A Model in the Making

Ekta Niketan

unlike most TB Centres

May 2024

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EKTA NIKETAN TB CENTRE – *Unlike other centres*

This report has been prepared by Dr Manan Ganguli who has worked in remote villages in India for over 30 years – treating tuberculosis (TB) patients, training health workers and helping to establish a community TB centre. Ekta Niketan, a popular TB Centre in a tribal village in the district of Deoghar, Jharkhand, is managed by a team of villagers who offer quality TB care (diagnosis, sputum testing and treatment) to patients in the area.

The growing popularity of Ekta Niketan in the last five years, between 2019 and 2023, is evidenced by the increasing number of TB patients accessing the centre during the period. This report looks into the key factors that make the TB centre different from other centres. Ekta Niketan reaches out to patients in remote villages.

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To know more about Ekta Niketan – its history, previous reports, relevant documents, photos and videos you may like to visit:

https://ekta-niketan.fourthworldaction.net

Ekta Niketan is a centre to treat tuberculosis (TB) without a doctor. Evolved through practice for over thirty years, it is a patient-centric community-based TB centre in a tribal village in India. Ekta Niketan is a showcase community TB programme. It is unlike many urban-based TB centres. Ekta Niketan's growing popularity among TB patients in the area says it all. It is a model in the making.

Experts and policy makers of TB control ponder how to reach patients in remote places. Their strategies have not made much inroads into halting the spread of the disease in remote rural communities. The conventional mindset – the mindset of a top-down medical approach, dominates amongst the policy makers, both national and international. Until recently (reference TB REACH WAVE 11 Call for Proposal), the concept of a community TB centre managed entirely by frontline workers has not been a priority. Learnings from Ekta Niketan show how to reach out to TB patients who do not access national TB elimination programmes in India and elsewhere. This report, a summary of learning during the last five years (2019–2023), is about how to control the spread of TB in remote places 'where there is no doctor'.

Ekta Niketan provides quality TB care for disadvantaged communities in Jharkhand. It has been possible because of a team of dedicated villagers who manage the centre; and because of generous donations from friends, colleagues, relatives, and a few organisations e.g. Richard Grove Foundation at the University of Sussex. Since 2019, the National TB Elimination programme, Jharkhand, has provided medical supplies free of cost – a tremendous help too. Ekta Niketan is not a 'renowned' TB centre, or a large 'NGO' – it therefore struggles to attract donors for funding support. Yet, this small TB centre shows how to address TB by working closely to local people.

The irregular supply of anti-TB drugs in 2023 has impacted India's TB control. To date (May 2024), Ekta Niketan has been purchasing medical supplies from the local market In order to maintain uninterrupted treatment for its TB patients. An editorial comment on 10 April 2024 in the Hindu, a reputed Indian newspaper, "*Gross mismanagement: On TB drug shortages and India's national TB programme. India is falling behind in efforts to control tuberculosis*" [https://www.thehindu.com/opinion/editorial/gross-mismanagement-the-hindu-editorial-on-tb-drug-shortages-and-indias-national-tb-programme/article68047044.ece] says it all.

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CONTENTS

Prologue

While Artificial Intelligence (AI), from self-driving cars to Neuralink (a super-tech brain chip), dominates all walks of life, and while India launches Chandrayaan-3 (a spacecraft) to the moon, Tuberculosis (TB), an age-old disease, continues to spread across the world. Despite the fact that improved diagnostic techniques and medicines to treat the disease are in place, experts and policy makers ponder how to control TB.

India, one of the few countries heavily burdened with TB, has an estimated 2.8 million cases, accounting for 27% of the global burden [Global TB Report 2023, WHO]. Each year, approximately 400,000 people die of TB in the country, representing 26% of global deaths due to TB. Experts from the WHO and similar UN-level organisations have praised the Indian Prime Minister for his commitment to controlling TB in the country. But the truth is, TB remains rampant in remote rural India, causing havoc to the lives of people therein.

Subjected to deforestation, displacements and land grabbing by private companies for mining and industrial purposes, and the lack of development and economic opportunities in tribal communities in India, the prevalence of the disease is considered 3 or more times higher in such communities compared to the national average. TB kills tribals and non-tribals alike though.

For over thirty years Ekta Niketan has witnessed the rising incidence of tuberculosis in marginalised communities in India; it has seen how poor the country's response is. But the current response, called the National TB Elimination programme is possibly the greatest blunder of all. The high prevalence of TB among migrant workers who work in distant cities and industrial hubs far away from their villages; the catastrophic costs incurred by TB patients in remote rural areas; and, the interruptions of essential anti-TB drug supplies during 2023-24 are some of the examples of the blunder of TB control in India.

Tuberculosis is a serious public health concern of in a vast country of 1.4 billion people.

PART ONE

Ekta Niketan TB Centre

Ekta Niketan is a non-governmental initiative to treat TB – a small setup in the centre of a village, where a team of village health workers diagnose TB clinically, examine sputum under a microscope, and dispense anti-TB drugs correctly, under the supervision of their medical doctor. They are trained to assess patient's compliance to treatment. Their TB patients and family members learn about the 'six-month course of treatment', about drug reactions, and the importance of a good diet while on treatment. Health workers maintain detailed information on each TB patient accessing the TB centre – medical record, nutritional status, economic information, travel distance, cost incurred in prior treatments and so forth.

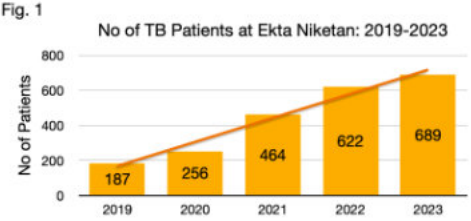
Patients get better here. A good number of patients are thin and weak weighing less than half their normal body weight. Ekta Niketan saves lives.

The growing popularity

Ekta Niketan is for people with TB who are marginalised – economically, socially and politically. TB patients and their families accessing its services find it a 'friendly' centre because health workers who manage the centre are fellow villagers. The bottom line is, Ekta Niketan offers quality TB care that is otherwise non-existent in the area. TB patients therefore make long and difficult journeys, often by-passing government TB centres, to reach this centre in a remote village.

The chart [Fig. 1] illustrates the number of TB patients at Ekta Niketan between 2019 and 2023, highlighting the growing popularity among TB patients in the area. These patients and their family members undertake long journeys by trains, buses, motor-bikes or bicycles to reach this remote centre. Distances patients travel to reach Ekta Niketan (2023 data) not only indicate the popularity of the centre but also emphasise the sorry state of TB care in the area [Fig. 2].

Fig. 1



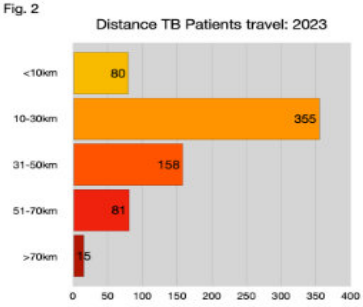
Year	No of TB Pt
2019	187
2020	256
2021	464
2022	622
2023	689

In this context, it demands mentioning that during Covid pandemic in 2020 when travel restrictions were at its peak, Ekta Niketan continued to function throughout the year except during the month of April [Fig. 3]. TB patients found alternate routes to reach the centre, by-passing police check-points. Also, the frontline team could maintain regular consultations with their medical doctor through Ekta Niketan's robust on-line consultation system.

