

Guidance Document on **Community Engagement under National Tuberculosis Elimination Programme**

September 2021



This Guidance Document is meant for State and District TB Officials to engage with community in India's TB elimination efforts.

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Message



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PREFACE




As a signatory to the Political Declaration during the first ever United Nations High Level Meeting on Tuberculosis (TB), India is committed to eliminating TB, an infectious disease that remains a major public health challenge in India. The vision of TB free India has been energized by the clarion call of Hon'ble Prime Minister of India to end TB in the country by 2025, five years ahead of the Sustainable Development Goal of ending TB by 2030.

India is also committed to strengthening focused investment in communities and the provision of person-centered care. Community-based TB elimination efforts cover a wide range of activities contributing to prevention, diagnosis, improved treatment adherence and quality of care that positively influence the outcomes of drug-susceptible, drug-resistant and HIV-associated TB.

In this context, and in consonance with our commitment to achieve TB elimination, I am pleased to present the "Guidance Document on Community Engagement under National Tuberculosis Elimination Programme" in India. This document provides a set of strategic steps and activities for effectively engaging the communities so that they are aware, informed and empowered. The relevant key subsets of the community such as TB survivors, institutional TB forums, vulnerable populations groups and Patient Support Groups have been identified in this document for in-depth engagement and participation.

I am sure this guidance document will further enrich the nation's efforts and commitment to achieve a TB-free society.

TB Harega, Desh Jeetega!


(Arti Ahuja)

Message



Dr. Sudarsan Mandal, MD
Deputy Director General
Head, Central TB Division
Project Director, NTEP



सत्यमेव जयते



MESSAGE

A TB-free India by 2025, five years ahead of the Sustainable Development Goals, is the future envisioned by our Hon'ble Prime Minister. To achieve this goal, the Government of India through the National Tuberculosis Elimination Programme (NTEP) has various strategies and mechanisms in place.

One such important strategies is the Community Engagement which is being operationalized through the States/ UTs across the country. Through the various experiences and learnings from the field, Central TB Division has collaborated with the partners to develop the Guidance Document on Community Engagement under NTEP. This document aims to support and strengthen the existing efforts of the States/ UTs to meaningfully engage the community. The document encourages to provide maximum platforms to have more interactions with the community thereby bringing about mutual trust and respect.

I am confident that the States & UTs will find this document useful in implementing the community engagement strategies. I also encourage the States & UTs to adapt the document to the local environment and accordingly make the modifications.

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Acknowledement

The the Set of Guidance Documents on Community Engagement has been developed to strengthen community's participation in India's mission to End TB by 2025.

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We hope the operational guidelines will support the States/ UTs for strengthening community engagement in all aspects of the TB services thereby achieving our target to end TB by 2025

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Introduction to the Guidance Documents on Community Engagement

Community engagement is a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes (WHO, 2017). Community engagement aids in strengthening the trust between the community and national programmes by providing a platform for the community to have their voices heard, their views considered and acknowledged. It ensures that they are informed of, and involved in issues which may impact their lives. Community engagement also helps in enhancing accountability of health services and improving the quality of care.

Community can play a critical role in the mission to end TB by supporting early case identification, full treatment and rehabilitation of TB patients, scale-up of TB prevention interventions, reducing stigma and discrimination related with TB, and in addressing the social determinants of TB.

The National TB Elimination Programme is envisaging to engage community through the following strategies:

- ❖ Establishing platforms for community to regularly interact with policy makers and programme managers and share their concerns, feedbacks and inputs for the programme.
- ❖ Promoting community participation in decision-making processes, planning and implementation of programme activities, service delivery and monitoring & evaluation
- ❖ Empowering TB survivors and affected populations to act as change agents and leaders of community movement against TB.
- ❖ Partnering with community level organizations and leverage existing community platforms for enhancing the reach and effectiveness of TB services.

Different steps required for the above have been initiated at the national level and the States and districts are now required to take these measures to the field levels. A set of guidelines/advisories in this regard are being shared by CTD for adoption by the States/UTs, and are listed below:

1. Guidance for Engaging with TB survivors and TB affected populations in TB Elimination
2. Guidance on TB Forums as an institutional platform for engaging with community.
3. Guidance for Engaging with Community Structures to drive and sustain Tuberculosis control initiatives within Communities, specifically vulnerable population
4. Guidelines for Establishing Patient Support Groups (PSGs) to drive and sustain community support for TB treatment and rehabilitation of TB patients

Each guidance provides the details of the intervention, steps required to be undertaken by the State/UT, financial aspects

(including incentives as applicable) and monitoring indicators. Relevant training materials are available on CTD website.

Additional guidance on PRI engagement, quality improvement measures with community participation, working with vulnerable populations, etc will be issued shortly.

While implementing the above, the following basic principles may be considered:

- ❖ Building trust and relationships and getting commitments from community leadership and other influencers for TB elimination is key to community engagement.
- ❖ Community engagement can only be sustained by identifying and mobilising community assets and strengths and by developing the community's capacity and resources to take decisions and subsequent action.
- ❖ Programme should be prepared to be flexible with the community's needs and sharing power with the community.
- ❖ Community collaboration requires long-term commitment.

State/UT and Districts shall make best use of the guidance provided to make the community led mission to end TB a reality.



