CAF IN ACTION

Operationalising a Community Accountability Framework in India

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Acknowledgements

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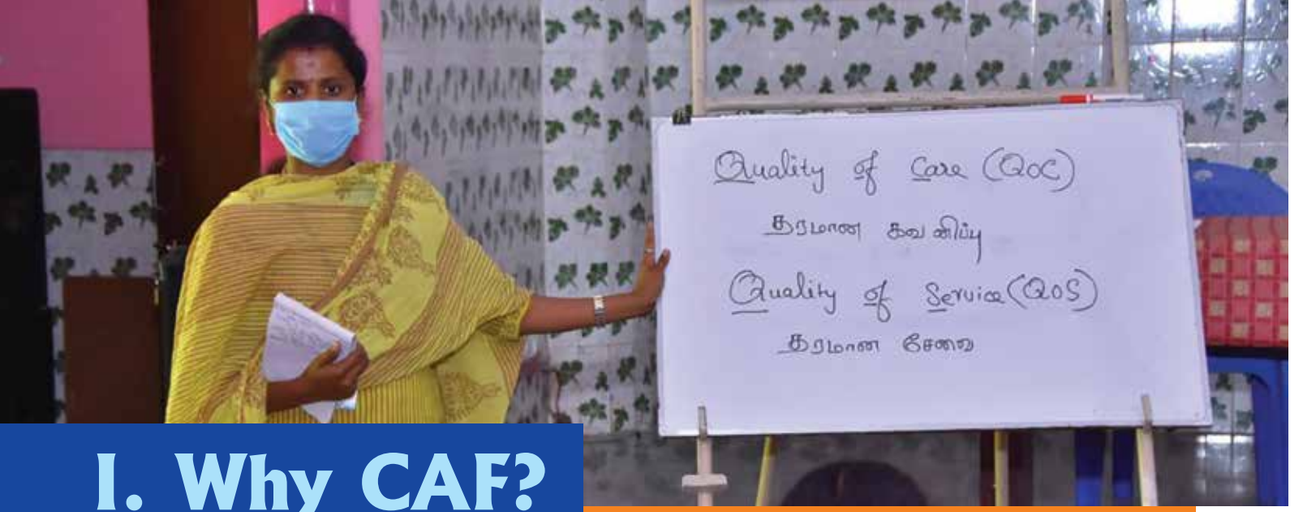


I. Why CAF?

The last decade has seen significant advances in the TB response, both globally and in India, in terms of new policies, strategies and tools to achieve TB elimination. The next United Nations High-Level Meeting on TB, scheduled for September 2023, is expected to further amplify collective action to end TB. In India, in keeping with the country's commitment to eliminate TB by 2025, efforts are on in mission-mode. New treatment regimens have been introduced, policies to improve access to services for vulnerable populations are being rolled out, demands for a TB vaccine are growing and communities are being meaningfully engaged.

In this context, the Accountability Leadership by Local communities for Inclusive, Enabling Services or ALLIES Project, implemented by REACH in four states in India with support from USAID, aims to build an enabling environment for TB elimination by leveraging community action as an ally to foster a culture of accountability. Through the ALLIES project, REACH is building on previous successes in identifying, training and engaging TB survivors as Champions, a model now formally adopted by the National TB Elimination Programme and scaled up across the country. The role of TB survivors-Champions in supporting people with TB, educating their communities, addressing stigma and improving TB care outcomes is widely acknowledged.

In keeping with the recommendations of the 2019 Joint Monitoring Mission and India's updated National Strategic Plan for TB Elimination (NSP 2020-25), the ALLIES project was designed to expand the role of TB-affected communities to provide bottom-up and community-led feedback to the health system. This is in sync with the WHO Multi Sectoral Accountability framework, that draws on principles of integrity, inclusivity, effectiveness and actionability to accelerate progress to end TB.

Central to the ALLIES project is a Community Accountability Framework (CAF), intended to improve the Quality of Care (QoC) and Quality of Services (QoS) for people and communities affected by TB. The CAF model was designed to enhance the accountability, coverage and effectiveness of the TB programme and generate demand by strengthening community confidence in TB services. Implemented by TB Champions working hand-in-hand with the NTEP, the CAF model has the potential to achieve multifold impact by institutionalising accountability, augmenting systemic capacity and enabling improved outcomes.

