

# From the ground up: Building a drug-resistant TB programme in Uganda



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# Executive summary

Uganda is one of the world's 22 high burden countries for tuberculosis (TB). Despite having a national treatment programme for drug-sensitive TB, there has been an emergence of drug-resistant strains of the disease, which are presenting a new and urgent threat to people's health. So far in Uganda, 226 cases of multidrug-resistant tuberculosis (MDR-TB) have been confirmed, spread across 40 districts, but the true figure is likely to be much higher.

Improvements in diagnostics in Uganda mean that drug-resistant tuberculosis (DR-TB) can now be diagnosed – but it can't yet be treated. As yet, there are no second-line TB drugs in the country. Until the government is able to offer treatment and care, people with drug-resistant TB will be left in limbo. Unless they can afford to leave the country and pay for treatment elsewhere, the most they can hope for is that the drugs become available in Uganda before their condition proves fatal. There is no data available for how many have already died.

The best way to stop the disease from spreading is to start patients on treatment early. Aware of the urgency of the problem, the Ugandan government is taking steps to start treating DR-TB. Funding for DR-TB drugs is on its way, the drug order has been placed, and the government is planning a 40-bed ward for DR-TB patients in Mulago hospital, in Kampala.

However, MSF's experience of treating DR-TB in Uganda strongly suggests that centralised care is not the answer. Many patients and their caregivers from rural districts will find it impossible to manage a lengthy stay in the capital, and default rates are likely to skyrocket.

MSF firmly believes that a feasible model of care already exists in the Ugandan context. Since 2009, MSF has been running a community-based and comprehensive TB treatment programme in Kitgum, in northern Uganda, hand in hand with the Ministry of Health.

The preliminary treatment outcomes of the DR-TB component in Kitgum have been promising: although the number of patients in the programme is small, since it began in 2009 there have been no defaulters, no treatment failures and no deaths. MSF puts the success down to the model of care they are using, which is comprehensive, decentralised, and community-based. In addition to the conventional components of care, two constituents have played a vital part: psychosocial counselling by trained counsellors to support patients through their treatment; and the use of village health teams, who are trained, supervised and rewarded for their work.

Community-based care has been shown to be safe, practical and extremely effective for DR-TB, leading to high adherence, close follow-up and encouraging outcomes. Patients treated within their communities benefit from the practical and emotional support of friends and family in coping with the side effects of the drugs and adhering to their treatment, while increased understanding of TB within communities leads to higher detection rates and reduced stigma associated with the disease. The model of care has proved to be feasible and widely accepted – by patients, local communities and healthcare staff alike.

**As the Ugandan government prepares to start treating people with DR-TB, MSF is convinced that its focus should be on providing comprehensive, decentralised and community-based care. In this report, MSF calls on all key stakeholders to assure quality rapid TB diagnosis, treatment and care, and argues that a scale-up of the decentralised and community-based approach, including access to second-line TB drugs at district level, is the most feasible method of averting the country's impending health crisis.**

## Médecins Sans Frontières

Médecins Sans Frontières (MSF), or Doctors without Borders, is an independent medical humanitarian organisation which delivers emergency aid in more than 65 countries around the world, to people affected by armed conflict, epidemics and natural and manmade disasters, as well as those excluded from healthcare. MSF's objective is to provide the best possible medical care, free of charge, to those in need, irrespective of their race, religion, ideology or politics.

MSF's international staff work hand in hand with locally recruited staff, often in close collaboration with local authorities and ministries of health. They operate on the injured, run vaccination campaigns, set up feeding programmes to combat malnutrition and offer psychological support to the traumatised, among other things. They also care for people living with HIV/AIDS, and treat people with diseases such as malaria, kala azar, sleeping sickness and tuberculosis (TB).

## MSF & Uganda

MSF has been providing medical and humanitarian assistance in Uganda since 1980, with programmes focusing on addressing high morbidity and mortality linked to people's poor access to healthcare. It has responded to outbreaks of disease, provided care to the victims of conflict, violence and neglect, and provided healthcare to refugees and internally displaced people. In addition, MSF has had programmes focusing on paediatrics, nutrition, sleeping sickness and reproductive health. Currently, MSF's medical programmes (run by its Dutch and French sections) focus on HIV/AIDS and sexual and gender-based violence, while the organisation also provides assistance to people suffering from the consequences of violence – including sexual violence – in the sub-regions of West Nile and Acholi.

MSF has a long history of responding to medical emergencies in Uganda, including epidemics of measles, malaria, cholera, meningitis and viral haemorrhagic fevers (Ebola, Marburg and yellow fever), and is equipped to react to emergencies such as natural disasters, the displacement of people from their homes and major influxes of trauma cases.

## MSF & TB

MSF has more than 25 years of experience treating TB, and currently runs TB treatment programmes in 43 countries around the world. It also treats patients with the most complicated drug-resistant forms of the disease, in contexts ranging from post-conflict environments to urban townships and remote rural populations. In 2010, MSF treated more than 22,865 patients for drug-sensitive TB, and 1,096 patients for drug-resistant TB.<sup>1</sup>

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- **MSF treats drug-sensitive tuberculosis in:** Armenia, Burkina Faso, Cambodia, China, Central African Republic, Democratic Republic of Congo, Ethiopia, Georgia, Guinea, India, Kenya, Kyrgyzstan, Liberia, Lesotho, Malawi, Mozambique, Myanmar, Russia, Sierra Leone, South Africa, South Sudan, Somalia, Swaziland, Uganda, Uzbekistan and Zimbabwe (as of January 2012)
- **MSF treats drug-resistant tuberculosis in:** Abkhazia, Armenia, Cambodia, Colombia, Democratic Republic of Congo, Georgia, India, Kenya, Kyrgyzstan, Myanmar, South Africa, South Sudan, Swaziland, Tajikistan, Uganda, Ukraine, Uzbekistan and Zimbabwe (as of January 2012)

# 1. Introduction

## 1.1 Tuberculosis

Tuberculosis, the infectious disease caused by the bacillus *Mycobacterium tuberculosis*, is the second leading cause of death from an infectious disease, after HIV/AIDS, with between 1.2 and 1.5 million deaths per year worldwide.<sup>2</sup> Although the absolute number of TB cases in 2010 has fallen since 2006,<sup>2</sup> these numbers remain well above the 1993 figures based on which the World Health Organization (WHO) declared TB a “global public health emergency”.

In 2010, globally there were 8.8 million cases of TB, including 1.1 million deaths from TB among HIV-negative people, and there were an additional 0.35 million deaths from people co-infected with HIV and TB.<sup>2</sup> Globally, about 13% of TB cases occur among people living with HIV, whereas in the African region the co-infection rates are 44% on average, and reach 80% in some countries.

Treatment for drug-sensitive tuberculosis (DS-TB) is effective in 90 to 100% of the patients who adhere to the six months of treatment, which today costs just US\$21<sup>3</sup> per patient. But despite the treatment being inexpensive, highly efficacious and widely available, in practice TB control

programmes seldom achieve these results, resulting in the disease remaining a major global health threat, and adding to the development of drug resistance.

## 1.2 Drug-resistant tuberculosis

In the vast majority of cases, drug-resistant tuberculosis (DR-TB) develops during the treatment of drug-sensitive TB: when patients fail to complete their full course of treatment; when healthcare workers provide the wrong treatment, the wrong dose, or the wrong length of time for taking the drugs; when the supply of drugs is interrupted; or when the drugs have expired or are of poor quality. DR-TB is of particular concern for people with weakened immune systems, such as people living with HIV/AIDS.

DR-TB drugs are more expensive, and the cost for each course of treatment is between US\$4,400 and US\$9,000 per patient for a standard 18-24 month treatment course for drugs procured through the Global Drug Facility/Green Light Committee.<sup>4</sup> For drugs purchased outside this mechanism, the prices may be even higher. Treatment for DR-TB is also

**Drug-sensitive tuberculosis (DS-TB)** is used to describe the most common form of TB, which can be treated with first-line TB drugs (isoniazid, rifampicin, ethambutol and pyrazinamide).

**Drug-resistant tuberculosis (DR-TB)** is used to describe all those strains of TB that show resistance to one or more of the common first-line drugs.

**Monodrug-resistant tuberculosis (mono DR-TB)** describes TB that is resistant to any one first-line drug.

**Multidrug-resistant tuberculosis (MDR-TB)** is defined as TB that is resistant to both isoniazid and rifampicin, the two most powerful first-line TB drugs.

**Polydrug-resistant tuberculosis (PDR-TB)** is defined as strains that are resistant to more than one first-line TB drug, but not to both isoniazid and rifampicin.

**Extensively drug-resistant tuberculosis (XDR-TB)** is defined as TB that is resistant to isoniazid and rifampicin, and also to second-line drugs, including at least one from the class of antibiotics known as fluoroquinolones, and at least one of the three injectable second-line drugs capreomycin, kanamycin and amikacin.

much more complex than for DS-TB, with patients having to take at least four second-line drugs once or twice a day for up to two years. This equates to at least ten tablets per day, many of which have serious side effects. For patients, adhering to the full course of treatment can be a major challenge.

### 1.3 STOP TB Strategy

In 2006, the WHO set ambitious targets for controlling and reducing the TB epidemic. The 'STOP TB Strategy' presented the model of delivery known as 'directly observed treatment short course' (DOTS) as key to successful TB outcomes.

The aims of the latest STOP TB Strategy for 2011-50 are: by 2015, to reduce TB prevalence and death rates by 50% compared to 1990; and, by 2050, to reduce the global incidence of active TB cases to less than one per one million people per year.

The other key components of the STOP TB Strategy address the challenges of drug-resistant TB and co-infection with HIV; the importance of engaging all care providers in TB care and control in order to strengthen health systems; the role of communities and people with TB; and the fundamental role of research and the development of new diagnostics, drugs and vaccines.

This report highlights MSF's experience of treating patients with TB through a comprehensive, decentralised and community-based model of care. MSF acknowledges that there are already good plans in place to address such elements as early access to rapid testing (including for HIV-positive patients), a proper drug supply for DOT, the integration of HIV and TB care, and paediatric TB care. However, MSF has chosen to discuss what is missing from those plans – specifically in terms of the value of psychosocial care, the use of incentives and enablers for patients and their families, and the effective use of village health teams within a community-based approach.

