



**Coordinating Meeting of the Tanzania TB
Community Forum in support of National TB
Response**

Meeting Report

VETA, Dodoma, Tanzania

Report Date: 15th - 16th November 2018

About the meeting

The meeting was organized by TTCF (Tanzania TB Community Forum). TTCF is a forum that brings together Civil Society Organizations (CSOs) including 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 Eastern Africa National Networks of AIDS and Health Service Organizations (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. The overall role of TTCF is to increase networking, coordination, information sharing, learning and dialogue amongst CSOs/CBOs and Community groups in the TB response. The meeting was organized for two days.

- The first day was more of sharing experiences of the TB community and Implementing partners.
- Day two focused on what is happen at global level and also identifying issues facing communities in their effort to end in Tanzania.

Day 1

Introductions and Objectives of the meeting

In this session participants introduced themselves and shared their expectations from this meeting. The following are the participant's summary of expectations:

- i) Learn more on how the community groups work
- ii) Know what are the challenges for the development of the forum
- iii) Make sure that there is collaboration among the community based organizations in eradicating TB
- iv) Share experiences on how community group work
- v) Come with a clear strategy on how to eradicate TB
- vi) See what the government had done and still doing in the eradication of TB.

In general, the meeting had the following objectives.

- i) To ensure that TB CSOs, implementing partners and NTLP are familiar with how they work together to support the TB response in Tanzania.
- ii) To build consensus on priority actions that should guide efforts at strengthening the national TB response in Tanzania.
- iii) To establish national accountability mechanisms for strengthening the national TB response.
- iv) To build strategic partnerships among stakeholders for policy, strategy and law reforms for effective TB response in Tanzania.
- v) To identify resource gaps, recommend other possible resources and support /provide Technical Support (TS) needs

Opening Remarks

The opening remarks were provided by Deputy Manager Dr. Mleoh representing the Program Manager. In his remarks Dr. Mleoh emphasized that people need to work together so that the goal of ending TB by 2035 can be reached. He welcomed the participants and encouraged everyone to participate fully contribute and shares their experiences.

Learning from the past

This session was mainly for sharing experiences and involved presentation from NTLP, implementing partners and TB community representatives present.

1) NTLP

This part was presented by Lilian Ishengoma from NTLP. She presented what the government has done in its process of ending TB in Tanzania. She also said that some regions are supported by various NGOs but there are other regions no support for community TB activities. The NTLP has had discussions with various donors and implementing partners to urge them to consider these regions and find fund to support these activities.

She also presented how the Community has contributed towards TB Case Detection. Since 2016, there has been a tremendous increase in community contribution in TB case detection in Tanzania. A total of 68,864 TB cases were notified in 2017, showing an increase of 6% compared to 2016. Implementation of

the community interventions were among the major contributing factors to this success. Fourth quarter of 2017, TB cases attributed from community referral raised to 14.5% from 6% (first quarter 2016) of all TB cases notified in the country. Significant community contribution has been realized also in Global Fund supported regions where notification has raised from 7% (first quarter 2016) to 16% (fourth quarter) in 2017. Therefore, community engagement in TB case detection is crucial in ending TB in Tanzania.

Discussion

- There was a concern on how the information is recorded and shared in the health facilities. A contributor gave an example that, there was a wrong recording for the TB patients in Ubungo as 82 cases were not recorded last year and there was no reason for these data to be left out.
- Another participant presented on the way the working environment is difficult. He said that, it is very difficult to go to Mererani mining center with his motor bike because there is a wall and the bike has to be left outside otherwise it will be very difficult to get it out. So he has to get another transport inside the wall and he has to pay for it. He added that, there is a very long distance from one mining center to the other and since he does not have his own transport it becomes very difficult for him to do his work. He urged the government to look for a way to remove this problem because mining centers are the big source of TB transmission.
- There was another suggestion for the government that, when they are doing their mentorship program, they should include the community based workers and groups because they are aware of what is really happening in the community.