> "We are proud to have been among the first states to test the Community Accountability Framework. Today, the NTEP has come such a long way and we have so many new policies and strategies. This is therefore the right time to be talking about the quality of care and services and the CAF helps us to do this in a systematic and meaningful way.
>
> **- Dr. Prashant Kumar Hota, Additional Director of Health Services (TB) cum STO, Government of Odisha, Bhubaneshwar**

With the evolution of the TB response and a transition to data-driven decision-making, an increased focus on the 'quality' of services has emerged. This, in tandem with the expanding role of communities as described above, was the genesis of CAF, a set of tools which sought to bring tangibility to the concept of accountable, value-focused healthcare. The CAF model adopts a multi-step 'Identify-Ideate-Implement' approach with three distinct stages:

1. Identification of gaps using a structured tool
2. Ideating potential solutions at the health system and community levels
3. Implementing solutions in a collaborative manner, involving either individual actions and/or health systems strengthening

This process epitomises the key philosophy of the project – that community-led monitoring must be truly collaborative, and lead to concrete, actionable solutions, through both technical and material support from a range of stakeholders. The TB programme staff and TB Champions have an integral role to play at every stage of CAF, and any success – i.e an improvement in the quality of care and services - is only achieved through joint action.

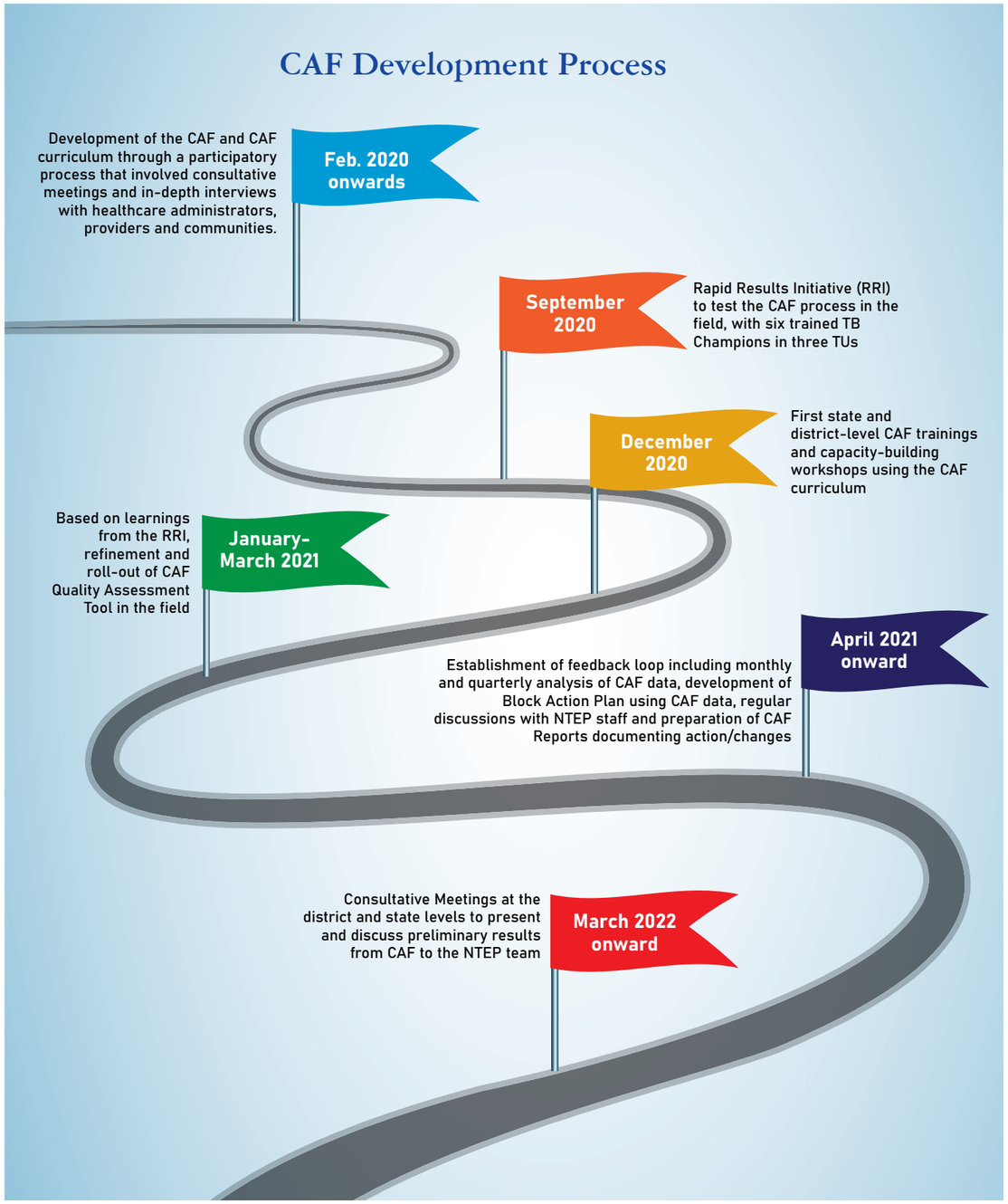
II. What is CAF?

