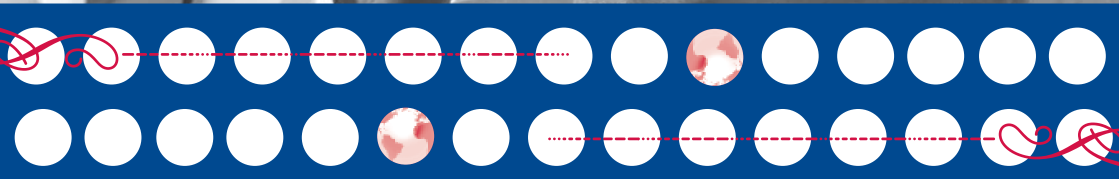
USAID
FROM THE AMERICAN PEOPLE

TB CARE II

COMMUNITY-BASED CARE FOR DRUG-RESISTANT TUBERCULOSIS:

A GUIDE FOR IMPLEMENTERS



FIRST EDITION: OCTOBER 2011

This guide is made possible by the support of the American people through the United States Agency for International Development (USAID). The contents of this report are the sole responsibility of TB CARE II, and do not necessarily reflect the views of USAID or the United States Government.

USAID | TB CARE II

FROM THE AMERICAN PEOPLE

COMMUNITY-BASED CARE FOR DRUG-RESISTANT TUBERCULOSIS:

A GUIDE FOR IMPLEMENTERS

FIRST EDITION: OCTOBER 2011

Copy editing: Katrina Noble, Partners In Health
Citation: USAID TB CARE II (2011) Community-based Care for Drug-resistant Tuberculosis: A Guide for Implementers

The Tuberculosis CARE Project, TB CARE, is funded by United States Agency for International Development (USAID) under Cooperative Agreement Number AID-0AA-A-10-00021. The project team includes prime recipient, University Research Co., LLC (URC), and sub-recipient organizations including Jhpiego, Partners In Health, Project HOPE along with the Canadian Lung Association; Clinical and Laboratory Standards Institute; Dartmouth Medical School: The Section of Infectious Disease and International Health; Euro Health Group; and The New Jersey Medical School Global Tuberculosis Institute.

About the Cover

Dr. Hind Satti (Partners In Health) examines a 14 year old girl with drug-resistant tuberculosis in Lesotho.

Photo credit: Rebecca Rollins, Partners In Health

Contributors and acknowledgements

Development of this guide was supported as a core activity of TB CARE II.

Editor-in-Chief:
KJ Seung, Deputy Director, TB CARE II, Partners In Health

Initial drafts were written by Hind Satti (Partners In Health, Lesotho) and Dalia Guerra, Eda Palacios, Lorena Mestanza, Katiuska Chalco, Maribel Muñoz, Jaime Bayona, Julio Acha, and José Yamanija (Socios En Salud, Peru).

The final draft was reviewed and edited by participants of the TB CARE II meeting on Community-based Care for DR-TB in Lesotho, September 2011 and others:
Fred Mugyenyi Asiimwe, Centers for Disease Control and Prevention, Lesotho
Grace Tsitsi Banda, Ministry of Health, Botswana
Frank Adae Bonsu, National TB Control Program, Ghana
Joseph Cavanaugh, Centers for Disease Control and Prevention, USA
Susan Gacheri, Ministry of Public Health and Sanitation, Kenya
Nii Nortey Hanson-Nortey, National TB Control Program, Ghana
Ernesto Jaramillo, World Health Organization, Switzerland
Benedita Helena José, National TB Control Program Ministry of Health, Mozambique
Henry Kanyerere, National TB Control Program, Malawi
Samuel Kasozi, National Tuberculosis and Leprosy Program, Uganda
Maureen Kamene Kimenye, Ministry of Public Health and Sanitation, Kenya
Llang Bridget Maama-Maime, National TB Control Program, Lesotho
Refiloe Matji, University Research Company
Max Meis, KNCV Tuberculosis Foundation, The Netherlands
Nona Rachel C. Mira, College of Public Health University of the Philippines, Manila
Norbert Ndjeka, National TB Control and Management, South Africa
John Nkonyana, Ministry of Health and Social Welfare, Lesotho
Likhapha Ntlamelle, Partners In Health, Lesotho
Michael L. Rich, Partners In Health
Nunurai Ruswa, Ministry of Health and Social Services, Namibia
Maria Angélica Salomão, World Health Organization, Regional Office for Africa
Peter Saranchuk, Médecins Sans Frontières, South Africa
Khairunisa Suleiman, AIDS and Rights Alliance for Southern Africa
Natalie Vlahakis, Médecins Sans Frontières, Lesotho
Francis Varaine, Médecins Sans Frontières
Claire Wingfield, Treatment Action Group
Mukadi Ya Diul, United States Agency for International Development

TABLE OF CONTENTS

1. INTRODUCTION 6
2. COMMUNITY-BASED CARE 7
3. COMMUNITY-BASED CARE MODEL 8
   3.1. Roles and responsibilities of the DR TB team. . . 9
   3.2. Responsibilities of the DR TB Community Nurse 12
   3.3. Participation of the DR TB Community Nurse in the outpatient clinic 13
   3.4. Integrated care for DR TB patients 14
   3.5. Communication with the community 15
   3.6. Appointment system 16
   3.7. TB infection control in the community 17
   3.8. Caring for caregivers 18
4. DR TB SUPPORTERS 19
   4.1. Profile of a DR TB Supporter 19
   4.2. Identification of DR TB Supporters 20
   4.3. Tools for the DR TB Supporter 21
   4.4. Initial training of DR TB Supporters 22
   4.5. Additional training for DR TB Supporters 23
   4.6. Reimbursements and performance-based compensation 24
   4.7. Monthly performance evaluation 25
   4.8. Monitoring DR TB Supporters 26
   4.9. The DOT Book 27
5. SOCIAL SUPPORT 28
   5.1. Home assessment 28
   5.2. Food packages 29
   5.3. Transportation 30
   5.4. Temporary accommodation 31
   5.5. Work 32

6. ADHERENCE SUPPORT 33
6.1. Directly Observed Treatment 34
6.2. Managing side effects and monitoring treatment 35
6.3. Support groups 36
6.4. Preventing default 37
7. SUPPLY CHAIN MANAGEMENT 38
7.1. Centralized control of second-line TB drugs . .38
7.2. Logbook for preparation of DR TB patient medication packs. 39
7.3. Standardized prescription form. 40
7.4. Order second-line TB drugs. 41
7.5. Don't forget to budget for… 42
7.6. Storage conditions in the community. 43
8. COMMON LABORATORY PROBLEMS. 44
8.1. Sputum samples are lost or dry out on the way to the facility 44
8.2. Losing track of DR TB suspects. 45
8.3. Blood tests for side effect screening. 47
9. CONTINUITY OF CARE 48
9.1. Discharge from the hospital. 48
9.2. Contact tracing 49
9.3. Follow-up after completion of treatment. 50
9.4. Additional considerations. 51
10. RECORDING AND REPORTING 52
10.1. Treatment Card for patients receiving second-line TB drugs. 52
10.2. Sample monthly report of community-based activities 53
10.3. Sample hospital discharge summary. 54
10.4. Sample transfer form 55
11. FREQUENTLY ASKED QUESTIONS 56
12. REFERENCES. 58

1. INTRODUCTION

Many countries are in the process of establishing or scaling up treatment of drug-resistant tuberculosis (DR TB). Effectively scaling up treatment will require addressing health systems–related issues, such as task shifting to alleviate human resources shortages and greater community engagement.

A principal challenge in establishing or scaling up treatment of DR TB is deciding what model of care to implement. A crucial step is bridging the gap between the hospital and the community to ensure continuity of care. For DR TB treatment to be truly patient-centered, patients must be supported in their homes and communities.

This guide provides practical, step-by-step guidance on how to organize, implement, and monitor community-based care for DR TB. It is equally useful for program planning or supervision. This guide does not replace other guidelines and documents that contain important medical information, such as *Guidelines for the Programmatic Management of Drug-resistant TB* (WHO, 2008 and 2011 updates), and *Management of MDR-TB: A Field Guide* (WHO, 2009).