Engaging with TB Survivors and TB Affected Communities in National TB Elimination Programme

Guidance to States/UTs for Engaging with TB Survivors and TB Affected Communities in National TB Elimination Programme

1. Introduction

The engagement of TB Champions is a priority for the National TB Elimination Programme, as outlined in the National Strategic Plan for 2017-25. A TB Champion is a TB survivor who has been trained using the standard training curriculum and is willing to work actively in the community for TB elimination. TB Champions can play a critical role in helping India achieve ending TB by 2025 and should be systematically engaged, in order to establish a community-led response to TB.

2. Scope

This document provides guidance on the identification, training, engagement, monitoring and incentivising of TB Champions at the state and district levels.

3. Identifying TB Champions

- ❖ NTEP staff, particularly those at the district and sub-district levels, can identify TB survivors as potential TB Champions from among people who have been cured of TB.
- ❖ TB survivors can also be identified through partner organisations, particularly those working with the private sector, through PPSAs etc.
- ❖ Care must be taken to ensure that only those TB survivors who are genuinely interested in working as TB Champions are selected for the capacity-building workshop and subsequent engagement.
- ❖ Care must also be taken to ensure a careful balance of TB Champions in terms of sex, gender and age to the greatest extent possible.
- ❖ The participation of women, transgender persons and representatives from various vulnerable populations is essential.
- ❖ Survivors of drug-resistant TB and extrapulmonary TB, in addition to those who have had drug-sensitive TB, must also be identified.

Criteria for Identifying Potential TB Champions

- ◆ Must be a TB survivor.
- ◆ Must be willing and eager to participate in the TB response.
- ◆ Must be willing to speak publicly about personal experience of TB.
- ◆ Must be willing to attend the capacity-building workshops and other meetings.
- ◆ Must be able to travel within the district/block.
- ◆ Must be willing to work as a TB Champion in the community and spend time as and when required. Some TB Champions will be able to dedicate more time than others and this is to be expected.

1. Training TB Champions

- ❖ TB survivors are trained as TB Champions through a standardised curriculum, available on CTD website. This comprehensive curriculum helps a TB Champion to strengthen their understanding of TB and develop skills for effective advocacy, communication and provision of peer support to people with TB.
- ❖ States who have identified TB survivors may contact CTD or the partner organisations working in the area for support with the capacity-building workshop at state or district levels.
- ❖ Only those TB survivors who complete the prescribed capacity-building may be referred to as TB Champions.
- ❖ Local facilitators for the workshop can be identified based on the sessions, including Medical Officers/WHO Consultants for the technical sessions, experienced TB Champions to co-facilitate some sessions and representatives of partner organisations for others.
- ❖ TB Champions shall also be offered ongoing training in areas which are identified by the State/UT or CTD, from time to time. These could be in the form of refresher training or mentoring under programme personnel/other TB champions or participation in different meetings.

2. Engaging TB Champions

- ❖ Trained TB Champions are motivated to work among their communities and can be engaged in several different ways and for different purposes. Some are listed below:
 - As peer supporters, supporting people with TB
 - To support the families of TB patients with health education, emotional support, etc
 - To organise community meetings for TB awareness creation, case finding, treatment support, etc.
 - To facilitate anti-stigma campaigns
 - Gather feedback for the programme
 - Support primary health care teams and TU teams in organizing field level activities.
- ❖ TB Champions shall be provided with necessary communication materials on TB and other requisite materials, as required.
- ❖ States are encouraged to work in coordination with CTD and partners to develop engagement modalities specific to their needs.
- ❖ IEC materials featuring TB Champions must be developed and widely disseminated.
- ❖ TB Champions must be made members of TB Forums and have the opportunity to speak freely and express their views at forum meetings.

- ❖ TB Champions shall be included as part of various committees, working groups etc. It is important to have the participation and contribution of a TB Champion in all discussions and not just restricted to discussions on community engagement.
- ❖ TB Champions shall be invited to monthly and quarter meetings of the NTEP and given opportunities to share their views.
- ❖ TB Champions shall be included as part of monitoring missions including the Joint Monitoring Mission, CIE etc.

Potential activities of a TB Champion

- ❖ Identify people with symptoms of TB and refer them for testing
- ❖ Personally accompany people to facilities to ensure they get tested promptly
- ❖ Participate in active case finding drives and educate people on TB
- ❖ Provide psychosocial and peer support to Persons with TB
- ❖ Motivate Persons with TB who dropped out of treatment to resume taking their medication and complete treatment successfully
- ❖ Visit Persons with TB and families for preparing families as care givers, address issues around stigma and motivate household contacts to undergo TB screening and treatment whenever required.
- ❖ Motivate people affected by TB to talk openly about TB
- ❖ Organize community meetings and address them on TB in local languages and dialects.

6. Incentivizing TB Champions

- ❖ The contribution of TB Champions must be recognised and rewarded through a set of incentives available to them.
- ❖ They shall be provided necessary support, especially for transport, to undertake different activities as planned by the State/District.
- ❖ They shall also be eligible for incentives available under the programme for informants, community treatment supporters, active case finding volunteers, etc.
- ❖ States shall design a set of non-monetary incentives, including, but not limited to the following:
 - Opportunity as trainers for State/district-level capacity-building workshops.
 - Recognition of their efforts at District, State and National levels.
 - Continued capacity-building and training opportunities, on TB, public speaking, effective communication etc.
 - Opportunities to speak and share their inspiring stories at various meetings and platforms.
 - Featuring TB Champion's work and contribution in various reports, communiques, publications, etc
 - Provision of Badge/ID Card/Diary as 'TB Champion'.
 - Provision of toolkits with different communication materials and education tools for supporting their work.