How CAF was developed

REACH's experience with TB Champions through the TB Call to Action project established the importance of building agency at the grassroots level, thereby mobilising change from those most affected. The development of the Community Accountability Framework began by identifying the key actors involved for a health system-community partnership, and clearly articulating their roles in the feedback process. This included:

- People with TB and their families,
- TB survivors-Champions and survivor-led networks
- The community-at-large
- Proximate providers (in the Indian context – ASHA, STS, Lab Technicians, Medical Officers)
- Health system administrators and leadership (State and District TB Officers and other senior officials)
- Key influencers and persons with authority (PRI members, Panchayat leaders, urban administrators etc.)

CAF Development Process



"We have been implementing the CAF model in Coimbatore for the last two years. As a result, we have been able to introduce some new strategies. For example, we have now mandated that all elderly people with TB should receive home visits from TB Champions. This is something that the TB Champions brought to our attention through CAF and we worked together to find a solution.

- Dr. M Sakthivel, Deputy Director of Medical (TB), Coimbatore, Tamilnadu

III. How CAF works

Setting: CAF is currently being implemented in 139 health facilities in 15 districts of four states – Chhattisgarh, Jharkhand, Odisha and Tamilnadu. Based on the average caseload, one or two TB Champions are linked with every facility, and work in close coordination with the NTEP and health system staff.

The tool: The CAF Quality Assessment Tool is structured around five key parameters that impact the quality of care and services: Timeliness, Access, Quality of Information received, Attitude of care providers, Attitude of families and communities. There are multiple questions under each parameter that seek to understand the experience of a person with TB along the care continuum. Most questions have follow-up probes to gather the necessary information. In addition, there is a background section that captures basic demographic details about the person with TB and their current TB status. The tool has been translated into Hindi, Odia and Tamil and is used in the respective local language.

TB Champions are trained to administer the tool in an empathetic manner and to record responses accurately. The process of administering the tool also becomes an opportunity to improve treatment literacy and help people with TB understand what to expect through the treatment period.

Excerpts from the CAF tool

1. How many days after testing were you given your diagnosis?
2. How many days after diagnosis were you initiated on treatment?
3. Did you receive your NPY funds within 30 days of starting treatment?
4. Was your weight taken at the TU when you started treatment?
5. Did you find it convenient during your first visit to the TU to locate the doctor, lab technician, X-ray technician etc.?
6. Was your regular drug intake interrupted at any point during treatment?
7. After starting your treatment, did you have to spend money out of pocket? If so, on what?
8. At the time you were diagnosed with lung TB, were you and your family counselled on cough hygiene?
9. After being diagnosed with any kind of TB, were you asked to take/offered a HIV test?
10. Was your sputum tested after two months of starting treatment?
11. Did the TU staff ensure your privacy and confidentiality?
12. How respectful are friends/community attitudes towards you?

Capacity-building for communities:
A multi-step training process has evolved for TB Champions:

1. The TB survivor - Champion training, as a foundational step
2. A community mentorship period, where newly trained TB Champions learn to work with their communities and understand the dynamics of working with health systems.
3. CAF training, where TB Champions learn about accountability and the overall CAF vision, their role in CAF, how to use the CAF tool, how to understand and analyse data and how to work in close collaboration with the programme

Sensitisation of health staff: In keeping with the mandate of the ALLIES project, the 'Achieving Excellence in TB Care and Services' or AETBCS curriculum was designed to equip NTEP staff and healthcare providers with basic concepts and skills to help adopt people-centred approaches while caring for people with TB and working with communities. Structured as four modules (Listen, Respect, Ally and Achieve), the two-day training seeks to set personal standards of ethical and professional excellence, institute a rights-respectful and efficient work culture in the health facility and establish effective partnerships between the health system and the community.

