FROM THE AMERICAN PEOPLE

DELIVERING COMPREHENSIVE SUPPORTIVE CARE TO PEOPLE WITH DRUG-RESISTANT TUBERCULOSIS

February 2019

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Cover Photo by: A MDR-TB survivor from North Jakarta, Indonesia, with a community health cadre volunteer. Photo by USAID.

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ACRONYMS

aDSM	Active Drug Safety Monitoring
BMI	Body Mass Index
DOT	Directly Observed Treatment
DOTS	Directly Observed Treatment, Short Course
DR-TB	Drug-resistant Tuberculosis
DST	Drug-Susceptibility Testing
ECG	Electrocardiogram
Global Fund	The Global Fund to Fight AIDS, Tuberculosis and Malaria
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
M&E	Monitoring and Evaluation
MDR-TB	Multidrug-resistant Tuberculosis
NGO	Non-governmental Organization
NTP	National TB Program
PMDT	Programmatic Management of Drug-Resistant Tuberculosis
SOP	Standard Operating Procedure
TB	Tuberculosis
USAID	United States Agency for International Development
WHO	World Health Organization
XDR-TB	Extensively Drug-Resistant Tuberculosis

TABLE OF CONTENTS

PART I: INTRODUCTION TO DELIVERING COMPREHENSIVE SUPPORTIVE CARE TO PEOPLE WITH DRUG-RESISTANT TUBERCULOSIS

1. Background

Drug-resistant tuberculosis (DR-TB) is a significant global health threat, with an estimated 600,000 cases occurring annually. The United States Government committed to address DR-TB, both domestically and internationally, in the *National Action Plan for Combating Multidrug-Resistant Tuberculosis*. This Practical Toolkit is part of that effort.

> ***"The number of MDR/RR-TB cases started on treatment in 2016 was only 22% of the estimated incidence of MDR/RR-TB…The latest treatment outcome data show treatment success rates of…54% for MDR/RR-TB and 30% for extensively drug-resistant TB (XDR-TB) (2014 cohort)."***
>
> **WHO Global TB Report, 2017**

In addition, as part of the World Health Organization's End TB Strategy,[1] there is a global push to provide universal access to testing and treatment for all forms of TB, including DR-TB, by scaling up new diagnostic technologies and introducing new drugs and shortened treatment regimens. *As we do so, however, there is an urgent need to increase the success rate for DR-TB treatment—right now, we are successfully treating only 54 percent of the people with DR-TB started on treatment—far below the global target of at least 75 percent cure.*

The substantial funds and effort spent on DR-TB diagnosis and treatment initiation are wasted if we do not support people with DR-TB until they are cured. People who remain sick continue to suffer, transmit drug-resistant disease to their families and communities, and may develop extensively drug-resistant TB (XDR-TB) or die. We run the risk of an exponential growth in the number of people with DR-TB, representing a global public health emergency with significant human and financial implications.

In large part, people who start DR-TB treatment but do not complete it represent the failure of health systems to provide adequate person-centered care and support. In addition to the significant side effects of currently available drugs, studies indicate that primary barriers to DR-TB treatment success include emotional and physical isolation; stigma and discrimination in the community and health system; financial strain; mental illness and substance use; other health conditions, especially HIV; poor understanding of the disease and treatment process; and poor access to health services.[2] Addressing these barriers requires a holistic approach to care rooted in person-centered case management.

Photo courtesy of TAC, South Africa

This *Toolkit* provides national TB control programs, implementing partners, community-based organizations, and support groups with a standardized framework for supportive services derived from international guidance and best practices from the field. Using the *Toolkit* will help programs deliver high-quality and effective care to people with DR-TB, with the goal of better outcomes for all.

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[1] World Health Organization, 2015.The End TB Strategy.

[2] Thomas, B., Shanmugam, P., Malaisamy, M., Ovung, S., Suresh, C., Subbaraman, R., Adinarayanan, S., and Nagarajan, K. Psycho-Socio-Economic Issues Challenging Multidrug Resistant Tuberculosis Patients: A Systematic Review. PLOS ONE 11(1): e0147397. doi:10.1371/journal.pone.0147397.

BOX 1: RATIONALE FOR A TOOLKIT ON COMPREHENSIVE SUPPORTIVE CARE FOR DR-TB PATIENTS

Global guidance documents clearly recognize the need to provide supportive, person-centered services to accomplish our shared goal of eliminating TB as a global public health threat by 2035. This need is rooted in and aligned with the fundamental human right to health as enshrined in Article 12 of the *International Covenant on Economic, Social and Cultural Rights*.

The table below provides a summary of key precedents for delivering a comprehensive supportive care package for patients with DR-TB (as well as any other TB patients in need of supportive care) that have been agreed upon by the global TB community through extensive consultative processes.

Document:	**Relevant sections:**
The End TB Strategy(& **Implementing the End TB Strategy: The essentials**) 2015	**Pillar 1:** Integrated person-centered care and prevention **Component B:** Treatment of all people with tuberculosis including drug-resistant tuberculosis, and patient support **Pillar 2**: Bold policies and supportive systems **Component C**: Universal health coverage policy, and regulatory frameworks for case notification, vital registration, quality and rational use of medicines, and infection control **Component D**: Social protection, poverty alleviation and actions on other determinants of tuberculosis
International Standards for TB Care 3rd edition 2014	**Standard 9**: A person-centered approach to treatment should be developed for all patients in order to promote adherence, improve quality of life, and relieve suffering. This approach should be based on the patient's needs and mutual respect between the patient and the provider. **Standard 17**: All providers should conduct a thorough assessment for co-morbid conditions and other factors that could affect tuberculosis treatment response or outcome and identify additional services that would support an optimal outcome for each patient. These services should be incorporated into an individualized plan of care that includes assessment of and referrals for treatment of other illnesses. Particular attention should be paid to diseases or conditions known to affect treatment outcome, for example, diabetes mellitus, drug and alcohol abuse, undernutrition, and tobacco smoking. Referrals to other psychosocial support services or to such services as antenatal or well-baby care should also be provided.
WHO Guidelines for the programmatic management of drug-resistant tuberculosis, 2011 update	**Recommendations on model of care**: Patients with multidrug-resistant TB (MDR-TB) should be treated using mainly ambulatory care rather than models of care based principally on hospitalization (conditional recommendation/very low quality evidence).
Companion handbook to the WHO guidelines on the programmatic management of drug-resistant tuberculosis 2014	**Chapter 9**: Initiating treatment **Chapter 12**: Person-centered care, social support and adherence to treatment **Chapter 13**: Palliative and end-of-life care **Chapter 18**: Models for delivering MDR-TB treatment and care **Chapter 19**: Community engagement to support universal access to diagnosis, care, and treatment of drug-resistant TB

While all these documents stipulate the provision of supportive services to patients, none provides clear, practical guidance and tools on *how* national TB programs, facilities, and health providers should do so. This document and its accompanying tools are intended to fill that gap.

2. Introduction to the Supportive Care Toolkit

This document is organized into two main parts: Part I, the *Introduction,* orients readers to a framework for developing a comprehensive supportive care package for people with DR-TB. The *Operational Toolkit* in Part II of this document provides adaptable tools to help implement the package across a wide variety of settings. The *Introduction* and *Operational Toolkit* can be used by the whole range of stakeholders to standardize and systematize the provision of supportive care services. By doing so, programs can improve their ability to monitor and measure the outcomes of these services; gather evidence to evaluate their cost-effectiveness; and better integrate this work within their overall strategic planning and grant application processes. *It is important to note that this approach can be applied to all people with TB who need support, regardless of whether their disease is drug-resistant or not, as a key component of improving treatment outcomes.*

The table below summarizes the materials provided in this *Toolkit*, their purpose, and the target audience for each one:

Material	**Content and purpose**	**Who should use**
Part I: Introduction to Delivering Supportive Care to People with Drug-resistant Tuberculosis	An overview that provides the rationale for supportive services, describes the comprehensive supportive care package and its generic elements, and summarizes steps in implementation.	National program staff, professional associations, health facility administrators, frontline health workers, community-based groups, patient support groups, technical partners, and donors to a standardized approach for delivering person-centered DR-TB supportive services.
Part II: Operational Toolkit for Delivering Supportive Care Services to People with Drug-resistant Tuberculosis	Contains step-by-step instructions, templates, forms, and examples to help programs translate the principles in the *Introduction* into a successful effort on the ground. The individual tools are described in the rows below.	All stakeholders in planning, implementing, and evaluating their supportive care packages.
Operational Toolkit Components		
"How-To" Guides	Provide detailed instructions on implementing each supportive care element, including menus of potential interventions that can be used, resources to consult in developing them, and case	Can be used by all stakeholders to plan and implement each supportive service using field-tested approaches.

Material	Content and purpose	Who should use
	studies of successful implementation in different settings.	
Supportive Care Status Assessment and Planning Tool	Helps programs identify what supportive care services are already being offered and what services should be added to provide comprehensive supportive care to people with DR-TB.	National-level stakeholders to develop a national set of supportive care services that are appropriate for the country. It can also be used by local teams to refine the national package of services for their specific setting, since circumstances may vary across the country.
Rapid Systems Assessment Tool	Evaluates the level of readiness for providing supportive care services at the national, sub-national, or facility level and helps plan how to fill existing gaps in policies, human resources and training, supplies and materials, and/or funding.	Health services managers at national, regional, and facility levels to help them evaluate what is already in place and what else is needed to be able to provide supportive services to people with DR-TB.
Local Operational Plan Template	Tool that can be adapted and used to specify services offered at a facility or local level and clearly define roles and responsibilities for delivering each service.	District and facility-level teams to plan the actual delivery of supportive services to patients at their facilities.
Patient Assessment and Individual Care Plan	Template that can be adapted and used in partnership with individual patients to identify their needs and plan delivery of supportive care services, both as in-patients and in ambulatory settings. The Plan should be used on an ongoing basis to monitor progress and address changing patient needs.	Frontline providers (doctors, nurses, social workers, peer counselors, etc.) in partnership with their patients to discuss care options and choose the ones most appropriate for each individual patient.
Monitoring and Evaluation Handbook	Provides information on approaches to assessing the results of your supportive care services package and tools to do so.	Managers and Monitoring and Evaluation (M&E) staff to develop workable M&E plans for assessing the effect of supportive services on DR-TB treatment outcomes.

*IMPLEMENTATION TIP *

All these tools are provided in a generic and modifiable format, so you are able to adapt them to local conditions, which will vary from country to country and may even vary from facility to facility. You should feel free to change things as appropriate for your own situation and to continue improving the documents and services as you gain experience on what works best.

If you already have tools or processes that serve the same purpose, there is no need to use these instead—these materials are provided for programs that are looking for tools they can use for planning and delivering supportive care services.

How the *Toolkit* was developed

This *Toolkit* was developed by USAID as part of the US Government response outlined in the *National Action Plan for Combating Multidrug-Resistant Tuberculosis,*[3] which includes the commitment that "*USAID will develop generic ancillary care packages (e.g., services and/or supplies not directly related to treatment, but that enable patients to continue therapy, such as pain or nausea medicine, food rations, supportive services) for MDR-TB patients*" and by 2018 will introduce the packages in 10 priority countries with high burdens of DR-TB.[4]

USAID consulted many sources and stakeholders in developing this final product. Peer-reviewed articles, global guidance documents, case studies, and project reports provided background on the state-of-the-art in-patient support services and person-centered care. Face-to-face meetings with affected community members, patient advocates, frontline providers, technical partners, national TB program staff, and donors augmented those data with real-life examples of what has worked and what still needs to be done. Online surveys (see Box 2) for the affected community, providers, and implementing partners provided additional data and confirmed themes from discussions and literature. Finally, four pilot country teams and key global stakeholders gave feedback on the draft documents before and during pilot testing.

In response to feedback from stakeholders, the *Toolkit* was developed keeping the following four key principles in mind:

Alignment: The *Toolkit* places heavy emphasis on ensuring that it is well-aligned with existing guidance on supportive care for DR-TB and that the products from this planning process can feed directly into national strategic plans, The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) concept notes and related processes.

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[3] https://www.usaid.gov/sites/default/files/documents/1864/NAP-for-Combating-MDR-TB-Year-One-Report-508-v10.pdf

[4] The 10 *National Action Plan* priority countries are Burma, China, India, Indonesia, Kazakhstan, Nigeria, Pakistan, Philippines, South Africa, and Ukraine.

Flexibility: The *Toolkit* does not prescribe the interventions by which each element of supportive care should be provided, but rather offers options based on existing best practices and innovations. It leaves room for users to add new approaches as they become relevant for their specific settings, and to adapt the interventions to the different needs and timelines of new treatment regimens and other innovations.

Collaboration: The *Toolkit* acknowledges and allows for the necessity of engaging other actors in providing supportive care services, whether they are other government departments, civil society organizations, corporations, donors, or others.

Person-centeredness: The *Toolkit* recognizes that there is not a "one-size-fits-all" approach to meeting individual needs and preferences. An individual patient-level tool allows providers and people with DR-TB to work in partnership, tailoring available support services to each person's unique needs.

A word about language used in this *Toolkit*

We recognize that being a "TB patient" is only one of many roles people with TB or DR-TB take on in their lives, and that their roles as patients are likely not the most important ones for them. Throughout this document, we try to use terminology that honors each individual's identity as a whole person. At the same time, we do use the term "patient" or "DR-TB patient" for two important reasons. First, we are acknowledging the fact that the majority of people with DR-TB are not being diagnosed and have no access to treatment, so saying "people with DR-TB" is not an accurate description of the population that currently has access to supportive care. Second, we want to be specific about the roles and relationships between different stakeholders in implementing supportive care interventions, and in an individual's unique role as a patient, that person acts as both a participant in and a consumer of supportive care services.

BOX 2: SUMMARY OF SURVEY RESPONSES FROM PATIENTS, PROVIDERS, AND TECHNICAL PARTNERS

In preparing this *Toolkit*, USAID conducted an open, confidential electronic survey of the affected community, frontline providers, and implementers in addition to interviewing patients, providers, and National TB Program (NTP) managers. The data collected brought out some interesting points to consider as you put together your supportive care package. For instance, 45 patients representing 16 countries who responded to the survey cited their own motivation to get better, their desire to get better to help their families, the caring attitude of their providers, the support of their families, and peer support from other patients as the five most important factors in their ability to complete treatment. The top five suggestions from patients for treatment support services that should be provided for DR-TB patients included education on TB, counseling for patients and their families, financial support/social insurance, peer support groups, and more involvement in decision-making about their care. Common barriers to treatment completion included side effects of the medications, the long duration of treatment, painful injections, the need to work to support family, and isolation. These responses support findings from the literature that low-cost psychosocial interventions using a person-centered approach can go a long way to improving treatment success rates and the quality of life for DR-TB patients.

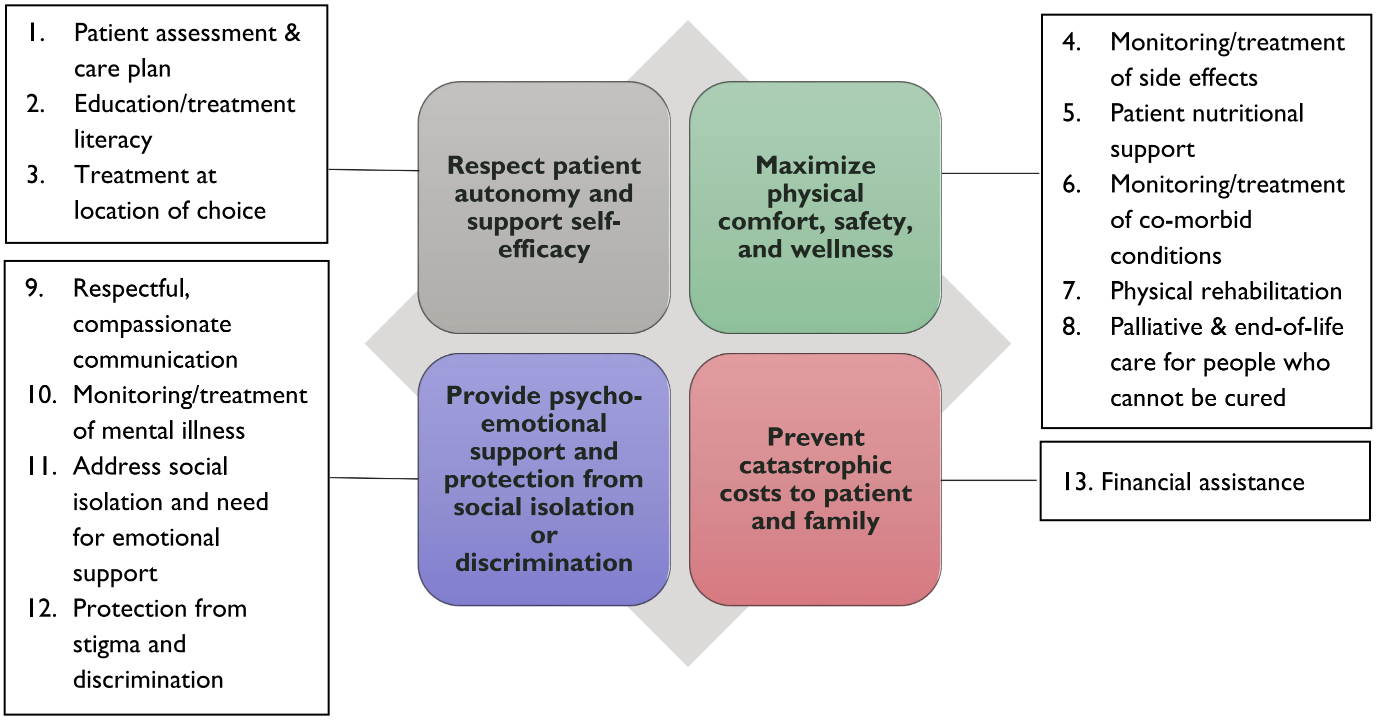
A total of 73 providers responded to the survey, representing 29 countries. From their perspective, the long duration of treatment, medication side effects, poverty, lack of understanding of DR-TB and treatment processes among patients, and competing life priorities are key barriers to treatment completion. They recommended patient education, food packages, counseling, financial support, and timely, effective treatment for side effects as key interventions to improve treatment adherence. In terms of their own needs, providers named linkages with community groups to provide support services to DR-TB patients, more training on medical management of DR-TB, training on assessing patients for psychosocial adherence barriers, social insurance or financial support for patients, and a steady supply of needed drugs and ancillary medications as the interventions that can best improve their care for DR-TB patients. More than 83 percent of respondents said they would use a psychosocial assessment tool with every DR-TB patient at the initiation of treatment if one were available.

Implementing partners' responses were similar to those of providers. The 49 respondents cited medication side effects, long treatment duration, poverty, competing life priorities, and the distance and time to access treatment as key barriers to treatment adherence. Financial and nutritional support is seen as key enablers for successful treatment completion, along with education, peer support and social support in general. Full survey results are provided in Annex 1.

3. The framework for delivering comprehensive supportive care for DR-TB

Patients, researchers, and existing guidance documents identify a number of supportive care services important to help people with DR-TB adhere to treatment, in addition to high-quality medical interventions that follow current guidance (e.g., access to rapid diagnostics, shortened treatment regimens and new drugs). Different sources organize these services in different ways, but the principles are the same. In this *Toolkit*, we have organized them into a framework with four thematic areas and 13 comprehensive supportive care elements using language aligned with a person-centered approach, as presented below.

The Supportive Care Framework



1. Patient assessment & care plan
2. Education/treatment literacy
3. Treatment at location of choice

4. Monitoring/treatment of side effects
5. Patient nutritional support
6. Monitoring/treatment of co-morbid conditions
7. Physical rehabilitation
8. Palliative & end-of-life care for people who cannot be cured

9. Respectful, compassionate communication
10. Monitoring/treatment of mental illness
11. Address social isolation and need for emotional support
12. Protection from stigma and discrimination

13. Financial assistance

The table below provides examples of how each of the comprehensive supportive care elements has been implemented in the field. There are many different potential services that can be offered to cover each element—what you select will depend on the needs of your specific populations.

Thematic area	Comprehensive care elements	Examples of services that can be provided to address each element
Respect patient autonomy and support self-efficacy	1. Thorough patient intake assessment and development of an individual care plan that meets each person's specific needs.	• A health care worker performs an assessment of the patient for physical, psychological, social, and financial enablers and barriers to successful treatment adherence at the time of treatment initiation using a standard form. • The health care worker and patient work together to complete an individual care plan that outlines the support the person will receive to complete treatment successfully. The person receives a copy to keep as a reference, along with the Patients' Charter.
	2. Patient and family education on DR-TB disease and treatment.	• Education sessions provided by a health care worker or other staff at diagnosis, treatment initiation, and throughout the course of care. • Audiovisual educational materials (e.g., videos) produced in appropriate, understandable and person-centered language. • Written educational materials (patient treatment booklet for the person to keep, posters, flip books, etc.). • TB information hotline. • Peer education and support groups.
	3. Provisions to treat patients at an appropriate location and timing of their choice (hospital in-patient, clinic, community or home). (*Note that programmatically, it will often be a combination of these care models.*)	• Hospital in-patient treatment for those who are too sick to be at home, live far from care, or have other circumstances that warrant hospitalization. • Ambulatory clinic-based care in which the person travels to the health facility. • Ambulatory community-based care model in which the patient is connected with a provider nearby his/her home, overseen by the responsible public health facility. • Home-based care model in which the health team travels to the patient to provide treatment services.
Maximize physical comfort, safety, and wellness	4. Regular monitoring for and treatment of side effects and adverse drug reactions.	• Verbal screening for side effects. • Development and use of adverse drug reaction surveillance and reporting system. • Vision monitoring.

Thematic area	Comprehensive care elements	Examples of services that can be provided to address each element
(Note that while this thematic area crosses over to medical management, it is so critical to treatment success that it has been included here.)		• Hearing monitoring. • Blood work to monitor liver function. • Monitoring of cardiac function. • Adequate supplies of the ancillary medications required to treat side effects.
	5. Patient nutritional support as needed to speed healing and reduce side effects of medications.	• Baseline and periodic nutritional assessments. • Food and nutritional supplements for the individual patient to address malnutrition, low Body Mass Index (BMI), improve tolerance to medications, etc.
	6. Regular monitoring and treatment of co-morbid physical conditions that affect the person's ability to reach cure.	• HIV counseling and testing for all patients. • Diabetes screening and testing as indicated. • Counseling on pregnancy during DR-TB treatment for women of reproductive age and testing as needed. • Assessment for excess alcohol use and referral for treatment. • Assessment for drug use and referral for treatment. • Assessment for mental deficits or physical disabilities that could affect treatment adherence and planning for support.
	7. Physical rehabilitation after cure as needed to help patients regain their highest level of health.	• Pulmonary rehabilitation therapy. • Hearing aids. • Other rehabilitation services as indicated.
	8. Palliative care for people who cannot be cured, including but not limited to reduction of pain and discomfort; and end-of-life care and support.	• Assessment of symptoms affecting quality of life and palliative care to reduce them. • Facility-based hospice care. • Home-based hospice care. • Patient and family counseling to prepare for end of life.
Provide psycho-emotional support and	9. Respectful and compassionate communication and counseling between	• Interpersonal communication and counseling training for all staff working with DR-TB patients, integrated within overall DR-TB training.