The above list is only indicative, but not exhaustive. The State/UT or District shall select and/or add, as deemed appropriate.
- ❖ States can make provisions in their PIP for these incentives, based on their planned engagement.

7. Monitoring TB Champions

The engagement of TB Champions and their efforts shall be monitored at various levels and the following are suggested:

- ❖ There must be a single point of contact within the NTEP for TB Champions who are being engaged by the programme.
- ❖ Regular monthly or quarterly review meetings must be held to understand the progress of activities of engaged TB Champions, using key indicators as suggested below:
 - Number of TB survivors identified as TB Champions
 - Number of TB survivors trained as TB Champions
 - Number of presumptive TB patients referred by TB Champions
 - Number and % of TB patients visited by TB Champions
 - Number and % of treatment interrupters/LFU retrieved back with involvement of TB Champions.
 - Number and % of Patient Support Group meetings participated by TB Champions
 - Number of community awareness events participated by TB Champions
- ❖ TB Champions shall be provided with standard reporting templates based on the nature of engagement. TB Champions must be trained to use these formats. They shall report to the MOTC/DTO on the following on a periodic basis:
 - Number of presumptive TB patients referred for diagnosis
 - Number of TB Patients visited
 - Number of households visited for education, contact tracing
 - Number of community events participated
 - Number of Patient Support Group meetings participated
 - Number of advocacy meetings conducted
- ❖ Routine data validation and verification practices must be followed to validate data submitted by TB Champions and give them feedback.
- ❖ States can explore the use of digital data collections tools, based on the profile of TB Champions.
- ❖ The TB Champions can also be linked to the state-level survivor-led network or its district chapters for continued mentoring support.
- ❖ Best practices in engagement of TB Champions and success stories must be documented and shared widely.

8. TB Champion registration on Nikshay

- ❖ TB Champions can be enrolled on Nikshay so that their services are available to TB patients on treatment. Detailed guidance in this regard will be shared separately.
- ❖ TB Champions can also be encouraged to use and popularise the TB Aarogya Saathi App.

9. Financing TB survivor engagement

- ❖ States/UTs shall budget TB Survivor and affected community engagement under NTEP in the State/UT NHM PIP. The funding can be for the following:
 - Capacity building of TB Survivors as TB Champions
 - Support to TB Champions for undertaking activities
 - Expenses for non-monetary incentives for TB Champions
 - Any other activities for promoting TB champion engagement in NTEP.

Role of TB Champions

Based on experiences of States and partner organizations, and feedback from TB Champions themselves, the role of a TB Champion is currently envisaged as five-fold:

1. **Supporting people with TB:** As survivors, TB Champions are considered 'peers' of people with TB and their families, and as such, can provide peer support to TB-affected communities. As a TB survivor, a TB Champion is best placed to use his or her own personal experience of TB to inspire and motivate someone currently on treatment. They can provide compassionate support, sometimes extending beyond TB to other health issues. They can also link people with TB to survivor-led networks and local support groups, thus helping them become part of a larger community and dispelling the loneliness that often accompanies a TB diagnosis.
2. **Improving community awareness of TB:** TB Champions can play a significant role in dispelling myths and misconceptions around TB and improving understanding of the disease among their communities. They can do this through community meetings in their communities, villages, towns and cities. At the meeting, the TB Champions can share their personal stories, thereby also helping to address issues of stigma and motivating other people with TB to speak up as well. They can share essential information on TB including its symptoms, where to go for diagnosis and treatment and the social support available for those affected. TB Champions can help create a supportive environment and encourage people with symptoms of TB as well as people with TB to come forward and seek timely care.
3. **Carrying out advocacy:** TB Champions can help raise the profile of TB among local community leaders and influencers including elected representatives, PRIs, industry leaders and business persons and the media among others. For instance, through one-to-one advocacy, TB Champions can call on elected representatives to play a greater role in efforts to end TB and galvanise action within their communities.
4. **Reducing stigma in the community:** As TB survivors, TB Champions can play a particularly powerful role in addressing issues related to stigma and discrimination. They can support people with TB who could be facing stigma or discrimination, whether within their families, workplaces, communities or health facilities. This is further described in the NTEP's Strategy to address stigma and discrimination.
5. **Provide real-time feedback to the health system:** TB Champions are a valuable and tangible link between the TB programme and the community at large. They can help identify any issues or challenges faced by people with TB and not only bring them to the programme's attention without any delay but also support the process of finding a solution.



TB Forums:
The Institutional Mechanism for Community Engagement under
National Tuberculosis Elimination Programme

TB Forums: The Institutional Mechanism for Community Engagement under National Tuberculosis Elimination Programme

1. Introduction

Community engagement has been identified as a key to the success of the NTEP programme with critical role of community in demand generation as well as in ensuring accountability of the programme to the community. TB Forum has been envisaged as an important mechanism for facilitating community engagement, by way of providing a platform for the community and the programme to come together and deliberate on various aspects of the programme. TB Forums are established at National, State and District levels.

