UNITED REPUBLIC OF TANZANIA – TB Community Network: a platform for a stronger community response to tuberculosis

CASE STUDY

TTCN members during 2018 Annual General Meeting in Morogoro, Tanzania (Photo: TTCN)

1. Introduction

The United Republic of Tanzania is one of the 30 countries with the highest burden of tuberculosis (TB) in the world. According to the World Health Organization (WHO), 142 000 people (253 per 100 000 population) fell ill with TB in 2018, of whom 40 000 (28%) were people living with HIV. However, only 75 828 people with TB were notified overall, leaving 47% of people still unreached by the national TB services (1).

Over the past 15 years, communities affected by TB have played an increasingly important role in implementing the National Strategic Plan (NSP) for TB in Tanzania. Their increasing involvement reflects the findings of studies conducted between 2003 and 2005, which showed that empowering and involving affected communities, including former TB patients, is an effective way of increasing TB case detection and improving TB treatment outcomes (2, 3, 4, 5).

Between 2005 and 2015, under the strong leadership of the National TB and Leprosy Programme (NTLP), Tanzania implemented a rapid scale-up of community-based TB activities. Former TB patient groups were created in all 169 districts across the country and international donors such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), the United States Agency for International Development, the Stop TB Partnership and the Norwegian Heart and Lung Patient Association played an important role in investing in community-based TB activities and supporting community-based and civil society organizations and other nongovernmental organizations involved in the TB response. The NTLP adopted the WHO community indicators for TB and put in place a community-based monitoring and evaluation system to capture the contribution of communities to TB outcomes. As a result, the community contribution to reaching the NSP targets has been systematically monitored through the national monitoring and evaluation system; TB community actors in Tanzania have been increasingly acknowledged as important stakeholders in the national TB response.

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2. Description of the problem

Initially, despite an enabling political environment, the rapid scale-up of TB groups led to a fragmentation of the TB community response in Tanzania. In the absence of a joint platform for community actors, community-based, civil society and nongovernmental organizations worked mostly in isolated "silos", which often resulted in a duplication of efforts in some areas and gaps in others. Community implementers were unable to coordinate and harmonize their work with national policies, which undermined their capacity to undertake strategic engagement with the Government and contribute to the development of national TB policies. This situation was further weakened by the lack of mechanisms through which the Government, development partners and other stakeholders could engage collectively with existing organizations that were implementing community TB work.

In response to this situation, in 2016 the Eastern Africa National Networks of AIDS and Health Service Organizations (EANNASO) carried out a mapping exercise of the geographical coverage and types of community TB services provided, as well as the extent to which vulnerable populations' needs were being met. "Community dialogues" were held with local communities to ensure that their perspectives informed the mapping. These provided valuable insights into the community TB response in Tanzania, its architecture, key stakeholders and their interrelationships and collaborative practices, and highlighted opportunities and gaps. Results confirmed that there were only 16 organizations working exclusively on TB across the country; 35 were working on TB and HIV and another 21 were engaged in cross-cutting themes. Out of 72 organizations, 10 were international nongovernmental organizations and 62 were local civil society organizations. In addition to registered organizations, the exercise identified 367 groups of former TB patients within the association of former TB patients MKUTA (Mapambano ya Kifua Kikuu na Ukimwi Tanzania in Swahili). MKUTA is based in the capital, Dar es Salaam, with group clusters at district level. Additionally, the mapping identified a large number of community service providers operating independently as community health volunteers at village level (5).

The results showed that, while communities were involved in the TB response, their activities were not coordinated and they did not speak with one voice. This was mainly due to the lack of a mechanism to enable the diverse and geographically widely located TB actors to engage formally with one another. On the basis of these findings, there was a recommendation to invest in a community platform to improve communication, coordination and networking and enable a more formal and harmonized engagement of all organizations already implementing community-based TB activities, thereby enhancing advocacy efforts, supporting the dissemination of good practices and improving service delivery outcomes.