Thematic area	Comprehensive care elements	Examples of services that can be provided to address each element
protect from social isolation or discrimination	providers and patients throughout care.	• Periodic patient surveys to assess level of satisfaction with provider-patient interactions. • Appointment of case managers, social workers, or patient care navigators for DR-TB patients to assist them in accessing care and connecting them with supportive services. • Formation of facility- or district-level DR-TB advisory committees composed of patients, community representatives, and providers to monitor DR-TB programs and advise on improvements.
	10. Regular monitoring and treatment of mental health conditions that affect the patient's ability to reach cure.	• Baseline and periodic depression screening. • Baseline and periodic assessment for other mental health conditions that may affect the ability to complete treatment. • Referral to mental health services and ongoing coordination of care. • Provision of ancillary medications to treat depression or other mental health conditions.
	11. Reduced social isolation through ongoing emotional support and encouragement to the person with DR-TB.	• Inclusion of family members in education and treatment processes. • Designated treatment supporter acceptable to the patient. • Peer support groups. • Linkages with community-based organizations to provide treatment adherence support services to DR-TB patients. • Periodic celebrations to acknowledge milestones toward cure.
	12. Protection of the person with DR-TB and family from stigma and discrimination in access to health care services, employment and community life; and facilitation of social rehabilitation.	• Provision of legal services to help patients obtain necessary registrations to access care. • Development and enforcement of anti-discrimination laws or workplace policies protecting employees with TB. • Community outreach and education strategies aimed at reducing stigma against people with TB within the community. • Engage community opinion leaders to normalize TB diagnosis and treatment.

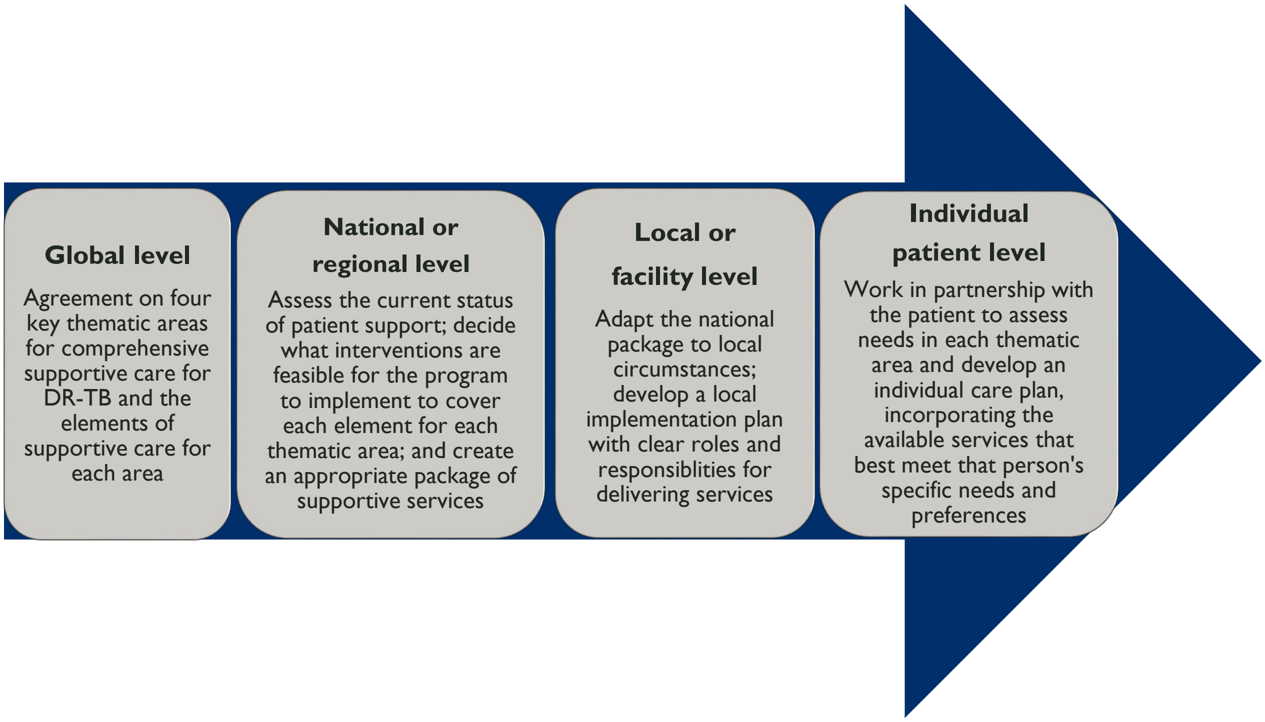
Thematic area	Comprehensive care elements	Examples of services that can be provided to address each element
		• Use of a standardized tool to measure stigma and development of specific plans to address it based on the findings.
Prevent catastrophic costs to person with DR-TB and family	13. Financial assistance as needed and feasible: direct, indirect, or both.	• Conditional cash transfers provided to patients contingent upon treatment adherence. • Unconditional cash transfers provided to patients but not linked to treatment adherence. • Inclusion of DR-TB patients in universal health coverage/social insurance schemes. • Microfinance schemes to assist affected people with small business ventures. • Support for transportation costs through the use of vouchers or direct provision of transportation. • Food packages for the patient and family to mitigate the health consequences of lost wages. • Food vouchers to purchase foods of choice. • Support for income-generating activities for people with DR-TB.

The framework presents all the elements that comprise a comprehensive approach to supportive care. The relative importance and approach to providing each of these 13 elements will vary across different settings, and it will be important for you to gather information from your own context to tailor services for your particular situation. In the table, we have provided some examples of supportive services currently being offered to people with DR-TB, but this list is neither exhaustive nor prescriptive—it is up to each country and each facility to decide how best to provide support to their patients.

It may be difficult for countries to cover all these elements at once, due to resource constraints or lack of needed skills and experience. The framework is meant to provide guidance on what elements constitute a complete package of patient support services. Countries should start by adding supportive services that are feasible to implement rapidly and will provide the greatest benefits to the greatest numbers of people. There are many considerations in choosing those services and implementing them. Section 4 below summarizes steps in the process, and the *Operational Toolkit* in Part II contains detailed instructions and tools to help you plan, implement, and assess your supportive care package.

How does this generic framework translate from a standardized to an individualized, person-centered approach?

The generic themes and care elements presented above are intended to be translated into specific services (interventions), at country, local, and individual patient levels. The process by which this happens is presented in the graphic below.



Global level

Agreement on four key thematic areas for comprehensive supportive care for DR-TB and the elements of supportive care for each area

National or regional level

Assess the current status of patient support; decide what interventions are feasible for the program to implement to cover each element for each thematic area; and create an appropriate package of supportive services

Local or facility level

Adapt the national package to local circumstances; develop a local implementation plan with clear roles and responsiblities for delivering services

Individual patient level

Work in partnership with the patient to assess needs in each thematic area and develop an individual care plan, incorporating the available services that best meet that person's specific needs and preferences

The process allows countries to take the generic framework developed at the global level and adapt it to the local context, choosing supportive services that are most appropriate for their setting. This first step results in a national package of services that is agreed upon by national-level stakeholders. From there, at the sub-national and local levels, the services may be further refined based on the specific needs of the local population—for instance, the services may need to be delivered differently in a rural versus an urban context, or for women as opposed to men. Once the specific services have been identified at the local level, a facility develops a specific plan for how the services will be provided to individual patients—which staff will be responsible for activities, and how all the stakeholders will work together to provide supportive care. Finally, the supportive care package gets tailored to the needs of each individual patient through the patient assessment and care planning process. In this final and most important step, frontline providers and patients work together to understand individual patient needs and match the available services to address those needs. Not every person will require every service—this approach allows for individual variations in patients' needs and preferences.

IMPLEMENTATION TIP

Most national TB control programs are not starting from zero in implementing DR-TB supportive care—many things are already happening at country level that fit into the framework of supportive care. This *Toolkit* is not meant to replace what is already there—it is meant to be used to examine where there might be gaps, and to help plan how to fill them over time to create a comprehensive package of supportive services.

4. Introducing and operationalizing supportive care services at country level

There are many different aspects of introducing a supportive care package, and they may vary in importance or in the order they happen in each country. This section gives you a general orientation to considerations as you move toward supportive care implementation and scale-up. Ideally, planning for supportive care should be integrated into your overall national planning cycles for TB—for instance, as you develop your next national strategic plan or Global Fund application, or when you develop your annual work plan.

Considerations at NATIONAL or REGIONAL level:

Creating political will and buy-in: Before you begin the technical work of developing, implementing, and monitoring supportive DR-TB care, it is important to ensure that the people who can influence the process are ready to support this effort. Unless you already have the full support of the necessary decision-makers at your level (whether it is national, provincial, local, or facility level), consider the following steps to help introduce the concept of supportive services and get the necessary buy-in before moving forward with other steps:

- Identify key stakeholders and consult with them in an introductory meeting (Note that stakeholders should always include patient representatives as an essential stakeholder group.)
- Present data on the current status of DR-TB treatment in your country or region and the need for improvements in treatment outcomes.
- Present relevant data on the importance of supportive care to improve treatment outcomes.
- Present the supportive care framework. Discuss questions and suggestions for implementing a package of supportive services.
- Get the agreement of key decision-makers to move forward with introducing or scaling up supportive care services.
- Comprise a small group that will be specifically responsible for developing the supportive care package and estimating the costs. Include representatives from all stakeholder groups as you would for any planning process, remembering that patient representatives are essential to this process.

Key Introductory Steps

Orientation to framework and buy-in at national level
↓
Generic national package developed and incorporated into policy
↓
Introduction plan developed
↓
Orientation & assessment of introductory sites
↓
Adaptation of generic package to local circumstances
↓
Local implementation plan
↓
Partnerships formed, all staff trained
↓
Implementation
↓
Monitoring and Evaluation
↓
Revision
↓
Expansion

Define a supportive care package: Use this *Toolkit* to translate the generic package into a package of services appropriate for your setting and circumstances. Consulting with a working group composed of stakeholder group representatives, especially patients, can help you adapt services to your setting. Alternatively, formative research using key informant interviews or focus group discussions can guide the development of an appropriate package of care at national or local levels.

- Review the thematic areas and comprehensive care elements; identify what services are already in place to cover the elements and where there are gaps. In consultation with all stakeholder groups, including and especially patient representatives, decide on the specific services the program will offer to deliver each element of the supportive care package to patients (You can use the *Supportive Care Status Analysis and Planning Template* in the *Operational Toolkit* to do this).
- Identify what additional services you can implement to cover as many elements as possible. Programs may not be able to introduce a comprehensive package all at once because of resource constraints or lack of training. In that case, we recommend that programs start with high-impact services that are feasible to implement immediately, and plan to create the foundation for gradually introducing more services as human and financial resources allow. What is feasible and high-impact will vary from setting to setting—you will have to determine the criteria you will use to decide what is most important to do first.
- Share the draft package with the larger stakeholder group for input before finalizing the services you will include in your package.

Develop an implementation plan: Once you have a list of services to implement, gather key health service managers and implementing partners to develop a draft implementation plan.

- Identify existing or planned processes, documents, or policies that are related to supportive care and decide on how to integrate the package into those efforts for maximum efficiency—for instance, into the national strategic planning process, national Programmatic Management of Drug-Resistant Tuberculosis (PMDT) protocols and procedures, or a Global Fund grant application.
- Identify where the package will be introduced and when and how expansion will happen, usually in phases.
- Based on the available epidemiological data, estimate the size of the patient population that will need DR-TB services for the coming year(s). Characterize that population as best as possible by gender, age groups, geographic distribution, and socioeconomic status.
- Decide on any criteria that will be used to determine which patients are provided with certain elements of the package (i.e., not all patients will require all support). Estimate the level of need for each of the services (i.e., how many patients will require each service and for how long).
- Use the *Rapid Systems Assessment* tool in the *Operational Toolkit* to assess what resources are already in place (policies, human resources, training, equipment and supplies, financial

resources, etc.) to fill the priority gaps and what is still needed at the sites selected for introduction or expansion (depending on where you are in the process).

- Develop an activity plan to cover the needs identified above for policy development, training, procurement, etc.
- Develop a monitoring and evaluation plan to help assess progress and the impact of supportive services.

Develop a budget and identify funding sources: Remember that, in addition to the actual supportive care interventions the program will implement, there are other activities and costs involved in doing so. These are mostly related to health systems activities that may be required to implement the supportive care services package, such as hiring additional staff, training, task shifting, policy changes or new policy development, strengthening the legal framework, creating partnerships, and other related items. The *Rapid Systems Assessment* tool allows you to identify those activities systematically and take their costs into account when planning your supportive care package.

Considerations at LOCAL or FACILITY level:

Get local buy-in for supportive services: Implementing a supportive care package may require changes to local policies and practices as well as those at the national level. Hold a workshop with local decision-makers and managers to orient them to the care package and get their support for introduction.

Adapt the national supportive service package to local circumstances: Conditions can vary significantly from one region of a country to another, or between urban and rural areas, and the service package may need to be adapted to fit your local realities. Similar to the process at national level, you can organize a small group of stakeholder representatives to assess the current status of supportive care services in your area and draft your local package of services. Patients are a key group for consultation, as they can advise you on what the target community values the most in terms of support.

Develop a local implementation plan: An assessment will be needed at the local or facility level, just as at the national level, to understand what resources are already in place and what else is required to deliver your package of supportive care. You can use the *Rapid Systems Assessment* tool to guide this process. In addition, you will need to be very specific about how you will deliver each of the services in the package, and who will do so. You will likely need to enlist providers in other departments outside the TB service and at other levels of the health system, as well as community-based organizations and other partners to provide all the services you have identified. It will be critical for you to develop clear roles and responsibilities and lines of communication for each member of the team who will be responsible for delivering supportive services. The *Local Operational Plan* template in the *Operational Toolkit* will walk you through the steps needed to implement the package successfully.

IMPLEMENTATION TIP

The *Operational Toolkit* contains all the tools and information you will need to start developing and implementing a comprehensive supportive care package. Please consult the resources there to learn how to address each supportive care element and plan for a successful introduction and scale-up.

BOX 3: QUESTIONS & ANSWERS ABOUT COMPREHENSIVE SUPPORTIVE CARE FOR DR-TB

WE HAVE ALREADY DEVELOPED A SUPPORTIVE CARE PACKAGE AND INCLUDED IT IN OUR PLANS AND LEGAL FRAMEWORK. DO WE NEED TO GO THROUGH THIS PROCESS?

Many countries are already in the process of developing or have implemented supportive care packages. While it is not required to use this process, you may be able to refine your interventions and target them to the patients most in need by going through the steps presented here, and to identify and fill any gaps in your supportive care.

WE ARE PLANNING TO INTRODUCE SHORTENED REGIMENS AND NEW DRUGS FOR DR-TB. DO WE STILL NEED TO PROVIDE SUPPORTIVE SERVICES TO DR-TB PATIENTS? WILL THEY CHANGE AS A RESULT OF THE DIFFERENT REGIMENS?

Patients and providers both acknowledge that the long duration of DR-TB treatment, side effects of medications, and painful injections are significant barriers to adherence. Shortened regimens, drugs with fewer side effects, and regimens without injectables will go a long way to helping people get through their DR-TB treatment successfully. However, while the duration of support may change and the needs may also change, in general supportive services are still strongly recommended as part of quality patient care. As you gain experience with new regimens, continue to survey patients to understand their needs and adjust your support package accordingly. The Patient Assessment and Care Plan tool included with this *Toolkit* can help you do this.

WE HAVE NO FUNDS TO PROVIDE SUPPORTIVE CARE SERVICES. HOW CAN WE MOVE FORWARD?

Many TB programs are underfunded and have difficulties covering all components of TB prevention, diagnosis, and care. However, when it comes to supportive services, there are many low- or no-cost interventions that can be tremendously helpful to patients, especially those that establish a caring and trusting relationship between providers and patients, provide information, or offer peer support. In addition, the TB program is not required to provide all these services on its own. It’s very important to map the other sources of funds and human resources outside the TB program that can be leveraged to provide some of the needed services. For instance, the government likely has broader social insurance schemes into which DR-TB patients can be incorporated. For example, in some countries the World Food Programme or government programs have sponsored food packages for needy patients and their families. Local community organizations may have income generation activities with which patients can be linked, or corporations may be able to cover the costs of essential supportive care for DR-TB patients in the geographic locations where they operate. There are many possibilities, and it is essential to identify and use these additional resources in your own setting.

Of course, there are also opportunities to fund these services through government allocations, Global Fund, and other donors. You can use the *Operational Toolkit* to help develop a budget for your services that can be included in funding proposals.

PART II: OPERATIONAL TOOLKIT FOR DELIVERING COMPREHENSIVE SUPPORTIVE CARE SERVICES TO PEOPLE WITH DRUG-RESISTANT TUBERCULOSIS

Introduction

There are many different aspects to developing and implementing a package of supportive care services for people with DR-TB—you need to ensure the buy-in of key decision-makers, decide what services you will offer, understand what preparation and procurement will be required to implement the package, develop a budget and identify funding, and plan for M&E. These activities will happen at the national and regional levels to plan for implementation, but also must happen at the local and facility levels to deliver these services to directly to DR-TB patients.

This *Toolkit* provides you with step-by-step guidance on how to operationalize the framework presented in the *Introduction*. It includes a number of tools that can be helpful in planning your supportive services, with instructions on how and when to use them. Our intention is that you can use the *Toolkit* to plan and implement your supportive service package without the need for extensive technical assistance—it gives you enough details and information to be able to do this important work on your own.

Part II of the *Toolkit* starts with information for national and regional level managers who will develop the overall plan for supportive service implementation. After that, it continues by providing additional guidance to local and facility level managers and staff about how to plan effective delivery of supportive services to your patient population. Many of the resources and tools included will be helpful at both levels but may be used in slightly different ways to accomplish your objectives.

These tools are here to help programs that do not already have processes or templates in place for these purposes. If you already have a system to plan and implement supportive services, there is no need to replace what you are doing with something new, unless you find some of these materials particularly helpful. The important thing is to have a systematic way of approaching your planning and monitoring so that you can gather the information necessary to continually improve what you are doing to support DR-TB patient treatment success.

All of these tools are provided in a modifiable format so you can change them in any way that makes them more useful for you. We encourage you to adapt the *Toolkit* for your own purposes and share your revised versions with us so that we can improve the generic version for future users.

Beginning the process at the national, regional, or local level

Below are step-by-step instructions that will help you plan implementation of supportive care services for people with DR-TB at the national, regional, or local levels. While these steps are listed in a specific, logical order, we know that things will be different in different settings—feel free to take what is useful for you and change or delete what is not relevant.

There are 10 basic steps in introducing a supportive care package for DR-TB patients. The steps are listed in the box below and described in detail in the text that follows. In most instances, the national TB control program (and its representatives at regional and local levels) will take the lead in managing this process and coordinating among the various stakeholders to implement and monitor the supportive services package. The descriptions below are focused on what happens at the national level, but they are equally useful for managers working to introduce the package of supportive services at a regional or even local level—you can adapt them as needed to fit your specific situation.

The 10-Step National, Regional, or Local Process for Introducing Supportive Care Services

1. Identify your stakeholders, orient them to the supportive care framework, and get their buy-in
2. Identify a Task Force to develop, revise, and finalize the national supportive services package and get stakeholder agreement on the package
3. Incorporate supportive care in national guidance documents and legal frameworks, as appropriate
4. Choose locations where package implementation will begin or expand
5. Analyze your policy, human resource, and material needs to prepare for implementation
6. Develop an implementation plan and budget
7. Identify funding sources
8. Plan how to monitor and evaluate your supportive services
9. Use the lessons learned to continue improving upon the services delivered
10. Develop an advocacy strategy and plan for sustainability of the supportive care package

Step 1. Identify your stakeholders, orient them to the supportive care framework, and get their buy-in. Identify stakeholder groups and specific organizations or individuals within each group who should be engaged in the process of developing and delivering your supportive services package to patients. Consider the potential groups listed below and add or change them as needed for your context. You can create a table like this one to organize your information:

Stakeholder group	**Specific individuals and/or organizations in that stakeholder group to engage**	**Contact information**
National TB Control Program (NTP)		
Other Ministry of Health (MoH) programs/divisions		
Other government ministries/agencies		
Technical partners		
Local implementing organizations		
Other relevant community-based and faith-based organizations		
Patient organizations		
Private health services/facilities		
Professional associations and academic institutions		
Frontline providers		
Corporations or other for-profit organizations		
Donors		

Plan and hold an orientation meeting for stakeholders. It is important to engage your stakeholders in this process from the earliest stages of development so you can create a broad base of support for implementation and identify additional resources that can help you in doing so. We recommend holding a half-day or full-day orientation meeting with all key stakeholder groups to present your data on DR-TB diagnosis and treatment outcomes, discuss the benefits of supportive services, introduce the supportive services framework, and answer their questions. This may be a stand-alone meeting or can also be inserted into the agenda of another existing meeting. From this meeting, you can identify interested members for a task force that will develop and oversee implementation of the package.

You will have to go through the following tasks to do so:

- Decide on a meeting date and venue
- Develop an agenda
- Invite participants
- Make logistical arrangements
- Prepare presentation(s), handouts, and other materials for distribution
- Conduct the meeting
- Follow-up on action items

Step 2. Identify a Task Force to develop, revise, and finalize the national supportive services package and get stakeholder agreement on the package.

Identifying the Task Force. To plan a package of services, we recommend appointing a short-term task force composed of 10-15 people who represent all the key stakeholder groups (including patients and frontline providers) and are empowered to make decisions about what services should form your supportive care package. The task force will make recommendations that the national TB control program can then adopt or revise. You can use the table below to identify your task force members. **Note that if you already have a DR-TB working group, that group may be appropriate to serve this function.** In either case, a clear Terms of Reference to guide the Task Force's work will support an efficient process.

Stakeholder group	Representative name	Contact information

Developing or revising your package of supportive care services**.** We recommend that you convene a one-day meeting of the task force to receive orientation to their Terms of Reference, review existing services, and plan any new ones needed. Consider what services are already in place and are working well. Have copies of the *How-To* guides (included in this *Toolkit*) available for each team member to consult for ideas about different ways to approach the services and complete the *Supportive Service Status Analysis* template as a group. This list of services will form the basis for your package and the rest of your planning process about how to introduce, evaluate, revise, and scale up your services.

The task force can start by reviewing what is already in place in your country to cover some of the elements of a comprehensive supportive care package—most countries are already providing a number of relevant services, but there may be some gaps that could be filled to improve results further. You have several resources in this toolkit that will help you through this process. They include the *"How-To"* guides for each element that can give you ideas of what other programs may have done and point you to additional resources, as well as the *Supportive Service Status Analysis* template that will help you systematically review the supportive care elements and assess where you stand on each one.

As described in the *Introduction,* many programs will not be able to cover all elements in the beginning, because of resource constraints or lack of expertise. Decide which elements are most important in your context—the ones that can yield the greatest benefit to the greatest number of patients and are feasible to implement in the short term—and give those elements highest priority. Below you will also find a list of 10 guiding questions that will help the task force organize their discussions as they select the services most appropriate for your context, and will guide them through the rest of the planning process.

Getting stakeholder agreement. Once the Task Force has developed your standard supportive care package, circulate or present the draft to your larger stakeholder group to get further buy-in and establish a common understanding of what services will be implemented. This can be done electronically, as part of another existing meeting, or as a stand-alone meeting if needed.

