

## Community Component in TB Reviews

This Guidance Note on Community Component in TB Reviews has been prepared to enable a consolidated understanding of this in the context of TB and to maximise the contribution of communities, civil society organisations and key affected populations (KAP's) in an effective TB response. It is not a set of instructions but is designed to stimulate and enhance thinking about the important and meaningful role that communities play in TB Control and how a comprehensive TB review should explore how communities are supported in a country's national TB response for greater impact.

### What is a TB Review?

The purpose of a TB Review is to assess a TB programme's development and to follow up on progress made in implementing previous TB review recommendations, and to identify challenges in order to effectively address them. TB reviews aim to make further recommendations on plans, pathways and operational approaches with the overall objective of informing the TB Control National Strategic Plans that contribute to the larger goal of global elimination of TB by 2050. Technical areas covered in a TB review vary but mostly focus on:

- Intensified Case Finding (ICF) through implementation of TB notification and improvement of surveillance systems
- Diagnostic and Laboratory network development and peripheral microscopy laboratories
- Scaling up and sustaining high-quality programmatic management of drug-resistant tuberculosis (PMDT) services.
- Childhood TB
- Advocacy and communications
- Community Involvement
- TB/HIV collaboration and modalities of joint activities between HIV/AIDS care and support and DOTS implementation
- Innovative strategies to engage the private sector for achieving universal access
- Provision of medium- and long-term technical assistance and coordination of TB control.

Information obtained through TB reviews is often used to further inform the following:

- Advocacy for domestic and international resource mobilization efforts
- Development of situational analysis, priority setting and development of work plans for Global Fund concept notes or consolidated proposals for phase- two Global Fund renewals.
- Assessment of progress towards the TB-related MDGs and the Stop TB Partnership national TB control targets.

What is often missing from this broad outline of TB Reviews is the Community Component. Without this component any review will present an incomplete picture with recommendations based on incomplete data which ultimately leads to a TB response that fails to address all of a country's TB needs

## What is the added value of Communities in the TB response?

Communities play an important role in addressing TB for the mere fact that they are the one who experience the lived reality of being affected by TB. This role is increasingly important due to the shift in understanding the need for integrated programming and delivery — not just of the biomedical side of health services but also of the social, education, legal services and economic support impact to accessing TB services. Community-based organizations and networks have thus a vital role to play in the development of such integrated and community-driven approaches to delivering health. In this context there are many services, and activities that communities deliver and take innovative approaches to:

- **Advocacy:** A function often misunderstood as negative and confrontational by governments and decision makers. However, advocacy has a positive role in highlighting TB and keeping it visible amongst many competing priorities. It is also important for encouraging legislative reform to remove barriers that impede certain KAP's to comfortably and safely access TB services, vital in the broader context of public health. The 'watchdog' function, so often undertaken by communities, particularly around quality of TB services, procurement and stock outs (of TB drugs), stigma and discrimination mitigation is an important and valuable conduit for reality based evidence that can inform the National TB Planning in service improvements.
- **Lived Experience:** The day to day experiences of communities with TB bring an understanding of what will and what will not work. Communities understand 'how' to deliver services effectively and to reach marginalised and hidden population groups. For example in certain regions women suffer disproportionately the consequences of TB even though TB affects men and women equally. They are often the last to get medical care and there are cultural and social barriers that negatively impact on a woman's access to TB services in such conditions. Communities groups that work closely with women or are run by women are vital for developing interventions that accommodate and address the specific TB needs of women.
- **Program Accountability:** There are community based systems that work towards making TB services accountable for example in Peru and other countries have community groups that meet and inform TB services such as Community Advisory Boards who are active around new TB drugs, assessing plans for clinical trials, overseeing research and advocating for price reductions. At a sub-regional level there may be Community Health Committees with a primary focus on access to TB treatment.
- **Direct Provision of Health services:** Communities also provide many services in collaboration with health services as well as separately. Communities participate in TB screening programmes, including supporting efforts for integrated screening of child health; they support retention in treatment programmes, including adherence support; they lead on stigma mitigation efforts and are often catalysts for change in attitudes and practices; they connect people to services; are flexible and responsive to needs and are important factors in what happens beyond the walls of the clinic. Communities support the continuum of care – from diagnosis, through treatment and ongoing care and support. Importantly, they disseminate TB prevention and risk reduction information in simple and easily understood language and empower people to be more TB aware, particularly among key affected populations.

With communities undertaking all of this work it is essential that the community component is included in TB Reviews. It is important that TB Reviews are balanced and look at both Health Services as well as the community services that support, reinforce and fill the service gaps that mainstream services are unable to cover.

## Involving Communities in TB Reviews

- **Communities as an integral part of the TB Review process:** The best approach is to include a community representative in all of the teams that are commissioned to undertake the TB Review. For example if there are six teams there should be a community representative in each one. This would help to mainstream community issues throughout the whole process and to ensure that the community components are addressed by each team. It would also help sensitise the review teams to community issues and enable 'buy in' to the importance of the community component. Close collaboration between community/ civil society organisations with the WHO Country Office and National TB Control Programme would help communities negotiate space on the TB Review Teams.
- **Community engagement needs to be budgeted for** and consideration should be given to capacitating community experts to understand the Review Process so that their participation is effective. This could be achieved through a one day training workshop for example and consideration could also be given to sensitising all reviewers on the importance of the community component.
- The **Terms of Reference** for the Team Leaders should include the requirement to support/facilitate the effective involvement of community representatives in the review process.
- It is key to ensure that Community Experts within the review teams are involved at every stage of the review process: Pre-review, planning and preparation, data collection, findings, recommendations and response.
- Furthermore it is important to develop review methodologies that are enabling because patient and community outreach discussions in clinics can often can serve the opposite purpose and instead isolate and stigmatise community members rather than encourage engagement. Therefore the process would be strengthened by assessing the most enabling methodologies, depending on the context. For instance including patient focus groups may be the best approach in certain settings in Africa and Asia while one to one patient interviews may be the preferred approach in certain settings.

