Learning from Red Cross Red Crescent community-based MDR-TB programmes

What National Societies can do to combat MDR-TB

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International Federation of Red Cross and Red Crescent Societies
Acknowledgement

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Health and care

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What National Societies can do to combat MDR-TB

Strategy 2020 voices the collective determination of the IFRC to move forward in tackling the major challenges that confront humanity in the next decade. Informed by the needs and vulnerabilities of the diverse communities with whom we work, as well as the basic rights and freedoms to which all are entitled, this strategy seeks to benefit all who look to Red Cross Red Crescent to help to build a more humane, dignified, and peaceful world.

Over the next ten years, the collective focus of the IFRC will be on achieving the following strategic aims:

1. Save lives, protect livelihoods, and strengthen recovery from disasters and crises
2. Enable healthy and safe living
3. Promote social inclusion and a culture of non-violence and peace
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Acronyms and abbreviations

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<td>ART</td>
<td>Antiretroviral therapy</td>
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<td>ASHA</td>
<td>Accredited Social Health Activist (India)</td>
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<td>BCC</td>
<td>Behaviour change communication</td>
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<td>CBO</td>
<td>Community-based organization</td>
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<td>CHW</td>
<td>Community health worker</td>
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<td>DOTS</td>
<td>Directly Observed Treatment Short course</td>
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<td>DST</td>
<td>Drug susceptibility testing</td>
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<td>GIPT</td>
<td>Greater Involvement of People with Tuberculosis</td>
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<td>IEC</td>
<td>Information, education, communication</td>
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<td>IFRC</td>
<td>International Federation of Red Cross and Red Crescent Societies</td>
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<td>IPT</td>
<td>Isoniazid preventive therapy</td>
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<td>KAP</td>
<td>Knowledge, attitude and practice</td>
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<tr>
<td>LPA</td>
<td>Line probe assay</td>
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<td>MDG</td>
<td>Millennium Development Goals</td>
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<td>MDR-TB</td>
<td>Multidrug-resistant TB</td>
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<td>MoH</td>
<td>Ministry of Health</td>
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<td>NGO</td>
<td>Non-governmental organization</td>
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<td>NTP</td>
<td>National Tuberculosis Programme</td>
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<td>PPM</td>
<td>Public private mix</td>
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<td>PLHIV</td>
<td>People living with HIV</td>
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<td>TB</td>
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<td>WHO</td>
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About this publication

This publication focuses on the experience of the International Federation of Red Cross and Red Crescent Societies (IFRC) in community-based multidrug-resistant tuberculosis (MDR-TB) programmes implemented since 2008 via the Red Cross Red Crescent National Societies in Kazakhstan, India and South Africa, and the lessons learnt during their implementation.

The main objective of the projects is to use Red Cross Red Crescent volunteers to increase the detection and treatment of tuberculosis, particularly MDR-TB, by selecting for support the most vulnerable patients requiring retreatment. All three of the tuberculosis projects were designed to support multidrug-resistant TB patients. Programmes aid people who need support and directly observed treatment (DOTS) activities to continue treatment for as long as necessary. An important element of each project is the provision of awareness-raising and education among families and the general population, in order to reduce stigma and discrimination.

This publication, detailing the lessons learnt from the MDR-TB programmes, is intended for Red Cross Red Crescent National Societies, individuals and groups with an interest to combat MDR-TB in their communities and around the world. It can be used by health care personnel, programme planners and programme evaluators at community level. The document outlines some principles in the design and implementation of a successful MDR-TB treatment and control programme at community level. The principles are not intended as a comprehensive or dogmatic approach to a complex disease, but are informed by the three years’ experience of United States Agency for International Development (USAID)-supported IFRC community projects on MDR-TB, noting the lessons learnt from country programmes and the challenges faced at community level. The document provides a series of observations on what is necessary to create a situation in which MDR-TB patients can be successfully cared for during their disease, while at the same time transmission of MDR-TB is effectively halted.

The publication is also in line with the key strategies identified and published by the IFRC in 2007, relevant to tackling the complex issue of MDR-TB in various contexts in the world.

Each topic gives the key elements that have been identified as potential areas of development for MDR-TB control, and those which may usefully be the subject of Red Cross Red Crescent advocacy efforts aimed at government-level decision-makers. The key elements are sometimes illustrated by case studies and personal stories. Following from the identification of the key elements, some practical recommendations that seem to be most relevant to achieve success and avoid errors in MDR-TB control are given to help National Societies decide on priority development areas in their TB programmes. These topics are:

a. Planning and coordination
b. Timely identification of MDR-TB patients and the link with HIV
c. Accessing “hard-to-reach” populations
d. Treatment adherence support
e. Patient and community empowerment, education and training, and infection control
f. Measuring health outcomes and providing evidence of impact of TB control programmes
Multidrug-resistant TB and extensively drug-resistant TB (XDR-TB) are major threats to TB control, with all countries at risk.

WHO estimates a prevalence of 650,000 cases of MDR-TB in 2010. In total 46,000 patients were enrolled on MDR-TB treatment, corresponding to just 16 per cent of the estimated number of MDR-TB patients that needed treatment. Over 150,000 deaths were caused by MDR-TB in 2008. MDR-TB cases are highest in Eastern Europe and central Asia, with more than 60 per cent of the world’s cases of MDR-TB occurring in China, India and the Russian Federation. As of August 2010, fifty-nine countries had reported at least one case of XDR-TB. In some settings, up to a third of all new TB patients are now being diagnosed with MDR-TB.

The standard six-month treatment with first-line anti-TB drugs is not effective for people with MDR-TB and XDR-TB. Instead, they must be treated with drugs that are less efficacious, more toxic and much more costly (typically US$ 2,000—5,000 per patient). The treatment time is up to two years, causes severe side effects and it can be difficult for the patient to maintain adherence. Non-compliance with MDR-TB treatment can lead to XDR-TB for which treatment options are severely limited.

The toll on public health from counterfeit drugs is an important but rather underestimated issue. Substandard TB drugs contribute to the development of resistance and increase by this mechanism the incidence of MDR-TB or even XDR-TB. It is possible that many individuals die because the drugs they are consuming are counterfeit. International Policy Network, a think tank in London mentions in its recent report Keeping It Real - Protecting the world’s poor from fake drugs: “Precise data on levels of fake tuberculosis drugs are scarce, yet one reliable study (Laserson, 2001) of six countries showed levels of fakes at 10 per cent. By these figures we assume that around 900,000 tuberculosis sufferers are at risk from fake drugs, half of whom (450,000) will die due to the ineffective treatment.”

In many countries today, the involvement of non-governmental organizations (NGOs) and community-based organizations (CBOs) in TB programmes is considered of vital importance. They have an active role in the fight against TB as a large majority of patients seek treatment from them. There are many areas where government agencies are not able to provide services to the population for a variety of reasons, including geographical barriers. Fortunately many community-based organizations are working in such areas, enjoying the trust and confidence of the local population and providing much needed health and other services close to people’s homes. This proximity to, and acceptance by, the population gives those organizations a vital role in health care service delivery, a fact now universally recognized.
The IFRC, the world’s largest humanitarian organization, has a specific place in this relationship. It provides assistance without discrimination as to nationality, race, religious beliefs, class or political opinions. The Federation is made up of 187 member Red Cross and Red Crescent National Societies, a secretariat based in Geneva, and over 60 delegations located at strategic points worldwide to support activities to prevent and alleviate human suffering, to protect life and health and to ensure respect for the human being. The seven Fundamental Principles\(^5\) of the Red Cross Red Crescent Movement, by which all National Societies abide, help to promote mutual understanding, friendship, cooperation and lasting peace among all peoples, as well as maintaining the National Society’s independence and autonomy in each member country. Working with a small staff and over 13 million active volunteers worldwide, National Societies are an essential, established and natural partner to help governments meet their commitments. Individual governments must ensure that their health and social welfare systems are capable of meeting their population’s needs. Red Cross Red Crescent National Societies can make a significant contribution, particularly with the most vulnerable. The Red Cross Red Crescent targets those at highest risk when affected by MDR-TB: HIV-positive patients, detainees, single mothers, children and particularly orphans, illicit drug users and alcohol-addicted patients, homeless, patients with other chronic diseases and immigrants who may be in a precarious situation. Included among the most vulnerable are those who have already been diagnosed with TB and are at risk of defaulting from their TB treatment if not given enough support. Factors influencing higher levels of vulnerability must partly be determined by the context and identified by both a health needs assessment and a baseline survey. If possible, the prevalence of MDR-TB in a given area should be known before targeting an intervention.

