

Patient Experience under India's Revised National  
Tuberculosis Control Programme in Pondicherry

by

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## **ABSTRACT**

While India's Revised National Tuberculosis Control Programme (RNTCP) has been a success on a statistical and national scale, awareness of the program and tuberculosis (TB) still remains low in many areas of India. In Puducherry (previously known as Pondicherry), a survey of 50 RNTCP patients reveals that only 40% had heard of TB before diagnosis, only 16% suspected that they had TB, and only 10% had heard of directly observed treatment short-course (DOTS). Women were more likely than men to have heard of TB (50% vs 35.3%, respectively) and DOTS (25% vs 2.9%, respectively), likely due to targeted TV advertisements during the day when men are out working. As expected, patients with more years of schooling were more likely to have heard of TB. Men were more likely to report missing doses, but women were more likely to report side effects. As income and years of schooling increased, the likelihood of seeking private treatment also increased likely due to less crowding and faster treatment in private settings. Most patients were happy with their experience under RNTCP, major complaints included side effects of taking the pills, missing work in order to obtain pills, and facing the stigma of having TB. Reported compliance was high overall, but 44% of patients reported missing at least one dose during the course of their treatment. While RNTCP has come a long way in reducing the morbidity and mortality of TB, it still has a long way to go especially in population awareness and prevention of multi-drug resistant TB.

## INTRODUCTION

### *A Tuberculosis (TB) Premiere*

TB is caused by an infectious bacillus bacterium called *Mycobacterium tuberculosis*. *M. tuberculosis* usually targets the lungs, but can also be extra-pulmonary. It is typically spread by close contact with an infected person, especially through air-borne droplets. Typical symptoms of TB include a persistent cough, blood in the sputum, fever, and weight loss (due to appetite loss). However not everyone infected will develop an active TB infection; most infected patients develop a latent form of TB infection, which is non-symptomatic and non-communicable. A latent TB infection can later progress into an active infection.<sup>25</sup>

TB is most common diagnosed by sputum microscopy and chest x-ray. Sputum smear microscopy is the oldest and cheapest form of diagnosis, and is commonly used in resource-limited countries.<sup>7</sup> Other methods include the TB skin test, blood tests, and culture methods.

The best way to prevent TB, is to avoid infection. This can be done by avoiding close contact with infected individuals and by following airborne infectious control protocols.<sup>27, 28</sup> A vaccine exists for TB, the bacillus Calmette-Guerin (BCG) vaccine, but its use is not standard worldwide.<sup>13, 20</sup>

First-line drugs against TB include rifampin, isoniazid, pyrazinamide, and ethambutol. Typical treatments include 2 months of an “intensive phase”, followed by a “continuation phase” that generally lasts between 4 to 7 months. Antibiotics are

also recommended for latent TB patients, which include isoniazid, rifampin, and rifapentine, to stop progression into active TB.

It is critical for patients to finish their treatment regimen, which generally takes 6 to 9 months. If treatment is stopped prematurely, as often occurs because patients feel better after the intensive phase and stop adhering to treatment regimen, it can lead to relapse and/or resistance. A major problem facing TB control is the development of a drug resistant strain of TB and multiple drug-resistant tuberculosis (MDR TB). By definition MDR TB are strains that are resistant to at least two anti-TB drugs, including either rifampin and/or isoniazid. MDR TB has to be treated by second-line drugs, examples include pyrazinamide, cycloserine, fluoroquinolones, etc., and should be closely monitored.<sup>4</sup> Major factors in MDR TB development is non-compliance to treatment regimens, private sector practices, and poor knowledge.<sup>1,24</sup>

