

UNITED REPUBLIC OF TANZANIA – A harmonized system to monitor the contribution of communities to the national TB response

CASE STUDY



A woman during household contact screening by local community health volunteers in Tanzania
(Photo: Isabelle Cartoux / WHO)

I. Introduction

Tuberculosis (TB) is one of the main public health emergencies in United Republic of Tanzania, causing the death of 38 000 people in 2018. The World Health Organization (WHO) estimates that, in the same year, 142 000 people fell ill with the disease but only 75 828 people were notified, meaning that 47% of all people with TB were not reached by the national health services. As described in the WHO End TB Strategy, communities can play an important role in finding people with TB who have been missed and they can effectively contribute to both TB notifications and treatment outcomes (1).

The National TB and Leprosy Programme (NTLP), established in Tanzania in 1977, has been a strong supporter of community engagement in the national TB response for the past 15 years. Tanzania was one of the first countries to implement the WHO ENGAGE-TB approach in 2012 and to include it in the National Strategic Plan (NSP) for TB.

To understand this favourable political context for community engagement, it is essential to look at the evidence base that shaped the national TB response in Tanzania. Three research studies were instrumental in

building a case for stronger engagement of communities in the TB response. A randomized controlled trial conducted in Kilombero district in 2003 showed that there was no significant difference in treatment outcome when comparing community-based TB treatment support with facility-based treatment support (2). This was confirmed by another randomized controlled trial conducted in Temeke district in 2004, showing that community-based treatment support, that relied on community supporters and former TB patients, was as effective as facility-based treatment support (3). A third study conducted in the Temeke district in 2005 showed that community-based treatment support was highly cost-effective compared with facility-based treatment support: costs fell by 27% for health services and 72% for people who were ill with TB (4).

These studies showed that empowering communities and involving them in providing community-based TB services was an effective and efficient way of improving TB treatment outcomes (5). As a result, from 2006 onwards, NTLP started rolling out and scaling up home-based treatment support. The first group of former TB patients in Tanzania, called MKIKUTE, was formally registered in 2007.

2. Description of the problem

In January 2010, NTLP documented MKIKUTE activities and the role played by former TB patients in the TB response, through what they called the “Temeke experience” (5). This documentation exercise shed a light on the critical role played by former TB patients in finding people with presumptive TB and providing TB care and treatment support. Accordingly, NTLP decided to replicate the Temeke experience and spearhead the scale-up of community-based TB activities across the country by establishing former TB patient groups in every district in Tanzania. A guide was created showing how to establish the groups, which was shared with all regional and district TB and leprosy coordinators. In each district, district TB and leprosy coordinators identified former TB patients willing to be part of community TB groups and linked them with TB health facilities. Training and stipends were provided by NTLP and its partners. The activities included screening for TB, treatment support, community mobilization and health education. Many former TB patients became community health volunteers and, by 2012, there were 395 TB groups established across the country and a national umbrella organization, MKUTA, was created to lead the groups.

A number of national and international partners worked with NTLP to implement the activities at community level, and provided support for community health volunteers. However, most partners were working in isolated “silos”, using different indicators and data collection tools, therefore making it extremely difficult for NTLP to monitor the impact of the work undertaken at community level and its contribution to TB notifications and treatment outcomes.

3. Proposed solutions

To improve the monitoring of community-based TB activities, NTLP decided to establish a harmonized community-based monitoring and evaluation (M&E) system that every implementing partner would have to adopt. The scope was to facilitate reporting and make data consolidation and comparison possible. The key events that led to the setup of the system and the core mechanism used for capturing and consolidating the community data are described below.

Early 2012 – consultation, dialogue, and harmonization

NTLP led a participatory and consultative process to raise awareness among partners of the need to use a single harmonized M&E system at community level. The initiative was welcomed, since partners recognized the need for a unified system. NTLP reviewed each partner’s data collection tools and developed a harmonized set of tools. A two-day national review workshop was organized in March 2012 with regional and district TB and leprosy coordinators, TB health professionals, international nongovernmental organizations, community-based and civil society organizations including MKUTA and MKIKUTE, and community health volunteers, to review and discuss the harmonized data collection tools and the community TB indicators (percentage of notified TB cases contributed by non-NTLP providers, and percentage of TB patients treated under home-based care). A few weeks later, in April 2012, the same stakeholders came together for a second national workshop to validate the new tools.