The process: Since 2020, the CAF process has continually evolved, factoring in feedback from all key actors. CAF currently has the following key steps:

Steps	What	Who	Where	When
Step 1	Filling of CAF Quality Assessment Tool (46 Questions)	TB Champions use the tool to meet people with TB currently on treatment and record their responses	At the health facility or home of person with TB (with their consent)	Every month. On average, 8 people with TB are met by TB Champions from each facility
Step 2	Preparation of Block Action Plan to address the identified and prioritised gaps	TB Champions analyse and consolidate responses to the CAF. They meet the NTEP staff to present and discuss the responses. If and when some gaps appear every month, this occasionally requires escalation to or intervention of senior officials	Systemic gaps (e.g., delays in sputum results) involve action-taking at the facility or district level. Individual-level gaps (e.g., stigma within families or limited access to nutritious food) involve action-taking at the individual or community levels	The 'resolution' of gaps is an ongoing cycle of action, depending on the local context. In some facilities, different gaps are identified every month
Step 3	Consultative meetings to share findings	Led by the NTEP, with active participation of TB Champions and other community stakeholders	At the block, district and state-levels	Usually once in a quarter

"As a TB Champion, I conduct CAF interviews and get an opportunity to interact with people with TB and understand their family situation and needs. With the support of the STS, I have linked many people to Nikshay Poshan Yojana. My goal is to ensure that they complete their treatment and remain healthy in a stigma-free society.

- Ms. Sangeetha Jhansirani, TB Champion, Villupuram, Tamilnadu

IV. The CAF Impact

This section presents a snapshot of the impact of CAF on the quality of TB care and services at health facilities. The graph below shows select indicators from the CAF data, consolidated for all project districts and states, for the October – December 2022 period, in comparison with the April – September 2021 period (with the exception of one indicator, for which the comparison period is October – December 2021).

The improvement in the indicators shown above can be attributed to the combined efforts of facility and district-level NTEP staff and TB Champions, in identifying and addressing gaps at the family, community and health system levels. The active follow-up to address every gap identified, in a collaborative and mutually respectful manner, is a core tenet of the CAF process. The 18+ months of CAF implementation have shown that health systems and communities can work in partnership, towards the collective goal of providing the highest quality of care and services to all people with TB.

