sampling bias. Each facility had only one facility manager and one health service provider in charge of TB service delivery, so these professionals were chosen through purposive sampling. TB patients at the facilities were selected randomly and only from public facilities because of greater patient flow.

The World Health Organization through its Stop TB program offers a helpful resource in understanding more about sampling and sample sizes (see next column).

Useful Reference:

Priorities in operational research to improve tuberculosis care and control. World Health Organization. 2011. – see p. 59

<http://stoptb.org/assets/documents/resources/publications/technical/StopTB%20Guide.pdf>

Ethical issues and considerations

As in most studies involving human subjects, you will want to make sure your study meets the ethical guidelines of your country. You may need to submit the study protocol to an internal review board (IRB) for approval prior to carrying out the surveys. In addition, you may need to get approval letters from the NTP and MOH. Once you start your survey, you will want to first confer to participants the purpose of the study and nature of the questions that will be asked, and then obtain informed consent from each study participant prior to their interview. In addition, it is important to explain that the participants' responses will remain confidential and anonymous and will be used for the study purpose only.

Pre-test Instruments

Before administering the surveys, pre-test each of them with a small number (e.g., 10) of respondents randomly selected from each survey's intended populations. If the surveys need to be translated, translate them before pre-testing. Ideally, translated surveys should be back-translated by someone other than the first translator to make sure that the translation is as accurate as possible. Once the survey is fully translated, it is ready to be pre-tested. The purpose of the pre-test is to find out:

- Whether there were any questions the respondents did not understand
- Which questions did not seem necessary
- Whether the words and phrases used in the surveys mean the same thing to respondents as to survey designers
- Whether the skip patterns between questions work properly

Modify the questions based on the results of the pre-test, keeping in mind that additional changes may be made after the interviewer training. See “**Box 2: Tips for Successful Pre-Testing**” for more information.

Field Implementation Phase

Training of supervisors and interviewers

First, it is important to put together a strong survey team – consisting of field interviewers and survey supervisors. Usually the training of interviewers lasts around 2-3 days. Ideally, you should hold a one-day overview training with field supervisors before the interview training starts. This overview session serves to:¹⁹

- Discuss purpose of the survey
- Discuss roles of supervisors and interviewers
- Review the questionnaire item by item
- Review respondent selection protocol
- Review proper interview and supervision techniques
- Review proper informed consent procedures
- Practice and interview, with feedback
- Review quality-control procedures in the field
- Discuss the role that supervisors play during interviewer training

The training itself should be attended by the survey supervisors and can include:²⁰

- Purpose of survey
- Content of questionnaires
- Proper interviewing techniques
- Field procedures, including selection of respondents
- Practice interviews through role plays
- Final field testing of questionnaire before data collection begins
- Practice of quality control measures by supervisors, such as reviewing completed questionnaires for errors

Gathering survey data

Quality control is essential in gathering survey data. Before collecting the data, ensure that there is a clear strategy for quality control of data collection.

It is advisable that each supervisor observes at least one interview per interviewer a day. During this process, the supervisor should not interrupt the interviewer, but rather quietly take notes on whether:²¹

Box 2: Tips for Successful Pre-Testing

1. Let the respondents know that you are pre-testing the survey instruments, and that you would like their feedback if any questions are unclear.
2. The respondents are the experts when it comes to understanding the questions. However, you must ultimately decide which of their suggestions are useful and which are impractical.
3. Look at the responses to any open-ended questions included in the instrument. Are the responses as detailed as you were expecting? If not, check to see if the wording, positioning or spacing of the question is sufficient.
4. Are there a lot of "do not know" responses? This may indicate a poorly constructed scale or unclear or inappropriate wording.
5. See if there are any questions that received more than one response, no response, or write-in answers. If this is the case, re-examine and refine your response scales.
6. Ensure that respondents had no trouble following instruction and skip patterns.
7. Time how long it takes to complete each survey. Questionnaires that are too long may frustrate your respondents or interviewers.

From: WHO. Stop TB Partnership. ACSM for TB control: A guide to developing knowledge, attitude and practice surveys. January 2008.

- respondent was selected correctly
- interviewer introduced him/herself correctly
- consent form was read at the beginning of the interview
- background information was filled out correctly (e.g., name of district, date, etc.)
- interviewer spoke clearly and slowly during the interview
- correct skip patterns were observed
- interviewer read questions exactly as written
- interviewer wrote legibly on the questionnaire
- interviewer did not react positively or negatively to respondent's answers either through words or body language.

After the interview, the supervisor should sit with the interviewer in a quiet place and review the notes he/she took for improvement if necessary.

Post-Intervention Phase

Data analysis

The first step in data analysis is to “clean” the data. This entails manual checks of the data after it has been collected to make sure that skip patterns are correct, responses are readable, and respondents have not selected conflicting answers (e.g., both “yes” and “no” are marked). If responses are conflicting, they will need to be eliminated from the questionnaire.

Next, you will want to develop a data analysis plan in which you will outline how the data will be analyzed. The data analysis plan will detail your survey objectives, the key questions that will answer each objective, and what analysis will be done for each specific question (e.g., frequency count, or cross-tabulation to highlight differences between population groups). You should then code all of the data and list the codes in a “codebook.” Next, choose a software for entering and analyzing the data (e.g., SPSS, Excel) and for presenting the data in a format that is easily understood (e.g., tables, charts, etc.).

There are many different types of interventions you can use to reach your target audiences. Survey results will illustrate whether the TB delay in your area is mainly attributed to the patient and his/her community, the health system, or both. If the patient component of delay is strong in your assessment, you may want to place more emphasis on behavior change communication programs among patients and their communities. If the delays are attributed more to health systems, you may want to focus your interventions more on addressing systemic issues such as ensuring continuity of services, availability of drugs, sound TB contact tracing or active case finding practices, engagement of all care providers through public-private mix (PPM) strategies, as well as changing behaviors of providers, etc. Examples of all of these types of interventions were described in Chapter 3.

Most likely, the causes of TB delay in your country or local area can be attributed to various social and economic issues as well as problems within the health service delivery system. These issues can lead a patient to delay seeking care or to seek care from an unqualified source. In order to prioritize interventions, you will need to think about:

- The relative importance of one cause of delay compared to another
- The feasibility of addressing specific causes of delay within a short to medium time period
- The cost/benefit of addressing one cause versus another
- The likely interaction and interchange between various causes, which require a joint effort to address
- The human resources needed to address different types of interventions

Match interventions to root causes

All activities to ensure a patient enters into effective treatment faster should be built around the patients themselves and their communities. A patient centered approach demands respect

Figure 3. Overview of intervention by root causes of delay

| Total Delay | |
|--|------------------------------------|
| Patient Delay | Health System Delay |
| Active case finding | System improvements |
| Behavior change patients and communities | Supportive health service delivery |
| Supportive health service delivery | |

for patients' rights as individuals and partners in TB care and control, and recognizes their unique circumstances and vulnerabilities. The TB Patients' Rights Charter²² emphasizes the right for TB patients and community members alike to have knowledge of this disease, how it was caused, and how it can be diagnosed and cured. The hope is that knowledge will empower people and communities to take an active role in recognizing TB symptoms, approaching health services, and promoting active participation in supporting TB patients. The Charter also stresses that patients have an inherent right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination. Patients that trust their health providers will be more likely to seek attention promptly and to adhere to the TB treatment, resulting in reduction of TB delays, improved cure rates, and a reduction of TB transmission.

A patient-centered strategy focuses on: engaging all stakeholders (e.g., NTP, policy makers, health care providers, NGOs, CBOs, patients and communities); recognizing patients' rights; enabling partnerships between stakeholders, patients, and providers; empowering and activating patients and communities to gather and share experiences; and monitoring and documenting (e.g., involving patients and communities in planning, monitoring, and documenting TB care activities).²³ In addition, throughout the toolkit, we point to useful resources that may help you gain a greater understanding of different topic areas covered in this manual.

In **Appendix B** we provide examples of interventions to reduce TB delay, many of which encompass the patient centered approach to TB. The interventions are based on the barriers related to delay that you identified in your surveys. These interventions are described in more detail below.

System Improvements

Clinical Guidelines: Create a system to ensure dissemination, availability, and awareness-raising of existing (especially newly developed) TB guidelines to all national and district-level NTP managers and public and private health care facilities from national to community levels. Work with national-level stakeholders to develop TB guidelines that do not yet exist.

Human resource development: Includes: training and continued education of all health care workers (including community health workers) involved in TB control; coordination between the NTP and Human Resources for Health (or equivalent) departments regarding staffing, filling of vacancies, and retention packages; supportive supervision; TB screening among health care workers (including community health workers).²⁴

Continuity of services: The delivery of care by the same health care provider throughout the course of treatment (where appropriate), and appropriate and timely referral and communication between providers. This includes integrating TB service delivery and information into health care services such as maternal health, child health, etc. as well as improving TB/HIV integration and coordination (i.e., referrals, diagnosis of co-infected patients). Examples of continuity of services include:

TB Drugs

- Ensure uninterrupted and timely supply of anti-TB drugs—including MDR-TB drugs—at all health care facilities, particularly at the union and village levels.
- Ensure continuous funding of drugs so as to avoid drug shortages. Additionally, you will need to ensure adequate follow-up on supervisory mechanisms to ensure timely drug forecasting and procurement.