TTCN Secretary meeting the Honorable Speaker of the Tanzania Parliament (Photo: TTCN)

3. Proposed solutions

In June 2017, EANNASO, MKUTA and NTLP convened a meeting, attended by about 30 organizations involved in the TB (or TB/HIV) community response, during which participants decided to create the Tanzania TB Community Forum (TTCF), which later became the Tanzania TB Community Network (TTCN) – now its official, registered name. Twenty-five local organizations signed the TTCF declaration, which outlines the overall goal of the Network and its commitment to the TB response: to advocate for an end to TB in Tanzania and increase universal access to high-quality TB services through improved community engagement. In particular, TTCN aims to: (1) mobilize resources for the TB response and for civil society organizations involved in community TB services; (2) conduct high-level TB advocacy; (3) provide a platform for better coordination, linking and networking of civil society organizations involved in TB community work; and (4) facilitate knowledge-sharing and communication among TTCF members. The Secretariat was initially provided by MKUTA, with EANNASO and NTLP providing technical support. To encourage all community organizations working in TB across Tanzania to join TTCN, membership was free of charge. National umbrella organizations such as MKUTA represent their members with one vote, while stand-alone organizations are directly represented in the forum and hold one vote each.

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From Forum to Network: key milestones (2017–2019)

Following the initial meeting, TTCF embarked on an institutional journey, whose key milestones are described below.

Appointment of a coordinator: EANNASO provided close mentoring and technical support to host and develop TTCF. In February 2018, the EANNASO TB Programme Officer was appointed as TTCF Coordinator.

Official registration: as TTCF was not registered as an official organization, it had less legitimacy when conducting high-level advocacy activities; it was unable to open a bank account and faced challenges when applying for funding from international donors. The registration process took over 16 months and was concluded in September 2019. The name was changed from "Forum" to "Network", which the authorities felt was less politically loaded.

Securing funding: The TTCN Secretariat host, EANNASO, was awarded the Stop TB Partnership Challenge Facility for Civil Society Round 8 grant from May 2018 to May 2019. This funding enabled TTCN to conduct a series of activities which are described in Section 4 below.

Interim Board: TTCN elected an interim Board during the first Steering Committee meeting on 14 November 2018.

Annual General Meeting: the first two meetings were held in November 2018 and August 2019. They provided an opportunity for members to network, discuss TTCN priorities, share information on their TB activities and raise concerns about implementation.

Strategic plan: from May 2018 onwards, the TTCN Secretariat launched a consultative and participatory process, fully engaging its community constituency, to develop a results-based Advocacy Strategic Plan for the period 2020–2024. The Plan was adopted during the Annual General Meeting in August 2019. It provides clear directions on how TTCN can leverage the most significant change for people with TB by 2024, while also strengthening itself and the capacity of each member.

Visual identity: a logo and a brochure were created; the brochure was produced in both English and Swahili.

Communication: good communication within the Network was critical, for both information-sharing and consensus-building purposes. General meetings are organized annually, and Network members are also part of a dedicated WhatsApp group, used by the Secretariat to share advocacy and resource mobilization opportunities with members, but also to gather ideas and understand priorities so as to represent them better.

TTCN Mission

"To support the improvement of health and wellbeing of communities through coordination, capacity building and promotion of innovative leadership among members to effectively contribute to ending TB in Tanzania.

TTCN Objectives

1. Promote networking, coordination, experience sharing, learning and dialogue amongst members and other key stakeholders in the national TB response;

2. Support implementation of quality, accessible and equitable TB services in the community through health and community systems strengthening;

3. Enhance greater participation of members and other stakeholders to advocate for development and implementation of TB policies and guidelines;

4. Enhance dissemination of information and facilitate communication and collaborations of members and stakeholders working to end TB in Tanzania."

Source: TTCN Constitution, August 2019.

TTCN governance

While TTCN governance is still a work in progress, the Constitution provides a thorough description of the envisioned governance structure, which is described below.

Annual General Meeting: this is the supreme decision-making body of TTCN. It is made up of at least one representative from each organization, with one vote each. While the Community Coordinator from NTLP usually attends the meetings, NTLP does not have a formal vote. During the meeting, TTCN appoints the seven members of the Board of Directors for a three-year period. New members, annual budget approval, plans and reports are covered in the meeting, as are by-laws, rules and regulations, organizational manuals and other TTCN policies.

TB is curable, take action...

Who We Are

The Tanzania TB Community Forum (TTCF) is a forum that brings together Civil Society Organizations (CSOs), Community Based Organization (CBOs), Community Groups and Partners working in areas of Tuberculosis (TB) and HIV in Tanzania. TTCF works through leadership, collaboration, education and community based advocacy to generate the implementation and ambition to close gaps to end TB. TTCF operates through a secretariat currently hosted by the the Eastern Africa National Networks of AIDS Service and Health Organisations (EANNASO) based in Arusha, Tanzania. The secretariat is governed by a Coordinating Board that sets strategic direction for the fight against TB in Tanzania. TTCF was established on June 9th, 2017 in Dodoma through TB Challenge for Civil Society Round 7 funded by the STOP TB Partnership Geneva and implemented by EANNASO.