2. Scope

This guidance document is intended to guide the States/UTs and Districts for constituting TB Forums at State/UT and District levels and for ensuring functioning of the State/UT/District TB Forums as the platforms for community engagement, with adequate participation and meaningful discussions by community members and other stakeholders for achieving the TB elimination goals.

3. Objectives of TB Forum

TB Forums are established with the following objectives:

- ❖ To engage with policymakers and implementers to ensure justice, rights and dignity of TB patients for effective service delivery.
- ❖ To supplement and complement government initiatives to enforce TB patient- friendly law, policy and programs.
- ❖ To reduce stigma and discrimination and ensure social security of TB patients, survivors and their families.
- ❖ To improve awareness on various government schemes, provisions, facilities available for TB patients and to improve treatment literacy and adherence among TB patients
- ❖ To engage in evidence base advocacy with the stakeholders to expand services.

4. Guidance on constitution and functioning of State/UT TB Forum

State/UT TB forums to be formed and functioning as per the composition and ToR mentioned below:

4.1. Composition of State TB Forum

- The State TB Forum shall be chaired by the Principal Secretary/Secretary (Health)
- The Mission Director (NHM) shall be the co-chair.
- Members shall include
 - ✦ Community representatives such as TB Champions, TB affected community representatives (such as relatives of the patients), TB survivor network representatives, PLHIV network representatives, etc

- ✦ Representatives of health department such as Director Health Services, Project Director – State AIDS Control Society, Officials from NHM SPMU, NPCDCS, RCH, NUHM etc
- ✦ Representatives from NGOs such as partner organisations, NGOs working in the State/District.
- ✦ Representatives of different departments such as Panchayati Raj, Rural Development, Social Welfare, Tribal Affairs, etc
- ✦ Representatives from academia, corporate sector
- ✦ Representative of TB Association, Professional Associations like IMA
- ✦ WHO NTEP Consultants.
- State TB Officer shall be the member secretary of the State TB Forum
- Special Invitees & Additional members (such as District TB Forum representatives) shall be co-opted by the Forum as and when required with approval of the Chairperson.
- The tenure of non-official members shall be for 2 years.

4.2. Terms of Reference of State TB Forum

- To advice on strategies for engaging communities affected by TB and increasing community participation in TB program
- To periodically review progress of involvement of community and network of people affected by TB in the programme
- Highlighting the concerns and needs of TB patients, to work with government and a broad range of individuals and organisations to develop better, and more responsive, health services.
- Enabling a dialogue between all stakeholders involved in a TB patient's care such as government (including local self-government), medical and paramedical associations, industry, the medical insurance companies, private healthcare providers and diagnostic centres.
- Facilitate nutritional support, linkages with social welfare schemes, and rehabilitation of TB patients.
- Facilitate redressal of grievances of TB patients

4.3. Frequency of meetings of State TB Forum

- The State TB Forum shall meet every six months.

4.4. Secretariat of State TB Forum

- State TB Cell shall act as the secretariat of State TB Forum.

4.5. Financial Support for functioning of State TB Forum

- The expenditure for meetings such as cost of venue, refreshments, stationary, communication and TA/DA for non-official members to attend the meeting shall be borne by the State TB Cell under NTEP.
- In addition, funds required for any other activity decided by the State TB Forum in connection with its ToR shall be borne under NTEP.
- Necessary funds shall be budgeted under NHM PIP by the State/UT.

1.6. Suggested agenda points for State TB Forum meetings

The TB Forums shall include the following agenda points in its meetings:

- An update on the initiatives taken by the programme to engage with community.
- Sharing of community's concerns & feedback:
 - ✦ Sharing of community concerns and feedback by the State TB Forum community representatives.

- ✦ Presentation on community concerns shared during the District TB Forum meetings
- ✦ Presentation on feedback received from community through any other mechanism.

(This to be followed by a discussion to identify action points at various levels to address these issues.)

- Action taken by the State/Districts on decisions in previous forum meetings.
- Plans & updates by various stakeholders (Govt departments & agencies, NGOs, media, other health programmes, etc) in TB elimination and in providing quality care.
- Information on newer initiatives in the programme for the TB Forum members.

5. District TB Forum

District TB Forums are to be established in all revenue districts. In case of having more number of NTEP districts, the DTO in charge of District Head Quarter shall look after the work of the District TB Forum. The composition and ToR of the district TB forum shall be as below:

1.1. Composition of District TB Forum

- The District TB Forum shall be chaired by the District Magistrate/District Collector
- The Chief Executive Officer of Zila Parishad/District Panchayat shall be the co-chair.
- Members shall include
 - ✦ Community representatives such as TB Champions, TB affected community representatives (such as relatives of the patients), TB survivor network representative ,PLHIV network representatives, etc
 - ✦ Representatives of health department such as Chief Medical/ Health Officer, Officials from NHM DPMU, NPCDCS, RCH, NUHM etc
 - ✦ Representatives of PRI
 - ✦ Representatives of NGOs such as partner organisations, NGOs working in the State/District.
 - ✦ Representatives of different departments such as Panchayati Raj, Rural Development, Social Welfare, Tribal Affairs, etc
 - ✦ Representatives from academia, corporate sector, media, legal experts, etc
 - ✦ Representative of TB Association, Professional Associations like IMA
 - ✦ WHO NTEP Consultants.
- District TB Officer shall be the member secretary of the District TB Forum
- Special Invitees & Additional members shall be co-opted by the Forum as and when required with the approval of the Chairperson.
- The tenure of non-official members shall be for 2 years.