Record Keeping

- Ensure a functional TB record-keeping system throughout the NTP network. This includes having data on TB/HIV co-infected cases, MDR-TB cases, and an adequate contact-tracing mechanism. One positive example of this is in Bangladesh where the NTP is currently working on incorporating TB/HIV co-infected cases in the recording sheets even though HIV prevalence among the general population is very low.

- Initiate a system for issuance of contact slips and follow up using community health care providers. This will increase case notification rates, especially for child TB cases which have a low case notification rate. In addition, it is recommended that facilities have a contact registry.

DOTS support

- Ensure that all providers link TB patients with community DOTS providers.
- Ensure that providers follow up and ask TB supporters about patient compliance with treatment regimens or check the patient treatment card provided by the TB supporter.

Other support

- Ensure that there is a system in place to provide TB patients with other needed support, so that they get tested for TB, initiate treatment, and do not default on treatment. Other types of support include: flexible clinic hours, multiple clinic locations, increasing numbers of DOTS providers, linkages to community-based services, transport subsidies, increasing hours DOTS providers are open, increasing numbers of DOTS providers.

Active case-finding: A variety of active case-finding strategies for tuberculosis have been used in the past, however there is still little evidence available on the effect of active case finding on TB. Current recommendations for active case finding prioritize risk groups with:⁴

- High TB prevalence (risk factor profile and/or poor access/delay)
- High risk of severe negative consequences for the individual if diagnosis is missed/delayed
- Low risk of harm to the individual from screening
- High transmission risk: potential impact of transmission within and beyond the risk group
- High feasibility and acceptability, reasonable cost

Strong recommendations

- Household contacts and other close contacts should be systematically screened for active TB
- People living with HIV should be systematically screened for active TB at each visit to a health facility
- Systematic screening for active TB should be done for current and former employees of workplaces with silica exposure

Conditional recommendations

- Systematic screening for active TB should be considered in prisons and other penitentiary institutions

Recommendations within health services

- Systematic screening for active TB should be considered in people with untreated fibrotic CXR lesions
- In settings where the TB prevalence is $\geq 100/100,000$ in the general population, systematic screening for active TB should be considered among people who are seeking care or who are in care and belong to selected risk groups (e.g. diabetes, undernourished, smokers, alcohol dependent, immunocompromised, elderly, pregnant women, etc)

Recommendations in the community

- Systematic screening may be considered for geographically defined sub-populations with extremely high levels of undetected TB ($>1\%$ prevalence)
- Systematic screening may be considered also for other sub-populations with very poor health care access, such as urban slum dwellers, homeless people, people living remote areas, indigenous populations, migrants, and other vulnerable groups.

Useful Reference:

WHO "Recommendations for Investigating Contacts of Persons with Infectious Tuberculosis in Low and Middle Income Countries" provides recommendations to assist national and local TB programs to develop case finding among people exposed to infectious TB: WHO. Recommendations for Investigating Contacts of Persons with Infectious Tuberculosis in Low- and Middle-Income Countries. 2010.

http://www.who.int/tb/publications/2012/contact_investigation2012/en/

Social protection for people with TB and TB affected households:

A large proportion of people with TB face catastrophic economic burdens related to the direct costs of health care (e.g., consultations, diagnostic tests, drugs and follow-up exams), the cost of transport and other expenses when seeking care and pursuing treatment, and the indirect costs associated with lost income due to illness and/or health-seeking and treatment requirements. Moreover, adverse social consequences due to TB stigma are common, including interruption of studies, loss of employment, divorce, and social isolation. The negative financial and social consequences often extend to the family of the person ill with TB. Even where TB

diagnosis and treatment may already be fully free of charge, other adverse financial and social costs are incurred by many. In order to combat these adverse consequences certain social protection measures are needed. These include measures created specifically for person affected by tuberculosis, and those deemed "TB sensitive" which encompass wider groups in need (i.e., all persons living in poverty). A measure is considered "TB sensitive" if it is supportive of the needs of those affected by TB, including:

- Schemes aimed at compensating for the adverse financial or social effects associated with TB diagnosis and treatment. These might include cash transfers, travel vouchers, and food packages;
- Legislation to protect people with TB from expulsion from the workplace, educational institutions, housing, transport systems, and even health institutions;
- Social insurance (such as "sickness insurance" or social welfare payments to compensate for income loss during illness or disability);
- Other instruments to promote and protect human rights, including eliminating stigma and discrimination, with special attention to gender, ethnicity, and protection of the vulnerable groups that are at particularly high risk of TB. These instruments should include capacity building for affected communities to express their TB needs and protect their rights; legal support if required for those subject to stigma and discrimination; as well accountability mechanisms for those who have impinged on human rights and those responsible for protecting these rights.

Universal health coverage (UHC): Equitable access to high-quality health care is a right that is essential for effective TB diagnosis, treatment and prevention. People ill with TB do not seek care knowing they are "TB patients," but as people with a health concern. UHC is fundamental for effective TB care and prevention as it is for all health goals. UHC is achieved through adequate, fair and sustainable prepayment financing of health care with full coverage combined with effective service quality assurance and monitoring and evaluation. This requires appropriate policies and regulations that ensure that all people can access and use the necessary health services, and that their families are protected from the catastrophic health costs associated with ill health. UHC can be financed through insurance premiums, taxes or other forms of revenue generation. Moving towards UHC is a process of progressive realization. This means that progress needs to be made on three fronts for all people: expanding the range of services available, the proportion of the costs of those services covered, and the proportion of the population covered.

For tuberculosis services specifically this means:

- Expanding access to the full range of services recommended in this TB Elimination Strategy under general health services, including regulated access and rational use of adequate and high-quality drugs, diagnostics and other supplies;
- Expanding the coverage of all costs, from consultations and tests for diagnosis through drug costs, follow-up testing during treatment and all related expenditures associated with staying in effective and complete preventive or curative treatment;
- Expanding access to services for all those in need, especially those vulnerable groups which have faced the most grave access barriers to date, and potentially worst outcomes given these barriers.

Engagement of all care providers through PPM: Public-private mix for DOTS (PPM DOTS) is an approach used to target a wide range of public and private health care providers not yet sufficiently linked to NTPs. Evidence has shown that PPM DOTS is a feasible and cost-effective strategy to increase case detection, cure rates, reach the poor, and reduce TB patients' financial burdens. Providers that can be targeted include, among others, medical colleges, general hospitals, health services under specific insurance schemes, prisons, army health services, NGOs, corporate health facilities, pharmacies, general practitioners, and informal private health care providers.²⁵

Supervision, Mentoring, Monitoring: Ensure that all providers—including village doctors and private sector providers—receive regular supervision, mentoring, and monitoring on TB on a monthly to quarterly basis. The following activities may be useful:

- Ensure that there is full or part-time dedicated and well-defined TB supervision capacity at the district, sub-district, union, and village levels.
- Develop an adequate feedback and follow-up system for supervision (both for supervision of providers as well as the supervisory system for drug forecasting and procurement) that goes beyond a written report and is provided after each supervisory visit

Capacity building of health care providers: A wide range of public and private health care workers involved in TB control need to be targeted, including the informal private sector which is often used by the poor and marginalized. The following activities may be useful:

- Train and provide continued education and job aids to health care workers in TB screening, appropriate referral to NTP services and/or treatment of TB, and effective communication with TB patients and persons with presumptive TB.

Useful Reference:

A document providing guidance for PPM DOTS implementation in countries has been developed by WHO Engaging all health care providers in TB control – guidance on implementing public-private mix approaches: 2006.

http://whqlibdoc.who.int/hq/2006/WHO_HTM_TB_2006.360_eng.pdf

- To increase the capacity of untrained and traditional healers to conduct correct diagnostic procedures, improve their referrals to NTP services. Untrained and traditional healers need to be aware of TB symptom screening methods so that they immediately refer those patients with symptoms to DOTS facilities for TB diagnosis and initiation of treatment. With proper education they will be able to provide DOTS follow up for treatment supervision at the community level and/or help to manage minor side effects.
- Include training and job aids for health care providers on interpersonal communication and counseling (IPC/C). Counseling is a critical need before and during treatment to improve treatment outcomes. Client trust and satisfaction with providers care will improve their health seeking behavior. Focus areas should include: emphasizing the need to screen TB contacts, asking a patient about other medications he/she is taking, explaining treatment regimens, reinforcing the importance of treatment adherence, explaining possible treatment side effects, treating patients with dignity and respect, providing timely and adequate TB information to patients and their family members, and communicating about TB/HIV.
- Assess the quality of TB training currently being conducted, including curriculum content and the skills of trainers. Since MDR-TB is a growing concern in many countries and newer technologies are being introduced (e.g., GeneXpert machines), ensure that training content includes MDR-TB diagnosis and treatment.
- Develop a functional Training Management Information System to coordinate with district-level NTP managers on newly recruited staff and those who need additional training. Develop a well-coordinated and continuous TB training mechanism. Ideally, this should be centrally funded with a training focal point at the NTP level, but operational at all levels to improve planning and ensure that you are meeting national and local training needs for public, NGO, private, and informal providers.

