



## APPLICATION OF PROGRAMME GUIDELINES FOR COMMUNITY-DRIVEN PROJECTS TO ELIMINATE TB AMONG MIGRANTS

*Proceedings of a Workshop organized at the UNION 2015 Conference  
TB & Migration Working Group*

### KEY HIGHLIGHTS FROM THE 2015 WORKSHOP

The 2015 workshop discussed the application of programme guidelines for community-driven projects to eliminate TB. Representatives of various organizations met and shared examples of successful projects and strategies used in reaching and working with migrant communities world-wide.

### TB & Migration Working Group Workshops, 2014-2015

The workshop conducted by the TB and Migration Working Group at the annual International Union against TB and Lung Disease (The Union) Conference, is part of a continuum of workshops held in 2013 and 2014 to address the need for community-driven TB prevention and treatment programmes for migrants and

mobile populations. The 2013 workshop emphasized the need for collaboration amongst employers and government to effectively structure TB programmes by addressing the unique needs of migrant, and the 2014 workshop focused on recommendation for guidelines on migrant community-driven projects.

The workshop facilitated a detailed set of group discussions on three topics. These include:

- I. Data Sharing
- II. Standardized Care
- III. Migrant-Specific Programme Funding

# I. DATA SHARING

**D**ata sharing is defined as having access to information, such as related to specific patients for diagnosis, treatment and contact tracing, to ensure continuity of care. Particularly for migrants crossing international borders, differing privacy laws and agreements among countries contribute to extemporary and non-standardized approaches in information sharing. In this regard, it has been difficult for National TB Programmes (NTPs) and clinicians to link people to care when they move, are deported, or return to their country of origin.

It is therefore essential that gaps in current data sharing strategies are clarified. This means providing technical advice, guidance, standardized tools, and training with potentially international agreements, to address these issues. Five key areas were identified in the discussions during the workshop. They are consent and privacy; types of information provided; process of information transfer; awareness of different laws between countries; and understanding of different migrant groups.

## *Consent/Privacy*

Before commencing treatment, it is important to obtain assurance from the patient to share their information. However, while ensuring confidentiality, there is also a need to balance consent with mandatory reporting obligations. In this regard, tools and processes would be needed to assist clinicians in enlisting patient commitment. Additionally, the sharing of information for contact tracing within the context of consent should also be considered for families that may be separated during conflict. This had been effectively demonstrated through the importance and utility of having multiple contacts and methods of contacts.

## *Type of Information Provided*

One of the necessary conditions for effective data sharing is providing standardized information and terminology via a common platform among clinicians, based on diagnostics outcomes, treatment course and status (commonality and standard indicators). The standardization of all reported indicators would be essential, and would allow for better comprehension of conditions in all countries.

## *Process of Information Transfer*

Consistency in identifiable data through the use of a unique “international code”, would be ideal in recognizing any person with TB across the globe. This would allow the possible sharing of information to patients via a smart device, or between programmes with a common generic E-platform. Particularly to prevent loss to follow-up when migrants move, contact tracing for NTPs in other countries can be facilitated through the WHO offices, IOM or IHR representatives, and additional information sharing arrangements between countries and government.

## *Awareness of Different Laws across Countries*

Acknowledging different practices of law on privacy, data protection, and data sharing, countries should consider the mandatory sharing of data between countries’ health care system in the context of international health regulation, such as identifying TB and/or other diseases (e.g. Ebola), and as a public health concern. This should also include the considerations of an individual exposed to pending deportation, within the context of irregular or economic migration laws.

## *Understanding of Different Migrant Groups*

There is diversity in migrant cohorts, and the reasons motivating migration pose specific challenges. Particularly, for migrant groups returning to conflict zones, migrants who regularly transit across borders, or migrants who are in countries without a legal status, additional conditions on sharing data of those who are undocumented/voluntary/displaced, or in conflict with the government in the country of return, should be key consideration in achieving universal data sharing.