2) NACOPHA

NACOPHA was represented by Mr. Kamugisha who presented as follows;

- National Council of People Living with HIV/AIDS (NACOPHA) is the umbrella organization established by People Living with HIV and AIDS (PLHIV) to serve as the Apex body and ultimate voice to advocate for issues and concerns of the PLHIV in Tanzania. It was founded in August 2003 and was registered in September 2005.
- Currently the Council works with more than 13 PLHIV networks and 167 PLHIV districts clusters
- NACOPHA in collaboration with National PLHIV Clusters and networks has been able to undertake the following activities: Building the capacity of PLHIV Clusters and networks, Advocacy, sensitization, awareness raising, community outreach and operational research as per identified need.

Discussion

- But he was told to tell the participants the relation of what he does in relation to TB. He said that, these two diseases cannot be separated because most people with HIV positive have TB and most TB patients are HIV positive though not all of them.
- Another participant suggested for TB patients who are very far from health centers to get at list medicine for 3 months instead of going to the hospital regularly.
- for the partners NACOPHA as an organization working in HIV and MKUTA working in TB, work together and in the next meeting they tell us what they have done together

MKUTA Presentation

MKUTA was represented by Ms. Rachael who presented as follows;

- The Mapambano ya Kifua Kikuu na Ukimwi Tanzania (MKUTA) is a National Umbrella Organization for TB Patients Clubs in Tanzania established in 2009. Since its inception the organization have more than 65 District TB Club as members with 1350 Community Health Care workers/Volunteers to date.
- MKUTA key role is to strengthen the capacity of its members to provide Community TB Care in the Country. As such, MKUTA has been working with the Ministry of Health through the National TB and Leprosy Program (NTLP).
- Key strategy for MKUTA include enhancing community awareness on TB and TB/HIV through the use of Former TB patients as key informants by giving testimonials in reducing defaulter rates and improving cure rates, patient's empowerment and active TB case finding.

Discussion

- The meeting resolved that in the next TTCF meeting, NACOPHA and MKUTA should present a report on how they have worked together.

EANNASO

EANNASO was presented by Rodrick Mugishagwe as follows;

- The Eastern Africa National Networks of AIDS Service Organizations (EANNASO) is a regional network of national networks of Civil Society and Community Based Organizations in seven

Eastern Africa Countries, namely: Kenya, Uganda, Tanzania, Rwanda, Burundi, Ethiopia and Southern Sudan.

- EANNASO's mission is to Increase the contribution of civil society and community groups in eliminating HIV, TB, Malaria and other associated diseases through strengthened coordination, programmatic alliance, capacity building and creation of an enabling environment.
- In Tanzania EANNASO is hosting and supporting the Tanzania TB Community Forum.
- EANNASO also has conducted community rights and gender assessment tools which aims at identifying the human rights and gender barriers facing people affected by TB.
- Rodrick also presented about the Anglophone Africa Platform that is hosted by EANNASO.

Discussion on the presentation

- The urge to understand GF processes not many CS know the processes so making it hard to engage. EANNASO commitment is to share the GF processes doc with the meeting.
- There were also concerns on the selection of PR and SSR how can CS be implementers.
- TB community's priorities not reflected in the funding requests

MDH

- In MDH presentation that was done by Dr. Lyimo, he said that, they are implementing ENGAGE TB approach, where several civil society organizations have been integrated TB control activities in their plans.
- They engage community groups, where they provide them with a little amount to support them in their activities. Community look for people who are suspected to have TB and collect their sputum then send them to the hospital and wait for the results. If there is a person who is sick, they help in directing that person to the hospital and remind him or her in attending into the hospitals to take their medicines. MDH are currently working in 5 regions including Dar es Salaam, Pwani, Geita, Kagera, and Dodoma.

TTCF

Ms. Olive Mumba informed TTCF members that coordinator who was working in MKUTA resigned without giving information as a result no work was done between November 2017 to February 2018. As the network had been newly formed it needed a person who is well knowledgeable about the network in order to keep it running.