From July 2012 to June 2014 – rollout of the harmonized M&E system

Once the harmonized M&E system was validated, a phased approach was used for its rollout.

Training of trainers: as a preliminary step, a training of trainers was organized for master trainers who would cascade the training down to community health volunteers at health facilities and at community level. The training focused on community health volunteers’ responsibilities and included a module on M&E, with a view to harmonizing practices and providing a minimum quality standard.

Phase 1 system rollout: in July 2012, the new M&E guide and data collection tools were printed and distributed to TB health professionals and community health volunteers in six regions supported through the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund). In September, with Global Fund support, master trainers conducted a series of about 50 two-day training sessions in every district of the six target regions.

Phase 2 system rollout: in early 2013, the tools were printed and distributed to the remaining 17 regions, supported by the United States Centers for Disease Control and Prevention through the President’s Emergency Fund for AIDS Relief (PEPFAR). In March 2013, over 80 two-day training sessions were provided by the same trainers, using the delivery format from Phase I. Although the new set of tools was rolled out across the country by mid-2013, it was still entirely paper-based and not yet fully functional. NTLP used an Access database system for TB data collection and analysis, which captured only home-based treatment support activities. It took a while, until mid-2016, for all TB health facilities to report against both community TB indicators.

Community-based M&E indicators

In the NTL Monitoring and Evaluation Plan for 2015–2020 and in the Electronic TB and Leprosy (ETL) Register, two key indicators capture community-based TB activities:

- ◆ percentage of notified TB cases, all forms, contributed by non-NTLP providers – community referrals;
- ◆ percentage of TB patients treated under home-based care.

From July 2014 to April 2019 – Refining the system and the tools

Creating a community referral system: in 2015, a community referral form was introduced. The form was completed by community health volunteers and given to health facilities to capture and report community referrals for TB.

From paper-based to electronic reporting: in July 2014, the Ministry of Health adopted the District Health Information System 2 (DHIS2), a web-based, integrated and interoperable electronic system, as the preferred software for the health management information system. Aggregate community referrals data were incorporated in DHIS2 in early 2016. By the end of 2017, DHIS2 was upgraded to become a case-based system known as the Electronic TB and Leprosy Register. Patient level data, including data on community referrals and home-based treatment support, is now recorded and reported on a monthly basis in the register, from health facility level upwards.

Refining the system with users' feedback: after the tools were rolled out, NTLP collected regular user feedback to improve the tools accordingly. An updated version was printed and distributed in 2014, and other important modifications were made in 2016 and 2017, when drug shops were added to the list of places where community health volunteers could identify people with presumptive TB, and when a separate “lost-to-follow-up TB register” was created.



Mwanne, a community health volunteer in Dar Es Salaam, completes the screening form during a household contact visit (Photo: Isabelle Cartoux / WHO)

How does the community TB M&E system work?

At community level: data collection starts with the completion of a community TB screening form (TB12) by community health volunteers during TB screening activities. If the person screened has signs or symptoms of TB, community health volunteers also complete part I of the community referral form (TB15) and hand it to the person, who is then referred to the nearest TB health facility and instructed to hand the community referral form over to the facility staff. People with presumptive TB who have a community referral form are exempted from the fees for the general medical consultation.



Mwanne completes the community referral form for a person with presumptive TB

(Photo: Isabelle Cartoux / WHO)

At facility level: once TB is confirmed, the health staff complete the treatment card (TB01), which collects basic epidemiological and clinical information, as well as specifying the TB regimen to be administered. The health staff also use the treatment card to record follow-up requirements. The card is kept at the health facility and is updated during each follow-up visit, to monitor treatment progress. The health staff tick a “referred by the community” checkbox to keep track of community referrals. The form also indicates whether a person with TB is receiving home-based or facility-based care.

Health staff also complete part 2 of the community referral form (TB15) which includes diagnosis results. This is later returned to the community health volunteers, enabling them to keep track of referral outcomes and review their own performance. After completing the treatment card, health professionals complete the TB ID card (TB02), which records the patient's name, age, sex, address, the health facility attended, the type of TB, treatment protocols and dates. This card is kept by the person with TB.



