ENGAGING AND EMPOWERING PANCHAYATS FOR ADDRESSING TB STIGMA AT THE GRASSROOTS

CHALLENGE OF TB

Even though India has made great strides in its fight against Tuberculosis, it still remains one of the most prevalent diseases in the country. Globally, India is among the eight countries that account for two thirds of the new TB cases. In 2019, India reported an estimated 24.04 lakh TB cases, with 79,144 deaths due to TB. Although TB is a curable disease, early intervention and adherence to medicine is necessary for being fully cured. Certain vulnerable groups such as those living with HIV and diabetes, those working in occupationally hazardous settings like miners and garment workers and those living on overcrowded and poorly ventilated settings are at a higher risk of contracting TB disease. Persons with HIV - TB co morbidity if left untreated or initiated late into treatment can lead to quick progression of the disease leading to morbidity and mortality.

Improper use of TB medication can spiral into a more dangerous form of Multidrug-Resistant TB (MDR-TB). MDR-TB requires second line treatment options, which are not only more expensive, but also more toxic. Even though TB medication and treatment is widely available and free of cost, barriers such as stigma associated with the disease, lack of awareness, poor health seeking behaviours, exclusion and poor reach to vulnerable communities and lack of community participation in TB programs places patients at greater risk and compromises on the impact of TB programs.

BARRIERS TO ACCESSING HEALTHCARE

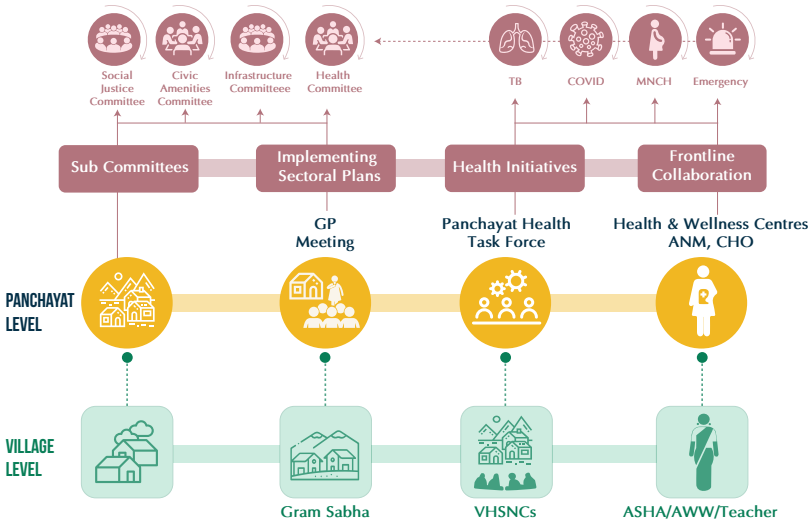
TB is a disease which, though curable, can have a debilitating impact on health and livelihoods of people if ignored. Unfortunately, TB is accompanied by several socio-cultural barriers such as stigma and discrimination, knowledge gaps among vulnerable populations, unmet patient needs for care, counselling and compassion, absence of patient-friendly systems of service delivery and lack of social mobilization efforts. These factors hinder the efforts of the TB programs. TB patients are often stigmatised making it difficult for them to seek and access diagnosis and treatment services. Women diagnosed with TB are particularly challenged since the TB positive status accentuates the underlying gender discrimination within families and communities. TB has a negative impact on the livelihoods of people, affecting incomes and thereby making families reluctant to seek treatment for the fear of losing earnings. The elderly especially often face challenges of transportation to reach diagnosis centres and medical dispensaries.

STRATEGY OF INVOLVING PANCHAYATI RAJ INSTITUTIONS (PRIs)

Article 40 of the Constitution of India incorporates the principle of autonomous self-rule at the local level. It states that, 'States shall take requisite steps to organise village panchayats and endow them with such powers and authority as may be necessary to enable them to work as units of self-governance'. Panchayats, therefore, are the lowest level of local self-government. Today, India has about 253,400 rural local bodies at the village level Gram Panchayats), and 6613 intermediary or block-level Panchayats, and 630 district level panchayats. There are about 3 million elected representatives of these panchayats, out of which 1.3 million are women. Thus, 70 per cent of India's population is covered through these local governance institutions. It is fascinating to visualize how the rural community has been mobilized into an electoral process that empowers them to take decisions for themselves. Even though PRIs were accorded constitutional status only in 1992, India has had a long tradition of panchayats in one form or another. PRIs are self-governing units at the rural level, with regular elections and flow of funds through the Finance Commission. The organisational structure of PRIs is such that it ensures representation at state and village level, thereby ensuring representatives at the top and bottom. One of the very effective roles that interventions can play is to intensify coordination between community structures, civil society organisations, self-help groups and PRIs. The core function of the PRI is to focus on sectoral issues of education, health and child-care, water and sanitation and community mobilisation in these primary sectors of development. The PRI has several mandated sub committees to carry out these functions effectively and convergently.