1.2. Terms of Reference of District TB Forum

- To advice on strategies for engaging communities affected by TB and increasing community participation in TB program
- To periodically review progress of involvement of community and network of people affected by TB in the programme
- Highlighting the concerns and needs of TB patients, to work with government and a broad range of individuals and organisations to develop better, and more responsive, health services.
- Enabling a dialogue between all stakeholders involved in a TB patient's care such as government (including local self-government), medical and paramedical associations, industry, the medical insurance companies, private healthcare providers and diagnostic centres.

- Facilitate nutritional support, linkages with social welfare schemes, and rehabilitation of TB patients.
- Facilitate redressal of grievances of TB patients.

5.3. Frequency of meetings of District TB Forum

- The District TB Forum shall meet at least once in every six months.

5.4. Secretariat of District TB Forum

- District TB Cell shall act as the secretariat of District TB Forum.

5.5. Financial Support for functioning of District TB Forum

- The expenditure for meeting such as cost of venue, refreshments, stationary, communication and TA/DA for non-official members to attend the meeting shall be borne by the District TB Cell under NTEP.
- In addition, the funds for any other activity decided by the District TB Forum in connection with its ToR shall be borne under NTEP.
- Necessary funds shall be budgeted under NHM PIP by the District.

1.6. Suggested agenda points for District TB Forum meetings

The TB Forums shall include the following in the meeting agenda:

- An update on the initiatives taken by the programme to engage with community.
- Sharing of community's concerns & feedback
 - ✦ Sharing of community concerns and feedback by community representatives in the District TB Forum
 - ✦ Presentation on feedback received from community through any other mechanism.

(This to be followed by a discussion to identify action points at various levels to address those issues.)

- Action taken by the District on decisions in previous forum meetings.
- Plans & updates by various stakeholders in TB elimination and in providing quality care.
- Information on newer initiatives in the programme for the TB Forum members.

6. Monitoring of State/District TB Forum Functioning

- The functioning of State/UT/District TB Forums shall be monitored based on following indicators:

Quantitative indicators (to be submitted on quarterly basis)

- ✦ Status of constitution of TB Forum in State & Districts.
- ✦ State/UT and District wise number of meetings conducted by State TB Forum and District TB Forums during the quarter.
- ✦ Number & percentage of State/UT/District TB Forum meetings in which community representatives participated.

Qualitative indicators (to be submitted within 2 weeks of meeting)

- ✦ Concerns raised by community representatives in the State/District TB Forum meeting and action points identified for addressing them.
- ✦ Support generated for TB services from different departments, NGOs, corporate sector, etc through the TB Forum meeting.
- ✦ States shall intimate the date of State TB Forum meeting to CTD in advance for preparing a calendar of TB Forum meetings. Similarly, Districts shall intimate the date of District TB Forum meetings to the State.
- ✦ Districts shall share a report on District TB Forum meeting with a copy of minutes of the meeting with the

State, preferably within 2 weeks of conducting the TB Forum meeting. The report shall list out key issues raised by community, which needs action at State and National levels.

- ✦ States shall compile reports received from Districts and key issues which need action at State level & national level. The report shall be discussed at State TB Forum meeting and actions to be undertaken at State level shall be identified. Any issues which need action at national level shall be informed to the Central TB Division within 2 weeks of conducting the State TB Forum meeting. States shall also share the copy of minutes of the State TB Forum meeting, as and when it is issued.



Guidelines for Engaging with Community Structures to Drive and Sustain Tuberculosis Elimination Initiatives within Communities, specifically Vulnerable Populations

Guidelines for Engaging with Community Structures to Drive and Sustain Tuberculosis Elimination Initiatives within Communities, specifically Vulnerable Populations

1. Introduction

Comprehensive and sustained efforts to eliminate TB are crucial, yet unattainable without the trust, involvement and ownership of communities where TB is most prevalent. Engagement with community structures is an innovative and sustainable approach that has proven to help make TB programs at the community level more responsive and effective. Community structure involvement helps reduce stigma associated with TB, increase demand for TB services, deepen our understanding of needs of communities, complement the TB control efforts of the health systems, reach the most marginalized community groups, fill the gap of “missing cases and finally help address diversity within communities. Integrating this initiative across states will help strengthen community driven TB response approach.

2. Scope

This guiding document has been prepared to assist the State and district NTEP teams clarity and the relevance of engaging with local community structures for TB control. This guiding document is aimed to help the teams devise clear implementation roadmaps and to adopt and integrate this initiative into the state and district PIPs as part of Community Engagement activities for TB elimination.

3. Key steps for State and district programme managers to engaging with community structures

3.1. Understanding a community structure

- I. A community structure refers to a semi- formal or formal/ organized and decentralized network of individuals representing a certain group (men/ women/ transgenders/ youth from marginalized or vulnerable communities/ informal and unorganised workers) in a defined geography, having a shared agenda and a welfare mandate, with its own operational systems and leadership.