TUBERCULOSIS TREATMENT CARD

Name (Three names): _____
 Physical Address: _____
 Place of work Hfacility Mines Other
 Area leader/Neighbour: _____
 Contact telephone (if available): _____
 National ID number _____
 Sex Male Female Age (yrs)
 Referred by: Self
 Community
 CTC
 Others (Specify) _____

Treatment Supporter Details
 Name of treatment supporter: _____
 Physical address: _____
 Telephone/mobile number of treatment supporter: _____

List of household contact of bacteriological confirmed TB patient

S/N	Name	age	sex	screened		outcome			started	
				Yes	No	TB	No TB	TB Rx	IPT	
1										
2										
3										
4										
5										
6										
7										

District registration No. _____
 Name of Health facility: _____
 DOT option
 Health facility DOT Home-based DOT
 Classification by site
 Pulmonary Classification by history of treatment
 New
 Previously treated
 Relapse
 Failure
 Lost to follow up
 Others (specify)
 Extra-pulmonary Site: _____
 HIV Status: Pos Neg Unknown
 HIV Care Registration No: _____
 CPT Yes Start date _____ No
 ART drugs Yes Start date _____ No
 * HIV status: Pos: Positive, Neg: Negative



Dr Mganga, District TB and Leprosy Coordinator of Kinondoni district, using the TB unit register (TB03) at Mwananyamala TB health facility, Dar Es Salaam
 (Photo: Isabelle Cartoux / WHO)



Community health worker Mwanze completes the presumptive TB register (TBI3A)
 (Photo: Isabelle Cartoux / WHO)

Lastly, health facility staff complete the TB unit register (TB03). This is where community referrals and treatment support options are recorded. The TB unit register lists each person on TB treatment and monitors progress and treatment outcomes. The TB unit register is the tool used by district TB and leprosy coordinators to enter TB patient information monthly in the electronic system (ETL/DHIS2). When entering the data electronically, district TB and leprosy coordinators also enter the source of referral for each person on treatment and indicate whether

patients are under home-based or facility-based care, thereby capturing communities' contribution towards TB notification and treatment outcomes.

Meanwhile, when community health volunteers visit the TB health facility (most visit health facilities several times a week, some daily), they complete the presumptive TB register (TBI3A) for those people that they have referred to the health facility.

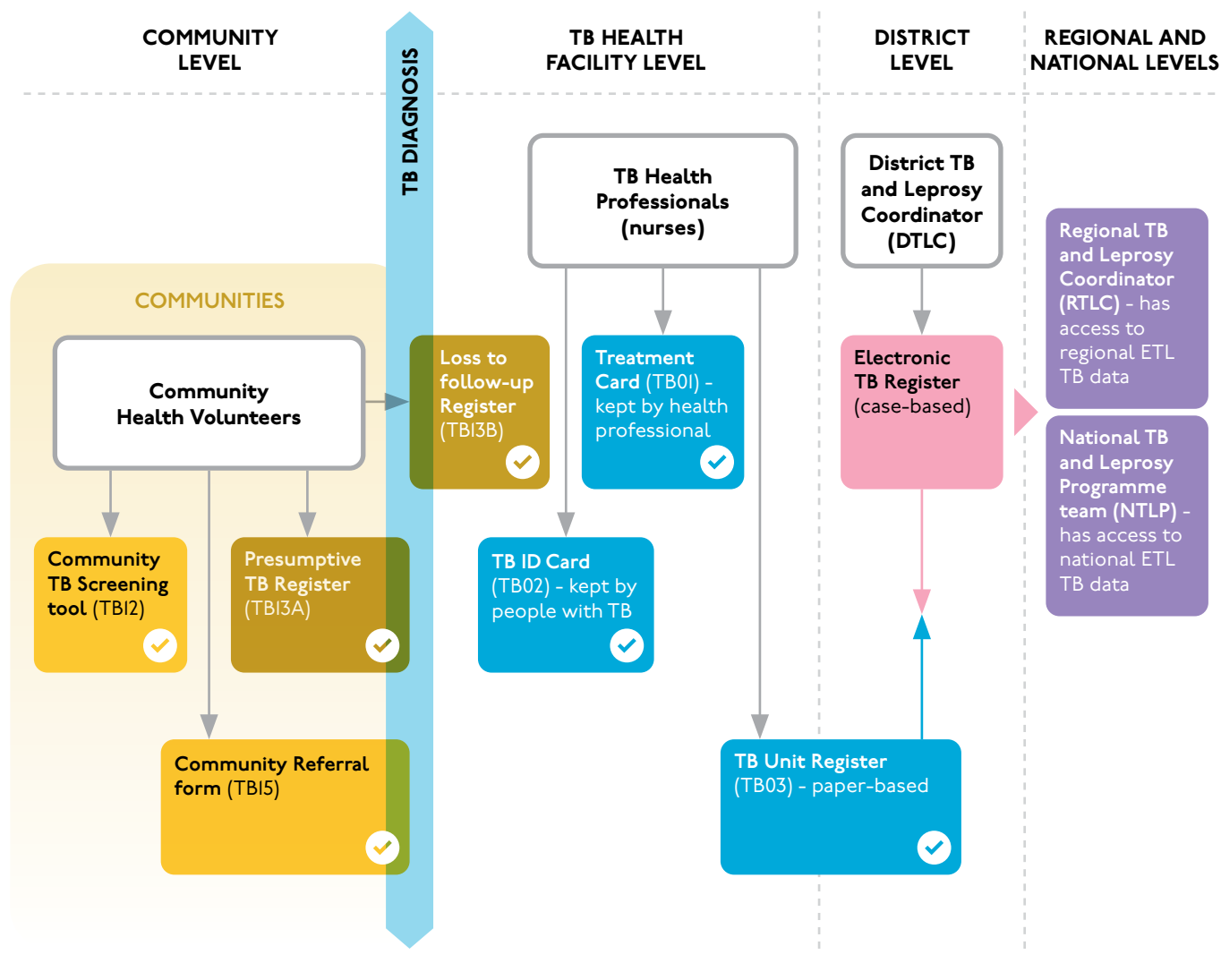
After receiving the community referral form back from health staff, community health volunteers update the presumptive TB register with diagnostic outcomes and treatment protocols. When community health volunteers are informed by health staff that a person diagnosed with TB did not start treatment or stopped coming to the health facility, community health volunteers complete the lost-to-follow-up register.

