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# Voices of Those Who Bear the Brunt – Experiences of Programme Personnel Concerning Private Sector Tuberculosis Notifications in Bengaluru City, India

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## ABSTRACT

This study aims to assess private and public sector contributions to Tuberculosis (TB) notification in Bengaluru city (2011 to 2016) and identify challenges of program personnel in their interaction with private practitioners and procedural barriers for TB notification from the private sector as perceived by them. A mixed methods study was carried out in Bengaluru city, India with TB notification data obtained from TB Units in addition to in-depth interviews with key program implementers. Results showed the contribution of private practitioners to TB notification to be about 20%. Barriers and challenges were: the private practitioners' hesitancy to refer the patients to public sector due to their fear of losing patients and dishonoring of diagnosis from private practitioners, lack of awareness about TB notification, lack of legal punitive measures and constant glitches on the notification website. These need to be resolved on priority to achieve the national target of TB elimination by 2025.

## KEYWORDS

TB notification; Nikshay; private practitioners; Bengaluru city

## Introduction

TB is one of the top 10 causes of death worldwide and is a leading cause of death from a single infectious agent (World Health Organization, 2018). In 2017, the estimated incidence of TB globally was 10.0 million out of which 2.7 million were from India (Central TB Division, Directorate General of Health Services, Ministry of Health and Family Welfare Services, 2018). Several studies from India have shown that the first point of contact for the majority of patients with TB (46–94%) is the private practitioner (Bronner Murrison et al., 2016; Satyanarayana et al., 2011).

TB notification is considered as a proxy indicator for TB incidence in a country with a strong reporting mechanism in place. In May 2012, the Revised National TB Control Program, RNTCP (RNTCP is presently called National TB Elimination Program, NTEP. Henceforth, the term NTEP will be used instead of RNTCP), made it mandatory for all the private practitioners to notify all types of patients they diagnosed with or treated for TB. The program had introduced a web-based online reporting system called Nikshay for TB notification in 2013 for both the public and private sector. However, the uptake of TB notification from private practitioners remains suboptimal at 21% (Central TB Division, Directorate General of Health Services, Ministry of Health and Family Welfare Services, 2018). There were studies conducted during 2012–15 at Pune, Maharashtra (Yeole, Khillare, Chadha, Lo, & Kumar, 2015), Alappuzha, Kerala (Philip et al., 2015), Mysore city (Singh Chadha et al., 2017) and New Delhi (Satpati et al., 2017) to look into enablers and barriers for TB notification. These studies have pointed out that lack of knowledge about TB notification, misconceptions about TB notification and absence of a simplified mechanism for TB notification were important barriers, and

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have provided meaningful recommendations for the program to pursue. Since then, there have been efforts from the program to improve the process and mechanisms for TB notification.

The NTEP National Strategic Plan for TB Elimination (2017–2025) envisages an increase in contribution to notification from the private sector by up to 60% by the year 2025 (Central TB Division, Directorate General of Health Services, Ministry of Health and Family Welfare, 2016, March). There was a revised gazette on TB notification in March 2018, from the Government of India (Government of India, 2018), which expanded the definition of private healthcare providers by including pharmacies besides the private practitioners.

Even after 5 years (since 2012, when TB notification became mandatory) of emphasis on TB notification from private practitioners and efforts being made to simplify the notification process, the notified cases fall far below the expectations. We chose to conduct a study in Bengaluru city, India as it has great disparity among the patients with TB diagnosed and registered for treatment (Suresh et al., 2017). This study aimed at identifying the challenges encountered during program personnel's interaction with private practitioners and the procedural barriers for TB notification from the private sector as perceived by NTEP program personnel.

## Material and methods

A mixed methods study was undertaken at Bengaluru city, India during May to August 2017. The quantitative data were collected in May followed by qualitative data collection between June and August 2017. The quantitative component included the collection of records and reports pertaining to TB notification in the city (data summaries including the name of the notification site, type of facility, number of patients referred for diagnosis, contribution to referral of presumptive TB) and the qualitative component included interviews with key program personnel engaged in TB notification.

### General settings

Administratively, the Bengaluru city is under the Bengaluru Bruhat Mahanagara Palike (BBMP) district, which covers a population of 7.8 million. The district has 125 public peripheral health institutions, 6 medical colleges (2 government and 4 private) and 2925 private health facilities registered under RNTCP for notification.