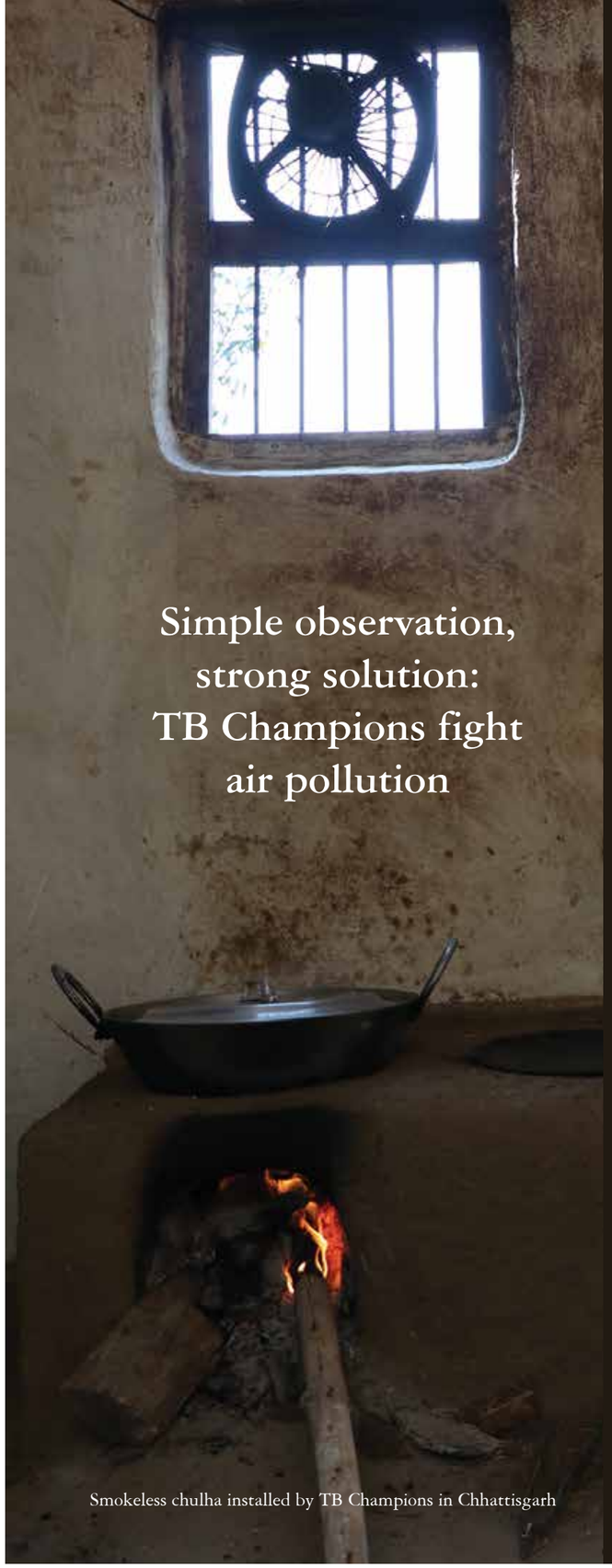
Key Indicators

Cumulative Results (As of Dec 2022)	
264	Number of TB Champions trained on CAF
139	Number of Facilities where CAF is currently being implemented
187	Number of TB Champions engaged for CAF
25194	Number of People with TB interviewed by TB Champions using CAF tool
1794	Number of Block Action Plans (BAP) prepared by TB Champions
1297	Number of PRI Members sensitised on TB
510	Number of PRI members engaged for TB activities and to find local solutions
177194	Number of people reached through various community mobilisation initiatives
684	Number of NTEP staff trained on the Achieving Excellence in TB Care and Services curriculum

> We have seen the role of TB Champions evolve over the last five years. TB Champions are a tremendous bridge between the programme and the community, and therefore the ideal people to facilitate feedback on our services. Today, through the CAF model and the efforts of the TB Champions, we are getting real-time feedback that helps us understand how we can constantly keep improving our services.
>
> **- Dr. S.M Zafarullah,** District TB Officer, Bokaro, Jharkhand

> I was initially quite skeptical about the CAF process. One part of me was also angry - who are these people to come and comment on the quality of our work? But over time, I began to see the value of the process, and how it was generating such important information. Today, I know that CAF has helped us provide better quality care to people with TB who come to this facility.
>
> **- Mr. Ashok Uikey, Senior Treatment Supervisor, Raipur DTC, Chhattisgarh**

> I have become more confident by engaging in the CAF process. My efforts have been acknowledged by the community and my presence in the TU is accepted by the healthcare staff. I am working to enable close coordination between the healthcare staff and persons with TB (and their families).
>
> **- Basudev Tung, TB Champion, Mayurbhanj, Odisha**



Simple observation, strong solution: TB Champions fight air pollution

In Chhattisgarh, TB Champions implementing CAF were committed to go beyond the biomedical aspects of TB and address various socio-economic factors that affected people with TB (PwTB). For instance, they informed PwTB about the different social support schemes that were available, and how they could be availed. During their CAF-related field visits, they encouraged families to avail the Pradhan Mantri Ujjwala Yojana (the central government scheme of providing LPG connections to BPL households) so that they had access to clean cooking fuel.

A simple, but recurring observation emerged. TB Champions noticed that many families had returned to the use of traditional chulhas despite having LPG connections in their households. This was perplexing - they had specifically counselled many families about the risks of indoor air pollution. Why had the families reverted to their old habits? The TB Champions spoke to the families again and many families had begun using chulhas while awaiting new connections or refills of their existing ones. Many earning members had lost their jobs during the COVID-19 pandemic and inflation had increased the burden on family budgets.