- Conduct regular monitoring and evaluation of participants who were trained to assess knowledge, skills, and intention to change practice behaviors after the training. Post-course follow-up trainings would be useful three–six months after the initial training.
- Develop TB job aids for informal health care workers, including an algorithm for identifying TB suspects and referrals.
- At the health facility level, during weekly clinical updates, discuss TB guidelines/standards. This will act as a refresher for service providers and onsite orientation for newly recruited staff before the latter receive any formal training.

Laboratory capacity and quality: Maintain and improve quality of existing laboratory network. Strengthen existing laboratory networks with more laboratories (where needed). Provide/strengthen External Quality Assurance of laboratories. Introduce laboratory accreditation schemes. Scale-up laboratory capacity to diagnose smear-negative TB, especially among people living with HIV. Expand laboratory capacity to test for first- and second-line drug resistance.²⁶

Behavioral change of patients and communities

Media material development and dissemination: Develop and disseminate tailored messages and innovative media materials through multiple sources focusing on, for example: symptoms of TB, where to find TB diagnostic and treatment services, reducing stigma to raise awareness of the severity of TB, and availability of free TB services. Messages and materials can be disseminated through health facilities, public plazas, community groups, NGOs, and the media (radio and TV), among others.

Social Mobilization: These are activities that empower local community and social networks to take an active role in the ACSM activities. Examples of activities include:

- TB community support groups that provide a reassuring environment to counter stigma and reduce negative or harmful attitudes towards TB patients among their family and community members.
- Health events and health classes to increase community awareness of TB transmission, infection prevention, and care, and to counter stigma.
- Developing regular support mechanisms at the community level to overcome access barriers – i.e. community organizing/fundraising to provide and arrange transportation to health care centers and provide for needs of community members to access and continue treatment (e.g., childcare, family support, etc.). Expansion of mobile

sputum collection units. Periodic community TB screening and sputum collection points.

- Increasing community-level involvement (e.g., through community groups, schools, religious institutions, private practice practitioner associations) to encourage demand for TB services in the community and improve early referral of patients.
- Conducting gender-sensitive outreach and communication targeting women, who may be less inclined to seek treatment than men due to: lower educational levels, limited authority to make decisions, fewer economic resources, and/or household and childcare duties that prevent them from leaving their home. Integrate information about TB and screening into other health care services such as antenatal care, reproductive health visits, child health and immunization visits.

Program advocacy: These activities help persuade decision makers and influential leaders to support TB prevention and care activities by developing or enabling policies and providing financial, logistical, and workforce resources. They also encourage people with TB symptoms to visit health facilities for testing, treatment, or information about TB. Additional advocacy interventions include:

- Conducting meetings with policy makers, local chambers of commerce, employers and workers associations to promote and ensure that TB patients' workers rights are respected.

Media advocacy: Encourage media outlets to cover TB-related topics regularly to raise problem awareness and communicate solutions.

Conclusion

The data that you collect with the help of this toolkit will provide the necessary information to not only measure causes of TB delay, but also design the proper interventions to address these delays. The tools presented in this guide need to be adapted and pre-tested to meet the needs of specific country programs. In addition, supplementary research such as focus groups and observations can complement the data gathered using the tools presented in this guide. It is also important to note that the sample interventions we have listed are mainly illustrative and will need to be adapted to country contexts to meet local and national TB control efforts.

Appendix A: Sample Surveys to Assess TB Delay

NTP Manager Survey

Name of District/Region: _____

Name of Interviewer: _____

Date: _____

Interviewer: Do not read responses, except where indicated. Mark all that apply.

Health clinic general

| Question | Selection | Comments |
|--|--|---|
| <p>Say: I would like to find out about what types of facilities diagnose and/or treat TB in your region/district? For each category of health facility, please give me the total number of health facilities, the number involved in DOTS, and the number that have laboratories for sputum smears.</p> | | |
| 1. Provider category | 2. Total number of health facilities in region/district | 3. # of which have laboratory facilities for sputum smear microscopy |
| Public primary health care units | | |
| Public hospitals | | |
| Medical colleges | | |
| For-profit private hospitals | | |
| For-profit private clinics | | |
| NGO (not-for-profit) hospitals | | |
| NGO (not-for profit) clinics | | |
| Others (e.g., pharmacies, traditional healers, etc.) | | |

Guidelines

| ID | Question | Selection | Comments |
|----|--|---|----------|
| 4 | <p>Does your office have the following national TB policies/guidelines available?</p> <p><i>(Read responses out loud. Mark all that apply)</i></p> | <p>1. <input type="checkbox"/> Adult TB</p> <p>2. <input type="checkbox"/> Pediatric TB</p> <p>3. <input type="checkbox"/> MDR/XDR</p> <p>4. <input type="checkbox"/> TB/HIV</p> <p>5. <input type="checkbox"/> Infection control</p> <p>6. <input type="checkbox"/> Essential drug list</p> <p>7. <input type="checkbox"/> PPM guidelines</p> <p>8. <input type="checkbox"/> TB communication strategy</p> | |

Training

| ID | Question | Selection | Comments |
|----|--|--|----------|
| 5 | How many facilities in your region/district have at least one person trained on TB? | _____ Number | |
| 6 | In your region/district, which personnel are trained in TB? <i>(Read responses out loud. Mark all that apply)</i> | 1. <input type="checkbox"/> Doctors 2. <input type="checkbox"/> Nurses 3. <input type="checkbox"/> Pharmacists 4. <input type="checkbox"/> Community Health Workers 5. <input type="checkbox"/> Non-traditional healers, village doctors 6. <input type="checkbox"/> Private practitioners 7. <input type="checkbox"/> Other (specify) | |

Drug/Supply Shortages

| | | | |
|----|---|--|--|
| 7 | Has the district/region experienced any TB drug shortages in 2012? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No <i>(Go to Q)</i> 3. <input type="checkbox"/> Don't know <i>(Go to Q)</i> | |
| 8 | For how long? | 1. <input type="checkbox"/> <1 month 2. <input type="checkbox"/> 1-3 months 3. <input type="checkbox"/> 3-6 months 4. <input type="checkbox"/> >6 months | |
| 9 | What were the reasons for the shortages? | 1. <input type="checkbox"/> Procurement not done on time 2. <input type="checkbox"/> Late delivery 3. <input type="checkbox"/> No requisition forms to order drugs 4. <input type="checkbox"/> Don't know 5. <input type="checkbox"/> Other <i>(specify)</i> | |
| 10 | Has the district/region experienced shortages of lab supplies for TB diagnosis in 2012? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No <i>(Go to Q)</i> 3. <input type="checkbox"/> Don't know <i>(Go to Q)</i> | |
| 11 | For how long? | 1. <input type="checkbox"/> <1 month 2. <input type="checkbox"/> 1-3 months 3. <input type="checkbox"/> 3-6 months 4. <input type="checkbox"/> >6 months | |
| 12 | What were the reasons for the shortages? | 1. <input type="checkbox"/> Procurement not done on time 2. <input type="checkbox"/> Late delivery 3. <input type="checkbox"/> No requisition forms to order drugs 4. <input type="checkbox"/> Don't know 5. <input type="checkbox"/> Other <i>(specify)</i> | |

Drug/Supply Shortage *continued*

| ID | Question | Selection | Comments |
|----|--|--|----------|
| 13 | Do you have supervisory mechanism in place in your region/district to ensure appropriate drug forecasting and procurement? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 14 | How often is this supervision conducted? | 1. <input type="checkbox"/> Monthly 2. <input type="checkbox"/> Quarterly 3. <input type="checkbox"/> Every 6 months 4. <input type="checkbox"/> Annually 5. <input type="checkbox"/> Don't know | |

Supervision of Laboratories

| | | | |
|----|---|--|--|
| 15 | Is there a system for external quality control for the laboratories providing TB diagnosis in your region/district? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 16 | Are laboratory supervisory visits being conducted in your region/district? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 17 | How often are these laboratory supervisory visits conducted? | 1. <input type="checkbox"/> Monthly 2. <input type="checkbox"/> Quarterly 3. <input type="checkbox"/> Every 6 months 4. <input type="checkbox"/> Annually 5. <input type="checkbox"/> Don't know | |

Supervision of health facilities

| | | | |
|----|---|---|--|
| 18 | Do you have a supervisory system in place for facilities providing TB services? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 19 | Is the supervisory system for TB only for government health facilities or also private health facilities? | 1. <input type="checkbox"/> Government 2. <input type="checkbox"/> Private 3. <input type="checkbox"/> Both | |
| 20 | Is the feedback being provided after each visit? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 21 | Is it written or verbal? | 1. <input type="checkbox"/> Written 2. <input type="checkbox"/> Verbal | |