### RNTCP program structure (India)

Each of the health facilities is considered a peripheral health institution for the purpose of reporting under NTEP. The districts are subdivided into TB units (TU; one per 0.5 million population) in which

**Table 1.** Demographic details of qualitative study participants.\*

Serial number	Qualitative study Participant	Sex	Education	Designation
1	Participant 1 (TBHV 1)	Female	Sanitary Inspector Diploma	Tuberculosis Health Visitor
2	Participant 2 (TBHV 2)	Female	Sanitary Inspector Diploma	Tuberculosis Health Visitor
3	Participant 3 (TBHV 3)	Male	Sanitary Inspector Diploma	Tuberculosis Health Visitor
4	Participant 4 (TBHV 4)	Male	Sanitary Inspector Diploma	Tuberculosis Health Visitor
5	Participant 5 (TBHV 5)	Male	Sanitary Inspector Diploma	Tuberculosis Health Visitor
6	Participant 6 (TBHV 6)	Male	Sanitary Inspector Diploma	Tuberculosis Health Visitor
7	Participant 7 (TBHV 7)	Male	Sanitary Inspector Diploma	Tuberculosis Health Visitor
8	Participant 8 (TBHV 8)	Male	Sanitary Inspector Diploma	Tuberculosis Health Visitor
9	Participant 9 (STS 1)	Male	Bachelor's Degree	Senior treatment Supervisor
10	Participant 10 (STS 2)	Male	Bachelor's Degree	Senior treatment Supervisor
11	Participant 11 (STS 3)	Male	Bachelor's Degree	Senior treatment Supervisor
12	Participant 12 (MOTC 1)	Female	Postgraduate degree in Medicine	Medical Officer of Tuberculosis Control
13	Participant 13 (MOTC 2)	Male	Postgraduate degree in Medicine	Medical Officer of Tuberculosis Control
14	Participant 14 (MOTC 3)	Male	Postgraduate degree in Medicine	Medical Officer of Tuberculosis Control

\*Details of the lone District Tuberculosis Officer interviewed is not given to maintain confidentiality.

program paramedical staff called TB Health Visitor (TBHV; one per 0.1 million population) and Senior Treatment Supervisors (STS; one per 0.5 million population) facilitate the TB notifications in their areas and monitor TB treatment. The Medical Officer-TB Control (MOTC; one for 5 million) supervises the implementation of the program in the area. A laboratory from a selected Primary Health Center in the area is identified as designated microscopy center (DMC) to perform sputum examination (one DMC for every 0.1 million population). All public health and private (registered with NTEP) facilities notify the patients diagnosed with TB to the program. The district TB officer (DTO) has overall responsibility of managing the program in the district. The paramedical staff (TBHV and STS) serve as a key link and facilitate the TB notification from the private practitioners. Upon receipt of information about a patient with TB from the private practitioners, the TBHV arranges for confirmation of diagnosis (by sputum examination using Ziehl Neelsen staining) and assigns a Nikshay identification number (unique number) to each notified patient with TB and thus the case is notified to the program. There were 14 NTEP TUs with 14 senior treatment supervisors (STSS) and 55 TB health visitors (TBHVs) in Bengaluru city in 2017.

### Data collection

Face-to-face in-depth interviews were conducted by the principal investigator with key program personnel (TBHV, STS, MO-TC & DTO). The TBHVs, STSs and MOTCs were selected randomly from the list. A total of 15 interviews were conducted among the program personnel (8 TBHVs, 3 STSs, 3 MOTCs and 1 DTO)(The demographic details of participants are given in Table 1); there was a 100% response rate. The interviews were held using an interview guide (Table 2) until a saturation point was attained, and no new information was forthcoming. Written informed consent was obtained prior to the interview. All interviews were audio recorded and each interview lasted for approximately 25 minutes. The interviews of all the TBHVs and STSs were conducted in the local language (Kannada) and for the other staff they were in English. The dialogs from local languages were translated to English, while the English interviews were transcribed verbatim. All interviews were held at the participants' workplace. The interviewer ensured that the interaction took place with prior appointment at an isolated area, away from other staff of the center. Thematic content analysis was used to identify emerging codes and themes in the transcripts. Two coders conducted the content analysis. A licensed version of NVivo Pro Version 11 was used for qualitative data analysis and management. The COREQ criteria for reporting qualitative studies were adopted for presenting the qualitative results of the present study (Tong, Sainsbury, & Craig, 2007).