The target audience for this guide is TB Program Managers, governments, policy makers, nongovernmental organizations (NGOs), donors and TB advocates.

2. COMMUNITY-BASED CARE…

…allows patients to receive DR TB treatment in their own community. This addresses one of the most serious barriers to adherence and facilitates directly observed treatment (DOT). Treatment at home is more convenient for patients than traveling to a clinic each day.

…is fully supervised. Community-based care is NOT self-administered. Each dose must be administered under DOT. Community-based care reduces cost in the health system and can be more cost-effective than hospital care, but in many ways it is more challenging to implement.

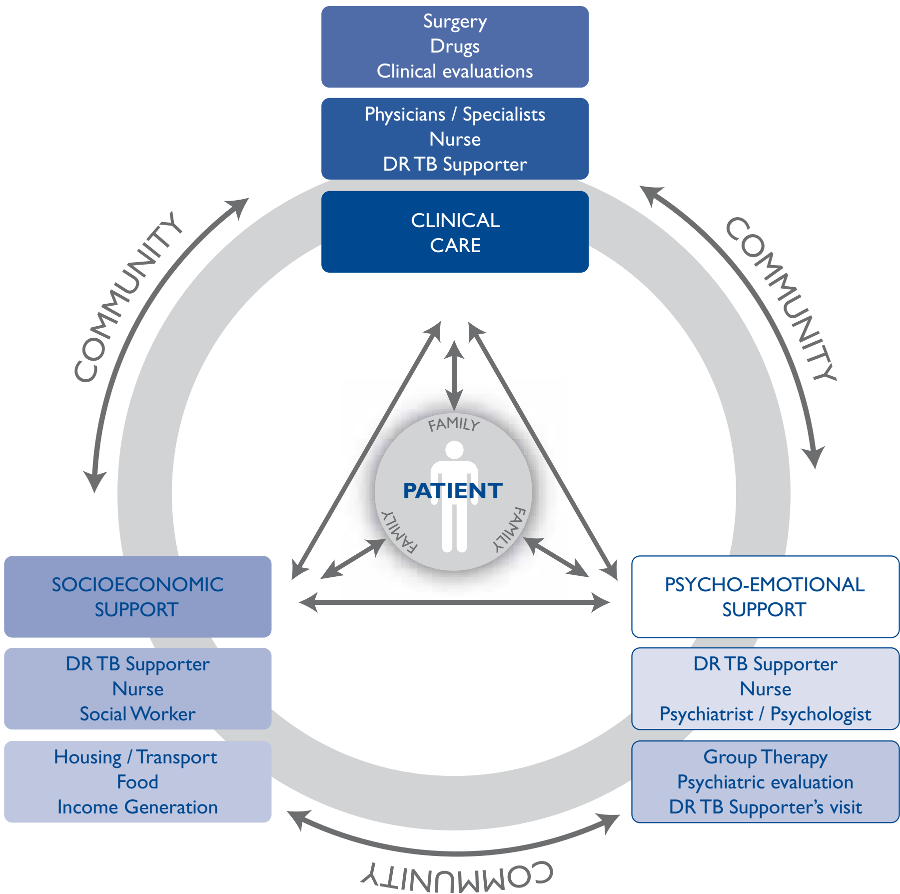
…uses compensated, trained, and supervised Community DR TB Supporters. Administration of DOT for DR TB is labor intensive. DR TB Supporters should receive something in exchange for their work in supporting DR TB patients throughout treatment.

…is compatible with hospital care. A system of community-based care needs to be developed to support patients when they are ready to return home, even in those settings where initial treatment is delivered in hospital.

…places the community and patients at the center of the response to DR TB. Community-based care increases community awareness about DR TB, which in turn can be a powerful force in changing attitudes and social norms regarding TB patients.

3. COMMUNITY-BASED CARE MODEL

All three types of support—clinical care, socioeconomic support, and psycho-emotional support—should be included in community-based care.[1]



3.1. Roles and responsibilities of the DR TB team

The national TB program should incorporate management of DR TB into overall TB management. Each level of management – central, regional, facility, and community – has specified workers with assigned roles. The exact level at which a specific function is provided will depend on the country and the burden of DR TB. The right column lists specific responsibilities; the left column lists possible roles that can take up these responsibilities.

At central level:

POSSIBLE ROLES	SPECIFIC RESPONSIBILITIES
National TB Program Manager National TB/HIV Coordinator National Monitoring and Evaluation (M&E) Officer	• Establish norms and procedures for the control of DR TB. • Plan, assess needs, monitor, and evaluate the program. • Advocate for community care. • Coordinate operational research on community care.
Regional TB Coordinator District TB Coordinator	• Organize, coordinate, and regularly supervise TB and DR TB diagnosis and treatment. • Coordinate with the central level, other institutions, e.g., NGOs and patient support systems. • Integrate DR TB with other services, e.g., HIV and maternal services.

3.1. Roles and responsibilities of the DR TB team CONT.

At health facility level:

POSSIBLE ROLES	SPECIFIC RESPONSIBILITIES
DR TB Clinician: • Doctor or other clinician assigned the responsibility for clinical management of DR TB in the district	• Diagnosis of DR TB, ensure quality of treatment, prescription, and initiation, and clinical follow-up during treatment. • Manage inpatients with severe disease and complications from treatment. • Monitor outpatients for problems that may arise during treatment, e.g., side effects, adherence problems, etc.
DR TB Hospital Team: • Nurses and nursing assistants with specific training in management of DR TB inpatients	• Share responsibility with the DR TB Clinician of the health care facility in management of inpatients with DR TB. • Coordinate clinical support services. • Supervise administration of inpatient treatment. • Coordinate with the DR TB Community Nurse on outpatient admission and discharging inpatients.
Community DR TB Team: • Nurses, nurse assistants, social workers, and others who are responsible for managing DR TB patients in the community • Approximate ratio: 1 nurse for every 50 patients	• Coordinate all DR TB community activities. • Perform home visits in case of medical or adherence problems. • Assesse and improve TB infection control in the home. • Identify and address socioeconomic problems. • Supervise DR TB supporters. • Coordinate with clinical, data, and pharmacy staff.
Laboratory technician Laboratory assistant	• Provide laboratory services for DR TB patients, including screening tests for side effects.
M&E officer Data clerk	• Maintain database (register) of all DR TB patients in the region/district. • Keep track of follow-up appointment dates for all DR TB patients. • Store outpatient records of all DR TB patients. • Produce timely reports according to the national guidelines.
Pharmacist Pharmacy technician Pharmacy assistant	• Manage second-line drug stock (inventory, forecasting, and drug supply) for the region/district. • Prepare pediatric anti-TB drug doses. • Prepare drug packs for each DR TB patient and deliver them to the community team.

3.1. Roles and responsibilities of the DR TB team CONT.

In the community:

POSSIBLE ROLES	SPECIFIC RESPONSIBILITIES
DR TB Supporter • Supports no more than 4 patients at any one time.	• Supervise all doses of second-line TB drugs in the community. • Identify possible side effects or complications and report them promptly to the DR TB Community Nurse. • Accompany the patient to all medical consultations. • Assist the patient in producing sputum samples monthly. • Receive monthly drug kit and verify that it is correct. • Screen household contacts for TB and HIV and refer them for diagnosis. • Provide education and emotional support for the patient and family.
Patients Family members	• Take all doses under the supervision of the DR TB Supporter. • Attend monthly consultations at the DR TB clinic. • Provide sputum and blood on a monthly basis for testing. • Report any difficulties or problems with their care. • Support the patient during treatment and report symptoms of TB in household contacts. • Implement proper infection control measures.

A DR TB patient receives treatment from a DR TB Nurse and Supporter in his home, Peru, 2007.

3.2. Responsibilities of the DR TB Community Nurse

The DR TB Community Nurse is responsible for coordinating care for DR TB patients in the community. The DR TB Community Nurse works as part of a team that may include other nurses and nursing assistants, as well as non-clinical staff such as social workers, drivers, and nutritionists. Clinical activities, such as the referral of medical emergencies, are an important part of the daily activities of the DR TB Community Nurse, who will need specific training in DR TB.

