

IMPACT REPORT

Engaging TB Survivors & Champions for a Community-led Response to TB



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leading the fight against TB

The TB Call to Action Project is a four-year initiative by REACH, supported by the United States Agency for International Development (USAID) and implemented in partnership with the Revised National TB Control Programme (RNTCP) at the national, state and district levels. There were six priority states – Assam, Bihar, Chhattisgarh, Jharkhand, Odisha and Uttar Pradesh.



Engaging TB survivors and Champions is a flagship intervention of the project.

CONTEXT

To achieve global elimination of tuberculosis (TB), progress in India is critical. India is committed to achieving TB elimination by 2025, ahead of the global targets, and is a signatory to the targets in the Declaration from the United Nations High Level Meeting (UNHLM), held in September 2018.

This significant political commitment is evident in the changes introduced over the last few years, including new diagnostics, quality-assured weight-based fixed dose combinations, a strong notification system that caters to both the public and the private sectors, Direct Benefit Transfer for people with TB, strong electronic supply-chain management systems, a multi-sectoral approach to TB and introduction of active case finding strategies and campaigns across the country, at scale.

However, the lack of general awareness about TB, delayed diagnosis, stigma and discrimination and out-of-pocket expenses remain challenges at the community level.

To achieve the ambitious UNHLM targets as well as those outlined in the National Strategic Plan, a multi-pronged approach addressing the social dimensions of TB is essential, as is the active involvement of affected communities in the TB response. The engagement of PLHIV (people living with HIV) in HIV care and support taught programmes and nations to rethink disease control strategy. Drawing on the lessons

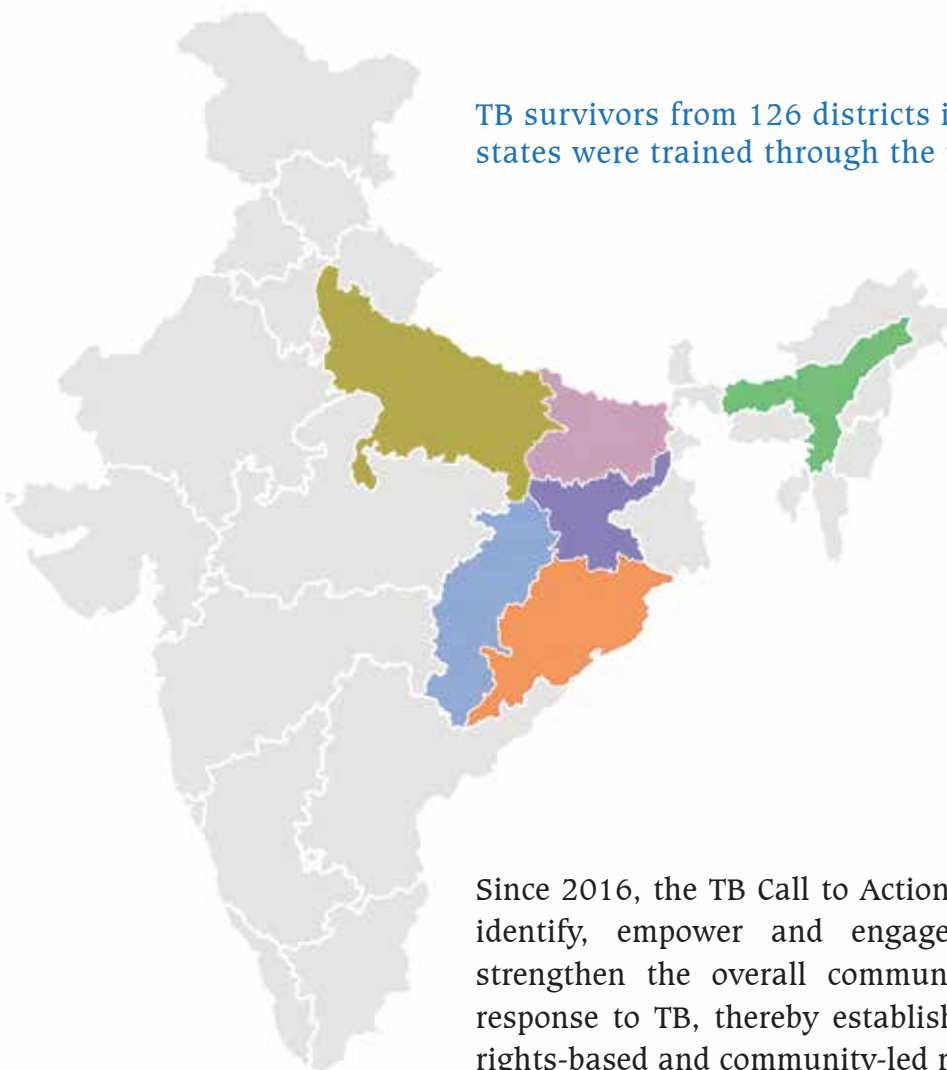
from the success of PLHIV networks, the TB Call to Action project explored the role of TB survivors as integral to the TB programme.