People with TB (specifically with MDR-TB), HIV, and with TB/HIV face numerous obstacles when seeking services at traditional clinic and hospital settings that are too few and too far from where patients live. Recognizing these barriers, national TB and HIV programmes as well as other partners have created community-based care and treatment programmes. These programmes allow community workers and volunteers to provide MDR-TB treatment and treatment support, such as DOTS, and to educate people on MDR-TB and other public health topics. These efforts have led to improved health outcomes for people through early discovery and treatment of their disease.

With funding from USAID, the IFRC and its member National Societies are working to find solutions that can support prevention, diagnosis and treatment of MDR-TB at community level. Red Cross Red Crescent MDR-TB activities in Kazakhstan, India and South Africa demonstrate a close link between the community and the formal health system through:

- adapting health services to a patient-centred approach
- improving the quality of interpersonal communication between care providers and patients
- increasing access to diagnostic services
- empowering patients, communities and civil society organizations through partnerships and the encouragement of active involvement and participation
- improving and promoting supportive communication methodologies
- measuring results and giving feedback to the stakeholders – health professionals and community representatives – including concrete short-term outcomes like treatment completion and success rates
Results of Red Cross Red Crescent pilot MDR-TB projects have been impressive, with a very high percentage of adherence to treatment reported. All projects are strictly monitored, with volunteers receiving training and constant supervision.

What makes the Red Cross Red Crescent approach different from other tuberculosis programmes is its ability to bring tuberculosis treatment to the people within their own communities. In particular, the most vulnerable people, often living in remote areas or slums, can be reached without them having to travel long distances, miss work and lose valuable income. Worldwide in 2011, the Red Cross Red Crescent provided daily care to 200,000 most vulnerable TB patients, of which 10,000 were patients with MDR-TB, and 40,000 were co-infected with HIV. Furthermore, five million community members were mobilized, with 14 million hours allocated through 80,000 Red Cross Red Crescent staff and volunteers.

This publication relates the challenges encountered by the three USAID-funded projects and some of the lessons learnt from dealing with them, many of which should be helpful to Red Cross Red Crescent National Societies undertaking community-based MDR-TB projects in their own country.
Challenges of MDR-TB

MDR-TB is defined as resistance to isoniazid and rifampicin, the two most important first-line drugs that are used in the treatment of TB. XDR-TB is defined as MDR-TB plus resistance to additional drugs: a fluoroquinolone and at least one second-line injectable drug.

MDR-TB is ubiquitous and man-made. The development of drug-resistant bacilli is almost always a consequence of human error and/or neglect resulting from a number of factors, such as poor management of the available drug supply or poor management of the person with drug-susceptible TB.

Compared to drug-susceptible TB, the management of MDR-TB is challenging and more complicated. The success of treatment depends on how quickly a TB patient is identified as having drug-resistant TB, whether an effective drug therapy is available and whether a patient is able to maintain an uninterrupted full course of treatment.

The priority challenges of MDR-TB are:

- absence of rapid and point of care diagnostic tools
- long course and complicated treatment
- system for the delivery of care
- infection control
- financial and cultural barriers
- access to services

Diagnosis

MDR-TB can only be diagnosed in a well-equipped, specialized laboratory. The widely-used method for diagnosing MDR-TB consists of growing TB bacteria in a specialized medium and in the presence of drugs for which resistance is being evaluated. Although there are more accurate, rapid and sophisticated methods, many laboratories worldwide do not yet have up-to-date techniques for the diagnosis of TB and for identification of drug resistance. With conventional drug susceptibility testing (DST) of cultured mycobacteria, results are typically available between one and three months later, which is too long to wait to begin treatment. Only molecular tests can detect resistance fast enough. Two advanced technologies – line probe assay (LPA) and Xpert MTB/RIF – are currently recommended for use by WHO, but are still relatively expensive. The LPA still requires laboratories with appropriate infrastructure and staff with specific skills.
Treatment

When MDR-TB patients are treated with second-line drugs, the likelihood of success is much smaller than in patients with drug-susceptible TB. Cure depends on the extent of the drug resistance, the severity of the disease and whether the patient’s immune system is compromised. Patients infected with HIV, for example, may have a higher mortality. Early and accurate diagnosis is important so that effective treatment may be provided as soon as possible. Effective treatment requires that high-quality second-line drugs are available, and that adequate training is provided to health professionals to administer the drugs. The second-line drugs used for the treatment of MDR-TB are often associated with severe side effects that can negatively affect patient adherence to treatment. Non-adherence results in low treatment success. Therefore medicines to minimize those side effects are extremely important and should be available, and in addition, patient support mechanisms must be in place, including psychosocial support and treatment adherence control.

System for delivery of care

Hospitals and clinicians in medical institutions play a critical role in MDR-TB control and provide multiple services that are instrumental to the diagnosis, treatment and control of TB infection and disease. However, the management of MDR-TB is a complex undertaking and requires the collaborative efforts of a broad range of individuals and organizations, both inside and outside the public health sector, particularly working at community level. These various persons and organizations have a role in improving the detection of TB cases, supporting treatment adherence, and in increasing community knowledge about TB transmission, infection control and hygiene. A coordinated system that clarifies roles and responsibilities for all the different actors involved in clinic and home-based care and support to MDR-TB patients is required.

Infection control

Because transmission of TB may not be immediately apparent, particularly at community level, TB infection control measures are critically important, especially in areas of high HIV prevalence. Most TB infection control efforts in high burden countries to date, however, have been limited to health care facilities and some congregate settings, such as prisons. Resources, such as respiratory protective equipment, are limited to help community health workers (CHWs) avoid infection while working with the communities they serve. The challenge is to improve resources and give adequate training so that infection control measures can be widely introduced.

MDR-TB management costs

In MDR-TB high burden countries, the costs associated with detection, treatment and psychosocial support are high. In many cases, systems are not in place to minimize the financial load by task-sharing with the “normal” TB programme. In no case should the costs be passed on directly to the patient. Persons with MDR-TB and those at high risk for MDR-TB should have equal access to support, treatment and clinical services, without taking into account their ability to pay.
Access to services

National TB programmes should ensure that patients with suspected or confirmed TB disease have ready access to diagnostic and treatment services that meet international standards. These services are often provided by state and/or locally supported TB specialist clinics and staffed by health department personnel or by contracted service providers. However, persons may seek medical care for TB infection or disease in the private medical sector. Regardless of where a person receives medical care, the primary responsibility for ensuring the quality and completeness of all TB-related services rests with state and local public health agencies. To ensure that standards of care are met, national TB programmes should develop and maintain close working relationships with all stakeholders and civil society and community-based partners. Special efforts to facilitate access to diagnosis and treatment need to be directed to those at high risk for both TB and non-adherence to therapy, such as persons who are homeless, mobile migrant populations, ex-prisoners and persons with substance abuse problems.
Programmatic issues: cornerstones

a) **Planning and coordination**

**Key elements**

The clinical situation for patients suffering from MDR-TB is complex and can be demoralizing for those who were treated for TB in the past. These patients must be treated for close to two years with second-line drugs that are generally toxic and therefore associated with severe side effects. For this reason, in addition to medical treatment, MDR-TB patients need psychosocial support during the course of their treatment.