Diagnostic Delay/Treatment Delay

| ID | Question | Selection | Comments |
|----|--|---|----------|
| 22 | Do you think that people with TB symptoms in this region/district delay in getting diagnosed for TB? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 23 | What do you think are the causes of delay in TB diagnosis? | Specify _____ | |
| 24 | Do you think that people with TB delay in getting treated for TB? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 25 | What do you think are the causes of delay in TB treatment? | Specify _____ | |
| 26 | Are there certain populations in your region/district who delay in getting diagnosed and/or treated for TB? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 27 | What types of populations delay? | Specify _____ | |
| 28 | Now, I will ask you about MDR-TB. Do you think that people with MDR-TB in your region/district delay in getting diagnosed for MDR-TB-TB? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 29 | What do you think are the causes of delay in MDR-TB diagnosis? | Specify _____ | |
| 30 | Do you think that people with MDR-TB delay in getting treated for MDR-TB? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 31 | What do you think are the causes of delay in MDR-TB treatment? | Specify _____ | |

TB access and support for TB patients

| | | | |
|----|---|---|--|
| 32 | Are there any incentive systems put in place at the regional/district-level to improve TB/MDR-TB diagnostics? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 33 | Does the NTP provide TB patients economic support for transportation? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |

TB access and support for TB patients *continued*

| ID | Question | Selection | Comments |
|------------|---|---|-----------------|
| 34 | Does the NTP provide TB patients food/nutrition support? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 35 | Are TB services in your region/district free of charge for all patients? | 4. <input type="checkbox"/> Yes 5. <input type="checkbox"/> No 6. <input type="checkbox"/> Don't know | |
| 36 | Are TB services in your region/district free of charge for all poor patients? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| PPM | | | |
| 37 | Is your region/district implementing a PPM strategy? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |

Health Facility Manager Survey

Name of Facility: _____

Location of Facility: _____

Name of Interviewer: _____

Date: _____

Interviewer: Do not read responses, except where indicated. Mark all that apply.

Health clinic general

| ID | Question | Selection | Comments |
|----|---|---|----------|
| 1 | Type of facility | 1. <input type="checkbox"/> Public primary health care unit 2. <input type="checkbox"/> Public hospital 3. <input type="checkbox"/> Medical college 4. <input type="checkbox"/> For-profit private hospital 5. <input type="checkbox"/> For-profit private clinic 6. <input type="checkbox"/> NGO (not-for-profit) hospital 7. <input type="checkbox"/> NGO (not-for-profit) clinic 8. <input type="checkbox"/> Other (<i>explain</i>) | |
| 2 | Inpatient only | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 3 | In addition to regular health care services, does the facility ever provide services for clients who are known to have TB or suspected to be TB infected? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (Stop Interview) | |
| 4 | How many days a week is the health facility open? | _____ Days | |
| 5 | What are the hours of operation? | 1. <input type="checkbox"/> Morning only 2. <input type="checkbox"/> Morning to afternoon 3. <input type="checkbox"/> Morning, afternoon, evening 4. <input type="checkbox"/> 24 hours | |
| 6 | In the last 12 months, how many new TB diagnoses were made at this facility? <i>(Ask to see record)</i> | _____ Number | |
| 7 | In the last 12 months, how many new MDR-TB diagnoses were made at this facility? <i>(Ask to see record)</i> | _____ Number | |

Health clinic general *continued*

| ID | Question | Selection | Comments |
|----|--|--|----------|
| 8 | In the last 12 months, how many patients were put on TB treatment? <i>(Ask to see record)</i> | _____ Number | |
| 9 | How many of those put on treatment were also diagnosed with HIV/AIDS? | _____ Number | |
| 10 | In the last 12 months, how many patients were put on MDR-TB treatment? <i>(Ask to see record)</i> | _____ Number | |
| 11 | Is this facility included in the national DOTS program? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 12 | From where does your facility receive referrals for TB management? | 1. <input type="checkbox"/> Government facilities 2. <input type="checkbox"/> Private doctors 3. <input type="checkbox"/> NGO Facilities 4. <input type="checkbox"/> Other <i>(explain)</i> | |
| 13 | How many staff provide TB diagnostic and/or treatment services at the facility? | _____ Number | |
| 14 | Is there a TB focal person for this facility? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |

Cost

Say: Are any of the following user-fee or charging practices applied to this facility for TB patients?

| | | | |
|----|---|---|--|
| 16 | For consultation | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 17 | For laboratory test | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 18 | For medications | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 19 | Are discounts or exemptions from fees allowed for some clients? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |

TB supervision

| | | | |
|----|---|---|--|
| 20 | Is there a TB supervisor for this facility? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
|----|---|---|--|

TB supervision *continued*

| ID | Question | Selection | Comments |
|----|--|--|----------|
| 21 | How often does the TB supervisor visit the facility? | 1. <input type="checkbox"/> Monthly 2. <input type="checkbox"/> Quarterly 3. <input type="checkbox"/> Every 6 months 4. <input type="checkbox"/> Annually 5. <input type="checkbox"/> Don't know | |
| 22 | In the last 12 months, how many times was the performance of TB staff assessed externally (from people outside the facility, eg. district hospital, funding agency)? | _____ times | |
| 23 | Is the result of external staff performance linked to staff salary or incentive payment? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |

Drug supply

| | | | |
|----|--|--|--|
| 24 | Has your facility experienced any TB drug shortages in the past year? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (<i>Go to Q</i>) 3. <input type="checkbox"/> Don't know (<i>Go to Q</i>) | |
| 25 | For how long? | 1. <input type="checkbox"/> <1 month 2. <input type="checkbox"/> 1-3 months 3. <input type="checkbox"/> 3-6 months 4. <input type="checkbox"/> >6 months | |
| 26 | What were the reasons for the shortages? | 1. <input type="checkbox"/> Procurement not done on time 2. <input type="checkbox"/> Late delivery 3. <input type="checkbox"/> No requisition forms to order drugs 4. <input type="checkbox"/> Don't know 5. <input type="checkbox"/> Other (<i>specify</i>) | |
| 27 | Has your facility experienced shortages of lab supplies for TB diagnosis in the past year? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (<i>Go to Q</i>) 3. <input type="checkbox"/> Don't know (<i>Go to Q</i>) | |
| 28 | For how long? | 1. <input type="checkbox"/> <1 month 2. <input type="checkbox"/> 1-3 months 3. <input type="checkbox"/> 3-6 months 4. <input type="checkbox"/> >6 months | |
| 29 | What were the reasons for the shortages? | 1. <input type="checkbox"/> Procurement not done on time 2. <input type="checkbox"/> Late delivery 3. <input type="checkbox"/> No requisition forms to order drugs 4. <input type="checkbox"/> Don't know 5. <input type="checkbox"/> Other (<i>specify</i>) | |

Policies/Guidelines

| ID | Question | Selection | Comments |
|----|---|---|----------|
| 30 | Are the following TB policies/guidelines available in your facility? <i>(Read responses out loud. Mark all that apply)</i> | 1. <input type="checkbox"/> Adult TB 2. <input type="checkbox"/> Pediatric TB 3. <input type="checkbox"/> MDR/XDR 4. <input type="checkbox"/> TB/HIV 5. <input type="checkbox"/> Infection control 6. <input type="checkbox"/> Essential drug list | |

Health management information system

| | | | |
|----|---|--|--|
| 31 | Does your facility have a TB register? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 32 | How frequently are reports on newly diagnosed TB cases submitted to someone outside of this facility? | 1. <input type="checkbox"/> Monthly or more often 2. <input type="checkbox"/> Every 2-3 months 3. <input type="checkbox"/> Every 4-6 months 4. <input type="checkbox"/> Every 6 months 5. <input type="checkbox"/> Never | |
| 33 | To whom are all reports sent? <i>(Mark all that apply)</i> | 1. <input type="checkbox"/> District hospital 2. <input type="checkbox"/> Regional public health department 3. <input type="checkbox"/> NTP 4. <input type="checkbox"/> Global Fund 5. <input type="checkbox"/> Other <i>(specify)</i> | |
| 34 | How frequently are reports on TB patients on treatment submitted to someone outside of this facility? | 1. <input type="checkbox"/> Monthly or more often 2. <input type="checkbox"/> Every 2-3 months 3. <input type="checkbox"/> Every 4-6 months 4. <input type="checkbox"/> Every 6 months 5. <input type="checkbox"/> Never | |
| 35 | To whom are all reports sent? <i>(Mark all that apply)</i> | 1. <input type="checkbox"/> District hospital 2. <input type="checkbox"/> Regional public health department 3. <input type="checkbox"/> NTP 4. <input type="checkbox"/> Global Fund 5. <input type="checkbox"/> Other <i>(specify)</i> | |