These are simple and relatively straightforward actions that would help ensure that communities are meaningfully involved in any TB review process and would be further strengthened by modifying the guidance on methodology to reflect these actions.

## Framing the Community Component Questions

While the best approach is the inclusion of TB Community Experts in TB reviews, understanding the work that communities do in any area of TB control should not be the domain of TB community experts alone but needs to systematically be main streamed to all other experts involved with reviews. Ultimately each area of TB work should be looking at the community contribution where relevant. This final section thus looks at the kind of questions that should be considered when undertaking the TB Review as a whole in order to mainstream the contribution of communities. It is not a prescriptive list, and not all questions may be relevant to every country, but it is designed to stimulate thinking about the kind of information needed to gain a clear understanding of the range and effectiveness of the community component of any TB response.

***NB: These questions below should be considered even if a community representative is unable to be a part of the specific technical team.***

- Community Experts should ensure specific questions are asked and information gathered that relate to key affected populations.
- Are key affected populations identified and through which process are they identified?
- Are key affected populations the focus of the TB programme interventions?
- What are the plans for addressing the specific needs of key affected populations?
- Have these plans been developed in consultation with key affected populations and organisations who work with them?
- Is there an enabling environment for the inclusion of key affected populations in planning and implementation of TB programmes and at which level?
- How will TB care delivery be measured and monitored in the key affected population groups?
- There are several additional areas for inclusion of community components however, below are *Community Component Questions* which are provided for guidance in the priority areas of Prevention, Intensified Case Finding, Diagnosis Treatment, and TB/HIV Co-infection.

### **Prevention**

- Do community infection control programmes exist?
- Do they adequately reach hard to access, hidden and key affected population groups?
- What TB prevention activities are there at community level?
- What are the activities at community and household level and who is delivering them?
- Are HIV organisations active in TB prevention initiatives?
- Is there a dedicated budget for community activities linked to the overall area of prevention?

### **Intensified Case-Finding**

Questions here should be about determining the extent of community involvement?

- What ICF activities are there at community and household level and who is delivering them?
- What is the level of knowledge of TB Symptoms, especially among KAP's?
- Where and how does case finding occur and any barriers to effective case finding?
- Are there specialised services targeting hard to reach, hidden or Key Affected Populations?
- Are HIV organisations screening for TB? Are ICF programmes integrated for example with Harm Reduction, HIV and maternal and new-born child health programmes?
- Is there a budget for community activities in this section?

### **Diagnosis**

- The review should be looking at how accessible diagnostic services, particularly for KAP's?
- The existence of any formal or informal community based referral system for KAP's?
- Are the monitoring and evaluation tools available to capture the number of community referrals? Are Health Care Workers sensitised to deal appropriately with KAP's?
- Is there sufficient education around sputum collection and what role do community based organisations play in collecting sputum?
- What is the communication process around Lab results and what are the timings associated with this?
- Are there effective referral, tracking and feedback systems in place?
- Is the contribution of community based organisations measured and captured?
- Is there a dedicated budget for community activities linked to the area of diagnosis?

## **Treatment**

It is important to explore if there are any barriers to equitable access to TB treatment:

- What are the barriers?
- Who finds it most difficult to access TB treatment?
- Are plans in place to overcome any barriers?
- One of the barriers might be the location of treatment centres so finding out where treatment is provided and if there are any treatment programmes based within community based organisations would be important?
- Other areas to be considered would be around the availability of community centred drug distribution points?
- How sensitive and responsive are treatment services to KAP's lifestyles, such as convenient opening times etc.?
- Are there specialised services targeting hard to reach, hidden or Key Affected Populations?
- Are services integrated for example with Harm Reduction, HIV and maternal and new-born child health programmes?
- Are HIV organisations screening for TB?
- What is the level of community involvement in treatment adherence support and what other kinds of support is being provided and by whom?
- What are the services at community and household level and who is delivering them?
- Consideration should be given to assessing the waiting time to initiate MDR Treatment and if there are any de-centralised DR/MDR services available?

It should be understood that this type of analysis is about understanding where treatment gaps are and how and by whom the gaps may be addressed?

Given the special challenges associated with child hood TB it would be important to ascertain what support is available for parents with a child on TB treatment and who is delivering the support?

- Is IPT available for child contacts?
- And what are the barriers for accessing treatment for children?
- Is there a dedicated budget for community activities linked to the overall area of treatment?

## **TB/HIV Co-infection**

- TB is the biggest additional health threat to people living with HIV and it is important to understand how TB and HIV services are linked to support those who are co-infected?
- Who is delivering the support and what are the barriers to effective treatment, care and support?
- Are there specialised services targeting hard to reach, hidden or Key Affected Populations?
- Who is providing HIV counselling and testing for TB patients?
- How much treatment adherence support is available and who is delivering it?
- Is there a dedicated budget for community activities linked to TB/HIV co-infection activities?

## **Conclusion**

TB Reviews are an important tool in 'Knowing your TB epidemic', understanding the scope and effectiveness of the existing TB response efforts and who is doing what and for highlighting gaps and areas that need improvement. But the outputs from a TB Review will only be as good as the inputs that are received which is why adding and exploring the Community Component is essential.

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