10 Questions for Planning Delivery of Each Supportive Care Element

1. Which services/interventions are most useful and feasible to provide this element in our specific setting? Are there examples from similar settings that can help us decide what might work best? (See *How-To* guides for ideas)
2. What is the status of providing this supportive care element right now? Are we not providing this service at all, providing on a limited basis, or providing fully to those in need? (Use the *Supportive Service Status Analysis* template to do so)
3. How many people are likely to need this service in the next planning period? What criteria will we use to determine who will receive this service?
4. What entity is best placed to deliver this service? Does it lie within the TB program, with another government department, or with civil society groups, corporations, or others?
5. What cadre of staff or volunteers is most appropriate to deliver these services? How many people would we need to deliver these services to everyone in need? Do we have sufficient staff already, or would we need to hire more?
6. Do we need to provide any additional training for staff to be able to implement these services?
7. Do we need to change any policies or guidance documents to be able to implement these services?
8. What material resources (e.g., forms, job aids, education materials) do we need to implement these interventions?
9. How much will it cost to provide these services to all who need them during the next planning period?
10. Where will the funding for these services come from?

Step 3. Incorporate supportive care into national documents, guidelines, and/or legal frameworks as appropriate. Implementing a supportive care package may require that you review and adjust national TB control guidance documents, such as the National Strategic Plan, policies or guidelines on treatment of TB/DR-TB or on supportive care for people with TB, or legal frameworks that pertain to TB. The Task Force can review existing documents and frameworks and make recommendations to the NTP on where changes need to be made to support implementation of a care package.

Step 4. Choose locations where package implementation will begin or expand. As you begin to introduce supportive services, consider the geographic areas that are priorities and estimate how many patients will need services in the coming planning period. Initially, you may want to do so in areas where it is most feasible in order to get some experience that will help you in planning scale-up to more challenging regions. For instance, you may want to choose locations with well-established DR-TB treatment programs, management willing to implement supportive care, sufficient staff, technical partner support, and existing linkages with community-based organizations. As you expand access, you can consider prioritizing areas with high patient burden and low treatment success to yield the greatest improvements to patient outcomes. The task force should decide on what criteria you will use to select sites for introduction/expansion of supportive care, and then select a manageable number of sites for the coming planning period. At the national level, you may decide to select provinces as "sites," while at regional level, you may be choosing districts or even facilities as the "sites." The table below can help organize the discussions and document agreements on these issues. Add more rows if needed.

<table>
<tr><td colspan="3">Criteria for site selection:
•
•
•
•
•</td></tr>
<tr><td>Site name
(Note that depending on the level of planning, this may be a province, district, or facility)</td><td>Location/contact information</td><td>Estimated number of DR-TB patients to be served in the next planning period*
(include new and continuing patients in the estimate)</td></tr>
<tr><td></td><td></td><td></td></tr>
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*For help in estimating the number of patients who will need services, you can use the table below.

A	B	C	D	E	F
Planning period	Estimated number of **bacteriologically positive pulmonary TB** cases to be diagnosed during this period	Proportion of bacteriologically positive pulmonary TB cases with DR-TB, according to our epidemiology (%)	Estimated number of DR-TB patients who will need supportive services in this cohort (B x C)	Estimated number of DR-TB patients from previous cohorts who will continue to need supportive services during the coming planning period	**Estimated total number of DR-TB patients who will need supportive services during the planning period** (D + E)

Step 5. **Analyze your policy, human resource, and material needs to prepare for implementation.** Assess what resources you will need to implement your supportive care package at the sites selected in Step 4. To do so, you will need to consider any policy changes you may need to make, staff training that might be required, procurement of supplies or equipment, partnerships to deliver services, and budget required. The task force can organize the analysis using the *Rapid Systems Assessment* tool that is included in this *Toolkit*.

Step 6. **Develop an implementation plan and budget**. Once the task force has analyzed what changes and additions will be needed to implement supportive services, the task force should work with the NTP and other key stakeholders to develop an implementation plan (work plan) for the coming planning period that lists the activities required for the preparatory and implementation phases. The plan should also identify who will be responsible for completing each activity, the timeline for activities, and the budget. **Ideally, the plan should be integrated within the framework of the overall NTP work plan for the year to avoid confusion, duplication of effort, or having activities overlooked.**

Step 7. Identify sources of funding for the implementation plan activities. Supportive care covers a wide range of services, some of which are outside the typical responsibilities of the TB program. While some TB program budget will be devoted to providing these services, consider what non-TB resources or funds might be available to contribute. For instance, there may be other social insurance programs within the government that can provide food packages or financial aid to people with DR-TB. Other health programs may be offering services that would be beneficial to DR-TB patients, such as support for mental illness or substance abuse treatment, that require only linkages. Also consider what donor funds might be accessed to expand supportive services, such as Global Fund monies.

Step 8. **Plan how to monitor and evaluate the effectiveness of your supportive services**. To be able to obtain ongoing funding and political support for these services, it is important for you to be able to describe what you have achieved in providing supportive services to DR-TB patients. The most obvious measures of effectiveness will be in seeing improved treatment outcomes—more patients being cured and fewer lost to follow-up, failed, or died. In addition to basic outcomes measures, which are the easiest data to collect, you could also look at interim treatment outcomes, time to culture conversion, rates of serious adverse events, catastrophic costs to patients and their families, and patient satisfaction as a few other indicators of success. However, this group of indicators may require additional effort, time, or training to gather correctly. You will have to weigh what evidence is essential to your evaluation and develop a plan to collect it. The *M&E Guide* included in this toolkit can give you help in planning and implementing efficient M&E for your supportive services.

Step 9. **Use the lessons learned to continue improving upon the services delivered.** Analyze your results on (at least) a yearly basis and use what you have learned to improve how supportive services are delivered. In addition to a yearly analysis and discussion in the context of regularly scheduled national review meetings, consider more frequent feedback from stakeholder groups involved in implementation so that challenges can be identified and addressed quickly. This is especially useful in the early stages of the introduction process. As you gain more experience and have more data to evaluate your efforts, you may be able to identify selected interventions for scale-up that provide the greatest benefits to the most patients as a way to use resources most effectively.

Step 10. Develop an advocacy strategy to sustain delivery of supportive care package services to people with DR-TB and/or TB. Countries have often experienced difficulties taking successful project-based interventions to scale because of lack of awareness and buy-in on the part of decision-makers. From the beginning of implementation planning, start identifying key stakeholders who can help support the financial sustainability of the care package and consider the data you may want to gather to make a strong argument for continuing these services. Some of those data will rely on indicators that are already gathered by the national program, while others may require a special effort to collect. The M&E section of this *Toolkit* can help you plan for data collection.

To make a convincing argument, think about your target audience, what messages they will respond to, and who should deliver those messages. Personal stories from people who received care package services and have been cured, along with solid data, are often useful in combination when trying to appeal for resources to continue your work.

Introducing supportive services at the facility level

The following pages provide instructions for facility-level managers who are working to implement supportive care services for DR-TB patients. Once agreement has been reached at the national, regional, or local level about a package of services to implement, you may need to adapt that package to your facility conditions, where circumstances will likely be different in certain ways and may require adjustments to the services you can provide. The steps below will help you take a generic set of services and adapt them to the needs of your specific patients. Many of the steps are similar to those at the national level but are more focused to your local area. In most cases, this process will be led by your facility managers and TB service managers in collaboration with your local TB control program manager.

Step 1. **Identify your stakeholders**. Identify who within your facility or among your partners will be involved in delivering supportive care to patients (either directly or indirectly) and engage them in the process of adapting, implementing, and monitoring the supportive services package. The table below includes many different possible stakeholder groups—you can edit them as appropriate for your setting.

Stakeholder group	**Specific individuals and/or organizations in that stakeholder group to engage**	**Contact information**
Local TB Control Program/health service administrators		
Facility managers		
TB doctors		
Other relevant specialist doctors		
TB laboratory staff		
Nurses		
Social workers		
Community health workers		
Patient representatives		

Stakeholder group	**Specific individuals and/or organizations in that stakeholder group to engage**	**Contact information**
TB data managers/analysts		
Legal aid staff (lawyers or paralegal staff)		
Social insurance scheme representatives		
Community leaders		
Local community-based and faith-based organizations who provide community health services (or have the potential to do so)		
Local corporations or other for-profit organizations that may be able to contribute resources for services		

Step 2. Develop a facility-specific plan for implementation. This step is the most important part of planning supportive services introduction, in which a facility details how services will be provided directly to DR-TB patients by frontline providers. You can use the *Facility Operational Plan* template to adapt the package of supportive care services for local conditions and plan for implementation. We recommend that you convene a one-day meeting of your stakeholders to discuss your facility package of services and complete the *Facility Operational Plan*.

2a. Orient facility stakeholders to the package framework. Present the four thematic areas and 13 elements of comprehensive supportive care and describe the services the NTP has proposed to provide.

2b. Review the services that have been proposed for the national level for each supportive care element.

- Discuss whether each of these services is appropriate for your facility, or how you need to change them to meet patients' needs and agree on a final list of services the facility will offer.
- To help you in this process, consider what services are already in place and are working well.
- Consult the *How-To* guides in this *Toolkit* for ideas about different ways to approach services.
- Use Section I of the *Facility Operational Plan* to record the services that your facility will provide, how they will be delivered, how often they will be delivered, and who will have primary responsibility for doing so. Remember that the TB department within the facility is NOT expected to provide all services on its own—some services may be delivered by other departments within the facility (for instance, treatment for co-morbid conditions such as HIV or depression) while others may be provided by community groups, volunteers, or other partner organizations. Be creative in identifying ways to use other existing resources to meet patients' needs.

2c. Assess what you have in place and what you will need to be able to implement the package of services you have agreed upon. Use Section II of the *Facility Operational Plan* to guide your assessment.

- Review any policy changes you may need to make at the local or facility level to allow you to provide the supportive care services.
- Assess whether your staff or partners will need additional training to be able to implement the services, and plan on how that training will be delivered.
- Consider whether any additional supplies or equipment will be needed for supportive services implementation, and develop a budget for any procurement needs.

2d. Identify the cadres of staff and the specific individuals within the facility as well as with your partners who will be engaged in delivering the supportive care services to DR-TB patients. Complete Section III of the *Facility Operational Plan* to identify the team and to clearly define the roles and responsibilities of each.

- Consider a multidisciplinary team whose skills and expertise meet the needs of the local patient population.
- Discuss whether a re-organization of current staff, additional staff, and/or other types of staff may be needed for implementation. Consider whether you can shift current tasks from one cadre to another to improve coverage.

2e. Define how the members of the team will communicate effectively with each other so that information critical to high-quality patient care is shared with the right team members at the right time. Use Section IV of the *Facility Operational Plan* to document your communications plan. In the initial stages of implementation, more frequent face-to-face interactions with all team members may be needed to address questions and ensure consistency across all team members. As you gain more experience, you can revisit the plan and revise it as needed, but make sure there is a communication system in place that all caregivers agree to and follow.

2f. Develop a clear plan for monitoring your supportive care activities and evaluating their effect. Here, you may consult with your local TB control program manager and/or facility data manager to develop a list of indicators you will monitor and develop a plan for how data will be collected and shared. In general, these indicators will be limited to interim and final treatment outcomes for your DR-TB patients, and comparisons between results before and after supportive services implementation.

2g. As you go through the implementation process, use feedback from staff, patients, partners, and other stakeholders to improve upon your supportive service delivery. You can obtain feedback through informal channels, at regular TB control meetings, through focus group discussions, or meetings of the supportive care team. In addition, the facility can consider periodic anonymous DR-TB patient satisfaction surveys to gauge how patients perceive the services you are offering—this is critical feedback for improving the supportive care package and focusing on the most important services for your specific patient population. The *M&E Guide* in this Toolkit can provide you with ideas and tools to use to track your results.

Step 3. Adequately prepare facility staff to provide person-centered supportive care. The plan you develop in Step 2 will include identifying all the training that staff will need to provide supportive services. One key component of supportive care is providing each patient with a thorough assessment of needs at the time they are starting treatment (Element 1 of Comprehensive Supportive Care), with regular check-ins as treatment progresses. This process is what allows the package of services to be tailored to individual patient needs and preferences. The *Patient Assessment and Care Plan* tool provided in this *Toolkit* allows frontline providers to approach this assessment in a systematic way. The tool can be adapted to your specific requirements, or pieces of it can be integrated into existing patient documentation. The *Care Plan* tool includes its own instructions—orientation to this document, or your adaptation of it, should be part of every training plan for staff at the facility level. Plan for refresher trainings at regular intervals or when there is turnover in the team members providing supportive care.

TOOLS

How-To Guides for the 13 Comprehensive Supportive Care Elements

How-To Guide #1: Thorough patient assessment & care plan

Thematic Area:	**Respect patient autonomy and support self-efficacy**
Comprehensive Care Element:	**1. Completion of a thorough patient intake assessment across all thematic areas and an individual care plan that meets each patient's specific needs.**
Rationale:	Documenting a patient's needs at the beginning of treatment and developing a care plan serves several purposes: • It helps establish an open and trusting relationship between patient and provider. • It helps identify potential barriers to treatment adherence early in the process so they can be addressed pro-actively. • It sets clear expectations for what services are available and what the patient will receive, as well as the patient's responsibilities in treatment. • It provides a written record of services that can be monitored, updated, and shared with the whole team of providers to avoid duplication of effort.
Examples of interventions to address this element: (this is not an exhaustive list)	• Standardized patient assessment and care plan completed by provider and patient at treatment initiation (adaptable *Patient Assessment and Care Plan* tool available with this toolkit). • Incorporate questions on non-medical needs and plans into existing patient treatment documentation. • Develop a checklist of non-medical needs and services to use during the intake process.
Steps in the process of introduction:	• Decide what intervention(s) is (are) most suitable for your context (see list above or develop your own intervention). • Convene a group to review/adapt the approach and tools you will use to conduct a patient assessment and develop a care plan. • Hold an orientation to the process for all staff/volunteers involved in DR-TB patient care (this should be done in conjunction with other scheduled training or meetings on DR-TB whenever possible). • Decide what cadre of staff or which individuals will be responsible for completing the plan. • Decide how the information will be shared with other team members as things change during treatment. • Develop an Standard Operating Procedure (SOP) for completion, regular updating, and monitoring care plans as part of other routine activities (e.g., patient follow-up visits, monthly health team meetings). • Print and distribute documents as needed.

TIPS for implementation:	- Complete the assessment and plan collaboratively with the patient—this will help establish rapport and promote patient participation in decision-making. - Allow enough time to complete it. It will likely take multiple visits to do so—that is fine. - Consider developing an electronic format so it can be easily shared with care team members inside and outside of the facility as needed. - Assure patients that information provided is confidential. Limit access to the information to those who need to know to provide high-quality care.
Resources available to you:	*Patient Assessment and Care Plan* tool that is part of this *Toolkit*

Example from the field

Ukraine: Assessing patients for risks using a standardized tool

In Ukraine, supportive services for DR-TB are currently funded by USAID or Global Fund on a project basis—there are not enough domestic resources allocated at present to provide every DR-TB patient with supportive care. To make the best use of available funds under the Challenge TB project supported by USAID, PATH and its local partners have implemented a screening process to identify DR-TB patients who are at a higher risk of not completing their DR-TB treatment after discharge from the hospital.

Prior to discharge, a member of the multidisciplinary DR-TB care team assesses each patient for the following risk factors using a standardized questionnaire:

- Homelessness
- Alcohol and/or drug dependence
- Unemployment
- History of incarceration
- Physical disability
- TB/HIV or other comorbidities (diabetes or Hepatitis B or C)

Persons with any of these risk factors are prioritized for supportive care services to improve their chances of cure (in addition to those for whom a doctor requests supportive services). Patients are offered services according to their needs, such as temporary housing; legal help to obtain the necessary legal documents to access treatment; substitution therapy for drug dependence; help with job searches; connection with social services; home visits for those who are unable to travel for treatment; travel reimbursements for those who do visit facilities for care; clothing; telephone cards; food supplementation; and psychological counseling. Patients have expressed their deep appreciation for the approach the multidisciplinary teams have taken and the care they have received. Thus far, by targeting the people who most need supportive care, the project has been able to help one of the oblasts in which it operates achieve the highest cure rates for DR-TB in the country.

A multidisciplinary team of providers in Ukraine assesses patients' risk factors for not completing treatment and devises a tailored plan of supportive care for each person. Photo credit: PATH.

How-To Guide #2: Patient & family education

Thematic Area:	**Respect patient autonomy and support self-efficacy**
Comprehensive Care Element:	**2. Patient and family education on DR-TB disease and treatment**
Rationale:	• Survey responses, patient testimonials, and the peer-reviewed literature emphasize the importance of patient and family understanding of DR-TB disease and treatment as an absolutely essential element of successful treatment. • Providing patients and their families with understandable information allows them to make better decisions for themselves and helps them understand what to expect during the course of treatment. • Using accurate information to dispel rumors and misinformation also helps reduce the fear and stigma that continues to surround TB.
Examples of interventions to address this element: (this is not an exhaustive list)	• Education sessions provided by a health care worker or other staff at diagnosis, treatment initiation, and throughout the course of care covering all relevant topics. • Audiovisual educational materials (e.g., videos) produced in appropriate, understandable and person-centered language. • Written educational materials (patient treatment booklet for the patient to keep, posters, flip books, etc.). • TB information hotline for patients and providers. • Peer education and support groups.
Steps in the process of introduction:	• Decide which interventions are most suitable for your context and target audiences (see list above or develop your own intervention). • Gather existing educational materials and adapt them as needed for your audience, including translation if appropriate. To the extent possible, avoid creating new materials. • Identify which staff or volunteers will be involved in patient and family education, and train them on the appropriate use of your materials. • Test your materials and approaches on your audience before finalizing them, so you can make adjustments. • Include patient and family education as part of the SOP for patient care and monitor implementation regularly.
TIPS for implementation:	• Plan to provide information during the entire course of treatment, from pre-diagnosis until treatment completion and follow-up. Reinforce previously provided information and ask the patient and family if they have additional questions as the treatment progresses. Use a checklist such as the one provided in the *Patient Assessment and Care Plan* to keep track of what topics have been covered and what remains for discussion. Ask patients and families about their questions each visit so you can address what is important to them.

	• Don't overwhelm the patient and family with too much information at once. Start with key messages (such as "your illness is curable") and gradually add more detailed information as the patient is able to absorb it. • ALWAYS check for understanding by asking the patient and family to tell you what they have learned in their own words—asking "do you understand?" is not sufficient to gauge understanding.
Resources available to you: (these are only a few resources out of hundreds available)	*Patient Assessment and Care Plan* tool that is part of this *Toolkit*
	The Patients' Charter for Tuberculosis Care http://www.challengetb.org/publications/tools/ua/The_Patients_Charter_for_Tuberculosis_Care.pdf
	Patient Support Interventions to improve adherence to drug resistant tuberculosis treatment COUNSELLING TOOLKIT (MSF Khayelitsha 2014) http://samumsf.org/documents/2014/06/khayelitsha_dr-tb-pt-support.pdf
	Multi-drug resistant TB: Make sure you know the facts (URC) http://www.urc-chs.com/resources/multi-drug-resistant-tb-make-sure-you-know-facts
	For a searchable online library of resources, please consult: https://findtbresources.cdc.gov/

Example from the field

China: Making Information Accessible through the 57 Zone Online Patient Community

In China's Yunnan Province, the population is spread across a large, mountainous area, making access to care and information more challenging. Through the CAP-TB project funded by USAID, FHI360 has supported a patient-owned and managed online social media platform where patients with TB and DR-TB and their family members can ask questions and get answers from their peers and their doctors and nurses. The "57 Zone" site is actively managed on a daily basis by local peer counselors who have been trained in TB and DR-TB treatment literacy and includes support from TB doctors and nurses to provide accurate and timely information to patients.

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Frequently asked questions include those related to TB drugs, managing side effects, where to access TB services, and how to interpret lab results. Patients can also post announcements, share photos, and access educational materials on the site. Accessing the site is free for users, and is a relatively low-cost intervention that reaches a very large number of patients and their families. Monthly operation of the site in Yunnan costs approximately 300 USD, including training and compensation for peer counselors and health care staff. For this small amount of money, the site supports more than 2,000 members who are part of the 57 Zone community in Yunnan.

57 Zone not only provides a forum for asking questions and receiving accurate information about TB and DR-TB, it also serves as a way for socially and geographically isolated patients to create a sense of community and to share their experiences with others, thereby giving them encouragement to continue their treatment.

As a result of its efforts, the China National Center for Disease Control awarded 57 Zone the Outstanding TB Volunteer Team of the Year in 2016. Now 57 Zone communities have been established in five provinces, with an anticipated nationwide scale-up in the coming years.

How-To Guide #3: Choice of location & timing for treatment

Thematic Area:	**Respect patient autonomy and support self-efficacy**
Comprehensive Care Element:	**3. Provisions to treat patients at an appropriate location and timing of their choice (hospital in-patient, clinic, community or home).**
Rationale:	• Long hospitalizations may discourage patients from continuing treatment and are extremely expensive for the health system. • Current global guidance recommends devolving DR-TB care to ambulatory models as quickly as possible. • Decentralization to bring DR-TB care closer to patients' homes decreases patient costs and time for transport and encourages treatment continuation. • Letting patients choose their preferred site for treatment respects their autonomy and allows them a higher level of control.
Examples of interventions to address this element: (this is not an exhaustive list)	• Hospital in-patient treatment arrangements for those who are too sick to be at home, live far from care, or have other circumstances that warrant hospitalization. • Thorough discharge planning for patients who have been hospitalized to ensure continuity of care during transition to outpatient services. • Home assessment for all patients to gauge suitability of the environment for the patient and family related to access to care, infection control, safety, etc. • Ambulatory clinic-based care model in which the patient travels to the health facility to receive treatment. • Ambulatory community-based care model in which the patient is connected with a provider nearby his/her home and travels to the provider's location for treatment, overseen by the responsible public health facility. • Home-based care model in which the health team travels to the patient to provide treatment services.
Steps in the process of introduction:	• Decide which models of care are most suitable for your context and target groups (see list above or develop your own interventions). Most programs will use several different models of care to address all patient needs in intensive and continuation phases of treatment. • Review current policies and make any necessary changes to support appropriate models of care. • Convene a group and develop or review SOPs for deciding on individual patient treatment approaches: ○ Criteria/algorithms for hospitalization versus outpatient treatment ○ Processes for ensuring continuity of care between in-patient and ambulatory settings ○ Roles and responsibilities of different cadres of staff in supporting treatment at convenient locations and times ○ List of local sites/providers who are able to provide DR-TB treatment

	• Train staff on the approach to treatment models as part of ongoing training on DR-TB. • Monitor progress and identify challenges that need to be addressed to improve the convenience of services to patients.
TIPS for implementation:	• There are many potential models of care—learn from what you have done in the past and what other countries are doing in similar circumstances to guide you in choosing models to try. • Develop very clear roles and responsibilities for ensuring continuity of care from in-patient to outpatient settings—this is often where patients become lost to follow-up. Using a multidisciplinary team approach to care, with facility and community providers in regular contact, can help maintain better continuity of care. • Assess factors such as waiting times, travel times, perceived service quality, patient outcomes, and costs to patients and the health system as you refine your models.
Resources available to you:	*Companion Handbook to the WHO Guidelines for the Programmatic Management of Drug-Resistant Tuberculosis (Chapter 18)* (WHO 2014) http://apps.who.int/medicinedocs/documents/s21662en/s21662en.pdf
	Community-Based Care for Drug-Resistant Tuberculosis: A Guide for Implementers(TB CARE II 2017) http://tbcare2.org/wp-content/uploads/2018/09/Community-Based-DR-TB-20180830-1.pdf
	Multi-Drug Resistant Tuberculosis: A Policy Framework on Decentralised and Deinstitutionalised Management for South Africa (SA Dept of Health 2011) http://www.tbfacts.org/wp-content/uploads/2015/08/SA-MDR-TB-Policy.pdf
	Decentralised, patient-centred models of delivering treatment and palliative care for people with M/XDR-TB(HATiP 2010) http://www.aidsmap.com/Decentralised-patient-centred-models-of-delivering-treatment-and-palliative-care-for-people-with-MXDR-TB/page/1520451/

Example from the field

South Africa: Decentralizing care to improve access

In South Africa, decentralization was implemented to address challenges associated with DR-TB diagnosis and treatment. The treatment success rate for the 2011 cohort of more than 6,000 people was only 45 percent. There was also a decrease in the total number of TB patients initiated on treatment from 406,082 to 332,170 for 2009 and 2013, respectively.