Frontline workers and quality care

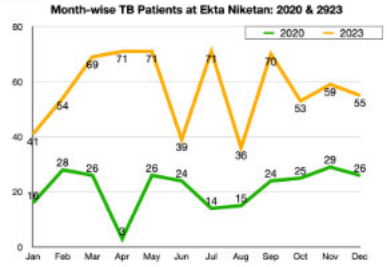
Ekta Niketan is managed by a team of six frontline workers (or village health workers) with minimal formal education. The team is supported by an experienced doctor who is available for medical consultations – in-person or through online video consultation. Except for a few patients requiring diagnostic support from the medical doctor, most diagnoses (and sputum tests) are made by the frontline workers. Standard forms, developed over time, are used for video consultations for each TB patient. These forms are presented in Annexure at the end of this document.

Fig. 2



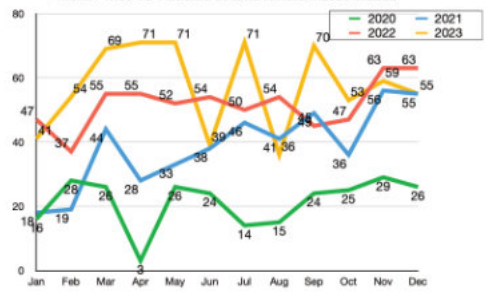
The rise in the number of TB patients accessing the TB centre and the absence of a significant drop in numbers during June-October when the medical doctor is not present for in-person consultations, indicates the quality of TB care frontline workers offer, also the robustness of the Ekta Niketan model regarding remote consultations [Fig. 4].

Fig. 3



	2020	2023
Jan	16	41
Feb	28	54
Mar	26	69
Apr	3	71
May	26	71
Jun	24	39
Jul	14	71
Aug	15	36
Sep	24	70
Oct	25	53
Nov	29	59
Dec	26	55
Total	256	689

Fig. 4



	2020	2021	2022	2023
Jan	16	18	47	41
Feb	28	19	37	54
Mar	26	44	55	69
Apr	3	28	55	71
May	26	33	52	71
Jun	24	38	54	39
Jul	14	46	50	71
Aug	15	41	54	36
Sep	24	49	45	70
Oct	25	36	47	53
Nov	29	56	63	59
Dec	26	55	63	55
Total	**256**	**463**	**622**	**689**

The desire to reach out to people with quality TB care is at the centre of the model. The recruitment of frontline workers and development of necessary skills is the fundamental. The conventional mind-set for selecting frontline workers, governmental or non-governmental, prioritises formal education, articulation skills, and the so-called 'choice' of community. At Ekta Niketan, the priorities are: interest in TB care, desire to learn, and commitment.

In recent years, officials from the government TB programme, from the state (Jharkhand) to central (Delhi) levels, made visits to monitor the "where there is no doctor" TB centre and its data. Visitors learned the capacity of frontline workers to manage the community-based TB centre, and the quality of its records.

Above left: District TB Officer (Deoghar), 2021

Above: District TB Officer (Deoghar), 2022.

Left: A central NTEP team (Delhi), 2023

Lost to follow-up patients

'Lost to follow up' (LTFU) i.e. patients not completing the full course of anti-TB treatment (earlier termed as 'defaulters') is the biggest challenge to TB control. Over the years public health experts have come up with various interventions to assist TB patients to complete the long-course of treatment. These include reducing of length of treatment with newer drugs; offering various incentives to TB patients;

organising national awareness campaign; deploying frontline workers or peer-support groups. None of these measures have quite worked. The challenges to address TB in marginalised communities are huge, particularly when the economic development priorities are not people-centric.

While a range of factors impact whether a TB patient will complete treatment or not, trust in the TB care is key. The Ekta Niketan TB care model is founded on building the 'trust' that most TB centres lack.

During the past five years, the TB centre has tried different measures to reduce LTFUs with mixed results. In 2023, however, the proportion of patients completing the full course of treatment has noticeably increased. This is due to the quality of TB care and the role of peers (individuals who have previously completed anti-TB treatment at Ekta Niketan). The fact that Ekta Niketan is managed by villagers with similar socio-economic, cultural, language and educational backgrounds to their patients is the foundation of the patients' trust. The reduction in LTFU patients at Ekta Niketan in 2023 is noticeable, estimated to be 14% (based on the first six months data), compared with 20-25%. in 2020-2022. New patients with suspected TB bringing voluntary sputum samples is also on the rise. Of the 689 TB patients registered for treatment In 2023, 131 patients brought morning sputum samples on their first visit.

Ekta Niketan never conducted 'early detection' campaigns, nor did it deploy volunteers to collect patients' sputum samples. Patients who brought sputum voluntarily were encouraged by fellow villagers to do so. These are the ones that will never discontinue treatment.

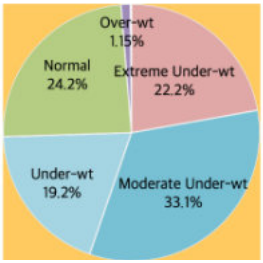
TB and severe undernutrition

In earlier reports, we highlighted nutritional status of TB patients – that people in villages lack protein in their diet and the majority are undernourished. The picture is no different in 2023.

Of the total 689 patients in 2023, the BMI of 604 adult TB patients (18 years and over) are presented below. Also see the chart Fig.5.

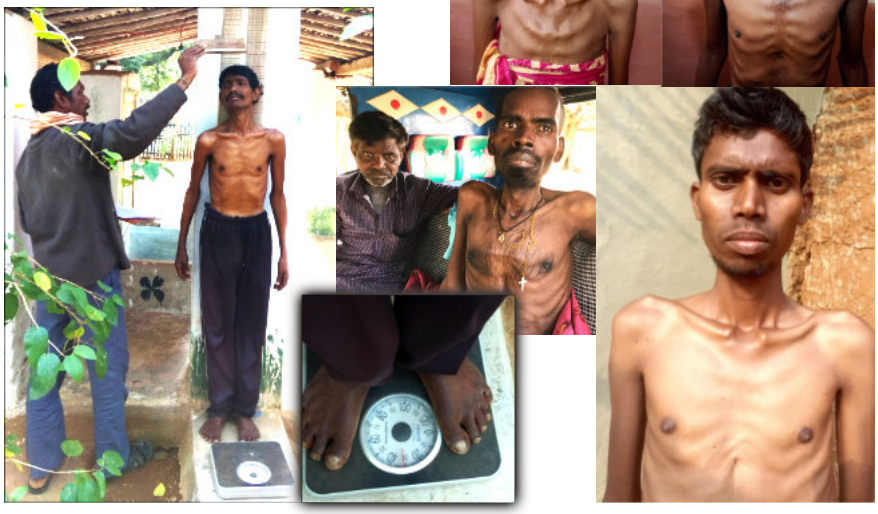
<15	15 - 16.99	17 - 18.49	18.5- 24.99	25- 29.99	>30
134	200	116	146	7	1
22.2%	33.1%	19.2%	24.2%	1.15%	0.15%

Fig. 5 Under-nourished TB Patients at Ekta Niketan: 2023



The government TB programme provides cash incentives for patients to purchase nutritious food during treatment. Where the whole family suffers under-nutrition and lack basic essentials for living, the cash incentives, if received, are spent on other essentials than eggs or lentils. In most cases the cash does not arrive during the patient's treatment!

