









Accelerating access to person-centred care for people with TB: A survivor-led initiative in Bihar, India IMPACT REPORT

Background

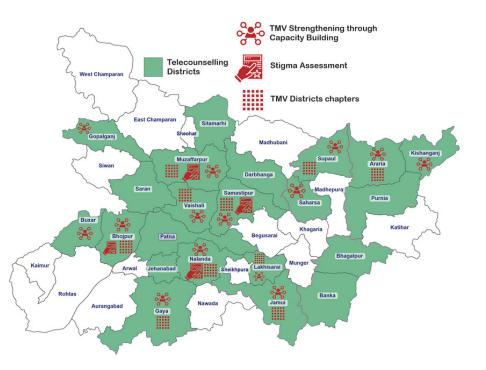
The involvement of TB survivors in the TB response is now recognised as a priority to achieve #EndTB goals, both globally and in India. Between 2016 and 2020, REACH implemented the TB Call to Action project in six states of India, with support from USAID, with the objective of supporting and strengthening the community response to TB. Through this project, REACH demonstrated a unique mechanism to identify, empower and engage TB survivors, resulting in the creation of India's first cadre of trained TB survivors as Champions, and the formation of survivor-led networks across India, including TB Mukt Vahini (TMV) in Bihar.



TB Champions with Honourable Minister for Health, Shri Mangal Pandey in November 2017 during the launch of TB Mukt Vahini - 13 TB Champions from seven districts of Bihar came together to form the network

About the project

In September 2020, REACH was awarded a grant by the Stop TB Partnership through Round 9 of the Challenge Facility for Civil Society (CFCS). Building on the results and lessons learnt from the TB Call to Action project, this project's activities were designed to strengthen TMV, Bihar's TB survivorled network to provide personcentred care to people with TB. All project activities were implemented in close coordination with the NTEP at the national, state and district levels. TMV members were involved in planning and executing the project.



Objectives



To strengthen the capacity of TB Champions and TMV members as advocates for people with TB



To develop and demonstrate a sustainable mechanism of peer counseling through a cadre of empowered, trained TB Champions



To enable TB Champions to advocate for the active involvement of local elected representatives



To build the evidence base on the impact of engaging affected communities through measurement of stigma and empowerment

Key milestones and activities

>>> Capacity-building of TB survivors

229 TB survivors from 14 districts of Bihar were trained through district-level capsular trainings, organised between October 2020 and January 2021, with support from the National TB Elimination Programme staff and health officials in the districts. **71%** of trained TB survivors were **men** and **29%** were **women; 77%** of the participants had had **drug-sensitive TB, 23%** had survived **drug-resistant TB.** The TB survivors learnt the basics of TB, the structure of the TB programme and the TB care cascade. They also had an opportunity to share their personal experiences with TB and their own journeys to cure.



Glimpses from the capacity building workshops for TB survivors in 14 districts of Bihar

>>> Establishment of TMV district chapters

In keeping with efforts to expand and strengthen TMV's presence, **district chapters of the network** were **formed in 10 districts**: Muzaffarpur, Samastipur, Gopalganj, Patna, Jamui, Lakhisarai, Araria, Kishanganj, Saharsa and Supaul. A senior member of TMV acts as a district focal point for the district chapter.



[•] It has been four years since TMV was formed and we continue to grow. In the past year, I have supported the training of nearly 30 TB survivors who are now working in their communities and supporting people with TB or those who have symptoms. If each of them trains 30 others, and so on, we will soon be able to together fulfil our dream of a TB Mukt Bihar.

- Anjana Singh, TB Champion and District Focal Point TB Mukt Vahini Bhojpur Chapter

TB Champions mentor other TB survivors



Members of the Vaishali chapter of TB Mukt Vahini

TB Champions of TB Mukt Vahini support each other and work together to address challenges that people with TB face. Through district chapters, TB Champions strengthen the involvement of TB-affected communities in their catchment areas. Experienced TB Champions guide newly trained TB survivors and build their capacity to become effective TB Champions themselves.

Abhishek Kumar is one such TB Champion. Having survived MDR-TB himself, he is aware of the many challenges that people with TB face."I know how it feels to have no motivation to complete the long duration of the treatment. I know how we hit rock bottom and lose all hope and give up on life. As TB Champions, we have the responsibility to inspire those with TB," he says.

When newly trained TB Champions have questions, experienced TB Champions like Abhishek and many others from the core TMV group step in to help them navigate the TB healthcare system and find local solutions.

A new TB Champion, Abhinandan Kumar from Vaishali, was counselling a woman with MDR-TB but was finding it difficult to convince her to continue treatment. There were arguments at home and she had no emotional support. Abhinandan felt it would be best to contact Abhishek for support.