The report begins with a description of the TB situation in Uganda, and goes on to describe in detail MSF's experience of treating TB in the north of the country. There is a separate chapter dedicated to the role of village health teams. The feasibility of this model of care is discussed, followed by a summary of the model of care, and the challenges of implementing it successfully in Uganda. The report ends with a number of recommendations addressed to key stakeholders.

**Whilst plans are already in place in Uganda to address many of the elements of comprehensive TB care, MSF has chosen to focus on those elements that are notably absent from the plans. MSF hopes the experience shared here will prompt a more effective approach to TB care in general.**

## 2. TB & Uganda

Uganda is among the 22 countries with the highest TB burden in the world. The Ugandan Ministry of Health (MoH) estimates that there are 330 new cases for every 100,000 people, which – in a population of 33 million – equates to 108,900 new cases per year.<sup>a</sup> With just 45,546 cases notified in 2010, the case detection rate for all forms of TB is less than 50%.<sup>2</sup> While the incidence of TB appears to be decreasing overall,<sup>b</sup> Uganda's treatment success rates are lower than in other countries in the region.

Based on estimates and cases of MDR-TB notified in 2010, Uganda should be expected to have at least 870 new cases of MDR-TB per year.<sup>c</sup> However, only 93 confirmed cases were detected in 2010, of which 10 were started on treatment. A 2011 country-wide study<sup>5</sup> and the WHO<sup>2</sup> found multidrug-resistant rates of 1.4% and 1.1% amongst new TB cases and 12.1% and 12% amongst retreatment cases respectively. Since 2008, with the capacity to diagnose at national level, 226 MDR-TB cases have been confirmed,<sup>d</sup> spread across approximately 40 Ugandan districts, but it is not clear how many of these people are still alive. What is clear from MoH and WHO survey data is that drug-resistant TB is an emerging issue in Uganda that, if not appropriately addressed, is certain to grow in severity.

### 2.1 Drug-sensitive TB

The Ugandan government has a TB treatment programme for drug-sensitive TB.<sup>6</sup> Its National Tuberculosis and Leprosy Programme (NTLP) has adopted the WHO's six-pronged Stop TB strategy<sup>7</sup> for implementing TB control activities in Uganda, which is integrated into general health services at the district, sub-district and community levels, with the help of village health teams (VHTs). The main challenges include the often erratic

supply of drugs, a lack of human resources, low motivation among health staff, poor counselling by healthcare workers on the use of drugs, and the practical difficulties of implementing community-based DOTS through VHTs who receive no financial incentives or rewards for their work. Another major challenge, in a country with a high proportion of HIV-positive TB patients, is that Uganda has not yet implemented a six-month regimen (with rifampicin for the entire treatment duration) which is known to improve outcomes for patients co-infected with HIV.

### 2.2 TB & children

Curable TB kills at least 130,000 children each year worldwide,<sup>8</sup> with rising numbers of children who are infected with drug-resistant forms of TB. Uganda's neglect of paediatric TB is no different from other contexts. Insufficient attention to care, research and development has led to a lack of diagnostic methods adapted to children's needs and a lack of appropriate drug formulations for children. This in turn has led to under-diagnosis and under-treatment of children with TB. However, as paediatric TB is an indicator for the current control of TB in the general population, and also acts as a future reservoir for TB disease, any successful TB control programme should include a paediatric focus.<sup>9</sup>

### 2.3 HIV/TB co-infection

HIV and TB are closely linked and, in Uganda, one out of every two TB patients tested is HIV-positive.<sup>e</sup> HIV infection is the main driving force of the TB epidemic and strongly influences the clinical aspects of TB. Cases tend to be less typical, with many extrapulmonary forms as well as less clear pulmonary forms. This poses critical problems for prompt and accurate diagnosis.

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a A disparity exists between MoH and WHO estimates. According to the WHO, the incidence of TB in Uganda is 209/100,000 population (range 168-254/100,000) and the prevalence is 193/100,000 population (range 95-306/100,000). These figures include HIV co-infection (Global TB Control Report 2011).

b Confirmation of the decrease is expected with the results of a national TB survey, planned for 2012.

c Estimates by Ugandan Ministry of Health and WHO. These numbers include both new and retreatment cases.

d Number of cases detected between 2008 and Oct 2011.

e In 2010, 54% of tested TB patients in Uganda were HIV-positive.

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*The government supplies sometimes tend to be low, they can run out of stocks, they may not be consistent.*

**Village health team member**

*I attained MDR-TB because of no-good drugs and because of the unavailability of drugs. Sometimes I used to get drugs that were nearly expired or drugs that had already expired. Also, the nurses and the doctors in the government hospital were not always reliable: you would go there once in a while and you might not see any doctor, anyone to give you any treatment, and you would go away without getting any drugs.*

**DR-TB patient**

Uganda implemented the WHO guidelines for collaborative HIV and TB services in 2007, which has led to an improvement in HIV testing amongst TB patients and in providing co-trimoxazole preventive therapy (CPT) to HIV-positive people to protect them against opportunistic infections and decrease mortality.<sup>f</sup> However, fewer than a quarter of co-infected HIV/TB patients are being provided with antiretroviral (ARV) treatment as recommended in the WHO guidelines,<sup>g</sup> and implementing a six-month regimen containing rifampicin in the continuation phase (as per the WHO guidelines for HIV-positive patients) is not yet in place.

Other challenges that still need to be addressed include: providing an integrated package of care for HIV/TB patients; providing a single consultation to co-infected patients; and the use of isoniazid prophylaxis to HIV-positive patients to protect them from developing active TB.

Providing an integrated package of care would require HIV services to be decentralised to a level where there is access to TB care, which is not the case at present.

## 2.4 TB drugs

The implications of using sub-standard drugs in the treatment of TB – both for an individual, and for the public health of a community – can be disastrous. Patients may fail treatment and, if they do not die, their resistance pattern may be amplified, requiring more complex treatment, and risking transmitting resistant strains to others. Only quality assured drugs should be used. There are several internationally recognised mechanisms that evaluate TB drugs: WHO pre-qualification;<sup>10</sup> approval by stringent regulatory authorities;<sup>h</sup> and evaluations by the Expert Review Panel of the Global Fund/Global Drug Facility.

The importance of a strengthened drug supply cannot be overstated. In a qualitative study<sup>11</sup> in 2011, both patients and health staff acknowledged the role of a regular supply of drugs in improving treatment success rates for DS-TB, in preventing future cases of MDR-TB, and in preventing the development of XDR-TB from MDR-TB treatment. They also acknowledged the need to strengthen health systems so as to avoid drug stock-outs and treatment interruptions.

## 2.5 Drug-resistant TB

Uganda already has the capacity to diagnose DR-TB, and is taking steps to improve it further by implementing the EXPAND-TB Project,<sup>i</sup> in collaboration with partners, with a focus on the four regions of Mable, Arua, Mbarara and Gulu. This will include the use of GeneXpert.<sup>j</sup> A sputum referral system, using Posta Uganda (the national mailing courier), is in place to transport sputum samples from all over the country to the National TB Reference Laboratory (NTRL) in Kampala,

<sup>f</sup> In 2010, 81% of TB patients in Uganda were tested for HIV, and 90% of HIV-positive people were started on CPT.

<sup>g</sup> In 2010, 24% of HIV-positive TB patients in Uganda were started on ARV treatment.

<sup>h</sup> The national drug regulatory authorities, which are members of the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH) are considered as Stringent Regulatory Authority (SRA), as per the Global Fund Quality Assurance Policy for Pharmaceutical Products from 1 July 2009. For further details and a list of countries which are members, observers or associates of the ICH, see [www.ich.org](http://www.ich.org).

<sup>i</sup> The EXPAND-TB (Expanding Access to New Diagnostics for TB) Project is a collaboration between the WHO, the Global Laboratory Initiative (GLI), the Foundation for Innovative New Diagnostics (FIND) and the Stop TB Partnership's Global Drug Facility (GDF).

<sup>j</sup> The GeneXpert is an innovative rapid PCR-based method that diagnoses TB and determines drug resistance for rifampicin with results available within as little as two hours.

which was nominated as a supranational reference laboratory by the WHO in August 2011.

By the end of 2010, Uganda had 2.9 smear laboratories per 100,000 population, 1.2 culture laboratories per five million population and 0.6 of both drug susceptibility testing (DST) and line probe assay laboratories per five million population. In addition, the WHO's policy guidance for the diagnosis of TB has begun to be rolled out.<sup>2</sup> However, fewer than 1% of the new cases and 9% of the retreatment cases notified in 2010 were tested for MDR-TB, which is far lower than those targets set out in the Global Plan to Stop TB, which aims for MDR-TB testing in 20% of new cases and 100% of retreatment cases.

Unfortunately, diagnosis on its own is not enough. Until the government is able to provide treatment, the situation for people with drug-resistant TB will remain desperate. MSF is the only organisation providing DR-TB care in Uganda, and the fortunate few who have been able to access treatment in the past two years mostly live in Kitgum and Lamwo districts, in northern Uganda, where MSF runs a comprehensive TB treatment programme in collaboration with the MoH. The remainder have no choice but to hope that treatment becomes available before they die of the disease.

## 2.6 Starting DR-TB treatment

Aware of the urgency of the problem, the government is taking steps to start DR-TB treatment and care. In 2011, guidelines on DR-TB<sup>12</sup> and infection control were published.<sup>13</sup> A national strategy to scale up is currently under development, while the need for leadership has been acknowledged and a national MDR-TB coordinator recruited. The Ministry of Health is in the process of rehabilitating a 40-bed isolation ward in Mulago hospital, Kampala, in anticipation of starting DR-TB patients on treatment.

The MoH's model of care, which is not yet finalised, proposes to start enrolling patients in Mulago hospital and then to decentralise the provision of care to four other regional sites (Mable, Arua, Mbarara and Gulu).

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*We had seven confirmed cases of DR-TB in our district – one of whom has died – but I believe there could be many more who are not yet diagnosed. And yet we cannot offer any assistance – it is very frustrating. The patients have no option but to stay at home with their families, and we know there is the possibility of them infecting others.*

**TB coordinator  
in a northern Ugandan district**

*There is nothing you can tell patients and their families – if you try to give them the real facts you will scare them even more. They think there is an end of the road, but the reality is that there is no option – if you get DR-TB you have to die.*

**TB coordinator  
in a northern Ugandan district**

## 2.7 The funding gap

While the intention to treat DR-TB is clear, the government lacks the drugs and has not yet developed the necessary infrastructure to do it well or comprehensively.