Diagnostic/Treatment Delay

| | | | |
|----|--|--|--|
| 36 | What is the estimated turn-around time for obtaining sputum microscopy results in your facility? | 1. <input type="checkbox"/> 1-3 days 2. <input type="checkbox"/> 4-6 days 3. <input type="checkbox"/> 7-10 days 4. <input type="checkbox"/> More than 10 days 5. <input type="checkbox"/> Don't know | |
|----|--|--|--|

Diagnostic/Treatment Delay *continued*

| ID | Question | Selection | Comments |
|----------------------|--|---|----------|
| 37 | What is the average time from receipt of result to starting a patient on TB treatment? | 1. _____ Days 2. <input type="checkbox"/> Regional public health department 3. <input type="checkbox"/> NTP 4. <input type="checkbox"/> Global Fund 5. <input type="checkbox"/> Other (<i>specify</i>) | |
| 38 | Does your facility experience delays in giving TB patients treatment? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (<i>Go to Q</i>) 3. <input type="checkbox"/> Don't know (<i>Go to Q</i>) | |
| 39 | What are the main causes for delay to provide TB treatment? (<i>Mark all that apply</i>) | 1. <input type="checkbox"/> No TB drugs available 2. <input type="checkbox"/> No TB beds available at facility 3. <input type="checkbox"/> Patient refusal for treatment 4. <input type="checkbox"/> Patient died before treatment initiation 5. <input type="checkbox"/> Other (<i>specify</i>) 6. <input type="checkbox"/> Don't know | |
| 40 | Did your health center diagnose/treat MDR-TB during the last year? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (<i>Go to Q</i>) | |
| 41 | What is the average estimated turn-around time for obtaining sputum culture results and DST? | 1. _____ Days 2. <input type="checkbox"/> Don't know | |
| 42 | What is the average time from receipt of results to starting patient on MDR/TB treatment? | 1. _____ Days 2. <input type="checkbox"/> No (<i>Go to Q</i>) | |
| 43 | Was there a delay in giving MDR/TB patients treatment? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (<i>Go to Q</i>) | |
| 44 | What were the main causes for delay to receive MDR-TB treatment? (<i>Mark all that apply</i>) | 1. <input type="checkbox"/> No MDR-TB drugs available 2. <input type="checkbox"/> No MDR-TB bed available at facility 3. <input type="checkbox"/> Patient refusal for treatment 4. <input type="checkbox"/> Patient died before treatment initiation 5. <input type="checkbox"/> Other (<i>specify</i>) 6. <input type="checkbox"/> Don't know | |
| IEC and IPC/C | | | |
| 45 | Does this facility offer education and counseling for all TB patients? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (<i>Go to Q 23</i>) 3. <input type="checkbox"/> Don't know (<i>Go to Q 23</i>) | |

IEC and IPC/C continued

| ID | Question | Selection | Comments |
|----|---|---|----------|
| 46 | Does this facility offer TB/HIV counseling? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 47 | Does this facility offer counseling for MDR-TB patients? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 48 | Who is responsible for providing TB counseling in your facility? <i>(Mark all that apply)</i> | 1. <input type="checkbox"/> Doctor 2. <input type="checkbox"/> Nurse 3. <input type="checkbox"/> Community health worker 4. <input type="checkbox"/> Social worker 5. <input type="checkbox"/> Other | |
| 49 | What topics are covered in TB patient education? <i>(Read responses out loud. Mark all that apply)</i> | 1. <input type="checkbox"/> TB symptoms 2. <input type="checkbox"/> Treatment adherence 3. <input type="checkbox"/> Contact screening 4. <input type="checkbox"/> Treatment side effects 5. <input type="checkbox"/> TB and HIV 6. <input type="checkbox"/> Healthy lifestyles/nutrition | |

Quality of Care

| | | | |
|----|---|---|--|
| 50 | Does your facility have a mechanism for evaluating patient satisfaction with TB services? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 51 | How is patient feedback obtained? | 1. <input type="checkbox"/> Patient complaint box 2. <input type="checkbox"/> Patient exit interview 3. <input type="checkbox"/> Patient services office 4. <input type="checkbox"/> Other | |

TB access and support

| | | | |
|----|--|---|--|
| 52 | Does your facility use an active case finding approach for TB diagnosis? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 53 | How do you conduct active case finding? | 1. <input type="checkbox"/> TB contacts 2. <input type="checkbox"/> Pediatric contacts 3. <input type="checkbox"/> HIV/AIDS 4. <input type="checkbox"/> Door to door 5. <input type="checkbox"/> Other <i>(specify)</i> | |
| 54 | Does the facility have support groups for TB patients? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |

TB Health Provider Survey

Name of Facility: _____

Location of Facility: _____

Name of Interviewer: _____

Date: _____

Interviewer: Do not read responses, except where indicated. Mark all that apply.

Health clinic general

| ID | Question | Selection | Comments |
|----|---|---|----------|
| 1 | Type of facility | 1. <input type="checkbox"/> Public primary health care unit 2. <input type="checkbox"/> Public hospital 3. <input type="checkbox"/> Medical college 4. <input type="checkbox"/> For-profit private hospital 5. <input type="checkbox"/> For-profit private clinic 6. <input type="checkbox"/> NGO (not-for-profit) hospital 7. <input type="checkbox"/> NGO (not-for-profit) clinic 8. <input type="checkbox"/> Other (<i>explain</i>) | |
| 2 | In your current position, and as part of your work for this facility, do you personally provide care for TB patients? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (Stop Interview) | |
| 3 | Gender | 1. <input type="checkbox"/> Male 2. <input type="checkbox"/> Female | |
| 4 | What is the highest level of education you have completed? | 1. <input type="checkbox"/> Elementary (Primary School) 2. <input type="checkbox"/> High School (Secondary School) 3. <input type="checkbox"/> University 4. <input type="checkbox"/> Post-graduate 5. <input type="checkbox"/> Other (<i>specify</i>) | |
| 5 | What is your position as health worker? (<i>Read responses out loud</i>) | 1. <input type="checkbox"/> Clinical Director 2. <input type="checkbox"/> Medical Doctor 3. <input type="checkbox"/> Nurse 4. <input type="checkbox"/> Midwife 5. <input type="checkbox"/> Pharmacist 6. <input type="checkbox"/> Community Health Worker 7. <input type="checkbox"/> Village Doctor | |

TB Knowledge

| ID | Question | Selection | Comments |
|----|---|--|----------|
| 6 | How can a person get TB? <i>(Do not read out answers. Mark all that are mentioned)</i> | <ul style="list-style-type: none"> 1. <input type="checkbox"/> Through the air when a person with TB coughs or sneezes 2. <input type="checkbox"/> Through handshake 3. <input type="checkbox"/> Through sharing dishes 4. <input type="checkbox"/> Through eating from the same plate 5. <input type="checkbox"/> Through touching items in public places 6. <input type="checkbox"/> Do not know 7. <input type="checkbox"/> Other <i>(specify)</i> | |
| 7 | What are the signs and symptoms of TB? <i>(Do not read out answers. Mark all that are mentioned)</i> | <ul style="list-style-type: none"> 1. <input type="checkbox"/> Close contact with active TB patient 2. <input type="checkbox"/> Cough that lasts longer than 2-3 weeks 3. <input type="checkbox"/> Fever 4. <input type="checkbox"/> Weight loss 5. <input type="checkbox"/> Fatigue/tiredness 6. <input type="checkbox"/> Do not know 7. <input type="checkbox"/> Other <i>(specify)</i> | |
| 8 | Can TB be cured? | <ul style="list-style-type: none"> 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |

Stigma

| | | | |
|---|---|---|--|
| 9 | When you treat a TB patient or suspect, how worried are you about contracting TB? <i>(Read responses out loud)</i> | <ul style="list-style-type: none"> 1. <input type="checkbox"/> Very worried 2. <input type="checkbox"/> Somewhat worried 3. <input type="checkbox"/> Not worried | |
|---|---|---|--|

