

Connecting the Dots

Linkage support for drug-resistant (DR-TB) patients identified from the private sector in **New Delhi, India**



National Tuberculosis Elimination Program (NTEP) is the public health initiative of government of India and aims for achieving universal access to TB diagnosis and treatment. Over the years, the programme has expanded its service of TB and drug resistant TB across the country with access to free diagnosis and anti-TB drugs.

The National Strategic Plan (NSP) sets out the strategic direction and key initiatives that the Ministry of Health and Family Welfare will undertake from 2017 to 2025 for working towards achieving the goals of eliminating TB by 2025.

TB Alert India - aims to prevent morbidity and mortality associated with TB by providing holistic care including addressing psycho-social and economic aspects which affect uptake of testing and treatment.

Clinton Health Action Initiative (CHAI) CHAI is working with partners to eliminate TB, helping governments to better identify, diagnose, treat, and prevent the disease to save lives and decrease transmission. We are also working with countries to roll out shorter preventative treatments to vulnerable, high-risk populations. And, we are helping governments to better understand and track the disease through innovative technology which enables them to make real-time, data-driven decisions.

TB Alert India thanks NTEP, the private healthcare sector, patients, paramedics, care givers and counsellors for the support and cooperation received during the project.

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Photographs: TB Alert India

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Drug-resistant Tuberculosis (DR-TB) in India

Tuberculosis is a major public health concern in India, with the country accounting for **27 per cent** of the world's cases with around **2.7 million** cases. Of these, **130,000** were drug-resistant TB (DR-TB) cases. As per the Global TB report 2019, only **44 per cent (58,347)** of the estimated multidrug-resistant cases (MDR-TB) were diagnosed and of these, **35.8 per cent (46,569)** of the estimated cases were put on treatment. This leaves **56 per cent** of estimated MDR-TB patients undiagnosed and **64 per cent** untreated. Delhi in particular, had a total of **28,123** cases in **2020** of which **1,836** were paediatric cases.

DR-TB and the private sector

The National Tuberculosis Elimination Programme (NTEP), the public sector TB Programme treats approximately **1.4 million** cases and the rest make for 'missing' cases that are not notified, and remain either undiagnosed or unaccountable, or are treated inadequately in the fragmented and unregulated private sector. The private sector's widespread reach across the country, close to home service delivery and ease of access, combined with relative distrust of quality of public sector services imply that majority of care in India is first sought in the private sector. However, the existing private healthcare structure with different systems of formal and informal medicines coupled with lack of regulatory oversight and enforcement results in variations in quality of care. The situation calls for engaging the private sector in TB control to achieve impact in addressing DR-TB in India.

TBAI - Engaging the private sector to address DR-TB

TB Alert India (TBAI) had learnings about the value of engaging with the private sector. Through JEET (Joint Effort for Elimination of Tuberculosis),¹ a collaborative effort between National Health Mission and CHAI (Clinton Health Access Initiative),² TBAI had engaged with the private sector to address the identified gaps in the diagnosis and treatment of patients as an implementing partner of CHAI. These efforts had revealed that the actors in the private healthcare sector were keen to address DR-TB but faced challenges like lack of awareness and manpower and time resources required for notification and treatment follow-ups. These learnings were used to deepen the private sector engagement and a focussed project was conceptualised to address the gaps.

1 It's Time. Joint Effort for Elimination of Tuberculosis (JEET) Annual Report 2018. Available at: <https://apps.who.int/iris/bitstream/handle/10665/329368/9789241565714-eng.pdf?ua=1>. Accessed 4 December 2021

2 Clinton Health Action Initiative (CHAI) supports the national TB programme in strengthening engagement with the private sector by setting up effective and sustainable systems to provide quality treatment to TB patients seeking care in the private sector nationally, along with the introduction of new and better medications. <https://www.clintonhealthaccess.org/india/>

The project was implemented in New Delhi, India with the objectives to link and refer patients from the private sector to NTEP DR-TB centres for pre-treatment evaluation and initiation of appropriate treatment where required. It also vested in the patient, the right to choose his/her healthcare provider, by giving them the choice to avail treatment from the public sector, but still stay connected to the private healthcare provider, who they trusted, or preferred. The project rested on three key innovations that could ensure accurate and prompt diagnosis, timely referrals and initiation of DR-TB treatment. These innovations and their components were:



Pre-treatment evaluation includes drug-susceptibility testing (DST) with counselling to ensure that patients are provided prompt, need-based optimised care with follow-up and support. This was an important component of the project.



Access to Treatment Coordinators

- Identify, refer, and link patients to the public sector;
- Ensure timely completion of PTEs and further initiation of treatment in the public sector;
- Facilitate DR-TB counselling services for both patients and caregivers;
- Follow up with patients and caregivers in the first two months of treatment.



Establishment of Call Centres

- Follow-up with patients and caregivers;
- Facilitate tele-counselling services for both patients and caregivers.



The Connect for Life™ (CfL) platform is an adherence tracking patient support tool provided with a free license by Johnson & Johnson Global Public Health R&D to the project. J&J also supported customisation of the platform and the creation of voice modules in Hindi and English.