Once patient information is in the ETL Register, data analysis, visualization and reports can be automatically generated

every month. District TB and leprosy coordinators can access TB patient data only for their own district, and regional coordinators only for their own region. The NTLP has access to TB patient data for the entire country, meaning that it can monitor performance at facility, district, regional and national level.

The diagram below (Fig. 1) represents the data flow in the community M&E system, from data collection to data analysis and visualization.

Fig. 1. Data flow in the community M&E system



- Data collectors / systems' contributions
- ETL register users
- Paper-based data collection tools
- Tools filled by CHVs at community level
- Tools filled by CHVs at TB facilities
- Tools filled by TB health professionals at facility level
- Electronics case-based register filled at district level

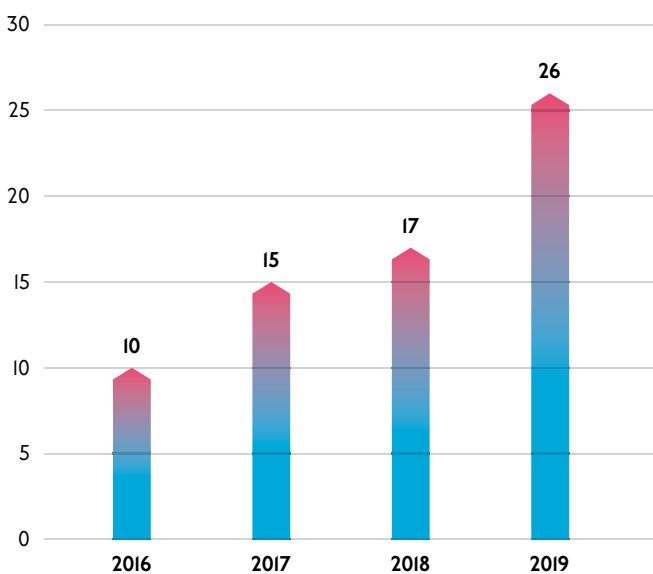
ETL register: Electronic TB and Leprosy Register;
CHV: community health volunteer.