IEC/IPCC

| | | | |
|----|--|---|--|
| 10 | In your work, do you provide education on TB to your patients? | <ul style="list-style-type: none"> 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No <i>(Go to Q)</i> | |
| 11 | If so, how do you provide education? <i>(Mark all that apply)</i> | <ul style="list-style-type: none"> 1. <input type="checkbox"/> Through talking 2. <input type="checkbox"/> Through pamphlets 3. <input type="checkbox"/> Through job aids 4. <input type="checkbox"/> Through posters 5. <input type="checkbox"/> Other | |
| 12 | What topics do you cover in TB patient education? | <ul style="list-style-type: none"> 1. <input type="checkbox"/> TB symptoms 2. <input type="checkbox"/> Treatment adherence 3. <input type="checkbox"/> Contact screening 4. <input type="checkbox"/> Treatment side effects 5. <input type="checkbox"/> TB and HIV 6. <input type="checkbox"/> Healthy lifestyles/nutrition | |

| Training | | | |
|---------------------|---|--|----------|
| ID | Question | Selection | Comments |
| 13 | Have you ever received training on providing TB health education? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 14 | When did you receive the training? | 1. <input type="checkbox"/> Less than 1 year ago 2. <input type="checkbox"/> 1-2 years ago 3. <input type="checkbox"/> More than 2 years ago | |
| 15 | In the last two years, have you ever received training on...? | 1. <input type="checkbox"/> TB Diagnosis 2. <input type="checkbox"/> TB Treatment 3. <input type="checkbox"/> M/XDR-TB Management 4. <input type="checkbox"/> TB in children 5. <input type="checkbox"/> TB infection control | |
| Supervision | | | |
| 16 | Within this facility, is there anyone who is responsible for supervising your work related to TB? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (<i>Go to Q</i>) | |
| 17 | How often do you meet with the supervisor for supervision purposes? | 1. <input type="checkbox"/> Never 2. <input type="checkbox"/> Monthly 3. <input type="checkbox"/> Quaterly 4. <input type="checkbox"/> Every 6 months 5. <input type="checkbox"/> Annually 6. <input type="checkbox"/> Other (<i>specify</i>) | |
| Policies/Guidelines | | | |
| 18 | Are the following TB policies/guidelines available in your facility? <i>(Read responses out loud. Mark all that apply)</i> | 1. <input type="checkbox"/> Adult TB 2. <input type="checkbox"/> Pediatric TB 3. <input type="checkbox"/> MDR/XDR 4. <input type="checkbox"/> TB/HIV 5. <input type="checkbox"/> Mobile populations 6. <input type="checkbox"/> Infection prevention 7. <input type="checkbox"/> Essential drug list | |
| Drug shortages | | | |
| 19 | Has your facility experienced shortages of the following drugs in the last 3 months? <i>(Read responses out loud. Mark all that apply)</i> | 1. <input type="checkbox"/> TB symptoms 2. <input type="checkbox"/> Treatment adherence 3. <input type="checkbox"/> Contact screening 4. <input type="checkbox"/> Treatment side effects 5. <input type="checkbox"/> TB and HIV 6. <input type="checkbox"/> Healthy lifestyles/nutrition | |

TB diagnosis

| ID | Question | Selection | Comments |
|----|--|---|----------|
| 20 | In your work, which of the following do you do to diagnose TB patients? <i>(Read out loud. Mark all that apply)</i> | 1. <input type="checkbox"/> Check for TB signs and symptoms 2. <input type="checkbox"/> Refer patient to outside facility for sputum smear 3. <input type="checkbox"/> Refer patient to outside facility for x-ray 4. <input type="checkbox"/> Refer patient to outside facility for skin test 5. <input type="checkbox"/> Do sputum smear <i>(Go to Q)</i> 6. <input type="checkbox"/> Do x-ray <i>(Go to Q)</i> 7. <input type="checkbox"/> Do skin test <i>(Go to Q)</i> 8. <input type="checkbox"/> Other <i>(specify)</i> | |
| 21 | Do you receive any incentives to diagnose TB patients? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |

TB referrals

| | | | |
|----|--|--|--|
| 22 | Do you follow up the patients you refer | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No <i>(Go to Q)</i> | |
| 23 | If yes, how do you follow up? <i>(Do not read out answers. Mark all that are mentioned)</i> | 1. <input type="checkbox"/> Contact with the referral centers 2. <input type="checkbox"/> Communicate with the patient afterward 3. <input type="checkbox"/> Go to household 4. <input type="checkbox"/> Other <i>(specify)</i> | |

Diagnostic Delay/Treatment Delay

| | | | |
|----|--|--|--|
| 24 | What is the estimated turn-around time for obtaining sputum microscopy results in your facility? | 1. <input type="checkbox"/> 1-3 days 2. <input type="checkbox"/> 4-6 days 3. <input type="checkbox"/> 7-10 days 4. <input type="checkbox"/> More than 10 days 5. <input type="checkbox"/> Don't know | |
| 25 | What is the average time from receipt of results to starting a patient on TB treatment? | 1. _____ Days 2. <input type="checkbox"/> Don't know | |
| 26 | Was there a delay in giving TB patients treatment? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No <i>(Go to Q)</i> 3. <input type="checkbox"/> Don't know <i>(Go to Q)</i> | |
| 27 | What were the main causes for delay to provide TB treatment? <i>(Mark all that apply)</i> | 1. <input type="checkbox"/> No TB drugs available 2. <input type="checkbox"/> No TB beds available at facility 3. <input type="checkbox"/> Patient refusal for treatment 4. <input type="checkbox"/> Patient died before treatment initiation 5. <input type="checkbox"/> Other <i>(specify)</i> 6. <input type="checkbox"/> Don't know | |

Diagnostic Delay/Treatment Delay *continued*

| ID | Question | Selection | Comments |
|----|--|--|----------|
| 28 | Did your health center diagnose/treat MDR-TB during the last year? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (<i>Go to Q</i>) | |
| 29 | What is the estimated turn-around time for obtaining sputum culture results and DST? | 1. _____ Days 2. <input type="checkbox"/> Don't know | |
| 30 | What is the average time from receipt of results to starting patient on MDR/TB treatment? | 1. _____ Days 2. <input type="checkbox"/> Don't know | |
| 31 | Was there a delay in giving MDR/TB patients treatment? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No (<i>Go to Q</i>) 3. <input type="checkbox"/> Don't know (<i>Go to Q</i>) | |
| 32 | What were the main causes for delay to receive MDR-TB treatment? (<i>Mark all that apply</i>) | 1. <input type="checkbox"/> No MDR-TB drugs available 2. <input type="checkbox"/> No MDR-TB beds available at facility 3. <input type="checkbox"/> Patient died before treatment initiation 4. <input type="checkbox"/> Other 5. <input type="checkbox"/> Don't know | |

TB Patient Survey

Type of Facility: _____

Location of Facility: _____

Name of Interviewer: _____

Date: _____

Interviewer: Do not read responses, except where indicated. Mark all that apply.

General demographics

| ID | Question | Selection | Comments |
|----|---|--|----------|
| 1 | How old are you? | 1. <input type="checkbox"/> 0-15 2. <input type="checkbox"/> 16-20 3. <input type="checkbox"/> 21-30 4. <input type="checkbox"/> 31-40 5. <input type="checkbox"/> 41-50 6. <input type="checkbox"/> Over 50 | |
| 2 | What is your gender? | 1. <input type="checkbox"/> Male 2. <input type="checkbox"/> Female | |
| 3 | What is the level of education you have completed? | 1. <input type="checkbox"/> No school 2. <input type="checkbox"/> Elementary 3. <input type="checkbox"/> High school 4. <input type="checkbox"/> College 5. <input type="checkbox"/> Higher education (professional or post-graduate) 6. <input type="checkbox"/> Religious schooling only 7. <input type="checkbox"/> literacy classes only | |
| 4 | Do you currently have paid employment? | 1. <input type="checkbox"/> No 2. <input type="checkbox"/> Yes | |
| 5 | How much time did it take you to get to this health clinic? | 1. <input type="checkbox"/> <30 minutes 2. <input type="checkbox"/> 31-60 minutes 3. <input type="checkbox"/> Between 1-2 hours 4. <input type="checkbox"/> More than 2 hours | |
| 6 | How many children live with you in your household? | _____ Number | |

TB attitudes, stigma

| ID | Question | Selection | Comments |
|----|---|--|----------|
| 7 | In your opinion, how serious a disease is TB? <i>(Read responses out loud)</i> | 1. <input type="checkbox"/> Very serious 2. <input type="checkbox"/> Somewhat serious 3. <input type="checkbox"/> Not very serious | |
| 8 | In your community, how is a person who has TB usually regarded/treated? | 1. <input type="checkbox"/> Most people reject him or her 2. <input type="checkbox"/> Most people are friendly, but they generally try to avoid him or her 3. <input type="checkbox"/> The community mostly supports and helps him or her 4. <input type="checkbox"/> Other <i>(please explain)</i> | |

Gender

| | | | |
|----|--|---|--|
| 9 | In your community, do women need to be accompanied by a man to visit a health care facility? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 10 | Who is more likely to get TB, men or women? Or is their risk the same? | 1. <input type="checkbox"/> Men more likely 2. <input type="checkbox"/> Women more likely 3. <input type="checkbox"/> Risk same 4. <input type="checkbox"/> Don't know | |