Creation of a DR-DOST cadre (with members from the community) through Connect for Life™

- Ensure timely reminders and support were provided to patients and caregivers through text messages;
- Support high-risk patients and attend to specific needs of patients such as adverse drug reactions, motivation to complete treatment and identification of risk factors;
- Document specific clinical information;
- Monitor visits of treatment coordinators.



The process

Step 1

New DR-TB patient identified from the private sector and referred to the NTEP DR-TB Centre and registered.

Step 2

Patient registered on CfL and message generated with all details of the patient.

Step 3

Cartridge Based Nucleic Acid Amplification Test (CBNAAT) and a second-line anti-TB drugs (SL-LPA) test conducted on the patient in the public sector.

Step 4

The results of the tests received along with details of the regimen recommended. The results conveyed to the patient and caregiver.

Step 5

Telecounseling given twice a week to keep the patient motivated.

Step 6

A repeat SL-LPA done and results documented in Connect for Life. Message sent to the patient and caregiver.

Step 8

Beginning of the treatment adherence phase.

Step 7

The treatment-centres initiated treatment on a specified date. A second message sent to the patient and caregiver.

Step 9

CfL message sent to the patient once a week for the next four weeks.

Step 10

Calls to caregivers once a fortnight for the next four weeks, for additional support.

Step 11

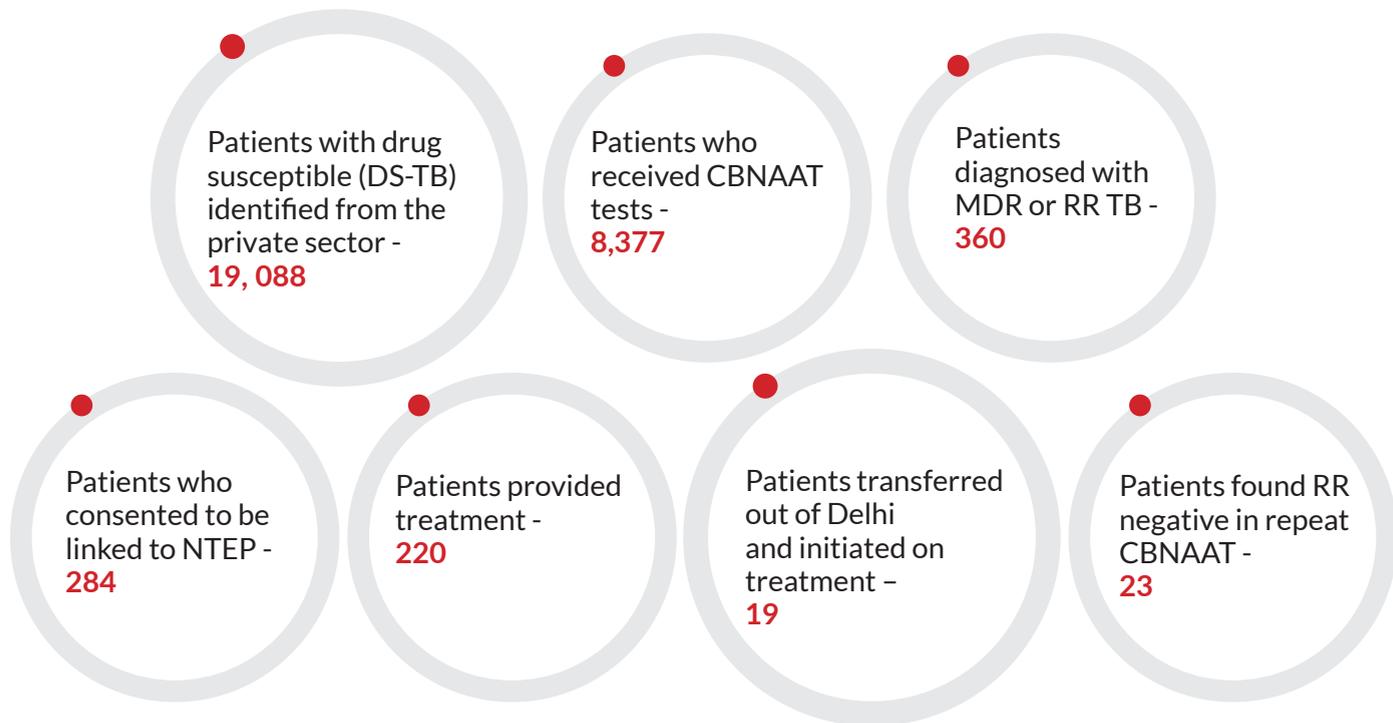
The patient and caregiver received tele-counseling once a week for four weeks.

Step 12

If the patient was high-risk or high priority tele-counseling was continued.

The results - encouraging and impactful

The results of the pilot project were encouraging as the figures demonstrate.



The Delhi State TB Office has integrated elements from the pilot model into their system. The state NTEP cell has deployed DOTS plus supervisors to provide initial counselling and facilitate links to NTEP services for DR-TB patients from private sector. The project team held a series of handholding and experience sharing workshops for them in order to build their capacity.