Challenges included the following:

- Long distance travel for hospital admissions and follow-up
- Long waiting times before admission and initiation on treatment due to lack of capacity
- Negative impact on social and economic status
- Risk of transmission in hospitals
- High levels of stigma

The main objective of decentralization was to treat DR-TB patients closer to their homes.

The first step in decentralization was to train healthcare workers on understanding the complex treatment regimen, laboratory drug susceptibility testing (DST), patient consultation, monitoring, and emotional support. Facilities had to undergo an accreditation process for essential elements, such as adequate supply of medicines, access to laboratories, assessment tests such as audiology and electrocardiogram (ECG) machines and recording and reporting mechanisms.

Within the decentralized approach there are different models of care: **the in-patient model** for patients who are not clinically well and often have co-morbidities that present secondary complications and **the ambulatory or outreach model** where patients are initiated at primary health care level. Patients managed through this model are stable and don't require admission and the outreach model of community health care workers is used to support patients. The intensive phase of treatment is provided by injection teams and once the phase ends, patients are supported by lay health workers/home-based care givers who serve as Directly-Observed Treatment (DOT) supporters. Care and management for patients involves a multidisciplinary team of clinicians, dieticians and social workers to support patients in their treatment journey.

Through decentralization, the National TB Program (NTP) has increased access to DR-TB care from 17 to 657 treatment initiation sites. All 53 districts in South Africa have at least one treatment initiation site and 238 sub-districts out of 277 have at least one DR-TB treatment initiation site. Treatment initiation is provided by either medical doctors, clinical nurse practitioners or clinical associates who have received training on DR-TB and are accredited. To date, decentralization in South Africa has 86 percent subdistrict coverage.

To complement the process of decentralization, the NTP implemented intensive TB education campaigns with the aim of educating individuals and communities about TB. Former patients cured from DR-TB have often played a role of encouraging and supporting patients to adhere and complete their treatment.

References:

Ndjeka, N. (2015). Treating DR-TB Patients in South Africa: Clinicians Course

Smith, J (n.d). Managing Drug Resistant Tuberculosis in South Africa: a decentralized approach to care. Yale University Global Health Leadership Institute

How-To Guide #4: Monitoring & timely treatment of side effects & adverse drug reactions

Thematic Area:	**Maximize physical comfort, safety, and wellness**
Comprehensive Care Element:	**4. Regular monitoring for and timely treatment of side effects and adverse drug reactions.**
Rationale:	• Patients cite side effects of medication as one of the most frequent barriers to treatment continuation. • Timely identification and treatment of side effects and adverse events can mean the difference between life and death or permanent disability for a patient. • The safety profile of new drugs used to treat DR-TB is as yet incomplete and patients placed on new drugs or regimens should receive active monitoring for serious adverse events.
Examples of interventions to address this element: (this is not an exhaustive list)	• Baseline and regular laboratory testing as indicated by national guidelines, depending on the drug regimen being used. • Daily questioning of patient by health worker about physical and mental health, and referral to a medical doctor if indicated. • Monthly examination by a physician during treatment. • Hotline or contact number for patients who believe they are experiencing side effects. • Maintenance of stocks of ancillary drugs for treatment of side effects.
Steps in the process of introduction:	• Implementation of treatment monitoring and active drug safety monitoring (aDSM) for new drugs and regimens should be undertaken through the National TB Control Program. Links to global guidance are provided below. A national plan and protocol should be in place to guide implementation at facility level.
TIPS for implementation:	• Seek technical assistance from partners as needed to develop plans and to train staff on monitoring patients for adverse events and ensuring prompt treatment.
Resources available to you:	*Frequently asked questions about active TB drug-safety monitoring and management (aDSM)* (WHO 2016) http://www.who.int/tb/areas-of-work/drug-resistant-tb/treatment/faq_adsm_2016.pdf?ua=1
	Active tuberculosis drug-safety monitoring and management (aDSM): Framework for implementation (WHO 2015) http://apps.who.int/iris/bitstream/10665/204465/1/WHO_HTM_TB_2015.28_eng.pdf?ua=1

	Sample data collection forms for aDSM for anti-TB drugs (WHO 2015) http://www.who.int/tb/areas-of-work/drug-resistant-tb/treatment/sample_data_collection_forms_for_adsm_18022016.pdf?ua=1
	A practical handbook on the pharmacovigilance of medicines used in the treatment of tuberculosis: Enhancing the Safety of the TB Patient (WHO 2012) http://www.who.int/medicines/publications/pharmacovigilance_tb/en/
	TB GUIDELINES for Nurses in the Care and Control of Tuberculosis and Multi-drug Resistant Tuberculosis, 3rd Edition (available in multiple languages) http://www.icn.ch/tb-mdr-tb-project/training-resources/training-package/guidelines-for-nurses.html

How-To Guide #5: Patient nutritional assessment & supplementation

Thematic Area:	**Maximize physical comfort, safety, and wellness**
Comprehensive Care Element:	**5. Nutritional support as needed to speed healing and reduce side effects of medications.** *Please note that this element is distinct from providing food packages to the patient and family to offset lost income and food insecurity—this element specifically addresses the need to provide patients with additional nutrition for medical reasons.*
Rationale:	• Many DR-TB patients are underweight. Low body mass index (BMI) may be a predictor of slow culture conversion and poor DR-TB treatment outcomes. • Malnourished individuals have weakened immune systems that make them more susceptible to disease and make it more difficult for them to recover quickly. • Food may help patients tolerate second-line drugs more easily and reduce nausea.
Examples of interventions to address this element: (this is not an exhaustive list)	• Baseline and periodic nutritional assessment: height/weight/BMI/caloric intake/food groups consumed. • Food and nutritional supplements for the individual patient for part or all of the treatment duration to address malnutrition, low BMI, improve tolerance of anti-TB medications, etc.
Steps in the process of introduction:	• Develop an annual budget based on the number of patients who may need nutritional supplements as part of their treatment. • Identify what resources are available to provide additional nutrition to patients, either within the TB program or from other sources (food security programs, corporate social responsibility programs, etc.). • Develop or revise existing policy to allow for nutritional assessment and subsequent supplementation for DR-TB patients who need it. • Identify which staff will perform nutritional assessments and train them to do so. • Develop a standard approach to performing a basic nutritional assessment on all DR-TB patients (e.g., calculating BMI or using a short standard questionnaire). Document the approach in an SOP and include the process for referral in cases of serious malnutrition. • Monitor progress on a quarterly basis as part of ongoing general supportive supervision. • Evaluate the effects of nutritional supplementation on culture conversion and treatment outcomes and adjust the approach as needed.

TIPS for implementation:	- Reach out to other facility staff who are nutritional specialists to support your efforts, if they are available. - Be familiar with nutritional programs that may be offered in your area and connect patients with them as feasible.
Resources available to you:	*Companion Handbook to the WHO Guidelines for the Programmatic Management of Drug-Resistant Tuberculosis (Chapter 5, section 5.14)* (WHO 2014) http://apps.who.int/medicinedocs/documents/s21662en/s21662en.pdf
	Guideline: Nutritional care and support for patients with tuberculosis (WHO 2013) http://apps.who.int/iris/bitstream/10665/94836/1/9789241506410_eng.pdf
	Subjective Global Assessment Tool (Subjective Global Assessment 2012). *Note: this is available only for purchase at present* http://subjectiveglobalassessment.com/

How-To Guide #6: Assessment & treatment of co-morbid conditions

Thematic Area:	**Maximize physical comfort, safety, and wellness**
Comprehensive Care Element:	**6. Regular monitoring and treatment of co-morbid physical conditions that affect the patient's ability to reach cure.**
Rationale:	• DR-TB treatment for patients with other illnesses is often complicated by medication interactions or intolerances and requires expert consultation. • People living with HIV are more likely to die with DR-TB than patients who are not co-infected because of late diagnosis and often advanced disease. • DR-TB treatment adherence may not be a priority for people with addictions or cognitive impairments and they may need additional support to complete treatment. • Patients dealing with multiple health issues are less likely to be able to cope (financially, physically, and/or psychologically) with the challenges of DR-TB treatment on top of other treatment they are receiving.
Examples of interventions to address this element: (this is not an exhaustive list)	• HIV counseling and testing for all DR-TB patients. • Diabetes screening and testing as indicated. • Counseling on pregnancy during DR-TB treatment for women of reproductive age and testing as needed. • Assessment for excess alcohol use and referral for treatment. • Assessment for drug use and referral for treatment. • Assessment for mental deficits or physical disabilities that could affect treatment adherence and planning for support.
Steps in the process of introduction:	• Review the epidemiology of diseases in your area and in your DR-TB patient population and decide which health conditions are most important to address for your DR-TB patients. • Develop a checklist for conditions that should be assessed when a patient is initiated on treatment. • Identify what assessments will be done by TB staff and what assessments may require referrals to other services. Work with the related services to develop an SOP that identifies roles and responsibilities for each needed assessment, and how results will be communicated and documented for the care team. • Train involved staff on how to perform assessments and referrals. • Monitor implementation on a quarterly basis in collaboration with all involved services to improve assessments and coordination of care between teams.
TIPS for implementation:	• There are many tools to support assessments for health conditions—use what is already in place in your facility or your country to the extent possible to avoid duplicating efforts. Consult with colleagues in other specialties to identify useful tools you can adapt before creating new ones.

Resources available to you:	*Companion Handbook to the WHO Guidelines for the Programmatic Management of Drug-Resistant Tuberculosis (Chapter 7)* (WHO 2014) http://apps.who.int/medicinedocs/documents/s21662en/s21662en.pdf
	Guidelines for the programmatic management of drug-resistant tuberculosis (Section 5 & Annex 3) (WHO 2011 update) – ARVs and DR-TB http://apps.who.int/iris/bitstream/10665/44597/1/9789241501583_eng.pdf
	Collaborative Framework for Care and Control of Tuberculosis and Diabetes (WHO/Union 2011) http://apps.who.int/iris/bitstream/10665/44698/1/9789241502252_eng.pdf
	AUDIT - The Alcohol Use Disorders Identification Test. Guidelines for Use in Primary Care. 2nd edition. (WHO 2001) http://apps.who.int/iris/bitstream/10665/67205/1/WHO_MSD_MSB_01.6a.pdf
	Standards for TB Care in India (Standard 10) (WHO 2014) http://www.tbcindia.nic.in/showfile.php?lid=3061

How-To Guide #7: Physical rehabilitation after cure

Thematic Area:	**Maximize physical comfort, safety, and wellness**
Comprehensive Care Element:	**7. Provide physical rehabilitation after cure as needed to help patients regain their highest level of health.**
Rationale:	• Some patients experience permanent physical disabilities (e.g., hearing loss, vision impairments) as a result of DR-TB treatment and will require support on an ongoing basis. • Lung function may be compromised following DR-TB, and patients can benefit from therapy to improve lung capacity.
Examples of interventions to address this element: (this is not an exhaustive list)	• Rigorous monitoring to identify signs of adverse events early to help prevent permanent disability or death. • Provision of hearing aids and other devices to aid patients with permanent disabilities. • Training of patients to regain maximum function. • Physical therapy to restore maximum function of lungs.
Steps in the process of introduction:	• Rehabilitation will likely be a service added later in the delivery of supportive services. Nevertheless, supporting patients to regain function following treatment is an important component of high-quality care that should be considered for development as program resources allow. • Estimate the number of patients who will suffer hearing loss and include hearing aids in your program budget. • Estimate the number of patients who will suffer non-correctable physical disabilities and work with other services to plan job training and other programs for these patients. Advocate for their inclusion in social insurance schemes. • Work with rehabilitation/physical therapy experts to develop a plan for rehabilitation services.
TIPS for implementation:	• Seek technical assistance to develop rehabilitative services if expertise does not exist locally.
Resources available to you:	*Note: Resources in this area are currently scant. As more literature and guidance is available, this list will be updated.*
	MD Guidelines on Tuberculosis Respiratory Rehabilitation https://www.mdguidelines.com/easyaccess/tuberculosis-respiratory/rehabilitation

	Marcos et al. The functional assessment of patients with pulmonary multidrug-resistant tuberculosis. *Respiratory Care*, 2012; 57(11): 1949-54. http://rc.rcjournal.com/content/respcare/57/11/1949.full.pdf
	Seddon, J. et al. Hearing loss in patients on treatment for drug-resistant tuberculosis. *ERJ Express* 2012; Published on June 14, 2012 as doi: 10.1183/09031936.00044812. https://www.researchgate.net/publication/225375608_Hearing_loss_in_patients_on_treatment_for_drug-resistant_tuberculosis
	Porecha, M. TB drug affects vision in some patients. *TB Online*, 2016. Available at: http://www.tbonline.info/posts/2016/10/12/tb-drug-affects-vision-some-patients/

How-To Guide #8: Palliative care for patients who can't be cured

Thematic Area:	**Maximize physical comfort, safety, and wellness**
Comprehensive Care Element:	**8. Palliative care for patients who cannot be cured.** *Please note that while palliative care has a broader definition, in this element we are referring specifically to patients for whom cure is not medically reasonable.*
Rationale:	• According to the WHO Companion Handbook, palliative care: ○ "provides relief from respiratory distress, pain and other symptoms; ○ affirms life and regards dying as a normal process; ○ intends neither to hasten nor to postpone death; ○ integrates the psychological and spiritual aspects of patient care; ○ offers a support system to help patients live as actively as possible until death; ○ offers a support system to help the family cope during the patient's illness and in their own bereavement; ○ uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; ○ enhances quality of life, and may also positively influence the course of illness; and ○ is applicable early in the course of illness, in conjunction with second-line anti-TB medications, with the main therapy intended to prolong life through cure." • Patients who cannot be cured continue to need medical care and psychosocial support to promote physical and emotional comfort during a time of transition and upheaval in family structure and function. • Palliative care intends to support the best possible quality of life while at the same time protecting others from transmission of highly resistant strains of DR-TB.
Examples of interventions to address this element: (this is not an exhaustive list)	• Palliative and end-of-life care based in settings that are feasible given the available resources and needs: hospital-based care, home-based, or other. • Provision of ancillary medications, particularly opioids, to reduce discomfort and respiratory distress. • Counseling to prepare the patient and family for death, and bereavement support following a patient's death.

Steps in the process of introduction:	• If one does not exist, compose a committee to review DR-TB cases recommended for discontinuation of curative treatment. • Develop guidelines for decision-making about who should be considered for discontinuation of treatment, and how the patient and family will be involved in the decision-making process. • Decide on what palliative and end-of-life services it is feasible for the program to provide. • Estimate the number of patients who may need palliative and end-of-life care in the coming planning period, identify available and needed resources to provide care, and develop a budget. (Include considerations related to infection control through hospitalization or other forms of respiratory isolation.) • Train relevant staff on how to provide palliative and end-of-life care. • Ensure rigorous infection control measures are put in place to protect staff and family from infection. • Work with social workers, psychology services, and/or faith-based groups to develop plans for collaboration on psychosocial and spiritual support to patients and their families. • Convene monthly or quarterly meetings of the care team to discuss cases, develop care plans, and support each other. • Identify and provide counseling or support resources for staff and volunteers working in palliative and end-of-life care to prevent depression and burnout.
TIPS for implementation:	• Try to partner with other departments that require palliative and end-of-life care for some patients, such as cancer services, so that experience and resources can be shared.
Resources available to you:	The PIH Guide to the Medical Management of Multidrug-Resistant Tuberculosis, 2nd edition. 12. Management of patients in whom MDR-TB treatment has failed. Available at: https://drtbnetwork.org/12-management-patients-whom-mdr-tb-treatment-has-failed
	Comprehensive Guidelines for TB and DRTB Palliative Care and Support (USAID – URC 2015) http://www.urc-chs.com/sites/default/files/Related percent20URC percent20publication_Palliative percent20Care percent20and percent20TB.pdf
	Managing MDR-TB in the community: from presentation to cure or end-of-life care (HATiP 2010) http://www.aidsmap.com/pdf/HATIP-167-October-18th-2010/page/1523026/

How-To Guide #9: Respectful & compassionate communication

Thematic Area:	**Provide psycho-emotional support and protect from social isolation or discrimination**
Comprehensive Care Element:	**9. Respectful and compassionate communication and counseling between providers and patients throughout care.**
Rationale:	• Survey data, patient feedback from the field, and the peer-reviewed literature suggest that a good relationship between patient and provider is one of the most critical elements of treatment success for DR-TB patients. • Good communication and counseling help establish a trusting relationship between patient and provider from the start. • It helps patients understand their disease and encourages them to become active participants in their care and treatment plan. • It helps patients access services appropriate to their needs. • It helps identify challenges to treatment adherence early in the process so they can be addressed pro-actively. • It helps patients to successfully complete treatment.
Examples of interventions to address this element: (this is not an exhaustive list)	• Integrate interpersonal communication and counseling training and refresher training into the overall DR-TB training at facility and/or district level. • Select and appoint case managers, social workers and /or patient care navigators to assist and link patients to DR-TB services. • Conduct periodic patient satisfaction surveys to gather information on services provided and patient level of satisfaction.
Steps in the process of introduction:	• Decide what intervention(s) is most suitable for your context (see list above or develop your own intervention). • Determine which staff will be primarily responsible for communicating with and counseling DR-TB patients and assess their skill levels and experience in doing so. • Develop an interpersonal communication and counseling training plan and integrate with other DR-TB trainings. • Review and modify existing communication and counseling training materials for providers, as appropriate for your setting. • Plan and conduct a workshop to train staff in effective communications and counseling for DR-TB patients. This workshop should be integrated with other training if possible for efficiency. • Develop patient satisfaction monitoring tool and integrate this into the overall supportive supervision tool for all TB activities.

TIPS for implementation:	- If expertise in communication and counseling is not available locally, work with a technical partner to support materials development and training. - Include hands-on exercises in any communications and counseling trainings so participants can practice their skills, with peer feedback. - Use information gathered from periodic patient satisfaction surveys to continue to improve the quality of communication and counseling services.
Resources available to you:	*Interpersonal Communication and Counseling for Clients on Tuberculosis and HIV and AIDS* (PATH 2009) – training curriculum http://www.path.org/publications/detail.php?i=1770
	Patient Support Interventions to improve adherence to drug resistant tuberculosis treatment COUNSELLING TOOLKIT (MSF Khayelitsha 2014) http://samumsf.org/documents/2014/06/khayelitsha_dr-tb-pt-support.pdf
	Managing Tuberculosis Patients and Improving Adherence (USCDC 2014) http://www.cdc.gov/tb/education/ssmodules/pdfs/module6v2.pdf
	Quote TB Light toolkit (TB CARE I) http://www.challengetb.org/library/ua

Example from the field

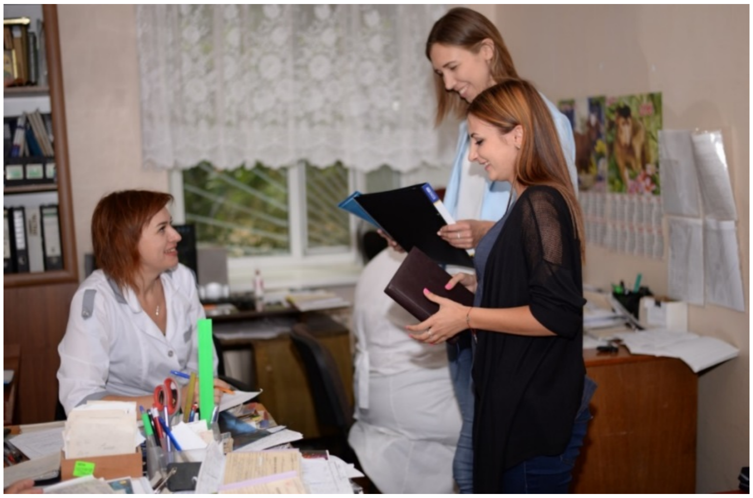
Ukraine: Interpersonal Communications and Counseling Training for Clinicians Improves Patient Access to Care

In Ukraine, stigma and discrimination within the health care system is a significant barrier to accessing services for many patients, particularly those who are socially marginalized for other reasons. A survey of TB patients conducted by PATH through a USAID-funded project found that poor interactions with providers had a significant impact on patients' behavior. As a direct result, a number of patients found it difficult to continue visiting a facility for TB treatment.

To address this major barrier to TB treatment success, PATH developed a curriculum and implemented a three-day training for health care providers on *Interpersonal Communication and Counseling for Clients on Tuberculosis and HIV and AIDS*. The training equipped providers with the knowledge and skills to communicate effectively with their patients, including how to listen actively, how to use educational materials appropriately, steps in helping patients make decisions about their care, and how to address counseling challenges. Practical exercises throughout the training helped providers master the skills needed to improve their relationships with their patients.

Following the training, PATH conducted another survey among patients and found that the level of satisfaction with provider interactions had increased significantly. Patients were more willing to return to the clinic for follow-up and continue on their treatment as a result. In addition, PATH found that providers themselves were happier in their dealings with patients after they had gained skills in better communications.

(You can find the link to the training curriculum under Resources above).



Participants in IPCC training practice their skills during a role play. Photo credit: PATH.

How-To Guide #10: Regular monitoring & treatment of mental health conditions

Thematic Area:	**Provide psycho-emotional support and protect from social isolation or discrimination**
Comprehensive Care Element:	**10. Regular monitoring and treatment of mental health conditions that affect the patient's ability to reach cure**
Rationale:	• Second-line anti-TB medications can cause depression and/or psychosis. • Mental illnesses and substance abuse have been identified and reported as major contributing factors for DR-TB patients to non-adherence and failure to complete DR-TB treatment. • Understanding and implementing interventions to address mental health needs and substance abuse patterns, along with other person-centered care interventions, can result in more DR-TB patients completing DR-TB treatment and successfully being cured.
Examples of interventions to address this element: (this is not an exhaustive list)	• Baseline and periodic assessment of patient's mental health condition that may affect treatment success. • Baseline and periodic assessment for depression using a standardized tool. • Baseline and periodic assessment of substance use that may affect the patient's ability to complete treatment. • Referrals to appropriate mental health services and coordination of care. • Procurement of/access to drugs to treat depression and other mental health conditions.
Steps in the process of introduction:	• Decide what intervention(s) is (are) most suitable for your context (see list above or develop your own intervention). • Identify and train staff to perform basic mental health screening. • Develop or modify existing standardized tools to assess and periodically monitor patients for depression and other mental health conditions from the start to treatment completion. • Develop a referral and feedback system used to refer patients to mental health services and receive feedback on the progress and outcomes.
TIPS for implementation:	• Even patients who do not have any mental health challenges at the beginning of treatment should receive baseline and periodic monitoring because of the potential for mental health changes due to second-line drugs, particularly cycloserine. • Establish good relationships with psychiatrists or psychologists in your facility or nearby facilities to leverage their expertise for your patients.
Resources available to you:	*Patient Health Questionnaire (PHQ-9) – depression screening tool* http://www.phqscreeners.com/sites/g/files/g10016261/f/201412/PHQ-9_English.pdf

	Psychiatric Morbidity and Other Factors Affecting Treatment Adherence in Pulmonary Tuberculosis Patients (Pachi et al. 2013) – journal article https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3649695/
	Surviving the mental health impact of tuberculosis and HIV/AIDS (PIH 2011) – blog post with examples http://www.pih.org/blog/surviving-the-mental-health-impact-of-tuberculosis-and-hiv-aids
	Rationale and Staff Evaluation of Using a "Therapeutic Milieu" for Substance Users Within a Tuberculosis Ward (Chemtob 2009) – journal article http://www.tandfonline.com/doi/full/10.1080/10826080802494701

Example from the field

Pakistan: Psychological assessments and treatment for people with DR-TB

Depression, anxiety, and somatoform symptoms including irritability, insomnia, nervousness, fatigue, and feelings of uselessness are the common manifestations of psycho-emotional challenges found in people with drug-resistant TB.