## II. STANDARDIZED CARE

### Standardizing Elements of TB Care: Diagnosis, Treatment, and Prevention

One of the requirements for comprehensive TB care is to define what elements of TB care should be standardized, and how these standards might be applied across international borders. It was unanimously recognized during the workshop that the standardization of treatment, namely to ensure compliance and completion, would most likely be the greatest challenge, surpassing the other two components on diagnosis and prevention. This is largely due to the inherent mobility characteristic of migrant and mobile population which then transforms as one of the biggest barriers in ensuring continuity of care and completion of treatment. In addition, migrants may originate from areas with higher TB/MDR-TB prevalence and move to areas of lower prevalence (particularly those migrating for economic reasons). In such cases, there may be significant risks differences for drug resistance in the country of origin, as well as different standards for treatment follow-up, of which migrants may not be aware of. Defining the standard of care and informing health care providers, patients, and the migration communities of such standards, is essential to the process. Furthermore, the differences in access to a range of medications and costs between different countries and National TB Programs, as well as availability of medication, and monitoring of treatment, poses additional challenges to international protocols and best practices.

#### Diagnosis

Within diagnostics, the choice of method from a range of technologies is often a decision rooted in funding availability. Although technologically advanced methods, such as the GeneXpert, have been proven to accelerate both case finding and detection of rifampicin resistance, the high utilization costs may decrease accessibility compared to conventional methods, such as sputum smear, or favoured less to the “gold standard” of culture and full drug susceptibility testing. It is important to define the screening and diagnosis algorithm such that the implementation of each variable in the algorithm is very clear: the symptoms to be included in the screening criteria; the indications for radiology imaging (recommend chest X-ray); the indications for sputum smear and/or rapid molecular testing (GeneXpert, line probe assay, or other method if available); and the indications for culture and drug susceptibility testing (for migrants who reside in a

community and are not in a cross-border, temporary facility, since results for these methods will take weeks or months to finalize).

#### Treatment

One of the challenges to providing standardized treatment is that Directly Observed Treatment (DOT) has yet to be universally adopted. In many countries where DOT is not provided as standard care throughout TB treatment for all non-migrants, it becomes even more challenging to ensure DOT for the migrant population.

One strategy to provide accountability throughout treatment could be by providing education to patients and their families, and mobilizing the community for patient support. Additionally, the End TB strategy emphasising patient-centred care, with a focus on assisting individual patients to complete treatment course, means that the development of a “DOT triage strategy” may be necessary to only include the most complicated and sickest patients (e.g. with X/MDR-TB) for strict daily application of DOT. For patients whose conditions are more stable and are better equipped with disease understanding and compliance, DOT can be supported via family or community with monthly clinic visits.

Keeping consistent with the World Health Organization’s focus on people-centred care, it is important to note that supporting TB and M/XDR-TB patients to successfully complete treatment requires more than monitoring drug intake on a daily basis. For many migrants, a diagnosis of TB may mean the loss of their livelihood, resulting in catastrophic costs. Thus, the inability to care for their families may take precedence over completing TB treatment.

Patients who “disappear” because they have moved to other countries, or back to their country of origin, is a big issue with multi-factorial influences. Political interventions (country’s law) and other factors need to be deliberated to counter this problem, as ensuring “family DOT or community DOT” will not be sufficient enough to prevent patients from moving out of the area to find work, or to return home.

A suggestion for possible remediation of patients lost during treatment is to extrapolate the concept of “passive and active case finding” to treatment support. In other words, some cases are “actively

found” within certain TB/MDR-TB risk groups, as opposed to “passively” waiting for them to come to the TB clinic. Similarly, active and aggressive ways can be devised to keep patients on treatment (e.g. active versus passive treatment retention). Nevertheless, it should be recognized that these efforts may be forsaken if patients need to move for economic reasons or if the country’s law do not allow them to stay in the country (e.g. unregistered migrants with MDR-TB in Thailand are deported back to their country of origin). Therefore, although very active or aggressive initiatives can attempt to keep patients on treatment, broader policy and legal factors may determine the final outcome.

### Prevention

Late diagnosis is a major risk for ongoing transmission. Many preventive activities require education for patients, families, and the community so that they understand the critical need to initiate treatment and evaluate close contacts. In countries with high TB prevalence, treatment can be limited for those with latent TB infection (LTBI) among people living with HIV (PLHIV).

### Government

Raising political will is a critical necessity that needs to be done through high-level advocacy (e.g. WHO to member states). This is due to the lack of situational control for those who care for migrant patients and are outside of the political network to do what needs to be done. Within such advocacy, member states need to be pressured to prioritize the changing of their laws, such as defining “illegal versus legal” migrants, so that there will be no difference for patients accessing care.