The TB Champions realised that the time had come for an innovative solution. They discussed the concept of smokeless chulhas with the local NTEP staff. With their support, training was given to the local Mitanins (ASHA workers). Together, they worked out that if even one family agreed to adopt a smokeless chulha in their house, 10 to 15 women (could) gather to observe the process of making the chulha and would be encouraged to introduce the same in their respective households. Those who were waiting to get their LPG cylinders filled began to install smokeless chulhas and slowly but steadily, the movement grew. Today, there are nearly 200 such chulhas across three districts in the state. The state NTEP has appreciated the initiative and now support the TB Champions in the process.

Smokeless chulha installed by TB Champions in Chhattisgarh

Road to recovery: prioritising mental health in TB

CAF allows TB Champions close access to the lives of people with TB and their families. During a field visit to the home of Ananta (name changed for privacy), a person with TB from Bhubaneswar in Odisha, TB Champion Sujata Pradhan discovered that Ananta was reluctant to take his medicines. Multiple conversations and some tactful probing by Sujata revealed that he was very depressed - refusing to eat, not wanting to leave the house, and refusing to speak to anyone. Ananta had fallen into a state of depression following his TB diagnosis and felt that taking medicines was pointless since he was going to die soon.

Initially, it was difficult for Sujata to convince him otherwise, but she never gave up hope. Drawing on what she'd learnt from her counselling training, she began visiting him regularly to dispel his fears and make him realise the importance of starting his TB treatment. She patiently listened to him during every visit, and slowly, responding to her sincerity, Ananta began opening up and expressing his feelings. Sujata encouraged him to take more interest in simple daily activities - listening to music, watching movies etc. She also shared her own journey of being a TB survivor. The constant connection and empathy motivated Ananta to begin taking his medicines. Today, he is cured of TB and has been able to overcome his self-stigma and develop a more developed a positive attitude towards life.

Prompt action and unyielding support help a family in crisis

In October 2022, Sandhya, a TB Champion from Gumla in Jharkhand, visited the home of Vishnu, a migrant worker from Patna, Bihar (name changed for privacy), who was on treatment for TB. She was shocked to see the family's living conditions. Vishnu was the primary breadwinner for the family, which included four children younger than six years but he was now unable to work. An auto rickshaw driver by profession, Vishnu was diagnosed with Pulmonary TB in September 2022. He felt physically weak, had low energy and was soon unable to take his auto out every day. He had even fainted on one occasion while on duty and had to be carried back home by his fellow auto drivers.

Sandhya immediately sprang into action and began the process of enrolling the family as a beneficiary under the Public Distribution Scheme (PDS). She also initiated the process of linking Vishnu to the Nikshya Poshan Yojana scheme. However, the family had migrated from Patna and had no documents available with them to support their enrolment in the PDS scheme.

Not one to give up and determined to find a quick solution, Sandhya met Ms. Kiran Bilung, Mukhiya of Nawagarh Panchayat in the block Vishnu lived in. Sandhya explained Vishnu's illness and the family's sufferings to the PRI member and requested her help and support. As a responsible PRI member, Ms. Bilung first explained to Sandhya how Vishnu and his family could have a long-term solution to their problem, if all the required identification documents could be arranged to enable enrolment in the PDS Scheme. Meanwhile, for immediate relief, Ms. Bilung registered herself as a Nikshay Mitra and arranged to provide 50 kgs of rice for October and an additional 25 kgs rice in the following month. She committed to giving Vishnu nutritional support until he was fully cured.

In the meantime, Sandhya continued to follow-up on the paperwork. Thanks to her diligent efforts, Vishnu received the first two NPY instalments, as well as some support under the state's Tribal Support Scheme. In addition, the constant emotional support and adherence counselling provided by Sandhya throughout this period helped Vishnu regain some weight and slowly begin to rebuild his health as well as that of his family.

Block Action Plan meeting underway at Balod in Chhattisgarh, with TB Champions analysing CAF data for the month, before presenting to the NTEP

TB Champion Poongodi from Vellore, Tamilnadu visiting the home of a person with TB to administer the CAF tool

A TB Champion's persistent efforts to resolve transport challenges

The most common issue highlighted by people with TB from Angara TU in Ranchi district of Jharkhand was the lack of transport facilities to commute from the village to the TU. This meant that most people on treatment were dependent on relatives who owned two-wheelers or had to wait for auto services to reach the TUs. This inevitably caused delays at different time points - in diagnosis, treatment initiation, submission of documents for NPY, weight and treatment monitoring and so on.