Retrospectively, the quantitative data of notification for all forms of TB from public and private practitioners from January 2011 to December 2016 were obtained from the BBMP District TB office. The quarterly data were collected by visiting each of the 14 TUs in Bengaluru City. All data were electronically entered into Microsoft Excel 2010 for further analysis.

**Table 2.** Topics included in the key program personnel interview guides.

Sl. no.	Topics
1	To explore the awareness, perceptions, beliefs and practices regarding the process of notification in Nikshay. <i>Main questions focused on source of knowledge, the process for private and government practitioners, functionalities involved and notification volume over last few months.</i>
2	To explore challenges faced in the process of notifying in Nikshay in general. <i>Main questions focused on challenges in the process, strategies adopted to solve problems and persons who helped solve problems.</i>
3	To explore notification of tuberculosis from private providers in Nikshay and challenges faced therein <i>Main questions focused on process of notification from private practitioners, challenges in notification from private practitioners, persons who solved their problems, benefits of notification from private practitioners, opinions about compulsory notification, opinions about incentives for notifying and suggestions to improve notification.</i>

## Ethics

The permission for the study was obtained from the District TB Officer, Bengaluru city and the State TB officer, Karnataka. The Institutional Ethics approval was obtained from the Ethics Committee of the Academy of Medical Education, Pariyaram, Kerala, India (Reference number G1.2747/12/ACME dated 20-06-2016).

## Results

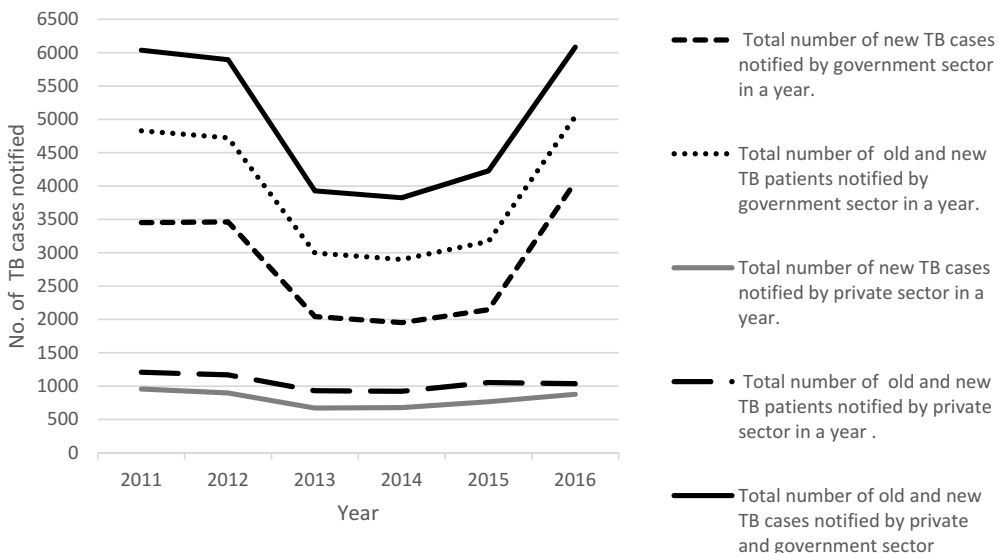
### Private practitioners' share of TB notification in Bengaluru city

The number of patients with TB notified in Bengaluru city from private practitioners showed a decreasing trend from the year 2011 to 2013, followed by a gradual increase in the notifications from 2014 onwards. The contribution of the private practitioners to the total TB notifications was about 20% between 2011 and 2016 (Figure 1).

Among the various categories of private practitioners in Bengaluru city, the lowest proportion of presumptive TB referrals for diagnosis was from the private sector other than the private medical colleges (14.9% in 2011 and 13.9% in 2016). Almost an equal share of such referrals came from the public sector and the medical colleges between 2011 and 2014. However, during 2015 and 2016 referrals were higher from government facilities, 50% in 2015 and 59.5% in 2016 (Table 3).