DECENTRALISED HEALTH PLANNING FOR TB ELIMINATION

Working with PRIs: An Integrated Approach



An approach that maximises on the available provisions within the National Health Mission and the RDPR. The strategy focuses on integrating the various operational committees and human resource structures at the village level such as the VHSCNs, Gram Sabhas, Health functionaries like the ASHAs, Anganwadi workers and School teachers with the panchayat level bodies like the panchayat health task force, Health and Wellness Centres (HWCs) as GP meetings to ensure collective actions on issues related to health and its social determinants at the village and GP level. This strategy is envisaged as being central to 'local level community action', which would develop to support the process of Decentralised Health Planning which includes TB control as a prime objective

This figure highlights an approach that maximises the available provisions within the National Health Mission and the Rural Development and Panchayat Raj Department (RDPR). The approach focuses on integrating various operational committees and human resource structures at the village level, such as the Village Health Sanitation and Nutrition Committee (VHSNC), gram sabhas, health functionaries like the ASHAs, Anganwadi workers and school teachers, with the panchayat level sub committees like health committee, panchayat health task force, Health and Wellness Centres (HWCs)-via GP meetings to ensure collective actions on issues related to health and its social determinants at the village and GP level. This strategy is envisaged as being central to 'local level community action', which would develop to support the process of 'Decentralised Health Planning' which includes TB control as a prime objective.

TOOLS OF ENGAGEMENT

- **STRENGTHENING PANCHAYAT HEALTH SUB-COMMITTEES:** Subcommittees like the Health and VHSNCs at the village level are existing mandated structures responsible to create ownership of health services and health decisions within the community. Training VHSNC members[1] on TB, clarifying their roles to support TB patients and conduct TB screening, would prove to be useful. The VHSNCs are allotted Rs 10,000 untied fund for health-related activities that can be leveraged for supporting TB patients and conducting IEC events. Additionally, states like Karnataka have established Panchayat COVID TASK forces at the GP and village levels for broader reach that are responsible for supporting doctors, health staff and ASHA workers in mitigating challenges of the pandemic, address barriers in community attitudes towards vaccination; ensure testing and create awareness to strengthen people's morale. This task force can be further leveraged to expand their scope to all other health initiatives including TB, at the village level, in close coordination with the VHSNCs. VHSNCs have always played an important role in immunization and the engagement of PRI leaders to ensure that services related to TB are part of VHND service provision in terms of screening, providing nutrition and treatment compliance counselling to existing cases and other aspects can be important.

- **COLLABORATION WITH THE PRI AND THE FRONTLINE WORKERS (FLWs):** Joint planning and action among PRI members and the FLWs will help build a supportive environment for health workers to discharge duties, as well as help PRI members to gain an understanding of challenges with respect to service delivery within the communities. As per guidelines, FLWs report to the VHSNC president, hence promoting accountability.

- **ACTIVE INVOLVEMENT OF PANCHAYAT LEADERS:** They are the direct representatives of the people, and should have access to mechanisms that can help them raise issues faced by the villages at the state and national levels. This will ensure that gaps in healthcare, such as provision of medication, testing and screening can be addressed. Since each panchayat faces different issues, the solutions cannot be uniform. Thus, care has to be taken to ensure unique solutions. Innovative solutions like the "Zero TB Panchayat Contest" along with the Ministry offering additional financial incentives for Panchayats can be organised to demonstrate zero or near zero TB cases over a predetermined time frame. PRI leaders from the most vulnerable communities need to involved and if any of them at TB survivors- they can share their journey with the community and other stakeholders for impact.

- **MOBILIZATION AND INFORMATION DISSEMINATION:** Panchayat leaders have to be trained to be an effective link between people and government machinery and can lead social mobilization efforts for health programs. Regular workshops should be organised, where state health practitioners inform them about TB, its symptoms, available facilities, and other important practices. The leaders should also have access to a database of the nearest treatment centers to ensure timely diagnosis so that they can guide the patients accordingly. The majority of GPs have information distribution infrastructures and should utilize the same to raise awareness.

- **LINKAGES BETWEEN PANCHAYATS AND HEALTH SERVICE SCHEMES:** Since the cost of treatment and medication of TB can act as a barrier in the treatment of the disease, panchayat leaders should be informed about health schemes that provide facilities at subsidised costs. This will ensure that the information reaches the community and they can access the services accordingly.

- **COMMUNITY MONITORING THROUGH VHSNCS AND GP SUB COMMITTEE:** There is a need to establish supportive community monitoring systems where PRI members are adequately provided planning and monitoring job aids that will help them to address their performance, measure the impact of their actions and also identify gaps and scope for improvement jointly and collaboratively with the FLWs and community members.