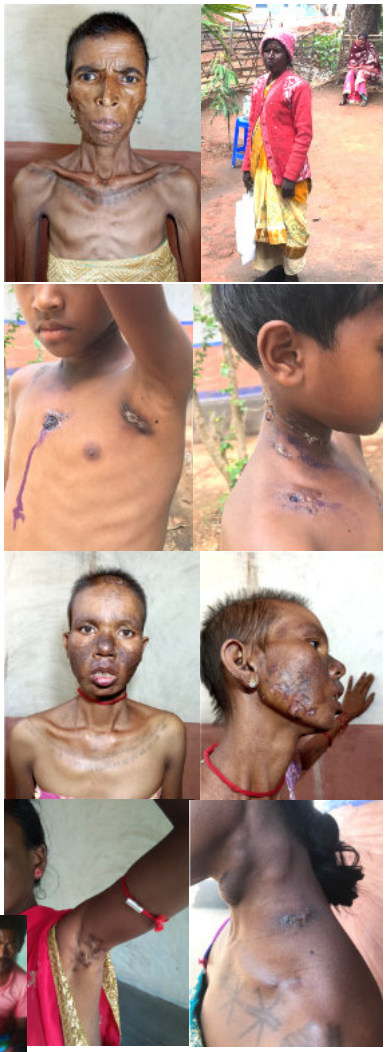
A large number of adult TB patients weigh between 30 and 40 kg. Some weigh under 25kg – these lack the strength to even stand on the weighing scales without assistance.



Severity, Extra-pulmonary TB and Deaths

Patients at Ekta Niketan present with different forms of TB – pulmonary as well as extra-pulmonary (TB of lymph nodes, skin, breast, bone, abdomen and so forth). These patients, extra-pulmonary ones in particular, are often wrongly treated elsewhere.

A section of patients, pulmonary and extra-pulmonary alike, are extremely malnourished, often with co-morbidities and severe complications. Some of these patients required specialised in-patient care, but such facilities are not available to the patients in question. In 2023, of the total 689 patients, 15 died who were extremely malnourished and with complications. But, a large number of patients responded to treatment remarkably well. They survived. Please refer to the table below and images of some of such patients who survived.



Pulmonary and extra-pulmonary patients at Ekta Niketan: 2023				
Pulmonary	Extra-pulmonary		Pulm.+Extra-pulm.	Death
	Lymph Node	Other		
595	56	38	30	15

NTEP and Ekta Niketan

The National Tuberculosis Elimination Programme (NTEP) needs to address several gaps in order to reach out to TB patients in marginalised communities. We will reflect on the gaps and challenges of the programme in Part Two. Ekta Niketan has been liaising with the national programme for several years such as notifying TB patients or participating in national events. Since 2019, the TB centre has been working closely with the NTEP receiving significant support from the programme – from the state to district levels in Jharkhand. Some of such supports are highlighted below.

A Treatment Unit (TU): In 2019 the TB centre was been recognised as a TU with a Nikshyay ID under the government programme. The recognition is a tremendous boost for frontline workers at Ekta Niketan.

Medical supplies: Ekta Niketan receives anti-TB drugs from the NTEP Deoghar district free of cost. It is worth mentioning that the medical supplies are for all patients from the surrounding districts who access the TB centre, not just for patients from the district of Deoghar.
Unfortunately the supply of drugs in

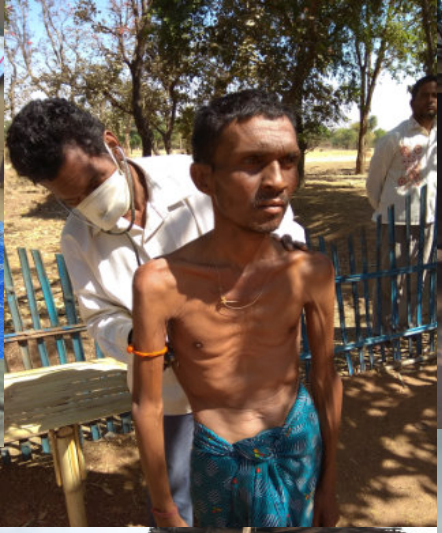
2023 (till date) has been irregular, as mentioned previously.

Diagnostic support: Sputum samples are examined under a microscope at Ekta Niketan, the quality of which has been verified by the district laboratory officials. In addition, the centre is able to send all sputum samples for CBNAAT diagnostics under a special provision of support.

Regular visits by the district TB centre: Relevant officials from the district NTEP make regular visits to monitor records and laboratory diagnostics.

Top & Right: NTEP officials with Ekta Niketan health workers and patients.

Right: District TB Officer with Ekta Niketan health workers.







PART TWO

Hard Talk

TB Care in India & NTEP

TB is one of the greatest blunders in public health history. The blunder is at its height in recent years. The disease remains neglected by most governments in developing countries. India is no exception. The old expression that 'TB is a disease of the poor' says it all – TB is a marker of development. Policy makers and public health specialists may talk about social and societal determinants of the disease but in practice TB is addressed within the bio-medical domain only, the very reason why TB continues to spread. TB has never caught the attention of donors, policy makers and public health experts the way it has for other health issues, say HIV, malaria or cardiac illnesses.

The hype to 'eliminate' TB

At the Delhi End TB Summit in March 2018, Indian Prime Minister announced that TB will be eliminated in the country 5 years ahead of the global target. *"Sathio, Duniya bhar me TB ko khatam karne ke liye barsh 2030 ke samay tai kiya giya hai. Lekin mein aaj ish manch se eek ghosna kar raha hun – bharat me 2030 se panch saal aur pahale aani 2025 tak TB ko khatam karne ka lakkash aapne tai kiya giya. ….. claps ⋯".* [*Friends, 2030 is the deadline fixed for eliminating TB across the world. But today I am announcing from this forum that India has decided to end TB 5 years before the target year i.e. by 2025 instead of 2030.*] In fact the global target of 2030 is to halt the spread (80% reduction of 2015 incidenceence so that the elimination of TB in 2050 can be realistically predicted. Public health experts and policy makers never questioned such ambitious statement but welcomed it as an outstanding political commitment. "*First time ever meeting on World TB Day, and first time ever, and let's keep this in mind, meeting in the country with the highest burden of TB but with the best plan, the highest ambition and most amazing activities implemented. claps …*", Dr Lucica Ditiu, Executive Director, Stop TB Partnership at the One World TB Summit in Varanasi, March 2023 (https://www.youtube.com/watch?v=xJzE9xeJ9wY). The irony is that the 'best plan' did not ensure uninterrupted drug supply for TB patients in that very year.

The global target is a blueprint for countries to reduce TB incidence 80% (from that of 2015) by 2030, also to reduce TB deaths by 90% and to eliminate catastrophic costs that households incur; it is not about eliminating TB by 2030.