The medical and psychosocial support of MDR-TB patients during the course of their treatment may require a high number of staff, both health workers and volunteers. The support must be carefully planned so that the labour-intensive workload does not have an impact on other programmes, specifically the programme for the management of drug-susceptible TB. Task-sharing with “normal” TB support should help to protect the whole TB programme.

The national TB control programme is the central coordinating body responsible for all TB care in each country. Given the complexity of managing MDR-TB, the national TB programme might consider building partnerships with other relevant health providers such as community-based and non-governmental organizations. The involvement of partner organizations in the programmatic management of MDR-TB will require careful planning and coordination. The national TB programme should play a key role in ensuring good coordination with and among partner organizations to guarantee their successful contribution to the management of MDR-TB patients.

Planning should be based on an understanding of local epidemiological data and on the capabilities and capacities of clinical and support services for patients. Fiscal resources available for TB control also determine the plan’s scope and direction. Policies and procedures should reflect national, state and local standards of care and should offer guidance in the management of TB and MDR-TB.

Coordinating care with other health-care providers and facilities is crucial to the prevention and control of TB. TB patients often receive care in a variety of settings, including:

- private practices
- hospitals
- HIV clinics
• community clinics
• correctional facilities
• nursing homes

To ensure that standards of care are met, national TB programmes should develop and maintain close working relationships with all actors. Treatment plans must be specific to individual patient needs. As patients move among the different settings, continuity of care may be compromised unless a system is in place to provide coordination of care.

Laboratory services should also be readily accessible to perform and provide results. TB prevention and control programmes should work closely with laboratories to ensure the rapid delivery of specimens to the laboratory and prompt reporting of smear results. Services should also be available to provide monitoring of bacteriologic response to therapy.

TB control programmes should provide education and training in the clinical and public health aspects of TB to all programme staff. Staff members should receive education at regular intervals on their particular responsibilities in the programme and should demonstrate proficiency in those areas. Based on the local epidemiology and needs, TB programmes should also educate health-care providers (both public and private), community members, public health officials and policy makers on TB prevention and control.

Planning will also include setting clear mechanisms for monitoring and evaluating activities and implementing a system for gathering and providing results and feedback from and to the partner organizations.

Lessons learnt

• MDR-TB control programmes should be tailored to fit the local infrastructure of the health system. The precise organizational structure of the programme may vary greatly between different settings depending on how local health care is provided. Transfer from hospitals to outpatient settings or between DOTS centres requires care, advance planning and good communication. Given the type of care required during the treatment of drug-resistant TB, a team of health workers including physicians, nurses and social workers is often used.
• In some countries, private practitioners manage most cases of drug-resistant TB. In these settings, it is important to involve the private sector in the design and technical aspects of the programme. Many public private mix (PPM) programmes have demonstrated effective and mutually beneficial cooperation. In PPM systems, patients and information move in both directions. For example, private providers can be compensated fairly through negotiated systems of reimbursement, and the public health system may provide clinic- or community-based DOTS as well as registering patients and their treatment outcomes.
• Project frameworks should be developed in each country for each programme. Rapid needs assessments should be conducted and monitoring and evaluation tools outlined with a special focus on vulnerable groups. Consistent programmes provide better results, better organization of partnerships and enhance accountability, all helping to facilitate external fund-raising. Human resource planning should be done together with the health ministry. This includes education and training programmes with the objective of building effective teams so that all staff and volunteers have the appropriate level of competence to care for MDR-TB (see section (e) Community empowerment, educa-
tion and training, and infection control). Stakeholder analysis, mapping competencies and possible fields of action, is a useful tool to achieve consensus in terms of roles and responsibilities.

- It is strongly recommended to seek international technical support through WHO and other technical agencies. The national TB control programme, in conjunction with other partners, should provide guidelines for the programmatic management of drug-resistant TB, following the WHO model.

What Red Cross Red Crescent National Societies can do

As a partner organization to the national TB programme, and in order to ensure a coordinated effort, National Societies should have representatives on existing multisectoral coordination bodies at local and national levels.

National Societies should find out about existing TB control programmes, such as global initiatives and national programmes in order to learn from them. Sharing information with relevant programmes helps reduce duplication of effort. Initiation of, and participation in research specifically related to TB case-finding, screening, access to diagnosis, treatment access and delivery, interactions between TB and HIV control programmes and infection control will be of benefit to the MDR-TB control programme.

To ensure accountability and a clear definition of roles and responsibilities in support of national TB objectives related to MDR-TB, a formal Memorandum of Understanding between the National Society and the Ministry of Health (MoH) should be signed. Clinical supervision must be guaranteed and terms of reference, roles and responsibilities established for health workers, Red Cross Red Crescent volunteers, social activists, etc.

Red Cross and Red Crescent National Societies are in a privileged position by their fundamental principles, in particular humanity, impartiality, neutrality and independence, to engage even with weaker governments to build new alliances and if necessary to bring in new partners for improving programmes in a sustainable way.

Commitment of the necessary resources, particularly for a strong central management team within the National Society, ensures that all elements are in place, from the procurement of second-line drugs to the appropriate implementation and monitoring of the MDR-TB control programme.

Before starting MDR-TB activities, National Societies need to be assured that all elements of MDR-TB control are in place: availability of high quality TB diagnostic services, long-term procurement of second-line quality drugs as well as their storage and distribution systems, coordination with other actors in the same sphere under the leadership of the national TB programme, appropriate implementation and monitoring strategies and feedback to all stakeholders. If these elements are in place, Red Cross Red Crescent can ensure that patients have access to social benefits and care. These may include nutritional support such as food parcels or a daily meal, or advice about a balanced and nutritious diet.
b) **Timely identification of MDR-TB patients and the link with HIV**

**Key elements**

**Timely identification**

Timely identification of MDR-TB patients is one of the most critical factors in controlling the spread of the disease. Criteria for the identification of patients who are at high risk of having MDR-TB should be set up. These might include, for example, patients who have failed TB treatment, those who have contact with a known MDR-TB patient, and those who had contact with a patient who died during the course of TB treatment. As an example, under current South African policy, certain groups of patients are screened for drug resistance. They include TB patients who have received treatment previously, close contacts of confirmed MDR-TB patients, patients who have had a poor clinical response to TB treatment, and high risk groups, such as health care workers, miners and prisoners.

Once a presumptive MDR-TB patient is identified, a specimen needs to be collected and sent to the laboratory to confirm the diagnosis. The most widespread current method consists of growing TB bacilli in a tube from a specimen collected from the patient. It is important to obtain a good specimen and to have a laboratory that is adequately equipped and staffed. However, TB culture results can take up to three months. While new molecular screening tools have recently become available, producing results in less than a week, they are not yet

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**Figure 1:** Notified cases of MDR-TB (2007-2009) and projected numbers of patients to be enrolled on treatment (2010-2011) in the 149 countries included in the Global Plan (grey), and targets included in the Global Plan (2011-2015) (blue).

Numbers are for smear and/or culture-positive cases of MDR-TB.
widely available, and are expensive, in general requiring infrastructure investment and staff training. GeneXpert is one of the new TB diagnosis tools that can produce results in around two hours.