- **Performs home visits in case of medical or adherence problems.**
  - Assesses the home and family at the beginning of treatment.
  - Visits the patient in case of medical problems, including adverse drug effects.
  - Screens family members for HIV and TB.
  - Educates the family and community about DR TB.
  - Tracks defaulters.
- **Identifies, reports, and addresses socioeconomic problems.**
  - Provides counseling and psycho-emotional support.
  - Coordinates DR TB support groups.
  - Helps patients obtain social support.
- **Supervises DR TB Supporters.**
  - Finds an acceptable DR TB Supporter for each patient.
  - Trains the DR TB Supporter (initial and refresher training).
  - Communicates with the DR TB Supporter in case of emergencies.
  - Monitors the DR TB Supporter monthly.
  - Conducts surprise visits to patients' homes to assess quality of DOT.
- **Coordinates with clinical, data, and pharmacy staff.**
  - Arranges for hospital admission for patients in case of medical emergencies.
  - Coordinates patients' transitions from the hospital to community-based care.
  - Coordinates the patients' next outpatient clinic visits.
  - Manages outpatient clinic schedules with the data team.
  - Works with the pharmacy team to deliver medications to patients.

3.3. Participation of the DR TB Community Nurse in the outpatient clinic

Because most of the activities of the DR TB Community Nurse are in the community, not at the facility, the Community Nurse needs to participate in the outpatient clinic activities in order to assess and supervise the DR TB Supporters. The duties of the DR TB Community Nurse during outpatient treatment will differ in each country but may include the following:

- **Organizing follow-up of DR TB patients:**
  - Using the Appointment System (see Section 3.6), collecting the files of the patients who are expected that day from the Records Team before the clinic opens.
  - Measuring patients' weight and vital signs.
  - Sending patients to collect blood and sputum samples.
  - Inspecting Treatment Cards and transferring tick records to the copy of the Treatment Card in the clinic files.
  - Discussing community/adherence issues with the DR TB Clinician.
  - Updating the Register for second-line drug treatment.
- **Arranging evaluation of new patients, such as those who are referred to the clinic as DR TB suspects:**
  - Reviewing the referral form.
  - Ensuring that the required tests are done (e.g., chest x-ray, blood and sputum samples) before the patient is seen by the DR TB Clinician.
- **Assessing and supervising DR TB Supporters:**
  - Conducting monthly performance evaluation of each DR TB Supporter (see Section 4.7) and correcting problems that are discovered.
  - Conducting refresher training for all DR TB Supporters (see Section 4.5).
  - Organize distribution of food packages, transportation reimbursements, and DR TB Supporter compensation (see Section 4.6).
- **Ensuring that patients are given the right amount of prescribed drugs:**
  - Sending prescriptions to pharmacy dispensing area.
  - Receiving patient packs from Pharmacy Team and checking quantities.
  - Educating patients and DR TB Supporters about regimen changes.
- **Ensuring that patients receive the correct follow-up appointments.**

3.4. Integrated care for DR TB patients

Patients who suffer from co-morbid conditions should receive care for these other conditions within the DR TB program.

- **Other chronic diseases (HIV, diabetes, etc.) should be managed during the same DR TB outpatient clinic visit.**
  - The patient drug pack prepared by the Pharmacy Team should include all medications prescribed for other conditions as well.
  - The Community DR TB Team should be trained in the management of other common chronic diseases in addition to DR TB.
- **Advantages of integrated care:**
  - It is more convenient for the patient. Because many DR TB patients are debilitated and struggling with side effects, integrated care decreases the likelihood of them abandoning therapy.
  - It reduces medical error and drug interactions, as one clinical team manages all of the different medications for the patient.
  - It decreases the risk of transmission to other patients, because infectious patients are not required to visit multiple clinics.
- **Integrated care is particularly important in the case of HIV co-infection. All HIV-related services (antiretroviral therapy, screening for opportunistic infection, etc.) should be provided in the DR TB clinic or at community level.**
- **Family planning is a particularly important part of integrated care for DR TB patients, who should not become pregnant while being treated for DR TB. Female DR TB patients of reproductive age should be counseled and assisted in finding an appropriate family planning method.**

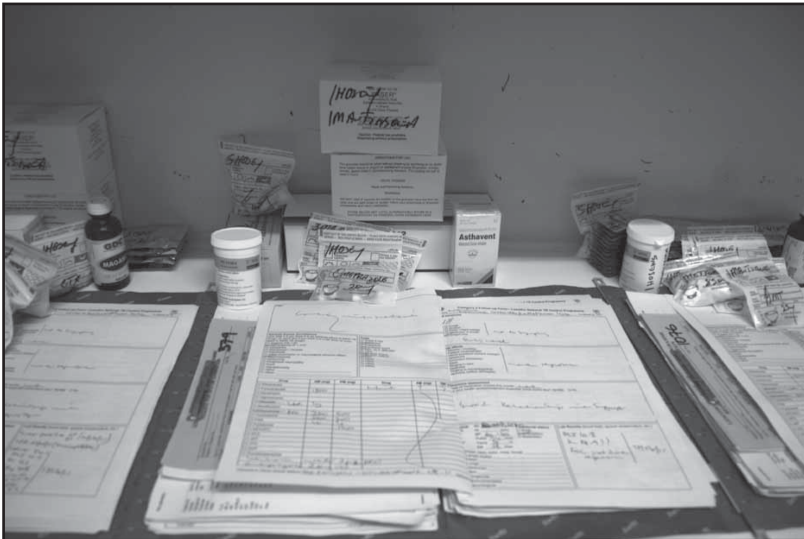
3.5. Communication with the community

- **The DR TB Supporter needs a reliable way to communicate with the DR TB Community Nurse in case of emergencies. In most countries, the best way is via mobile phone.**
  - The DR TB Community Nurse should write his or her contact number in the DR TB Supporter DOT book.
  - Patients and families should be instructed to contact the DR TB Supporter immediately in case of emergency.
  - The DR TB Supporter can be instructed to send an SMS or "flash" the Community Nurse, and then receive a call back.
- **If the patient has any problem, the DR TB Supporter should call the Community Nurse immediately. These problems may include:**
  - Side effects
  - Missed doses
  - Running out of drugs early
  - Unable to attend the clinic due to weather conditions (e.g., flooded river)
- **A free regional/district hotline should be organized to allow DR TB Supporters to communicate with the DR TB Community Team if a specific DR TB Community Nurse is in an area without network access. The hotline can be set up at a hospital; hospital staff will then be responsible for communicating to the DR TB Community Team about the patient.**

3.6. Appointment system

Patients should be evaluated at the clinic every month.

- All appointment dates should be communicated to a Records Team (preferably at the facility that coordinates the patient's care) that keeps track of all appointments in a calendar database.
- On DR TB clinic days, the Records Team should instruct the Pharmacy Team to prepare the refills for the patients to be evaluated at the outpatient clinic.
- Patients who are discharged from the hospital can be given an appointment on the next available day at the clinic.



Monthly drug pack prepared for patients in the central pharmacy, Lesotho 2011.

3.7. TB infection control in the community

- **One of the best methods of infection control is effective treatment. Early diagnosis and rapid initiation of treatment should be the priority for any TB control program.**
- **The home visit is an excellent opportunity for the DR TB Community Nurse to assess and improve infection control in the home. They should:**
  – Educate the patient and family about how to determine if the patient is still infectious; explain the most recent results of the sputum analysis.
  – Improve natural ventilation and exposure to sun within the home.
  – Screen family members for symptoms of TB.
  – Offer HIV testing to all family members in high HIV-prevalence settings, or if the patient is HIV positive.
  – Advise patients on cough hygiene, such as covering their mouths with tissues, handkerchiefs, or surgical masks when coughing.
  – Advise patients to minimize contact with infants and children during the initial months of treatment.
  – Advise patients to sleep in a separate, well-ventilated room during the initial months of treatment if possible.
  – Advise patients to collect their sputum in a plastic bag or jar and teach them how to bury or dispose of it.
- **DR TB Supporters are at increased risk for occupational disease. The following steps should be taken to reduce risk.**
  – DR TB Supporters should know their HIV status and preferably be HIV negative. DR TB Supporters should be offered HIV testing on a regular basis as long as they work with TB patients, as is done for doctors and nurses.
  – DR TB Supporters should know the sputum status of their patient. If the sputum culture is positive, this means the patient is still infectious.
  – Each DR TB Supporter should receive two disposable particulate respirators (N95 or FFP2) on a monthly basis if the patient is culture-positive and be trained on how and when to use them.