Our Vision
Tanzania Free of Tuberculosis

Our Mission
TB Communities in Tanzania empowered and coordinated to contribute to ending TB by 2030.

Objectives
- To increase networking, coordination, information sharing, learning and dialogue amongst CSOs/CBOs and Community groups in the TB response.
- To support implementation of good quality, accessible and equitable TB services in the community through health and community systems strengthening
- To generate, disseminate information and facilitate communication and collaborations of stakeholders working to end TB in Tanzania.
- To establish a platform to ensure a conducive environment that will promote ending TB by 2030.
- Work in partnership with the National Tuberculosis and Leprosy Program (NTLP) to end the TB epidemic in Tanzania.

Programmatic Focus
- Increased investments to TB Community engagement in national TB response
- Policy Advocacy towards an enabling environment
- Coordination, Linkage and Networking of and for TB CSOs for effective engagement
- TB Knowledge and Information Management

Thematic Areas
- Policy Advocacy
- Community Systems Strengthening
- Community Representation and Empowerment
- Research and Documentation
- Community Monitoring and Performance Tracking

Our Values
1. **Passion:** Dedication to our mission, vision, objectives, community, forum and each other
2. **Respect:** Being honest and forthright in everything we do, while understanding and valuing the contributions and priorities of others.

3. **Teamwork:** Work collaboratively towards common goals
4. **Honest:** We share information freely, because being open benefits everyone.
5. **Responsible:** We honor the trust given to us by community through being accountable for our actions.
6. **Confidentiality:** We value people and treat every information we receive as self -confidential.
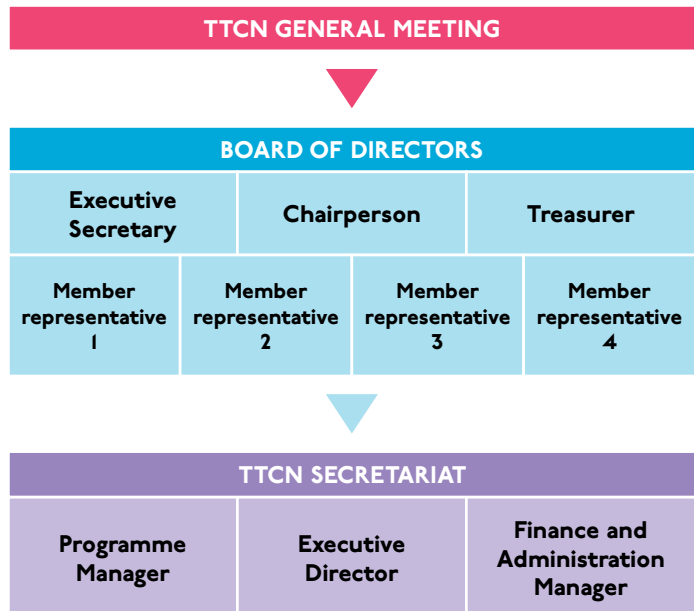
Membership

Members of TTCF are drawn from a variety of CBOs, people affected by TB, advocates and more. All are passionate about ending TB, recognizing its significance as an important public health problem Tanzania. All members are also passionate about national engagement on TB issues and the move towards elimination by 2030. The TB Forum works closely with a range of other partner organizations with shared aims regarding TB in the country. Membership is free.

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TB is curable, join us today to end TB in Tanzania

TTCN brochure in English

Board of Directors: Board members meet twice yearly and also on an ad-hoc basis if needed. They are responsible for writing TTCN rules and regulations, leading the development of the Strategic Plan and developing organizational manuals and policies. They also appoint auditors and recruit TTCN Secretariat staff, including the Executive Director, who is a member of the Secretariat. Currently, the interim Executive Secretary (a member of the Board of Directors) also acts as the TTCN Coordinator. These two distinct mandates will be clearly separated when the General Election takes place in 2020.

Secretariat: a fully-fledged Secretariat is envisioned to operationalize the TTCN Strategic Plan. However, the recruitment of staff will depend on funding. In the interim, the Coordinator is currently assisted by a volunteer Programme Assistant from EANNASO, to enable the continued development of the organization and to progress with the agenda for community TB activities.