### *HIV and TB*

Around 4.9% of all TB patients in India are also infected with HIV, and India has the third highest HIV burden of any country, with as estimated 2.39 million infected people (0.31% prevalence). Six states (Andhra Pradesh, Karnataka, Manipur, Maharashtra, Nagaland, and Tamil Nadu) account for 57% of HIV patients and are classified as high prevalence states. However, these same six high prevalence states only account for 39% of the incidence rate, indicating a shift of incidence from these high prevalence states to lower prevalence states.<sup>31</sup> TB is the leading killer of HIV-positive people, accounting for 25% of HIV-related deaths. Due

to the weakened immune system of HIV patients, they are 29 times more likely to develop and succumb to TB infections.<sup>6</sup> HIV-positive status is also the highest risk factor for latent TB developing into an active infection.<sup>28</sup> Since 2004, the number of HIV-positive TB patients went from very low to 364,000 by 2013. Among recorded HIV-positive TB patients, 70% were on anti-retroviral therapy (ART).<sup>6</sup> Upon starting ART, HIV patients had a 57% higher risk for contracting TB, with the risk rapidly decaying as ART continues.<sup>12</sup> With respect to MDR TB/HIV co-infection, patients had similar treatment success rates, but a higher mortality.<sup>9</sup> Understandably, a major focus of TB control programs has been on improving detection/reporting of HIV/TB co-infected patients and better management of these patients.<sup>6, 33</sup>

### *Public Health Significance of Tuberculosis*

About 22% of the world is infected with TB, with an estimated 10.4 million new cases and 1.7 million deaths per year from the disease in 2016.<sup>23</sup> 56% of these cases were in south-east Asia and western pacific regions, with India and China accounting for 24% and 11% of total cases respectively. Another 25% were in the African regions, which also suffer the greatest morbidity and mortality rates respective to population.<sup>6</sup> 22 high burden countries account for 80% of all estimated cases.<sup>8, 31</sup> In 2013, 6.1 million actual cases were reported, 5.7 million new cases and 0.4 million existing cases.<sup>6</sup> TB disproportionally affects the poor, with over 95% of TB related deaths located in low- and middle-income countries.<sup>32</sup> Men are more affected by TB, with about 60% of TB cases occurring amongst men. However there are still 3.3 million cases and 510,000 TB-related deaths in women, and it is one of

the top 5 causes of death for women between the ages of 15 and 44.<sup>6,32</sup> Children accounted for 550,000 cases and 80,000 TB-related deaths.<sup>6</sup>

TB is deadly if untreated, where up to two-thirds of untreated TB patients will die.<sup>32</sup> TB ranks as the 7<sup>th</sup> killer of all deaths.<sup>31</sup> Untreated patients also potentially infect 10-15 other people.<sup>32</sup> However, front-line drugs in a short-course treatment regimen can cure 90% of TB cases.<sup>6</sup> Latent cases exhibit no symptoms and are not infectious, but may develop an active TB infection in about 10% of the time.<sup>32</sup> An estimated 480,000 people developed MDR TB, which poses a significant public health challenge due to the difficult nature of treating these patients. 1.1 million people (13%) of the 9 million people who developed TB in 2013 are estimated to be coinfecting with HIV.<sup>4,32</sup>

Since 1990 the global TB mortality rate has fallen by 45% and the prevalence rate has fallen by 41%. The 2015 Millennium Development Goal of halting and reversing TB incidence rates has been achieved globally, and post-2015 goals include a 95% reduction in TB deaths and 90% reduction in TB incidence by 2035.

### *Demographic Characteristics of India and Puducherry*

India is a nation of 1.2 billion people, the second largest in the world. The National Family Health Survey is conducted by the government, with the most recent in 2005-2006.<sup>17</sup> As a quick overview of the nation, the fertility per women is 2.7, with the median age of first birth being 19.8 years of age. Modern family planning is used in 48.5% of the time, with female sterilization being the most

popular (37.8%). Condom and pill use are 5.2% and 3.1%, respectively. 78.1% of children receive the BCG vaccine.<sup>17</sup>

The District Level Household and Facility Survey (DLHS) is conducted by the Ministry of Health and Family Welfare, and serves to provide a database on a district level to benchmark, examine, and evaluate various needs and programs. There have been four such surveys, the first in 1998-1999, the second in 2002-2004, the third in 2007-2008, and the most recent in 2012-2013. The following data reflects the results of the DLHS in the Puducherry of India. In DLHS-4, 5,210 households were surveyed, 1,296 rural and 3,914 urban. This was a 20% increase from DLHS-3, which surveyed 4,333 households, 959 rural and 3,374 rural. Literacy in people ages 7+ remained about the same from 90% to 89.6%, and mean household size has slightly decreased, from 4.4 to 4.1. Electricity access has also risen, from 96.9% to 99.4%. That rise can largely be attributed to better electrical access in rural areas, where it rose from 90.8% to 98.9%, while the urban access rose from 97.7% to 99.1%. The difference in electrical access between urban and rural areas was 6.9% in DLHS-3, but that gap was closed to 0.2% in DHLS-4.<sup>2</sup>