3.8. Caring for caregivers

- **Health workers are at risk for DR TB in high-burden TB settings because they are constantly exposed to infectious TB patients.**
  - Health workers should be trained in infection prevention and control when they start working in high-burden TB settings. Written infection control policies, procedures and job aids should be made available to them.
  - Health workers should be provided with the personal protective equipment necessary for caring for DR TB patients.
  - All health workers who are diagnosed with TB should have sputum sent for drug susceptibility testing.
- **Health workers living with HIV are at the highest risk for developing TB and DR TB, so HIV testing is an important part of occupational safety.**
  - Health workers (especially doctors and nurses) often do not want to know their status, but this should be a priority of the occupational health and safety program.
  - All health workers should be offered HIV testing before starting to work with TB patients, and should continue to be tested on a regular basis while this work continues.
- **Health workers who develop TB or DR TB disease may have legal protection or recourse. It is the responsibility of the employer to ensure that health workers have priority access to occupational health and safety programs and appropriate diagnosis and treatment.**
- **Health workers who undergo treatment for DR TB have special needs.**
  - Health workers frequently do not accept that they are patients. They manipulate those who treat them, particularly the DR TB Supporter. DR TB Supporters of health workers should have prior experience, commitment to the work, ability to persuade, and be immune to manipulation.
  - Many health workers change their names in order to receive treatment at another health care facility so that their colleagues do not find out they have TB, for fear of losing their jobs.

4. DR TB SUPPORTERS

4.1. Profile of a DR TB Supporter

– Should preferably be selected from existing community health workers;
– Is chosen by or is acceptable to the patient and his or her family;
– Is active, strong and not too old to work;
– Is available to support the patient at any time during the day or night;
– Can observe confidentiality of the patient's records;
– Has a stable living situation near the patient;
– Has basic literacy skills (should be able to read and write);
– Is motivated to care for DR TB patients;
– Is committed to supporting the patient for the full length of treatment;
– Should not have a health condition that could lead to immune-suppression; *
– Has received basic TB training and DR TB-specific training.

- It is not recommended to appoint a member of the patient's family as their DR TB Supporter. The family relationship may interfere with his or her ability to monitor treatment.
- Young and preferably female DR TB Supporters are recommended for pediatric patients; the parents or family members of the child are not appropriate to supervise doses.
- DR TB Supporters should live near the patient. This makes twice-daily DOT feasible. Additionally, in case of medical emergencies, the family should be able to contact the DR TB Supporter quickly. A neighbor is ideal.
- DR TB Supporters should be compensated, trained, and supervised. "Volunteers" who are not closely supervised cannot be assumed to be providing DOT.

* The most common type of immunosuppression is HIV/AIDS, but chronic illnesses such as diabetes also suppress the immune system and are a risk factor for TB infection and disease.

4.2. Identification of DR TB Supporters

- A DR TB supporter should be someone from the community who meets the profile (see Section 4.1).
- DR TB Supporters may be selected from existing pools of community health workers who meet the profile qualifications. Community health workers are good candidates because they have often already received some training on TB and HIV.
- If there are communities without enough DR TB Supporters, then augment the existing pool of community health workers with community members who are interested in supporting DR TB patients.

DR TB Supporter discusses DR TB with a community member, Peru, 2007.

4.3. Tools for the DR TB Supporter

- Mobile phone (or other means of communication) and adequate airtime
- DOT Book
- Pens or pencils
- Ruler
- Umbrella
- Torch
- Waterproof bag
- Lockable container at home (to keep confidential documents)
- Reliable means or funding for urgent transportation
- Identification

4.4. Initial training of DR TB Supporters

DR TB Supporters should receive specific training in DR TB, which is necessary to provide DOT; complete training can generally be accomplished within two weeks (less if they have had previous training on TB and HIV).

- **WHO's *Training plan for a new community TB treatment supporter* is an excellent foundation for initial training for DR TB Supporters.[2] The training should cover:**
  - – Basic information about TB and HIV.
  - – Role and responsibilities of the DR TB Supporter on an individual basis and as part of the broader clinical team.
  - – How to talk to DR TB patients in the first encounter.
  - – How to read the treatment card.
  - – How to give DOT.
  - – How to mark the treatment card.
  - – About common side effects and how to identify them.
  - – About ancillary drugs used to treat side effects.
  - – How to encourage the patient to continue coming to the clinic for TB treatment.
  - – How and when to make referrals for medical evaluation.
  - – What to do if a patient misses a scheduled treatment.
  - – How to obtain a resupply of drugs.
  - – Appropriate storage of drugs.
  - – What to do if the patient or the DR TB Supporter must be away for a few days.
  - – When to send the patient back to the health facility for follow-up.
  - – The importance of sputum and blood tests every month.
  - – Infection control at home, including universal precautions and needle disposal.
  - – How to use and store a particulate respirator (N95 or FFP2).
  - – TB screening for adults and children.
  - – Patient rights and patient confidentiality.

- **In the beginning of the program, DR TB Supporters can receive initial training one-on-one from a medical health care worker (e.g., nurse or clinical officer). As the number of patients grows, it is more efficient to systematically train all potential DR TB Supporters in each community.**

- **The DR TB Supporter should also be mentored during the first few weeks of treatment. The DR TB Community Nurse should watch the DR TB Supporter observe doses in the home, at the clinic, or in the hospital, while reinforcing the above lessons.**

4.5. Additional training for DR TB Supporters

DR TB Supporters without previous medical training can learn to prepare medications and give intramuscular injections within two weeks. Given the shortages of health workers in many resource-limited settings, task-oriented training of DR TB Supporters to give intramuscular injections may be the best option to expand community-based care for DR TB, so long as it is well monitored and supervised by the Community DR TB Team.

- **Training may consist of the following phases:**
  - Arrange for the DR TB Supporter to be present while the patient is being injected by the DR TB Community Nurse. This could be in the patient's home, at rented housing, or in the hospital.
  - Phase 1: Prepare medication and inject the patient while explaining each step.
  - Phase 2: Prepare medication and inject the patient while the DR TB Supporter explains each step.
  - Phase 3: Watch the DR TB Supporter prepare medication and inject the patient.
- **Monthly refresher training should be done at each monthly clinic evaluation by the DR TB Community Nurse. Topics should include:**
  - How DR TB is created and how it is transmitted
  - Drugs used in the treatment of DR TB
  - Distinction between intensive and continuation phases
  - Roles and responsibilities of all members of the DR TB team
  - How to encourage patients to take treatment
  - Side effects
  - When to refer patients for medical evaluation prior to their next scheduled appointment (e.g., in the case of severe or concerning adverse events, deteriorating health)
  - Importance of monitoring treatment with sputum and blood tests
  - Risk factors for default
  - Screening household contacts for TB
  - Principles of infection control, include disposal of hazardous materials
  - Patient rights and patient confidentiality

4.6. Reimbursements and performance-based compensation

The DR TB Supporter should be reimbursed for all costs incurred as part of the execution of their duties, including (but not necessarily limited to) the cost of transportation to the monthly medical consultation and any additional expenses required for medical emergencies.