Health access barriers, such as lack of knowledge and awareness, stigma, economic constraints, work obligations or restricted clinic hours often result in tardy diagnosis of TB and MDR-TB. Tackling these barriers should be an element in the national TB programme policy.

**Links with HIV**

People living with HIV (PLHIV) are at higher risk of developing TB than HIV-uninfected individuals, and timely diagnosis is vital. The medical treatment of MDR-TB in the HIV-infected patient is often more complex because of the number of drugs that must be taken, and the potential of an interaction between TB and HIV drugs that can exacerbate adverse effects, in terms of frequency and severity.

The diagnosis of TB in HIV-positive people might be difficult, particularly in HIV-infected individuals whose immune system may be compromised, as they tend to present symptoms that are not typical of tuberculosis. The presentation of TB and MDR-TB is more likely to be extra-pulmonary or sputum smear-negative than in HIV-uninfected TB patients. This can result in misdiagnosis or delays in diagnosis and, in turn, higher morbidity and mortality rates. The use of new molecular TB diagnosis tools improves the ability to diagnose TB in HIV patients in time and is recommended where available.

**Lessons learnt**

- Prevention of MDR-TB starts with the early identification of individuals who are more likely to have MDR-TB, and confirmation of the diagnosis with the results from submission of a specimen to a laboratory. Failure of care for MDR-TB can lead to the generation of further or highly resistant strains of Mycobacterium tuberculosis with the risk of spread in the community.
- An analysis of barriers to early diagnosis and start of treatment should be made in order to prioritize problems and permit intervention. Standard operating procedures for identification of MDR-TB should be developed by national TB programmes. All partners in the TB programme should be well informed on the risk factors for drug-resistant TB, and should target key population groups for drug susceptibility testing as well as manage standard recording and referral mechanisms as approved by national TB programmes.
- In line with national policy, rapid diagnostic techniques for MDR-TB should be employed when possible and appropriate.
- MDR-TB community awareness should be expanded through education and communication campaigns, demonstrating its consequence not only for the individual patient but for the community as a whole. This should be carried out in a way that strictly respects the rights of patients in order to avoid stigma and discrimination.
- In areas where MDR-TB is known to be a problem in HIV-positive patients, and where resources permit, all PLHIV with TB should be tested for MDR-TB in line with the national TB and HIV integrated strategy.
- Experience shows that linking HIV and TB programmes helps to refer patients rapidly to the specific care team, i.e. to introduce antiretroviral therapy (ART) promptly in MDR-TB/HIV patients. The linking of HIV programmes with MDR-TB programmes provides better coordination in support activities devoted to both health conditions.
What Red Cross Red Crescent National Societies can do

Activities designed to promote timely diagnosis and immediate treatment of MDR-TB should be a regular feature of the TB programmes of National Societies. National Societies should provide extensive health education, and strengthen social mobilization, communication and referral systems to provide timely diagnosis of new MDR-TB cases. Programmes should aim at high treatment adherence and low default rates.

Case study: The South African Red Cross Society raising awareness of TB and MDR-TB

The South African Red Cross Society conducts an integrated programme of community education and participation to achieve improved case detection. Building on its experience with HIV and in partnership with the national TB programme (NTP), the South African Red Cross Society decided to expand and address specific barriers to MDR-TB care-seeking by focusing on vulnerable populations, such as the most affected urban poor and PLHIV.

The initial step was to negotiate the programme with local TB services in Cape Town City Department that had several years of implementation experience, as well as the management and technical assistance capacity needed to oversee the efforts of smaller, less experienced community associations.

The programme promoted the participation of traditional healers, home-care providers and community leaders, seeking to utilize their links in the community to encourage referral of suspects and to promote better awareness of TB within their networks.

The project conducted training sessions and refresher training on technical aspects of TB for the volunteer community care providers. Other training topics included Information Education and Communication (IEC) and Behaviour Change Communication (BCC), effective techniques for collaborating with healthcare workers in the delivery of community-based TB services.

Once trained, the programme staff and volunteers were able to implement BCC activities. One of the most important interventions was a series of TB sensitization activities that, while applicable to the entire population, was particularly targeted at vulnerable populations such as PLHIV and urban poor.

South African Red Cross implements TB and MDR-TB awareness by using two types of intervention in the communities. The first is through door-to-door and public awareness campaigns where the care workers visit homes in teams, talk to family members, hold open door campaigns at clinics or public places and distribute pamphlets as a means of raising awareness. They also provide voluntary counselling and testing for the community, facilitating the referral of suspected cases to TB clinics.

The second intervention is through community training where care providers spend more time educating community leaders such as traditional healers, teachers, religious leaders, councillors and street committees. Care workers report spending at least four to five hours per session to ensure a proper understanding of MDR-TB is acquired. A combination of all these activities helps to send many more MDR-TB suspects to diagnostic centres for sputum testing.
Red Cross and Red Crescent community care facilitators should be involved in the case-finding/case detection mechanisms of national/local TB programmes. Case-finding is easily integrated into community-based activities and should target high-risk and hard-to-reach populations. House-to-house surveys, contact tracing and enlistment of other community referral resources (soup kitchens or comedores, schools, religious organizations, health NGOs, institutions where people congregate and private practitioners) are some of the strategies employed to detect those patients that would otherwise elude identification.

In close collaboration with the national TB programme, and in line with its policy and priorities, National Societies should advocate to promote the widespread use of new diagnostic tools, taking into consideration their availability and patients’ access to MDR-TB treatment.

Red Cross Red Crescent and other partners should work with the national TB programme to include testing for MDR-TB for all PLHIV with TB. Through the fundamental principles Red Cross Red Crescent National Societies are in a good position to advocate for routine HIV testing for all patients suffering from TB and for routine TB and MDR-TB testing for PLHIV.

HIV patients are at risk for stigma and discrimination. The broad horizontal approach of National Societies in promoting the fundamental principles helps to improve community awareness and health education of the crucial aspect of the dignity of the concerned persons and their families.

National Societies, in their HIV counselling and testing activities, can integrate information on TB and MDR-TB.

c) Accessing “hard-to-reach” populations

Key elements

TB and MDR-TB affects disproportionately the most vulnerable groups of society. The factors that cause these groups to be vulnerable are also those that make them harder to reach through traditional TB services, as well as making them less likely to adhere to treatment once they are reached.

Tackling the MDR-TB situation in vulnerable populations must be a key element in any comprehensive strategy to reduce and eventually eliminate MDR-TB. “Hard-to-find” and “hard-to-reach” populations belong often to the socio-economically disadvantaged groups where the issue of the right to health represents a major challenge to TB control efforts. Socially marginalized or excluded people form heterogeneous risk groups for MDR-TB: HIV-positive patients, detainees, single mothers, children and particularly orphans, illicit drug users and alcohol-addicted patients, homeless, patients with other chronic diseases and immigrants living in a precarious situation. Many of these may be considered hard-to-reach groups.

Hard-to-reach persons can find it difficult to recognize TB symptoms and access diagnostic and treatment services. They may also have problems in self-administering treatment, and attending regular appointments for clinical
follow-up. This can lead to incomplete treatment with the potential to develop MDR-TB. Very often they will consult traditional healers, using their often restricted financial resources, leaving none for a consultation with the formal medical services.

A good example of hard-to-reach populations can be found among ex-prisoners. Prisoners and people living in places of detention are exposed to high risk for TB and HIV. Multi-drug resistant TB is also more common in prison settings. In many cases TB and HIV are combined with drug addiction. Challenges in prisons include absence of rapid diagnosis, low implementation of isoniazid preventive therapy, absence of opioid substitution therapy, and high rates of loss to follow-up after release from prison, which is seen as a major contributor to poor treatment outcomes. The removal of passports as a result of imprisonment and the absence of a registered residency address upon release mean that ex-prisoners face difficulties to register for and continue TB or HIV treatment.