To address this need that emerged through the CAF process, TB Champion Rajkumar Mahto initiated conversations with many local leaders including PRI members, Sahiyyas and crucially, Community Health Officers (CHOs) of the seven Health and Wellness Centres (HWC) in Angara block. Following many rounds of discussions, it was agreed that CHOs would provide TB medicines at the HWC, thereby eliminating the need to visit the TU. Weight monitoring is also being done at HWCs. The TB Champion participated in CHO training, sharing stories of people with TB from the field, and requesting CHOs to play an active role in all TB activities. In addition, PRI members agreed to mobilise funds to provide an alternative local transport facility for emergencies. Rajkumar continues to actively follow-up and is hopeful that this will be organised soon.

Joint efforts to reduce delays in treatment initiation

In the Thuraiyur TB Unit in Trichy district of Tamilnadu, TB Champion Akilandeswari found that several people with TB from that facility were experiencing a delay in treatment initiation. Within 3 days of diagnosis, treatment should have been initiated but that was not the case. Akilandeswari probed into the matter and found out that there were a few reasons for this delay. In many cases, PwTB were not returning to the TU after receiving their test results over the phone. Some of them had given the numbers of their neighbours or relatives because of which they received the information much later.

80% of the population of Thuraiyur lives in rural areas, with clusters of villages with predominantly tribal communities. Lack of transport and resistance towards taking treatment in a government hospital were some other reasons for the delay in treatment.

Akilandeswari shared this information with the TU staff and joint efforts were taken to improve this. Pre-test counselling during sputum collection was strengthened. People visiting the TU for testing were informed about the free government treatment and the services available, the importance of early diagnosis and the advantages of quick treatment initiation. Test results were provided to PwTB on the same day as sample collection. Alternative contact numbers were recorded and accompanying family members were sensitised to follow up immediately, should the diagnosis be positive. Home visits were also made as soon as test results were available, in case the person with TB was not reachable over the phone.

These continuous efforts brought about a significant reduction in delays in treatment initiation. Over a 11-month period, this reduced from 38% of PwTB not initiated on treatment in three days of diagnosis, to nearly zero. The DTO visited the TU and discussed the gaps identified during the CAF process and gave suggestions on follow-up actions.

TB Champion Nitu Gyare on a follow-up house visit to the home of a person with TB

TB Champion Sandhya Singh addressing a meeting in Gulma, Jharkhand

TB Champion Komal Singh Nishad facilitating a community meeting in Balod, Chhattisgarh

Measure to get better: sustained action for regular weight measurement

Between April and June 2022, TB Champions in Coimbatore district of Tamilnadu observed a common trend in their CAF analysis - around 32% of people with TB (97 out of 304) did not have any change in weight recorded every month. Weight measurement is a critical monitoring tool in TB treatment. TB Champions spoke to people with TB and found that many were not visiting the TUs regularly; only family members would visit to collect the medicines. In the absence of the STS/health visitor (HV), the pharmacist and health staff at the TU would only distribute drugs and not necessarily measure and record the weight of the person with TB.

This feedback was presented and discussed at the consultative and review meetings. The STS and TB Champion worked together to follow up with those PwTBs whose weight had not been recorded. The team motivated everyone on treatment to visit the TU every month, to ensure that their weight was recorded. For those PwTB who were not in a position to visit the hospital due to severe health issues, the team guided the family members to record the weight at any nearby facility or ICDS centres and send the readings to the NTEP.

The health staff were specially instructed by the BMO and MO to record the weight of PwTBs in the absence of TU staff. In addition, TBCs mobilised local financial support and provided the TUs with weighing machines. These efforts collectively brought about a 21% improvement in nine months in weight measurement indicators of PwTB in Coimbatore district.