Willing communities: Many TB survivors have been through a lot of hardships – economic, emotional and social – and are keen to ensure that others do not suffer similarly. TB survivors can play a critical role in supporting people with TB and in bridging the gap between the service provider and the service user. There was however no clear understanding of their role in the TB response, nor a mechanism for them to get involved in a meaningful manner. There were few to none formal networks led by survivors.

A receptive programme: There have been efforts to engage survivors in the past; however, these were sporadic. A primary goal of this project was to design and demonstrate a mechanism to build the capacity of survivors and position them as allies to the programme, with a clearly defined role and the potential for tangible results.

THE INTERVENTION

TB survivors from 126 districts in six states were trained through the project



Since 2016, the TB Call to Action Project has sought to identify, empower and engage TB survivors, and strengthen the overall community preparedness and response to TB, thereby establishing a person-centred, rights-based and community-led response to TB.



1. Capacity-building of TB survivors

Capacity-building workshops were the first step towards building a pool of trained TB Champions who could be powerful advocates on behalf of affected communities at the state and national levels. The workshops were designed to be as participatory as possible, with a focus on two key intertwined aspects:

- **Knowledge-building:** Supporting participants to contextualise their personal experiences of TB within the overall TB response, thereby identifying key advocacy focus areas
- **Skills-building:** Helping participants develop advocacy and communication skills, specifically focusing on the ability to tell their stories in an impactful manner and identify and build effective partnerships

A critical step was identifying TB survivors to participate in the capacity-building workshop. This was initially done primarily through the TB programme officials at the state and district level, who nominated survivors they thought could be potential Champions. In some cases, partner organisations nominated participants. In the second round, several survivors were identified through word-of-mouth and by their peers who had been trained in the first round.

Stage 1: Call for Applications and Selection	
Open Call for Applications	<ul style="list-style-type: none"> ■ Criteria for participation be clearly defined - must be a TB survivor, willing to participate in TB response, willing to speak publicly about personal TB story ■ Application form disseminated via State/District ■ TB authorities/Partner organisations
Shortlisting	<ul style="list-style-type: none"> ■ Listing and review of applications ■ Personal interviews via phone/in person with applicants to verify details and confirm willingness to be a TB Champion ■ Identifying as many female participants as possible
Workshop planning	<ul style="list-style-type: none"> ■ Development/customisation of workshop agenda & materials, as per the state's requirements ■ Identification of facilitators, including as many previously trained TB Survivors as possible

Stage 2: Capacity-Building – TB Survivors to TB Champions

Participation in Workshop

- Three-four day workshop focusing on
 - strengthening knowledge of TB
 - understanding structure of the TB programme
 - building advocacy skills

Sharing personal stories

- Focus on effective story-telling, translating personal story into advocacy messages
- Recording of personal testimonials on video/through photo-shoots

Interacting with other Survivors

- Often first time a participant had met other TB survivors
- Creation of a safe space to share stories through 'My TB Story' session
- Pathways exercise opportunity to identify/discuss common challenges

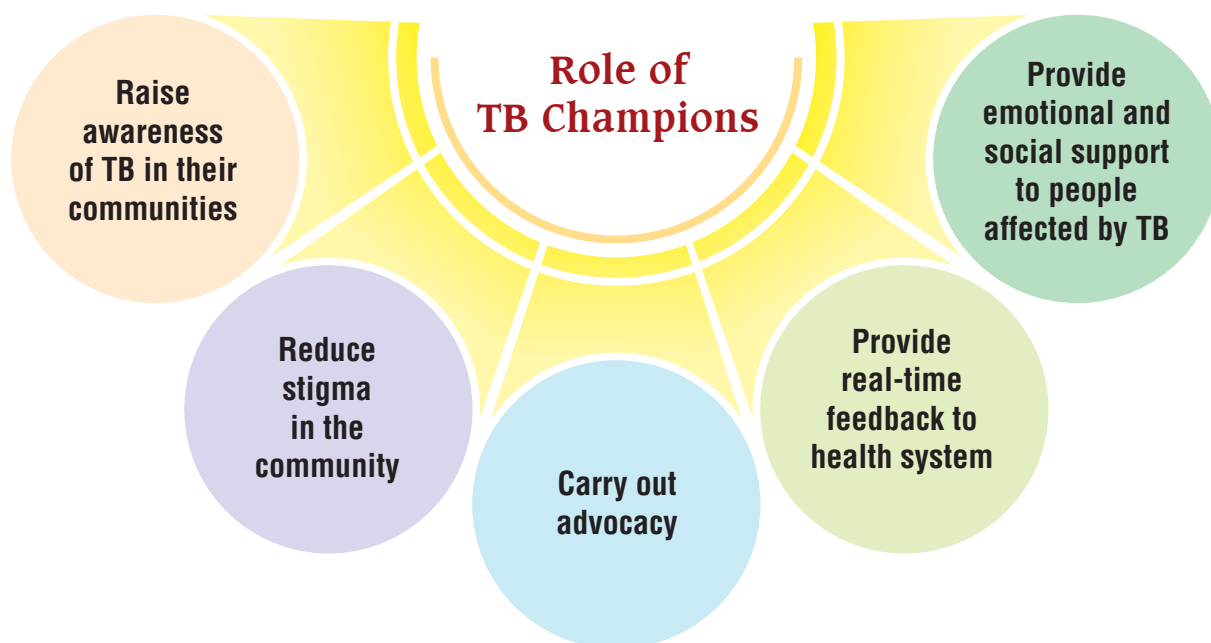
Simultaneously, efforts were underway to create an enabling environment for the active engagement of TB Champions, through sustained advocacy efforts with key stakeholders including the TB programme at national, state and district levels, elected representatives, district administration officials, the media and others. The emphasis was on highlighting the value of engaging survivors as Champions, and the potential positive impact their participation could have on the TB response. Public health officials were also invited to participate in the capacity-building workshops and interact with the TB Champions.