Eliminating TB & Quality of TB Care

Eliminating TB in a vast country with 1.4 billion people who harbouring a quarter of global infections is an uphill task. While the hype of 'eliminate' TB has brought along a number of changes to the national tuberculosis control programme, from renaming the programme itself (as the National Tuberculosis Elimination Programme) to measures like strengthening public-private mix, cash doles for nutritional support, nationwide publicity to eliminate TB; and while the profile of a 'fast, prompt, results-based' TB programme has been promoted in the international arena, the plight of TB patients in marginalised communities has not changed at all. The disease is spreading fast, patients go to local untrained practitioners ('Jhola Chhap' doctors) and private practitioners in towns rather than to government TB centres, frontline workers lack the motivation to work in TB. TB patients in villages spend huge sums of money on unnecessary tests and the wrong treatments.

TB patients who access Ekta Niketan for treatment by-passing their respective primary and district TB centres give this account of TB care in their areas. The picture is similar in other disadvantaged areas across the country.

The quality of TB care is in a sorry state; NTEP needs an overhaul at all levels. In this context, the Ekta Niketan model is a way forward to reach patients with quality care in remote rural communities.

Treatment delay and drug-resistance go hand in hand. Patients during the delay period, often 3-6 months, opt for treatment by private doctors who prescribe non-standard anti-TB treatment and unnecessary tests. Private doctors under the government's 'public-private mix' (PPM) policy, particularly practitioners in semi-rural small towns, make the best of both worlds - avail free anti-TB drugs from the government but prescribe other drugs and tests from their pharmacy and laboratory.

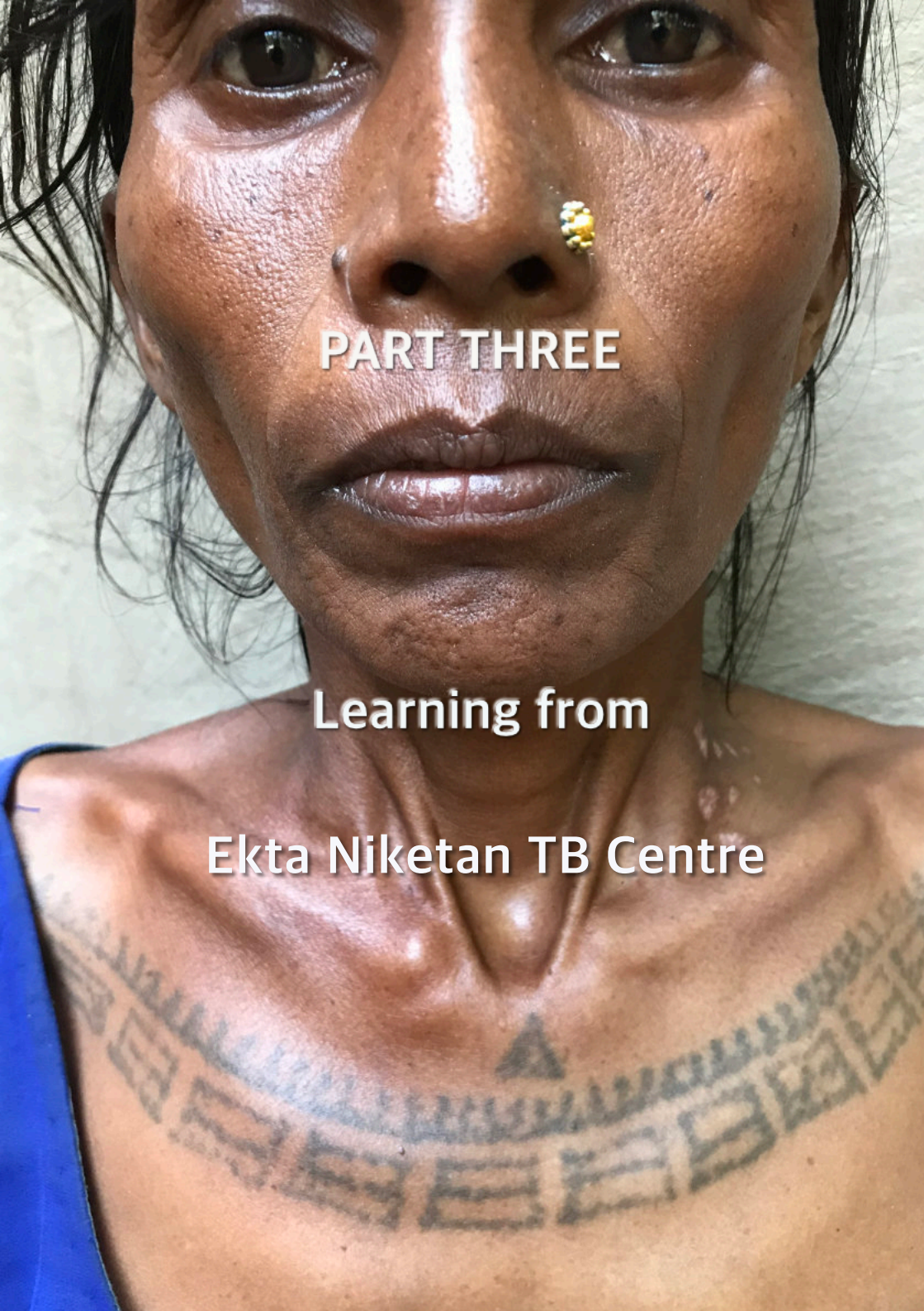
Ekta Niketan has patients who could not afford anti-TB treatment at such clinics under the PPM. These doctors are a menace to TB care in India, yet experts stick to their fallacious policy.

Reaching out and Frontline workers

Community health workers (or female health volunteers) in India, with basic training to recognise common health problems, are the ones to reach out to TB patients in the communities in question. However, this large force of grassroots workers are, in general, under-utilised in TB control. To compensate this, the NTEP has engaged cured TB patients and other community members to encourage early diagnosis and the continuation of the full course of treatment. None of these measures are quite working, at least in the area where Ekta Niketan operates.

Health workers at Ekta Niketan and its cured TB patients have roles similar to NTEP but the modus operandi is different. Here, health workers manage a TB centre i.e. diagnose clinically and under a microscope; in addition they encourage early diagnosis and completion of treatment.

Ekta Niketan is a different model. Here, some TB patients even contribute whatever small money they have to help run the centre – reaching out in the truest sense.


PART THREE
Learning from
Ekta Niketan TB Centre

Learning from Ekta Niketan

This report is about addressing TB where there is no TB doctor. It is also to remind policy-makers that they are far removed from the people who suffer from TB most. The mindset of health professionals prevents them from seeing TB beyond 'treatment' no matter what they may say in public about the root causes of TB.

TB is a marker of development. The high spread of TB in remote rural and tribal communities signifies the nature of the development that India is currently going through. India's economic growth has nothing to do with halting the spread of TB in the foreseeable future. While India announces that the country will eliminate TB by 2025, the basic anti-TB drugs have not been available for almost a year. This is no surprise but highlights the mess we are in. This report highlights the need for an overhaul of India's TB programme at all levels.