To keep the forum running EANNASO and MKUTA appointed Rodrick Mugishagwe who was closely working with the coordinator to hold the position until they can find someone to take over the responsibilities. And Since Rodrick is based in Arusha the EANNASO had to become the new host of the forum. Members were happy with the decision.

Group discussions

Participants were divided into five groups to discuss various challenges faced by communities in the national TB response. Group presentation was conducted in day 2.

DAY 2

1. Group Presentation of the challenges

As a results of community discussion the following gaps and recommendations were identified.

a) TB Prevention

Gaps

- Poor people response on TB issues in the community
- Limited TB knowledge in the community
- Stigma and discrimination amongst communities and health care providers
- Poor participation and collaboration of some health care providers and community based workers.
- Misconception about TB
- Limited funding for community based activities

Recommendations

- Conduct more awareness so as to change the behavior of the society
- Awareness and capacity building of health care providers so as to reduce stigma
- The government and partners should allocate more funds to support community groups working in TB.

b) Treatment of TB.

Gaps

- Patients failure to complete treatment
- The health centers being far from the patient's residence
- The fear of losing their jobs especially to temporary workers

- Drug stock outs in some areas
- TB is associated with superstitious beliefs

Recommendations

- Education patients about the importance of completing treatment
- There is need to increase the participation to health care providers in TB care
- The patients who live far from the health centers should be given enough medicines for at least 3 months.
- There is need to strengthen care bag services (This is where Nurse or community health worker moves with a TB medicines to follow where the patients live).
- Use community media to create awareness about TB
- Implementation of the TB at workplace policy
- Ministry of health should order TB medicines based actual estimation
- Sensitize the community and the traditional healers about TB.

c) Coordination

Gaps

- There is no coordination of community group activities at the community level.
- Lack of community participation in developing the national strategic plan from the beginning and limited knowledge on the national strategic plan.

Recommendations

- The National TB program should ensure that there is coordination among the community groups at community level.
- The NTLP should ensure that communities are involved in the development of the national strategic plan from the beginning

d) TB case detection

Gaps

- Low awareness about TB in the community
- The health facilities are very far
- Some health facilities do not provide TB services
- Misconception about TB
- Poverty

- Poor TB knowledge of the health providers
- Case detection among children under 5 years is still very low
- Delays of TB screening results from laboratories
- TB patients being given treatment before testing through X rays.

e) TB/HIV integration

Gaps

- TB/HIV integration has not been effective for example there is a difference health services provided for HIV and those provided TB.
- Health policy does not draft TB as priority as it did to HIV, so the stakeholders and the society do not take TB as a burden that also concerns them.

Recommendations

- The integration of TB/HIV services should be strengthened from community to national level.
- The policy makers, stakeholders, and others should be motivated to see TB as a priority like how they did with HIV

2. UN High Level Meeting on TB, ACT, Stop TB partnership

This session was presented by Evelyn Kibuchi from STOP TB Partnership in Kenya and a representative ACT Africa. She said that for the first time in history, the high level meeting which include high ranking government officials from most countries of the world talked about TB and was then seen as the burden and killing many people. Before setting the priorities to the HLM, Olive presented a background of the HLM. The presentation helped the participant to understanding the HLM and process involved.

She also presented about ACT which stands for the African Coalition of TB Advocates. It was established under Stop TB partnership. For now, it is only in Ghana but wishes to be implemented in all African nations especially those with high burden of TB.

She also talked about what stop TB partnership is all about. And she said that, the biggest work for the partnership is finding new TB positive cases that are not yet found and make sure they get treatment also make sure that TB ends by 2030.

Discussion

- Participants agreed that MKUTA should look for a way to start and host ACT in Tanzania.

3. mHealth

Agatha from NTLP also presented.

- She stated that, they wrote a proposal for the Uhuru torch to carry TB message in it and they are still waiting for the answer from the government. They also wrote proposal to the donors to support that activity but they are also waiting for an answer from them.
- She also talked about TB caucus, where some members of the parliament are involved to be part of the team that fights TB. In the beginning if there was a MP wanted to participate she or he participated for free but for now they will have to pay a small amount of money to be part of it. The leader of the Tanzania TB caucus is very passionate and very hard working and hoping to see so many things from him.
- Agatha also said that, NTLP has introduced a way of accessing information about TB through a mobile phone which is by dialing *152*05#. Through this number, a person will be able to know if he or she has TB symptoms and be directed to the nearest health facility that provides TB services. If a person is found with TB, then she gets messages of encouragement and messages to remind her when to get her or his medicines.