Lessons learnt

• MDR-TB cannot be controlled at population level without specific targeted efforts to tackle the disease among hard-to-reach groups. People at risk of TB and MDR-TB from hard-to-reach groups should be able to access services that allow timely diagnosis and effective treatment and that are tailored to their needs. This requires the national TB programme to oversee a strategy for the commissioning of TB prevention and control activities, including local needs assessment, multidisciplinary TB support, the provision of rapid access to TB services and raising and sustaining awareness of TB among hard-to-reach populations, health professionals and those working with hard-to-reach groups. It also requires the identification and managing of latent TB among substance misusers and prison populations and the identification of pulmonary TB among those accessing homeless or substance misuse services.

• TB services that are not geared towards the needs of urban hard-to-reach groups carry a future risk of higher rates of TB and drug-resistant strains, rendering the disease once again untreatable. Clear selection criteria are required for targeting the intervention to the most vulnerable who are at risk of default and those who stay out of health systems.

• Prompt and quality care should be tailored to the needs of most vulnerable populations in general and hard-to-reach populations in particular. This requires a sustained commitment of resources that reflects the complexity of delivering tailored interventions, such as outreach services for DOTS, over a long period of time. The better the outreach activities perform, the more the influx of MDR-TB patients will challenge the health system, firstly by an increased number of patients and secondly by the diversity of the background and/or the co-morbidity of those patients. This situation will require specific competences in the field of communication and relationship-building (i.e. with the homeless, illicit drug users and alcohol-addicted, HIV patients under ART treatment, etc.).

• Transmission in prisons is an important source of spread of drug-resistant TB in some countries, and infection control measures can reduce incidence substantially. In many cases, inmates are released from prison before they finish treatment. Close coordination and communication with the civilian TB control programme, advance planning, targeted social support and specific procedures for transferring care will help ensure that patients complete treatment after release from prison.

• Alliances with traditional healers can not only help to reach new patients but can also give credibility to treatment, motivating the patients to follow it.
What Red Cross Red Crescent National Societies can do

National Societies have a role in case finding. Proactive case finding can be carried out among hard-to-reach groups at the community level. For example, contact with homeless people can be made in places where they congregate, such as day centres, temporary shelters and hostels.

Those groups with the highest burden of disease are the same groups that have the poorest access to health services and are least likely to complete treatment. Red Cross Red Crescent volunteers can build relationships with these groups.

Case study: Working against stigma and discrimination. The story of Iqbal in India.

“We were strictly told not to interact with him much. We do not allow our small children near him and have given him a separate plate for food and his clothes are washed by himself. This disease cannot be cured and he is old and will not last for long” said a daughter-in-law of the big family. She also explained that they are worried that Iqbal may spread the disease to others in the family and so they largely confine him to the other end of the house.

The Red Cross volunteer along with the government TB officer visited Iqbal’s house after he had defaulted on treatment many times. Living in Sira Gate, a suburb with a high population of migrants and lower socio-economic groups, little or no infrastructure like roads, health centres or sanitation, this family considered TB as an irrevocable curse. Squabbles within the family for the ancestral house had only added to the stress which resulted in Iqbal being more neglected.

Repeated visits and discussions by Red Cross volunteers saw the family members slowly open up to them. Family members themselves were scared of the patient. When they realised the volunteers were working towards the family’s good, they were open to listen to them. With support from the local health workers (Anganwadi worker, Accredited Social Health Activist (ASHA)), the Red Cross volunteers patiently discussed the disease, its treatment and the possibility of Iqbal gaining back his health. They also explained the importance of adherence and completion of treatment without default for the complete eight months. Most important was the information-sharing on the danger of stopping the treatment midway leading to multi-drug resistant TB, which is more complex to treat. While the family knew that the treatment is free of cost, they came to know it is very effective too.

The family finally agreed to send him for treatment. Iqbal started attending the Primary Health centre for treatment, escorted by the Red Cross volunteers. After the intense course was over, the local ASHA worker took over as the DOTS provider. The family is now aware of locally available nutritious food, thanks to the counselling by the Red Cross volunteers. They also understand about preventing the spread of respiratory infections by following proper respiratory etiquette, like covering the mouth and nose while coughing, etc.

Iqbal, 60, completed his treatment in November 2010 and is now declared free of the disease. He profusely thanks and admires the commitment of the Red Cross in sending different staff and volunteers to motivate him and his family, all so that he could be cured. He actively spreads the word of TB treatment and is happy that his family also is relieved and better informed now.
and can accompany patients to health facilities to promote confidence in the health service. Personalized relationships will as well raise the awareness of those patients and motivate them to learn more about their disease and eventually become active in a self-help group to be provided with even more support. Community-based social support coordinated with TB clinical services includes directly observing every dose of treatment and providing practical help with housing, addiction and other unmet health and social care problems.

When treatments start, Red Cross Red Crescent volunteers can implement DOTS strategies to ensure optimal adherence and follow-up for the patient. At the same time, the family becomes a focus of interest through psychosocial support, health education to prevent the spread of MDR-TB within the family, and if necessary supplies of food or even financial incentives to help maintain the cohesion of the family.

For ex-prisoners, Red Cross and Red Crescent can provide psychosocial support, incentives and a DOTS supporter nurse or volunteers to encourage them to keep in touch with the health system on release from prison. This should help reduce default from treatment and loss to follow-up. Prisoners should obtain care equivalent to that provided for the civilian population, and care should be continuous on transfer in and out of places of detention.

Red Cross Red Crescent will always address strong non-discrimination and no stigma messages as a crosscutting component of each MDR-TB programme. Through advocacy, National Societies can promote the rights of all MDR-TB patients and advocate for the strengthening of the health system so that treatment is accessible to all.

d) Treatment adherence support

Key elements

The relative complexity of MDR-TB care makes it more likely that there will be treatment adherence problems. MDR-TB is characterized by:

- a long period of treatment with many medicines and daily injections
- more expense for the family in sites or places where hospitalization is required, as family members have to stay with the patient. In addition to out of pocket expenses, there are indirect costs linked to the lack of productivity and/or loss of income during this period
- more clinical symptoms because of more frequent and severe side-effects
- more risk of stigma and discrimination because of the long treatment process

Because most of the MDR-TB patients would have been treated in the past for TB, it is likely that poor adherence might have been the reason for the development of MDR-TB in these patients.

Therefore, adherence is an essential element to prevent the generation of even more difficult forms of resistant TB, and programmes that support adherence are vital. The scientific literature documents how adherence interventions among people with MDR-TB can result in treatment completion rates as high as those for people with drug-susceptible TB.

Key to adherence success is the understanding by the patient of his/her condition and an agreement to partner the health care worker throughout the course
of his/her treatment. Good communication between care provider and patient is the first step in the partnership. Adherence improves when the patient can take an active role in stabilizing or recovering from the health problem. The health staff must take a bio-psycho-social approach that gives thought to the patient’s point of view, his or her beliefs and health concept.

Case study: Kazakh Red Crescent Society. Improving adherence through training and social support networking

The MDR-TB community project began in 2008, as a partnership between Kazakh Red Crescent Society, IFRC and USAID. The programme is closely coordinated with the National TB Programme (NTP) and is implemented in two cities, Almaty and Kyzylorda.

The project involved intensive training and engagement of community nurses both to work directly in the community to provide TB services, and to build communication skills and social support networks for patients and families.