Finally, the overhaul of NTEP will have little benefit unless there is an overhaul of organisations like WHO. Such organisations and their experts need to be down-to-earth, honest and sincere to stop TB that kills the poor silently.

Ekta Niketan TB centre has witnessed the impact of TB in disadvantaged areas for over 30 years.

Ekta Niketan TB centre is managed by frontline workers. It offers standard treatment to a large number of TB patients in the area – there is no set catchment area or population coverage. The diagnoses are monitored by a medical doctor experienced in TB; the quality of care is of a high standard.

The lessons learned from Ekta Niketan can be of value to address TB in remote communities where 70% of India's population live. It is a model to reach out to those populations who are not reached under the current model.

The model is replicable,
A. If frontline TB centres are created and are managed by community members as in Ekta Niketan

B. If diagnostic tools and monitoring support to frontline TB centres are standardised

C. If TB frontline workers are trained in diagnostics and other relevant skills to manage TB centres

D. If nutritional support in kind is provided to all TB patients

E. If NTEP changes its policy of 'public- private' mix, and finally

F. If effective management at district and higher levels are in place.


PART FOUR
A Few TB Patients
&
Their Stories

TB patients who come to Ekta Niketan narrate their plight to search for proper treatment – how they have exhausted everything at private clinics in town, how they made trips to their nearby government TB centres without result, how their community health workers refused to accompany them unless they pay for traves and incentives. Their stories are much the same – 'we did not know where to go for proper treatment'.

In this section, we have picked up a few such patients from the images on 'Part Four'. All of them thought that they would never be cured. All survived. [Names used here are not their real names.]

Surajmuni's husband hired an auto-rickshaw to bring her to Ekta Niketan. Their village

Dukhiadih is about 35 kilometres from Ekta Niketan. She had Lupus Vulgaris, a not-so-common form of skin TB. Prior to Ekta Niketan he took her to a private hospital in Giridih. Thinking it might be a malignant condition, the doctor referred her to a specialist centre in the the capital Ranchi.

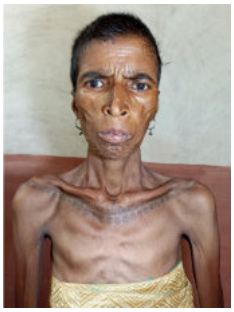
Her husband could not afford the specialist investigations and treatment in Ranchi. So, Surajmuni stayed at home.

Neighbours advised her to see a 'spirit doctor', so he tried; then herbal medicines – but nothing worked. The ulcer on her thigh grew. When she came to Ekta Niketan in June 2022, she was unable to walk. The Ekta Niketan doctor examined Surajmuni inside the auto-rickshaw.

Surajmuni's treatment started with a

course of anti-TB drugs and measures to keep her wound clean. She responded to treatment remarkably well.

An Ekta Niketan health worker visited her in Dukhiadih several times and consulted with their doctor with video link regularly during the period that the doctor was not at Ekta Niketan.
In March 2023, Surajmuni came to Ekta Niketan with her husband to attend a meeting on "Women and TB".

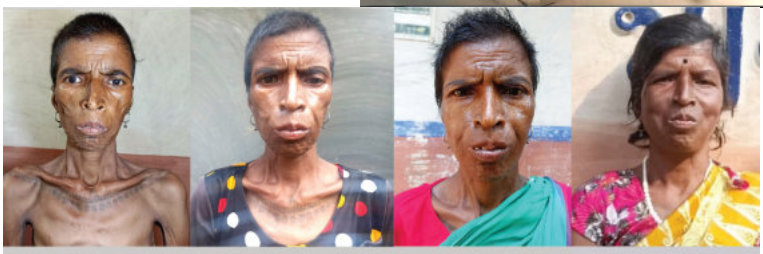


Lilmuni Baske from Jogidih village in the district of Giridih came to Ekta Niketan in late July of 2022. She weighed 22kg.

After one year of their marriage, Lilmuni's husband left her. She returned to her parents. When her parents passed away, her elder brother took care of Lilmuni. She therefore lives in Jogidih with her brother's family. Lilmuni is now in her 40s.

When Lilmuni contracted TB, she was treated by a local untrained practitioner ('jhola doctor'), then a trained medical doctor at a market place near their village. After trying various treatments for about 3 months her brother brought her to Ekta Niketan. She was very thin and emaciated, so weak that she could not stand without support, let alone walk.

Lilmuni needed nutrition, regular follow-up and controlled treatment. Lilmuni survived.



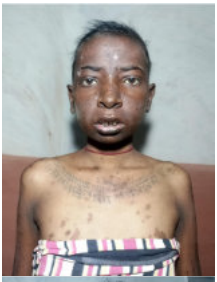
In February 2024, Lilmuni came to Ekta Niketan on her own to collect her medicines. Next month she will complete her course of anti-TB treatment.

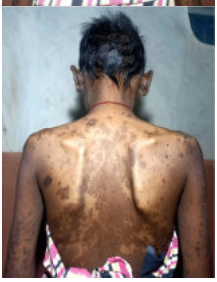
Md Islam, a boy of 11 years old, came to Ekta Niketan with his father. His uncle accompanied as he knew Ekta NIketan. The family lives in a village 55 kilometres away. He had cough for over one year and was not eating well. On his first visit in February 2024, his father showed a bunch of prescriptions, X-rays and folders with names of private hospitals and laboratories. Obviously the 'folders had' cost them a fortune!

Islam's father could afford private treatment; he was ready to spend whatever it required to get his son better. Apart from the local jhola doctor, he took Islam to a private clinic in Giridih, then to Ranchi (the capital of Jharkhand); then back to Giridih in 2023, before coming to Ekta Niketan. Islam had several X-rays, Ultra Sound, CT Scan and various tests.

Islam is now on anti-TB treatment and is doing well. His treatment continues.

Minoti Tudu of Bhatupur village (Gandey block) of the district of Giridih, 20 years old, unmarried, came to Ekta Niketan in December 2023. She was in a very bad shape. On their first visit to Ekta Niketan, Minoti was not able to walk. Too weak to stand, her father had to carry her to the clinic. She developed skin ulcers, black patches all over her body, face and back (a form of TB skin) as well as signs of TB lungs. Minoti weighed 30kg at the time.





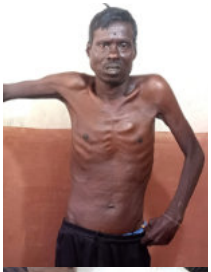
The family had been to a private clinic in Giridih where they spent large sums of money on various tests and medicines with no results.

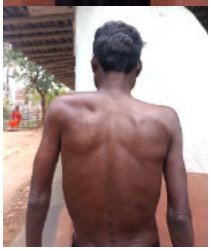
Ekta Niketan health workers consulted with their doctor on video call as the doctor was not present at the time. Anti-TB treatment was initiated.

Minoti responded to anti-TB treatment – her black patches started to fade away; ulcers dried up; she could walk; and, gained 6kg in a couple of months.