### Results from the in-depth interviews

Information that emerged from the data was identified and coded into five major themes. The coding tree is shown in Figure 2. Figure 3 depicts the path (black arrow) of TB notification in Bengaluru city and links the path with the themes. A brief description of the themes and quotes from the interviews are described below.



**Figure 1.** Government and private practitioner TB notification, Bangalore city 2011–2016. **New TB case**—A TB patient who has never had treatment for TB or has taken treatment for less than 1 month, **Old TB case** (previously treated TB patient) has received 1 month or more of anti-TB drugs in the past (NTEP definitions).

**Table 3.** Presumptive tuberculosis (TB) referral for diagnosis to NTEP designated microscopy centers from various health sectors in Bengaluru City, 2011–2016.

Year	Bangalore City population (in millions)	Presumptive TB referral from M sectors N (%)	Presumptive TB referral from H, G sectors N (%)	Presumptive TB referral from C, P, N sectors N (%)	Total Presumptive TB referral from all sectors N (%)
2011	4.70	21,039 (44.5%)	19,191 (40.6%)	7,061 (14.9%)	47,291 (100%)
2012	7.48	21,491 (46.9%)	17,783 (38.8%)	6,575 (14.3%)	45,849 (100%)
2013	7.58	18,589 (44.0%)	16,612 (39.3%)	7,006 (16.6%)	42,207 (100%)
2014	7.67	22,352 (44.3%)	20,068 (39.7%)	8,052 (15.9%)	50,472 (100%)
2015	7.77	19,793 (35.7%)	27,700 (50.0%)	7,888 (14.2%)	55,381 (100%)
2016	7.87	16,548 (26.5%)	37,069 (59.5%)	8,672 (13.9%)	62,289 (100%)

M = Medical colleges (2 government and 4 private).

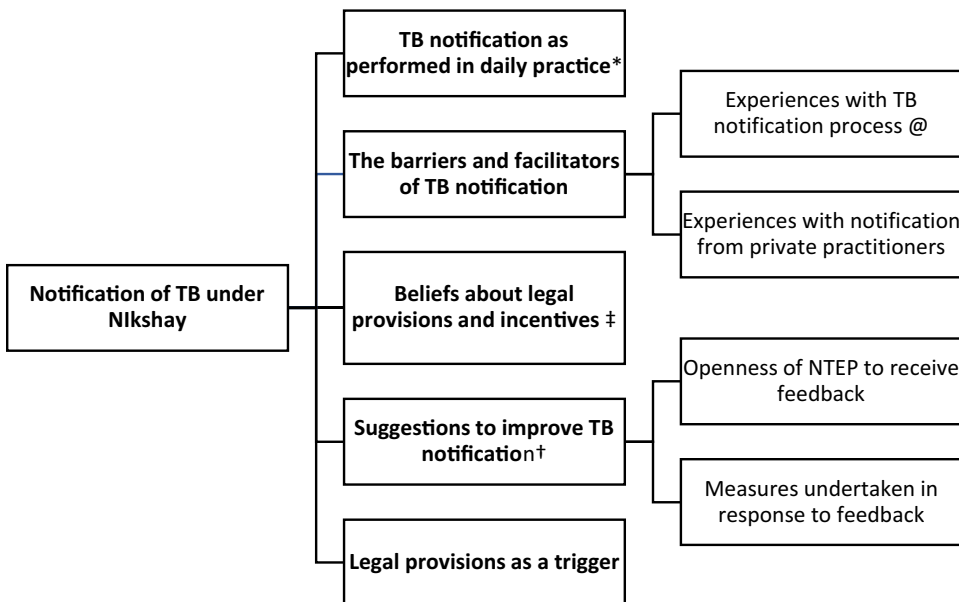
H = Government facilities in Bengaluru City under BBMP administration.

G = Government facilities under other government administration.

C = Corporate providers.

N = Providers under NGOs.

P = Other private providers.

**Figure 2.** Coding tree depicting the major themes derived from the interviews (shown in bold) of NTEP personnel.

### **Experiences of program personnel with TB notification from private practitioners**

#### **Experiences during private provider-public provider interaction when seeking TB notification**

After waiting for hours to meet the private practitioners, many of them would be unwilling to notify. The common reasons for this response as perceived by the respondents were the private practitioners' fear of losing a patient, private practitioners favoring daily treatment regimens over intermittent regimens, sense of confidentiality breach felt by private practitioners and a fear of being targeted by the program. One TBHV felt that the patients were made to run from pillar to post for diagnosis and treatment and hence were not in favor of seeking diagnosis and treatment from the public facilities.