Births to women aged 15-19 out of total births rose from 2% to 2.7%, with the mean number of children ever born to women 40-49 remaining about the same from 2.4 to 2.3. Family planning dropped from 59.4% to 53.6%, with female sterilization being the most popular method, 48.7% in DHLS-3 dropping to 48.3% in DHLS-4. Condom and pill use were at 1.2% and 0.4%, respectively, in DHLS-4, a significant drop from their DHLS-3 counterparts, 4.3% and 0.5%, respectively. Delivery at institution remained high at 99.7% (99% in DHLS-3), and delivery with a



skilled health professional mirrored this at 99.7% (99.4% in DHLS-3). However, 44.3% of women had a pregnancy complicated in DHLS-4, a drop from 51.5 in DHLS-3.<sup>2</sup>

The percentage of children that received the BCG vaccine dropped from 96.6% to 94.3%. DLHS-3 does not have data about persons suffering from TB, but in DLHS-4, 0.4% of all respondents suffered from TB, 0.5% rural and 0.4% urban. Puducherry is one of three states that are classified as moderate prevalence states for TB/HIV co-infection.<sup>31</sup>

The percentage of villages that had a primary health care facility (PHC) within 10km rose was 100% across both DHLS-3 and DHLS-4. The percentage of PHCs that were 24/7 slightly rose from 73.3% to 73.9%.<sup>2</sup>

### *TB in India*

India has the highest number of new TB cases in the world. Out of the estimated 9.4 million global incidence rate of TB, about 2 million are estimated to be in India.<sup>31</sup> Annually, the direct and indirect costs amount to \$23.7 billion.<sup>31</sup> It is also estimated that 40% of the Indian population is infected with the bacillus responsible for TB. TB alone accounts for 17.6% of communicable disease deaths and 3.5% of all deaths.<sup>31, 32</sup>

It is estimated that in terms of disability-adjusted life years, 80% of the burden of TB is due to premature death.<sup>31</sup> It creates a great socio-economic burden because TB usually affects people in their most productive years (70% of TB patients are between 15 and 54 years old). 60% of TB patients are male, but female

TB patients typically are affected at young ages (50% of female TB patients are under 3 years old). Additionally, each patient loses on average 3 to 4 months of work time, which can account for 20% to 30% of the patient's annual household income.<sup>31</sup> Since TB usually affects the poor, this can be extremely crippling and a great burden for these low socio-economic status populations.

Despite TB's great morbidity burden, its greatest burden comes from its mortality. It is estimated that a typical TB case under the Revised National Tuberculosis Control Program burden is \$12,235 and incurs a DALY of 4.1. However, a TB death burden is \$67,305 and incurs a DALY of 21.3.

From 1997-2006, 6.3 million patients have been treated under RNTCP, resulting in a total of 29.2 million DALYs prevented and 1.3 million lives saved. Each TB patient successfully treated under RNTCP has netted \$13,935 in economic health and 4.6 DALYs.<sup>31</sup>

### *National Tuberculosis Control Programme (NTP)*

The NTP program was started in 1962 as a community-approach effort to combat TB, with a focus on rural areas. The program was born out of the need for a cost-effective, easy, and widely acceptable protocol to combat rising threat of TB in the face of limited resources, lack of trained personnel and equipment.<sup>16</sup> The program was based on sputum microscopy diagnosis and health sub-centers to distribute drugs. The lack of funding, however, caused a shortage of drugs, and with no healthcare worker oversight, it relied upon luck and faith that patients would adhere to treatment regimens. Due to this, and numerous other problems, NTP was

not effective in its goal of detection, treatment, and coverage, and in 1992 a review committee decided that it had to be revised.<sup>19</sup>