There has been no national allocation of funds for the procurement of DR-TB drugs, while a delay in the approval of Global Fund Round 6 Phase 2 has held up the process of starting the confirmed DR-TB patients on treatment. Fortunately, the Global Fund's approval has now been given, and the first drugs are expected to arrive in Uganda by June 2012.

However, the long-term outlook remains uncertain with the cancellation of Global Fund Round 11, which could have devastating consequences on the future of DR-TB treatment in Uganda.



**Okello Christopher** lives in Gulu district, in northern Uganda. His wife, Alanyo Joyce, was diagnosed with TB in 2006, soon after giving birth to their ninth child. Both mother and baby were treated for TB, but while the child recovered, Alanyo Joyce's condition got steadily worse. Finally, during her fifth course of treatment, Alanyo Joyce learnt that she had drug-resistant TB. With no treatment available in Gulu district, she died in October 2011.

Okello Christopher worries about his children having been exposed to DR-TB. "My 17-year-old daughter was in the hospital with me, helping to take care of her mother, and for a long time we were with the patient without any protection. Thankfully, none of my children have been diagnosed with TB, but every time one of them coughs, I worry."

Five years of caring for his wife have taken a heavy toll on Okello Christopher and the couple's children. "Since my wife got sick, our biggest problem has been not having enough food. As my wife's caretaker, I was away in hospital most of the time looking after her, so I couldn't organise the family to tend our crops. Since she fell ill five years ago, we've had very poor harvests. Most of our children have had to drop out of school because we had no money to pay for it."

His relatives and neighbours have done what they can to help. "At first, people were scared, but then the health centre gave a lot of information and health education, and today there's no stigma. People are supportive. They have bought me salt, brought food for the family and, when I planted cotton, the villagers came to help me harvest it. I feel bad saying it, but now my wife has died, at least I am able to get on with other things and look after my family."

## 3. MSF's experience of treating TB in northern Uganda

MSF started treating HIV and TB patients in northern Uganda in 2007, after years of providing emergency lifesaving assistance to people who had been displaced from their homes as a result of the war between the Ugandan government and the Lord's Resistance Army (LRA).

In 2007 MSF, in cooperation with the MoH, started the provision of HIV and TB care in Madi Opei health centre IV. The delivery of HIV and TB care was then extended to Kitgum Matidi health centre in 2009, while in 2011 TB care was delivered in 18 health facilities within the two districts of Kitgum and Lamwo. MSF's mobile TB teams visit the 18 health centres on a rota basis, carrying out consultations and providing training to MoH staff. MSF and the MoH jointly admitted 506 TB patients in 2011.\*

In 2008, the MoH in Kitgum was confronted with its first identified case of drug-resistant TB. In 2009, MSF started screening DR-TB patients. The first confirmed patient with multidrug-resistant TB had failed first-line treatment three times since 2007. The patient was initiated on DR-TB treatment by MSF in December 2009.

Since the start in 2009, MSF has successfully scaled up its programme for DR-TB, with positive preliminary outcomes. By the end of 2011, a small cohort of 17 patients was on treatment, with no defaulters or treatment failures reported. The first MDR-TB patient successfully completed the two-year course of treatment in December 2011.

MSF puts the success of the programme down to the treatment delivery model used, which is comprehensive, decentralised and community-based, and is adapted to suit the context. The emphasis has been on effective approaches to rapid quality diagnostic and treatment protocols, as well as on a tailored approach to how treatment is delivered. This includes two vital components (also supported by other health

partners): psychosocial counselling by trained counsellors to support patients through their treatment, and community support through trained village health teams (VHTs). All of the components of TB care within the approach are considered essential, and are discussed in detail below.

### 3.1 Case finding

Suspected TB cases are identified in the community by VHTs (see section 4). People are referred to the nearest health centre if they have had a cough for more than two weeks, or if they have been in close contact with a smear-positive TB patient. TB suspects are also identified by MoH or MSF health staff in outpatient and inpatient departments of health facilities, in HIV clinics and in the district TB wards.

Screening for DR-TB – by referring sputum samples for culture and DST – is carried out for patients who are failing first-line treatment, for retreatment cases, for close contacts of patients with DR-TB and for HIV patients suspected of TB. In Kitgum and Lamwo, 82% of the DR-TB screened cases were failures to first-line treatment. More than 50% of the DR-TB suspects were identified in the primary healthcare system, highlighting the relevance of peripheral health centres being able to identify and diagnose suspected cases.

### 3.2 Diagnosis

An MSF laboratory technician provides on-site diagnostics for DS-TB (with microscopy and Ziehl-Nielsen staining) if there is no MoH laboratory technician present. On the advice of a medical doctor, X-rays are carried out at St Joseph's hospital.

In 2009, MSF began by sending the samples for DST and culture to the Institute of Tropical Medicine (ITM) in Antwerp, Belgium. Since January 2011, because of the NTRL's

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\* The French section of MSF also treats TB in Uganda. In Arua district, in western Uganda, it runs a comprehensive TB programme with an MDR-TB cohort of 14 patients since 2006, six of whom are still on treatment. Its approach involves hospitalisation during the clinical phase, and provision of DOTS by MSF's clinical team. As yet, there is no VHT involvement.



**Gadi Eddy**, 26, from Kitgum district, was the first person to be diagnosed with DR-TB in Uganda.

"I first realised I had TB in 2008, and immediately I began treatment. After some time we realised that this TB didn't respond to any of the drugs. None of the other people in northern Uganda yet knew about DR-TB, and I was the first person to be diagnosed with it. The lab assistant told me there were no more options. What came into my mind was that there was MSF – they might be able to help me. I began getting my treatment from MSF on 16 December 2009. The treatment started

from home, and initially I was very eager to take the drugs. But after the first few weeks, it became harder to tolerate them. After two or three months, I became critically ill, and I was admitted to St Joseph's hospital for two weeks.

When I came back home, I lived in this house and my family lived in the one next door. My mother was looking after me, as my wife was busy making bread and selling it in the market to get some money to buy food. I used to see my children from a distance. I felt so bad because there was no possibility that I could get closer to them.

For the past five years I have been down, I have not done anything meaningful. But recently I began gaining some little energy, because I was getting more tolerant of the drugs and their side effects. Now I am working again, making shoes.

Two years after starting, I'm the first man in Uganda to finish DR-TB treatment. I feel happy because I don't have to take any more drugs and I have no side effects. I haven't yet regained my full energy and full strength, and I still can't play football like I used to. But I feel very, very good. Now I've finished my treatment, there's not any bad thing disturbing me, I'm ok."

improvements, MSF has been sending follow-up samples of enrolled DR-TB patients for culture to the NTRL only, and diagnostic samples for culture and DST to both the NTRL and ITM.

In line with the need for rapid quality diagnostic tools and processes, MSF is currently lobbying the MoH to include Kitgum in the list of districts that will pilot the GeneXpert device, supported by FIND as part of the EXPAND-TB project.

### 3.3 Treatment: drug-sensitive TB

Treatment for DS-TB has two distinct phases: the 'intensive' phase, which lasts between two and three months; and the 'continuation' phase, which lasts for either four or six months. Patients with DS-TB collect their drugs from the local health centre and return home with a weekly or fortnightly supply, which they administer themselves under the supervision of a treatment supporter. They revisit the clinic at regular intervals to collect their drugs, preferably coinciding with one of the scheduled weekly visits by MSF's mobile team.

### 3.4 Treatment: multidrug-resistant TB

Treatment for MDR-TB has the same two phases, which last longer and are significantly more challenging for patients. The 'intensive' phase lasts from six to eight months, during which patients receive painful daily injections, as well as at least ten pills per day, many of which have severe side effects which often need to be treated with other medication. Patients with other illnesses or co-infections such as HIV have to take additional drugs. It is not uncommon for a patient to take 35 pills in one day.

For MDR-TB, the 'continuation' phase generally lasts from 14 to 18 months. Patients still take daily doses of multiple drugs, but no longer need a daily injection. Although patients are less infectious and can interact with family and friends, the sheer length of the treatment makes it very challenging. Counselling and psychosocial support are crucial at this stage, as patients are frequently demoralised and anxious about the future; others may be tempted to stop taking the drugs once they begin to feel better.

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*They collected the sputum. The doctor told me I would have to wait for the results. "How long will the results take to come back?" I asked. She told me, "Have courage. It's a minimum of three months. Go and wait for the results at home."*

**DR-TB patient**

*Before MSF, TB was neglected and went undiagnosed. Now everyone is aware of it, and suspects can go to hospital for X-rays.*

**Village health team member**

*To people starting treatment, I'm going to say, don't fear drugs and you will get cured. If you fear drugs, then you won't get cured.*

**DR-TB patient**

*I was coughing seriously so they said, "You cannot go to school while you are coughing like this".*

**DR-TB patient**

### 3.5 Treatment delivery models

For the intensive phase of DR-TB treatment, the conventional model of care in high burden countries is hospital-based, with patients kept within an isolation ward until they are clinically stable and their sputum has converted from smear-positive to negative. The arguments used in support of this model of care are that it is easier for staff to manage the treatment and side effects, while reducing the risk of spreading the disease within the community.

However, evidence has shown that transmission rates within the community are not reduced by hospital-based care, while the risks to health workers and other patients are substantially increased.<sup>14</sup> At the same time, there are significant economic and social costs to hospital-based care,



**Opira Churchill**, 35, from Kitgum, has six children and worked as a butcher until he was diagnosed with DR-TB.

“My wives and children are not here – they left because of my sickness.” He finds the treatment

hard, but his health has improved dramatically in the past few months. “My weight has risen to 65 kg, up from just 39 kg. It’s very difficult to take the drugs. Yesterday evening I swallowed 22 tablets, this morning I swallowed 12, which makes 34. Plus my antiretrovirals – in the morning one, in the evening two. That’s 37 pills every single day. I’m tired and I’m weak, and that is why I look like an old man.”

With only five months of treatment left, Opira Churchill is thinking about starting up a small business – something that won’t be too tiring – and is enjoying having visitors again. “Before, my relatives were afraid to come here, and I stayed alone. No one came to visit me, no one came to talk to me. But now I’m happy that they are coming back to see me again.”