Sometimes there was a delay in notification of cases from the private practitioners. The patients would have been admitted for a week or more at the hospital and then notified only upon discharge. Lack of awareness about TB notification, its process and importance also contributed to delay. Incentives provided to practitioners who attend updates on NTEP were thought to be insignificant.

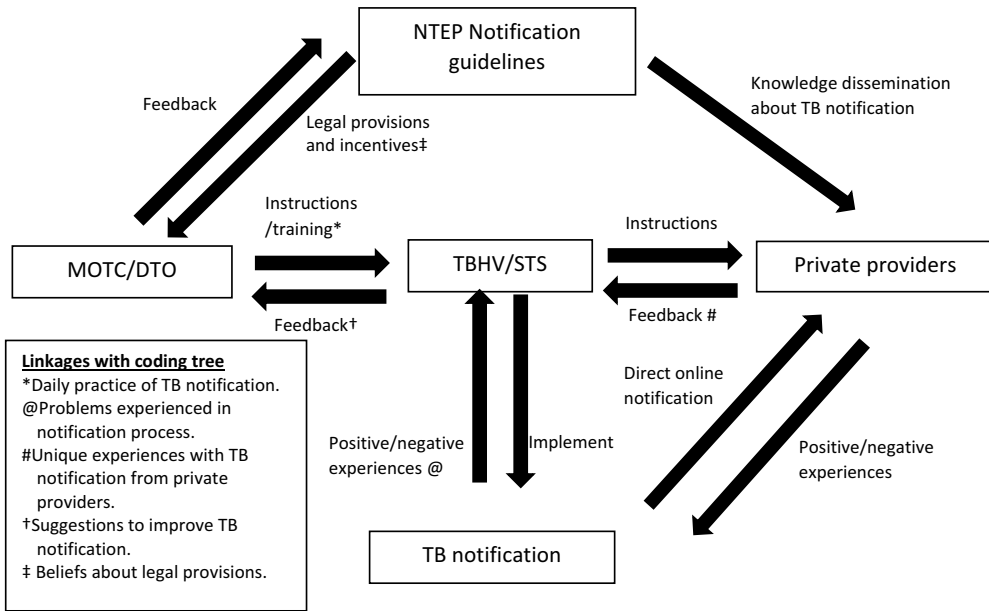


Figure 3. Diagram depicting the ways of routing of TB notification with superimposed themes.

They just give travelling allowance to the doctors, Rupees 200-300. Sometimes not even that. Only if they have personal interest, they are doing it (attending meeting), that's all. (TBHV)

### **Practice of direct online notification by private practitioners**

Very few private practitioners were directly notifying patients with TB through the Nikshay website. It was generally agreed that this could be because they were busy and did not have the time to do it.

### **Notifications from standalone clinics vs. corporate hospitals and nursing homes**

The standalone clinics posed problems in terms of access to TBHVs for notification due to their unpredictable timings. Most often, they also did not have a laboratory attached, and so they tended to refer presumptive patients with TB to public facilities for diagnosis. The corporate hospitals and nursing homes, on the other hand, were more accessible to TBHVs and most of their patients were registered for notification. However, there was more resistance to notification of patients with TB as they had in-house laboratories and insisted that all diagnostic procedures be done there itself.

Small clinics (standalone) will send more (notification). In small clinics, they will say there is a government or public hospital, you go there, do your test and come back to me. Whereas in a nursing home, they insist the patient goes to their laboratory only. (TBHV)

### **Procedural barriers for TB notification**

#### **TB notification for patients referred from private practitioner**

There was agreement among all respondents about the process of TB notification. It was also well acknowledged that the diagnostic test(s) for TB had to be repeated in the government set up even if the tests had come positive earlier in a private laboratory.

We have to do the exam (test) in the designated microscopy centre and it has to come out as positive there. Some (patients) agree to this and some do not agree. (STS)

One respondent mentioned the fact that the goal of TB notification was to notify all probable and confirmed patients with TB. However, due to time constraints and constraints on physical facilities (access to computers, fast internet coverage), at present only confirmed patients with TB are notified.