Following training, the team of Kazakh Red Crescent Society nurses conducted a mapping exercise of all the homes and families of patients by means of a list provided by the NTP. They visited all houses to determine health risk factors, such as the level of access to clean water and sanitation. The exercise also identified the most vulnerable socio-economic groups according to determined criteria (e.g. those suffering from extreme poverty, unemployment or from drug and alcohol abuse), and indicated TB suspects and patients.

The next step was to set up a social support network, mapping all the local civil society organizations, schools, community leaders and commercial enterprises that could provide any type of support to the population. The Kazakh Red Crescent team visited these potential network partners, explaining their project and establishing partnerships for eventual support for TB patients and their families. This has resulted in a new sense of community ownership and commitment toward patient support, manifested in the introduction of such services as transport to the TB dispensary and the donation of food parcels and hygiene kits.

Nurses provide a comprehensive package of community services under the leadership of the two team leaders. Their main tasks include:

- contact tracing within households and peer communities (e.g. friends, work, school, etc.)
- follow-up with patients to ensure that they go to their monthly medical check at the TB dispensaries, with organization of transport, if needed
- daily visits to TB clinics to collect medicines
- provision of DOTS at the homes of patients
- updating patient treatment cards
- additional care as needed (e.g. food, treatment for side effects, socio-emotional support, with special efforts made in the case of patients suffering from alcohol and drug problems) to ensure treatment adherence

The nurses maintain the registers and forward data to the TB clinics. They also undertake a wide range of health education activities in the neighbourhood, schools, religious institutions and community organizations, in addition to distributing informational pamphlets and promotional materials.
Lessons learnt

- Adherence to treatment is a vital element in the fight against TB and even more difficult forms of drug-resistant TB. Programmes that support treatment adherence are therefore essential. Having MDR-TB is an emotionally devastating experience for patients and their families. In many cases, it is linked to socio-economic problems, which need to be recognized.

- The monitoring of adherence (through daily home visits, accompanying patients to clinics, telephone calls or text reminders), using simple procedures and clearly defined indicators, allows for the compilation of results coming from different care teams of a given area. Feedback should guide the continuing medical training of volunteers and health staff to focus on good working practices and to improve failing activities.

What Red Cross Red Crescent National Societies can do

Red Cross Red Crescent care facilitators should be well informed about models of treatment delivery services by national programmes, whether clinic-based or community-based. If the MDR-TB treatment is home-based, the work of Red Cross Red Crescent care facilitators must be closely linked with a multidisciplinary team of physician, nurse and social worker. All patients under Red Cross Red Crescent support and their families should receive education about MDR-TB, its treatment, potential adverse drug effects and the need for adherence to therapy. Because MDR-TB treatment could be the last therapeutic option for many patients and because there is a serious public health consequence if therapy fails on a patient with MDR-TB, all Red Cross Red Crescent patients with MDR-TB must receive directly observed treatment (DOTS).

It is recommended that Red Cross Red Crescent programmes should include strong social, nutritional and psychological support elements. These support elements have been shown to be important catalysts to improve adherence.

The systematic monitoring of adherence should be carried out by those undertaking daily home visits, accompanying patients to clinics or reminding of clinic appointments through telephone calls or text messages. Red Cross Red Crescent volunteers who undertake these tasks should be trained to provide systematic feedback against clearly defined indicators. A system to collect and analyse the results of the feedback should be in place within the TB programme of the National Society, and, if necessary, action taken to improve failing activities. Feedback should also be supplied to the national TB programme and other partners.
e) Community and patient empowerment, education and training, and infection control

Key elements

**Community and patient empowerment**

Empowerment means having sufficient physical and financial resources (material empowerment), control (psychosocial empowerment) and voice (political empowerment) to have the freedom to live healthy lives. One component of material empowerment related to health services can be achieved by the promotion of basic health insurances shared by community members. Other interventions could seek for income generation activities. Active involvement of the community through social events, such as theatre, music, storytelling, drawing, food and drink creates psychosocial empowerment. Participation in programme planning, implementation and monitoring is a way to promote political empowerment and to contribute to better governance, even in relatively unstable political situations. Through a diversity of community interventions, different members of the community can engage, find a role and recognition.

The Patients’ Charter for Tuberculosis Care practises the principle of Greater Involvement of People with Tuberculosis (GIPT). The empowerment of people with the disease encourages effective collaboration with health providers and authorities and is essential in the fight to stop tuberculosis and to raise the standard of care. The Charter, which is a tool for the entire tuberculosis community, provides a “patient-powered” standard for care.

Patients’ rights include:

- care (access to quality care, education and prevention measures)
- dignity (the right to be treated with respect and dignity, without stigma, prejudice or discrimination by health providers and authorities)
- information (on the disease, the dosage of medicaments and the sharing of experiences with peers)
- choice (for a second medical opinion, to participate or not in research)
- confidentiality (by all involved health staff)
- justice (right to complain)
- organization (right to join self-help organizations, NGOs, and to participate as a “stakeholder”)
- security (of work, nutritional security and food supplements if needed)

Patients’ responsibilities include the sharing of information (with health staff), adherence to the treatment, a contribution to community health and a demonstration of solidarity.

**Education and training**

In community-based MDR-TB programmes staff and volunteers play a significant role in determining the best way of supporting and communicating with the patient for the most effective results. Appropriately trained staff and volunteers determine the success of any project.
Education and training are essential for sustainable control programmes and for empowering community and patients. Training should be directed not only to healthcare providers but also to decision-makers, especially those who influence health education curricula. Education and training are also important for community members, household contacts and patients, the latter to ensure that they understand their role in the partnership between them and the health care provider to improve treatment adherence. Training is also necessary if former patients are used as an additional resource to support other patients throughout their treatment.

National TB Programmes, WHO, as well as many international and national TB organizations have in many countries produced TB and HIV training materials. They include trainings at primary health care and community levels. All training initiatives, however, need to be well planned and coordinated.

Many health workers have not in the past received training in the field of communication and medical relationship-building. As a consequence, care providers fear to address psychosocial issues, feeling uncomfortable with sharing the emotions of their patients. Short training, however, is beginning to improve the situation and trainees are rewarded when they apply what they have learnt to their daily work.

Infection control measures

Education and training are also key to the introduction and maintenance of infection control measures. MDR-TB is transmitted in the same way as drug-susceptible TB. Well-documented outbreaks of highly drug-resistant TB constitute convincing evidence that MDR-TB is transmissible, especially among vulnerable populations. Therefore, it is very important to ensure that there are clear human resources and infection control policies for all staff and volunteers involved in MDR-TB programming, and that all actors receive education and training, as well as adequate resources, on infection control measures.

TB infection control measures at the community level are critically important, particularly in areas of high HIV prevalence. Most efforts to date, however, have focused on larger healthcare settings and facilities, neglecting community settings. As a result of this neglect, there are limited resources available to help community workers and volunteers avoid becoming infected themselves while working with the communities they serve. Again, education and training given to community members on the importance of the infection control policy in community settings is a vital element to ensure that measures are put in place and maintained.

Lessons learnt

- Community participation will increase the sustainability of the project: the greater the participation, the greater the sustainability.
- Community involvement and communication with community leaders can greatly facilitate implementation of treatment and respond to needs that cannot be met by medical services alone. Community education, involvement and organization around TB issues can encourage a feeling of community ownership of control programmes and reduce stigma. In some circumstances, communities have helped to address the interim needs of patients, including the provision of DOTS, food and/or housing.
- Health education sessions need careful preparation to customize the message to the audience and to create a symbolic sense by the event in itself demonstrating solidarity, non-discrimination and the potential for an active contribution to health for all.
• For an effective response to TB, it is crucial that patients, caregivers, social and health institutions work together at all levels. The acceptability and feasibility of the diverse support interventions should be checked to avoid collateral damage to the patient and or the community.