- **In addition to reimbursement for expenses, DR TB supporters should be recognized and compensated for their time and services.**
  - Monetary payment may be referred to as a stipend or allowance, rather than a salary, which implies contractual employment.
  - Non-monetary payment may be used as an alternative to monetary payment. Examples include: food packages, bicycles, priority or free access to health and human services (e.g., health insurance), livestock, additional training, and clothing.
- **Compensation should be tied to performance, as assessed during monthly supervision and evaluation (see Section 4.7). During the monthly evaluation of the patient, the DR TB Community Nurse will also evaluate each DR TB Supporter. If his or her performance is acceptable, the DR TB Supporter receives the monthly compensation.**
  - The DR TB Community Nurse will not compensate DR TB Supporters unless they perform all of the above responsibilities during the preceding month.
  - If performance is not acceptable for two months in a row, the DR TB Community Nurse will immediately find an alternate DR TB Supporter for the patient.
- **If the DR TB Supporter cannot supervise treatment, he or she should inform the DR TB Community Nurse in advance, so that another supervisor can be found, and no doses are missed.**
- **If the DR TB Supporter does not fulfill his or her responsibilities, he or she should be replaced immediately. This should be made clear to the DR TB Supporter from the outset.**

4.7. Monthly performance evaluation

The DR TB Community Nurse should evaluate the DR TB Supporter on a monthly basis. This can be done during the clinic visit at the outpatient facility with both the patient and DR TB Supporter, or it can be done during a home visit.

Understands	Circle the appropriate number: 1=poor, 5=excellent	N/A (tick)
The patient's TB treatment regimen (names and doses)	1 2 3 4 5	
Common side effects of the TB treatment regimen	1 2 3 4 5	
All other drugs taken by the patient and why	1 2 3 4 5	
Whether the patient is infectious (smear or culture positive)	1 2 3 4 5	
Patient's HIV status/CD4 count	1 2 3 4 5	

Performance (during the past month)	Circle the appropriate number: 1=poor, 5=excellent	N/A (tick)
Treatment card filled properly/good condition	1 2 3 4 5	
Patient's appraisal of the supporter: punctuality, assiduity, supportiveness	1 2 3 4 5	
DOT book filled properly/good condition	1 2 3 4 5	
Medication bag kept in good condition	1 2 3 4 5	
Provided DOT correctly	1 2 3 4 5	
Notified community nurse in case of any problems	1 2 3 4 5	
Addressed any social problems	1 2 3 4 5	
Up to date on own HIV testing	1 2 3 4 5	
Household contact screening	1 2 3 4 5	

4.8. Monitoring DR TB Supporters

- The DR TB Community Nurse performs spot home visits at any time during the day for the purpose of evaluating and supervising the DR TB Supporter. The DR TB Community Nurse should make an unannounced visit to the patient's home first to ask the patient and his or her family about the DR TB Supporter. The DR TB Supporter should then be called to discuss any issues and reinforce teaching points.
- Pill counts should be done at monthly evaluations or during spot visits. The DR TB Community Nurse should count the remaining pills and compare this number to the amount of pills that should be remaining based on the number of days since the medication bag was replenished. If there are any extra or missing pills, the DR TB Supporter should explain.
- The patient should regularly be asked about the DR TB Supporter (e.g., "Is the DR TB Supporter prompt? Does he or she have a good attitude? Does he or she work around the patient's schedule? Is the relationship still a good one?").
- The DR TB supporter should be asked to assess his or her own performance at monthly evaluations (e.g., "How do you think you are doing? What are you struggling with?").
- The DR TB Supporter should keep the treatment card, even if the TB medications are kept in the patient's home. The DR TB Supporter should read the exact treatment regimen listed on the card and tick immediately after observing the morning or evening dose.

4.9. The DOT Book

The DOT Book is a notebook kept by the DR TB Supporter. The DR TB Supporter records all medications administered, including side effect medications, prophylaxis, and antiretroviral therapy.

Date	Drug	Morning	Evening	Signature
15/9/07	Z			
15/9/07	ETO			
15/9/07	OFX			
15/9/07	CS			
15/9/07	PAS			
15/9/07	AZT-3TC			
15/9/07	EFV			
15/9/07	CTX			
15/9/07	B6			

5. SOCIAL SUPPORT

5.1. Home assessment

The DR TB Community Nurse should perform a home assessment at the beginning of treatment for all patients. This allows the clinical and public health teams to understand the social and family environment and conditions of TB transmission for each patient. This sample assessment form may be adapted to specific countries.

Social		
How many people are sharing the household with the patient?		
How many are HIV positive or suffer from another chronic disease?		
How many are below 5 or above 50 years of age?		
Is this the patient's only residence?		
Economic		
Does the patient receive a source of income (grant/work)?	Yes	No
From what material is the patient's residence constructed?		
What is the ratio of employed persons versus unemployed persons in the household?		
Habits		
Does the patient smoke?	Yes	No
Does the patient drink alcohol or take drugs?	Yes	No
Does anyone else in the household drink or take drugs?	Yes	No
TB Knowledge		
Do the patient and the family understand how TB is transmitted?	Yes	No
Does the family understand the need to be screened for TB?	Yes	No
Infection Control[3]		
Does the house have enough windows?	Yes	No
Does the patient have lots of visitors?	Yes	No
Does the patient sleep in a separate room?	Yes	No
Does the patient socialize in outdoor spaces while sputum positive?	Yes	No
Hygiene		
Is the patient able to demonstrate good cough hygiene?	Yes	No
Does the patient know how to safely dispose of sputum?	Yes	No

Comments

5.2. Food packages

Food packages have two purposes for DR TB: they improve nutritional status and act as powerful adherence enablers. They should be considered a part of the treatment regimen, and just as important as medications.

- Because patients often share their food packages with their families, the size of the food package may need to be adjusted according to the number of family members. The food package should be increased if it is not enough for the whole family and there is no other source of income.
- Food packages should be designed according to World Food Program (WFP) guidelines for HIV patients starting antiretroviral therapy and TB patients starting treatment.[4]
- The exact composition of the food package will depend on the country, but may include:
  - Cereals (maize, rice, wheat bulgur, sorghum, millets, etc.)
  - Pulses (peas, beans, lentils, etc.)
  - Oil
  - Fortified blended foods
  - Sugar/salt
  - Animal products (canned fish, beef and cheese, and dried fish)
  - Dried skimmed milk
- If there are any commodities that are commonly used by patients to make acidic foods to be taken with PASER® (for example, sorghum flour for sour porridge), these should be included in the food package.

5.3. Transportation

DR TB patients often are asked to make many trips to the hospital, clinic or laboratory. For this reason, they may have more out-of-pocket expenses due to transportation than other TB patients.

- **Every effort should be made to consolidate the trips required each month.**
- **Reimbursement for transport expenses is an important enabler for DR TB treatment.**
  - Patients should be reimbursed for transportation expenses according to individual need (geographic location and method of transport).
  - Because DR TB Supporters are also required to accompany the patient to each clinic visit, they should also receive reimbursement for transport (see Section 4.6).

A DR TB Supporter conducts daily home visits to DR TB patients, Peru, 2007.

5.4. Temporary accommodation

While it is usually best for patients to live with or near their families, there are situations when it is in the interest of the patient to move closer to the treatment facility. National TB programs may arrange such accommodation, or may collaborate with other agencies and stakeholders to do so.

- **Temporary accommodation, or hostels, may be needed for DR TB patients who:**
  – live in very remote areas;
  – need to be monitored closely;
  – are too ill to go home, but too well to be in the hospital; or
  – are homeless or have very difficult family situations.
- **Temporary accommodation may be outfitted with all the necessities of living:**
  – Bed and other simple furniture
  – Bedding and blankets
  – Long-lasting insecticide-treated bed nets
  – Cooking stove and fuel
  – Pots and other cooking implements
  – Washing basin, soap (laundry and bath)
  – TV or radio
- **Food packages, cleaning, and cooking should be provided for very weak or ill patients.**

5.5. Work

TB mostly affects patients who are in their most productive age. Nearly all TB patients contribute to their family income. The stress of needing income often means that many patients work until their health has completely deteriorated.

- **Patients should be sputum culture negative before returning to work.**
  - Patients should be encouraged to resume work as soon as their sputum is culture negative. This allows patients to reintegrate into society and earn money for their families.
  - Some patients will not want to return to work even if they are in good health, for fear of falling sick again. These patients need counseling and psychological support to facilitate their return to the workforce.
- **Those without skills or jobs should be encouraged to engage in income generating activities such as:**
  - Sewing circles
  - Gardening
  - Raising chickens or pigs
  - Operating phones
  - Shops
- **It may also be a worthwhile investment to pay for school fees for school-age children, or for additional vocational training for adults, such as sign language classes for patients with injectable-related hearing loss.**
- **National TB programs may implement such social support themselves, or may collaborate with other agencies and stakeholders to manage income-generating activities, job training, and education projects.**

6. ADHERENCE SUPPORT

Treatment for DR TB is long and often complicated. Success of treatment relies heavily on adherence, which in turn relies on:

- A good understanding by the patient of the fundamentals of DR TB and its treatment;
- Commitment from the patient to participate in treatment;
- Support of the patient by the family; and
- Good communication between the provider, the patient, and the family.