### *Revised National Tuberculosis Control Programme (RNTCP)*

In 1997 RNTCP was launched due to the inadequacies of NTP, and its goal was to achieve a detection rate of 70% and a cure rate of 85% with the addition of Directly Observed Treatment Short-course (DOTS).<sup>27, 30</sup> With earmarked drugs for each patient (guaranteeing a full treatment supply for each patient) and healthcare worker oversight (guaranteeing patient adherence), RNTCP solved many problems NTP encountered. The service was planned to be expanded across the whole nation, which was obtained in March 2006.<sup>24</sup> Shortly after nationwide expansion, RNTCP achieve the >70% detection rate and >85% cure rate in 2007.<sup>24, 31</sup> Additionally, there was a decline in the rate of MDR TB development after implementation of RNTCP .<sup>10</sup> The implementation of RNTCP has reduced TB fatality from greater than 25% to less than 5%.<sup>31</sup>

To achieve this goal, RNTCP has implemented many different programs. A Tribal Action Plan allows for the staffing and operation of TB units in difficult to reach areas, and a public-private mix scheme allows for non-government organizations (NGOs) and private practitioners to participate in RNTCP. Despite these programs, case detection rates in tribal areas are still below RNTCP targets and public-private cooperation can still be improved upon .<sup>15, 22, 26</sup> 291 public and private medical colleges participate in RNTCP, and there are also joint programs between RNTCP and National AIDS Control Program (NACP) that conduct collaborative activities.<sup>18</sup>

### *Diagnostic techniques for TB*

Under RNTCP, a TB diagnosis is suspected if the patient has a fever, cough, blood in sputum, or weight loss, especially if over the past two weeks. Initial diagnostic test involves sputum microscopy. If positive for TB infectious agent, the patient is enrolled into RNTCP. If negative, another sputum test is collected especially in the presence of continued symptoms. If positive, patient is enrolled into RNTCP. If negative, a chest x-ray is conducted. If positive for TB, the patient is enrolled into RNTCP. If negative, the patient is cleared.

### *Directly Observed Treatment Short-course (DOTS)*

DOTS is a program where drugs and the consumption of drugs is monitored by a healthcare worker. This involves the patient receiving drugs at a DOTS unit every other day to consume medication under the supervision of a healthcare worker. This “intensive phase” lasts two months. After that, the patient goes through a four month period where the patient receives a week’s worth (3) of drugs and is required to show the empty blister packs to receive next week’s drugs.

### *Current Challenges In TB Control*

Urban areas present a challenge for RNTCP due to increased transmission because of higher population densities and the preference of patients to enter private sector treatment outside of RNTCP. Another major challenge is the misuse or discontinuation of drug treatment regimen, which leads to development of MDR

TB.<sup>24</sup> This often occurs because patients begin to feel better after only a few weeks of treatment, and stop treatment despite not being cured, leading to possible resurgence of TB.<sup>29</sup> Loss of follow up among patients also presents a challenge, especially among children TB patients.<sup>5</sup> Patient follow up and education could be used to reduce the incidence of both drug misuse and continuation, in conjunction with private sector efforts.<sup>11</sup> Private sector protocols are also not always consistent with standards set by RNTCP guidelines, which reduces the effectiveness of TB control programs.<sup>21</sup>

While sputum tests have been a diagnostic standard, the deployment of more rapid, molecular based tests is a current objective. Initial reports indicate that these tests perform just as effectively, but are much less time-consuming, thus resulting in a quicker turn-around time and allows for quicker patient care.<sup>24</sup>

The development of new vaccines and drugs are also essential for the continued effectiveness of RNTCP. A more effective vaccine could prevent more incidents of TB transmission and encourage a higher percent of vaccinations among the population. New drugs are needed to curtail the spread of MDR TB.<sup>3, 20</sup>

Low awareness and lack of familiarity with TB amongst medical personal is another factor that leads to delayed diagnosis and increases transmission in hospital settings.<sup>14</sup> Education and refreshers of all hospital staff on TB protocol can lead to quicker diagnosis and reduced transmission.<sup>14</sup>

## **OBJECTIVES**

Establish a missing feedback link between the patient's perception and experience of the RNTCP program and the hospital's diagnosis and treatment regimen. Qualitative improvements and suggestions will be drawn from patients.

