Community Engagement for a people centered and community led TB Response

Background

COMMUNITY ENGAGEMENT is defined as the process of working collaboratively with and through communities to address issues affecting their well-being, including influencing systems and serving as catalysts for changing polices, programs and practices, more patient sensitive.

Despite the best efforts of health systems, about 40% of people who develop TB in India are still either not diagnosed, or are not reported. Even among those reported and/or diagnosed for TB, many are lost to follow up, both with drug sensitive and drug resistant TB. The patients who are being treated in the private sector do not get adequate treatment support. TB patients are affected by social and political factors (such as stigma and discrimination, availability and access to services at a convenient time and in their social context like work, migration, gender etc.), and economic barriers (for example, the cost of transport, ancillary medicines and investigations in private sector).

The role of community engagement in contributing to TB prevention, diagnosis and treatment, especially among marginalized and vulnerable population, and for those with who seek care from to private health sector, is therefore well recognized.

Community engagement for TB covers a wide range of activities that contribute to the detection, referral and treatment of people with drug-susceptible, drug-resistant and HIV-associated TB. They are conducted outside the premises of formal health facilities (e.g. hospitals, health centres and clinics) in community-based structures (e.g. schools, places of worship, congregate settings, markets) and homesteads.

Scope of Community Engagement for TB

<u>Patient support services through Community participation</u>

Patient support services to be carried out through community-based TB activities, depending on the state, district and local context

Awareness creation and stigma reduction: Awareness-raising, behavior change communications, community mobilization for reduction of stigma and discrimination

Screening: Screening for TB and TB-related morbidity (ex. HIV counselling and testing, diabetes), contact tracing, sputum collection and transport, including through home visits

Referral: Referring for diagnosis of TB and related diseases, linking with clinics, transport support and facilitation, accompaniment, use of referral forms

Treatment adherence support: Home visits, adherence counselling, stigma reduction, pill counting, home-based care

Social support: Cash transfers, insurance schemes, nutrition support and supplementation, voluntary savings and loans, Linkages with existing social welfare schemes

Equity and Non-discrimination – identification of key communities of traditionally not empowered for greater inclusion, anti-stigma charter

Community Empowerment activities for sustainable community engagement

***Inform*:** Improve community awareness on TB, facilities available, care and prevention, and encourage them to support TB prevention and care services

Empower: Build capacity of community on awareness creation, demand generation, advocacy, service delivery, process of monitoring and accountability, facilitate implementation, planning and decision-making, management of services, peer learning and teaching

Institutionalize: Establish formal structures for community engagement at National, State and District level for planning and decision making, prioritization of TB affected people for inclusion in TB service delivery and programme management

Accountability platform: Create mechanism of feedback on TB care services to the providers at all level, use community monitoring tools

Financing: General sustainable financing mechanism for community response to TB

The scope of community engagement will evolve over a period of time under RNTCP.

Proposed Community Engagement Interventions

1. Institutional Structure

For community-led response to TB, National TB forum, State TB Forum and District TB Forums to be created of persons affected with TB along with decision makers and programme managers. At sub-district and village level, community led TB forum of TB affected people creation will be facilitated. Create network of TB Champions / Kshay Veer at village level.

Community members of the Forums will be formed using collective process of election of members from the community groups, patient forums, civil society engagement, community based organization, ASHA, AWW, Gramsevak, NGOs and nomination by the programme.

Terms of references of these TB Forums are to advice the programme for strategies on engaging communities and increasing community participation in TB program, to periodically review progress of NGO related activities and involvement of communities and facilitate community financing to sustain TB patients support services through community. The ToR will also include community monitoring through feedback

on public and private services, drug supply, service quality and response to drug resistant TB.

Patient forums will be part of RNTCP sub-committee of District Health Society at district and State Health Society State level.

2. Community Empowerment

Capacity building activities for community led response to TB will be conducted for community and existing community based organization or local civil society organization, if no community organization exists.

Community empowerment will start from mobilization of TB champions (TB Survivors), people affected by TB (family members of TB patients) and community volunteers. Members of the patient support forums will be selected from the community

Capacity building programmes for peer learning, counselling, advocacy, service delivery, planning, management, monitoring, resource mobilization participatory decision making will be conducted through professional agency which has proven community experience

Facilitate formation of the community led TB forums to community based organization. Support TB forums to register, mobilise resources, and plan projects to deliver sustainable TB patient support services.