### **Physical infrastructure**

Implementers' lack of access to dedicated computers and internet and Nikshay website-related problems resulted in delayed notification and inconvenience to patients.

Yes, personally I have sat down 2-3 times (at a computer) and found that it takes around 20 minutes for doing one entry. It will be difficult for him to deliver other functions. If it is fast enough, it will be good. (MOTC)

The other hospital staff will be working on the existing lone computer. They will say wait for 10 minutes or half an hour. No patient will wait for so long. (TBHV)

Possibility of duplication of notification was also a cause for concern. Sometimes data that were saved had to be reentered due to software issues.

### **Insisting on details of patients for registration**

Some patients felt an intrusion into their privacy when requested for providing their *Aadhar* number (a unique identification number provided to each citizen by the Government of India) and bank details, especially those notified from corporate or super speciality hospitals. The possibility of duplication of notification in spite of being linked with a unique identification number in the present study was attributed by the program personnel to an inherent problem with the notification software.

There are some super speciality hospitals and corporate hospitals, they do not disclose their (patient's) secrets. There, the patients say - we will pay, do not disclose our information. (STS)

### **Measures to improve TB notification from private sector**

#### **Beliefs about legal provisions for notification and incentives for reporting patients with TB**

It was broadly agreed that legal provisions will improve notification from the private practitioners mainly due to the penal clauses for noncompliance. Duplication of notification was anticipated, if some unique identity was not used to tag a notification. However, respondents expressed concern about misuse of incentive driven notification for monetary gain.

#### **Legal provisions as a trigger for notifications**

The respondents strongly believed that the increase in TB notifications seen from the year 2014 onwards was because compulsory TB notification was implemented during that year.

Previously before Nikshay, it was only 20-30%, not too much. After making it mandatory, now it is around 70-80% people are reporting. (MOTC)

I have not seen private practitioner getting a notice. They have to be given some notice and they should think someone is supervising them. ... (MOTC)

#### **Lack of authoritativeness for paramedical staff**

The TBHVs and STSs not being doctors perceived a barrier between themselves and the private practitioners. The practitioners seemed to ignore them and brush off their requests for TB notification. Even their peers reportedly underplayed their requests for sharing computers at their workplace for the purpose of TB notification.

We have told everything, they (private practitioners) say we will do it (notify patients with TB), but they ignore it. I think an MBBS doctor only should approach them, then they will speak with respect. If we go, they say go, we are very busy now; they do not give us respect. (TBHV)



But there is a difference when a higher authority asks (ask other health functionaries at the TU for the computer to be shared for notification work) and we ask. (STS)

### ***Streamlining issues related to Nikshay website***

The respondents felt that there was a need to resolve technical issues with the Nikshay website and train the TBHVs and STSs in troubleshooting problems. They were of the opinion that the website is not user-friendly and not devised for field conditions. The training imparted for routine usage was insufficient especially while combating trouble shooting day-to-day issues.

[You must] Just read from a book and they have given us a module, that's all. They should give hands on training and they should teach troubleshooting also. (TBHV)

Access to computers, preferably one at every microscopy center, was desired. Continuing medical education programs for updating the private practitioners about changes in NTEP guidelines and provision of adequate incentives for attending such meets were also proposed.

### ***Building a bond of trust***

It was the experience that repeated visits of TBHV to private practitioners ensured that a trustful relationship developed. This trust was further strengthened when the practitioners were allowed to become DOT providers for their patients. This strategy also ensured that the patients were in touch with their trusted doctors, and at the same time, National guidelines were adhered to.

## **Discussion**

Overall, the study reveals that inadequate infrastructure, inappropriate training imparted to implementers and issues related to the Nikshay website have led to decreased notification from the private sector. The private practitioners' notification is less than 20% as observed in the last 5 years with no signs of massive escalation. Even the private practitioners' apprehension to notify the disease continues to remain even after 5 years of mandatory TB notification.

The reasons for low volume of notifications from private practitioners as perceived by the program staff were fear of losing patients to NTEP, sense of confidentiality-breach if patients' details were made available to NTEP, fear of being targeted by NTEP, lack of awareness about TB notification and lack of time to carry-out TB notification.