### Policy-makers (WHO)

There is a need to standardize specific definitions that can impact a country’s mandate to care for migrants. In some countries (e.g. Japan) with international transfers (in/out), there may not be motivation for monitoring due to the lack of an existing definition for this category of patients. In this regard, a minimum standard of care defined by WHO should be considered for mandatory implementation in countries. While recognizing country-specific challenges, or nuances that may require flexibility in guidance, a necessary first step is to define minimum standards of care.

### Non-governmental Organizations

There should be considerations for non-governmental organizations (NGOs) to have a defined complementary role in providing standardized care. In addition, a form of standardization, regardless of funder or specific projects, should provide consistency for the continuous support of TB treatment and care for patients.

### Public and Private Sectors

Being aware of the complicated situation for migrants than for non-migrants, private sector engagement (including the pharmaceutical industry and health providers) and standardization is critical. This includes physicians in the private sector trained in the basics of TB and MDR-TB diagnosis, prevention and treatment, and providing care similar to that provided for non-migrants, as well as ready availability and accessibility of low cost treatment.

### Community

The scope of the community includes family, household, neighbours, and work colleagues. The community’s role needs to be defined for possible standardization of community engagement for migrants with TB and MDR-TB. Communities can also be engaged to address support for DOT. Additionally, application for monitoring community’s support should be considered to ensure quality assurance.

### Platform for Information Sharing and Exchange among Migrant Healthcare Workers

Information sharing, exchange, and analysis can be helpful to stakeholders to better understand the situation on the ground, and identify gaps in care and standardization deviation. An electronic tool is being explored for communication between clinicians in Europe to assist with continuity of care that may have a broader international application.



### III. MIGRANT-SPECIFIC PROGRAMME FUNDING

Constraints on funding are often an implication due to difficulties in estimating the numbers of mobile populations. Without an estimation of the numbers affected, it can be difficult to allocate funding to TB care for migrants. This is often a bigger challenge with the increasing urbanization of migrants and refugees who can be hard to reach, as opposed to those residing in camps. Within the arena of applying appropriate technology, in addition to solutions for reaching all the 'missed' migrants, there is a need for more evidence comparing PPD (Purified Protein Derivative) testing with Quantiferon to establish an effective low-cost device to test migrants for LTBI (latent TB Infection). Additionally, there is a need to identify innovative funding solutions to ensure necessary social support, such as the provision of food packages, in tandem with overall treatment and care.

Regarding funding, key donors, such as The Global Fund as well as the National TB Programmes, should be

consulted with an aim to further fund TB programmes for migrant populations, including those in irregular situations, to support cost effective technologies, sustainable stockpiles of medical products for diagnostics and treatment in hard-to-reach areas, and address challenges in the provision of essential social support, such as nutritional supplements. With longstanding grant agreements or national strategic plans put in place, adaptation to changing scenarios of migrants and refugee populations should also be considered to modify funding practices accordingly.

On effective partnerships, the need for a more substantial engagement with patient organizations and CSOs (Civil Society Organizations) in the care and oversight for migrants in irregular status is critical while ensuring confidentiality for them. There is also a need for more effective advocacy and research to justify and support the need to integrate migrants' health needs in national health systems.

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## Example of Data Sharing

### Case Study Utilizing MCN Health Network



**A**nisha (fictitious name), a 25 year old female from India, was in the US for six months with her husband on work visa doing IT work in a Midwestern State. She presented to the hospital with a two week history of fever, chills, cough, and shortness of breath, and was admitted on June 28, 2013, with a fever of 38.3 degrees celsius, weighing 43.1 kg, and ill appearing. Chest x-ray revealed right sided upper lobe infiltrate and right pleural effusion. Quantiferon tested positive and bronchoscopy indicated “caseating granulomas and positive acid fast bacilli (AFB) on smear. After a TB diagnosis, she began a RIPE regimen on July 16 but suffered severe nausea/vomiting with dehydration, anaemia (9.6/31), and severe weight loss to 36.7 kg (BMI 15.0) that eventually required a PEG tube for feeding, and a PICC line. On August 15 2013, Isoniazid (INH) treatment

stopped and she remained on the other three drugs throughout her treatment. (Pansensitive TB smear negative within two weeks of starting treatment).