TB Champions Mentorship Programme

A six-month mentorship programme was designed to engaged the trained TB Champions and help them translate their commitment into action. Over the six months, the TB Champion had the following mandate:



Over 45 TB Champions from four states and ten Champions at the national level were enrolled in the first round of the mentorship programme. Based on the feedback and learnings, the second round was designed to be more results-oriented. Each Champion was asked to support at least 60 people with TB over the six-month period; conduct at least two community meetings every month; advocate with local stakeholders; and lead two anti-stigma campaigns.

Mentor's role: Each TB Champion was assigned a mentor, usually based in their state, and if possible the district itself, so as to be easily available for support. The mentor was usually a social worker or a development practitioner, and someone preferably with a sound understanding of the public health system and the TB programme, especially at the sub-district level. The mentor also participated in the capacity-building workshops and committed to being available to guide and advise the TB Champion for six months. The mentor was responsible for ensuring that the TB Champion was able to complete all the planned activities, and for accurate documentation as per the prescribed formats.

Both the TB Champion and mentor received a financial incentive over the six months, to support their travel, expenses related to community meetings, and the time they invested in the programme.

Monitoring and feedback mechanism

A robust monitoring and feedback mechanism was an integral part of the mentorship program. This mechanism consisted of:

Management Information System (MIS): To strengthen the monitoring of the mentorship programme and document the achievement of the TB Champions, a MIS was developed. This MIS records quantitative and qualitative information about the outreach and advocacy efforts of the Champions; a line-list of people with TB supported by the champions and other relevant details. The MIS also included pre-designed formats to be submitted on a monthly basis via the mentors. Training on the MIS and use of the various forms was part of the capacity-building workshop agenda for both TB Champions and their mentors.

Regular Review Meetings: TB Champions and their mentors attended two review meetings over the six months, to discuss and address any challenges that emerged. These review meetings also gave the Champions to share their progress with state health officials and get their guidance. In addition, mentors also took part in monthly review meetings to analyse the available data and identify solutions to persistent challenges.

Field visits: The REACH team – from the national and state levels – conducted frequent visits to the districts for supportive supervision, often attending community meetings, meeting District TB Cell officials and providing on-site guidance to the Champions.

Stakeholders and their role

Central TB Division

- Overall review of mentorship design and regular feedback
- Revising community engagement strategy
- Guidance to State TB Cells

State TB Cell

- Guidance to District TB Cell
- Participation in review meetings

District TB Cell

- Inviting TB champions to participate in meetings at facilities
- Displaying TB Champion posters at facilities
- Linking TB Champions to people with TB who required emotional or social support

Toolkit for TB Champions

A toolkit was developed for TB Champions who enrolled in the six-month mentorship programme. The toolkit contained three categories of materials.

I. Materials for use by the TB Champions themselves, including Frequently Asked Questions on TB, a handbook on TB, TB Champion badges and personalised posters for display at facilities.

II. Materials to be given to people with TB, including a Fight TB booklet and TB Mitra cards

III. Materials for use at community meetings including leaflets, posters, door stickers etc.

All materials were made available in Hindi, Odia and Assamese.



2. Forming and Strengthening Survivor-led Networks

Networks led by affected communities have the potential to be powerful actors in the TB response and can take the lead in forging a rights-based approach. At the capacity-building workshops, network formation featured on the agenda, and participants had an opportunity to discuss the need for networks and their willingness to come together under a common umbrella.