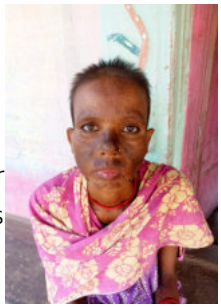
Teklal Tudu, 50 years old, from Sathibad village (Chipuadi) of Giridih district came to Ekta Niketan in late February 2024. The movement of his left shoulder was significantly restricted and he had an oozing wound on his left arm. On further inquiry, he mentioned about the injury he sustained after a fall; also, that a private doctor in Giridih drained the abscess he developed at the site of the injury.

The private hospital charged Teklal Rs.50,000 for the treatment. His wound did not heal; and, the movement of his arm became further restricted. He also developed signs of TB lungs. So, he came to the TB centre after his neighbour told him about Ekta Niketan.



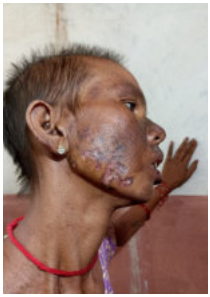


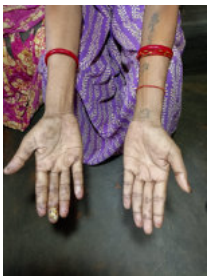
Tekla was suffering from TB bone (Osteomyelitis) and TB lungs. Teklal continues his anti-TB treatment at Ekta Niketan. After two months, the left shoulder is much better (still restricted though); also, he does not have a cough anymore. Telal is on the mend; he feels better.



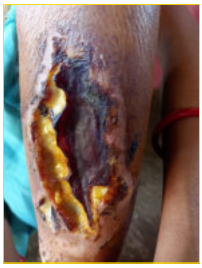
Chandoni from Fatepur, the same village as the TB centre, came to Ekta Niketan in September 2023. Her complaints were much the same as Surajmuni (and Minoti) mentioned earlier. Chandoni's ulcers were much more widespread though – on either side of her face, on her fingers and toes.

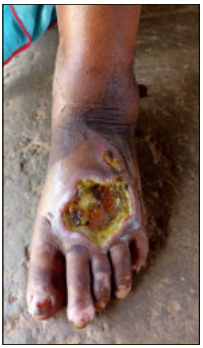
Chandoni is 30 years, unmarried. She did not have typical TB symptoms, so the family did not think of bringing her to the TB centre. After trying one place after another for about five months, they finally came to Ekta Niketan.

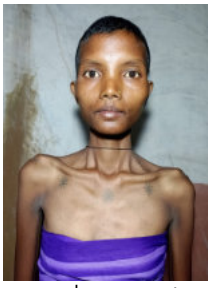




Health workers are familiar with managing such patients with TB of skin. The treatment was initiated after tele-consulting with their doctor. In two-three weeks of anti-TB treatment, the ulcers on her face, fingers and toes started to heal. However, Chandoni had a set-back with new ulcers appearing on her legs. Health workers encouraging her to continue has paid off. Chandoni responded to treatment. Chandoni responded to treatment.







Sonamuni Hansda's village Murgadangal (Margomunda) in the district of Deoghar is about 25 km from the Ekta Niketan TB centre. Her husband died about five years ago; she came to her parents in Murgadangal with her son. Sonamuni, 30 years old, is the eldest in the family of four – three brothers and one sister. Her mother-in-law is equally concerned about Sonamuni's wellbeing.

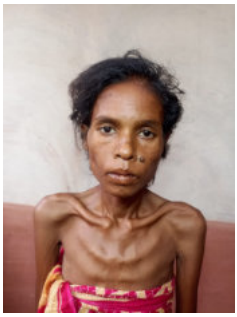
On her first visit to Ekta Niketan in late October 2023, the family hired auto-rickshaw; her mother and mother-in-law accompanied. Thin and weak Sonamuni weighed 26kg. Sonamuni was seen by the doctor over a video link (a routine practice for each TB patient when the doctor is not at Ekta Niketan in-person). The treatment was initiated in line with Lilmuni's (mentioned earlier).

By April 2024, Sonamuni's appetite was back; she gained 5kg.

When Sonamuni seemed out of danger, her health deteriorated again. At the time of writing in May, Sonamuni has lost the weight she initially gained; she has started coughing up blood again. We will update on Sonamuni's progresso.

People like Sonamuni in the area have little choice but this basic community TB centre.

Sonodi Hembrom, the last patient in this series, is like many other young women in the area whose lungs are riddled with TB bacteria, whose families have exhausted money on wrong treatment and unnecessary tests.



They come to Ekta Niketan very late (sometimes too late) as families try first their local 'doctor', and then one or two private clinics in nearby towns.

The food they eat lacks any form of nutrition. They are skin and bone like Sonodi. The outlook is grim.

Sonodi has a six month old baby. Her weak body does not produce breast milk. The baby is thin and weak too. Sonodi's other child, five years old, is in danger of contracting TB.

Sonodi's village is about 35 kilomitres from the Ekta Niketan TB centre. She started treatment in April 2024. She is on anti-TB treatment much in line with Lilmuni featured earlier. Her husband reports Sonodi's progress on a daily basis, as Lilmuni's brother did.

Sonodi is doing well. We will update.

Epilogue

This report is not about Ekta Niketan, a unique community TB centre in a remote village in India. This report is about failures to save lives – people who die silently from TB.

This report points its finger to public health professionals who express concerns about TB but have little clue about the agony families go through when one dies from the disease. 'Concerned' health professionals attend conferences and workshops and discuss new diagnostic tools, paediatric TB, nutritional supplements and so forth.

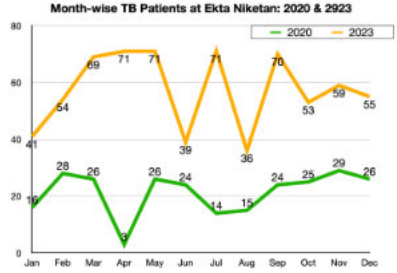
Then, some of the above professionals who establish themselves as 'experts' or 'consultants' take part in preparing new strategies to control TB at the global level. This report questions their honesty and sincerity to address TB.

This report, taking India's example, talks about political gimmicks. The very fact India claims to eliminate TB, meanwhile the supply of essential anti-TB drugs are in shortage for almost a year does not require explaining that it is a gimmick.

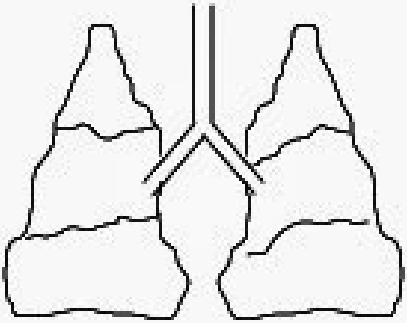
The suffering of people who already struggle to survive becomes multiplied when someone in the family contracts the disease.

This report welcomes your thoughts on ways forward to end the misery of people with TB, to save lives.