While visitors help to lift his spirits, Opira Churchill is apprehensive about the future, and staying optimistic can be a real struggle. “Because of my general weakness, I’m doubting that I will finish the treatment. I’m doubting, I’m still so very doubtful that I’m going to get cured.”

where large numbers of patients – frequently isolated, demoralised, and geographically distant from their families – end up defaulting from their treatment and becoming lost to follow-up.<sup>15</sup> Many others die while on the waiting list for a hospital bed.<sup>16</sup>

In Kitgum, a minority of MSF's DR-TB patients are admitted to an isolation unit during the intensive phase for variable durations of time, in either St Joseph's or Madi Opei hospitals. Criteria for admitting a patient to hospital include: a severe clinical condition requiring close monitoring; providing time for VHTs to address infection control measures at household level; and if there is no dedicated medical team to provide care, medical follow-up and drug administration at household level.

Where possible, DR-TB patients are treated in the community. Patients are accompanied to local clinics to receive injections, while the remaining drugs are administered in their own homes with DOT. According to preliminary results, community-based care has been shown to be safe, practical and feasible for DR-TB, leading to high adherence and case follow-up and favourable outcomes.<sup>14,16</sup>

Patients benefit from the support of friends and family in coping with the side effects of the drugs and adhering to their treatment, while infection control is managed with education and training. As in all of the programmes where MSF treats DR-TB, in Uganda MSF is using a combined approach that includes both community-based care and a limited time in hospital, according to patients' needs.

### 3.6 Monitoring

All DR-TB patients are monitored, evaluated and provided with treatment for side effects on each of their visits to the health centre. Monitoring of side effects during both the intensive and continuation phases is done clinically, and further investigations and symptomatic treatment are carried out where necessary.

### 3.7 Counselling and psychosocial support

The community-based model focuses on a patient-centred approach to administering treatment and

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*Since they discharged me from the hospital and I went back home, I have not had any difficulties in the treatment, because I have never missed even a single day.*

**DR-TB patient**

*Treatment at home gives me time to do other activities. I can go to the farm and go to school as well as taking treatment.*

**DR-TB patient**

care, based on the patients' needs and on mutual respect between patient and health provider. Psychosocial support, counselling and adherence support are central to the patient-centred strategy. In a country like Uganda, where more than 85% of people live in rural areas and often at some distance from the nearest medical facility, encouraging patients to take their health responsibilities seriously is of particular importance, and patients and their families are supported before and throughout the treatment by trained counsellors and VHTs.

Before starting treatment, patients with DR-TB, along with their treatment supporter (usually a VHT member), receive initiation and adherence counselling to assess and promote adherence to the treatment regimen and to address poor adherence when it occurs. In the intensive phase, they receive follow-up or adherence counselling, in the form of individual sessions, every two weeks, dropping to once a month during the continuation phase.

The topics covered in counselling sessions include: side effects; infection control; the importance of family support; the duration of the treatment; and the need for patients to remain in the same area until they have completed their treatment, or to inform the health professional if this is not possible.

Counsellors make an effort to understand patients' individual circumstances, and to tailor counselling

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*Counselling is the best. When you go to see the patient, you must counsel him or her how to take drugs, how to live with the neighbours, and you must counsel the family members also.*

**Village health team member**

*I help deal with social issues that arise – within families, or between patients and their caretakers. When there are quarrels and misunderstandings, I sit down with them, find out what the issue is, and help them look for alternatives.*

**Okeny Richard Dick,  
MSF DR-TB counsellor**

*It is easy for the patient to open up, to relieve the depression and the stress... we can touch the patient psychologically, emotionally. All the support we provide gives a lot of hope to the patient.*

**MSF health worker**

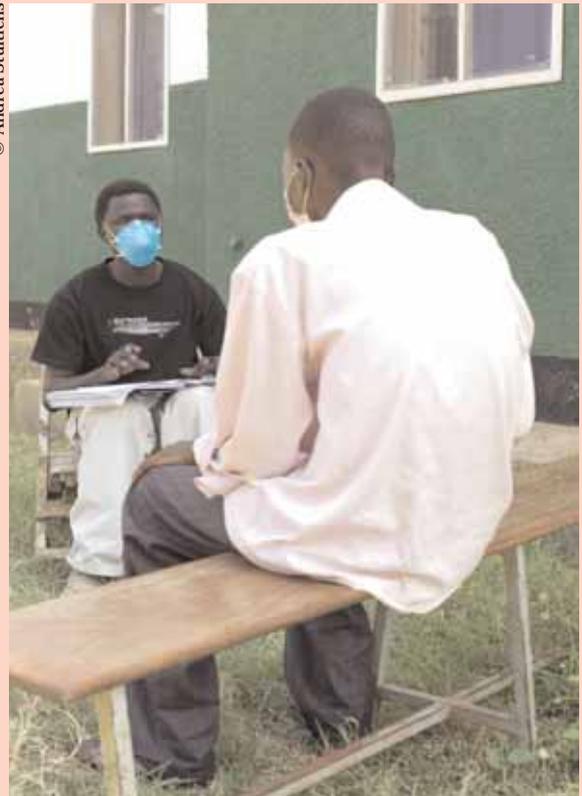
*Patients at home are a little bit relaxed in mind. Though they have the burden of many pills, they are not always being psychologically tortured, like all those patients in a hospital setting.*

**Okeny Richard Dick,  
MSF DR-TB counsellor**

so as to address potential adherence issues. For DR-TB patients, counselling holds a special significance, and is crucial in helping them manage the large quantities of drugs, the adverse effects and the psychological challenges of such a tough course of treatment. Before starting treatment, DR-TB patients are counselled so as to manage their expectations, and all patients sign a form agreeing to fully commit to the treatment.

All TB patients are counselled and offered HIV testing. About one-third of those tested are found

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MSF counsellor Okeny Richard Dick counsels new DR-TB patient Komakech Dennis in the grounds of St Joseph's hospital, in Kitgum, northern Uganda.

Richard says, "My role as a counsellor is not always to give patients solutions, but to help them generate their own solutions so that they can handle situations for themselves."

to be co-infected with HIV. All of these patients are enrolled in the MoH's HIV programme, and all receive counselling (with initial counselling also from MSF). According to the MoH, those patients with a CD4 count below 350 are initiated on ARV treatment. According to WHO recommendations, all HIV/TB co-infected patients should be started on ARV treatment irrespective of their CD4 count, but this has not yet been implemented by the MoH, in spite of its new ARV guidelines. MSF is lobbying for this at the district level.



**Komakech Richard**, 28, farmed his land near Kitgum before falling ill with DR-TB. "It began gradually like ordinary TB – the exact road I cannot say. The government did its level best to cure me, but I feel happy that I was referred to MSF."

After a stay in St Joseph's hospital, he is looking for a place to live. "I have been told that my treatment will last for two years, and I will complete the rest of it outside, when I have rented a house. I'm looking forward to that. Several times I've found a house in the surrounding area, but on hearing that I've got DR-TB, the landlord refuses to rent it to me. That is one of the hardships of having DR-TB."

He has come up against stigma within the hospital as well as outside it. "Even the fellow patients and their caretakers are feeling bad because they have the fear that I will infect them with my disease, so they have no good times with me. There is nothing to keep me busy here in the hospital, nothing entertaining or refreshing, I sleep or I sit here. I expect to get more peace and happiness when I have my own place."

Komakech Richard's treatment is going well, but he is anxious about the future. "I've got a lot of thoughts in my mind. I've been on such tough medical treatment for nine years that I've been unable to earn any money. The little money I have raised, I use for buying essentials. I would like to be able to take care of my young children and prepare their future."

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*We help integrate patients back into their communities – and their workplaces, if they were working before they were sick. We start the process two or three months before the patient is declared uninfected, so that the community and the employers are already aware of the patient's condition. We make sure that they are really accepted.*

**Okeny Richard Dick,  
MSF DR-TB counsellor**

*The first thing is to start the treatment: that is the best method of infection control and can even prevent the spread of DR-TB to the community.*

**Dr Kalyan Krishna, MSF TB doctor**

*At first, when my wife fell ill, the people in our village were scared. But then the health centre gave a lot of health education and advice about preventive measures and not sitting very close. From that time, people have had some information, and today there's no stigma, no pointing or anything. The village has been very supportive.*

**Husband of DR-TB patient**

### 3.8 Enablers and incentives

Patients are motivated to adhere to their treatment with a variety of 'enablers'. In MSF's programme in Uganda, these include providing all patients with a mosquito net, radios with batteries and, if they are able to read, with books and newspapers, to help them stave off boredom and keep up their spirits. Incentives include fortnightly food parcels to encourage healthy eating and help patients regain their weight and strength.

MSF staff and village health teams also support the patients in living as normal a life as possible during treatment, and make efforts to help them back into work or education.

MSF's experience in northern Uganda is that these enablers and incentives play a key role in motivating patients to see the challenging and lengthy treatment process through to its end.

### 3.9 Infection control

The most effective means of infection control is to identify cases and get patients on treatment as quickly as possible. Once patients are diagnosed and have started treatment, the potential for them to infect others reduces substantially, even for DR-TB patients. In a qualitative study carried out in 2011,<sup>11</sup> it was noteworthy that the fear of nosocomial transmission, as well as the association of treatment at home with a heightened risk of secondary transmission of DR-TB, was found to be less of an issue for patients than for health workers or stakeholders. Patients were more concerned with nosocomial transmission within a hospital environment. Whilst more research is needed to examine secondary transmission of DR-TB, it is important to consider how such knowledge or thinking may guide the practice and behaviour of the health practitioner and how a patient and his or her family may respond to this.

To minimise the risk of transmission, MSF staff and VHTs educate and inform patients, their families and the wider community about infection control measures. A single MSF staff member is given overall responsibility for ensuring that administrative, environmental and personal protective measures are fully implemented. With the above research findings in mind, the training of health workers must touch on the impact of personal attitudes that may be contrary to the evidence in regard to infection control.

Administrative measures include identifying a person responsible for infection control; training staff, caretakers and VHTs on infection control; endorsing regulations for immuno-compromised staff, family members and caretakers; isolating DR-TB patients while they are infectious; limiting the number of visitors that patients receive, whether at home or in an isolation unit; sleeping separately during the intensive phase; and cough hygiene (covering the nose and mouth with a tissue during coughing).

Environmental measures include assessing the condition of patients' houses to ensure that infection control measures are in place. In some cases, MSF has made renovations to the doors and windows of houses to improve natural ventilation, and has built separate thatched huts in patients' home compounds where patients can live while they are at the most infectious stage of the disease.