The trend of TB notification from private practitioners in Bengaluru city is similar to those reported for the same period for India in the NTEP Annual TB report, 2017 (Central TB Division, Directorate General of Health Services, Ministry of Health and Family Welfare, 2017) and NTEP Annual TB reports, 2012–2014 (Central TB Division, 2014; Central TB Division, Directorate General Health Services, 2013; Central TB Division, Directorate General of Health Services, Ministry of Health and Family Welfare, 2013). The trend of TB notification (2011–17) in Bengaluru city almost remained the same except for a slight surge in 2014 and may be attributed to the due emphasis for implementation during the initial years. The contribution of 20% to total TB notification from private practitioners in our study was comparable to the proportion estimated in Pune city, India (Yeole et al., 2015). The proportion of all presumptive TB referrals to DMCs coming from corporate hospitals, NGO-based practitioners and other private practitioners was only about 15%. This has to be viewed in the context that a large proportion of patients resort to the private sector at the first instance (Bronner Murrison et al., 2016; Charles et al., 2010; Kapoor, Raman, Sachdeva, & Satyanarayana, 2012). Medical colleges and government health centers in Bengaluru city contributed equally to presumptive TB referrals, which is consistent with other parts of the country (Sharma et al., 2013).

Equipping the end-users with improved access to dedicated computers, continued connectivity, periodic hands-on training and a well-conducted help desk remains the key and will certainly make the notification procedure a smooth process. It is necessary to educate patients and convince them

about the necessity of providing *Aadhar* (personal identification) number, bank account details and other information during notification.

The key perceived reasons for private practitioners' hesitancy to notify TB mentioned hitherto have also been reported in several other studies in India (Artawan Eka Putra et al., 2013; Atre, 2014; Nagaraja, Achanta, Kumar, & Satyanarayana, 2014; Rangan et al., 2004; Satpati et al., 2017; Uplekar et al., 2016; Velayutham et al., 2015; Yeole et al., 2015). Though the program has made efforts to gain the confidence and trust from the private sector in all these years, there remains a huge void in garnering support of the private sector. It is evident from our study findings that the corporate hospitals and nursing homes were found to be more difficult to deal when compared to standalone clinics. It was the experience of the respondents that frequent visits to private practitioners' facilities helped them in building trust. Chadha *et al.* had similar experience in Mysore and had opined that one-on-one interaction was all that the private practitioners expected, and they were not interested in any other incentives to notify patients with TB (Singh Chadha et al., 2017). The program personnel felt that not being a doctor could have lowered the impact on the seriousness of notification; a similar perception was found in a study conducted in Pune (Yeole et al., 2015) and New Delhi (Satpati et al., 2017).

For the implementers to work more confidently, support from program managers, health authorities and district administrators remains absolutely essential during difficult case scenarios. The respondents also felt that recent changes in legal provisions for TB notification and incentive-based notification would positively help increase volume of notification, if duplication of data and misuse of incentives were checked.

We propose that the Social Learning Theory and the Precede/Proceed Models (Stålsby Lundborg & Tamhankar, 2014) may help understand barriers and find solutions for the lack of TB notification from the private sector. While the concepts of 'self-efficacy', 'expectations' and 'observational learning' provide clues to how private practitioners learn, the concepts of 'reinforcement', 'social support' and the 'precede/proceed model' could guide support strategies.

The results of this study are grounded in narrative data and are logical. There are parallels that can be drawn across the views of different categories of participants. The authors believe that reflexivity has been applied during data collection. Other strengths of this study are that it voices the opinions and feelings of the crucial frontline workers and that the study settings are based in an urban area, which is the epitome of private sector. However, there may be differences between perceptions of the interviewed implementers and the ground reality. Findings of the present study may be limited in its transferability due to variations in contexts elsewhere in other Indian urban conglomerates. That the perspectives of the private practitioners have not been elicited could also be a limitation of this study.

To conclude, TB notification from the private sector in Bengaluru city was suboptimal. The challenges and procedural barriers to TB notification from the private sector remain unaddressed. We strongly suggest the following two activities by all the district health program managers to increase TB notification from the private sector: (1) upscaling the electronic notification to a simple, user-friendly and seamless facility; and (2) undertaking deliberate efforts to engage with private practitioners by higher authorities through one-to-one interactions to allay their fears, misconceptions and keep them updated about any development in the guidelines. It is high-time for the program to mitigate these challenges on priority in order to achieve the targets as TB elimination by 2025 as envisioned by the Government of India.

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## Disclosure statement

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