3.2. Mapping of high risk pockets in respective TU/DTC with local community & frontline workers

- i. Conduct a social mapping exercise for each TU/DTC area
- ii. Ensure participation from men, women, community leaders, religious leaders, local influencers and health functionaries
- iii. Draw a map of the local area, with chalk on the open ground, and mark out organizations working for the welfare of the community. These may included self-help groups, slum development associations, youth associations, labour unions, faith-based organizations, Village Health Sanitation and Nutrition Committees (VHSNCs), CBOs of vulnerable communities and NREGA groups.

- iv. Engage in discussions with the community to identify the most active structures in the area.

3.3. Conduct consultations with the community structures

- i. After the identification of the structures, have informal discussion with members of these structures individually.
- ii. Understand the goals, objectives, the number of members and reach of each structure
- iii. Prioritise these consultations with structures operating in areas with high burden of TB.
- iv. Through these consultations, assess the willingness of the structures to work for TB awareness and community health.

3.4. Apply the selection checklist to identify appropriate structures

- i. To see which of the community structures fulfilled the engagement criteria.
- ii. The criteria include a) Number of members, b) Regularity of meetings, c) Initiatives undertaken by the community structure for social welfare, d) Willingness to participate in health and TB initiatives.

3.5. Record details of the Community structures

- i. Enter the details of each community structure into a standard template to help tracking.
- ii. The template will include the following: a) name of community structure, b) Name of TU/DMC, c) name of DTC, d) Unique Id assigned to the community structure, e) type of community structure (SHG, Slum association, VHSNC, CBO, youth groups, labour union etc), f) date of initiating health and TB activities, g) activities supported by the CS, h) name of the CS leader, i) contact number of Cs leader

| Sl. No. | Name of Community structure/ | Name of TU | Name of DMC | Unique ID of community structure (will be generated by concerned M&E) | Type of community structure (see the code list) | Date of initiating TB activities | Activities supported by the community structure (see code list) | Name of Person Incharge with Location/Landmark | Contact No. |
|---------|------------------------------|------------|-------------|---|---|----------------------------------|---|--|-------------|
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3.6. Training community structure leaders

- i. Capacity building for community structure leaders in a two-day training process.
- ii. The topics to cover in the training may include:
 - Objective and expectation setting
 - The potential of community structures
 - The importance of listening and sharing
 - Building motivation and self esteem
 - Understanding the basics of TB
 - Understanding the experience of TB patients
 - Health as a right
 - Prioritising vulnerable communities
 - The importance of community influence
 - The role of community leadership

- Preparing for real life scenarios
 - Support system available to patients
 - Formulating action points and way forward
- iii. The training module for community structures is available on CTD website.

4. Suggested activities by Community Structures

- i. Creating awareness and mitigating stigma. This involves:
 - Act as community influencers
 - Lead community engagement and awareness activities in their locality
 - Conduct campaigns/ events to promote positive messaging around TB
 - Influence family members for stigma mitigation (particularly against women)
 - Convey health messages and support the needs of individual TB patients such as nutrition support and sponsoring transport costs etc
 - Act as a link between the TB patients, communities and the structures of which they are members.
- ii. Promoting Health seeking behaviour and TB detection. This involves:
 - Establishing Health Information Centres (HIC) in communities: HICs are easily accessible sources of information on TB within communities, owned and operated by members of community structures in the area.
 - Sensitize community members about TB and help improve their health seeking behaviour.
 - Refer TB symptomatic persons for testing and treatment.
- iii. Conduct health camps and other health promotion events
 - Conduct health/ screening camps or other health related events (both TB and non-TB) to address the needs of the groups they represent
- iv. Advocacy and networking:
 - Actively network and collaborate with other community structures operating in the area to support patients, especially those with higher risks.
 - Attend patient support group meetings, and facilitating sessions such as the preparation of nutritious food.
 - Support advocacy efforts by TB patient advocates to improve quality of services
 - Develop a feedback loop with the NTEP at facility, district and state level to ensure patient friendly and quality services.

5. Monitoring community structures

- i. The community structure engagement can be tracked and monitored using the following monthly indicators:
 - Number of sensitizations for CS
 - Number of CS members trained
 - Number of regular monthly meetings held with CS
 - Number of learning visits organized for members of CS
 - Number of IEC tools created for CS
 - Number of awareness campaigns and events conducted by CS
 - Number of persons identified and referred through CS

- Number advocacy meetings conducted by CS collaboratively with TB patient advocates
 - Number of persons tested positive for TB who were referred through CS
 - Number of patients linked to social entitlements and other support through CS
 - PSGs supported by CS (space, sessions, facilitation etc.)
 - Number of CS who mobilized local resources to support TB patients and families
 - Number of events/ efforts conducted collaboratively between local community structures and with NTEP
- ii. Some of the outcomes that can be tracked are:
- Increased participation of community structures in stigma reduction activities (awareness campaigns, events)
 - Increased number of community structures mobilizing local resources (cash or kind) for needy patients and families
 - Improved linkages for nutrition and counselling support for TB patients and families
 - Improved TB case detection through participation of community structures
 - Increased collaboration/ networking among community structures to take collective actions for awareness, stigma mitigation and patient support