4. Outcomes

Data captured by the ETL Register from 2016 show a compelling upwards trend in the community contribution to TB notifications. The number of people with confirmed TB (all cases) referred by community health volunteers grew from 7018 (10.3% of all notifications) in 2016, to 20 940 (26% of all notifications) in 2019. The ETL data also show that people continued to choose community-based care as their preferred treatment option (approximately 92% between 2016 and 2019). This shows that community health volunteers play an important and well accepted role not only in finding people with TB in the community, but also in providing psychosocial and treatment support. See Fig. 2 below.

Fig. 2. National trend in community contribution to TB notifications

(as a percentage of all TB notifications)



Source: Electronic TB and Leprosy register, Tanzania.

Data on the community contribution to TB notification were used to inform the Global Fund application in 2017, resulting in an increase in financial support for community TB interventions.

Furthermore, the implementation of the ETL Register has allowed NTLP to analyse the performance of community-based TB services in different geographical areas and to promptly investigate challenges hampering service delivery. Lilian Ishengoma, the Community TB Care Coordinator at NTLP, commented: *“Rolling out the harmonized community TB M&E system countrywide has simplified monitoring of community TB services. We [NTLP] are now able to identify shortcomings in a timely manner from any TB health facility and are able to act promptly to improve services. Transparency has also increased and it has been easier to measure the investment outcome among implementing partners”*.

5. Challenges and lessons learned

Strong political leadership

NTLP played a leading role in rolling out the harmonized community-based M&E system for TB. Bringing together all stakeholders involved in community-based interventions and facilitating a participatory approach were key steps in securing consensus and support from all national and international implementing partners.

Data quality

The M&E system relies on the completeness and accuracy of the data collected by community health volunteers at community level and by health workers at facility level. It has been observed that the quality of data entered by community health volunteers varies, often depending on their level of education and on the time they have been performing the task. While some community health volunteers perform very well, others can find it challenging to enter accurate and reliable data or can require more time to be fully independent in data collection tasks. Quality assurance mechanisms need to be in place to ensure completeness, reliability and accuracy of data. In some programmes in Tanzania, a cadre of community health volunteer leaders was created; these are senior and experienced volunteers, trained to provide supportive supervision and mentoring for newer volunteers, particularly in checking data completeness and accuracy. The use of electronic forms, which was introduced in some areas, also improved data quality and accuracy; one of the volunteers interviewed for this case study mentioned that the availability of electronic tablets made it much easier for her to collect data on the spot. Before the electronic forms were introduced, she used to take notes in a paper notebook and not complete the forms until the end of the day, which was time-consuming and more prone to errors.

Duplication of data

Given the high level of mobility, especially in big cities, people diagnosed with TB can sometimes be difficult to trace and follow up. Some may not give a correct address and phone number because they do not want to be contacted, or for fear of being stigmatized. Furthermore, despite the presence of a TB ID card, there is no national identification system or unique identifier code in Tanzania, meaning that duplicates in the system are possible.

Capturing community referrals

The community referral mechanism relies on people with presumptive TB bringing the community referral form with them when they visit the health facility. Despite the incentive to bring the form, which allows them to get the general medical consultation free of charge, some people still forget it, which means that the community referral is not entered into in the system. These faulty reports can sometimes be identified by community health volunteers when they look at TB unit registers and recognize the names of people that they themselves have referred, but this does not always happen. It is therefore likely that community referrals are, to some extent, underreported.

Understanding the indicators

At the beginning of rollout of the new community referral mechanism, there was some confusion amongst health professionals on the definition of community referrals. They had systematically reported as community referrals people who presented at the health facility accompanied by a relative. This was later clarified through facility exchange meetings, where it was explained that only people referred by a community health volunteer should be recorded as community referrals.

“First, I am known by the council leader, I am known everywhere in the community where I work. I am known as someone who helps the community, so I can’t drop out now! I want to help others because I have been cured of TB myself. Besides, being a community health volunteer gives me a status and recognition from the community. I have even been called doctor!” Mwanne, former TB patient and a CHV since 2011.