## **MATERIALS AND METHODS**

### *Study Population*

The study population consisted of TB patients that had either completed their whole TB regimen or at least the intensive phase of the regimen. They were located in both rural and urban areas of Puducherry.

### *Survey Protocol*

The survey was initially constructed in English. Afterwards, a Tamil (the local language) version was created to be used with the study population. Field visits were conducted over a three-week period. The visits included a social worker, sometimes a postgraduate, and the author. The postgraduate or social worker would conduct the interview in Tamil, while I was there to sort out any problems or questions with the survey/survey responses.

## RESULTS

### *Demographic Analysis*

The patient subject population consisted of 50 people that either finished at least intensive phase of RNTCP. 68% of the subjects were male, average age was 47.3, average level of education was 5.5 years (out of 12 year standard), and average income was 6204.2 With regards to marital status, 8% were single, 88% were married, 0% were divorced, and 4% were widowed. Hindus accounted for 94% of the study population, with Muslims making up 2% and Christians making up 4%. 74% had nuclear families while the remaining 26% had joint families. The majority (64%) lived in rural areas while the other 36% lived in urban areas.

### *Survey Symptom Responses*

Subjects on average rated their general health over their lifespan as 9.3 out of a 10-point scale. Immediately before treatment (while they were suffering from TB), they rated their health as 4.16, a 5.14 drop in average. After finishing treatment, their self health rating jumped to 8.34, on average an increase of 4.18. When asked about symptoms that made them seek treatment, 52% reported fever, 80% reported cough, 14% reported weight loss, 36% reported blood in sputum, and 10% reported other symptoms such as headache, body ache, and tiredness.

### *Survey Pre-diagnosis Responses*

When asked if they had ever heard of TB before, 40% responded with yes. When asked about DOTS, only 10% have heard about it before. Only 16% of the subjects suspected that they had TB when they went to the hospital. 28% of subjects sought treatment at a private hospital before going to a public health center. Factors that convinced subjects to seek treatment were: feeling bad (90%), spouse requested (6%), friend requested (2%), and others (8%) such as accidental diagnosis or referrals.

### *Survey Diagnosis Responses*

92% of subjects were first diagnosed at a public location. Of those subjects, 22.4% were at a public health center, 36.7% were at a general hospital, 32.7% were at JIPMER, and 8% were at other public centers such as medical school hospitals. For the private hospital subjects, they paid on average 9962.5 rupees before being referred to a public hospital. Healthcare workers informed the patient that the tests were being conducted for TB 92% of the time. In 63.3% of cases, sputum tests were conducted first, 6.1% of cases x-rays were conducted first, and 30.6% of the time both were conducted together during the same visit. On average, the distance to the diagnosis center was 10.4 kilometers, with public transportation/bus (54%), motorcycle (24%), walking (8%), and other (8%) being the most popular forms of transportation. Overall the average wait time was 39.7 hours, but that average was heavily skewed by the number of subjects that were admitted as inpatients for a couple of days before diagnosis. Without counting any patient that spent over 10



hours in the diagnostic center, the average was 1.4 hours. Of those that spent over 10 hours in the diagnostic center, the average is 120.9 hours but again this number was skewed by a patient that spent a month as an inpatient. The average travel expenses to the diagnostic center was 112.8 rupees. 30% of subjects had previously visited another public healthcare facility before finally getting diagnosed with TB.

### *Survey Treatment Responses*

82% of subjects were referred to a different DOTS unit than the one that they were diagnosed at. At those DOTS units, 46% of subjects reported being told that they were being put on a DOTS treatment. 18.4% of subjects reported feeling uncomfortable discussing issues with their healthcare provider, with reasons such as lack of privacy, feeling de-humanized, and/or healthcare workers being demeaning towards subjects. 52% of patients reported difficulty consuming the medication, with the most frequent complaint being the size of the tablets. Subjects reported that 94% of DOTS providers checked compliance when dispensing drugs. Only 44% of subjects admitted to missing a dose, with a reported average of 2.7 missed doses. 66% of subjects reported side effects while on medication, with giddiness and vomiting as the top side effects. 51% of subjects reported being provided information on DOTS, and 94% of subjects reported receiving information about the drugs. For each visit to the TB unit, subjects spent an average of 15 minutes and the average distance was 1.26 km, 8.74 km closer on average.