Personal protective measures include ensuring the proper use of N95 respiratory masks for all staff, treatment supporters and caretakers during the patient's intensive phase of testing and treatment. They also include screening all staff members for signs and symptoms of TB and HIV and offering appropriate care, support and treatment if they are found to be infected.

### 3.10 Contact tracing

Close contacts of sputum-positive DS-TB patients are traced and evaluated at the time of treatment initiation. Contacts of enrolled DR-TB patients are also traced and evaluated clinically. If the signs and symptoms of TB are present, sputum samples are referred for culture and DST. Two-thirds of the contacts of enrolled DR-TB patients in the Kitgum programme have been traced, one of whom has been confirmed with MDR-TB.

While contacts are traced and evaluated at the time of treatment initiation, there has been no systematic follow-up of contacts within the DR-TB programme. However, on each home visit, the DR-TB team makes enquiries about possible TB symptoms amongst the patient's contacts.

There is also periodic monitoring of the outcome and effectiveness of contact tracing.

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An MSF counsellor holds up one of the T-shirts given to all staff and village health team members in MSF's TB programme in Kitgum and Lamwo district. In addition to financial incentives, practical gifts like bicycles, clothes, books and bags can help to sustain the motivation of village health teams and make their work easier.

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*Twice a month the VHTs come with their patients to the hospital. One patient was asking another, how did you manage to finish the 24 months with all these side effects? And the others were sharing their problems and ideas, which is very nice. Each one was acting as an 'expert client'.*

**Dr Kalyan Krishna, MSF TB doctor**

*Last year they took me to the hospital to see a certain patient. When I reached the hospital, they took me to that room where that man is. I found out that that man really did not want to even take the drugs, he wanted to run away from the treatment. That man was really in a very dangerous stage. It was disturbing the nurses and the doctors, so they wanted me to come and encourage him that this drug cannot kill him and that he should take the drugs.*

**DR-TB patient**

### 3.11 Children

Children are diagnosed with TB based on clinical grounds and with the support of X-rays. The introduction of GeneXpert will improve diagnostics in children and is in the process of being rolled out.

All child contacts of TB patients, as well as all HIV-positive children, are actively screened for signs and symptoms of TB and are adequately investigated. Until now, no paediatric contact cases have been identified. However, one MDR-TB patient started treatment before the age of 15, though the index case was not identified.

### 3.12 Mobile teams

MSF's mobile teams for DS-TB are composed of a counsellor, a clinical officer and a laboratory technician, supervised by an outreach team supervisor. The teams work closely with MoH staff to carry out consultations and counselling sessions, and train their counterparts in diagnosis, treatment and the drug ordering process.

MSF's mobile team for DR-TB consists of a clinical

officer, a counsellor and a nurse, supervised by a medical doctor.

### 3.13 Expert clients

'Expert clients' are former or existing patients who share their own experiences of TB to motivate others to continue with their treatment. The network of expert clients is an informal one, encouraged by fortnightly meetings of VHTs and patients at a local health centre, when they come to collect drugs and to have medical check-ups and counselling sessions. At these informal meetings, people volunteer to share the challenges of their treatment and suggest possible solutions. As well as being an important source of motivation for other patients, expert clients have also taken part in regional radio talk shows to help raise awareness about TB.

### 3.14 Partnership with the Ministry of Health

MSF's integrated TB treatment programme in northern Uganda is being implemented hand in hand with the MoH, a partnership which operates at different levels.

At community level, MSF and the MoH have cooperated in the process of identifying VHTs and providing clinical on-the-job and theoretical training sessions to health staff working in local health centres.

At district level, MSF is currently rehabilitating an isolation unit in Kitgum general hospital, to facilitate the safe hospitalisation of DR-TB patients who are in need of inpatient care. MSF has also trained MoH staff in Kitgum general hospital on data analysis, drug supply chain and ordering, infection control measures, and water and sanitation. Close collaboration with the MoH has allowed MSF to play an active role in the decision making process over treatment regimens and in the strategic planning for implementing an integrated TB programme in northern Uganda run entirely by the MoH.

At national level, the DR-TB programme in Kitgum is seen as a pilot for the government's plans to decentralise DR-TB care in Uganda. MSF provides regular feedback on the evolution and challenges of implementing the programme in its drive to provide the best quality services.



**Oyella Mercy** is a 15-year-old schoolgirl from Kitgum, She describes how she caught the disease: "It was transmitted from our father. He died in 2008 at St Joseph's hospital in Kitgum. I was 13 years old when I got TB. I had stomach pains, and a cough, and I used to vomit. I went to hospital, just me myself, for one year."

The treatment failed, and in 2010 she was diagnosed with DR-TB and began treatment with MSF. "I started getting injections for six months. After stopping I started taking drugs. Some drugs are difficult: I felt some pain in the joints and stomach pains."

Now in the last few months of her treatment, and no longer infectious, Oyella Mercy is well enough to have returned to education. "Now I am feeling a little good. I'm going to school - I like learning. When the treatment is finished in May, I'll feel happy, I'll play with my friends and I'll dance, because I'll be cured."

## 4. Village health teams: bridging the gap

Village health teams are a part of the MoH system and a vital and valued element of this community-based, patient-centred model of care. The teams are made up of local people, selected by villagers and registered with the MoH, who help to deliver healthcare to people within their own communities.

The concept of VHTs has been developed and promoted by the Ugandan government since 2001 as an effective and affordable way of delivering healthcare in rural areas – one of Uganda's major health challenges.<sup>17</sup> The government finalised its latest guidelines on VHTs in 2010,<sup>18</sup> recommending that budgetary provision and planning for VHTs be put in place at all levels.

However, the VHT system is currently being implemented on an unsystematic basis, and the volunteers receive no financial reward from the government, despite the recommendations of its own guidelines. So far it has been left to partner organisations such as MSF to put the new system into practice. At times this has been undermined

by a lack of coordination, with partner organisations employing and rewarding VHTs in an ad hoc manner. Despite the practical challenges, MSF's experience with VHTs is very positive, and considers them to have a vital role in scaling up TB care.

By bringing health services to communities, VHTs help to bridge the gap between rural people and the formal health system. In terms of TB treatment, they help to break down the barriers that prevent so many people from seeking treatment in the first place – barriers which, according to a recent study,<sup>19</sup> include the social stigma of a disease that is widely associated with HIV, as well as the practical and financial difficulties of travelling to distant health facilities, to be assisted by health staff who are perceived as 'unfriendly' and who cannot offer the instant cure promised by traditional healers.

By active case-finding within their community, VHTs can help to get TB suspects speedily tested, diagnosed and on treatment, aiding the patients' recovery and preventing them from spreading the infection to their family and neighbours. And by accompanying patients to the health clinic, as well as providing directly observed treatment to patients in their own homes, VHTs also bypass the need for patients to queue for a lengthy stay in an overcrowded hospital, with all its associated disadvantages.

MSF began by piloting the use of VHTs in community-based activities for TB and sexual and gender-based violence in five health centres, using VHTs who were previously inactive and untrained. In line with the MoH guidelines, MSF provided training and incentives, paid on a quarterly basis. Within only a few months, case detection rates for TB in the VHTs' areas had increased significantly (see figure 1), with a total of 42 patients – 95% of whom were referred by VHTs – diagnosed and started on treatment between July and October 2010. Although sufficient data does not yet exist to prove the long-term effects of involving VHTs in TB case detection, MSF believes that these trends will increase over time.

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*The community they sat down and selected me to be a VHT. I was happy, because they put their trust in you when they choose you to work with your community as a VHT.*

**Village health team member**

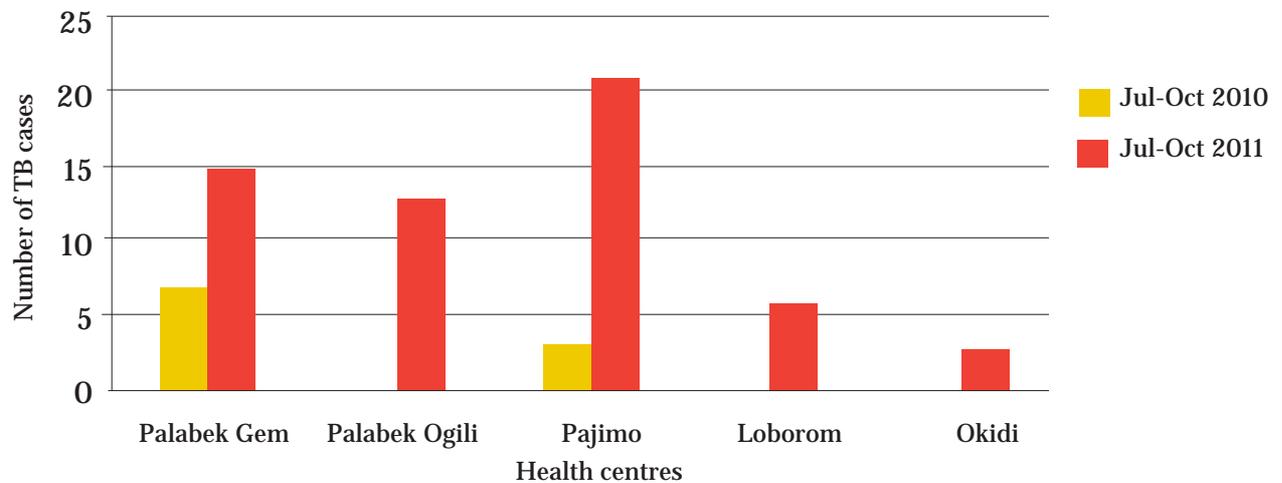
*The government has a beautiful guideline for VHTs – now they just need to implement it.*

**Dr Kalyan Krishna, MSF TB doctor**

*All the VHTs seem motivated and the health assistant taking care of them is motivated. They seem interested in taking care of their own people in their communities, which is very nice.*

**Dr Pratibha Seshadri, MSF TB doctor**

**Figure 1: Number of TB cases diagnosed and started on treatment before and after VHT involvement**



Regular training, supervision, evaluation and general support are essential for the VHT system to be successful. From January to June 2011, MSF identified and trained 780 VHTs (one per village) in how to identify and refer TB suspects, how to trace contacts and defaulters, as well as in infection control measures and TB/HIV co-infection. The training was conducted in each of the 18 health centres where MSF is involved, in collaboration with MoH health assistants. The VHTs will receive further follow-up training after six months.