Former TB patient and community health volunteer Mwanne at Mwananyamala TB health facility, Dar Es Salaam
(Photo: Isabelle Cartoux/WHO)

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Retention of community health volunteers

Key informants interviewed in Dar Es Salaam in February 2020 commended the work carried out by community health volunteers with little financial incentive.¹ In Tanzania, community health volunteers generally do not receive a regular stipend, and there are often disparities in the way implementing partners motivate them. Some partners provide non-monetary incentives, like bicycles or bags, while others do not. Financial incentives, when offered, can also vary; in general, community health volunteers receive between 40 000 and 80 000 Tanzanian shillings (US\$ 17–34) per month, which mostly covers their travel expenses. As a result of these disparities and of the limited monetary incentives, implementing partners often find it challenging to retain community health volunteers. This is further exacerbated by the fact that most community interventions are time-bound, and community health volunteers do not receive incentives to continue their activities once the intervention is over. Although many volunteers, particularly ex-TB patients, still find their motivation in helping the community, harmonizing the way that community health volunteers are motivated and incentivized would be an important step in ensuring retention and in formalizing this category of worker. Some key informants also mentioned that data collection and reporting practices among community health volunteers improve over time, thus highlighting the fact that retaining community health volunteers and minimizing turnover would have a positive impact on community interventions and data quality.

Collaboration between TB health professionals and community health volunteers

The community M&E system relies primarily on the work of community health volunteers and health staff; the accuracy and consistency of the data depends on the information these two types of worker collect and enter in the system on a daily basis. Good communication and close collaboration between them are essential if the community M&E system is to operate smoothly. It was observed that mentoring between health professionals and community health volunteers can play an important role in boosting volunteer performance and increasing appreciation of their work among health professionals. To strengthen the collaboration between these two types of worker, community health volunteers supported health professionals at the clinics with tasks such as weighing patients, providing health education, tracing people who gave up on treatment, etc., while TB health professionals played a quality assurance role, checking that forms and registers from community health volunteers were adequately completed. Clinics also introduced community health volunteers to TB health professionals before activities started, ensured that community health volunteers had a dedicated space where they could enter data and invited them to the quarterly exchange meetings at the health facilities. The purpose of these meetings is to gather all stakeholders around the table to ensure that data are captured correctly in all forms and registers; they are also an opportunity to discuss potential issues and agree upon solutions.

¹ Key informants interviewed on 4–7 February 2020 were: Mwanne Abdallah, community health volunteer at Mwananyamala TB health clinic; Dr Christine Chipaga, NTLP; Lilian Ishengoma, NTLP; Dr John Lyimo, Management and Development for Health; Dr Maliwaza Mganga, district TB and leprosy coordinator, Kinondoni; Dr Rose Olotu, PATH; Ms Agnes Samani, TB health professional at Mwananyamala TB Health facility.

6. Conclusions

The national rollout of a harmonized community-based M&E system was a key milestone for communities in Tanzania, whose work and contribution to the national TB response are now being recognized at community, facility, district, regional and national level. The process also contributed greatly to strengthening the coordination amongst NTLP and other TB stakeholders, another key feature of successful community-based TB service delivery. Although the data that reach the national level still do not give a comprehensive picture of all the work done at community level in Tanzania, the inclusion of the two community TB indicators in the Monitoring and Evaluation Plan of the NSP for 2015–2020 enables NTLP to monitor the performance of the community interventions, while building the necessary evidence for future investments to strengthen community-based TB services.

- 1 Global tuberculosis report 2019. Geneva: World Health Organization; 2019 (https://www.who.int/tb/publications/global_report/en/, accessed 22 June 2020).
- 2 Lwilla F, Schellenberg D, Masanja H, Acosta C, Galindo C, Aponte J et al. Evaluation of efficacy of community-based vs. institutional-based directly observed short-course treatment for the control of tuberculosis in Kilombero district, Tanzania. *Trop Med Int Health*. 2003;8(3):204-10.
- 3 Wandwalo E, Kapalata N, Egwaga S, Morkve O. Effectiveness of community-based directly observed treatment for tuberculosis in an urban setting in Tanzania: a randomised controlled trial. *Int J Tuberc Lung Dis*. 2004;8:1248-54.
- 4 Wandwalo E, Robberstad B, Morkve O. Cost and cost-effectiveness of community based and health facility based directly observed treatment of tuberculosis in Dar es Salaam, Tanzania. Cost effectiveness and resource allocation. *Cost Eff Resour Alloc*. 2005. 14;3:6. doi:10.1186/1478-7547-3-6.
- 5 Community based TB care: experience from Temeke, Tanzania. Empowerment and involvement of former tuberculosis patients in tuberculosis control. Dar Es Salaam: National TB and Leprosy Programme; 2010.