4. Planning for World TB Day

Racheal presented steps to be taken in preparation for world TB day

- Identify stake holders
- Prepare brochures
- Meeting for the TB members and involve organizations that are working on HIV (the meeting should be hosted by NTLP)
- Preparation for the work of motivation and testing
- Preparation of the purchasing of the medical equipment
- Do evaluation of the event before and after the actual day of the event.
- Write report after the event.

Way forward

A way forward was presented by Olive Mumba from EANNASO as follows;

- Registration of the forum is under way.

- Work on the 3-year advocacy & strategic plan of the forum in early 2019.

Conclusion

The meeting was a success. Most of the invited participants were able to attend and the objective of the meeting was met. The participants also said that the meeting met their expectations.

Annex

List of Participants

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Agenda

Day 1: Thursday, 15th November 2018

Time	Session	Responsible	Session Chair
08:30-09:00	Arrival and Registration	Beatrice Mdobi	Rodrick Mugishagwe
09:00-09:30	Welcome Remarks and Expectation	Olive Mumba	
09:30-10:00	Opening Remarks	NTLP	
10:00-10:15	Introduction, Expectations, Leadership and Logistics	John Lyimo	
10:15-10:30	Workshop Objectives, Norms, Agenda	Rodrick Mugishagwe	
10:30-11:00	Tea Break	All	
11:00-11:30	Current Status and Community interventions	NTLP	
11:30-12:30	Local presentation on Intervention, Achievements, Challenges and Lessons leant	NACOPHA MKUTA SHDEPHA+	
	Stop TB Partnership Community Leadership and Mobilization Award	Maulid Ntahondi	
12:30-13:00	TTCF report 2018	Rodrick Mugishagwe	
13:00-14:00	Lunch	All	Rajabu Kimosa
14:00-15:00	Presentation by Implementing partners on Intervention, Achievements, Challenges and Lessons leant	MDH AMREF PATH/KNCV EANNASO	
15:00-16:00	Plenary Session Gaps identification and recommendation / CSO TB Priorities Charter	Dickens Bwana	

Day 2: Friday, 16th November 2018

Time	Activity Description	Responsible	Session Chair
08:30-09:00	CSOs priorities - Recap of Day 1	Rajabu Kimosa	Rachael Jacob
09:00-10:00	Introduction to <ul style="list-style-type: none"> • Global TB Action Plan • Africa Coalition of TB Activist • Africa TB Caucus 	Eveline Kibuchi – STOP TB Partnership Kenya	
10:00-10:30	Tea Break	All	
10:30-11:00	Introduction to <ul style="list-style-type: none"> • Tanzania TB Caucus • mHealth 	Agatha Mshanga - NTLP	
11:00-11:30	Introduction to TB HLM <ul style="list-style-type: none"> • Process • Declaration content 	Eveline Kibuchi – STOP TB Partnership Kenya	
11:30-12:00	Revisiting the <ul style="list-style-type: none"> • Tanzania CSOs Position statement • Advocacy road map 	Rodrick Mugishagwe	
12:00-13:00	Group Work <ul style="list-style-type: none"> • Developing Advocacy priority action Plan 	Claudio Msengezi	
13:00-14:00	Lunch		
14:00-15:00	Group work plenary discussion <ul style="list-style-type: none"> • Advocacy priority action Plan 	Claudio Msengezi	
15:00-16:00	Planning for World TB Day	Rachael Jacob - MKUTA	
16:00-17:00	Wayforward	Olive Mumba - EANNASO	
	Vote of thanks	MKUTA Bukoba	
	Closing Remarks	MDH	
	Closing	NTLP	
			Olive Mumba