TB Knowledge

| | | | |
|----|---|---|--|
| 11 | How can a person get TB? <i>(Do not read out loud. Mark all that are mentioned)</i> | 1. <input type="checkbox"/> Through handshakes 2. <input type="checkbox"/> Through the air when a person with TB coughs or sneezes 3. <input type="checkbox"/> Through sharing dishes 4. <input type="checkbox"/> Through eating from the same plate 5. <input type="checkbox"/> Through touching items in public places (doorknobs, handles in transportation, etc.) 6. <input type="checkbox"/> Do not know 7. <input type="checkbox"/> Other <i>(please explain)</i> | |
| 12 | Can TB be cured? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 13 | How can someone with TB be cured? <i>(Do not read out loud. Mark all that are mentioned)</i> | 1. <input type="checkbox"/> Herbal remedies 2. <input type="checkbox"/> Home rest without medicine 3. <input type="checkbox"/> Praying 4. <input type="checkbox"/> Specific drugs given by health center 5. <input type="checkbox"/> DOTS 6. <input type="checkbox"/> Do not know 7. <input type="checkbox"/> Other <i>(please explain)</i> | |

| Care delay | | | |
|------------------|--|---|----------|
| ID | Question | Selection | Comments |
| 14 | How long were you sick with TB symptoms (e.g., cough, fever, weight loss, etc.) before you first sought care? <i>(Convert weeks/months into days)</i> | _____ Days | |
| Care preferences | | | |
| 15 | When you first noticed you had TB symptoms (cough, fever, etc.), where did you first go for care? <i>(Mark one)</i> | 1. <input type="checkbox"/> Traditional healer 2. <input type="checkbox"/> Private practitioner/health center 3. <input type="checkbox"/> Pharmacist/vendor 4. <input type="checkbox"/> Public clinic/hospital/health center 5. <input type="checkbox"/> Self-treated 6. <input type="checkbox"/> Other | |
| 16 | Why did you go there? | 1. <input type="checkbox"/> Was cheaper 2. <input type="checkbox"/> Was closer 3. <input type="checkbox"/> More convenient schedule 4. <input type="checkbox"/> Better care received 5. <input type="checkbox"/> Better attitude from health workers 6. <input type="checkbox"/> Trusted more 7. <input type="checkbox"/> Other (explain) | |
| Quality of care | | | |
| 17 | Are you happy with the TB service you are getting from this health center? <i>(Read responses)</i> | 1. <input type="checkbox"/> Very satisfied 2. <input type="checkbox"/> Somewhat satisfied 3. <input type="checkbox"/> Not satisfied | |
| 18 | Is the level of TB service you are getting from this health center? <i>(Read responses)</i> | 1. <input type="checkbox"/> Better than expected <i>(Go to Q)</i> 2. <input type="checkbox"/> Same as expected <i>(Go to Q)</i> 3. <input type="checkbox"/> Worse than expected | |
| 19 | Where would you prefer to get the TB service? | 1. <input type="checkbox"/> Traditional healer 2. <input type="checkbox"/> Private practitioner 3. <input type="checkbox"/> Pharmacist/vendor 4. <input type="checkbox"/> Public clinic/hospital/health center 5. <input type="checkbox"/> Other <i>(explain)</i> | |
| 20 | Are you satisfied with the waiting time at the clinic? <i>(Read responses)</i> | 1. <input type="checkbox"/> Very satisfied 2. <input type="checkbox"/> Somewhat satisfied 3. <input type="checkbox"/> Not satisfied | |

| Cost | | | |
|--|---|--|----------|
| ID | Question | Selection | Comments |
| 21 | Did you have to pay for transportation to get here? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 22 | Did you have to pay for consultation/tests? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 23 | Are you satisfied with the cost of consultation/tests? <i>(Read responses)</i> | 1. <input type="checkbox"/> Very satisfied 2. <input type="checkbox"/> Somewhat satisfied 3. <input type="checkbox"/> Not satisfied | |
| 24 | Did you have to pay for TB medicines? | 3. <input type="checkbox"/> Yes 4. <input type="checkbox"/> No | |
| 25 | Are you satisfied with the cost of the TB medicine? <i>(Read responses)</i> | 1. <input type="checkbox"/> Very satisfied 2. <input type="checkbox"/> Somewhat satisfied 3. <input type="checkbox"/> Not satisfied | |
| TB suspect vs. TB patient | | | |
| 26 | What brought you to the health center today? | 1. <input type="checkbox"/> TB screening <i>(End questionnaire)</i> 2. <input type="checkbox"/> TB treatment 3. <input type="checkbox"/> None of the above | |
| Diagnostic Delay | | | |
| 27 | To help find out if you have TB, did you do a sputum test (spit)? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No _____ 3. <input type="checkbox"/> Don't know | |
| 28 | How many days did it take from the time you took the test until you found out you had TB? | Days | |
| 29 | How many visits did you have to make to the health center to find out you had TB? | 1. <input type="checkbox"/> 1 2. <input type="checkbox"/> 2 3. <input type="checkbox"/> 3 4. <input type="checkbox"/> 4 or more _____ | |
| Treatment delay | | | |
| 30 | How many days did it take from when you were told you had TB until you began treatment? | Days | |
| Interpersonal Communication and Counseling | | | |
| 31 | Were you given information about the need to have your family members/close contacts screened for TB? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |

Interpersonal Communication and Counseling *continued*

| ID | Question | Selection | Comments |
|-----------|--|---|-----------------|
| 32 | Did you receive information on possible side effects on treatment? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |
| 33 | Have you been connected to a DOTS supporter? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Don't know | |
| 34 | Were you advised to get an HIV test? | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Have already been tested for HIV | |
| 35 | Did you get tested for HIV | 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No | |

Chart Assessment Tool

Instructions:

Use existing TB facility recording and reporting registries that the health center has to fill out/adapt the chart assessment tool. Registries that the health center may have include: TB suspect register; TB laboratory register; TB treatment register; Patient treatment form; Case finding form.

At each site, randomly select 20 patients from the TB suspect register per health facility and record the dates (month/day/year) for each visit/examination/treatment performed in the chart assessment tool. Find these same patients in the other registers and record their data (see shaded areas in the chart assessment collection tool).

For example:

TB lab registers

- The same selected patients (from the suspect registers) should be tracked and recorded in the TB lab register section of the chart assessment tool.

TB treatment registers & Patients TB treatment from

- After tracing the patients on the lab register, the same patients should be tracked on the TB treatment registers and patient treatment forms and dates for each examination be added to the chart assessment tool.

| Chart Assessment Tool | | | | | |
|--|---------------------|------------------------|-----------------------|---------------------------|--------------------------------------|
| Patient Name: _____ | | | | | |
| Location: _____ | | | | | |
| Date of assessment: _____ | | | | | |
| Name of person doing assessment: _____ | | | | | |
| | TB Suspect Register | TB Laboratory Register | TB Treatment Register | Patient TB Treatment Form | Case Finding Form (where applicable) |
| | Date (Mo/Day/Year) | Date (Mo/Day/Year) | Date (Mo/Day/Year) | Date (Mo/Day/Year) | Date (Mo/Day/Year) |
| A. Clinic Visits | | | | | |
| 1. Date of first health facility visit | | | | | |
| 2. Date of second health facility visit | | | | | |
| 3. Date of third health facility visit | | | | | |
| B. TB | | | | | |
| 4. Date sputum smear taken | | | | | |
| 5. Sputum smear result obtained | | | | | |
| 6. Date of diagnosis of TB based on SPUTUM AFB test | | | | | |
| C. Access to TB Treatment (First Line/Second Line) | | | | | |
| 7. Prescription written for FLD anti-TB drugs | | | | | |
| 8. Prescription sent to pharmacy (by clinician or patient) | | | | | |
| 9. Date of initiation of treatment FLD anti-TB drugs | | | | | |

Appendix B: Sample Interventions to Reduce TB Delay

Appendix B. Sample Interventions to Reduce TB Delay*

| What is the barrier? | What sample interventions could be used? |
|---|---|
| Behavioral Change Among Patients and Communities | |
| Target Group: General population, vulnerable groups, people with TB symptoms and TB patients/Community groups/NGOs | |
| Poor knowledge of TB symptoms, TB care and cure | <ul style="list-style-type: none"> • World TB day • Mass media, small media • Enhance IPC/C of health care providers and community health workers • Social mobilization activities (i.e., health classes, health events, community level support activities) • Peer education at community or interest group meetings • Actively involve current and former TB patients in TB ACSM activities |
| Attribution of TB symptoms to other conditions | |
| Low risk perception of TB severity | |
| Negative perception of health services | |
| Patients seeking care from multiple providers | |
| Self-medication with homeopathic or unprescribed drugs | |
| Stigma | <ul style="list-style-type: none"> • TB support groups • Health events • Health classes • Training of health providers • Advocacy to community leaders; community groups; anti-stigma messages through community influentials and community groups |
| Gender-related norms | <ul style="list-style-type: none"> • Conduct gender-sensitive outreach • Integrate information about TB into other services (antenatal care; reproductive health; child health; immunizations) |
| Time, cost, distance to DOTS facility | <ul style="list-style-type: none"> • Address misperceptions of cost through mass media, social mobilization activities • Work with community groups, community leaders, regional health officials, NGOs, to establish community support schemes (e.g., covering cost of transport) |
| Health Systems Changes | |
| Target Group: National/District TB Management and Supervision | |
| Availability of guidelines | Ensure availability and distribution (to local levels) of TB guidelines, including those related to TB/HIV and TB in children |
| Poor support and supervision of PPM activities | Establish links and collaborate with the full range of care providers through PPM approaches |
| Poor laboratory staff capacity building | Training and motivation of laboratory staff on TB bacteriological tests, laboratory turnaround time and institutionalization of regular laboratory mentoring and supervision |
| Insufficient training of health staff in TB protocols | Coordinate with Health Facility management and District Management teams to conduct training of health care workers on TB guidelines and protocols |

* Adapted from: Training curriculum – Overcoming barriers to TB control: the role of advocacy, communication and social mobilization. STOP TB, Partnership. 2011

What is the barrier?