#### 4.1 Village health teams as DOT providers

Beside identifying and referring TB suspects to the health centres, the VHTs are also responsible for tracing defaulter patients. When a TB patient misses an appointment, the VHT coordinator informs the relevant VHT member for the patient's area, who then traces the patient.

For DS-TB, each VHT member provides treatment support for several patients, visiting each patient once or twice a day.

For DR-TB, each VHT member is responsible for a single patient, whom they accompany to the local health centre to receive injectables and collect drug re-fills. They visit patients in their homes twice a day to deliver directly observed treatment, ensuring that patients take the correct number and combination of drugs. On each visit they go

through a checklist of side effects and relay the information to the DR-TB team. They also provide information on how to manage side effects, on infection control, and on diet and general wellbeing.

Because the VHTs are known members of the community, they are widely accepted and relationships of trust with the patients are quickly established.

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*The way they're giving out the treatment is also good because they do what is called the DOT treatment. It means you take the treatment while they are supervising you. When you've taken it, then they go. If you don't take it, they will not go.*

**DR-TB patient**

*I can administer the drugs, I can collect the drugs for the patient weekly and give it to them.*

**Village health team member**

*Having people coming home, chatting with you, it is nice and encourages you to take the drugs.*

**DR-TB patient**

“ ”

*MSF is currently the sole organisation treating DR-TB. Our approach – of incentivising VHTs to deliver the drugs – has never been implemented before. It's a realistic model which can easily be replicated by the Ministry of Health and can be continued even after MSF leaves.*

**Dr Kalyan Krishna, MSF TB doctor**

*We get incentives quarterly. They give us money, and they give us a certificate to say we did our training. It's good because if they give us incentives we can buy something for ourselves.*

**Village health team member**

*We have challenges. The distance from home to the health centre is far: nine km for me, 20 km for him. We get here on foot. If possible they could give us transport in the form of a bicycle. And if possible they could provide us with gumboots and raincoat for the rainy season, otherwise there is nothing to protect you.*

**Village health team member**

*The village health team system is working well, and will continue to work well as long as the Ministry of Health continues to incentivise them. If they don't incentivise them, they will just find that the VHTs don't want to deliver drugs anymore, and the whole system could crumble.*

**Dr Pratibha Seshadri, MSF**

The valuable practical and emotional support offered by VHTs – both in the intensive and in the continuation phase of TB treatment – has a positive effect on preventing defaulters and ultimately improving treatment success rates.

## 4.2 Incentives for village health teams

VHTs provide a service to their communities by playing a vital role in home-based TB treatment. It is important that their efforts are recognised and rewarded through a variety of forms, not least financial incentives. There is growing evidence and endorsement by the WHO that paying incentives strengthens the performance of community health workers (CHWs) or VHTs, which states: “Many successful programmes use multiple incentives over time to keep CHWs motivated. A systematic effort that plans for multiple incentives over time can build up a CHW's continuing sense of satisfaction and fulfilment.”<sup>14</sup> The Ugandan government's guidelines suggest a minimum monthly compensation of UGX 10,000 (US\$5),<sup>18</sup> which should be budgeted for alongside costs for diagnostics and medical supplies.

Training, supervision and practical gifts help to sustain the motivation of VHTs, while enablers such as bicycles to facilitate their journeys, waterproof coats and boots for the rainy season, as well as bags, T-shirts, pens and books, can help to make their work easier. VHTs should also be reimbursed for any expenses incurred in the course of their work.

Currently, MSF is paying incentives to 780 VHTs in Kitgum and Lamwo districts. However, VHTs recruited by the MoH elsewhere in northern Uganda are performing their roles on an ad hoc and voluntary basis, without any regular financial reward by the MoH, despite the recommendations of the government's guidelines. In most districts, incentive packages are not budgeted for or implemented. Without clear direction as to their role, and without the necessary support – which should be monitored in terms of what incentivises and what may disincentivise health workers<sup>20</sup> – the huge potential of village health teams will not be met.



**Atto Betty**, 32, is a village health team member in Kitgum. "I've been a VHT for three or four months – I'm very new. I was chosen by the community: they put their trust in me to help them. Now I'm working together with them. I went on training, like a nurse – I have the certificate. I enjoy my work, and I wish to continue for as long as I'm needed."

Atto Betty is supporting her niece, 15-year-old Oyella Mercy, through her treatment for DR-TB. She visits her twice a day at her home in Kitgum to check on her condition, to make sure that she has washed, eaten and brushed her teeth, and to administer her drugs.

"Since she is fearing taking the drugs, I need to talk to her in a good way – not harassing her. Sometimes she does not want to take the drugs, so I deal with her like a baby, and then she accept what I am telling her: I say now we are going to take drugs, don't fear anything, we are going to get cured."

## 5. Feasibility

### 5.1 Acceptance

A 2011 study<sup>11</sup> of MSF's treatment model in northern Uganda concluded that there is a strong preference amongst patients for home-based treatment and care. The home environment is seen as being conducive to recovery, allowing free time for other activities, and making caregiving easier to manage for family members. The proximity to family and friends makes patients feel supported psychosocially, which helps with their adherence as well as their emotional wellbeing. It is perceived by patients to be less expensive, with fewer socio-economic barriers and with the treatment process made easier by a focus on enablers.

Community members interviewed for the study were supportive of patients being treated at home, stating that this helped reduce stigma, while healthcare workers were unanimously positive.

The study concluded that the community-based model of care “is a patient-friendly, accessible, acceptable and feasible model of MDR-TB treatment in this setting.”

### 5.2 Outcomes

In 2010, MSF treated 314 TB patients with first-line drugs in 10 MSF-supported health facilities in Kitgum and Lamwo districts. Of these, 98.7% had

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*If I was in the hospital in Kampala the cost for transport is very expensive and someone must come to see you and stay for one month maybe, then they cannot do other things in this time and it would be very costly.*

**DR-TB patient**

*After the sensitisation, people are living normal lives, they are supporting us and others with ideas, we can chat freely.*

**Family member of DR-TB patient**

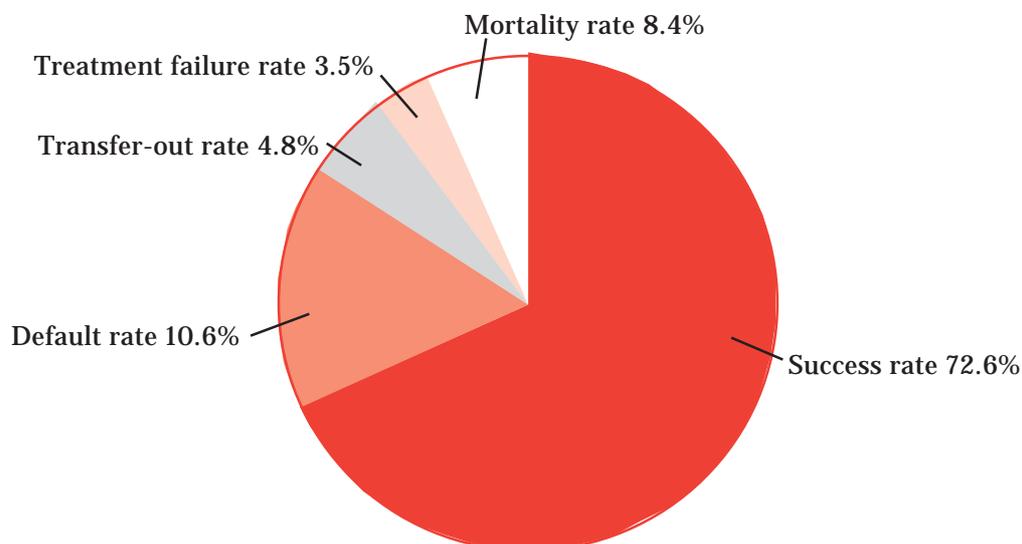
*In the hospital there are very many people there and you cannot admit everyone in the health centres. The VHTs giving at home I think is better than keeping everyone in the hospital.*

**Ministry of Health nurse**

*Sometimes in the hospital there was no one to fetch me food, water, to care for me. I was in that hospital for one full year. Sometimes I could go for a whole month without anybody visiting me.*

**DR-TB patient**

**Figure 2: Outcomes for drug-sensitive TB in Kitgum and Lamwo districts**



known outcomes, with a success rate of 72.6%, a default rate of 10.6%, a transfer-out rate of 4.8%, a treatment failure rate of 3.5% and a mortality rate of 8.4%. Half of the deaths were amongst patients co-infected with HIV.

From mid-2009 to late-2011, MSF enrolled 17 patients in the DR-TB programme. Treatment and management was following WHO recommendations. Of these, 12 patients were confirmed with MDR-TB, one patient with polydrug-resistant TB and four patients with monodrug-resistant TB. One case of MDR-TB was in a child under 15 years old.