In the care package pilot in Pakistan, the team focused on improving mental health status of patients, which was a significant barrier to treatment completion. They developed training modules for staff and guidelines for counseling. Psychologists participated as part of the multidisciplinary team, performing intake assessments (Mini Mental State Examination) was conducted, using the Hospital Anxiety and Depression Scale to rate each person's psychiatric status.

Patients identified with depression and/or anxiety received the services of an expert psychologist through a patient-friendly health education module, developed taking the country context into account. Face-to-face counseling was supplemented with audiovisual materials, including a film and short health messages in local languages.

The package of psychological services markedly improved the mental health status of patients. Mild depression was found to be one of the common mental health manifestations among DR-TB patients. At baseline evaluation 24 percent of the patients in the cohort receiving care package services suffered from mild depression, whereas at the end of four months treatment only 2 percent remained mildly depressed. Similarly, Generalized Anxiety Disorder fell from 26 percent to 5 percent of patients during the same period.

How-To Guide #11: Reduce social isolation & provide emotional support

Thematic Area:	**Provide psycho-emotional support and protect from social isolation or discrimination**
Comprehensive Care Element:	**11. Reduce social isolation and provide emotional support and encouragement to the patient**
Rationale:	• In the survey conducted as part of this project, patients named isolation as one of the biggest challenges in completing TB treatment. • Increasing awareness of DR-TB disease among families and communities and including family and communities in patient care creates a caring and non-discriminating environment in which patients feel supported and cared for throughout their treatment. • When patients are provided with emotional support and are encouraged to continue, they are more likely to complete treatment and be cured.
Examples of interventions to address this element: (this is not an exhaustive list)	• Include family members in education and treatment processes. • Designate a treatment supporter acceptable to the patient. • Develop peer support groups and provide financing for them to meet regularly. • Link patients and families with community-based organizations to provide treatment adherence support services to DR-TB patients. • Use eHealth messages of encouragement to complement face-to-face interactions. • Hold periodic celebrations to acknowledge milestones toward cure. • Engage community leaders to provide encouragement to DR-TB patients.

Steps in the process of introduction:	• Decide what intervention(s) is most suitable for your context (see list above or develop your own intervention). • Review existing educational materials on DR-TB and adapt and translate as needed for family, peer educators and communities (avoid developing new materials). • Identify peer educators to support patients with treatment adherence and set up peer educator teams or groups. It is important to develop a clear scope of work outlining the activities the peer educator is responsible for, how often, and where. • Identify and create linkages with community organizations and groups that can provide treatment support services for DR-TB patients. Train them as needed to provide basic services. • Hold an orientation workshop for families, community representatives, peer educators, providers, and representatives from community organizations and groups and patients to introduce DR-TB and discuss and agree on the steps of "How to reduce social isolation and support the DR-TB patient through treatment." • Agree on motivational and achievement schemes to encourage patients to stay on treatment.
TIPS for implementation:	• Think about different approaches to keeping in touch with patients—through phone calls, text messages, video or Skype, etc.—remember that face-to-face interactions are not the only way to help people feel less isolated. • Peer supporters are very much appreciated by patients because they can relate to what patients are going through and can offer practical advice. • Seek out groups outside the TB program that can help patients decrease their social isolation but do provide them with adequate training in infection control as appropriate.
Resources available to you:	*Lessons Learned from Best Practices in Psycho-Socio-Economic Support for Tuberculosis Patients (TB CARE I & II 2014)* http://www.challengetb.org/publications/tools/costing/Best_practices_pyscho-socio-economic_support_for_TB_patients.pdf
	Best Practices in Prevention, Control and Care for Drug-resistant Tuberculosis (WHO Euro 2013) http://www.euro.who.int/__data/assets/pdf_file/0020/216650/Best-practices-in-prevention,control-and-care-for-drugresistant-tuberculosis-Eng.pdf

	A New Health Club for People Living with Chronic Diseases (JHPIEGO 2016) – blog post https://www.jhpiego.org/success-story/new-health-club-people-living-chronic-diseases/

How-To Guide #12: Protect from stigma & discrimination

Thematic Area:	**Provide psycho-emotional support and protect from social isolation or discrimination**
Comprehensive Care Element:	**12. Protection of the patient and family from stigma and discrimination in access to health care services, employment and community life; and facilitation of social rehabilitation.**
Rationale:	• Access to health care may be limited by the lack of registration papers in the location where the patient is living which can lead to fragmented care and social isolation. • Fear of stigma is often cited as a reason for patients not initiating treatment or dropping out before completing treatment. • Access to health care may be limited by stigma and discrimination within health facilities for some people who have DR-TB because of their illness or their socioeconomic situation. • Patients may lose their jobs or be isolated in the community because of social misconceptions about TB and fear among community members. • Even after they have been cured, some people may face ongoing discrimination because of misconceptions and fear.
Examples of interventions to address this element: (this is not an exhaustive list)	• Development and enforcement of anti-discrimination laws or workplace policies protecting employees from being fired or having TB. • Community outreach and education strategies aimed at reducing stigma against people with TB within the community. • Engagement of community leaders and other influential people to address stigma and discrimination at all levels and "normalize" DR-TB diagnosis and treatment. • Use of a standardized tool to measure stigma and development of specific plans to address it based on the findings. • Engagement of media to bring to attention the devastating impact stigma and discrimination have against DR-TB patients in family and society in whole. • Hiring legal aid for patients who need support with registration papers so they can access treatment, address discrimination in employment, and other related matters.

Steps in the process of introduction:	• Decide what intervention(s) is (are) most suitable for your context (see list above or develop your own intervention). • Prioritize target populations for anti-stigma and discrimination interventions, starting with staff at health facilities that may receive and treat people with DR-TB as well as communities with high rates of TB, where self-stigma may be an issue. • Obtain technical assistance to conduct surveys that explore the beliefs and behaviors that lead to stigma and discrimination and develop interventions to address those beliefs and behaviors. • Plan additional steps based on the information obtained from surveys.
TIPS for implementation:	• Obtain technical assistance to develop interventions if you need additional expertise—take lessons from HIV and adapt them to your needs. • Identify relevant groups to advocate for stigma and discrimination policies and guidelines. • Engage DR-TB patients and family members in the process. • Engage respected community members, celebrities, and the media to bring about awareness, share stories and highlight the impact of stigma and discrimination on patients and society.
Resources available to you:	*Understanding and challenging TB stigma: Toolkit for action (International HIV/AIDS Alliance et al – TARGETS Consortium 2009)* http://targets.lshtm.ac.uk/resources/Publications/TB_and_Stigma_Eng2.pdf
	From the Inside Out: Dealing with TB-related self-stigma and shame: A toolkit for people living with or personally affected by TB to deal with self-stigma (The Work for Change & KNCV) www.end-self-stigma.com
	The Health Care Facility TB Stigma Reduction Package (KNCV & TB PROOF) www.end-stigma-in-health-care.com
	Tuberculosis and Stigmatization: Pathways and Interventions (Courtwright & Turner 2010) – journal article https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2882973/
	TB Stigma Measurement Guidance & TB Stigma Measurement Companion Curriculum (KNCV) www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf http://www.challengetb.org/publications/tools/ua/TB_Stigma_Companion_Curriculum.pdf

	Measuring stigma associated with tuberculosis and HIV/AIDS in southern Thailand: exploratory and confirmatory factor analyses of two new scales (Van Rie et al. 2008) – journal article http://onlinelibrary.wiley.com/doi/10.1111/j.1365-3156.2007.01971.x/full
	The joint WHO-ILO-UNAIDS policy guidelines on improving health workers' access to HIV and TB prevention, treatment, care and support services: A Guidance Note (Who, Ilo & Unaids 2010) http://www.who.int/occupational_health/publications/hiv_tb_guidelines/guidance_note_edited.pdf
	Starting a TB Workplace Programme: Principles (World Economic Forum 2008) http://www.lillyglobalhealth.com/en/media/pdfs/business_south_africa_wef.pdf
	Workplace Policy on HIV And AIDS, TB and Other Opportunistic Illnesses For The Tourism Industry In Zimbabwe (Zimbabwe Ministry of Tourism and ILO 2014) http://www.ilo.org/wcmsp5/groups/public/---ed_dialogue/---sector/documents/publication/wcms_329319.pdf
	Kumar, B. Rehabilitation of treated TB patients: Social, psychological and economic aspects. *Intl Journal of Mycobacteriology*, Dec 2016: 5(Supp 1): S129-S130. http://www.sciencedirect.com/science/article/pii/S221255311630245X

How-To Guide #13: Financial support

Thematic Area:	**Prevent catastrophic costs to patient and family**
Comprehensive Care Element:	**13. Provide financial assistance as needed, directly, indirectly, or both as appropriate.**
Rationale:	• Patients and studies cite financial barriers to continuing DR-TB treatment as one of the main difficulties in completing treatment. • Providing short-term financial support to patients and their families is a good investment—in the long term, it prevents unnecessary deaths, ongoing transmission, and the resulting loss of productivity.
Examples of interventions to address this element: (this is not an exhaustive list)	• Free DR-TB diagnosis, free second-line drugs and ancillary medications, and free monitoring tests. • Conditional cash transfers provided to patients contingent upon treatment adherence. • Unconditional cash transfers provided to patients but not linked to treatment adherence. • Inclusion of DR-TB patients in universal health coverage/social insurance schemes. • Microfinance schemes to assist patients with small business ventures. • Support for transportation costs through the use of vouchers or direct provision of transportation. • Food packages for the patient and family to mitigate the health consequences of lost wages. • Food vouchers to purchase foods of choice. • Support for income-generating activities for DR-TB patients.
Steps in the process of introduction:	• At national or provincial level, decide what kinds of financial support could be provided to patients facing catastrophic costs as a result of their illness. • Agree on the criteria for determining patient eligibility for financial support and document those in a written policy. • Estimate the number of patients who will need financial support for the next planning period and develop a budget. • Establish formal partnerships with other government or non-government sources of financial support for DR-TB patients, as appropriate. • Orient providers and community supporters to the policy and how to help patients access financial support. • Inform patients and families about available types of support at treatment initiation, during visits, and through pamphlets or posters. • Develop a system for tracking disbursements of funds or goods to patients and assess the effect of support on treatment outcomes. Adjust the approach as needed.

TIPS for implementation:	- At a local level, you may have additional sources of funding or goods that you can access—do a quick landscape analysis to see if there are any community funds, corporate programs, or other sources for additional funding to make the program sustainable. - Not every patient will need or want financial support. Doing a quick survey of patients to assess what types of support are most helpful can aid in tailoring your approach and help you avoid wasting resources on goods or services your patients don't want.
Resources available to you:	*Eliminating the Catastrophic Economic Burden of TB: Universal Health Coverage and Social Protection Opportunities (WHO 2013) – global consultation presentations* http://www.who.int/tb/uhc_socprotection_brazil_presentations/en/
	Questions and Answers on Universal Health Coverage (WHO) http://www.who.int/healthsystems/topics/financing/uhc_qa/en/
	Making Health a Right for All: Universal Health Coverage and Tuberculosis (ACTION 2014) – discussion paper http://www.actionforglobalhealth.eu/fileadmin/AfGH_Intranet/AFGH/Publications/AfGH-Action_UHC-and-TB-Paper_March-14_PDF-for-general-use.pdf
	HIV, AIDS, TB and Nutrition (WFP 2013) https://www.wfp.org/content/hiv-aids-tb-and-nutrition
	Lessons Learned from Best Practices in Psycho-Socio-Economic Support for Tuberculosis Patients (TB CARE I & II 2014) http://www.challengetb.org/publications/tools/costing/Best_practices_pyscho-socio-economic_support_for_TB_patients.pdf

Assessment and Planning Tools

SUPPORTIVE CARE SERVICES STATUS ANALYSIS TEMPLATE

You can use this form to quickly list services you are already providing that cover some of the elements of comprehensive care. Write those in the third column. In the fourth column, list any services you would like to add to cover gaps you have identified in your current package of supportive care. The services listed here will form your generic supportive care package. See Step 2 of the introduction process for more details.

Thematic area	**Comprehensive care elements**	**Services currently in place & level of coverage**	**Additional service(s) to fill gaps** *(Ideally, the target for a comprehensive supportive care package is to provide at least one service to cover each element but start with what is feasible and build from there.)*
Respect patient autonomy and support self-efficacy	1. Thorough patient intake assessment across all thematic areas and completion of an individual care plan.		
	2. Patient and family education on DR-TB disease and treatment.		
	3. Provisions to treat patients at an appropriate location and timing of their choice (hospital in-patient, clinic, community or home). (*Note that for the program, it will most likely be a combination of these care models.*)		

Thematic area	**Comprehensive care elements**	**Services currently in place & level of coverage**	**Additional service(s) to fill gaps** *(Ideally, the target for a comprehensive supportive care package is to provide at least one service to cover each element but start with what is feasible and build from there.)*
Maximize physical comfort, safety, and wellness	4. Regular monitoring for and treatment of side effects and adverse drug reactions.		
	5. Nutritional support for the patient as needed to speed healing and reduce side effects of medications. *(Note that this is separate from family food support.)*		
	6. Regular monitoring and treatment of co-morbid physical conditions that affect the patient's ability to reach cure.		
	7. Provide physical rehabilitation after cure as needed to help patients regain their highest level of health.		
	8. Provide palliative and end-of-life care for patients who cannot be cured.		

Thematic area	**Comprehensive care elements**	**Services currently in place & level of coverage**	**Additional service(s) to fill gaps** *(Ideally, the target for a comprehensive supportive care package is to provide at least one service to cover each element but start with what is feasible and build from there.)*
Provide psycho-emotional support and protect from social isolation or discrimination	9. Respectful and compassionate communication and counseling between providers and patients throughout care.		
	10. Regular monitoring and treatment of mental health conditions that affect the patient's ability to reach cure.		
	11. Reduce social isolation and provide emotional support and encouragement to the patient.		
	12. Protect patient and family from stigma and discrimination in employment and community life and facilitate social rehabilitation.		

Thematic area	**Comprehensive care elements**	**Services currently in place & level of coverage**	**Additional service(s) to fill gaps** *(Ideally, the target for a comprehensive supportive care package is to provide at least one service to cover each element but start with what is feasible and build from there.)*
Prevent catastrophic costs to patient and family	13. Provide financial assistance as needed—direct, indirect, or both.		

QUICK SCAN OF ENABLING ENVIRONMENT FOR CARE PACKAGE IMPLEMENTATION

Instructions: Once you have chosen services to include in your supportive care package, do a quick assessment of whether everything is already in place to support implementation, or you will have to make changes in the health systems areas listed in the columns. For the elements where changes are needed, you can then complete a rapid systems assessment template for each service to help detail your plan for implementing and financing that service.

Package Element	Services	Assessment	Policy	Guidelines/ SOPs	Infrastructure & material resources	Human resources	Training	Partnerships	Financing	M&E
1		Available								
		Changes needed								
2		Available								
		Changes needed								
3		Available								
		Changes needed								
4		Available								
		Changes needed								
5		Available								
		Changes needed								
6		Available								
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11		Available								
		Changes needed								
12		Available								
		Changes needed								
13		Available								
		Changes needed								
Other		Available								
		Changes needed								

RAPID SYSTEMS ASSESSMENT TOOL

Instructions: You can use the following form to assess your system's readiness to provide supportive care services for DR-TB patients and to identify what additional resources you may need to implement your care package successfully. **Use one form for each comprehensive element you plan to cover.** You can copy the table as many times as necessary to cover each element.

This process can become long if you are covering all 13 elements with services. **Rather than filling out an assessment form for each element, we suggest you focus on the elements for which you are adding NEW services that you have not planned and budgeted previously**. If you identify gaps in existing services, you can also complete a form for those. If you have supportive service elements that are already integrated into your policies, systems and budgets, you may not need to complete a form for those elements.

In the "Comprehensive Element" row, check the box for the one element you are assessing with the form. Below that, enter a short title for the service you will provide. In the next row, provide a specific description of what this service includes—what specifically will be provided, by whom, how often, and for how long. For example, you want to add a service to cover the "Financial support" element of the package. You list your service as "*Nutritional support for patient and family*" then describe it in the row below as *"Monthly food vouchers in the amount of $20 will be given to all patients by the supervising Directly Observed Treatment, Short Course (DOTS) nurse at their monthly clinic visit until the completion of treatment."*

In the next step, list any criteria you will use to decide who will get this intervention. Will all DR-TB patients be eligible to receive this service, or will there be limits based on income, location, or other factors? Knowing this will help assess whether additional policies or protocols might be needed and to determine how many clients may need this particular service. Then estimate the number of DR-TB patients who will need this service (e.g., Will the total estimated number of DR-TB patients you will diagnose need this service, or will only a proportion of the patients require it?). Include the time period you are making the estimate for—is it one year, three years, five years?

For each system dimension (policy, guidelines, infrastructure, etc.), ask yourselves what is already available to support implementation of that intervention, and what changes or additions are necessary to enable implementation. Take into account the number of people you will be trying to serve, their geographic distribution, and other relevant factors as you discuss your needs. To the extent feasible, quantify the changes and additions that are needed to simplify the costing exercise.

In Human Resources, think about not only how many staff you have or will need, but what cadre of staff will be delivering the service and where they are/will be located. Consider task shifting to the extent feasible. For the Partnerships section, consider non-traditional partners who may be able to cost-share interventions or could even integrate the intervention within existing programs. Are there other government departments or programs that are already delivering similar services? Are there private companies or other civil society organizations that could help support these efforts? The same principles apply to Financing. Try to think of new sources of funding you could develop to support your intervention, rather than continuing to rely on Global Fund or bilateral donors.

For M&E, consider whether there are data you need to collect to evaluate the intervention that are currently not being captured by the system. How will you go about evaluating the effectiveness of this intervention? Can you use your current data to do so? Are there partnerships you could form with an academic institution to support a special study of the intervention, if that is warranted?

Thematic Area	**Patient autonomy**	**Physical comfort**	**Psychosocial support**	**Financial support**
Comprehensive Element (check the ONE element you are assessing on this sheet – use separate sheets for each element)	☐ 1. Patient assessment ☐ 2. Education ☐ 3. Treatment location	☐ 4. Side effects monitoring ☐ 5. Nutritional support ☐ 6. Co-morbid conditions ☐ 7. Physical rehabilitation ☐ 8. Palliative/end-of-life care	☐ 9. Respectful communication ☐ 10. Mental health ☐ 11. Reduce social isolation ☐ 12. Protect from stigma and discrimination	☐ 13. Financial assistance
Proposed service(s) (List what service(s) will be used to cover this element)				
Description of service(s) (Provide specific details of the service)				

Criteria used to decide who will receive the service(s) (If you cannot provide the service to all patients, list the criteria you will use to decide who is eligible for the service)	**1.** **2.** **3.** **(Etc.)**	
Estimated number of DR-TB patients to be served (For the current planning/budget period, estimate about how many patients will need this service)		
Time period (What time period are you making this plan for?)		
	What is currently in place? (For each topic area below, list what is already available to support implementation of this service.)	**What changes or additions are needed?** (For each topic area below, list what else is needed before you can implement the service.)
1. Policy		
2. Guidelines/SOPs		

3. Infrastructure & material resources		
4. Human resources (number and cadre)		
5. Training		
6. Partnerships		
7. Financing		
8. M&E		

FACILITY OPERATIONAL PLAN

Implementing Comprehensive Supportive Services for DR-TB Patients

The most important step in planning supportive services introduction is the one in which a facility details how services will be provided directly to DR-TB patients by frontline providers. You can use this form to adapt the package of supportive care services for local conditions and plan for implementation. There are many different ways to go about this—if you have other tools to use, that is fine. We recommend that you convene a one-day meeting of your stakeholders to discuss your facility package of services and complete the Plan. See the section above on "Introducing Supportive Services at the Facility Level" (page 31) for more detailed instructions.

Facility name	

I. MENU OF SUPPORTIVE SERVICES WE WILL PROVIDE

Use this section to list the services you will provide at your facility. In column 2, list the services that the generic national package includes (if one exists). If the services you will provide are the same as those in the generic package, you can just note "same" or put a check mark in column 3. If you are unable to provide that service or must adapt it in some way for your area, you can note that in column 3. In column 4, describe how you will deliver that service or develop a process for doing so. In column 5, list when a service will be provided (e.g., "at treatment initiation" or "monthly throughout treatment." In the last column, put in the name(s) or the position(s) that will be primarily responsible for providing that service.

We will provide the following supportive services:

Supportive Care Element	**Supportive service(s) included in the generic national package**	**Supportive service(s) we will provide locally**	**How delivered/process**	**When/ frequency**	**Who responsible**
1. Patient assessment & care plan					
Supportive Care Element	**Supportive service(s) included in the generic national package**	**Supportive service(s) we will provide locally**	**How delivered/process**	**When/ frequency**	**Who responsible**
2. Patient & family education					
3. Treatment at location of patient's choice					

4. Monitoring & treatment of side effects					
5. Patient nutritional supplementation					
6. Assessment & treatment of co-morbid conditions					
7. Physical rehabilitation					
8. Palliative and end-of-life care					
Supportive Care Element	**Supportive service(s) included in the generic national package**	**Supportive service(s) we will provide locally**	**How delivered/process**	**When/ frequency**	**Who responsible**
9. Respectful & compassionate communication with providers					

10. Assessment & treatment of mental health conditions					
11. Reduce isolation & provide emotional support					
12. Protect from stigma & discrimination					
13. Financial support					

II. PREPARING TO DELIVER SUPPORTIVE SERVICES

Use this section to assess if there are any changes or additions required to begin implementing your package of services.

1. Policy needs: Does implementation of the above services require any local policy changes?
   - ☐ Yes
   - ☐ No

If yes, complete the following table: (add rows if needed)

Policy changes needed	Who responsible	Due date	Approval plan

2. Training needs: Does implementation of the above services require any staff training?
   - ☐ Yes
   - ☐ No

If yes, complete the following table: (to the extent possible, cover all topics in one or two trainings instead of separate trainings for each topic)

Training topics	**Which staff to be trained**	**Number to be trained**	**When/how long**	**By whom**	**Budget**

3. Supplies/equipment needs: Does implementation of the above services require any additional supplies or equipment?
   - ☐ Yes
   - ☐ No

If yes, complete the following table: (add rows if needed)

Supplies/equipment needed (*list only those not currently available or not in sufficient quantity*)	**Quantity needed for next planning period**	**Unit cost**	**Total cost**

III. SUPPORTIVE CARE TEAM

In this section, list the names of the staff who will form your care team, including doctors, nurses, social workers, community health workers, and community-based organization members, etc., and define clear responsibilities for each one.

