Delivering Comprehensive Supportive Care to People with Drug-resistant Tuberculosis:

A Practical Toolkit

Version 1.0

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ACRONYMS AND ABBREVIATIONS

DR-TB	Drug-resistant tuberculosis
HIV	Human immunodeficiency virus
M&E	Monitoring and evaluation
MDR-TB	Multidrug-resistant tuberculosis
NGO	Non-governmental organization
PMDT	Programmatic management of drug-resistant tuberculosis
TB	Tuberculosis
USAID	United States Agency for International Development
WHO	World Health Organization
XDR-TB	Extensively drug-resistant tuberculosis

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INTRODUCTION TODELIVERING COMPREHENSIVE SUPPORTIVE CARE TOPEOPLE WITH DRUG-RESISTANT TUBERCULOSIS

1. Background

> ***"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**

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 to Combat Multidrug-resistant Tuberculosis*. This Practical Toolkit is part of that effort.

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% of the people with DR-TB started on treatment—far below the global target of at least 75% 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 *Practical Toolkit* provides national TB control programs, implementing partners, community-based organizations, and supportgroups 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.

[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: ASystematic 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 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 document, 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.	Orient 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 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.	For use by 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 studies of successful implementation in different settings.	Can be used by all stakeholders to plan and implement each supportive service using field-tested approaches.

Material	Content and purpose	Who should use
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.	Targeted for use by 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.	Meant for 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.	For use by 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.	For use by frontline providers (doctors, nurses, social workers, peer counselors, etc.) in partnership withtheir 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.	Meant for managers and M&E staff to develop workable M&E plans for assessing the effect of supportive services on DR-TB treatment outcomes.

***IMPLEMENTATION TIP ***

All of these tools are provided in a generic and modifiable Microsoft Word 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, Global Fund concept notes and related processes.

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.

[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.

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 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% 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 are 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.

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,	• 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

Thematic area	Comprehensive care elements	Examples of services that can be provided to address each element
	clinic, community or home). (*Note that programmatically, it will often be a combination of these care models.*)	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 (*Note that while this thematic area crosses over to medical management, it is so critical to treatment success that it has been included here.*)	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. • 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 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	• Pulmonary rehabilitation therapy. • Hearing aids.

Thematic area	Comprehensive care elements	Examples of services that can be provided to address each element
	help patients regain their highest level of health.	• 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 for incurable patients and their families.	• 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 protect from social isolation or discrimination	9. Respectful and compassionate communication and counseling between providers and patients throughout care.	• Interpersonal communication and counseling training for all staff working with DR-TB patients, integrated within overall DR-TB training. • 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	• Inclusion of family members in education and

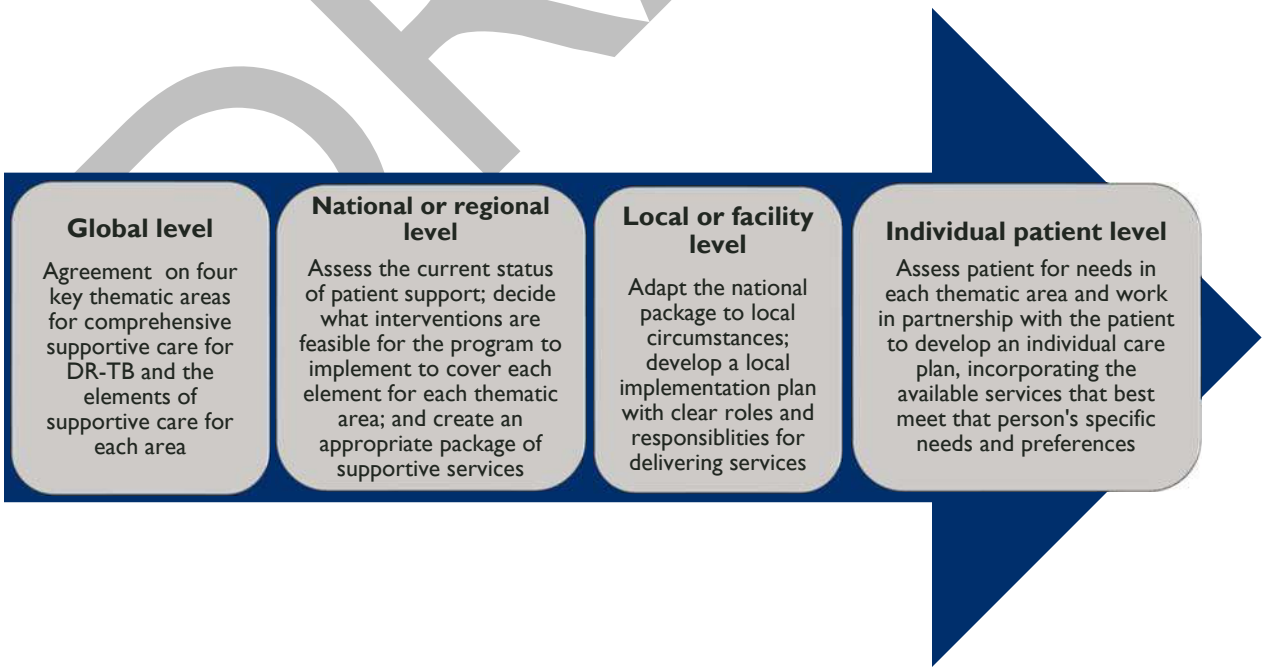
Thematic area	Comprehensive care elements	Examples of services that can be provided to address each element
	isolation through ongoing emotional support and encouragement to the person with DR-TB.	treatment processes. • Designated treatment supporter acceptable to the patient. • Peer support groups. • 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. • 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.

We acknowledge that 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.



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

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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.

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 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.

An MDR-TB survivor from North Jakarta, Indonesia with a community health volunteer. Photo: USAID.