At the end of 2011, 14 of the patients in the DR-TB cohort were still on treatment. Two monodrug-resistant TB cases and one MDR-TB case had completed treatment and been declared cured. Nine MDR-TB patients had completed the intensive phase. All were culture-converted at six months, with an average of 79 days to culture conversion, and with the intensive phase lasting an average of 7.8 months. Of these, eight patients had been on treatment for more than 12 months with consistent negative cultures. The figure for missed

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*No complication has ever arisen through home-based management and care – like defaulting, or somebody running away leaving treatment – it has never been reported yet.*

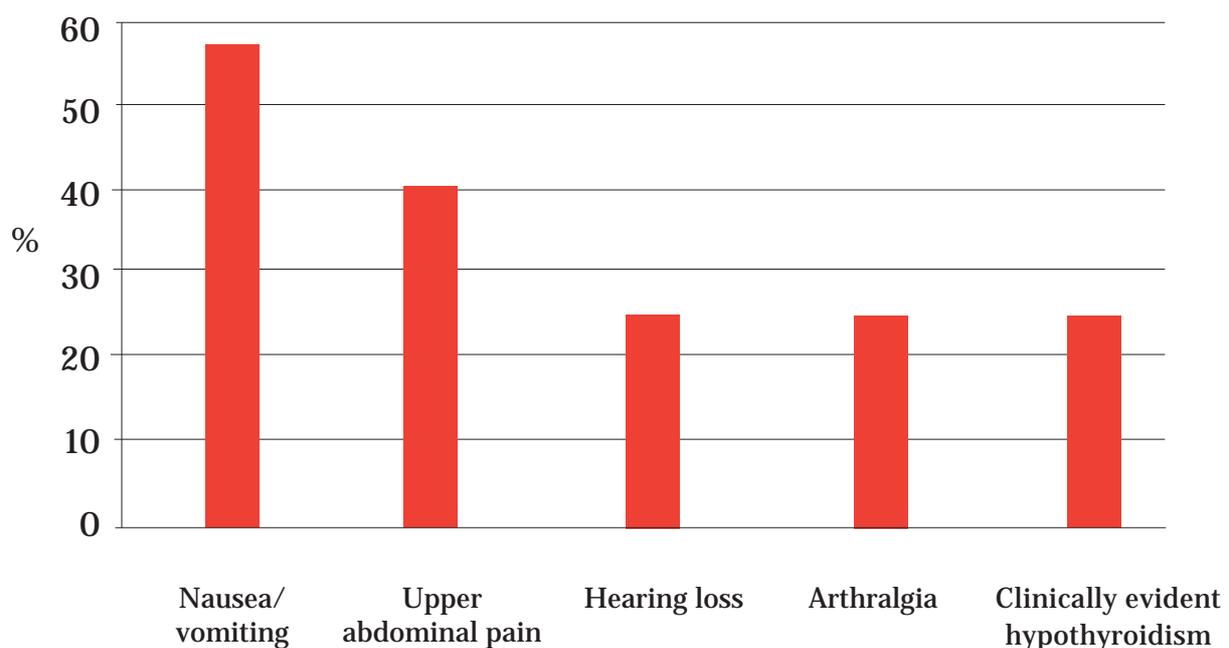
**MSF health worker**

days of treatment stood at one per patient, accounting for 0.28% of the total days of treatment.

The main side effects observed in MDR-TB patients were nausea and vomiting (58%), upper abdominal pain (41%), hearing loss (25%) arthralgia (25%) and clinically evident hypothyroidism requiring thyroxin supplementation (25%).

The interim outcomes from this cohort are encouraging. No patients in MSF's MDR-TB programme have defaulted from their treatment and none have died.

**Figure 3: Side effects in MSF's cohort of MDR-TB patients**





**Komakech Dennis** was at boarding school, living in an overcrowded student hostel, when he fell ill with DR-TB. With no treatment available in his home district of Gulu, his condition was deteriorating rapidly. At the last moment, MSF was able to admit him to the treatment programme in Kitgum.

"My condition was so bad – people were praying that I would get better. It was a good day for me yesterday, seeing MSF and being brought here by them. I was very happy – in fact it was the happiest day of my life."

## 6. Summary: a comprehensive model of TB care

MSF's experience of providing care for TB patients in northern Uganda alongside the MoH strongly suggests that the community-based model, as an effective and sustainable approach to care, could be successfully replicated elsewhere in the country.

As well as a focus on the important issues of rapid diagnostics, early treatment and a reliable quality drug supply, credit for the programme's success is also due to aspects of care which are not in the current national framework of delivery, including psychosocial support, incentives and enablers, and specialised community care.

Essential to its success are that the programme is comprehensive, the approach is decentralised, and the care is provided at home or in the community.

### 6.1 Comprehensive: for all

Comprehensive TB care means that treatment is provided for all people affected by all forms of the disease. This includes the most vulnerable people, such as children, malnourished patients, HIV co-infected patients, internally displaced people etc. TB is treated in all of its forms, whether pulmonary or extrapulmonary, drug-sensitive or drug-resistant. The care that patients receive is of high quality, side effects are actively managed, and they can expect to be diagnosed promptly and offered treatment without delay, free of charge and with quality-assured drugs.

Infection control measures (environmental, administrative and personal protective) are instituted through the training of caretakers, patients, family members and healthcare providers. In addition, personal protective equipment and necessary renovations to living spaces should ideally be provided for patients and their families. Contacts are traced to investigate household transmission, and education activities are carried out amongst the wider community to contain the spread of infection and to reduce stigma associated with the disease.

Health education, psychosocial support and counselling – before starting the treatment and throughout its course – are of primary importance both for DS-TB and DR-TB. They also play a key role in preventing patients from defaulting.

Patients' progress is consistently monitored and all efforts are made to maintain adherence to treatment until they are cured.

### 6.2 Decentralised: for a rural context

The main objective of decentralising care is to bring it closer to the patients in need. When TB treatment is centralised or regionalised – meaning that it is available only from a hospital in either the capital or a regional city – it can present numerous problems for patients from rural districts. Patients may be obliged to leave their homes, families and livelihoods in order to access care and to complete their treatment.

For many rural TB sufferers, travelling to a hospital many hours away is not only unwelcome but unfeasible. In addition, studies have shown that a centralised approach necessitating inpatient hospital care is more costly for the health providers as well as posing the risk of nosocomial and cross-infections.<sup>14,15</sup>

Decentralised care, by contrast, increases rates of case detection as well as increasing access to

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*They told me to go to Mulago hospital, in Kampala. To go there is very expensive, and because of the problem of money, I didn't go.*

**DR-TB patient**

*At home, the chances of getting new infections is very little, unlike in the hospital where you are mixed up with so many patients with the probability of getting a new infection.*

**Family member of DR-TB patient**

*Treatment needs to be available close to people's homes. If it was closer, maybe my wife would have benefited from the care and would be alive today.*

**Husband of DR-TB patient who died because no treatment was available**

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*Centralised care is okay theoretically – but, in practice, will a poor person from the village, who has never even been to Kampala before, survive in that situation? If the treatment is made available not very far away from the patient's home, the patients will be comfortable, and their relatives will be comfortable. But going to Mulago – that would be a big problem.*

**TB coordinator in a northern Ugandan district**

*It's good for patients to be cared for at home, because that is easy. If you go to the hospital, it is so very expensive to buy something to eat there, you leave the children at home here, and nobody takes care of them. If you are at home, you take care of your children, and the patient, and you go to work in your fields also.*

**Village health team member**

*We go through the village leader to mobilise a patient's surrounding neighbours – 10 or 20 households – and sensitise them about TB.*

*When I started working, community members were not very aware of DR-TB, but through the efforts of the team, people got to know about it. They used to discriminate against TB patients, but now the community accept them and support them well.*

**Okeny Richard Dick,  
MSF DR-TB counsellor**

*Home-based care is a fantastic model – it's probably the perfect model of care. I've not seen drug resistant TB patients being taken care of so well anywhere else.*

**Dr Pratibha Seshadri, MSF TB doctor**

*The good thing is that we have very good community structures, like the village health teams. They are brilliant. They can be a very useful resource in the future: they are trained and they are very flexible – they can help us a lot.*

**TB coordinator  
in a northern Ugandan district**

treatment after diagnosis. Care should be provided at district level, so that people with TB living in rural areas can travel to their local town, within their own district, for DR-TB treatment.

Those patients on DR-TB treatment and in need of hospitalisation can be admitted to isolation wards in the district hospital, while clinically stable patients – in both the intensive and continuation phases of treatment – receive care within their communities. This is done by creating a link with a nearby health facility and with a local VHT member. VHTs must be trained in the administration of directly observed treatment, with the possibility of future training in giving injectables.

### **6.3 Community-based: working with the population**

Providing care within the community has a range of benefits, allowing patients to remain at home, where they can benefit from the support of families and

friends and enjoy the distractions of everyday life, making the treatment and side effects more bearable.

Rural communities are generally accepting of patients staying at home for the duration of their treatment, and this model of care has been shown to increase public understanding of TB and decrease the stigma associated with it.<sup>11</sup> Infection control is managed within the community, with education, advice and practical support. This community-based model of care actively engages the community and TB patients in the decision-making progress, one of the aims of the WHO's six-pronged Stop TB Strategy.

Village health teams are key to community-based treatment. With the right training, guidance and support, these community members can take on a range of responsibilities and play an important and active role.

## 7. Challenges

From its experience implementing TB and HIV programmes in different parts of Uganda, in partnership with the MoH, MSF sees a number of challenges ahead. For a comprehensive TB programme to be implemented successfully, the following needs must be addressed:

### 7.1 A successful comprehensive TB strategy

MSF has identified the following components as key challenges to achieving a successful comprehensive approach:

#### a) Pursuing high-quality DOTS expansion and enhancements

The NTLP/WHO DOTS strategy has been adopted by Uganda on paper. However, it is not adequately implemented, increasing the risk of defaulting, treatment failure and drug resistance.

Implementing community-based DOTS in a country where more than 85% of the population live in rural areas is critical. At present, patients' care relies heavily on the performance of VHTs who are inadequately trained and do not receive the recommended financial support.

#### b) Access for patients with HIV/TB co-infection and DR-TB

There is a need to scale up HIV/TB collaborative activities as defined in the MoH's NTLP manual, especially testing for DR-TB in HIV-infected patients as per WHO guidelines, and integrating HIV and TB care so that patients can receive care for both diseases at the same time.<sup>21</sup> The introduction of a 'one stop service' should be considered, as the benefits for patients – both in terms of access and adherence – have been demonstrated in other similar contexts.<sup>22,23</sup>

Access to rapid quality DR-TB diagnostics over the past few years has improved, through the implementation of DR-TB testing for new TB cases, retreatment TB cases and those co-infected with HIV, although it is still far from meeting the targets of the Global Plan to Stop TB 2011-2015. Despite recent improvements, continued national testing for DR-TB, without the ability either to provide treatment or to prevent primary infections at

community and household level, is a major cause of concern. The emphasis must be on having the capacity to rapidly diagnose patients and to provide effective treatment and care.

The hardest cases to manage are children infected with both HIV and DR-TB, for whom limited treatment formulations, adapted to children, are available. Although many gaps remain with regard to the existing diagnostic tools and treatment for children with TB, there are existing recommendations that can be adopted and tools that should be implemented.<sup>9</sup>

#### c) Ensuring presence of qualified medical staff and supplies

A key challenge for the MoH is to cover the human resources needs of health centres and hospitals across the country, guaranteeing that there are sufficient numbers of qualified and motivated staff willing to work in even the most remote areas of the country. In order to deliver quality and free-of-charge medical care, the MoH must also guarantee an uninterrupted supply of drugs, medical supplies and equipment to all districts.