TTCN GENERAL MEETING

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BOARD OF DIRECTORS			
Executive Secretary		Chairperson	Treasurer
Member representative 1	Member representative 2	Member representative 3	Member representative 4

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TTCN SECRETARIAT		
Programme Manager	Executive Director	Finance and Administration Manager

Envisioned TTCN structure

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4. Outcomes

TTCN maintains a list of all organizations involved in community TB activities, with whom it shares information and documents related to national TB policies (e.g. the National TB Strategic Plan, TB fact sheets, etc.), enabling community members to access relevant information about TB while also creating a greater sense of collective ownership of the national TB response. Interviews conducted with TTCN members and NTLP in February 2020, revealed that the TB community response is now perceived as more coordinated and less fragmented than before, with TB communities and civil society speaking with one voice when communicating key TB messages, making them better placed to conduct advocacy and influence the national TB agenda.[1]

Contribution to the United Nations High-level Meeting on TB

Ahead of the first-ever United Nations High-level Meeting on the Fight Against Tuberculosis, held in New York in September 2018, TTCN played a key role in mobilizing Tanzanian civil society and TB communities and coordinated the development of a position statement that was shared with the Tanzanian Government. Through TTCN, civil society called for high-level political leadership on TB and for high-level participation in the Meeting. Although civil society advocated for the President of Tanzania to attend the Meeting, the participation of the Minister of Foreign Affairs was still celebrated as a success by the TB community. The position statement was a key step in formalizing and voicing priorities and recommendations from communities affected by TB. Without TTCN, many organizations would not have been aware of the event and able to contribute.

Dialogue with Members of Parliament

In November 2018, TTCN facilitated the establishment of a TB Caucus to support the development of the 2019 Parliamentary Plan for TB. Specifically, the aim was to support Members of Parliament in developing a concept note, making TB a priority agenda item during the Uhuru Torch Race in 2019, an important event in Tanzania.[2] TTCN representatives also seized this opportunity to discuss domestic resource mobilization for TB and inclusion of TB in the agenda of the HIV and AIDS Parliamentary Committee.

Dialogue forums

Through support from the Global Fund grant 2018–2020, TTCN also holds dialogue forums where TB representatives from the Tanzania National Coordination Mechanism for the Global Fund (TNCM) are invited to participate and to share feedback from the Coordination Mechanism while also reporting back to it the issues raised during the forums.

Collaboration between State and non-State actors

The establishment of TTCN created the opportunity for a direct dialogue between the Tanzanian Government and the communities involved in the TB response. The Community TB Care Coordinator of NTLP is invited to attend TTCN general meetings, where she has the opportunity to listen to members' experiences, concerns and priorities and take them into account. Lilian Ishengoma, the current Coordinator, commented: *"The Tanzania TB Community Network is a very important organization because […] CSOs [civil society organizations] working with communities and with people affected by TB should be involved in the TB response. We expect the community response to be coordinated and this is now possible thanks to the Network. It can support communities to raise their voices, express their needs and make recommendations. As government, we need to listen to them and their advice, to improve our activities for the TB response."*

Minister of Health, Community Development, Gender, Elderly and Children Hon. Ummy Mwalimu (Photo: TTCN)

Inputs into the National Strategic Plan

The TTCN was invited to attend an NTLP consultative meeting in 2019, where its representatives highlighted key gaps in the 2015–2020 NSP and formulated recommendations for the next NSP iteration. For example, TTCN pointed out that, in the current NSP, there was little information on TB-related stigma and gender considerations were lacking; one of the recommendations to NTLP was to conduct a stigma assessment study. Additionally, TTCN is also taking part in the development of the Community, Rights and Gender Assessment Action Plan for 2020.

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1   Key informants interviewed were: Dickens Bwana, MKIKUTE/MKUTA; Lilian Ishengoma, NTLP; Dr John Lyimo, Management and Development for Health; Onesmus Mlewa Kalama, EANNASO Rodrick Mugishagwe, EANNASO.
2   Uhuru Torch is the national symbol of Tanzania. It represents freedom and light.

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TTCN Secretariat meeting with key parliamentarians in Tanzania (Photo: TTCN)

Community TB Technical Working Group

The TTCN was invited by the Ministry of Health, Community Development, Gender, Elderly and Children to take part in the Community TB Technical Working Group. This mechanism was created in January 2019 with support from WHO, through the Global Fund Strategic Initiative grant, with the scope of strengthening community TB care in Tanzania by providing strategic and technical guidance for NTLP. The TTCN Coordinator attends the quarterly meetings of the Working Group and represents TTCN members.