Support to CBOs to mobilize resource for TB care and prevention services, identified and taken up by them.

Train TB survivors and champions to advocate and demand quality health care. While there have been some efforts to address this and create a network of TB advocates, there is still a shortfall of mechanisms to provide long-term support and tools to TB advocates to play a more significant role in policy advocacy, counselling, and addressing stigma and discrimination. TB Champions/ TB Survivors will be trained on counseling methods and communication skills and will act as Peer Counsellors at the community level.

Development and Institutionalization of a TB champion mentorship programme will be part of the National TB Response. This will be carried out by identifying, training and supporting TB champions to be patient advocates.

Sensitizing Village Health Sanitation and Nutrition Committee, Mahila Aarogya Samiti, Panchayat Raj Institute, Self Help Groups, Youth Club on TB and the complexities of diagnosis and treatment. PRIs/VHSNC/MAS can facilitate effective communication between facilities, public or private, that diagnose and treat TB and can influence the communities they serve to link TB patients with social welfare schemes.

Patient support groups for TB is a useful mechanism to improve treatment compliance and engage with family members. It will provide a platform where TB patients and their family members or caregivers can have an open discussion about the disease, challenges associated with the illness and its treatment. This will help reduce isolation and increase their self-esteem. These groups will play an important role in providing support, addressing stigma and discrimination, support treatment compliance. (this has been successfully implemented in Kerala)

The programme will support the community groups through a federation of community organizations who will be provided National Level ToT/ Sensitization. The federation will conduct the training and hand holding of community groups through cascade trainings.

3. Community Information

The district, Taluk and village TB champions will lead in community awareness on TB. They will be supported by Community/ local radio stations and other mass media tools. ANMs, ASHA's and other health workers in the village will have access to specialized training on TB and TB awareness. They will support the TB champions in the awareness campaigns. (some local language radio capsules have been produced by project Axshaya and can be used as a starter.)

Community based TB information and service centre Kiosk to be established within the reach of community. The Kiosks will offer community friendly diagnostic and treatment services through effective public and private linkages. It will provide flexi -DOT, serve as sputum collection and transportation centres, drop-in information centres, and provide counselling services. The Kiosk will have extended / flexi hours of work and manned by community volunteers. Scope of such Kiosk will be expanded for linkage of TB patients to provide information on the existing Social Protection Schemes, facilitate the process of linking the TB patients and families to various schemes and also do the follow up for the respective departments.

Patient charter on TB care has been prepared under RNTCP. It will be revised by TB champions and community members along with RNTCP and disseminated widely through public and private sector.

Partnership with faith based organizations and faith leaders is required to ensure change in social norms connected with TB knowledge and care. They can be powerful advocacy and change agents as was seen in the case of eradication of polio in India. Sensitized religious leaders will be engaged as spokespersons to reach community members and mobilise community for seeking early diagnosis and treatment for TB, as well as address stigma and discrimination among the community members.

4. Community led monitoring

Provide community-led monitoring tools and facilitate use of these tools. (One such tools have been started in collaboration with REACH). Train TB champions and

community members on Mobile based application for providing feedback on TB services to identify critical gaps in TB care delivery. Under TB Call to Action, 'TB Mitra' an android & iOS based application has been developed which can be tested and then used to track issues and challenges faced by the community and to help resolving them.

Establish a Call Centre to provide information and grievance redressal services to TB patients and other community members.

Patient reported score/rate cards can be developed to get feedback from TB patients on TB Care services which they have availed. It will enhance accountability and quality of TB services.

Community representatives from TB forums will be involved in reviews of district state and at the national level.

Funding and implementation support

On short term

- Funding support for community empowerment will be through domestic budget along with accountability framework.
- Existing institutional framework will be utilized for financial resources.
- Implementation support for establishing community empowerment mechanism is planned through developmental partners with extensive experience of community engagement and reputation of being community friendly.
- Funding support for service delivery through community will be used from existing partnership options under RNTCP and innovations under PPM activities.

On long term

- Learnings of the community led interventions will be formalized and incorporated within programme structures and sustained community engagement will be ensured.
- The mechanisms will be subjected to mid-term review by 2020.