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*I strongly advise the government to give more strength to the availability of staff in the government hospital, and strengthen their capabilities, and make there be DR-TB drugs available – of course good drugs, not expired drugs.*

**DR-TB patient**

*If we continue to deal with DR-TB in the way that we are doing, it will probably stay at the current prevalence of 11 percent, or it will come down. But if it's mismanaged, it's going to skyrocket. It's going to become 20 percent, 30 percent. I really hope that doesn't happen.*

**Dr Pratibha Seshadri, MSF TB doctor**

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*The first thing to do is to ensure that the DR-TB drugs are procured properly and are brought to Uganda, because without the drugs, nothing works. When they start treatment, they should use a decentralised approach, taking the treatment to peripheral, regional hospitals, and using VHTs to deliver home-based care.*

**Dr Kalyan Krishna, MSF TB doctor**

*Our leaders – the local leaders, even the top government officials – why don't they talk about TB? It's not enough to remain silent. They should advocate so that we get enough support, otherwise we will be dying here silently. DR-TB is real and is a big threat, and we need to work together with partners to try to control it.*

**TB coordinator in a northern Ugandan district**

## 7.2 An effective model of DR-TB treatment and care

For a successful comprehensive TB strategy, it is vital to adapt the approach to treatment delivery according to the context. Acknowledging the achievements and adopting the model of DR-TB treatment and care piloted in the Kitgum programme would be a major strength for Uganda's national TB strategy.

### a) Decentralised

Based on published research and MSF's experience in the Kitgum programme, MSF advocates for decentralised DR-TB treatment, with a hospital-based intensive phase (where and when required) that remains as short and as close to the patient's home as possible. Provision of injections during the intensive phase should be assured, either at a local health centre or through trained VHTs, as should DOTS in patients' own homes during the intensive and continuation phases of treatment. The role of the VHT is key to ensuring adherence and

completion of DR-TB treatment. Decentralised treatment allows for more patients to be initiated promptly on treatment, as compared to a centralised model.

### b) Counselling and psychosocial support

The concept of TB counselling by a trained professional is not part of any TB control strategy, yet the role it plays is significant, and it can make or break the ability of patients to adhere to their treatment. Official recognition for counselling as part of TB (and HIV) control would have a significant positive impact.

## 7.3 Immediate and future guaranteed supply of DR-TB drugs

Until now, the districts of Uganda have had no access to second-line TB drugs. If DR-TB is left unidentified and untreated, the disease will continue to spread. The waiting time for Global Fund Round 6 Phase 2 approval has been long, and second-line TB drugs have still not reached the National Medical Store. There is a current waiting list of 237 confirmed DR-TB cases. As yet, there is no plan for a decentralised supply of DR-TB drugs (expected by mid-2012) for the districts of Uganda.

## 7.4 Funding

TB in Uganda has been structurally underfunded for many years. Since 2006, the funds available have been below requirements, and over the past five years the funding gap has widened.

The total TB budget planned for Uganda in 2011 was US\$ 23 million, of which only 48% (US\$ 11 million) became available. Of the available funds, 76% was provided by the Global Fund and 3% by domestic sources.<sup>24</sup>

For 2012, a reduced TB budget of US\$ 20 million has been presented, of which only 31% (US\$ 6 million) is expected to be funded. The percentage of the Global Fund's contribution has been reduced to 56%, whereas the available funds from domestic resources has increased to 5%.<sup>24</sup>

More funds need to be made available for TB treatment and care, and priorities need to be established for the use of existing funds.



**Lamwaka Grace**, 28, from Kitgum, was studying agriculture when she got sick. “My life was becoming more and more difficult. I was coughing, my legs were swelling, I could not move and I could not breathe. That was really a state of death. My parents had to carry me to the hospital. I’ve been told I was given a blood transfusion and air. They didn’t yet know it was DR-TB – it was new in Kitgum.”

After being diagnosed, Lamwaka Grace began treatment with MSF in March 2010. Now she has only four months of treatment left, and is feeling strong and healthy again. “Today I cooked, I fetched water – in fact I do all the domestic work – and I don’t even get tired. It’s now difficult to tell me apart from someone who is not sick.”

Feeling well has its own dangers, as patients may be tempted to stop taking the drugs before the course of treatment has finished. “Because I find I’m ok, really this is the most difficult time. But I know why I started the treatment and so I will finish it. On 31 March I will say goodbye to the drugs.”

Lamwaka Grace knows what she wants in the future. “I have already made my plans: first of all I want to go back to school, to continue with my profession. If God performs a miracle, I will join the others in September.”

## 8. Conclusion

Drug-resistant TB is an emerging health threat in Uganda. There is interest in addressing many of the essential challenges of comprehensive TB care, including access to rapid testing (including for HIV-positive patients), a proper drug supply for DOT, the integration of HIV and TB care, paediatrics, and secured funding. In this report, MSF has chosen to focus on those components currently missing from Uganda's strategy, that is, how to implement a decentralised, comprehensive and community-based model of care.

MSF's comprehensive TB programme in northern Uganda has shown encouraging preliminary

outcomes for treatment and adherence, and MSF believes that this model of care is both effective and sustainable. It is also widely accepted and valued by patients, local communities and healthcare workers. Village health teams are an important element of this model. While their role is already well defined in the rural Ugandan context, for their potential to be realised in terms of DR-TB care, VHTs need to be consistently incentivised financially for their work.

As the government prepares to start treating people with DR-TB, MSF is convinced that, by replicating this model throughout the country, Uganda's unfolding DR-TB crisis can be averted.

## 9. Recommendations

MSF's years of experience providing TB and HIV care in northern Uganda have led it to believe that the challenges of providing TB care can only be overcome if all stakeholders agree on a common approach. MSF calls on the following key stakeholders to guarantee the provision of the best possible TB treatment and care, at the same time acknowledging that access to diagnostics and the integration of HIV and TB care (including introducing the WHO guidelines on testing for DR-TB in HIV-infected patients) should be an ongoing priority:

### ■ Government of Uganda

MSF calls on the Government of Uganda, including the Ministry of Health and the Ministry of Finance, to increase the funds allocated to tackle this unfolding public health crisis. Uganda depends for a large part on foreign donors to meet its medical needs, but – irrespective of whether funding from abroad continues at current levels – there is an urgent need for the Ugandan government to close the funding gap.

### ■ Ministry of Health officials: Permanent Secretary, Director General, Assistant Commissioner for Health, NTL Programme Manager, MDR-TB Coordinator

MSF calls on the officials of the Ministry of Health to acknowledge – and act on – the need to strengthen the existing TB control programme and to include drug-resistant TB as part of a comprehensive TB strategy.

In particular, there is an urgent need for:

- Consistent efforts to ensure that rapid quality diagnosis and immediate treatment of all forms of TB are accessible to men, women and children in Uganda.
- The uptake of a decentralised, community-based model of DR-TB care. This will enable a large number of people to be detected and started on treatment, and it is likely to result in high adherence rates.

- Testing for DR-TB in all HIV/TB co-infected patients, as per WHO guidelines.
- An integration of HIV and TB care, whereby patients are able to receive care for both diseases at the same time.
- A continued supply of quality-assured WHO-recommended TB drugs to regional referral hospitals, district hospitals and health centres.
- Drugs and supplies for treating DR-TB to be made immediately available, and then to be continuously supplied, according to the needs of people with DR-TB in the country.
- Provision of training to Ministry of Health staff at district and health centre level on the diagnosis and management of DR-TB.

#### ■ **Ministry of Finance, Chief Administrative Officers, district local councils**

MSF calls on the Ministry of Finance, district local councils and chief administrative officers to assure that village health teams are budgeted for and remunerated according to the Ministry of Health's VHT guidelines. Budget allocations should be reviewed to include all the components proven to be essential for successful scale-up.

#### ■ **World Health Organization**

MSF calls on the WHO to influence and support the recommendation of a decentralised,

community-based model of care in Uganda, in keeping with the STOP TB strategy.

#### ■ **Donors: Global Fund, USAID, World Bank**

MSF calls on the Global Fund, USAID and the World Bank to ensure that the investments made in diagnostics for DR-TB are followed by similar investments in treatment provision and the assurance of quality of care for all those diagnosed with DR-TB. Continued drug sensitivity testing should go hand in hand with the provision of treatment and care.

#### ■ **Community leaders, religious leaders, district health officers, Ministry of Health TB focal persons, STOP TB Partnership, mission and private hospitals**

MSF recommends adequate planning and the allocation of budgets for activities related to DR-TB care at district level – including hospitals, health centres and VHTs – in line with a decentralised, comprehensive and community-based model of care.

#### ■ **Patients and caretakers**

MSF asks patients and caretakers to continue to support themselves and their communities through 'expert' peer support, through lobbying, and through being activists for their own care.

## TB&ME

TB&ME is a blogging platform launched by MSF as part of our aim to highlight the patient's perspective and develop patient-centred services. DR-TB patients from around the globe blog their experiences of living with the disease, suggest what is needed to improved their care and services, and discuss the issues that affect their lives.

Current bloggers are from Armenia (also published in Russian), Australia, India, the Philippines, South Africa, Swaziland, Uganda and the United Kingdom, while the first blogger writing in a non-English language has just joined the project from the Central African Republic.

**To read the words of DR-TB patients from around the world, including those in MSF's Kitgum programme, visit: <http://msf.ca/blogs/tb>.**

**We would like to thank all the staff and patients in MSF's programme in Kitgum, as well as all those who consented to their words and photographs being included in this report.**

## 10. Annexes

### Abbreviations

ARV	antiretroviral
CPT	co-trimoxazole preventive therapy
DOT	directly observed treatment
DOTS	directly observed treatment short-course
DR-TB	drug-resistant tuberculosis
DS-TB	drug-sensitive tuberculosis
DST	drug susceptibility testing
IPT	isoniazid preventive therapy
MDR-TB	multidrug-resistant tuberculosis
MoH	Ministry of Health
NLTP	National TB and Leprosy Programme
USAID	United States Agency for International Development
VHT	village health team
WHO	World Health Organization
XDR-TB	extensively drug-resistant tuberculosis

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Photos: Front cover: Oyella Mercy (left) and Atto Betty attend an informal meeting of patients and village health team members to share experiences and difficulties, and to help find solutions.

Back cover: Counsellor Okeny Richard Dick (right) talks to patient Opira Churchill outside the thatched hut which MSF constructed for him in his family's compound.