The first such network, Touched by TB, was formed at the national level, as an outcome of the Regional Capacity-building workshop for TB survivors from the Asia Pacific region, held in New Delhi in April 2017. State-level networks were announced by survivors from Bihar, Jharkhand, Odisha and Assam in 2017-18, and by Uttar Pradesh and Chhattisgarh in 2018-19.

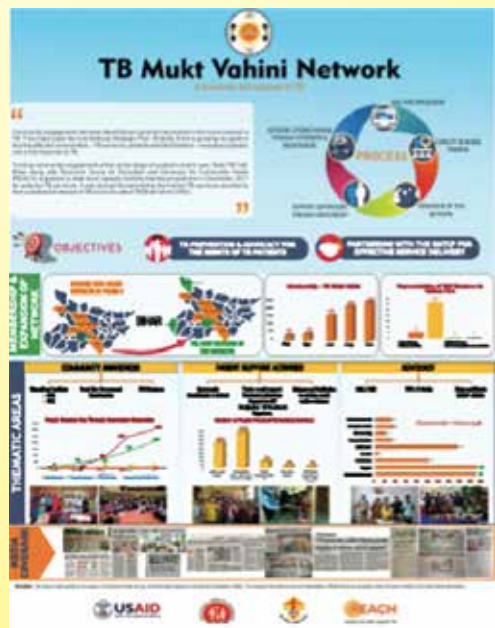
National	Touched by TB
Bihar	TB Mukht Vahini (TMV)
Jharkhand	TEJ (TB Elimination from Jharkhand)
Odisha	Kalinga TB Survivors Network
Assam	Jyoti End TB Assam (JETA)
Chhattisgarh	TB Mukht Chhattisgarh
Uttar Pradesh	UP TB Elimination Force

“ बिहार के हमारे साथी ने कैसे ज़िंदगी जीत ली जाती है, इसका बयान किया। जिन लोगो नें TB पर जीत हासिल की हैं, ऐसे ही एक व्यक्ति का यहां भाषण हुआ जिसके कारण विश्वास पैदा होता है। ”

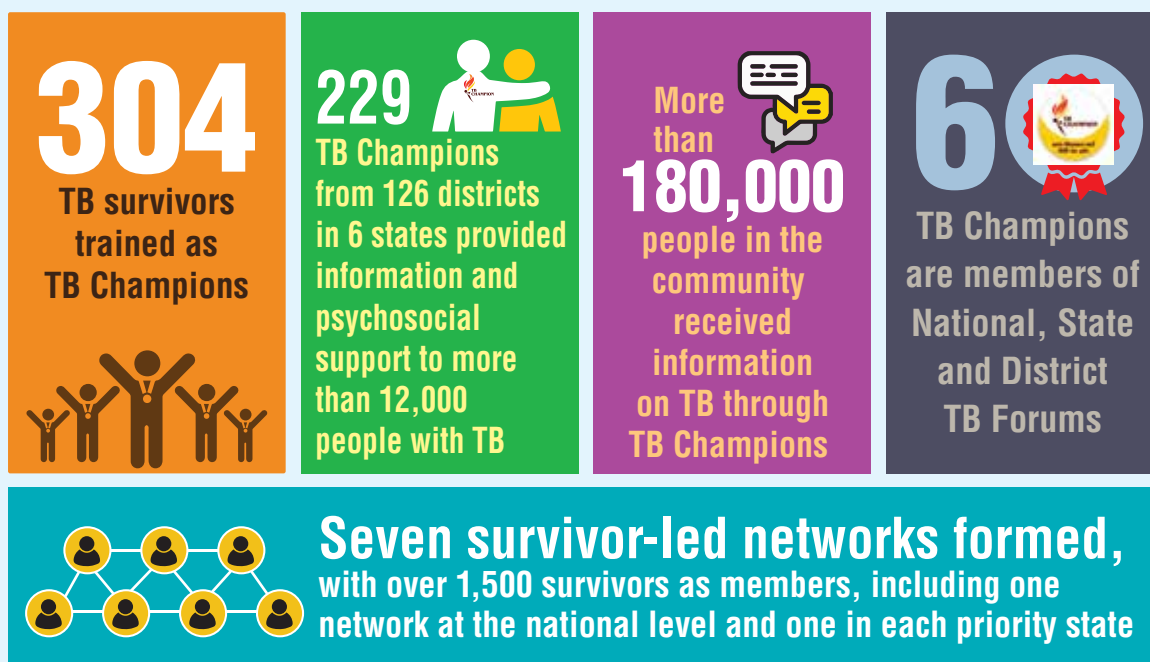
*Honorable Prime Minister Mr. Narendra Modi,
at the Delhi End TB Summit, March 2018,
mentioning TB Champion Sudeshwar Singh from Bihar*

Key achievements:

- To date, over 1500 survivors have joined the different networks.
- In 2019, TB Mukht Vahini and TEJ were formally registered as independent bodies under the Societies Act.
- TB Mukht Vahini was selected as a best practice at the 5th National Summit on Good & Replicable Practices and Innovations in Public Healthcare Systems that took place in Kaziranga, Assam in November 2018.
- TB Mukht Vahini was also selected for an oral abstract presentation at the 50th Union World Conference on Lung Health, held in Hyderabad in October 2019.
- Networks have also taken out awareness rallies, advocated with district health officials and formed district chapters.