An MDR TB nurse administers MDR TB treatment to a patient in her home, Lesotho 2008.

6.1. Directly Observed Treatment

Intake of TB medication must be observed throughout treatment. Doses are administered twice a day. Depending on the patient's situation, one or both of these doses can be administered in the community. The DR TB Supporter should notify the DR TB Community Nurse within 24 hours of a missed dose.

- **In fully community-based DOT:**
  - All doses are observed by a DR TB Supporter in the patient's home.
  - During the injectable phase, a nurse or another qualified individual should inject the patient at a suitable location.
- **In combined facility/community-based DOT:**
  - Facility health workers supervise the morning dose. The facility should be the one closest to the patient's home. During the injectable phase, a facility nurse should inject the patient each morning.
  - A DR TB Supporter supervises doses during the evenings, weekends, and holidays.
- **A program may use both DOT strategies, depending on the patient's situation.**
  - Some patients cannot visit a facility, such as those suffering from severe illness or side effects, patients with complex work schedules, patients suffering from mental illness, or patients who are children or in old age. There may not be a nearby health facility for patients in rural areas. For these patients, fully community-based DOT should be used.
- **DOT should be organized in accordance to the needs of the patient.**
  - The DR TB Supporter generally supervises doses in the patient's home, but in exceptional cases the patient may visit the home of the DR TB Supporter, for example, for reasons of confidentiality.
  - DOT may occasionally be administered in other places, such as the patient's workplace. Where available, a workplace health facility may be used. In such cases, employers play a big role in supporting adherence and should be engaged as part of the team.

6.2. Managing side effects and monitoring treatment

Side effects are the most important reason why patients default from treatment. These can occur at any time during treatment. In most cases these are mild, but occasionally they can be severe. It is important to detect and resolve them quickly.

- Daily DOT is an opportunity for early detection of side effects. The DR TB Community Nurse and the DR TB Supporter should be conversant with the potential side effects that could be produced by the regimen that the patient is receiving. The DR TB Supporter should have an easy mode of communication with Community Nurse that is open 24 hours a day.
  - If side effects are mild, the Community Nurse can monitor and manage them with pre-established protocols.
  - If side effects are severe, the Community Nurse should arrange for appropriate medical referral.
- The DR TB Supporter should also monitor for signs that the patient is improving.
  - Signs that treatment is working include decreased cough and sputum and weight gain.
  - If the patient is having fevers or night sweats, difficulty breathing or hemoptysis, the DR TB Supporter should notify the Community Nurse, who will arrange for appropriate medical referral.

A TB patient is examined by a DR TB clinician in her home, Lesotho, 2008.

6.3. Support groups[5]

A support group allows patients with DR TB to meet and socialize with other patients and provide emotional support to each other.

- **A counselor, social worker or someone trained in facilitating support groups should facilitate the support group. The DR TB Community Nurse may co-facilitate the group.**
- **Clear eligibility criteria should be created for participation in each support group.**
  - Participation should be generally reserved for patients who are sputum negative and are no longer infectious.
  - Cured patients may also be invited to support groups, as they provide hope to patients who are still in treatment.
  - Some groups may be reserved for patients with serious psychosocial issues and may require a facilitator with psychiatric training.
- **Other groups may be largely self-organized and appropriate only for patients without psychiatric issues.**
- **Support groups may need help in inviting participants, finding a safe meeting place and other organizational issues.**
- **At the end of each support group meeting, the facilitator and co-facilitator should stay behind to discuss and analyze the proceedings.**

6.4. Preventing default[6]

Patients should be observed closely for signs that they might default from treatment, such as missed visits or refusal to take doses. The following steps should be taken for patients with these warning signs.

1. **Home visit.** During the home visit, it may be possible to identify more clinical problems than during the monthly clinic evaluation.

2. **Manage side effects.** This is the most common reason for default.

3. **Counseling.** Does the patient no longer want to continue treatment because he or she feels better? Does the patient have greater confidence in alternative or folk medicine?

4. **Address economic problems.** Many patients are unable to work when they are ill, and they may be the primary wage earners for their family. Are basic housing, food, and clothing needs covered?

5. **Address addiction or other social problems.** Is there alcohol or drug abuse in the home? Patients should be encouraged to stop or decrease consumption if it interferes with their treatment.

6. **Address problems with health personnel or the DR TB Supporter.** Is the patient mistreated by the healthcare facility? Does the DR TB Supporter arrive late? The patient should be considered part of the DR TB team.

7. **Involve the family.** Family is the most important source of psychosocial support for the patient.

8. **Involve community leaders.** Community and religious leaders can be helpful if there are community-wide issues such as stigma toward DR TB patients.

7. SUPPLY CHAIN MANAGEMENT

7.1. Centralized control of second-line TB drugs

Monthly patient drug packs should include TB drugs, ancillary drugs for treatment of side effects, other drugs used to treat co-morbid diseases such as HIV or diabetes, and family planning supplies.

- **Patient drug packs should be assembled by the Pharmacy Team and delivered to DR TB Supporters by the Community DR TB Team.**
  - In advance of the patient's monthly appointment, the Records Team should send the patient's file to the pharmacy dispensary.
  - The Pharmacy Team will pack the prescribed drugs in approved and sealable bags.
  - A 30-day supply should be packed for each second-line TB drug. This gives a 2-day buffer that may be necessary in case of lost doses (e.g., lost doses due to vomiting).
  - The Pharmacy Team should verify each patient drug pack and sign the logbook before delivering the packs to the Community Team and DR TB Supporters.
  - The Community Team should verify each patient pack and sign the logbook when receiving the packs from the Pharmacy Team.
- **When patient drug packs are sent to a remote site, the pharmacy staff team should prepare a small extra supply of second-line drugs for the DR TB Community Nurse. If the clinicians at the site change the prescription, the DR TB Community Nurse should adjust the patient drug packs accordingly.**
- **All extra drugs, including those from patients who have died during the month, should be brought back to the central pharmacy by the Community Team for other patients or for destruction.**

7.2. Logbook for preparation of DR TB patient medication packs

The Logbook should be maintained by the Pharmacy Team and kept in the area used to prepare patient drug packs.

Date	Patient Registration Number	Time case file received	Prepared by (Pharmacy Team)	Checked by (Pharmacy Team)	Received by (Community Team)

7.3. Standardized prescription form

A standardized prescription form can reduce clinician and pharmacy error. The DR TB Clinician fills out the form and passes it to the Pharmacy Team, which prepares the patient drug pack. This form can also be included as part of DR TB clinic follow-up forms and hospital discharge summaries.

The prescription form should include the most commonly prescribed TB and other medications; blank spaces are included at the bottom for uncommonly prescribed medications. The below example is not exhaustive; programs in different countries may choose to add other commonly used drugs.