2. Incentivising community structures – A few suggestions.

- i. Activity based incentives: As per the GOI guidelines, informant incentive of 500 INR per patient diagnosed with TB and 1000 INR or 5000 INR for every patient cured is available. Issue a circular to transfer the amount to the community structures which helped in case detection and treatment completion of TB patients.
- ii. Include community structure involvement as an activity into the state and district PIPs with required budget allotted for training them.
- iii. Non monetary incentives like facilitation by local rotary/MP/MLA etc.
- iv. Recognition during World TB Day
- v. Invite to participate in various meetings and share their experience
- vi. Showcase the work of Community Structures through TB communique, events & publications.
- vii. Naming a TB Diagnostic/treatment facility after a very active TB Champion.

Annexure 1: Community Structure Identification Checklist

| S.No. | Criteria | Yes | No |
|-------|---|-----|----|
| 1. | Does the community structure have a goal or vision? | | |
| 2. | Does the community structure have proactive and involved leadership? | | |
| 3 | Does the community structure currently work on health and related issues? | | |
| 4 | Does the community structure have regular or registered members? | | |
| 5 | Does the community structure conduct regular meetings? | | |
| 6 | Does the community structure have the support, trust and goodwill of the larger communities where they operate? | | |
| 7 | Do they represent any vulnerable population group? | | |
| | Total score | | |

If there are more than four ticks under the 'yes' column, frontline workers may proceed to engage with that community structure.



Guidance for Establishing Patient Support Groups (PSGs) to drive and sustain community support for TB treatment and rehabilitation of TB Patients.

Guidelines for Establishing Patient Support Groups (PSGs) to drive and sustain community support for TB treatment and rehabilitation of TB Patients.

1. Introduction

Role of Patient Support Groups (PSGs) in supporting care of chronic conditions is well established. Meetings of PSGs in TB enable patient friendly interactions, which help address psychological issues and overcome stigma. They also serve as platform for TB patients and their caregivers to support one another by sharing experiences regarding treatment, as well as their concerns. PSG meetings also facilitate interaction between doctor and patients and their care givers, addressing some of the common issues related to treatment and side effects. This in turn, builds confidence among patients regarding treatment which becomes an enhancing factor for adherence.

PSGs are founded on the belief that peer support can potentially help patients deal with challenges that they face during their treatment period, including the management of side effects. Several TB patients find their treatment period stressful and having a peer to talk to, who has undergone similar challenges, and a doctor or counsellor to answer their questions, will help build their confidence and realization that they are not alone in this journey. The approach is human centered as it involves perspectives from the patients and their care givers encouraging them to openly discuss their concerns and thus creating meaningful experiences.

2. Scope

This guiding document has been prepared to assist the state and district NTEP teams understand the relevance of engaging with PSGs for TB control and elimination. The intent is to help the teams devise clear implementation roadmaps to adopt, and integrate this initiative as part of activities for TB elimination.

3. Key objectives of PSGs

PSG meetings can be conducted at the health facility on a fixed day and fixed time every month. Objectives of the PSGs are multi layered. PSG can be utilized at various levels as follows:

- ❖ **Individual level-** Enable the patient's sense of self confidence and self-esteem
- ❖ **Group level-** Build collective strength and solidarity among the patients attending the group meetings, and improve their treatment experience by learning from the experience of peers.
- ❖ **Facility level-** Enhance the quality of patient's interactions with the providers and provide patients with a safe space to interact with providers outside the consultation room & opportunity to demand for services.

4. Why conduct PSGs?

- ❖ **Hope and solidarity:** Platforms like PSG can offer TB patients hope and a sense of solidarity. Due to their first-hand TB experience, patient's involvement in stigma reduction activities in the community, and supporting treatment completion of other patients can be highly effective.

- ❖ **Supporting the vulnerable:** PSGs become especially valuable for vulnerable patients belonging to a certain occupation or living in an institutional setting with no family support or caregiver. Thus, PSGs serve as a platform for TB patients and their caregivers to support one another by sharing experiences regarding treatment and concerns about confidentiality.
- ❖ **Easy access to care and support:** This platform becomes an easy point of access to all patients in a given area at a given point in time during the treatment phase to avail additional care and support services such as psycho-social counselling, nutrition support, provision of incentives and linkages to social entitlements for improving treatment adherence.

5. Preparations for roll-out of Patient Support Groups

- ❖ State/UT shall decide to conduct the PSG meetings on a fixed day every month across the State/UT or shall suggest Districts/TB Units to schedule the same on a fixed date for their district/facility.
- ❖ The decided date for PSG meeting and venue shall be widely disseminated among the TB patients, and all TB patients shall be invited to attend the meeting.
- ❖ Facilitators at TU/PHI level shall be identified from among the NTEP personnel/Primary Health Care team. They shall be trained on conducting of PSGs using the prescribed curriculum. They shall also be provided with necessary IEC materials, tools etc for conducting the meeting.
- ❖ All TB Units and other implementing units such as PHCs/Sub Centres shall also be oriented on PSG.

6. Steps involved in conducting PSGs

6.1. Formation of PSGs

At every TB Unit PSGs shall be formed, followed by meetings every month. The patients who are at higher risk for complications and those who are likely to have challenges in adherence to treatment shall be given priority for participation. Meetings will also be open to caregivers.