## DISCUSSION

When split by gender, females had heard about TB (50% vs 35.3%) and DOTS (25% vs 2.9%) than men. This can be attributed to women tending to stay home while the men worked during the day, and watching more TV where ads about TB/DOTS are run. Men were more likely to report missing a dose (52.9% vs 25%), while women were more likely to report side effects (81.3% vs 58.8%). Men likely reported more missed doses because they more missed doses due to work, while reporting less side effects to not appear weak.

When separated by age, those above 50 had an average of 3.1 years of schooling while those below 50 had an average of 7.9 years of schooling. This is likely a product of society moving towards more education as a whole. However, those over 50 had an average family income higher than those under 50 (7208.7 vs 5076.9 rupees, respectively). This could be due to many factors, such as subjects over 50 counting their children's income.

Subjects that had any years of schooling on average earned more, were more likely to seek private treatment, and more likely to have heard of TB or DOTS. This is naturally explained by higher education status leading to a more informed population, with regards to both hearing of the disease and of treatment options for it. However, they had similar rates of reported missed doses, provided DOTS info by healthcare worker, and suspected TB at the same rate.

Subjects that had a family income of over 6,000 rupees were much more likely to seek private treatment (36% vs 17.4%) than those below 6,000 rupees.

This is due to poorer families not being able to afford the more expensive, but quicker, private facilities.

Subjects on the whole greatly valued and appreciated the services provided under RNTCP. Even though there were difficulties/improvements that could be made to the program, it is the opinion of the author that the subjects were so happy to have such a service available to them free of cost to alleviate them of a heavily burdening disease.

While not entirely under the control of RNTCP, the stigma of having TB was reported by several subjects. For example, a subject had a terrible healthcare facility experience where the nurse told the entire waiting room that the subject had TB, which greatly shamed the subject. When the author went to a couple of houses, subjects also quickly ushered the author into their homes so that the subject could be discussed privately, another symptom of fearing stigma from neighbors.

66% of subjects reported side effects with the drugs, which was the most common complaint, followed by difficulty in swallowing large pills. The size and side effects of these drugs could be reduced, but will obviously come with an increased cost of drug production.

Additionally, some subject reported that getting drugs would force them to miss work, a common complaint from subjects that worked as daily laborers. When faced with such a low income to begin with, a subject remarked that it came down to feeding his family or getting the drugs.

Lastly, subjects also reported feeling de-humanized by healthcare workers. The nurses or doctors would stand abnormally far away, wear masks, and attempt minimal interactions with the subjects. While some of these are standard infectious disease containment procedure, it made the subjects feel like they were being treated as less than human.

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# Appendix

## Patient Survey (in English)

### Patient Survey

A. Background																			
1.	Gender: 1. Male 2. Female																		
2.	Age: _____ years																		
3.	Education:																		
4.	Occupation: 1. Unskilled 2. Skilled 3. Semiprofessional 4. Professional 5. Others																		
5.	Income:																		
6.	Locality:																		
B. Symptoms																			
7.	How would you describe your general health over your lifespan? 1    2    3    4    5    6    7    8    9    10																		
8.	How would you describe your general health immediately before treatment? _____ 1    2    3    4    5    6    7    8    9    10																		
9.	How would you describe your general health immediately after treatment (IP)? _____ 1    2    3    4    5    6    7    8    9    10																		
10.	Do you like to choose over various options available for treatment of TB or you want the doctor to decide before getting treated? 1. I would like to 2. Let doctor decide 3. Other, Specify																		
11.	What were your symptoms that made you seek healthcare? 1. Fever (>2 weeks) 2. Cough (2 weeks) 3. Weight loss 4. Blood in sputum 5. Others, specify																		
12.	Were you asked about <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th></th> <th>Persistent cough</th> <th>Persistent fever</th> <th>Weight loss</th> <th>Blood in sputum</th> <th>Others, specify_____</th> </tr> </thead> <tbody> <tr> <td>Yes</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>No</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>		Persistent cough	Persistent fever	Weight loss	Blood in sputum	Others, specify_____	Yes						No					
	Persistent cough	Persistent fever	Weight loss	Blood in sputum	Others, specify_____														
Yes																			
No																			
C. Pre-Diagnosis																			
13.	Have you heard of the disease Tuberculosis (TB) before getting diagnosed? 1. Yes 2. No If yes, specify																		
14.	Have you heard of the DOTS treatment regimen before getting diagnosed? 1. Yes 2. No If yes, specify																		
15.	Did you ever suspect that you were suffering from TB before getting diagnosed? 1. Yes 2. No If yes, specify																		
16.	What are the factors that convinced you to seek medical attention? Friend told me 2. Spouse asked me 3. I wasn't feeling good 4. Others, specify_____																		