Fig. 3



	2020	2023
Jan	16	41
Feb	28	54
Mar	26	69
Apr	3	71
May	26	71
Jun	24	39
Jul	14	71
Aug	15	36
Sep	24	70
Oct	25	53
Nov	29	59
Dec	26	55
Total	256	689



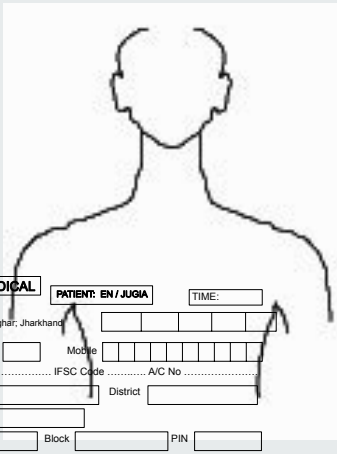
FORM 1

SL No	Token No	Niksya ID	Adhaar No	BPL Y/N	Name	Surname	Gender M/F/T	Age Yrs	Father/Mother/ Husband Name	Race*	Mobile No

* Santal/Kol/Hindu/Muslim/Christian/Other

PART FIVE

ANNEXURE



TB: MEDICAL

PATIENT: EN / JUGIA

TIME:

DATE:

EKTA NIKETAN TB CENTRE

Village PATEPUR; PO JAGDISHPUR; Madhpur (815353); Deoghar; Jharkhand

Serial No. ..... BPL Y/N DISTANCE Mobile

Token No ..... Nikshay ID ..... Aadhar No ..... IFSC Code ..... A/C No .....

Name: Vill: District

Date: Name of F / M / H: Block:

Panchyat: Post: Block: PIN:

Token:

COMPLIANCE 2023

Name: Village: M/F: Age:

M/F Age Weight Height BMI Santal/Kol/Hindu/Muslim/Christian/Other

	FACTOR		COMPLIANCE SCORE CARD						
A	DETERMINATION	8	7	6		4	3	2	1
	मन-तेज								
B	FAMILY SUPPORT		7	6		4	3	2	1
	घर सापोर्ट								
C	DISTANCE		7	6		4	3	2	1
	दुरी								
D	AREA SUPPORT		7	6		4	3	2	1
	ऐरिया सापोर्ट								
E	OCCUPATION					4	3	2	1
	कमाई								
F	POVERTY			6	5	4	3	2	1
	ग़रीबी								

SCORE FINAL SCORE

PULMONARY:

Cough - how long? Cough + Blood Y/N Chest pain Y/N Where

Fever Y/N Anorexia Y/N Weakness Anaemia

Vit B Jaundice Oedema

LN: Y/N

Skin darker? Y/N Trachea shift Y/N Creps/Ronchi/Bronchial? Y/N Diminished Sd? Y/N

RED	ORANGE	BLUE	GREEN

Notes:

Migrant? Y/N Breastfeeding? Y/N Support need? Y/N

Date	Wt	Sputum	CBNAAT	HIV	Diabetes

X-RAY TREATMENT DELAY

% + %

SPT BROUGHT

Where treated? Current: Jhola | Private | Govt | AIIMS | Herbal | Spirit | Homeo | Other

What tests? X-ray | Sputum | USD | Blood | Urine | Other

TRANSFER FROM

For any TB programme, documentation is an equally important part of the work. In this section we have selected a few tools that are in regular use at Ekta Niketan TB Centre - for data collection, documentation and for medical consultations purposes.

For more information, please write to: manan.ganguli@smallsimple.co.uk

DATE:

TB: MEDICAL

PATIENT: EN / JUGIA

TIME:

EKTA NIKETAN TB CENTRE

Village FATEPUR; PO JAGDISHPUR; Madhpur (815353); Deoghar; Jharkhand

Serial No. …… BPL **Y / N** DISTANCE Mobile

Token No …….. Nikshay ID …… Aadhar No …… IFSC Code …….. A/C No ……

Name Village District

Name of Father/Mother/Husband/Wife

Panchyat Post Block PIN

M/F Age Weight Height BMI Santal/Kol/Hindu/Muslim/Christian/Other

PULMONARY:

Cough - how long? Cough + Blood **Y / N** Chest pain **Y / N** Where

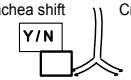
TIME:

Fever **Y / N** Anorexia **Y / N** Weakness + ++ +++ ++++ Anaemia + ++ +++ ++++

Vit B + ++ +++ ++++ Jaundice + ++ +++ ++++ Oedema + ++ +++ ++++

LN: Y / N

Skin darker? **Y / N** Trachea shift **Y / N**



Creps/Ronchi/Bronchial? **Y / N**

Diminished Sd? **Y / N**

RED	**ORANGE**	BLUE	GREEN

Notes:

Migrant? **Y / N** Breastfeeding? **Y / N** Support need? **Y / N**

Date	Wt	Sputum	CBNAAT	HIV	Diabetes

X-RAY

TREATMENT DELAY

% + %

SPT BROUGHT

Where treated? Current | Jhola | Private | Govt | AIIMS | Herbal | Spirit | Homeo | Other |

What tests? | X-ray | Sputum | USD | Blood | Urine | Other |

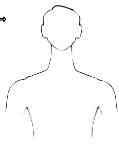
TRANSFER	FROM

Treatment history | EN | Jhola | Private | Govt | AIIMS | Herbal | Homeo | Other |

Direct	Private	Govt

LYMPH NODE Where? | Cervical | Axilla | Abdomen | How many? | Single | Multiple |

Position | Left | Right | Both |



Where treated? | Jhola | Private | Govt | AIIMS | Herbal | Spirit | Homeo | Other |

STATUS | New | LTFU | Relapse | TB TYPE | PULM | LN | SKIN | ABDOMEN | BONE | COMBINE |

COMPLIANCE | 10 | 9 | 8 | 7 | 6 | 5 | 4 | 3 | 2 | 1 |

Token:

TREATMENT:

TIME:

Name: Village: Age: M/F: WT:

DATE	Daily/Alt	FDC	Isoniaz	Rifampicin	Pyrazinam	Ethambutol	Ofloxacin	Strepto. Inj
DATE	Vit-B	Vit-C	Iron	Calcium	Styptovit	Prednisol	Chlorphen	Paracetamol
DATE	Amoxy	Cipro	Doxy	DS/SS				

OTHER TB

SKIN	ABDOMEN	BONE	COMBINE	OTHER

Symptoms/ Findings:

Tests:

SPUTUM BOX	
DATE	No

MONEY RCVD	
DATE	AMOUNT

ADDITIONAL NOTE:

CURE	COMPLETE	LTFU	TRANSFER	DEATH

DETERMINING SCALE OF SERIOUS TB: DIAGNOSTIC ALGORITHM (PULMONARY + HEMOPTYSIS)						
		5	4	3	2	1
1	**Weight/BMI**	<30kg	30-35kg	35-45kg	45-50kg	>50kg
2	**Cough+Blood**	Current; or <1wk	Recent - <2wks	Recent - <2 months	Recent - 2-4 months	Recent - 4-6 months
3	**Sputum**	2	1	Scanty - > 5	Scanty - < 5	Negative
4	**Diminished Sd**	Marked diminished	Matches with vocal sd/ percussion	Yes but does not match with vocal sd	Doubt	No
5	**Trachea Shift**	Distinct + pulm signs corresponds	Distinct + wt loss	Distinct	Possibly	No
6	**Creps; Creps + Rhonchi**	Creps - extended	Creps + Diminished Sd	Creps + Chest pain corresponds	Creps - some areas	Creps - not distinct
7	**LN/ Extra-Pulm**	Active LN + Pulm	Active LN + past Pulm	Active LN	LN - Not active	No
8	**H/o TB treatment**	Within 1 year defaulter	Within 1 year Private	Within 1 year Govt	Within 1-3 yrs	>3 yrs
9	**Anorexia**	Marked; corresponds wt loss	Marked; does not correspond wt loss	Some + wt loss and/fever	Some; no wt loss	No
10	**Skin colour**	Distinct + Pt endorse	Distinct	Possibly	Not sure	No