[1]10,000 rupees/year is provided to VHSNCs towards addressing health issues

IMPORTANT PRI INITIATIVES

The Kshaya Muktha Karnataka (Tuberculosis-free Karnataka) program aims to eradicate TB in Karnataka by involving PRIs and ensuring TB eradication at the grassroots for TB free gram sabhas. It aims to involve inter-department coordination between the RDPR, Health, Labour, Urban Development, Woman and Child Development and other government agencies, along with the Non-Governmental Organisations (NGOs). TB free Gram Panchayats will ensure that the PRI members are the principal stakeholders of all TB activities to realize the dream of a "zero TB village". The panchayat will be the focal point to get suspected patients for early diagnosis, as it is a curable disease.

Kerala took the landmark decision to devolve 33 per cent of planned budgetary allocation as untied funds to panchayats. This roughly means that each of the nearly 1000-gram panchayats in the state receive more than 10 million rupees as largely untied funds. They are also separately provided with maintenance grants. To ensure a participatory and community led approach, a people people-led campaign was launched, with more than one hundred thousand volunteers-who worked to understand needs, data collection, implementation and monitoring and evaluation of impact.

Gender Inclusion and Potential Impact: Over the years, Elected Women Representatives (EWRs) have become powerful leaders of change to address the most serious issues affecting their villages and districts: ensuring a lens of transparency and effectiveness. They are also an inspiration, especially for the young to participate in the process of changemaking. An example is Meena Behen, the first woman village sarpanch in Vyara, Gujarat. She heads an all-women Panchayat and started a self-help group that allowed the introduction of economic activity to her village.

GLOBAL EXAMPLES

DENGUE FEVER, JAKARTA

Penjaringan village's local government took an active role in fighting against dengue fever by supporting door to door surveys of residents. If someone was found to have dengue fever, eradication of mosquito nests was carried out around the houses. The village was able to reduce its caseload of dengue fever drastically.

MALARIA, ARMENIA

In 2011, Armenia was added to WHO's list of malaria free countries. This could be achieved through the participation of various partners, including local governments. The Interagency Coordination Committee collaborated with local governments, who endorsed the national plan for malaria elimination and coordinated with local epidemiological surveillance bodies. The Ministry of Health also worked with local governments to aid with diagnosis and treatment of patients.

INDIAN PRACTICES

POLIO ERADICATION

The Social Mobilisation Network (SMNet) was managed by UNICEF and was created as a strategy to eradicate polio by engaging >7000 frontline social mobilizers to advocate for vaccination in

some of the most underserved, marginalized, and at-risk communities in India. This was achieved by engaging local leaders from panchayats in mobilising their respective communities. This was

done through building "polio gates," inaugurating booths/campaigns and ensuring proper visibility of materials. 'Polio gates' were made with polio banners and erected at key locations to advertise a polio immunisation round.

CORE GROUP POLIO PROJECT (CGPP)

Over the past 20 years, the CGPP team for polio eradication created a vast network of community influencers who support health workers in immunization, especially for polio and campaigns. During 2019 – 2020, the CGPP staff were scaled back due to fewer polio-specific activities, but the current staff and former polio influencers maintain an informal, unfunded network. CGPP staff concerned about the potential negative impact of COVID 19 on immunization and public health, in general, recognized an opportunity to engage this informal network.

CGPP's Block Mobilization Coordinators contacted the influencers to form Community Action Groups (CAGs), with 5-6 members in each, with the goal of creating an enabling environment for the health workers as well as COVID-affected persons and their families.

The CAG is a community-focused approach that works to address critical issues like vaccine hesitancy during polio immunization campaigns and promotion of COVID Appropriate Behaviour. The group often includes village heads and leaders, health workers, school teachers, religious leaders, ration dealers, shopkeepers, local quacks/doctors, etc. These group members are accessible to the community for discussing any issues related to immunization and COVID-19. It not only informs and educates the community about COVID-19 and other health issues but most importantly, provides support through tangible action. CAGs meet regularly, every alternate week or so and identify families that need support.

COVID-19

Since the majority of the Indian population still resides in rural areas, it is necessary to ensure widespread vaccination. To do so, involvement of PRIs is very important. Thus, the Ministry of Panchayati Raj entrusted various roles to PRIs, such as: registration of healthcare workers under and creation of awareness among the residents. Vaccine hesitancy, fuelled by lack of information, has also proven to be a barrier. To address this, panchayats across the country have taken creative steps. For example, the gram panchayat in Hingoli district of Maharashtra offered insurance to those who got vaccinated, so as to dispel fears. A sarpanch in Odisha's Kushumjore village was able to inspire confidence in people by making door-to-door visits and offering reassurance.

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