KEY RESULTS



Capacity Building

304 TB Survivors were trained as TB Champions across six states. 20% were women

State	No of TB survivors trained as TB Champions			% of districts covered
	Male	Female	Total	
National	10	4	14	
Assam	43	11	54	80%
Bihar	41	11	52	52%
Chhattisgarh	43	11	54	100%
Jharkhand	39	11	50	95%
Odisha	43	6	49	76%
Uttar Pradesh	25	6	31	16%
Total	244	60	304	

“We should have three to four lakh TB Champions in the country.”

- *Dr. Harsh Vardhan, Honourable Union Minister, Health and Family Welfare, Govt. of India, at the launch of the TB Harega Desh Jeetega campaign in September 2019*

TB Champions Mentorship Programme

Among them, 229 (75% of trained TB Champions) were engaged under the mentorship programme.

	No of TB Champions engaged as 'Mentees'			No of Mentors who provided support to Champions
	Male	Female	Total	
Assam	22	8	30	5
Bihar	38	15	53	10
Chhattisgarh	28	6	34	6
Jharkhand	37	12	49	9
Odisha	34	5	39	5
Uttar Pradesh	19	5	24	7
Total	178	51	229	42

Supporting people with TB

State	Assam	Bihar	Chhattisgarh	Jharkhand	Odisha	Uttar Pradesh	Total
No of people with TB who received support from TB Champions	1459	3017	2177	2123	2093	1652	12521

Making communities aware of TB

TB Champions provided information on TB to 1,90,521 people through 1873 general awareness and sensitisation meetings. An estimated 53% of the meeting participants were female.

From TB survivors to Champions and Community Leaders

In addition to providing information and emotional support to people with TB and sensitising communities, TB Champions have evolved as advocates and leaders in the communities.

- They have identified people with symptoms of TB and referred them for testing; in many cases, Champions have personally accompanied people with facilities to ensure they are tested promptly.
- They have linked people with TB to available benefits, including Nikshay Poshan Yojana.
- Champions have played a significant role in motivating people who had dropped out of treatment to resume taking their medication, and complete their treatment successfully.

- They have gone door-to-door, visiting people with TB, speaking to their families and friends and addressing any issues around stigma.
- Through anti-stigma campaigns, Champions have motivated people to talk openly about TB, and advocated for the rights of people affected by TB.
- Champions have conducted meetings for community groups and audiences that were previously entirely unaware of TB.
- They have been able to use local languages and dialects to convey information on TB
- Their advocacy efforts have resulted in the involvement of Panchayat leaders and other community leaders.
- They have worked closely with the TB programme, giving them real-time feedback on TB services and identifying any potential bottlenecks in access to services.



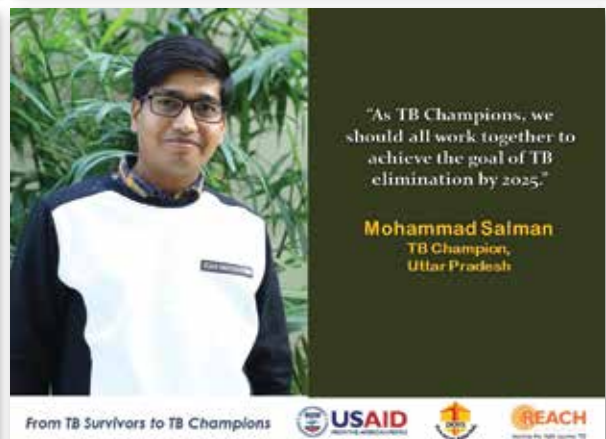
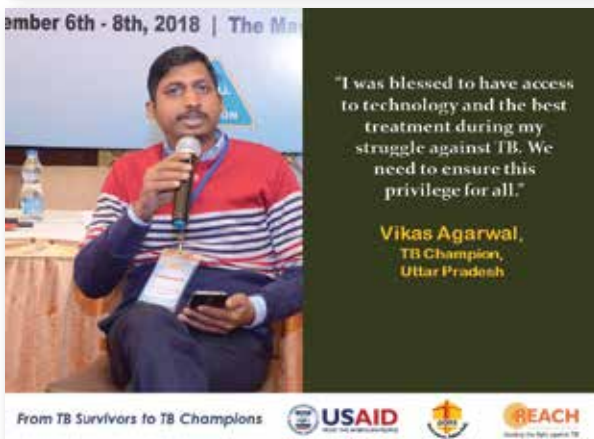
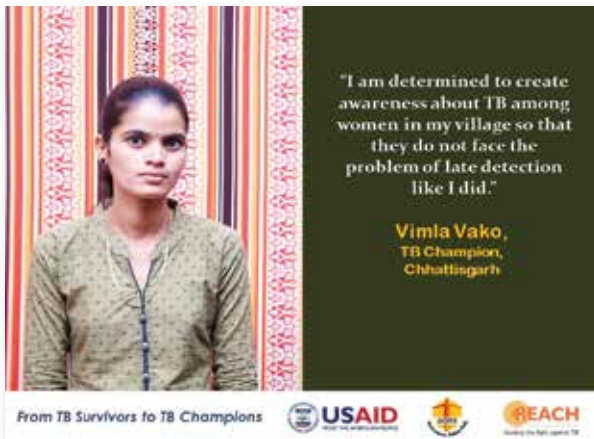
TB Champions in decision-making bodies