DETERMINING SCALE OF SERIOUS TB: DIAGNOSTIC ALGORITHM (PULMONARY + NO HEMOPTYSIS)						
		5	4	3	2	1
1	**Weight/BMI**	<30kg	30-35kg	35-45kg	45-50kg	>50kg
2	**Cough**	>2 mnths	1-2 months	3 wks	2 wks	1 wk
3	**Sputum**	2	1	Scanty	Negative	Negative
4	**Diminished Sd**	Marked diminished	Matches with vocal sd/ percussion	Yes but does not match with vocal sd	Doubt	No
5	**Trachea Shift**	Distinct + corresponds	Distinct + wt loss	Distinct	Possibly	No
6	**Creps; Creps + Rhonchi**	Creps - extended	Creps + Diminished Sd	Creps + Chest pain corresponds	Creps - occasional creps	Creps - not distinct
7	**LN/ Extra-Pulm**	Active LN + Pulm	Active LN + past Pulm	Active LN	LN - Not active	No
8	**H/o TB treatment**	Within 1 year defaulter	Within 1 year Private	Within 1 year Govt	Within 1-3 yrs	>3 yrs
9	**Anorexia**	Marked; corresponds wt loss	Marked; does not correspond wt loss	Some + wt loss and/fever	Some; no wt loss	No
10	**Skin colour**	Distinct + Pt endorse	Distinct	Possibly	Not sure	No

Token:

COMPLIANCE 2023

Date:

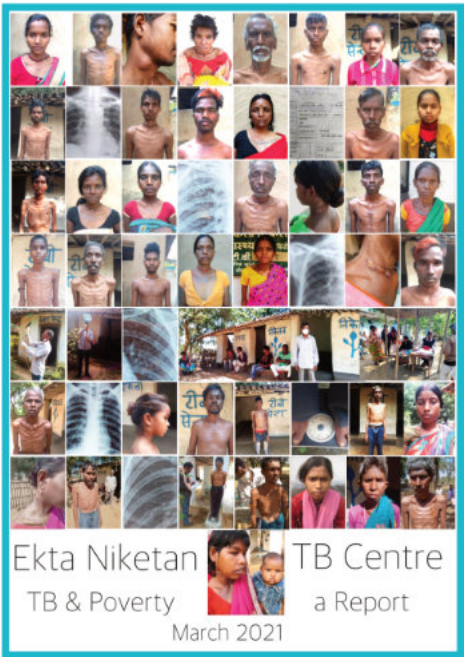
Name:

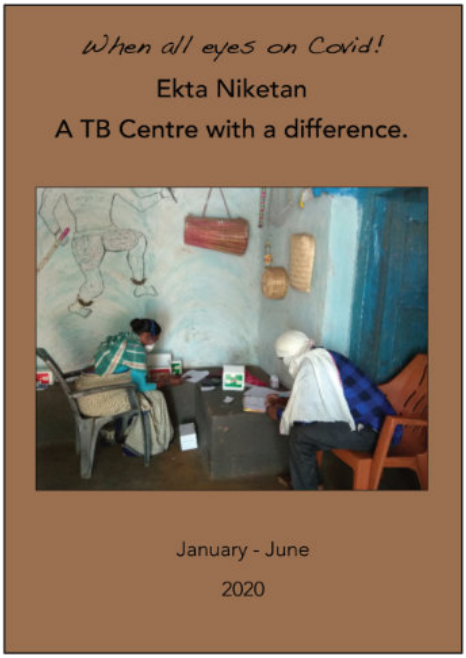
Village:

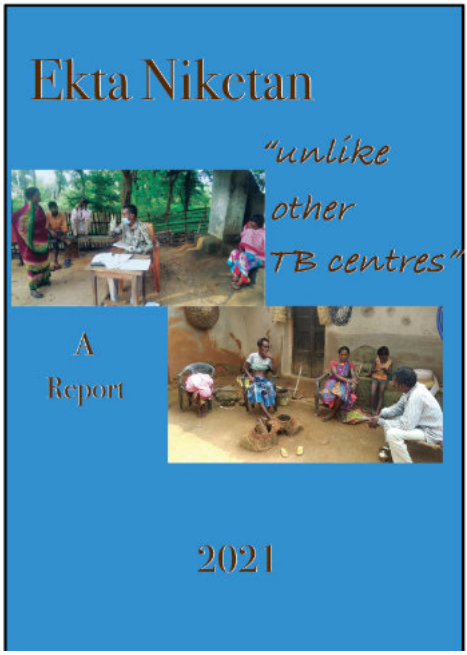
M/F:

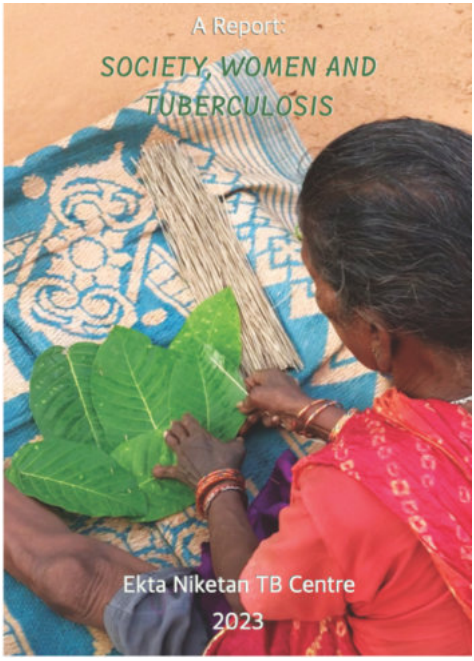
Age:

	FACTOR		COMPLIANCE SCORE CARD									SCORE	FINAL SCORE
A	DETERMINATION	8	7	6		4	3	2	1				
	मन-तेज												
B	FAMILY SUPPORT		7	6		4	3	2	1				
	घर सापोर्ट												
C	DISTANCE		7	6		4	3	2	1				
	दुरी												
D	AREA SUPPORT		7	6		4	3	2	1				
	ऐरिया सापोर्ट												
E	OCCUPATION					4	3	2	1				
	कमाई												
F	POVERTY			6	5	4	3	2	1				
	ग़रीबी												
G	TREATMENT TRUST	8	7	6		4	3	2	1				
	बिश्वास												
H	ALCOHOL					4	3	2	1	0			
	दारु												
I	WOMEN					4	3	2	1	0			
	महिला												
									TOTAL				


Ekta Niketan
TB & Poverty
TB Centre
a Report
March 2021


When all eyes on Covid!
Ekta Niketan
A TB Centre with a difference.
January - June
2020


Ekta Niketan
"unlike
other
TB centres"
A
Report
2021


A Report:
SOCIETY, WOMEN AND
TUBERCULOSIS
Ekta Niketan TB Centre
2023