Drug	DOSE			
	Morning (mg)	Mid-day (mg)	Morning (mg)	Midnight (mg)
Isoniazid				
Rifampicin				
Ethambutol				
Pyrazinamide				
Kanamycin				
Capreomycin				
Levofloxacin				
Moxifloxacin				
Ethionamide				
Cycloserine				
PAS				
AZT-3TC				
EFV				
D4T-3TC-NVP				
TDF-3TC-EFV				
Metoclopramide				
Levothyroxine				

7.4. Order second-line TB drugs

- **Ordering second-line TB drugs is a very important activity that is done at the central level.**
  - Some second-line drugs may take a very long time to arrive in the country after being ordered. Order at least 9 months in advance to be safe.
  - Some second-line drugs have short half-lives, including cycloserine and capreomycin. Deliveries of these drugs should be staggered in order to avoid expiration.
- **The following formulas can be used to calculate orders of second-line drugs. They assume that patients are evenly distributed across weight classes. Once the program has grown, the actual weight distribution of patients in the program can be used for these calculations.**

Drug (unit)	Quantity to Order	Assumptions
Pyrazinamide (500 mg tab)	$3 \times D \times P$	Mean consumption is 1500 mg/day
Kanamycin (1 gr vial)	$1 \times D \times P$	Will discard unused portion of vial
Capreomycin (1 gr vial)	$1 \times D \times P$	Will discard unused portion of vial
Ethionamide (250 mg tab)	$3 \times D \times P$	Mean consumption is 750 mg/day
Cycloserine (250 mg tab)	$3 \times D \times P$	Mean consumption is 750 mg/day
PASER (4 gr sachet)	$2 \times D \times P$	Most patients receive 8 gm/day
Levofloxacin (250 mg tab)	$D \times (P/2)$	Half the patients are <50 kg (750 mg/day)
Levofloxacin (500 mg tab)	$3 \times D \times (P/2)$	Half the patients are >50 kg (1000 mg/day)

D = Number of days that patients receive treatment in the time period for which you are ordering

P = Number of patients taking the drug.

7.5. Don't forget to budget for…

- Syringes, needles, and water for injection. Approved needle disposal containers are also needed for each DR TB Supporter who is providing injections. These disposal containers need to be collected and disposed by the Community DR TB Team according to national protocol.
- A small amount of first-line TB drugs. The National TB Program should estimate the small percentage of patients who:
  - – are susceptible to some of the first-line TB drugs. Isoniazid or rifampicin susceptibility is rare, but there will be a few patients who will be using these drugs.
  - – need high-dose isoniazid, a "third-line" drug of unclear efficacy.
  - – do not have DR TB, but are using second-line TB drugs because of allergies to first-line TB drugs.
- Ancillary drugs for side effects. Some may be available widely because they are considered essential drugs, but many are not. The National TB Program should ensure that Pharmacy Teams at facility levels have access to sufficient quantities of commonly used ancillary drugs:
  - – Anti-emetics: metoclopramide, prochlorperazine
  - – Anti-depressants: sertraline, fluoxetine
  - – Anti-convulsants: phenytoin
  - – Anti-psychotics: haloperidol, risperidone
  - – Antihistamines: chlorpheniramine
  - – Anti-diarrheals: loperamide
  - – For neuropathic pain: amitriptyline
  - – Family planning: depot medroxyprogesterone acetate
  - – For physical pain and air hunger: opioids
- Monitoring tests. Most of the basic blood tests for screening and treatment of side effects are available in any hospital. However, additional funds may be necessary for these tests, especially in hospitals where there are DR TB inpatients that often require frequent monitoring. The National TB Program should ensure that Laboratory Teams at all facilities have sufficient equipment and reagents to perform all necessary tests.
- Approved particulate respirators (N95 or FFP2) for hospital staff, laboratory staff, community staff, and DR TB Supporters.

7.6. Storage conditions in the community

- For storage packs or containers for second-line TB drugs, consider the following options:
  - Wooden boxes are durable, but can be difficult to take to and from the pharmacy.
  - Canvas bags are light and convenient, but may tear after several months, so a sufficient supply of replacement bags will be necessary.
  - Synthetic bags are heavier but more durable than canvas bags. Some are insulated and may help protect the drugs from extreme temperatures.
- PASER® is one of the brands of PAS that is available through the Global Drug Facility. PASER® should be stored in a refrigerator in the pharmacy, but is stable at room temperature for several weeks. This means that the monthly drug pack, once delivered to the patient or DR TB Supporter, does not need to be refrigerated unless temperatures are extremely high. The patient and DR TB Supporter should be instructed to keep the drug pack in a part of the house that does not experience extreme cold or heat. Heat-stable brands of PAS are also available through the Global Drug Facility.

8. COMMON LABORATORY PROBLEMS

8.1. Sputum samples are lost or dry out on the way to the facility

A well-structured system for sputum collection and transportation should be established.

- **Sputum samples should be cultured within 72 hours (3 days).**
  - For specimens that can be cultured in less than 3 days: Refrigerate at +4 °C until transport or immediately transport to the laboratory for processing.
  - For specimens that will be cultured more than 72 hours after collection: 1 percent cetylpyridinium chloride (CPC) can be used to preserve the specimen for up to two weeks. Specimens with CPC in them should not be refrigerated as the CPC will crystallize and be ineffective.
  - CPC tubes should be provided to health facilities on a regular basis, along with instructions on how to prepare sputum samples for transport to the laboratory.
  - CPC is not permitted for liquid media; therefore, specimens decontaminated with CPC cannot be used if the laboratory does susceptibility testing on liquid media.
- **For areas that are remote from a culture laboratory, new methods appropriate for peripheral laboratories (e.g., Xpert MTB/RIF®) are becoming more available. CPC should not be used for these methods.**

8.2. Losing track of DR TB suspects

A system should be established to communicate drug susceptibility testing (DST) results in a timely fashion to clinicians at all levels. This system may use paper result forms, text messages, or the internet.

- Without a strong communication system, DST results may be lost in transit between the national TB laboratory and the district-level clinicians who ordered the test. The national TB laboratory may not be able to find the clinician who originally ordered the DST.
- The National TB Program should regularly review the records of the national TB laboratory at least monthly for any new patients who have been diagnosed with DR TB. These names and addresses should be communicated to the appropriate person in the respective region/district/facility who will trace the patients and make sure that they are started on appropriate treatment.
- DST results may arrive many months after they are ordered, making it difficult for district-level clinicians to track the patient for whom the DST was ordered.
- The following register can be used at district-level facilities to make sure that all DR TB suspects are accounted for and DST results have been received. The Community DR TB Team can evaluate turn-around-time on a regular basis.

DATE	DR TB suspect number	Name	Sex	Age	Contact information	Date sputum collected	Date sputum sent to lab	Date results received	Smear results		HIV test (pos/ neg/ refused)	DST results	Treatment start date	Comments
									1	2				

8.3. Blood tests for side effect screening

- WHO guidelines recommend screening for side effects that can be caused by second-line TB drugs.[7] These side effects include acute renal failure, hypokalemia, hepatitis, and hypothyroidism. The following blood tests should therefore be available, preferably at the district level:
  - Urea, creatinine, and electrolytes
  - Liver function tests
  - Full blood count
  - Thyroid stimulating hormone
- Point-of-care testing is an excellent way to improve screening for side effects. When blood tests are done at the district or regional hospital, blood samples may be lost and results may be delayed or lost. For some analyses, handheld devices using cartridges allow results to be read instantly and appropriate treatment started quickly. Some devices are portable and can be taken along to home visits. Specific tests depend on the manufacturer, but the following tests are often available:
  - Urea, creatinine, and electrolytes
  - Hemoglobin

9. CONTINUITY OF CARE

9.1. Discharge from the hospital

- **For continuity of care, it is essential that there is good communication before discharge among representatives from the hospital (e.g., clinician or hospital nurse), DR TB Community Nurse, DR TB Supporter, patient, and family. All parties should:**
  - Agree that the patient is medically stable for discharge.
  - Agree to where the patient should be sent (home or other housing situation such as temporary accommodation, see Section 5.4).
  - Ensure the pharmacy prepares the correct patient pack before discharge.
  - Prepare transportation from the hospital.
  - Agree on the discharge plan.
- **The DR TB Community Nurse should perform a home assessment prior to discharge for all patients (see Section 5.1). If adherence issues are identified, then the Community Nurse will conduct a follow-up home assessment focusing on adherence issues.**

A woman supports her mother who is an MDR TB patient, Lesotho, 2008.

9.2. Contact tracing

Upon diagnosis, a list of close contacts, including those from outside of the household, should be developed and kept in the patient's clinical record. During the initial home assessment, the DR TB Community Nurse screens all household contacts; there-after, it is the role of the DR TB Supporter to regularly screen identified household contacts.