Supportive services care team members: *(add rows as needed)*

Name	**Title**	**Roles & responsibilities**

IV. COMMUNICATIONS

Describe how the members of the care team will communicate with each other about patient status or changes. (*e.g., monthly face-to-face meetings, weekly phone check-ins, text messages, other*)

V. MONITORING & EVALUATION

Develop a simple plan for how you will monitor progress on implementing your package of supportive services and evaluate its impact. We recommend you concentrate on only a few indicators and use ones for which data are already available as a first step, such as culture conversion and treatment outcomes. If you want to add special indicators or consider time-limited studies to explore impact further, that is also possible. You can refer to the M&E Guide in this *Toolkit* for guidance on how to do so.

Indicator we will measure	**How calculated**	**Target, if any**	**Data source**	**Frequency**	**Who is responsible**

PATIENT ASSESSMENT AND DR-TB CARE AND TREATMENT PLAN

How to use the *Patient Assessment and Care Plan*

This tool forms the basis for understanding DR-TB patient needs and preferences and developing an individualized plan of care to help that person complete treatment successfully. It includes medical, social, psychological, and financial questions that will help you understand what barriers a patient may face in adhering to and completing treatment.

1. Who should complete this form?

Ideally, a health care provider and a patient should work together to complete this form, as a useful way to begin establishing a trusting relationship between the patient and the health team. A doctor, nurse, social worker, psychologist, or other professional who cares for the patient could be the person to complete the form with the patient, depending on time, availability, and expertise. Decide who in your facility will be responsible for doing so, and make sure they are familiar with the form.

2. When should we complete this form?

This form should be completed at the beginning of care, but <u>you do not need to complete it all at one time</u>. It will likely take several visits with the patient to finish the form completely, which could take several weeks. Use your best judgment about when to begin this process—when patients first receive their diagnosis, they may be very upset and unable to talk about these issues, or they may be too ill to have a conversation. That is not an appropriate time to try to complete this form. Choose a time when the patient is calm, feeling well enough to talk, and then find a private place to do so that ensures the patient can talk with you confidentially. Emphasize that this information will remain confidential and will only be shared with members of the patient's care team who need to know to provide that person with the best support possible. Start with the easiest questions and postpone asking more sensitive questions until later when you and the patient know each other better.

3. How do I explain this to the patient?

Tell the patient that you would like to work with him or her to understand questions and concerns he or she may have, and to identify any challenges he or she may face in being treated for DR-TB. Explain that the purpose of the assessment is to develop a plan, so the health team can provide him or her with the support services needed to get well.

4. What do I do with the completed form?

This form is meant to be used on an ongoing basis to monitor the services the patient should be receiving, and to assess any changes in the patient's status that may require a change in the services being provided. As treatment continues, you can ask the patient if anything has changed, and then adjust the care plan to address those changes. Use the "Status" column to do so.

Ideally, a copy of the form should be kept with the patient's record and shared with other providers who may be caring for the patient—for example, with the primary health care provider after discharge from the hospital, and with any community-based organization that may provide support to the patient. The form is also meant to be shared with the patient, so he or she is aware and has a written record of what services he or she can expect to receive from the health care team. Having this form in an electronic format will simplify the process of updating and sharing it with others.

PATIENT ASSESSMENT AND DR-TB CARE AND TREATMENT PLAN

Patient name:	
Gender:	
Date of birth:	
Address:	
Phone numbers:	
Contact information for someone who will know how to reach the patient if he or she becomes lost to follow-up:	
Household member names and ages:	1. 2. 3. 4. 5. 6. (add as needed)
Primary language: **Secondary language:**	

1. Provide patients with understandable and accurate information about DR-TB disease, diagnosis, and treatment.

Assessment	**Plan**	**Status/Changes to Plan** (*Update at each visit or as things change*)
The patient's current level of knowledge about TB, DR-TB and treatment is: ☐ I am not at all familiar with TB ☐ I know a little about TB ☐ I know what TB is but not a lot about treatment ☐ I know about TB and treatment ☐ I am very familiar with TB, DR-TB and treatment *"This is what I believe about TB, DR-TB and treatment right now:*" (write below in patient's own words)	Patient will receive education sessions at the beginning of treatment to cover the following information: ☐ What causes tuberculosis ☐ What TB infection and disease do to the body ☐ How TB is spread and how to prevent infecting others ☐ How household members and other close contacts will be evaluated for TB ☐ What drug-resistant TB is ☐ How long treatment will be and why it's important to complete all treatment ☐ The names of the medications patient will receive, what they look like, how often patient will take them, how much of each one patient will take, and how they are taken (by mouth or through injection) ☐ Possible side effects of each medication, tips for reducing side effects, and how patient will be monitored for side effects ☐ What to do if patient experiences side effects from the medicine ☐ What tests patient will receive before starting medicine (at baseline) and periodically during treatment to help health care providers understand patient's level of health now and to notice any changes during treatment ☐ Where and how patient will receive treatment ☐ Who will support patient during treatment ☐ What other support services are available for patient and family members during treatment ☐ Patient rights and responsibilities while being treated for DR-TB	(*Record date and information provided on that date*)

If the patient has questions in between visits to the health facility, the patient should:

____

2. **Provide treatment at a location that is most convenient and appropriate for the patient and feasible for the TB program.**

In this area, there are options for receiving treatment at the following locations: (list the available options)

☐

a. In the beginning (intensive) phase of treatment, the patient will receive treatment at ____ for approximately _________ weeks.
b. The patient will receive continuing treatment at ___________________________________.

3. **The patient will receive the following medications to treat DR-TB:** (list as appropriate)

Name of medication	**What it looks like**	**How much to take per dose**	**How often to take it and when**	**Changes (***date and describe any changes to treatment, including reason for change***)**

4. **The patient will receive regular monitoring for side effects of the medications and treatment for them as needed. If the patient experiences side effects, providers will treat them promptly and explain what the treatment is for to the patient.**

The monitoring will include the following tests: (*list as appropriate according to national guidelines*)

Test	**How often**	**Dates & Results (record dates of each test and results)**
Verbal questioning about any discomfort the patient is feeling		
Hearing test		
Vision test		

Blood test		
Heart monitoring		
(*Add to list as needed*)		

If needed, the patient will receive nutritional support to help the patient's body heal and make it easier to take medications.

Assessment	**Plan**	**Status/Changes to Plan** (*Update at each visit or as things change*)
Body mass index: _____________ (height in cm/weight in kg) The patient is: ☐ Underweight BMI = <18.5 ☐ Normal weight BMI = 18.5–24.9 ☐ Overweight BMI = 25–29.9 ☐ Obese BMI = 30 or greater The patient currently eats ______ meals per day on average. The main foods the patient eats are:	The patient will receive the following nutritional support during DR-TB treatment: (*list options available and check the ones the patient will receive*) ☐ Vitamin supplements during treatment ☐ Extra protein ☐ *(Add to list as needed)* ☐ The patient does not need nutritional support	

5. **The patient will receive testing for, monitoring of and treatment as needed for any other illnesses that may affect the patient's ability to complete DR-TB treatment.** These illnesses include HIV, diabetes, alcohol use, drug use, and others.

<table>
<tr><th>Assessment</th><th>Plan</th></tr>
<tr>
<td>The patient has been diagnosed with the following illnesses: (check all that apply)
☐ HIV
☐ Diabetes
☐ Alcohol use
☐ Drug use
☐ Other: ________________

The patient needs evaluation for the following illnesses: (check all that apply)
☐ HIV
☐ Diabetes
☐ Alcohol use
☐ Drug use
☐ Other: ________________</td>
<td>The health care provider team will link the patient with and help coordinate the following services:
<table>
<tr><th>Service</th><th>Where</th><th>When</th><th>Status/Changes</th></tr>
<tr><td>☐ HIV counseling & testing</td><td></td><td></td><td></td></tr>
<tr><td>☐ Antiretroviral therapy/HIV care and treatment</td><td></td><td></td><td></td></tr>
<tr><td>☐ Diabetes testing</td><td></td><td></td><td></td></tr>
<tr><td>☐ Diabetes care and treatment</td><td></td><td></td><td></td></tr>
<tr><td>☐ Alcohol use counseling and treatment</td><td></td><td></td><td></td></tr>
<tr><td>☐ Drug use counseling and treatment</td><td></td><td></td><td></td></tr>
</table>
</td>
</tr>
</table>

6. **The patient will receive support to maintain a healthy emotional state during treatment, and to reduce feelings of depression, sadness, worry, or isolation.**

Assessment	**Plan**	**Status/Changes to Plan** (*Update at each visit or as things change*)
Ask the patient about his or her current emotional state: ☐ Hopeful ☐ Strong ☐ Relieved ☐ Depressed/Sad/Hopeless ☐ Anxious/Afraid/Worried ☐ In denial ☐ Angry ☐ Guilty ☐ Isolated/Alone ☐ Other___________	The patient would like to receive the following support to help cope with the illness: (list all available options) ☐ Support from family ☐ Support from a community leader ☐ Counseling from a peer or treatment supporter ☐ Participation in a peer support group ☐ Individual psychological assessment & counseling ☐ Antidepressant medication ☐ (*add options that are locally available*) ☐ Other ______________________	

7. The patient will be supported to help cope with stigma or discrimination he or she may face related to DR-TB.

Assessment	**Plan**	**Status/Changes to Plan** (*Update at each visit or as things change*)
The patient is concerned about stigma or discrimination he or she may face in: ☐ The family ☐ The community ☐ The workplace ☐ The health facility ☐ Other________________ ☐ The patient is not concerned about stigma and discrimination	The health care team and treatment supporter will help to overcome stigma or discrimination by:	

8. The patient will be supported to avoid a huge financial burden related to TB illness and treatment.

Assessment	**Plan**	**Status/Changes to Plan** (*Update at each visit or as things change*)
Before the illness, the patient was: (check all that apply) ☐ The main wage earner in the family ☐ A secondary wage earner in the family ☐ The primary care-giver for the family (preparing meals, taking care of the household) ☐ A secondary care-giver for the family ☐ Not a wage-earner or care-giver Right now, the patient is: ☐ Employed and working ☐ Employed, but not working because of the illness ☐ A student attending school ☐ A student not attending school because of my illness ☐ Unemployed or only temporarily employed If employed, the patient's job is: ______________________________	The patient will receive the following support to cover the costs related to TB illness and treatment: (*list all available options and tick those chosen for this patient*) ☐ Transportation vouchers ☐ Food vouchers ☐ Food packages ☐ Enrollment in a social insurance scheme ☐ Temporary housing during treatment ☐ Microloan ☐ Enrollment in an income generating activity program ☐ Money that will be given to me for each month of treatment I complete ☐ Other money (describe) ☐ Other_________________	

Assessment	**Plan**	**Status/Changes to Plan** (*Update at each visit or as things change*)
The average monthly family income in the last six months was: (*list income bands relevant for your country and add as needed*) ☐ Less than ___________ ☐ Between ___________ and __________ ☐ Between ___________ and __________ ☐ More than _____________ Right now, the patient is receiving the following help not related to illness: (*list any assistance being provided currently*)		

9. The patient will be supported to address additional challenges he or she faces in completing treatment.

Assessment	**Plan**	**Status/Changes to Plan** (*Update at each visit or as things change*)
There are additional challenges the patient faces in trying to complete DR-TB treatment. These include the following: ☐ The patient is a child ☐ The patient is a migrant worker ☐ The patient is a refugee or internally displaced person ☐ The patient is a nomad ☐ The patient is homeless ☐ The patient is a prisoner ☐ The patient is not registered as a resident of this area ☐ The patient does not have necessary legal documents ☐ The patient does not have full control over personal healthcare decisions ☐ The patient cannot visit a health facility without accompaniment ☐ Other:	The patient will receive the following support to help overcome these challenges: (list)	

I have been diagnosed with drug-resistant tuberculosis and I would like to be treated so I can recover from my illness. This document describes the supportive services I will receive. I have discussed my needs with my health care provider and have agreed that the services above are the ones I need to help me get cured. As I continue treatment, my health care providers and I will continue to discuss any changes in my needs and will revise this plan to reflect those changes.

(Optional to include patient/guardian signature)

____

MONITORING & EVALUATION GUIDE

Introduction

To ensure improvements in the quality of DR-TB care and ultimately treatment success of your patients, it will be important to monitor and evaluate a selected set of both process and outcome indicators. Some suggested indicators are included for your consideration for your setting.

Some key areas that you may want to assess are:

1. Improvements in DR-TB patient outcomes as a result of supportive care
2. Improvements in patient satisfaction by comparing a baseline (pre-implementation) patient population to an evaluation (post-implementation) population
3. The feasibility and acceptability of the comprehensive care package in your setting

1. Assessing Programmatic Data on Patient Outcomes

The ultimate goal of the supportive care package is to achieve better outcomes for patients with DR-TB. Programmatic outcomes can be assessed to estimate the impact the care package has had on clinical outcomes (recognizing that there are many factors in play at any given time). Outcomes for sites implementing the package can be compared to historical outcomes data from the same site or to current outcomes data from comparable sites where the care package is not being implemented. Potential indicators include the following:

Identification & Enrollment

- Number of DR-TB cases diagnosed (new and retreatment)
- Number and proportion of diagnosed DR-TB patients initiated on treatment
- Initial loss-to-follow-up rate (lost after diagnosis and before treatment was initiated)

Interim Patient Treatment Outcomes

- Proportion of patients with negative culture at six months
- Death rate
- Loss to follow-up rate
- Treatment failure rate

Final Patient Treatment Outcomes

- Treatment success rate (cured + successfully completed treatment)
- Death rate
- Loss to follow up rate
- Treatment failure rate

Means of collection: *Review of standard programmatic data*

Suggested timeline: Outcomes data from the same site (using historical data) or a comparable site that will serve as your comparator can be collected at any time, since these data should be available from the NTP. They can be obtained when you are ready to perform your comparison. Outcomes data from the implementing site should be obtained when available from the NTP; this is usually 24-36 months after the last person in the cohort has completed DR-TB treatment. This timeframe will be different for patients receiving the newer, 9-month short-course treatment for DR-TB.

2. Assessing Patient Satisfaction

Patient satisfaction and engagement in care is critical to achieving optimal patient outcomes. There are two ways to approach measurement of patient satisfaction. First and simplest is to survey those patients who are receiving supportive services to understand their level of satisfaction with the care they are getting. These data can be used to identify any areas for quality improvement and to identify which services are most important to your patient population.

Second and more complex is to compare the levels of satisfaction between patients who are receiving supportive services and those who are not. This second approach is useful if you are trying to determine the relative importance of the supportive services you are providing (i.e., as opposed to standard care) and assess whether supportive services have a noticeable effect on patient satisfaction and therefore patient outcomes.

The comparator group will be the cohort of patients who are receiving DR-TB treatment with the supportive care package. Both populations can be surveyed regarding their satisfaction with their DR-TB care using standardized questions covering the different elements of the supportive care package.

Means of collection: Survey of patients who have received care with and without the supportive care package. An example of a patient satisfaction survey follows the M&E guide.

Timeframe: A baseline cohort selected at the sites where the DR-TB package will be implemented should be surveyed before implementation begins. A comparison cohort at comparable sites where the supportive care package has not become available yet can be surveyed at any time during the pilot. To ensure patients have a significant experience to reflect upon, it is recommended that patients being surveyed for a baseline should have received at least 6 months of treatment, ideally with all or most of it being outpatient care.

3. Assessing Feasibility and Acceptability

The feasibility and acceptability of the DR-TB supportive care package to the managers and providers who must implement it on the ground are important for high-quality care and the sustainability of the services. Interviews and focus group discussions with managers and staff involved in implementation can help determine the potential for swift scale-up and sustainability. In addition, data on the time and resources required to provide the services can help further refine the package by identifying where processes may be streamlined for better efficiency.

Recognizing that many health systems in high DR-TB burden countries are already stretched thin, try to select only those indicators that will provide information you can act upon—avoid unnecessary questions. This assessment allows you to quantify what it takes to implement the care package in terms of personnel, training, time, supplies/materials and resources. Data for this portion of the assessment could include the following:

Feasibility Indicators (collected post-implementation)

- Time/resources to assess the current status of supportive care and plan for implementation
- Time/resources to initiate the services, including training of health care workers (HCWs), additional hires, additional supplies, additional services/referrals
- Time/resources to maintain the services provided

Means of collection: *Surveys of healthcare managers and healthcare workers, review of budgets and other costing data*

Acceptability Indicators (collected post-implementation)

- NTP/HCW satisfaction with training
- NTP/HCW response regarding required changes in their practice
- NTP/HCW response to additional time/effort to implement the services
- NTP/HCW reports of their patients' satisfaction/adherence
- NTP/HCW overall response to implementing the services

Means of collection: *Surveys for focus group discussions with NTP staff and healthcare workers.* Sample surveys for the healthcare managers, healthcare workers and NTP staff follow this M&E guide. The goal is to interview all cadres of healthcare providers (medical doctors, clinical officers, nurses, pharmacists, social workers, other health professionals) and administrative staff (intake or registration clerks), NTP officers and any outreach or community health workers that were involved in or provided oversight of the care package delivery to patients.

Timeframe: Surveys should be administered by trained interviewers or self-administered at the end of a pre-determined implementation period, e.g., 6 months or longer. Focus groups should be conducted by trained facilitators at the same time.

1. Treatment outcomes data collection tool

(Note that you are free to adapt this table as desired based on your specific needs. You may add or remove indicators as desired.)

	Baseline cohort	**Evaluation cohort**
Cohort year		
Geographic area covered		
Data on identification and enrollment		
Number of DR-TB patients diagnosed		
Number and proportion of DR-TB patients initiated on appropriate treatment		
Number and proportion of DR-TB patients dying prior to treatment initiation		
Number and proportion of DR-TB patients lost to follow-up prior to treatment initiation		
Interim treatment outcome data		
Number and proportion of DR-TB patients with negative culture at six months		
Number and proportion of DR-TB patients who initiated treatment who died by six months		
Number and proportion of DR-TB patients who initiated treatment who died by six months		

Number and proportion of DR-TB patients who initiated treatment lost to follow-up by six months		
Number and proportion of DR-TB patients who initiated treatment who failed by six months		
Final treatment outcome data		
Treatment success (number and proportion)		
Died (number and proportion)		
Lost to follow up (number and proportion)		
Failed (number and proportion)		

2. Patient Satisfaction Survey

(Note that this survey should be adapted to your setting. For instance, if you offer a different package of services than those listed in Question 1, change the list to reflect your specific package.)

Drug-Resistant Tuberculosis Patient Survey

Thank you for taking this survey about the drug-resistant tuberculosis care you are receiving at this facility. Answering the questions in this survey is entirely voluntary. You are free to decline to participate in this survey if you do not wish to do so. You are also free to decline to answer any question you are not comfortable answering. All your answers are anonymous and cannot be traced back to you. They will be grouped with all the other responses we receive and used to assess how well we are meeting the needs of our patients. We are interested to learn about your experience receiving care for DR-TB to improve and expand services in the future.

Survey date and time:				
Facility code:				
Patient accepted to complete the survey:	Yes		No	

1. To support its patients, this facility offers some services to help you complete your drug-resistant TB treatment.

Which, if any, of the following supportive services have you received from this facility?

☐ Small group TB health education session
☐ Medical staff (doctor or nurse) one-on-one counselling (face to face)
☐ Lay counsellor one-on-one counselling (face to face)
☐ Free TB medicines
☐ Assistance to collect a social grant (met with a social worker)
☐ Psychological support (met with a psychologist)
☐ Nutritional support
☐ Transport assistance
☐ Rehabilitative services
☐ Other services ________________________________
☐ None of the above

2. How satisfied are you with the healthcare services you have received so far at this facility? (Indicate by selecting a number below that matches your level of satisfaction)

1 2 3 4 5 6 7 8 9 10

Very dissatisfied Neutral Very satisfied

3. What are the things that your healthcare providers currently do that are most helpful to you continuing your treatment for drug-resistant TB? (Select up to 3)

☐ Small group TB health education session
☐ Medical staff one-on-one counselling (face to face)
☐ Peer counsellor one-on-one counselling (face to face)
☐ Free TB medicines
☐ Assistance to collect a social grant
☐ Psychological support
☐ Nutritional support
☐ Transport assistance
☐ Rehabilitative services
☐ Other___________________________________
☐ None of the above

4. Of the services you have received, which services (if any) have been least helpful, or you feel you could do without?
(Select up to 3)

☐ Small group TB health education session
☐ Medical staff one-on-one counselling (face to face)
☐ Peer counsellor one-on-one counselling (face to face)
☐ Free TB medicines
☐ Assistance to collect a social grant
☐ Psychological support
☐ Nutritional support
☐ Transport assistance
☐ Rehabilitative services
☐ Other ___________________________________
☐ None of the above

5. If additional services were to be made available which of the following services do you think would help you the most in continuing and completing your treatment?

(Select all that apply)

☐ Small group TB health education session
☐ Medical staff one-on-one counselling (face to face)
☐ Peer counsellor one-on-one counselling (face to face)
☐ Assistance to collect a social grant
☐ Unlimited medicines supply (no stock-outs)
☐ Psychological support
☐ Nutritional support
☐ Transport assistance
☐ Rehabilitative services
☐ Other
☐ None of the above

Please explain:

____

6. In terms of the interaction between you and your healthcare providers, please mark whether you agree or disagree with the following statements:

(Indicate with an "X")

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
6.1 The healthcare providers here make me feel at ease when they see me (they are friendly and warm towards me, and not cold or abrupt)					
6.2 The healthcare providers here treat me with respect, as if I matter					
6.3 The healthcare providers here listen to my problems/issues, questions					
6.4 The healthcare providers have taught me a lot about my disease					
6.5 The healthcare providers have taught my family a lot about my disease					

6.6 The healthcare providers have given me the support I need for all the medical conditions I face					
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
6.7 I have been able to participate fully in decisions about my DR TB treatment					

7. People with drug-resistant TB sometimes also have other health conditions such as diabetes or HIV infection or other illnesses. Do you have any other health conditions?

☐ Yes
☐ No (Skip to question #9)
☐ Not sure

8. I feel that my healthcare providers have met the needs of my other health conditions. (Indicate by selecting a number below)

1 2 3 4 5 6 7 8 9 10

Strongly Disagree Neutral Strongly Agree

9. I feel my health care team has helped me deal with the emotional and/or mental stress of having DR-TB. (Indicate by selecting a number below)

1 2 3 4 5 6 7 8 9 10

Strongly Disagree Neutral Strongly Agree

10. Having healthcare facilities operate at times and locations that are convenient to you is important in supporting your care. Please check whether you agree or disagree with the following statements.

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
9.1	This facility provides care at times that are convenient for me					
9.2	This facility provides care at locations that are convenient for me					
9.3	The waiting times to see the healthcare providers are acceptable to me					
9.4	The facility is usually clean and neat					

11. At this point in your treatment, what has been the most difficult aspect for you to cope with?

☐ The medicines are difficult to take and/or make me feel ill
☐ I feel isolated and alone
☐ I can't participate in my usual activities such as working, taking care of my family, and/or attending school
☐ Having drug-resistant TB has been a financial hardship for me/my family
☐ Other people's reaction of blaming me for having drug-resistant TB and/or treating me as if I don't matter
☐ Other____

12. Right now, how do you feel about your treatment for drug-resistant TB and your future? (Choose the answer closest to how you are feeling)

☐ Optimistic that I will be cured / capable of coping with my disease
☐ Sad or depressed about my situation
☐ Worried or overwhelmed about my situation
☐ Confused or uncertain about my situation
☐ Angry about my situation
☐ Neutral - I don't feel anything special
☐ Other____

13. Is there anything else you would like to add about your level of satisfaction with the services you have received for your drug-resistant TB treatment at this facility?