TB Champions were nominated/elected as members of various bodies and forums.

- Three TB Champions were nominated to the India Country Coordination Mechanism as the main and alternate members – Sudeshwar Singh from TB Mukh Vahini, Dr Gopa Kumar from Touched by TB, and Rekha Verma from TEJ.
- 59 Champions are members of National, State and District TB Forums.
- Champions were invited as members of several working groups set up by the Central TB Division.

TB Champions on Social Media

To raise the profile and visibility of TB Champions, social media campaigns were curated. A #MondayMotivation series was launched on Twitter in October 2018, featuring posters with motivational quotes of TB Champions, and a new post every Monday for six months. Women TB Champions participated in '#WomenEndingTB', in March 2019, to recognise the efforts and contribution of women in various capacities to end TB.



TB Champions lead Anti-stigma Campaigns

Over the six-month mentorship programme, TB Champions led a minimum of two anti-stigma campaigns, working closely with their community leaders and garnering their support.



TB Champions in the news

TB Champions are frontline soldiers in fight against the menace, says official

Assam's TB Champions complete six-month mentorship programme



WORKSHOP FOCUS ON FIGHTING DISEASE TB champs spread awareness

ACHINTYANGANGULY Tuberculosis Control Program (TBC) — a tuberculosis (TB) control initiative of the Union government. According to Kanya Sharma, national programme manager of TBC, Assam, TB champions have been 50,000 across the state. "As per government records the death rate is up to 10 per cent in the state," she said.

"The intention of the workshop was to form a group of TB survivors so that they can help in spreading awareness among villages in their respective areas. This will further reach out to patients to approach the nearest government facilities and seek treatment under the Revised National TB Control Strategy (RNTSC), said Sharma.

SEARCH also carries out similar activities in other states like Assam, Bihar and Odisha under TB Call to Action (TBCA), a project initiated by the US Agency for International Development (USAID). The workshop also addressed a point charter addressed to health, tragedy, state's additional chief secretary and in charge of the state health department who was also on the concluding day.

The factor of demands included a campaign for eradication stigma, reduction in the distance between villages and TB centers and providing nutritional and financial support to patients.

Tuberculosis survivors in Assam float platform to help fight disease

Kampan Khatu Assam's TB Champions have formed a platform to help fight tuberculosis. The platform, known as TB Champions, will work to reduce the burden of the disease in the state. A large number of the population has been affected by the disease, and the TB Champions are working to help them. The platform will provide support to TB survivors and help them to get the treatment they need. The platform will also work to raise awareness about TB and help to reduce the stigma associated with the disease.

राज्य में टीबी के घंटे से सज़ुरा विचारलेखले लेखों के लिए पहली बार कार्यक्रम का आयोजन टीबी से जंग जीत चुके लोग मरीजों के लिए प्रेरणा : सुधीर त्रिपाठी

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Outcast to TB champion — 22-yr-old rebuilt her life

Asmita Tandan Odisha woman who lost nearly everything to disease is now powering anti-TB campaign

PAINFUL STRUGGLE In 2015, Chandra, a 22-year-old woman, was diagnosed with TB. She lost her job and her health. She was outcast by her family and friends. But she didn't give up. She started a campaign to help other TB survivors. She is now a TB champion and is helping to raise awareness about the disease.

TB survivors take out rallies in Bhubaneswar

Home > States > Odisha

TB champion Bibek Ranjan Padhi led the rally in Jajpur in which 200 students and teachers participated.

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By Express News Service

BHUBANESWAR: Tuberculosis survivors and champions of Kalinga Survivors Network along with other stakeholders organised first-of-its-kind simultaneous rallies to raise awareness on TB in six districts on Saturday.