National debate on community health workers

There is currently a drive, led by the Ministry of Health, Community Development, Gender, Elderly and Children and civil society, to move away from the existing community volunteer model and create a new category of worker, the community health worker. TTCN took part in the discussions on a remuneration scheme for community health workers and was able to represent TB-affected communities that are calling for this new cadre.

Community-based monitoring system for TB

One of TTCN's planned next steps is to set up a digital community-based monitoring system for TB. The aim is to monitor and document barriers experienced by the community in accessing TB services (e.g. TB drug stock-outs, users having to pay for services that should be free, TB stigma at health facilities or in the community). Data collected through this mechanism will be used by TTCN members to inform advocacy activities that address these barriers.

5. Challenges and lessons learned

Financial sustainability

In a context of scarce resources and increased competition, securing donor funding is an ongoing challenge for TTCN. Donors are increasingly funding service-oriented responses rather than advocacy, coordination and networking activities. In addition, while resource mobilization efforts are necessary to secure funding and enable basic functioning of the Network, limited skilled staff are available for these types of activities. Because of the lack of a clear resource mobilization strategy and the scarcity of funding, TTCN members and the Secretariat have occasionally found themselves in competition for allocation of resources.

Internal communication

Smooth internal communication among TTCN members and with the Secretariat is key for the Network to fulfil its role. With members scattered across the country, limited resources for face-to-face meetings and weak technological capacity (some members have little or no access to the internet), this is still a challenging area for TTCN, compounded by the lack of a clear internal communication strategy.

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Consensus-building

Formal mechanisms allowing TTCN members to reach a consensus are not yet fully functional. Most consultations and feedback are currently conducted via WhatsApp, with all the limitations that this implies.

Stakeholder support

From the TTCN Secretariat's perspective, there is a need to improve stakeholder support for TTCN by increasing the capacity of the Steering Committee and Interim Board and the time allocated to TTCN by its members. The Secretariat also highlights the need to identify allies among relevant Government authorities and to strengthen TTCN engagement with them to secure their support in implementing the TTCN Strategic Plan.

Strong legitimacy

TTCN was created following a request from grassroots organizations that wanted a stronger voice within decision-making circles and more support at community level. This gives TTCN strong legitimacy and a mandate to represent TB community stakeholders at national level. The presence in TTCN of organizations of former TB patients, such as MKUTA, ensures that the voices of communities and people affected by TB are heard; MKUTA groups make up to 60% of TTCN's membership base.

Capacity-building

TTCN has a strong mandate and the potential to build its members' capacity, not only in TB programming but also in key areas such as resource mobilization, monitoring and evaluation, governance and financial management. One member describes it as an "avenue for learning". However, a fine balance needs to be struck between strengthening TTCN itself, organizationally and programmatically, and strengthening its member organizations. TTCN exists to serve its members, but only a strong TTCN can fulfil its ambitious mandate.

Opportunities for TB/HIV integration

TTCN provides a substantial opportunity to encourage and support the participation of organizations that are not yet engaged in the TB response, particularly HIV/AIDS organizations. As MKUTA programme manager commented: *"There is a big opportunity to have many actors in the fight against TB. There are many HIV actors out there. If we can ensure they include TB, we can double the fight."*

6. Conclusions

Close coordination between community stakeholders is critically important for strengthening the community response to TB and improving TB outcomes; at implementation level, it allows optimization of the coverage and quality of TB services; at programmatic level, it translates into stronger advocacy capacity, greater recognition and the ability to influence national TB policies. TTNC was created to enhance coordination among community TB implementers and has already come a long way in fulfilling its mandate: it has created an avenue for its members to network, coordinate and engage, at local and national level, allowing community implementers to be increasingly recognized as primary TB stakeholders and enabling them to influence national TB policies. For TTCN to continue fulfilling its mandate, organizational strengthening and financial support for the Network and its members will be crucial over the next few years. Inclusion of TTCN activities in the new Global Fund grant application for 2020–2022 will be extremely important in order to sustain the Network and further strengthen coordination among all TB stakeholders and ensure that community actors will continue to make a growing contribution to the national TB response in Tanzania.

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 direct 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 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.

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