Finally, we'd like to learn a little more about you.

I am: ☐ Male ☐ Female ☐ Other ☐ Decline to answer	**I am:** ☐ Single (never been married) ☐ Married ☐ Divorced ☐ Separated ☐ Widowed	**My age:**
I started my drug-resistant TB treatment in ____________________(Month & Year)		
I have been told that my total course of treatment will be for _______ months		
I am employed: ☐ Fulltime ☐ Employed ☐ Part-time ☐ Unemployed ☐ Retired ☐ Grant recipient	On average, it takes me _____hours and ______minutes to get from my home to this facility and I travel most of the way by ☐ walking ☐ bus ☐ taxi ☐ car ☐ motorcycle ☐ bicycle	

3. Feasibility and Acceptance Survey of Healthcare Workers/Managers and National TB Program Staff – Post-implementation

(Note that this survey can be implemented individually in paper or electronic format, or as part of a focus group discussion. Modify it as needed to reflect your specific situation.)

Survey date and time: ____

Facility code: ____

Thank you for taking this survey about your experience with implementing the person-centered supportive care package during this pilot project. Answering the questions in this survey is entirely voluntary. You are free to decline to participate in this survey if you do not wish to do so. Your decision whether or not to take part will have no effect on your relationship with your employer or with the implementing partner. If you agree to participate, you are also free to decline to answer any question you are not comfortable answering. All your answers are anonymous and cannot be traced back to you. They will be grouped with all the other responses we receive and used to assess the feasibility, acceptability, and sustainability of delivering this package of supportive care to patients. We are interested to learn about your experience providing supportive care to DR-TB patients to help in revising the approach and expanding to additional facilities in the future.

First, we would like to understand your thoughts on the time and resources needed to implement the supportive care package.

1. Implementing the supportive services package at my facility required the following:
   - ☐ Special training of current staff
   - ☐ On-going mentoring services for trained staff
   - ☐ Additional hires of new staff
   - ☐ Special training of new staff
   - ☐ Purchases of additional supplies (e.g. ECG machines, KUDU wave)
   - ☐ Additional services or new activities provided at our facility
   - ☐ A system for new referrals for auxiliary services or providers
   - ☐ New policies/orders/protocols/approvals
   - ☐ Task shifting to other cadres of staff in the facility
   - ☐ Partnerships with community-based organizations
   - ☐ Other_____________________________

2. FOR MANAGERS/ADMINISTRATORS (otherwise skip to question #3). Please check whether you agree or disagree with the following statements:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
2.1. The time and resources required to assess our current delivery practices and any gaps seemed reasonable/acceptable	☐	☐	☐	☐	☐
2.2. The time and resources needed to understand/be oriented to the comprehensive care seemed reasonable/acceptable	☐	☐	☐	☐	☐
2.3. The time and resources needed to develop the operational plan to initiate the services at my facility seemed reasonable/acceptable	☐	☐	☐	☐	☐
2.4. The time and resources to maintain the supportive services package at my facility seemed reasonable/acceptable	☐	☐	☐	☐	☐
2.5. The time and resources for training staff to implement the supportive services package seemed reasonable/acceptable	☐	☐	☐	☐	☐
2.6. The time and resources to assess to the supportive services package seemed reasonable/acceptable	☐	☐	☐	☐	☐

3. Overall, I think the supportive care package is helping our patients to adhere to and/or complete their treatment.

1 2 3 4 5 6 7 8 9 10

Strongly Disagree Neutral Strongly Agree

Next we would like to know how satisfied you were with the implementation process of the supportive services package.

4. Please check whether you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
4.1. My training prepared me well for my role in providing the supportive services package	☐	☐	☐	☐	☐
4.2. The pre-implementation training should have been longer	☐	☐	☐	☐	☐
4.3. I have had to significantly change what I do since the supportive services package has been implemented	☐	☐	☐	☐	☐
4.4. I have to spend significantly more time in my job since the supportive services package has been implemented	☐	☐	☐	☐	☐
4.6. My work is more satisfying since the supportive services package has been implemented.	☐	☐	☐	☐	☐

5. Overall, I think the implementation of the supportive care package went well.

1 2 3 4 5 6 7 8 9 10

Strongly Disagree Neutral Strongly Agree

My suggestions for improving the implementation at future sites are:______________________

6. Since the care package has been implemented at your facility, what has been the impact on patient waiting times?
   - ☐ Much shorter
   - ☐ Somewhat shorter
   - ☐ About the same
   - ☐ Somewhat longer
   - ☐ Much longer

7. Since the introduction of the care package, how much time do you spend face-to-face time with patients compared with before the care package implementation?
   - ☐ Much less
   - ☐ Somewhat less
   - ☐ About the same
   - ☐ Somewhat more
   - ☐ Much more

8. Since the introduction of the care package, how much time do you spend on paperwork compared with before the care package implementation?
   ☐ Much less
   ☐ Somewhat less
   ☐ About the same
   ☐ Somewhat more
   ☐ Much more

9. Please check whether you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
9.1. I've noticed a positive change in patient attitudes and/or behaviors since the implementation of the supportive care package.	☐	☐	☐	☐	☐
9.2. My patients seem more satisfied with their care since the supportive services package has been implemented	☐	☐	☐	☐	☐
9.3. I believe that the supportive care package is helping our patients adhere to or complete their treatment.	☐	☐	☐	☐	☐
9.4. I've noticed a positive change in staff attitudes and/or behaviors since the implementation of the supportive care package.	☐	☐	☐	☐	☐
9.5. This approach to patient care is an improvement over what we did before.	☐	☐	☐	☐	☐

Finally, we'd like to learn a little more about you.

10. I am:
   ☐ Male
   ☐ Female
   ☐ Other
   ☐ Decline to answer

11. My age is _______years. (drop down menu with 15 through 99)

12. I have worked at this facility for _______ years.

13. I have worked in healthcare for ________ years

14. My role at this facility is (check all that apply):
    - ☐ Doctor /Clinician
    - ☐ Nurse
    - ☐ Facility Operational Manager
    - ☐ Pharmacist
    - ☐ Community health worker
    - ☐ Psychologist
    - ☐ Lay counsellor
    - ☐ Social worker
    - ☐ Dietician / Nutritionist
    - ☐ Administrative staff / Data Capturer
    - ☐ District / Sub-district Coordinator
    - ☐ National Health Laboratory Service (NHLS) Coordinator
    - ☐ Radiology technician
    - ☐ Audiometrist
    - ☐ Other ___________________________

ANNEX I: DR-TB SUPPORTIVE CARE SURVEY RESULTS

Background

To help understand DR-TB patient needs and experiences, USAID developed three questionnaires tailored to three key stakeholder groups: DR-TB and TB patients; frontline health care providers; and implementing technical partners. Questionnaires included demographic information, multiple choice questions, and open-ended questions. The surveys were conducted and data collated using Survey Monkey. Announcement of the survey was made through TB networks (Stop TB Partnership, GCTA, and individual groups at country level) and announcement flyers distributed at the World Lung Health conference in Liverpool in fall 2016. Responses were collected for a period of three months.

There were 168 respondents total who provided feedback about services accessed, services provided, challenges faced, and suggestions to improve DR-TB patient care. Responses are grouped and analyzed below. Although the information from these surveys proved useful to inform development of the *Practical Guide*, it should be noted that the data presented here in no way reflect a representative sample because of practical limitations to this exercise. The surveys were available only in English, and Internet access was required to complete the questions. More female patients responded to the survey than males, which isn't representative of the DR-TB patient population. While responses came from a number of countries, the Philippines was heavily represented while other countries had fewer respondents in spite of high burdens of DR-TB.

Nevertheless, the results provide interesting juxtapositions between the views of patients and their providers. In general, they confirm the findings of the literature on patient barriers and needs, and the importance of addressing these issues to improve DR-TB treatment outcomes.

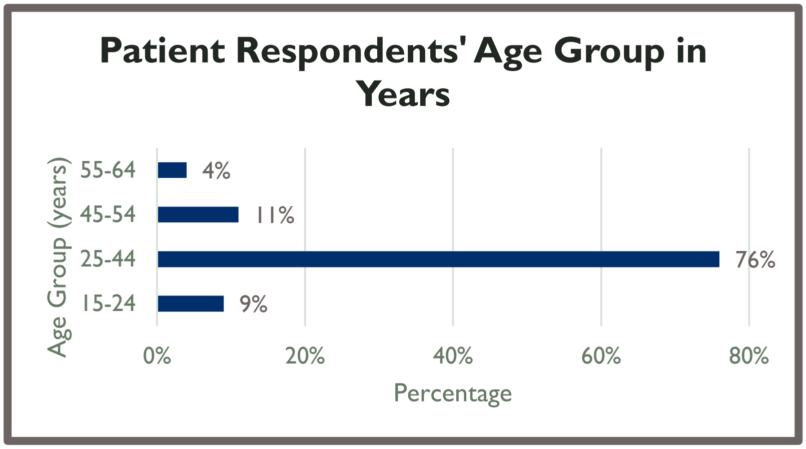
The results of the surveys are described in the following pages, including suggestions from the respondents on how different levels of support can be improved to increase the quality of care DR-TB patients receive.

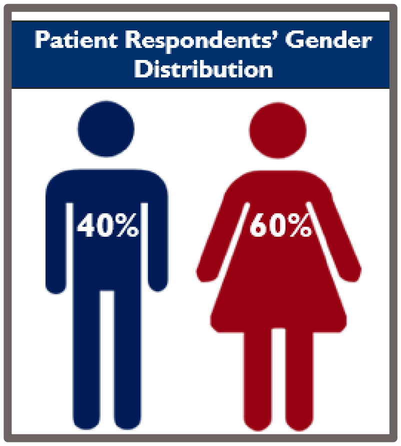
> ***"Addressing DR-TB today is a huge investment for the future."***
>
> ***—Health Care Provider***

Patient Survey Data Summary

Who responded to the survey?

A total of 45 patients living in 16 different countries responded to the patient survey. Over half were cured or completed DR-TB patients while about one-third of respondents are receiving treatment for DR-TB. One patient stopped treatment and two patients were cured of DS-TB. An activist and two non-governmental organization (NGO) workers also took the survey. The majority of respondents were between the ages of 25-44 years old with 60 percent of them females and 40 percent males.


Patient Respondents' Age Group in Years


Patient Respondents' Gender Distribution

Type of DR-TB Patients

55% of DR-TB patient respondents were cured or completed treatment

32% of DR-TB patient respondents were currently on treatment at the time of the survey

2% of DR-TB patient respondents did not complete treatment

11% of DR-TB patient respondents didn't fall into one of the above categories

When Patient Respondents Completed Treatment

69% of patient respondents completed treatment between 2000-2016, with the majority of patients completing in 2015 or 2016

28% of patient respondents were still on treatment at the time of the survey

3% of patient respondents stopped treatment before completing

When and where patients receive(d) treatment:

With the exception of one patient who moved to a different country while undergoing treatment, all the patients received treatment in their home countries. Patients reported completing treatment from 2000-2016, with 46 percent of them finishing in 2015 and 2016. Over half of the respondents were not hospitalized during the course of treatment and almost 70 percent of those who were hospitalized were in the hospital for less than 6 months.

Amount of Time Patient Respondents Spent in the Hospital

14% less than 1 month
12% 1-3 months
5% 4-6 months
14% greater than 6 months

55% of patient respondents were never hospitalized

Patient respondents received treatment from a variety of health providers. Almost half of respondents started in-patient treatment while one-fifth started at community public health providers. The majority of patient respondents who selected "other" received treatment at designated MDR-TB treatment centers.

As treatment continued, the in-patient treatment decreased by about half to less than 20 percent and the public health facilities more than doubled to 45 percent.

Patient Respondents' Initial Treatment Delivery Location

44% of patient respondents received inpatient initial treatment.

21% of patient respondents received initial treatment from a public health provider in the community

5% of patient respondents received initial treatment from a public health provider at home

5% of patient respondents received initial treatment from a private provider

2% of patient respondents didn't know where they first received treatment

Patient Respondents' Continued Treatment Location

19% of patient respondents continued inpatient treatment

45% of patient respondents continued treatment from a public health facility

12% of patient respondents continued treatment from a public health provider at home

5% of patient respondents continued treatment from a private provider

17% of patient respondents continued treatment from other types of providers

Patient respondents received home-based care about 2.5 times more frequently than at treatment initiation and fewer respondents were visiting MDR-TB specific facilities.

Important factors in patient success

Strikingly, patients most frequently cited their own motivation and the emotional support from family, providers, and peers as the key elements in helping them get through treatment successfully. These less tangible (and less costly) supports have the potential to make a difference between completing treatment and discontinuing treatment before cure.

Table 1. Factors that were most helpful to patients in completing their treatment	Proportion of respondents
My own motivation to get better	73.3 percent
My desire to get better to take care of my family	60.0 percent
The support of my family to get better	46.7 percent
The caring attitude of my health providers	46.7 percent
Support from other DR-TB patients	42.2 percent
Being treated with respect by my health care provider	31.1 percent
Education about DR-TB and my treatment	28.9 percent
Timely treatment of side effects I experienced from the medication	22.2 percent
Counseling to help me with the fear and emotional strain of having DR-TB	20.0 percent
Being involved in making decisions about my DR-TB care	17.8 percent
Being treated in the hospital	15.6 percent
A designated treatment supporter who helped me	8.9 percent
Being able to take treatment in the community	8.9 percent
Financial support from outside my family	8.9 percent
Support from community leaders	8.9 percent
Support to pay for transportation for treatment	8.9 percent
A shortened treatment regimen	4.4 percent
Cash incentives to help me continue treatment	4.4 percent

Table 1. Factors that were most helpful to patients in completing their treatment	Proportion of respondents
Other	4.4 percent
Food packages	2.2 percent
Not applicable	2.2 percent

Patient Experience

"Strengthening the DR-TB patients in the national response is a big help. The DR-TB survivor has a big role in the community; they can help in case finding and in peer education with the proper training and capacity building."

Patient Experience

"More public awareness is badly needed. The side effects were very hard to live with and the whole experience was incredibly isolating."

Patient Experience

"Support groups are so important, connecting people who are on treatment or giving them access to an online community, health workers supporting patients in side effects as they are a MAJOR PROBLEM with treatment"

Barriers to success

Over half of the patient respondents felt that the biggest barriers were the long treatment and side effects of the medications, with a third of them expressing painful injections to be a barrier in adhering to treatment. About one-quarter of patients reported that the need to support their families and the feeling of isolation were a barrier to complete treatment. These responses suggest that shortened regimens, all-oral regimens, financial aid, and emotional support can further improve treatment outcomes.

Table 2. Factors that made it most difficult to complete treatment	Proportion of respondents
The treatment was very long	53.3 percent
The medicine made me feel sick	51.1 percent
The injections were painful	33.3 percent
I needed to work to support my family	26.7 percent
I felt very alone	24.4 percent
Other	22.2 percent

Table 2. Factors that made it most difficult to complete treatment	Proportion of respondents
I was afraid I was going to die	20.0 percent
I have psychological challenges (such as depression, mental illness)	20.0 percent
I didn't have money to pay for treatment (including money for transport, doctor fees, etc.)	17.8 percent
I was very weak	17.8 percent
I was afraid my family would be stigmatized by the community	15.6 percent
I did not face problems completing treatment	15.6 percent
There were no medicines to treat the side effects of the DR-TB treatment	13.3 percent
I was away from my family for a long time	13.3 percent
I have other illnesses that made it more difficult to complete treatment (HIV, diabetes, etc.)	11.1 percent
I had to travel a long distance to reach treatment	11.1 percent
I was afraid my community would stigmatize me	8.9 percent
I did not understand my illness or my treatment well	4.4 percent
I had no food to eat with my medication	4.4 percent
I was afraid my family would reject or stigmatize me	4.4 percent
I was afraid I would not be able to have children because I had DR-TB	4.4 percent
I have a substance use challenge (such as alcohol, drugs)	4.4 percent
Not applicable	4.4 percent
I was afraid I would not be able to get married if people knew I had DR-TB	2.2 percent
I was treated badly (disrespectfully) by my health care providers	2.2 percent
I had to wait a long time to receive my medication at the health facility	2.2 percent
There were stock-outs of the medication I needed during my treatment	2.2 percent
I did not have a designated treatment supporter	0.0 percent

Recommendations for TB programs from patients

Sixty percent of patient respondents recommend that national TB programs offer education on DR-TB, treatment, and transmission as well as counseling for both patients and families to reduce fear and stigma. Almost half of the patient respondents recommend NTPs have financial/social insurance programs for patients. Access to peer support groups, involvement in treatment decisions, and respectful treatment from health providers were recommended by at least 40 percent of patient respondents.

Table 3. Patient respondents' advice to the national TB program in their country on the five most important treatment support services for DR-TB patients in getting cured	**Proportion of respondents**
Education on DR-TB, treatment, and protecting family members from getting sick	60.0 percent
Counseling for patients and families to reduce fear and stigma	60.0 percent
Financial support/social insurance to reduce the burden on the family	48.9 percent
Creation of peer support groups	46.7 percent
More involvement of patients in decision-making about their care (patient choice)	42.2 percent
Respectful treatment from health providers	40.0 percent
Food packages/nutritional supplementation	37.8 percent
Timely and effective treatment of medication side effects	35.6 percent
Referrals and support to treat other health conditions such as depression, substance use, HIV, diabetes or others	20.0 percent
Treatment at home	17.8 percent
Transportation support to reach treatment	13.3 percent
Other (please specify)	11.1 percent

Table 3. Patient respondents' advice to the national TB program in their country on the five most important treatment support services for DR-TB patients in getting cured	Proportion of respondents
Treatment in the community	6.7 percent
A designated treatment supporter	6.7 percent
Treatment in the hospital	4.4 percent

Patient Experiences

"Globally close contacts of DR-TB patients are a large and growing population that is being ignored. Lack of diagnostic options or treatment evidence is not being addressed with nearly the urgency it should be and consequently thousands of people become ill and die every year from a preventable disease. I am a medical doctor so could initiate care myself (knowing the considerable data limitations), but the vast majority of patients have no options."

❖

"I am also a medical doctor; I feel there should be a patient based treatment in my country. I learn a lot from being an MDR TB patient. Not to blame patients, we need to understand why they are not taking treatments and why they are not seeking treatment."

❖

"Improve the conduciveness of the health facility, confidentiality (separation of newly screened patients and continuing treatment patients, status quo of each patient, records and other background info.), increase the health staffs/personnel, medical and financial support to other patients with other illness, and conducive rooms/buildings for patients from far-flung/remote areas."

❖

"It´s very difficult when you have TB and fight against the disease, but also you have to fight against the health system because it doesn´t work. Then you realize that you are sometimes on your own. I had to travel 4 countries to get cured, because lack of medicines, labs not reliable, lack of tools for 2nd line testing, not health system to support a very, very expensive treatment."

❖

"My country has high TB incidence especially increase on DR -TB to my constituency of Ex-Miners and their families. We need to strengthen in research why increase in DR-TB among migrant populations especially ex-miners and their families. Further strengthening the community health system like prevention, treatment management and psychosocial support. Again the duration of treatment taking must be improved to shorter term so more work needs done by the developing of medicines."

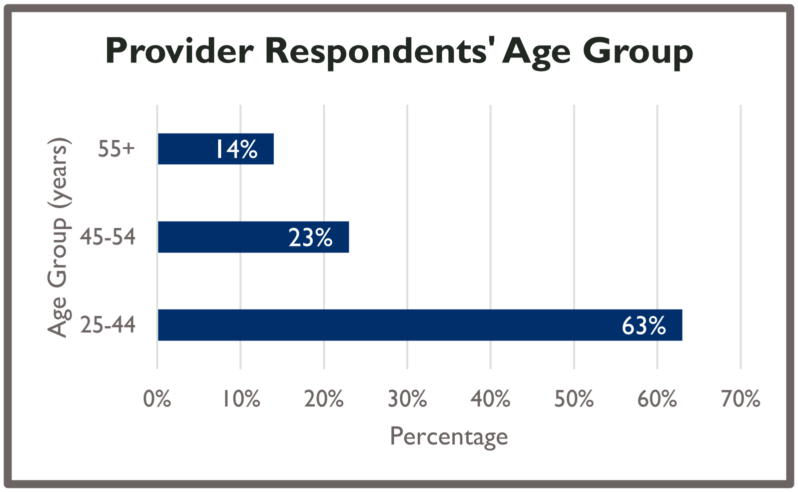
Provider Survey Data Summary

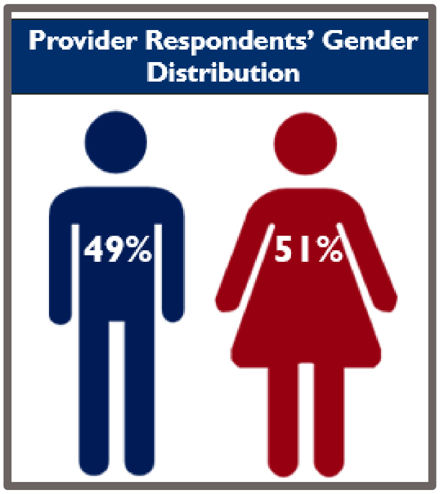
Who responded to the survey?

A total of 74 frontline providers working in 29 different countries responded to the survey. They included a wide range of practitioners: doctors, nurses, community health workers, social workers, a traditional healer, staff and volunteers of community groups and NGOs, researchers, a psychologist, pharmacists, a pharmacovigilance officer, a communications officer, an epidemiologist, a laboratorian, and an NTP manager at local level.


Provider Respondents' Professions

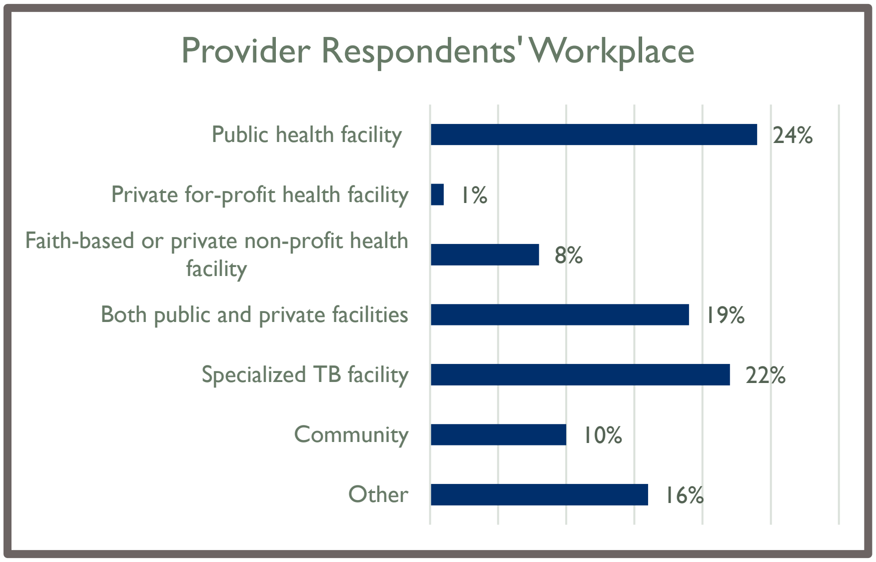
Slightly more women than men responded to the survey, with the majority belonging to the 25-44 years age range.