Some learnings

- The project call centres played a critical role in ensuring that patients continued treatment and the executives also helped in providing feedback about patients who needed extra support from NTEP officials.
- The follow-up calls ensured that patients stayed with the treatment and also helped to create action plans for patients who missed doses.
- The caregivers felt involved and appreciated for the role they were playing in the patient's treatment journey.

The TB Alert India DR-TB project addressed critical gaps experienced by patients accessing treatment in the private sector. By ensuring they stayed with the treatment till they achieved complete cure, the project averted further spread of the infection among the target beneficiaries and demonstrated that scaling up such programmes can go a long way in reducing DR-TB deaths, as well as reduce infections.





The impact – in the voice of the patients and healthcare providers



The follow-up calls, and messages were a constant comforting factor that I was not alone in this fight.

DR-TB patient, Delhi.



It was only after struggling for more than four months that I got referred to the programme and finally have been put on correct diagnosis and treatment. The counselling helps me deal with my day-to-day anxieties about the strong medication. It also helps my family believe I will be fine soon. The calls from the call centre helped my family to take precautions against getting infected.

DR-TB patient, Delhi.



The counselling provided by TCs and call centre agents helped my 14-year-old daughter fight back and get well. There were times when she completely lost hope, but the regular calls and messages reminded her that she just needed to be a little strong. She is now going to school and is back to studying for her pre-board exams.

Father of a DR-TB patient.



I suffered from cough and cold for 10-12 days in spite of treatment. My X-ray report revealed that I had TB and I was referred to a government hospital. After tests, I was diagnosed with DR-TB and put on treatment. My husband and I were counselled about benefits of being treated at a government facility. I am now in my 7th month of treatment and all services have been free of cost. I have been guided by the DR-TB team who are always available to me.

Radha, DR-TB patient.



“My daughter fell ill and did not recover even after medication. She was also rapidly losing weight. I took her to a private clinic where they ran tests on her and found she had MDR-TB. She was then referred to a government hospital and the DR-TB team helped us throughout the process. They counselled her and got her the treatment. Even when she had side-effects from the treatment, the team motivated her to stay with the treatment. Now she has successfully completed two months of treatment and receives regular help. She is getting better.

Father of a DR-TB patient.



Dr. KUSHAL MATHUR

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Dated: 28 JUL 2020

DR TB LINKAGE Request

It is a very useful + patient friendly project. Has helped lots of TB + MDR TB patients with treatment + medical care.

Timings : Monday to Friday : 9 AM to 1 PM & 5 PM to 7:30 PM
Saturday : 9 AM to 1 PM & 3:30 PM to 6:00 PM
Not available For Private Consultation : 3:30 to 5 PM. Contact : 999992227
Resi : 196, Sukhdev Vihar, New Delhi : 110025

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Main Road, Opp. Bagh Wala School,
Palam Colony, New Delhi - 110045
Ph: 25365960, 26364402
Reg. No. 49400121 to 6
DHS : 712

Patient Name: _____ Age & Sex: _____ Date: _____
SHC/PPD No.: _____

DR. GYAN VATSA
M.B.B.S., M.D. (P.H.)
PATHOLOGY
MON TO SAT
11:00 TO 3:00 PM
7:30 TO 8:30 PM

Vital Signs: Allergic to: _____
BP: _____ PR: _____ Temp: _____ Height: _____
Weight: _____ Nutritional Screening (if applicable) _____ Pain (0, 1, 2, 3)

Clinical Details: I would like to thank the team of DR TB Control program, for helping and assisting our patient with MDR TB in their management and helping in achieving our goal of eradication TB by 2025

Thankyou
Dr. Gyan Vatsa
25/7/20

Investigation Advice:



ANAND MAYA HOSPITAL PVT. LTD.

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18/02/20

I would like to thank the team of TB control program for helping and assisting our patient with MDR TB in their management and helping in achieving our goal of eradication.

Thankyou
Dr. Prasad

Dr. Sudhir Yadav

M.B.B.S.
Ex. Medical Officer (H.P. Govt.)
Ex. Vice President J.L.N. Medical College
Ajmer (Rajasthan)
Regd. No. DMC 1273

RZ-28P/13, Mangal Bazar Gali,
Indra Park, Palam Colony,
New Delhi-110045
Timing : 9:00 a.m. to 1:00 p.m.
5:00 p.m. to 9:00 p.m.
Sunday 9:00 a.m. to 1:00 p.m.

Date: 27/7/2020

DR TB Linkage Page

One my patient MDR TB case is successful and eradicated by the team. She is very negative and fine and happy with the treatment help.

Dr. SUDHIR YADAV
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Date: 28/7/20

To whom it MAY concern.

This is to certify that St. Stephen's Hospital regularly has been working with Mr. NOOR MOHAMMED (D.R.T.B. Treatment coordinator, T.B. AHEAD INDIA) who have enabled us to get excellent service from him and this provides much needed psychiatric service for our T.B & M.O.R T.B. patients. This is vital for hospitals and needs all combining similar service.

Dr. MOHIT SHARMA
M.B.B.S., D.M.C. 1273

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