- **Household contacts of DR TB patients are people living in the same household. These may include:**
  - People spending nights in the same room as the patient, including spouses, children, caretakers, etc.
  - People spending time in common living areas.
- **All household contacts should receive HIV counseling and testing in high HIV prevalence settings, or if the patient is HIV-positive.**
- **All children below five years of age should receive a baseline chest x-ray and evaluation by a clinician, even if they are asymptomatic.**
- **Adult close contacts who answer yes to any question on the symptom screen should receive:**
  - A chest x-ray
  - A sputum smear, culture, and drug susceptibility test
  - An evaluation by a clinician, preferably the DR TB Clinician. The evaluation should include a history and physical examination.
- **Close contacts of DR TB patients should receive careful clinical follow-up for a period of at least two years, especially children. If active disease develops, appropriate DR TB treatment should be initiated.**
- **The routine use of second-line drugs for chemoprophylaxis in DR TB contacts is currently not recommended.**

9.3. Follow-up after completion of treatment

After completing treatment, each patient should be followed for the next two years with clinical and bacteriologic screening in accordance with the National TB Program guidelines.

- Patients should be instructed to return to the health facility for evaluation in case they experience recurrence of TB symptoms.
- Household contacts should be instructed that the risk of developing DR TB continues after the patient has been cured and that they should report to the health facility if they develop any TB symptoms.
- Proper referrals for other medical and social services should be put in place prior to discharge from treatment. Patients should be referred to the proper nearest clinic for follow-up of chronic medical problems (such as HIV or diabetes) that were managed by the DR TB clinical team during treatment.

A member of the DR TB team prepares medication for an MDR TB patient, Lesotho, 2008.

9.4. Additional considerations

Some types of patients may need special protocols and considerations for treatment. These protocols should be developed at a national level and disseminated to all regions/ districts.

- HIV co-infected
- Children
- Pregnant women
- Elderly
- Diabetics
- Alcohol or substance abusers
- Prisoners
- Health workers

10. RECORDING AND REPORTING

10.1. Treatment Card for patients receiving second-line TB drugs

There should be two copies of the Treatment Card[8]:

- One copy should be given to the DR TB Supporter, who is responsible for recording all doses. Generally, the patient should not keep the Treatment Card, but this will depend on the National TB Program protocol.
- One copy is kept in the clinic outpatient file.
- At each monthly medical consultation, the information from the treatment card kept by the DR TB Supporter should be transferred to the treatment card kept at the clinic.
- Any changes to the treatment regimen should be noted on both Treatment Cards.

10.2. Sample monthly report of community-based activities

Report for ______ /______ (month/year)

New patient enrollment

Number started on treatment	
Number of new DR TB patients who are HIV-positive	
Number started at home	
Number started in the hospital	
List of districts with new DR TB patients	

Home visits

Number of home assessments	
Number of home visits for other reasons	

Temporary accommodation

Patient name	District	Dates	Reason for accommodation

List of emergencies (provide a brief explanation of each):

List of patients who were discharged from treatment:

List of patients who died at home:

10.3. Sample hospital discharge summary

Patient name ______________________________ Registration number ____________________

Age ______________________________ Sex ______________________________

Address ______________________________ Telephone ______________________________

Date of admission ______________________________ Date of discharge______________________________

Facility where the patient will receive outpatient care ______________________________

Hospital course:

Procedures received while hospitalized:

Discharge diagnoses:

Follow-up (appointments, labs):

Drug	DOSE			
	Morning (mg)	Mid-day (mg)	Evening (mg)	Midnight (mg)
Isoniazid				
Rifampicin				
Ethambutol				
Pyrazinamide				
Kanamycin				
Capreomycin				
Levofloxacin				
Moxifloxacin				
Ethionamide				
Cycloserine				
PAS				
Metoclopramide				
Levothyroxine				

10.4. Sample transfer form

Patient name ________________________________ Registration number ___________________

Age __________________ Sex _______________ Date of transfer ______________________

Receiving clinician ____

Date discussed with receiving clinician____

Contact information of receiving clinic ____

Reason for transfer:

Presenting symptoms and treatment course:

Please find attached photocopies of the patient's treatment card and most recent bacteriology and drug susceptibility testing results. For additional information, please contact us.

Clinician's name_____________________________ Signature ___________________________

Clinician's contact information ____

11. FREQUENTLY ASKED QUESTIONS

- **Does treating patients at home pose a risk to the community?**

  The reality is that by the time the vast majority of patients have been diagnosed with DR TB, they have been infectious for months or even years. This means that their close household contacts may already be infected. Taking the patient out of the home does not change this fact. Rather, it is important to explain to the family members how to decrease the risk of developing active TB disease, to explain the symptoms of active TB, and to implement a system of screening household contacts of DR TB patients.

- **Isn't it important to isolate patients with DR TB?**

  Isolation is less important than treatment. It is very difficult to truly isolate a TB patient. Hospitals, even those designated for the treatment of DR TB, are usually not adequately equipped for isolation of airborne infections. Nosocomial transmission is very common, and is dangerous for other patients as well as hospital staff. Effective treatment, on the other hand, results quickly in a non-infectious patient, no matter where the patient is.

- **Is DOT really necessary?**

  DOT is even more important for DR TB treatment. Second-line TB drugs have many side effects and DR TB treatment is very long. Treatment with these drugs represents the last possibility for these patients to be cured. Most patients will default without daily support. It is also important to monitor patients for serious side effects. DOT can and should be provided in a supportive, rather than punitive, manner.

- **What is compensation for DR TB Supporters?**

  DR TB Supporters should be compensated for their time and effort in supporting patients. Sometimes DR TB Supporters are given means to accomplish their duties (e.g., transport reimbursement, basic tools and materials); this is NOT compensation. Compensation is above and beyond reimbursement of the out-of-pocket costs of doing the job.

11. Frequently Asked Questions CONT.

- **Why do DR TB Supporters need to be compensated for their work?**

  Reciprocity is an ethical principal to reward ("compensate") someone who does a service for benefit of the community. It is true that there are some people who will participate in community health work – even to expose themselves to significant risk – for no compensation. However, in many poor communities, this is not feasible as a long-term strategy, because people need a way to put food on the table. Compensation of DR TB Supporters creates a more sustainable community-based program. It is expensive to continually be recruiting and training new people to replace those who left because their work was not sufficiently rewarded.

- **Do enablers such as food packages and transportation reimbursement improve TB treatment outcomes?**

  Yes. One of the most important TB treatment outcomes is patient adherence. There is credible evidence that food packages and transportation reimbursement are powerful enablers that improve patient adherence to TB treatment. It is true that there is less evidence of the effect of nutrition on other TB treatment outcomes, compared to the very strong evidence showing that food improves the outcomes of HIV-positive patients. There are a number of ongoing studies that are looking at the effect of nutritional supplements on TB treatment outcomes.

12. REFERENCES

1. Adapted from Chalco K, Guerra D, Llaro K, et al. *SES Guide for Nurses on MDR-TB and DOTS-Plus*. Lima: SES, 2006.
2. World Health Organization. *Management of Tuberculosis Training for Health Facility Staff, 2nd edition. E Identify and Supervise Community TB Treatment Supporters* (WHO/HTM/TB/2009.423e)
3. Family Health International. *Simplified Checklist for TB Infection Control*. 2010.
4. World Food Programme. *Food Assistance in the Context of HIV:* Ration Design Guide. Rome: WFP, 2008.
5. Acha J, Sweetland A, Castillo H. S*ES Guide for Psychosocial Support Group for Patients with MDR-TB*. Socios EnSalud Sucursal Peru: Lima, 2004.
6. Chalco K, Guerra D, Llaro K, et al. *SES Guide for Nurses on MDR-TB and DOTS-Plus.* Lima: SES, 2006.
7. World Health Organization. *Management of MDR-TB: A field guide* (WHO/HTM/TB/2008.402). Geneva: WHO, 2009.
8. World Health Organization. *Guidelines for the programmatic management of drug-resistant tuberculosis, Emergency update 2008* (WHO/HTM/TB/2008.402). Geneva: WHO, 2008.

U.S. Agency for International Development
1300 Pennsylvania Avenue, NW
Washington, DC 20523
Tel: (202) 712-0000
Fax: (202) 216-3524
www.usaid.gov

MIX
Paper
FSC® C002933