Provider Respondents' Age Group


Provider Respondents' Gender Distribution

Where do they work?

Providers who responded work in a wide variety of settings. Those who chose "other" as their response include research units, community-based organizations and other NGO facilities, and prisons. Almost 19 percent of respondents work in both public and private facilities, while 21.6 percent work in a specialized TB facility.



Provider Perspective

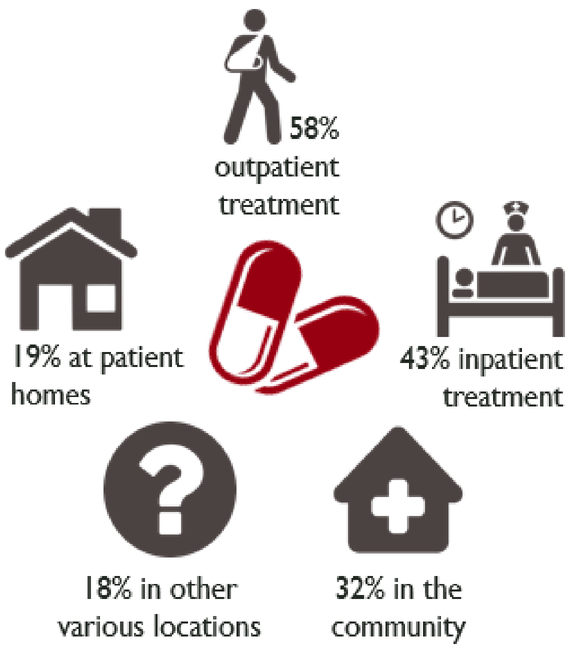
"[Have more] community awareness on DR-TB intensified through health talks, skits, radio and TV programs as well as incorporating the topic in all learning institutions."

The majority of providers care for DR-TB patients at a facility, as both in-patients and outpatients. The proportion of community- and home-based care is lower. Those in the "other" category are patient educators and supporters and technical advisors to programs.

Provider Perspective

"Helping high TB burden countries move toward adopting the 9-month regimen for MDR-TB and insuring [steady] drug supply would play a big role in maximizing adherence. Obviously, comprehensive social support that takes in consideration patient's obligations towards family is key also to treatment success."

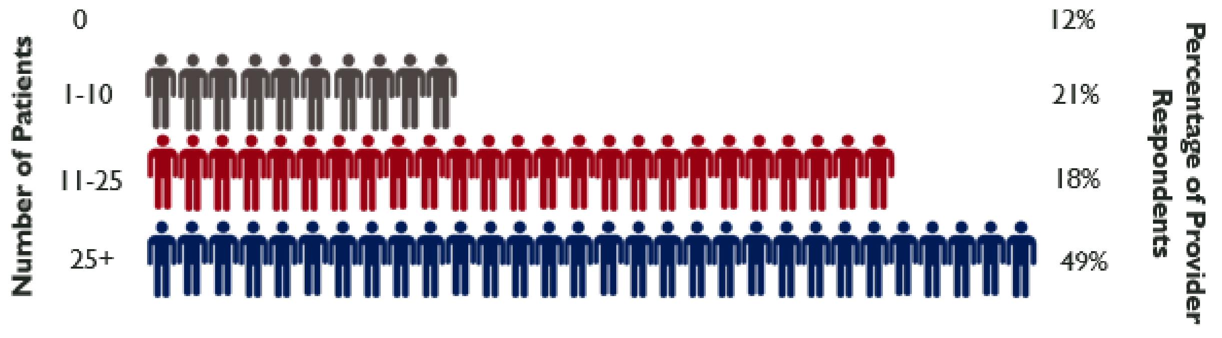
Provider Respondents' Treatment Location for DR-TB Patients



What is their level of experience?

Almost half of the providers care for a large number of DR-TB patients each year—more than 25 patients—and thus have a deep knowledge of both enablers and barriers to successful treatment and cure.

Number of DR-TB Patients Provider Respondents Cared for in the Past 12 Months



Almost half of respondents had received specific training on DR-TB diagnosis and management, either from the national TB control program, a technical partner, or both. Notably, less than 20 percent of providers had any DR-TB training as part of their pre-service education, and 13.9 percent had received no formal training on DR-TB at all.

The majority of respondents who had training on DR-TB had also received information on the psychosocial dimensions of patient care as part of their training package.

Provider Respondents' Training

64% of provider respondents said their training included information on treatment support from a psychosocial angle, such as dealing with social isolation, depression, financial challenges, poor nutrition, or stigma

20% of provider respondents have not receive such training

16% of provider respondents have never received DR-TB training

Provider Perspective

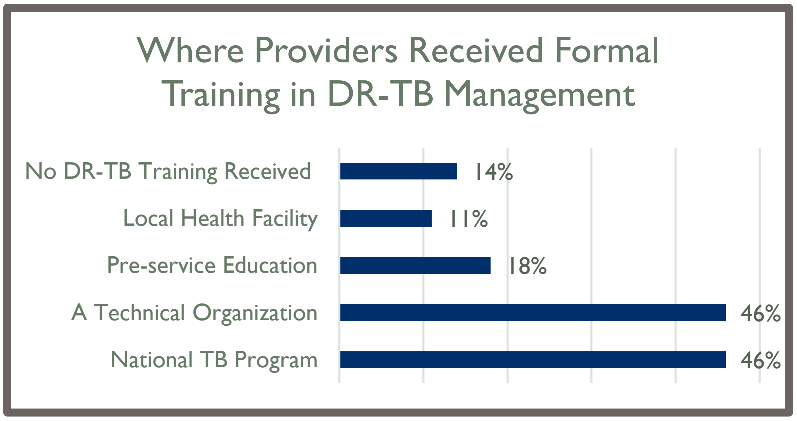
"There should be four-levels of support to DR-TB patients to complete the treatment -

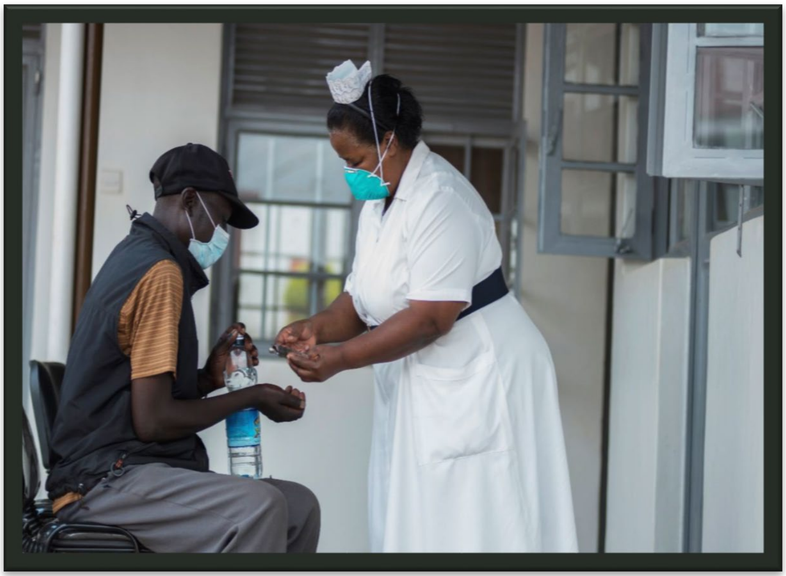
1. Psychosocial support to patient

2. Support to family of DR-TB

3. Community Engagement in favor of DR-TB patients

4. Strategy to support DR-TB with physical and financial assistance."





Nurse Sister Theresa Kitandwe hands out a patient's MDR-TB medication at the drug-resistant TB ward at Mubende Regional Referral Hospital in Western Uganda. Photo: USAID.

What has their experience shown them?

Table 4 shows provider opinions related to the major barriers their patients face in adhering to treatment. The full list of possible responses is included in the table. Half or more respondents listed the following barriers as the most important challenges for their patients:

- Long course of treatment
- Side effects of the medication
- Poverty in general
- Lack of understanding of the disease and the need for treatment

Table 4. Providers' Opinions of the Five Most Important Barriers Preventing Their Patients from Completing DR-TB Treatment

Barrier	Response percent	Response #
Long course of treatment	66.2 percent	49
Side effects of the medication	55.4 percent	41
Poverty in general	51.4 percent	38
Lack of understanding of the disease and need for treatment	50.0 percent	37
Competing priorities for patients (such as the need to care for family or attend work)	40.5 percent	30
Distance and time for traveling to receive treatment	25.7 percent	19
Lack of food to take medications	23.0 percent	17
Painful injections	17.6 percent	13
Poor physical health upon treatment initiation	16.2 percent	12
Cultural beliefs that conflict with treatment	14.9 percent	11
Fear of stigma and discrimination (including related to marriage)	14.9 percent	11
Other co-morbid conditions such as HIV or diabetes	12.2 percent	9
Poor/discriminatory treatment of patients by health care providers	9.5 percent	7
Lack of trust in the health system	9.5 percent	7
Fear of job loss	8.1 percent	6
Long wait times to receive treatment at the health facility	6.8 percent	5
Homelessness	6.8 percent	5

Table 4. Providers' Opinions of the Five Most Important Barriers Preventing Their Patients from Completing DR-TB Treatment

Inadequate experience of providers who are treating DR-TB patients	6.8 percent	5
Long hospitalization	5.4 percent	4
Substance use	5.4 percent	4
Isolation and fear of the disease or death	5.4 percent	4
Migration	5.4 percent	4
Other (please specify)	5.4 percent	4
No medications to treat side effects available	4.1 percent	3
DR-TB drug stock-outs or waiting lists for treatment due to insufficient drug supplies	4.1 percent	3
Lack of designated treatment supporter	4.1 percent	3
Poor quality DR-TB drugs	4.1 percent	3
Other mental illness, including depression prior to treatment	2.7 percent	2
Extensive resistance to DR-TB drugs	2.7 percent	2
Fear of inability to have children	0.0 percent	0
Influence of family or friends	0.0 percent	0

In terms of services that providers feel it is important to provide to DR-TB patients for treatment completion, more than half of respondents listed patient education, food and nutritional supplementation, and counseling to reduce fear and stigma as essential elements of patient care. In addition to the choices listed below in the table, providers mentioned the need to develop shorter, safer, and better-tolerated regimens as an important factor in treatment success going forward.

Table 5. Providers' Opinions of the Most Important Treatment Support Interventions for DR-TB Patients' Treatment Completion

Intervention	Response percent	Response #
Education on DR-TB, treatment, and protecting family members from getting sick	64.9 percent	48
Food packages/nutritional supplementation	59.5 percent	44
Counseling for patients and families to reduce fear and stigma	56.8 percent	42
Financial support/social insurance to reduce the burden on the family	47.3 percent	35
Timely and effective treatment of side effects	41.9 percent	31
Transportation support to reach treatment	35.1 percent	26
Treatment in the community	28.4 percent	21
A designated treatment supporter	27.0 percent	20
More involvement of patients in decision-making about their care	27.0 percent	20
Creation of peer support groups	25.7 percent	19
Treatment at home	23.0 percent	17
Referrals and support to treat other health conditions such as depression, substance use, HIV, diabetes or others	23.0 percent	17
Respectful treatment from health providers	20.3 percent	15
Other (please specify)	5.4 percent	4
Treatment in the hospital	2.7 percent	2

What do they need to do better?

Providers were also asked to identify the support they need to provide better care for their patients. Eight interventions were chosen by more than one-quarter of respondents, in the following order:

- Partnership with community organizations who can provide social support to patients
- More training on medical management of DR-TB and side effects
- Training on assessing patients for psychosocial barriers to treatment adherence
- Social insurance and other financial support for patients
- A steady supply of drugs to treat DR-TB and auxiliary drugs to treat side effects
- An assigned social worker or other trained staff to provide education and counseling to patients
- Training on interpersonal communications and counseling
- Training on infection control
- The full range of responses is presented in the table 6 below.

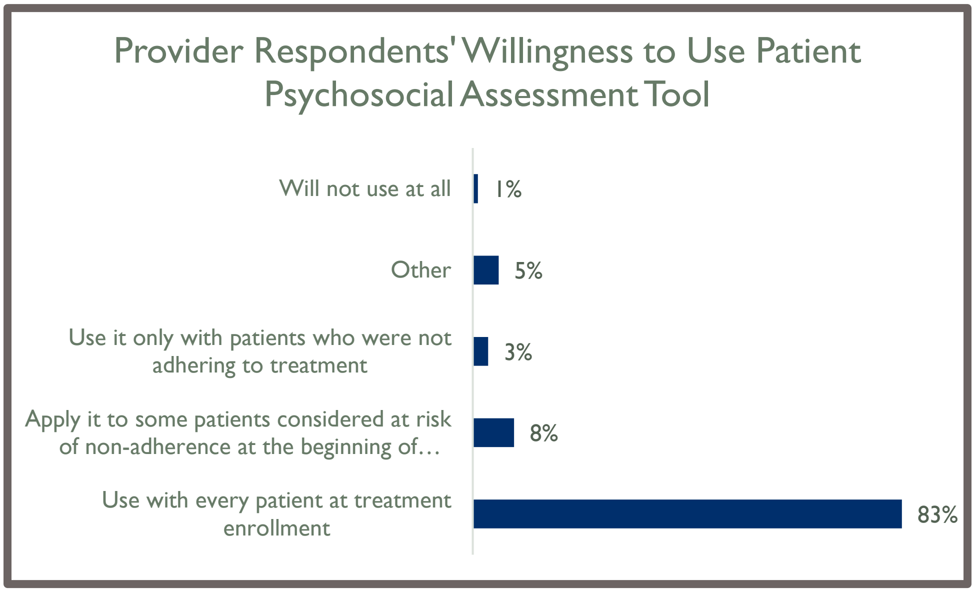
Table 6. Providers' Needs to Improve Their Care for DR-TB Patients

Intervention	Response percent	Response #
Partnership with community organizations who can provide social support to patients	60.8 percent	45
More training on medical management of DR-TB and side effects	52.7 percent	39
Training on assessing patients for psychosocial barriers to treatment adherence	48.6 percent	36
Social insurance and other financial support for patients	43.2 percent	32
A steady supply of drugs to treat DR-TB and auxiliary drugs to treat side effects	43.2 percent	32
An assigned social worker or other trained staff to provide education and counseling to my patients	40.5 percent	30
Training on interpersonal communications and counseling	37.8 percent	28
Training on infection control	25.7 percent	19

Table 6. Providers' Needs to Improve Their Care for DR-TB Patients

More time for me to provide education and counseling to my patients	21.6 percent	16
Personal protective equipment for me to use	18.9 percent	14
Additional compensation for working with DR-TB	18.9 percent	14
Simple job aids to help me provide high-quality care	14.9 percent	11
Upgrades to the facility in which I work	13.5 percent	10
Other (please specify)	9.5 percent	7
Regular payment of my salary	5.4 percent	4
I do not want to care for DR-TB patients	0.0 percent	0

The vast majority of providers responded that they would use a simple tool to assess the psychosocial and financial needs of their patients and develop an individualized care plan. More than 82 percent said they would use such a tool with every patient, and an additional 8 percent said they would use it with patients they considered at risk for non-adherence.



Provider Perspectives

"I strongly feel that community-based treatment in partnership with community-based organizations (NGOs) would be the way to go to resolve the very lost to follow ups in my country. Timed financial assistance as well as decentralization to community health centers has not seemed to make a difference."

❖

"[Provide] more education to health care workers about DR-TB to avoid stigma. Both me and my DR-TB patients are looked in a way of stigmatizing us. I am in a facility where my DR-TB unit is new for decentralization purpose but I am struggling with the colleagues yet we have very good results in terms of cases findings and TB management."

❖

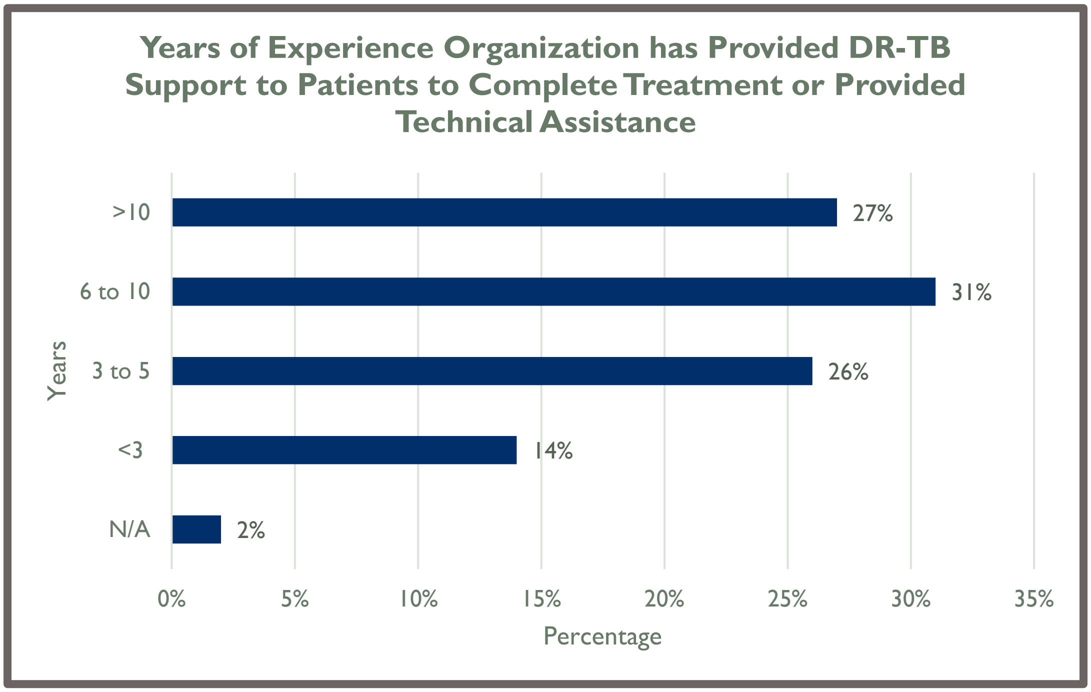
"We have [to] treat DR-TB patients with care and respect them for who they are since they have a right to access health care services and they are humans and not people from a different planet."

Implementer Survey Data Summary

What organizations did the implementers represent?

The 49 implementer respondents represented 23 different organizations including The Union, , WHO, Ministries of Health, local/district health departments, National TB Programs, KNCV Tuberculosis Foundation, Philippines Business for Social Progress, Biomedical Research Training Institute, Columbia University, Burnet Institute Myanmar, PATH, Management Sciences for Health, FHI360, Clinton Health Access Initiative, Chemonics International, and the USAID Challenge TB project.

Almost 85 percent of the organizations represented have supported DR-TB patients for at least 3 years. Over a quarter of the organizations represented have been supporting DR-TB patients for over 10 years while a third of them have been supporting DR-TB patients for 6-10 years.



How have implementers supported patients?

Over half the implementer respondents provide timely and effective treatment to help with side effects and education on DR-TB, treatment, and transmission to family members. Forty-five percent of implementer respondents offer transportation support and programs to promote respectful treatment from health providers. Over 40 percent of implementer respondents have financial/social insurance programs for DR-TB patients and their families. Table 7 provides the full list of services implementer respondents' offer.

Table 7. Key support elements the implementers have provided or recommended that helped DR-TB patients complete treatment?

Timely and effective treatment to deal with side effects	59.2 percent
Education on DR-TB, treatment, and protecting family members from getting sick	53.1 percent
Respectful treatment from health providers	44.9 percent
Transportation support to reach treatment	44.9 percent
Financial support/social insurance to reduce the burden on the family	40.8 percent
Food packages/nutritional supplementation	38.8 percent
Counseling for patients and families to reduce fear and stigma	34.7 percent
Treatment at home	26.5 percent
Treatment in the community	26.5 percent
Referrals and support to treat other health conditions such as depression, substance use, HIV, diabetes or others	26.5 percent
Creation of peer support groups	22.4 percent
Treatment in the hospital	16.3 percent
More involvement of patients in decision-making about their care (patient choice)	16.3 percent
A designated treatment supporter	12.2 percent
Conditional cash transfers to treatment supporters/care providers	10.2 percent
Other	3.7 percent
Conditional cash transfers to patients for treatment milestones	2.0 percent
Not applicable - our organization does not provide or recommend such support	2.0 percent

What do implementers perceive as barriers to patients completing treatment?

The majority of the implementer respondents believe that side effects of the medication and long treatment are barriers for patients to adhere to treatment. At least one-third of respondents felt that general poverty, competing priorities, and distance/time to travel for treatment are barriers for treatment completion.

Implementer Perspective

"I suggest that the tool also has components to grasp patients' and care takers perspectives."

Implementer Perspective

"Electronic surveillance system and electronic TB records to increases efficient data management and sharing"

Table 8. Key barriers for patients who did not complete DR-TB treatment according to the implementers' experience	
Side effects of the medication	59.2 percent
Long course of treatment	53.1 percent
Poverty in general	42.9 percent
Competing priorities for patients (such as the need to care for family or attend work)	38.8 percent
Distance and time for traveling to receive treatment	32.7 percent
Lack of understanding of the disease and need for treatment	24.5 percent
Migration	24.5 percent
Fear of stigma and discrimination (including related to marriage)	18.4 percent
Fear of job loss	18.4 percent
Lack of food to take medications	16.3 percent
Poor physical health upon treatment initiation	16.3 percent
Other co-morbid conditions such as HIV or diabetes	16.3 percent
No medications to treat side effects available	14.3 percent
Painful injections	12.2 percent
Homelessness	12.2 percent
Long hospitalization	8.2 percent
Substance use	8.2 percent
Influence of family or friends	8.2 percent
Lack of designated treatment supporter	8.2 percent

Table 8. Key barriers for patients who did not complete DR-TB treatment according to the implementers' experience	
Cultural beliefs that conflict with treatment	6.1 percent
Lack of trust in the health system	6.1 percent
DR-TB drug stock-outs or waiting lists for treatment due to insufficient drug supplies	6.1 percent
Long wait times to receive treatment at the health facility	6.1 percent
Inadequate experience of providers who are treating DR-TB patients	6.1 percent
Poor/discriminatory treatment of patients by health care providers	4.1 percent
Other mental illness, including depression prior to treatment	4.1 percent
Isolation and fear of the disease or death	4.1 percent
Extensive resistance to DR-TB drugs	4.1 percent
Fear of inability to have children	2.0 percent
Poor quality DR-TB drugs	2.0 percent
Other	1.3 percent

Implementer Perspectives

Tools implementers find helpful in supporting DR-TB patients on treatment:

- *mHealth technology*
- *SMS treatment reminders (one for caretakers)*
- *Data collection and reporting tool*
- *WHO/NTP/Community Care guidelines (international, national, and local guidelines)*
- *PMDT updating guideline*
- *Checklists (i.e. side effect monitoring)*
- *Strategic plan for laboratory development*
- *Maintenance of lab equipment guidance*
- *Quality control guidance*
- *Infection control guidance*
- *iDOTS implementation guidance*
- *Ancillary drugs to help with side effects*
- *Teaching aids for TB education*
- *Provision of halfway houses for patients*

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"Comorbid mental disorders are associated with treatment delays, poor medication adherence, and low treatment completion rates and therefore greater morbidity, mortality, drug resistance, and community transmission due to prolonged infectiousness. Several low-cost, non-pharmaceutical, efficacious mental health treatment interventions that can be delivered by non-mental health specialists and incorporating routine screening and such interventions is essential to curb the MDR-TB epidemic."

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"[We] should also advocate this [tool] to not only the NTP persons but also to physicians in all steps"