> “Every month, I wait for TB Champions Sandhya and Nirmal, who are attached to my TU, to come and start the CAF process in the field. Initially I was a little hesitant to share any details with them. But over time, after seeing how people with TB respond to their peer supporters, my trust and confidence in the quality improvement process they follow through CAF has been fully and firmly established.
>
> **- Ms. Alka Tirkey, Senior Treatment Supervisor, Gumla, Jharkhand**

> “TB Champion Chandra got in touch with me and explained the impact that TB can have on people and their families. I have since made it a point to refer people in my Panchayat who have any symptoms of TB to the nearest government facility. I have also ensured the availability of mobile X-rays. I strive to make my Panchayat TB-free.
>
> **- Mr. Chelladurai,** Panchayat President, Maradi Panchayat, Trichy, Tamilnadu

> “When the TB Champion came to meet me at my home, I was pleasantly surprised. This was an opportunity for me to ask many questions about the treatment, what precautions I could take and so many other aspects. It was so reassuring to know that I could contact the TB Champions anytime I needed any help.
>
> **- Lalit Kumar Yadav Newari Khurd, on treatment for TB, Balod, Chhattisgarh**

V. Reflections on CAF: Early lessons learnt

This section offers some reflections on the CAF journey so far and some early thoughts for the way forward.

On the philosophy and process:

- One of the unique characteristics of CAF is that it is a process of communities coming together to measure the quality of care and quality of services offered by the health systems in their geographies. It is a true manifestation and democratisation of the idea of community-led monitoring which transforms the community from being passive recipients of care to active stakeholders who contribute to change things for the better. Active engagement of the community in identifying the gaps is the first, and essential step, in solving a problem.
- At the core of CAF is finding answers to some of the most pressing challenges at the local level in a participatory manner. The process of bringing together all the relevant stakeholders at one platform to solve problems locally also serves to put TB in the spotlight. This is an acknowledgement of the shared responsibility to find a collective solution.
- The CAF process has led to a realisation that accountability is a two-way process. While health systems constantly strive for better delivery of services, communities have to not only demand but also contribute to finding solutions.
- The CAF has underlined the significance of delivery of TB-related services to the last mile through TB Champions who are regarded and respected as community leaders.
- Investment in communities inevitably reaps benefits beyond TB. This was evident during the COVID-19 pandemic, when empowered TB Champions played a key role in educating their communities about COVID-19, promoting vaccine uptake and adoption of COVID-appropriate behaviours.
- The active participation of TB Champions in the CAF process has increased the trust of the health system in affected communities, and has resulted in a continued willingness to engage them.

On data for decision-making:

- The experience of implementing CAF has reinforced the first-hand role of communities in generating authentic data and evidence from the field.
- A careful look at the data that has emerged from CAF suggests that a constant tracking of the performance of the health systems and real-time feedback from the community leads to positive changes, such as significant reductions in delay in treatment initiation or shorter turnaround time in getting the diagnosis results and several other aspects of the care cascade.
- The CAF process establishes the usefulness of having alternative datasets for decision-making at the local level which are missed out in the process of examining trends at the district, state and national levels.
- A one-size-fits-all approach works for neither problems nor solutions. The CAF process has underlined that being inclusive is critical in finding solutions. It is important to look at the gaps that different sets of people may experience while interacting with the health systems and while finding solutions it is equally important to be sensitive to the needs of various groups.

On community-led multisectoral action:

- One of the major learnings from the CAF process has been that there are latent resources within the community which TB Champions are able to tap, once they identify the problem. Examples have included meeting nutritional needs, organising alternatives to local transport systems, linking people to appropriate support systems etc.
- Panchayati Raj Institution representatives have emerged as strong local governance bodies and there is a visible commitment to contribute towards TB Elimination. However, while sharing the CAF findings with the PRIs it is observed that while there is a willingness to contribute, there is a need to further clarify their role and responsibilities.
- While the CAF process has helped identify gaps within the TB response, it touches the broader aspects of development by linking persons in need to other developmental and social security schemes, through the tangible efforts of TB Champions
- The CAF model demonstrates the potential impact a truly meaningful partnership between the health system and communities can have, driven by a sense of joint ownership and a mutual goal - to provide the highest quality of care and services to all people with TB.

REACH is an India-based non-profit organisation working on tuberculosis for 25 years. Since 2016, REACH has been working with support from USAID to introduce, strengthen and institutionalise a community-led response to TB in India, initially through the TB Call to Action project (2016-2020) and currently through The Accountability Leadership by Local Communities for Inclusive, Enabling Services or ALLIES Project (2019 - 2023). These efforts have resulted in recognition of the need to engage TB-affected communities and the formal adoption and scale-up of the TB survivor - TB Champion model by the Government of India. The ALLIES Project is currently being implemented in four states of India, with the guidance of the National TB Elimination Programme and through the committed efforts of TB survivors-Champions.

25 REACH
Equitable Health for All

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