Upon expressing pending return to India, she was referred to MCN’s Health Network (HN) Program where an associate contacted India NTP, sent INF with patient’s clinical information, and requested information of closest TB clinic. By September 5 2013, a MCN case manager spoke to her and learned that she would be seeking care with a private physician once she return to India on the 6th of September. To buffer this transition, she was already given two weeks of medication. Three weeks later, a HN case manager spoke with her in India and received the phone number of the private physician. Thereafter, the case manager spoke with a physician at the government hospital where the medical records had been sent, and confirmed that the patient was seeking care from a private physician. The HCN case manager spoke with the private physician and sent all the medical records. The attending physician stated that the patient was in treatment and doing well. During the telephone correspondence, language was a noted barrier but it was resolved quickly when an appropriate interpreter was engaged.

From November 2013 to March 2014, monthly calls were made by the case manager to the private physician and he reported that the patient was doing consistently well. A final call was made to the patient on 10 April to confirm completion date on 25 March 2014 and was informed no further assistance would be required. MCN closed the case on 15 April 2014 and sent the confirmed treatment completion records back to the enrolling clinic in Midwest. Overall, 17 clinic calls were made, 12 to the patient, and a total of 48 pages were sent to two locations.

## Example of Delivering Standardized Care

### Strengthening MDR-TB Decentralization at the Provincial level in Thailand through Multi-disciplinary TB teams

**T**hailand is a middle-income country with the most successful universal health care system in the Greater Mekong. However, persistently high TB prevalence has kept the country on the list of the WHO's high burden TB countries, and there are concerns that weaknesses in the health system may ultimately promote MDR-TB generation. In fact, according to the World Health Organization's "post-2015" classification of high-burden countries, Thailand is one of 14 countries that are high burden for TB, TB/HIV, and MDR-TB.

For the past several years, Thailand's Bureau of Tuberculosis (BTB) has made an effort to decentralize MDR-TB expertise outside the central level in Bangkok. In line with this priority, the USAID's Control and Prevention of Tuberculosis (CAP-TB) project focused on Rayong Province to strengthen the TB health system at the provincial level. With a population of approximately 700,000, Rayong is a coastal province with a large proportion of internal migrants from throughout Thailand, and cross-border migrants from Myanmar and Cambodia. MDR-TB case notification in Rayong is also one of the highest compared to other provinces, as is HIV prevalence and HIV co-infection among those with TB and MDR-TB. One of the major challenges in providing TB care is to keep migrants in the system throughout the treatment period. However, as they often do not stay in the area permanently and can change jobs, many patients are at risk of treatment interruption, or becoming permanently lost to follow-up.

Through the USAID-funded CAP-TB Project, the Rayong Provincial Health Office (PHO) coordinated with the provincial immigration, labour, and disease control offices to collect data and update migrant workers database; conducted TB screening for migrant workers during health exams registration purposes, or work permit renewal; implemented screening algorithms to find and screen presumptive TB patients among migrants; and also ensured the availability of TB clinics that meet the NTP's standard in the areas and districts where migrant or cross-border populations are present. Lastly, the PHO also followed the TB prevalence rate reported by both public and private health care facilities.



In the context of funding for migrants with TB and MDR-TB, registered migrants in Thailand can be covered under a health insurance card purchased by their employers. Each card cost THB2100 (USD\$ 59.80), with THB 500 (USD\$ 14.20) for physical examination fee and THB1600 (USD\$ 45.60) for medicine and treatment fee. Unregistered migrants are also supported by The Global Fund (TGF) on case finding, education activities, and medicine for drug susceptible TB. For patients with MDR-TB, the BTB may sponsor treatment if there is an identifiable employer; otherwise, unregistered migrants with MDR-TB would be deported back to their country of origin.

Through the CAP-TB project, monthly multi-disciplinary "TB Team" meetings were held to improve linkages in the provincial TB system, with the overall goal to maximize continuity of care for all patients, both Thai and non-Thai. The CAP-TB coordinators created critical links within the TB network, patients, and communities. In addition, village health volunteers were trained on TB prevention, diagnosis, and treatment, and monthly teaching conferences were organized to increase the capacity of MDR-TB expertise through an innovative platform for education on an online mobile application (QStream). The overall success for MDR-TB treatment

in the Rayong 2013 cohort was 65%, significantly higher than the national average of 49%.

The total number of migrants registered in Rayong Province is approximately 62,595 (with no estimation

available for unregistered migrants), and a total of 4,683 migrants have been screened for TB and MDR-TB. From 2012 to 2015, 439 migrants were diagnosed with TB or MDR-TB in Rayong; two migrants with MDR-TB are currently on treatment.



Participants to the workshop organized by the TB & Migration Working Group at the UNION 2015 Conference in Cape Town.