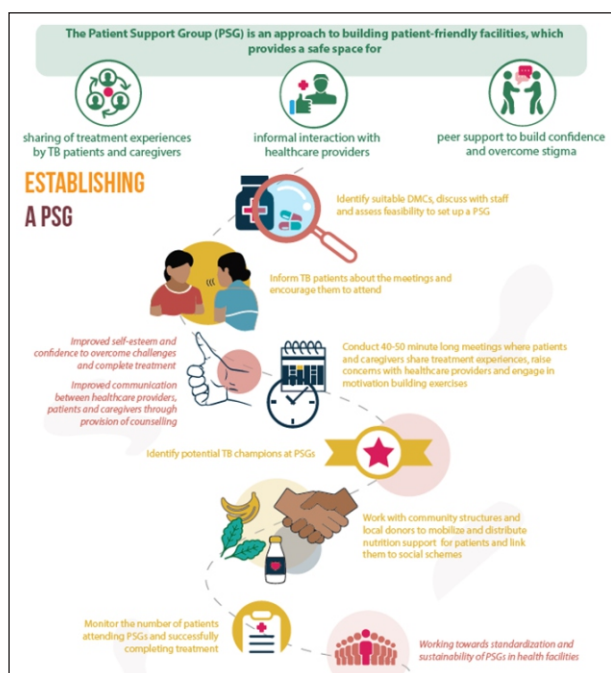
PSG meetings can also be conducted at the community level where there are clusters of patients. These meetings can be conducted at Primary Health Centres or Sub Centres or venues outside the facilities by involving community structures and volunteers.

The PSG can be formed under the MO TB Control (MO-TC) and its meetings can be facilitated by STS/ STLS/ Community Health Officer/Multi-Purpose Health Workers and TB Champions. One official should be identified and trained in organizing the Patient Support Groups in each TU. The facilitator or co-facilitator should attend the meeting, even if it is conducted outside the TU premises.

The meeting shall be conducted in such a way so that privacy and confidentiality of the patient participants are protected and they feel comfortable to attend the meeting.

6.2. Identify TB champions from the PSG meetings as Co-facilitator

The TU Team shall identify TB champions who could be a co-facilitator of the PSG, with the potential and willingness



to share their experiences, and motivate other patients in the group. A clear set of criteria should be identified to select TB champions as co-facilitator of PSG. These TB Champions shall be oriented on PSG and peer counselling skills.

6.3. Suggested flow of the PSG meeting

At the start of each meeting, the facilitator or co-facilitator shall introduce him/herself, briefly narrate the purpose of the meeting and welcome all the participants. Following this, the participants shall introduce themselves, however, it may not be mandatory.

The facilitator can then ask the patients in the meeting to share their experience with treatment and difficulties, if any. Once the issues are shared by patients or their caregivers, the facilitator and co-facilitator shall discuss those concerns one by one, preferably by inviting other patients who had addressed similar issues in their treatment and by sharing examples from his/her life.

The facilitator shall also introduce various topics of interest to the participants and generate discussion among the participants. Potential topics include Treatment adherence, stigma and disclosure, nutrition, healthy habits, keeping family safe from TB, etc.

6.4. Facilitate linkages to nutrition and other forms of support for TB patients

The PSG to be utilized as a platform to link patients to care and support services like counselling, nutrition and social entitlements, either from the NTEP or through other public schemes or through community structures.

6.5. Facilitate involvement of Community structures & community influencers

The PSG facilitator shall promote involvement of Community Structure members & community influencers in the PSG meetings, so as to generate support for TB patients. However, such involvement should be informed to the TB patients attending the meeting as they should be comfortable being seen as a TB patient.

6.6. Create linkages with medical support systems

TB patients who develop side effects or have an unpleasant experience due to medication, should be linked for medical support during the meetings. Medical Doctor/STS/TBHV/CHO shall provide counselling to patients regarding side effects of the TB treatment and how to address the issues.

6.7. Facilitate interactions of family members with MO/ NTEP staff

The PSG meetings shall be used to counsel the caregivers on how to take care of the patient at home.

Training module on facilitating Patient Support Groups for TB patients is available at CTD website.

7. Finance

The expenditure for PSG meetings such as capacity building, meeting cost, etc shall be met from funds provisioned under NTEP for Patient Provider meetings, trainings, etc.

8. Monitoring functioning of PSGs

The following shall be monitored on a regular basis by the State/District:

- ❖ Number of TUs with NTEP personnel trained in facilitating Patient Support Group meetings
- ❖ Number of TUs which formed Patient Support Groups
- ❖ Number of Patient Support Group meetings conducted during the period.
- ❖ Total number of patients participated in the Patient Support Group meetings.
 - % of Patients under TB Treatment who attended at least one PSG meeting.

In addition, the outcomes from Patient Support Group meetings shall be tracked using the following indicators:

- Improvement in TB Treatment adherence among patients attended PSG
- Changes in proportion of treatment interrupters, LFU
- Changes in patients reporting adverse drug reactions.
- Improvement in TPT uptake by eligible household contacts.

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Central TB Division
Ministry of Health & Family Welfare
Government of India