"I told Abhinandan to visit their home and talk to the woman's family and explain to them the importance of taking treatment regularly and also help them understand the risks of dropping out of treatment. Abhinandan counselled them to support her and we are very happy she is now back on treatment," Abhishek says.

"Initially when I started working as a TB Champion, I felt hesitant and I did not understand how to handle difficult situations with tact. Abhishek mentored me, and now I am confidently providing telecounseling support to people on treatment," Abhinandan says.

"A TB Champion in every village is our goal. And together, we will eventually achieve our mission of TB-free and stigma free communities in Bihar," says Abhishek.

>>> Leadership training

In order to strengthen TMV as a survivor-led network, a first-of-its-kind 'Leadership Training for TB Champions' was held in March and June 2021. The training module was developed and rolled out in collaboration with Acumen Academy, a global capacity-development institute for the social sector. 20 TB Champions, all TMV governing body and executive committee members, participated in the training. The training focused on understanding the qualities of a leader, working with different factions within a community, conflict resolution and public speaking. After the training, participants provided valuable feedback, to help refine and strengthen the module.

For TMV, the leadership training was very helpful. Leadership qualities are necessary to bring out change. The training helped us overcome any fear of public speaking. It encouraged us to inspire other TMV members to work as a team. The training also helped us learn conflict resolution and negotiate to solve issues by understanding each other's perspectives and thinking creatively. Applying these learnings to our activities has been very helpful.⁹⁹

> - Raazya Mumtaz, TB Champion and Treasurer, TB Mukt Vahini

>>> Engaging TB Champions to measure stigma

In order to understand and measure the level and impact of stigma associated with TB, TB Champions of TMV carried out a stigma assessment using the Stop TB Partnership's stigma assessment tool. Stigma assessment was rolled out in **four districts** - Samastipur, Muzaffarpur, Bhojpur and Nalanda. A TB Champion was trained to administer the tools and carry out the data collection in each of these districts. The **four TB Champions reached out to 100 people with TB, 200 family members of people with TB, 100 members of the community and 32 health care providers.**

>>> TB Champion Empowerment Index developed

In order to improve understanding of the impact of the different capacity-building efforts on TB Champions, REACH worked with TMV members to construct and test an Empowerment Index. Intended to be used as a tangible tool to measure empowerment amongst TB-affected communities, the Index was constructed through individual conversations and group discussions with over 30 TB Champions. It includes a list of curated indicators to measure and quantify the impact of all efforts to train and engage TB Champions, thereby providing a way to go beyond anecdotal evidence of empowerment.

>> World TB Day

National level: TB Champion and TMV member Sharda Kumari was felicitated during the World TB Day Programme organised by the Ministry of Health & Family Welfare, Govt of India in New Delhi. Sharda was among five TB Champions who received the award in the presence of then Honourable Minister of Health and Family Welfare, Dr. Harsh Vardhan, then Honourable Minister of State, Health & Family Welfare, Shri Ashwini Kumar Choubey and Smt Arti Ahuja IAS, Additional Secretary Health, MoHFW.



State level: Bihar Health Minister Shri Mangal Pandey honoured Bihar's TB Champions Jitendra Prasad, Smriti Kumari and Ramdayal Mahto with awards for their contribution towards TB elimination in the state during the observance of World TB Day in Patna on 24 March 2021.



>>> Anti-stigma campaign



Members of TMV announced a **state-wide anti-stigma campaign** in the run up to World TB Day 2021 to urge local influencers to pledge to addressing stigma associated with TB. The campaign was formally launched on **17 March by Deputy Chief Minister of Bihar**, Smt Renu Devi at her residence in the presence of TB Champions and the State TB Officer.

75 TB Champions from 10 districts of Bihar participated in the campaign and organised programmes in their communities.

They also urged local leaders to pledge to reduce TB stigma and support the TB Champions in their efforts to eliminate TB. TB Champions reached out to **295 panchayat members and 2800 people** from the community through **128 awareness meetings**.

The campaign concluded with **Bihar's Health Minister Shri Mangal Pandey taking the antistigma pledge** along with TMV members.

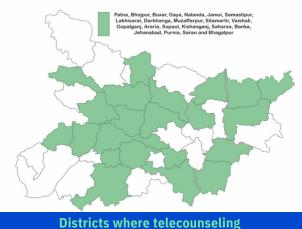


Providing person-centred support through telecounseling to people with TB during COVID-19 pandemic

Based on their own experiences of TB, TB Champions have frequently expressed the need for peer support for affected communities. This was especially evident during the COVID-19 pandemic; the impact of COVID-19 on TB services is well documented, particularly in terms of access to care and services as well as health-seeking behaviour.