• Each organization must be aware of all the other organizations’ specific contributions. Just as important is the patient’s voice. Participation and a voice in their own care by all patients are factors that are being increasingly emphasized.

• Standard training in community MDR-TB should include:
  • case detection (analysis of the barriers to diagnosis, techniques, international detection goals)
  • effective communication skills with patients to motivate them for diagnosis, to support treatment adherence and to give psychosocial support to them and their families
  • preventive strategies to limit the spread of MDR-TB, particularly among PLHIV
  • prevention and care for caregivers (family members, volunteers, and health care workers)
  • referral mechanisms to and between HIV and TB clinics
  • IEC on MDR-TB, TB and HIV to increase community awareness of both infections and their inter-relationship
  • infection control measures at household and community level
  • patient and community empowerment strategies and social mobilization approaches
  • rationale behind, and function of, monitoring and surveillance activities

• Before designing a new training curriculum, synergies within the health system should be sought, and whenever possible, shared. Training requires time and substantial financial resources, and sharing when possible is time and cost-effective.

• Before starting, the diversity of trainees and their backgrounds should be known. There will be different training needs to provide the necessary skills for all aspects of the programme, for example with case-finding and adherence support. Early analysis of what is required will help to customize the content and provide coherence between the different training tracks.

• Training sessions should follow modern pedagogical principles of adult learning, that is they should be learner-centred and objective-based with the active participation of the trainees through techniques such as role play, discussion and simulation. The older-style method of training, which is more teacher-centred, is less effective. The quality of training should be monitored by means of a final evaluation, or a simple end-test.

• Proper planning for training of trainers and refresher training should be in place as well as continuing medical education. Mentorship as a form of training should also be considered.

• Appropriate training contributes strongly to team-building and improves self-confidence in the field, which might be particularly relevant when other groups like the HIV programme staff or the social worker for marginalized patients is part of the MDR-TB team.

• After training, performance in the field should be monitored by direct supervision (through expert and/or peer-driven evaluation). Training should be closely linked with national policy, in order to make it sustainable. Building a curriculum on a solid recognized basis is recommended. The criteria for training should be clear in order that national training institutions can offer appropriate and standardized training. If the training can be accredited with a recognized academic qualification, it will achieve credibility.

• Information, education and communication (IEC) materials should be avail-
able within the community for use by care providers and volunteers. Training on their optimum use in communities is essential.

**What Red Cross Red Crescent National Societies can do**

The Red Cross Red Crescent, with its promotion of the dignity of the individual, has the necessary expertise to support the patient-centred approach within a community setting, and to empower patients. National Societies should always train volunteers and staff in the fundamental principles.

Red Cross Red Crescent local branches’ strengths are their close proximity to communities, their membership-based governance structures and their staff and volunteers who have been deliberately recruited from the local community. These factors create an environment whereby the community is empowered to take part in planning and decision-making.

Creating patient support groups can provide peer support for those affected and for their family members throughout the treatment process. Putting the focus on the patient also creates opportunities for tailored participatory health education or counselling sessions, with the content dictated by the TB patient’s specific needs.

Red Cross Red Crescent National Societies supply material empowerment by paying for the schooling of the patient’s children and for transport to the health

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**Case study:**

**Patients as experts in Kazakh Red Crescent Society**

The Kazakhstan project aimed to recruit community members and successfully-treated patients to become DOTS providers within hard-to-reach urban slum areas. The objective was to increase case detection, reduce social stigma and ensure minimum default on treatment. The intervention was complemented by communication activities to increase early case-finding. In total 17 ex-TB patients were involved in the programme as Red Crescent volunteers. They played an important role in reducing TB-related stigma, as their positive example can not only motivate TB suspects to seek diagnosis (in large part by showing that the disease need not be fatal), but can also encourage other former patients and community members to become DOTS providers and TB advocates themselves. Together with nurses and psychologists, ex-TB patients are a critical part of the multidisciplinary project team. Since the start of the programme in 2008, the team achieved a 90 per cent treatment completion rate among 201 MDR-TB patients. Ex-TB patients are also engaged in the referral for testing of people with TB signs. With their support, 55 new cases of TB were identified.

Encouraged and empowered, TB patients publicly shared their TB experiences through highly effective forums, conferences, media interviews, support group meetings and training workshops for health staff.

The project has also helped raise awareness of the disease. By making TB patients more effective ambassadors, they have made significant strides in helping TB patients to receive better treatment by health personnel, suspects to seek an early diagnosis and state government officials to dedicate more resources for TB control programmes.
centre. They may also return a patient to his or her job after treatment. The provision of food and second-hand clothes is another approach that empowers patients to undergo long-term treatment and aids faster recovery.

Further training and skills development of patients as advocates and their participation in programmes can reinforce the patient-powered approach to TB service delivery, specifically in MDR-TB diagnosis and access to treatment. This approach, which entails both the patient and provider recognizing their rights and duties, can be the catalyst for significant improvement in treatment adherence rates. Empowered patients, working in collaboration with their local TB programmes, have proved effective advocates for better access to quality DOTS. All Red Cross Red Crescent care facilitators involved in home-based care or outreach settings should be trained on detecting the signs and symptoms of TB (especially among PLHIV). Training should include the role of care facilitators in educating people about the importance of reporting symptoms or signs.

Human resource planning and development training should be part of MDR-TB programmes to ensure that Red Cross Red Crescent staff and volunteers who have contact with people with MDR-TB have an appropriate level of competence.

The conceptualization and planning of continuing medical training is time-intensive. Today, however, many National Societies take advantage of training provided by the IFRC, which encourages the sharing of good practice and experience.

Programme staff must be well aware of infection control policies introduced by national or local health authorities. Red Cross Red Crescent care facilitators who visit clients with MDR-TB should take precautions to protect themselves and client family members from exposure. They should introduce household environmental control activities: fresh air, open windows, fans etc. They should advise clients on cough etiquette, for example, to cover their mouth and nose with a tissue when coughing or sneezing. If care facilitators are involved in sputum collection, it should be performed outdoors, away from other persons, windows or ventilation intakes. Red Cross Red Crescent care facilitators should not perform any cough-inducing procedures on people with suspected or confirmed infectious TB disease inside their homes.

Red Cross Red Crescent care facilitators, especially those caring for PLHIV, should be offered TB testing.

f) Measuring health outcomes and providing evidence of impact of TB control programmes

Key elements

The target included in the Millennium Development Goals (MDGs) is that TB incidence should be falling by 2015. The Stop TB Partnership has set two additional targets, which are to halve rates of prevalence and mortality by 2015 compared with their levels in 1990. Mortality rates at global level fell by around 35 per cent between 1990 and 2009, and the target of a 50 per cent reduction by 2015 could be achieved if the current rate of decline is sustained.
Health outcomes

Health outcomes for people with MDR-TB can be much worse than those with drug-susceptible TB. Stigma against TB and MDR-TB, particularly among PLHIV, prisoners and drug users, contributes to poor outcomes, as it requires integrated interventions between TB, HIV and harm reduction services both in civil and prison health systems. As an example, the ex-prisoner who injects drugs, is living with HIV and infected with TB is more likely to be at risk of high stigma, exclusion of care and failing recovery.

TB and HIV services are often differently organized in many countries and are not as integrated as they could be. Better case detection, good adherence and treatment completion are imperative for MDR-TB programmes, and they can be achieved. Treatment programmes can help address the gap in health outcomes when organized properly.

Advocacy is needed for TB and MDR-TB to build the capacity of civil society, and to engage those decision-makers who have the power to influence change.