What sample interventions could be used?

Health Systems Changes *continued*

Target Group: General population, vulnerable groups, people with TB symptoms and TB patients/Community groups/NGOs

| | |
|---|--|
| High rotation of personnel | <ul style="list-style-type: none"> • Coordinate between the NTP and Human Resources for Health (or equivalent) departments regarding staffing, filling of vacancies, and retention packages • Provide supportive supervision for health workers |
| Insufficient supervision of clinical services and laboratories | Ensure availability and distribution (to local levels) of TB guidelines, including those related to TB/HIV and TB in children |
| Drug Management | Procurement of anti-TB drugs through GDF |
| Supply chain delays | Fixed-dose combination of drugs |
| Lack of insurance mechanisms covering TB for poor | <ul style="list-style-type: none"> • Elimination of user fees that affect both access to care • Advocacy towards community leaders, community groups |
| Poor identification of TB suspects | Establish system for contact tracing and active case finding in selected high risk groups |
| High rotation of staff resulting in patient being seen by multiple health providers | Coordinate between the NTP and Human Resources for Health (or equivalent) departments regarding staffing, filling of vacancies, and retentions packages |
| Poor availability and quality of laboratory services to diagnose TB and monitor treatment of TB | <ul style="list-style-type: none"> • Maintain and improve quality of existing laboratory network • Strengthen existing laboratory networks with more laboratories (where needed) • Provide/strengthen External Quality Assurance of laboratories; introduce laboratory accreditation schemes • Scale up laboratory capacity to diagnose smear-negative TB, especially among people living with HIV • Expand laboratory capacity to test for first-and-second-line drug resistance |

Target Group: Health service delivery providers (DOTS, public, private, informal...)

| | |
|--|--|
| Poor quality services | Interpersonal communication and counseling training for health care providers |
| Health providers fail to give adequate information to TB patients/health provider stigma | Interpersonal communication and counseling training for health care providers |
| Lack of linkages between DOTS, non-DOTS and other providers | <ul style="list-style-type: none"> • Training and continued education of all health care providers (including community health workers and informal providers) involved in TB control • Job aids • Mobilize HIV stakeholders to provide TB prevention, treatment, and care services to all people living with HIV |
| Poor provider knowledge and compliance with TB diagnostic and treatment protocols | <ul style="list-style-type: none"> • Use of international standards for TB care (ISTC) • Scale up TB seeing among people living with HIV |

What is the barrier?

What sample interventions could be used?

Health Systems Changes *continued*

Target Group: Health service facilities

| | |
|--|---|
| <p>Poor quality of patient management; poor physical environment</p> | <p>Quality improvement activities</p> |
| <p>Lack of functioning HMIS system</p> | <ul style="list-style-type: none"> • Electronic registers • Include TB/HIV cases on TB registers • Contact tracing |
| <p>Stock out of lab supplies</p> | <ul style="list-style-type: none"> • Involve laboratory staff in projection, quantification and ordering of laboratory supplies • Strengthen supply chain management for laboratory commodities |
| <p>Inadequate lab performance</p> | <ul style="list-style-type: none"> • Labs should enroll in an TB external quality assurance (EQA) proficiency scheme involving quaterly distribution of EQA materials • Mentorship program involving mentors from within the lab and from higher level laboratories in the area should be established |
| <p>Poor Coordination between lab and health clinics to report test results</p> | <ul style="list-style-type: none"> • Institute regular meetings between the clinicians, nurses and laboratory staff to address turnaround time for test results |

Appendix C: The Patients' Charter for Tuberculosis Care

Patients' Rights

You have the right to:

Care

- The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness
- The right to receive medical advice and treatment which fully meets the new International Standards for Tuberculosis Care, centering on patient needs, including those with multidrug-resistant tuberculosis (MDR-TB) or tuberculosis-human immunodeficiency virus (HIV) coinfections and preventative treatment for young children and others considered to be at high risk
- The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs.

Dignity

- The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities
- The right to quality healthcare in a dignified environment, with moral support from family, friends, and the community.

Information

- The right to information about what healthcare services are available for tuberculosis and what responsibilities, engagements, and direct or indirect costs are involved
- The right to receive a timely, concise, and clear description of the medical condition, with diagnosis, prognosis (an opinion as to the likely future course of the illness), and treatment proposed, with communication of common risks and appropriate alternatives
- The right to know the names and dosages of any medication or intervention to be prescribed, its normal actions and potential side-effects, and its possible impact on other conditions or treatments
- The right of access to medical information which relates to the patient's condition and treatment and to a copy of the medical record if requested by the patient or a person authorized by the patient
- The right to meet, share experiences with peers and other patients and to voluntary counseling at any time from diagnosis through treatment completion.

Choice

- The right to a second medical opinion, with access to previous medical records
- The right to accept or refuse surgical interventions if chemotherapy is possible and to be informed of the likely medical and statutory consequences within the context of a communicable disease
- The right to choose whether or not to take part in research programs without compromising care.

Confidence

- The right to have personal privacy, dignity, religious beliefs, and culture respected
 - The right to have information relating to the medical condition kept confidential and released to other authorities contingent upon the patient's consent
-

Justice

- The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly
 - The right to appeal to a higher authority if the above is not respected and to be informed in writing of the outcome
-

Organization

- The right to join, or to establish, organizations of people with or affected by tuberculosis and to seek support for the development of these clubs and community-based associations through the health providers, authorities, and civil society
 - The right to participate as “stakeholders” in the development, implementation, monitoring, and evaluation of tuberculosis policies and programs with local, national, and international health authorities
-

Security

- The right to job security after diagnosis or appropriate rehabilitation upon completion of treatment
- The right to nutritional security or food supplements if needed to meet treatment requirements

Patients' Responsibilities

You have the responsibility to:

Share Information

- The responsibility to provide the healthcare giver as much information as possible about present health, past illnesses, any allergies, and any other relevant details
- The responsibility to provide information to the health provider about contacts with immediate family, friends, and others who may be vulnerable to tuberculosis or may have been infected by contact

Follow Treatment

- The responsibility to follow the prescribed and agreed treatment plan and to conscientiously comply with the instructions given to protect the patient's health, and that of others
- The responsibility to inform the health provider of any difficulties or problems with following treatment or if any part of the treatment is not clearly understood

Contribute to Community Health

- The responsibility to contribute to community well-being by encouraging others to seek medical advice if they exhibit the symptoms of tuberculosis
- The responsibility to show consideration for the rights of other patients and healthcare providers, understanding that this is the dignified basis and respectful foundation of the tuberculosis community

Show Solidarity

- The moral responsibility of showing solidarity with other patients, marching together towards cure
- The moral responsibility to share information and knowledge gained during treatment and to pass this expertise to others in the community, making empowerment contagious
- The moral responsibility to join in efforts to make the community tuberculosis free

Useful Resources

WHO. ACSM for TB control: A handbook for country programmes. December 2007.

http://www.stoptb.org/assets/documents/resources/publications/acsm/ACSM_Handbook.pdf

WHO. ACSM for TB control: A guide to developing knowledge, attitude and practice surveys. January 2008.

http://www.stoptb.org/assets/documents/resources/publications/acsm/ACSM_KAP%20GUIDE.pdf

WHO. Engaging all health care providers in TB control – guidance on implementing public-private mix approaches. Geneva: 2006.

http://whqlibdoc.who.int/hq/2006/WHO_HTM_TB_2006.360_eng.pdf

Tuberculosis Coalition for Technical Assistance International standards for tuberculosis care (ISTC). The Hague: Tuberculosis Coalition for Technical Assistance, 2006.

http://www.stoptb.org/assets/documents/resources/publications/acsm/istc_report.pdf

WHO. Recommendations for Investigating Contacts of Persons with Infectious Tuberculosis in Low- and Middle-Income Countries. 2010.

http://www.who.int/tb/publications/2012/contact_investigation2012/en/

Stop TB Partnership. Training Curriculum - Overcoming barriers to TB control: the role of advocacy, communication and social mobilization. August 2011.

<http://www.stoptb.org/assets/documents/resources/publications/acsm/ACSM%20Training%20Curriculum.pdf>

WHO. Advocacy, communication and social mobilization to fight TB: a 10-year framework for action/ ASCM Subgroup at Country Level. 2006.

http://www.who.int/tb/people_and_communities/advocacy_communication/en/index.html

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