To mitigate the impact of the pandemic and provide critical support to people on treatment for TB, over 40 TB Champions and members of TB Mukt Vahini were engaged to provide structured telecounseling support.

This initiative also addressed the challenges of restricted mobility and limited access to healthcare workers and information on TB, as a result of the pandemic.



initiative was implemented



- Potential peer counselors were identified from eight districts.
- In May 2021, an in-depth virtual training for the first batch of 22 TB Champions was held, with a focus on strengthening their understanding of person-centred care. Officials from the Bihar State TB Cell, District TB Officers and WHO consultants participated in the training.
- The trained TB Champions began contacting people with TB on the phone, based on the lists provided by the NTEP.
- When calling people with TB, TB Champions sought to understand any specific needs they had, such as not having an adequate supply of medicines, not receiving nutrition support, experiencing side-effects etc.
- These were then shared with the NTEP staff at the district and state levels for their immediate action.
- The TB Champions followed up with the person with TB to ensure they had received the support they needed.
- In August, an additional 23 TB Champions were trained to provide telecounseling support.
- TB Champions were also trained to do digital data entry using Kobo Collect.
- Virtual and in-person review meetings were held at regular intervals to provide additional training and support the TB Champions.

Issues identified	Support provided by TB Champions
PwTB unsure of next steps, facing stigma, discrimination or domestic violence	Regular emotional and psychosocial support, acting as a sounding board and speaking with families, when possible and with the consent of PwTB
Shortage of medicines	Coordinating with the NTEP and ensuring that PwTB received medicines on time, with minimal interruptions in treatment
PwTB due for follow up examination	Encouraging PwTB to go for follow-up examinations on due date and guiding them to the nearest facility
PwTB unaware of their rights and responsibilities	Empowering PwTB by helping them understand all about TB and TB treatment
PwTB identified by NTEP as lost to follow up	Motivation to restart treatment and linkage to NTEP
Irregular or improper intake of medicines	Providing counselling for treatment adherence and correct way of taking medications
PwTB migrating between places	Supporting PwTB with information and facilitating transfer-out process without interrupting the treatment
PwTB not getting benefits of Nikshay Poshan Yojana (NPY)	Facilitating access to NPY by coordinating with NTEP



TB Champion Anjana doing telecounseling

TB Champion is there when no one else is

Usha Kumari is a TB Champion from Vaishali, Bihar and an MDR-TB survivor. She has been providing telecounseling support to people with TB during the pandemic. A busy mother of three, she wakes up earlier than everyone else at home to complete her household chores and gets her kids ready for school and by 10 a.m., she starts her telecounseling work.

During one such counseling session, Usha was speaking to Sumit*. Sumit had TB a couple of years ago, and his wife had left him then. He managed to complete his treatment and also got married again. Earlier this year, Sumit developed symptoms of TB once again - this time, he was ready to give up. During these dark times, Usha was a ray of hope.

"He was facing side-effects and was scared that he would not make it. He had also lost hope and was lonely. He even told me not to call him anymore as his neighbours had come to know that he had TB again. He was hesitant to even talk to me but I told him that I knew what he was going through. I told him how I too had struggled during my treatment. I motivated him and offered to speak to his wife as well," Usha said.

During the telecounseling, Sumit told Usha that he would take a few medicines in the morning and the rest in the evening. "When I got to know this, I explained to him why it was important to take the medicines correctly and encouraged him to take them regularly. After two months, his health started to improve and I spoke to him again and asked him to go for follow-up tests. I was with him every step of the way and am proud I could help him to complete the treatment," says Usha.



TB Champion Usha Kumari

TB Champion helps woman with TB get her medicines before they ran out



TB Champion Kanchan Kumari

Sunita* is a resident of Katra in Muzaffarpur district of Bihar. She is married and is taking treatment for TB from her maternal home in Gaighat. When TB Champion Kanchan spoke to Sunita earlier in the year, all seemed well. But during the second counselling session in mid-July, Sunita said she was at her in-laws' and had medicines for only three more days. She expressed her inability to travel from her in-laws' home to her mother's to collect the medicines and asked Kanchan what to do. Sunita said that her mother-in-law did not understand the importance of treatment and was not happy that Sunita wanted to go back to her maternal home again.

Kanchan asked if her husband could help explain the situation to his mother - but he was away in Assam for work. Sunita said she would try speaking to her husband, but she knew what his answer would be – that she should do whatever his mother said. Nevertheless, Kanchan encouraged Sunita to speak to her husband and also offered to speak to her mother-in-law.