महिलाओं को दी गयी यक्ष्मा की जानकारी



कार्यक्रम में मौजूद टीबी वैधियन स्मृति व अ अन्य.

राष्ट्र अंतरराष्ट्रीय महिला दिवस के मौके पर शुक्रवार को प्रखंड क्षेत्र के गोपालपुर में जागरूकता कार्यक्रम चलाया गया. इस दौरान महिलाओं को यक्ष्मा रोग से बचाव को लेकर जानकारी दी गयी. मौके पर टीबी को मात देकर सामान्य जीवन जी रही टीबी वैधियन सिद्धि कुमारी ने स्मृति कुमारी ने महिलाओं को यक्ष्मा रोग से बचाव को लेकर जागरूक किया. इस दौरान स्मृति ने बताया कि सरकार यक्ष्मा रोग को लेकर अलग-अलग तरह के अभियान चला रही है. इसे लेकर हर अस्पताल में टीबी का मुक्त ब्रह्मण किया जाता है और उन्हें समय-समय पर डॉट्स मूहिया कराया जाता है. स्मृति ने

जिंदगी की जंग जीत दूसरों का बढ़ रहे हौसला

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टीबी मुक्ति वाहिनी ने जगाई मरीजों के अंदर जिजीविषा

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TB Champions Speak Up

TB Champions were invited to speak at several meetings, by the government, USAID, REACH and other organisations. They spoke not just of how their lives had been affected by TB but also about their role as TB Champions and their commitment to being an integral actor in the TB response.



Sudeshwar Singh, TB Champion from Bihar speaks at the inaugural session of the Delhi End TB Summit chaired by the Honourable Prime Minister Shri Narendra Modi on 13th March 2018



B Chinmayee, TB Champion from Ganjam in Odisha, speaks at the launch of the TB Harega Jeetega Campaign in September 2019



TB Champion Anjana Singh from Bihar felicitated by Ms. Preeti Sudan, Secretary, Ministry of Health and Family Welfare, Government of India on World TB Day 2019



TB Champion Minoti Puran from Jorhat, Assam, speaks live on a talk show on TB broadcast by Doordarshan Guwahati



TB Champion and Touched by TB member Dean Lewis speaks at a meeting of TB Communities organised by REACH in September 2018



TB Champions interact with USAID Administrator Mark Green in Hyderabad in November 2017



TB Champions at the Regional Review Meeting (East Zone) of State TB Forums under RNTCP organised by Central TB Division and REACH in Raipur in March 2019



TB Champions with senior health officials at the first ever Training of Trainers, held in New Delhi in October 2019