Measuring impact

The ability to present an intervention’s beneficial impact quantitatively and qualitatively is critical for communicating the project’s success, the further expansion of activities and the advocacy strategy. Anecdotal data alone are not enough to support the continuation or scaling up of activities within TB programmes; donors and national TB programme managers require evidence that the activities are making a difference in case detection and treatment outcomes.

In 2011, over 80,000 volunteers and staff from Red Cross Red Crescent National Societies provided daily care to 200,000 most vulnerable TB patients, many of whom were classed as hard-to-reach, or particularly vulnerable. Of the patients reached, 10,000 had MDR-TB and 40,000 were co-infected with HIV.

While the Red Cross Red Crescent approach is successful, it is still known that around 90 per cent of patients with MDR-TB are not being diagnosed and treated according to international guidelines; many HIV-positive TB cases do not know their HIV status. To date, it has not been possible to show an
association between HIV and MDR-TB at population level. However, new HIV infections are also on the rise in countries with higher proportions of multi-resistant TB cases. Based on current data, HIV-infected TB patients in Estonia, Latvia and the Republic of Moldova appear to be more at risk of harbouring MDR-TB strains\textsuperscript{13}.

One of the most significant indicators to measure the impact of a given MDR-TB programme, and one which countries should make their goal, is the testing of 100 per cent of previously treated TB (and not cured) patients for MDR-TB, as well as the testing of any new TB patients considered at high risk of having MDR-TB (estimated globally at around 20 per cent of all new TB patients).

**Case study: The story of Shabbir\textsuperscript{14} in India**

Maralur Dinne on the outskirts of Tumkur, a town with nearly 500,000 inhabitants, attracts migrants and students because of its location next to the highway and its cheaper accommodation. It is classified as an area “to be developed” and does not have proper drinking water or sewage connections. Diseases like tuberculosis, diarrhoea and even HIV infection are particularly common in the community, largely through lack of easy access to healthcare and poor educational opportunities.

Shabbir is a migrant who works at a different job each day in the local grain markets, or any job which comes his way. His wife wraps beedis (local tobacco wrapped in small dry leaves) to support their four children. They do not have steady employment or food security. Shabbir is also alcoholic and was diagnosed with tuberculosis after a series of fevers and a cough, when he lost on earnings.

He was put on treatment in the district TB centre, but it was difficult for him to travel to the hospital, pay his fares and still make a living. When he started feeling better after a couple of weeks, he decided to save on the fare and start working. Feeling better lasted only a couple of days and Shabbir was back to ill health and missing work. This further pushed him to alcohol and into a vicious cycle.

In April 2010, Radha, a Red Cross volunteer, approached his family through the district TB centre. She not only patiently learnt of the family and the problems caused by Shabbir’s ill health, but also gave more information on TB and explained the importance of adherence and completion of treatment without default for the complete eight months. She drew their attention to the danger of stopping the treatment midway, leading to MDR-TB, which is more difficult to treat and takes longer. Understanding the financial situation, she was able to motivate Shabbir and his family members to ensure he adheres and completes the treatment.

The volunteer also worked with the TB officers to change his treatment centre to a primary health centre nearer to his home for the initial intense course and eventually to the local ASHA as DOTS provider, practically next door. This vastly improved Shabbir’s mindset and adherence for the treatment. Radha has also been sharing information on using locally available nutritious food to improve the nutrition status of the patient and the family and on preventing the spread of respiratory infections by following proper respiratory etiquette like covering the mouth and nose while coughing, etc.

In his own words, Shabbir commented: “Just like any other disease, I thought I was cured when I started feeling well. When Radha told us that the germs are inside me and can be cured only after eight months’ treatment, I came to know why I was falling ill again and again.”

Shabbir has been sputum-negative in the last three follow-ups and has two weeks of treatment left. He is positive about completing and being cured of the dreaded TB. His family is now confident that they can look forward to a disease-free future.
Lessons learnt

- There is a need to improve structural mechanisms to maximize collaboration and coordination between different health sectors, civil and prison services, national TB control, HIV programmes and civil society.
- National health authorities should strengthen surveillance systems and implement joint recording and reporting formats so that progress in implementing integrated health activities can be adequately tracked, and action taken to improve if necessary.
- The horizontal approach to MDR-TB care is effective. Care should not evolve to a vertical programme which is top-down, rather than community or home-based. The rights and dignity of the patient are vital elements in TB control.
- Accurate and reliable data are the backbone of any health intervention, including MDR-TB programmes. Unfortunately, the availability of reliable data is limited. Collection and reporting of data, at least for the most important indicators, need to be improved.

What Red Cross Red Crescent National Societies can do

To improve health outcomes, Red Cross Red Crescent programmes should include activities that advocate for equal TB/MDR-TB/HIV services for all the civilian population, including those most at risk, and marginalized groups.

All Red Cross Red Crescent MDR-TB programmes should collaborate with key partners to ensure universal access to comprehensive TB and HIV prevention, treatment and care. Care should be provided in a holistic person-centred way that allows good access and adherence in one setting, if possible.

Red Cross Red Crescent activities are not "stand-alone" activities and are linked to identified gaps in case detection and treatment outcome targets. Programmes are expected to yield measurable changes in case detection indicators, such as the number of TB suspects presenting themselves at DOTS centres for further evaluation of symptoms.

It is critical to incorporate monitoring and evaluation fully into wider planning processes so that data collection needs, data sources and reporting methodologies are clearly articulated.

In most cases, Red Cross Red Crescent implementers have been able to carry out baseline knowledge, attitude and practice (KAP) surveys and focus group discussions to document TB information needs and related ideas and behaviours. However, in some cases, baseline KAPs have not been followed up with end-line surveys, making it difficult to credit changes definitively to the specific interventions. This shortcoming illustrates why it is essential, when implementing a baseline survey, to budget and plan for an end-line survey using the same population.
References and further reading


5. The seven Fundamental Principles of the International Red Cross Red Crescent Movement: humanity, impartiality, neutrality, independence, voluntary service, unity and universality. See below.


8. The updated version of the Global Plan, covering the years 2011-15, launched by the Stop TB Partnership in October 2010.

9. The patient’s name has been changed to protect confidentiality.

10. Anganwadi is a government sponsored childcare and mother-care centre in India.


14. The patient’s name has been changed to protect confidentiality.
Humanity The International Red Cross and Red Crescent Movement, born of a desire to bring assistance without discrimination to the wounded on the battlefield, endeavours, in its international and national capacity, to prevent and alleviate human suffering wherever it may be found. Its purpose is to protect life and health and to ensure respect for the human being. It promotes mutual understanding, friendship, cooperation and lasting peace amongst all peoples.

Impartiality It makes no discrimination as to nationality, race, religious beliefs, class or political opinions. It endeavours to relieve the suffering of individuals, being guided solely by their needs, and to give priority to the most urgent cases of distress.

Neutrality In order to enjoy the confidence of all, the Movement may not take sides in hostilities or engage at any time in controversies of a political, racial, religious or ideological nature.

Independence The Movement is independent. The National Societies, while auxiliaries in the humanitarian services of their governments and subject to the laws of their respective countries, must always maintain their autonomy so that they may be able at all times to act in accordance with the principles of the Movement.

Voluntary service It is a voluntary relief movement not prompted in any manner by desire for gain.

Unity There can be only one Red Cross or Red Crescent Society in any one country. It must be open to all. It must carry on its humanitarian work throughout its territory.

Universality The International Red Cross and Red Crescent Movement, in which all societies have equal status and share equal responsibilities and duties in helping each other, is worldwide.
For more information on this IFRC publication, please contact:

In Geneva
Lasha Gogudze
Senior Officer, Health Department
lasha.gogudze@ifrc.org

www.ifrc.org
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