Kanchan told Sunita's mother-in-law all about TB and why it was so important for her to finish the six month treatment. However, her mother-inlaw retorted that a private doctor had said Sunita was fine. She didn't trust the medicines Sunita was taking and thought Sunita was making excuses to go to her maternal home again. Kanchan realised the mother-in-law would be of no help in this situation, and asked Sunita to seek her husband or mother's help. But Sunita's mother had passed away.

Kanchan knew she had to act fast. She encouraged Sunita to go back to her maternal home. At a time when no one was willing to help her, Sunita had Kanchan. She braved the rain and reached the TB centre in Gaighat in the afternoon to collect her medicines, but found the centre was locked. Kanchan immediately contacted the Senior Treatment Supervisor there and facilitated medicines for Sunita, who did not have her treatment card. The STS helped locate it and the following Monday, arranged for Sunita to collect her medicines and her card. Kanchan then encouraged Sunita to continue the treatment from her in-laws' home and facilitated the transfer-out process.

>> Social media campaigns

Social media campaigns featuring the work of TB Champions and members of the survivor-led network TB Mukt Vahini were disseminated every quarter. The campaigns, which included photos and video slideshows, aimed to increase public understanding of the role of TB Champions and survivor-led networks.



SMRITI KUMARI

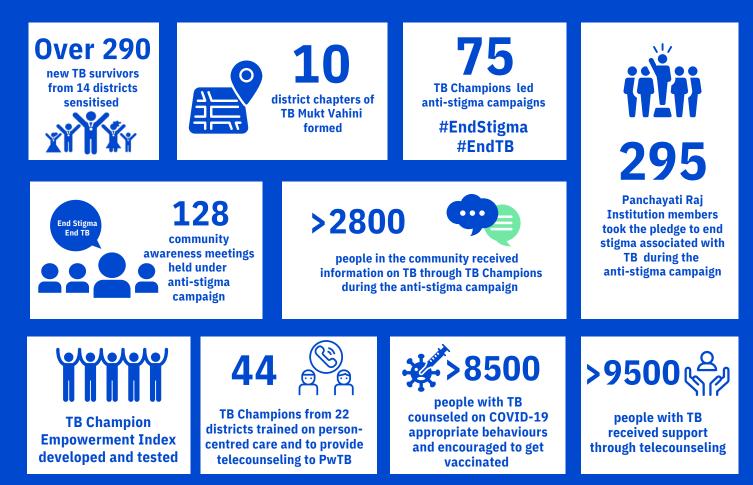
TB Survivor, TB Champion and Member, TMV



RAJIV KUMAR TB Survivor, TB Champion and Member, TMV Stop B Partnership



Key Results



During the COVID-19 pandemic, there were many challenges in supporting people with TB who were on treatment. TB Champions and members of TB Mukt Vahini stepped in at this opportune time to support the NTEP, by contacting people with TB on the phone and identifying any challenges they were facing. They then shared this information with us and we were able to take quick action. Through their efforts, TB Champions have demonstrated the importance of peer counseling, particularly during a time when there were many restrictions on movement and people with TB could not access services easily. Our collaboration with TB Mukt Vahini and TB Champions has resulted in a unique community partnership, with a mutual goal of ensuring that every person with TB in Bihar gets the highest quality of care possible. I wish TMV all the very best and hope they continue to support people with TB, raise awareness about TB and help us end the stigma associated with TB.

- Dr B K Mishra, State TB Officer, Bihar

About CFCS

As a multi-donor mechanism predominantly supported by USAID and the Global Fund to Fight Aids, Tuberculosis and Malaria TB Strategic Initiative, the CFCS is the Stop TB Partnership's grant mechanism for TB affected community, civil society, and grassroots organizations to transform the TB response so that it promotes and protects human rights and gender equality. Strengthening community and civil society actor engagement is an ethical and programmatic imperative in this pursuit.

About TB Mukt Vahini

A first-of-its-kind network, of and by TB survivors, TMV was born in 2017 as an outcome of the first training of TB survivors in Bihar organised by REACH. TMV has supported PwTB, sensitised communities and advocated with various stakeholders. TMV members are part of National, State and District TB Forums. TMV is a registered body under Societies Act. Membership has grown to over 400 from 23 districts.The expansion and strengthening of TMV was supported by REACH through the CFCS project.

About REACH

Resource Group For Education and Advocacy for Community Health or REACH is a nonprofit organisation established in 1999. Through an unrelenting focus on TB for the last two decades, REACH has been a key partner in India's efforts to end TB, by developing innovative strategies to engage a range of stakeholders including the public health system, private sector, TB-affected communities, business leaders, celebrities and the media.

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