TB Champions at the Union Conference



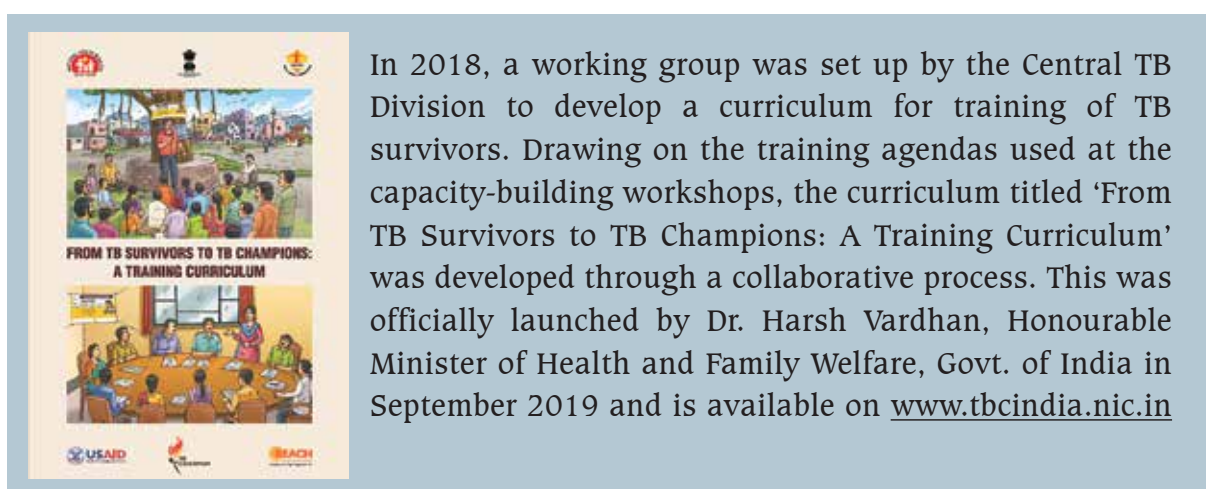
Short films featuring TB Champions



Key challenges & learnings

- Trained TB Champions are highly motivated to work with and among their communities and must be supported with monetary incentives and continued trainings.
- Identifying and motivating TB survivors to attend the capacity-building workshops was a considerable challenge at the start of the programme. Related challenges including convincing District TB Cell officials of the purpose and value of the mentorship programme, and ensuring their understanding of the concept; and selection of survivors based on gender, age and other criteria.
- Several of the TB Champions had 'starting trouble' – not knowing how to approach health officials; unable to get details of people with TB to contact; and not knowing how to conduct community meetings, or whom to approach for various permissions. However, this changed with time and most Champions were able to address these challenges effectively.
- The TB Champions faced identity issues – they were often confused with health workers and had to invest considerable time and energy in explaining their role and responsibilities. On occasion, the expectations from TB Champions were disproportionate to what they could offer.
- Given the distances between health facilities within a district, TB Champions were largely limited to supporting people with TB in one or two blocks. However, there were often requests or demands from other blocks of the district, and Champions found it difficult to travel to these areas.
- The fear of stigma or discrimination does not deter a TB survivor from working as a Champion. TB Champions are increasingly recognised as leaders within their communities and gradually become the go-to persons for all health issues, extending beyond TB.
- Being a TB Champion and working with the health system for the benefit of other people with TB is an empowering experience for a TB survivor. Most TB Champions reported advancement in their knowledge, skills and overall social standing.
- TB Champions are best placed to provide real-time information to the programme and can help establish a constant feedback loop, such as on the availability of drugs, provision of quality services, availability of TB programme staff etc. This will also help the programme understand the expectations of people with TB.
- Mentors played a critical role in building the capacity and confidence of TB Champions, and supporting them to fulfil their mandate successfully. They also provided a lot of support in documentation and in submitting the necessary reports. However, the Identification of mentors, particularly in specific districts, is a challenge. In the long term, experienced TB Champions are best positioned to be mentors themselves.

- The RNTCP values the contribution of the TB Champions to all its activities and is willing to support the TB Champions to work jointly towards the goal of TB elimination at all levels. TB Champions have been actively involved in Active Case Finding drives in most states, and have been involved as treatment supporters for people with TB.
- Survivor-led networks can harness the power of communities and provide a framework to synergise individual efforts, optimise cross-learning, and channel the collective voice of the members. Being a network member reduces the loneliness of having TB or life after TB.



“People affected by TB should be aware of their rights. As survivors themselves, TB Champions can play a major role in supporting those on treatment for TB as well as their families.”

- *Mr. Vikas Sheel IAS, Joint Secretary, Ministry of Health and Family Welfare, Govt. of India, speaking at the valedictory session of the Training of Trainers workshop held in New Delhi in October 2019.*

“TB Champions have played a major role in helping people with drug-resistant TB. We hope they continue to work with the same dedication to help reduce the burden of TB in India.”

- *Dr. K S Sachdeva, Deputy Director General, Central TB Division, Ministry of Health and Family Welfare, Govt. of India, speaking at the valedictory session of the Training of Trainers workshop held in New Delhi in October 2019*

“I really want to express my appreciation for the work and commitment of TB Champions who were attending the review meeting and you are real heroes of the national TB response.”

- *Dr. Priyanka Shukla, Mission Director, NHM, Chhattisgarh, at Regional Review Meeting (Eastern Region) of State TB Forums for Community Engagement under RNTCP in Raipur, Chhattisgarh in March 201*
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एक गाँव, एक समुदाय, टीबी से आजाद हो जाएं!



टीबी मरीजों का सहयोग और उद्धार।

आइये
मिलकर करें
टीबी का
अंत



“I will communicate to the District TB Officers of the twelve districts to include the TB Champions as treatment supporters and members of District TB Forums.”

- *Dr. Santosh Gupta, State TB Officer, Uttar Pradesh, speaking at Mentorship Program End-term Review meeting in September 2019*

About REACH

Resource Group for Education and Advocacy for Community Health (REACH) is a Chennai-based non-profit organisation established in 1999 in response to the roll out of the Revised National TB Control Programme (RNTCP) in Tamil Nadu. Through an unrelenting focus on TB for two decades, REACH has engaged various stakeholders for a multi-sectoral and comprehensive response to TB, including the Central TB Division, State and District TB Cells, private health care providers, business leaders, celebrities, the media, people with TB and affected communities. REACH has consistently supported the RNTCP in its efforts to prevent, detect and treat TB, by providing holistic care and support along the care cascade to people affected by TB.

With support from USAID, REACH has implemented the Tuberculosis Call to Action Project since 2016 in six priority states – Assam, Bihar, Chhattisgarh, Jharkhand, Odisha, Uttar Pradesh. Through this project, REACH has created a cadre of TB survivors and Champions who are actively engaged in the TB response, advocated for the participation of industries through the Employer Led Model, engaged elected representatives for greater attention to TB, facilitated inter-sectoral coordination between various departments (beyond health) and piloted TB Mitra, a unique mobile-based application for use by communities.

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