**Patient Survey**

17.	Did you ever seek any private clinic or medical college or hospital or any dispensary for your illness related to TB before coming under RNTCP? 1. Yes 2. No If Yes, Why? What was the reason for referring you to RNTCP?
<b>D. Diagnosis</b>	
18.	Have you been visiting many health care facility before reaching the place where you have been diagnosed? 1. Yes 2. No. If No, Jump to Q.23
19.	How many visits to the HCF (for symptoms of TB) before being tested for sputum AFB?
20.	How many visits to the HCF (for symptoms of TB) before being started on ATT?
21.	If Yes, How many health care facility did you visit before reaching the place where you have been diagnosed?
22.	Did you ever feel any sort of discomfort for being referred to many health care facility? 1. Yes 2. No If Yes, rate it  1      2      3      4      5      6      7      8      9      10
23.	How much time did you take to any seek medical attention from the day of onset of symptoms?
24.	How much time did the health care system take to diagnose TB from the day of onset of symptoms?
25.	In which health care facility have you been told that you are suffering from TB? 1. Public 2. Private If public, how much did you spend (in Rs.) for the investigations in private health care facility? If private, how much did you spend (in Rs.) for the investigations? If private, what are all the investigations done for TB?
26.	Which investigation was done 1 <sup>st</sup> in the HCF for diagnosing TB? 1. Sputum for AFB 2. CXR 3. Both
27.	Were you been explained that the diagnostic test being done is for TB? 1. Yes 2. No If no, Do you wish to know that you were being investigated for TB?
28.	Did you have any issues with timing, privacy & technique of sputum collection? If so, how could they be addressed?
29.	How far (in km) and which is the place where you have been diagnosed that you have been suffering from TB? 1. DMC, 2. PHC, 3. CHC, 4. GH, 5. District hospital, 6. Others, Specify
30.	How did you come to this diagnostic center? 1. Walk 2. Motorcycle 3. Bicycle 5. Public transport 6. Hired a taxi 7. Others, specify
31.	How much does a one-time two-way transportation cost (in Rs.) for travel to this diagnostic center?
32.	With respect to the diagnostic center, how satisfied were you with [1-10 scale] Waiting time Waiting area Patient-healthcare provider interaction Time spend with healthcare provider Privacy Support Staff Condition of medical equipment Cleanliness of hospital
33.	How much time did you spend in total at the diagnostic center?

**Patient Survey**

34.	How long did you wait at the diagnostic center?
35.	What could be done to improve on the diagnostic process?
<b>E. Treatment</b>	
36.	Was there a delay between diagnosis and treatment?
37.	Did the healthcare provider tell you that you were putting you on DOTS regimen? 1. Yes 2. No
38.	Would you like the treatment options for TB to be discussed? 1. Yes 2. No
39.	Did you see the same healthcare provider during follow up? 1. Yes 2. No
40.	Did you feel comfortable discussing any potential issues with your healthcare provider? 1. Yes 2. No
41.	Where have you taken treatment for TB? 1. Public 2. Private 3. Both
42.	How far was the DOTS provider from your home?
43.	Have you ever had difficulties going to the DOTS center?
44.	On average, how much total time did you spend at the DOTS center?
45.	On average, how long was the wait before taking your medication?
46.	Did you have to pay anything for your medication?
47.	Did you have any difficulties obtaining the medication? If yes, what could be done to make obtaining medication easier?
48.	Did you have any difficulties consuming the medication? If yes, how could the medication be changed to make consumption easier?
49.	Did you have any side effects while taking the medication? If yes, what side effects?
50.	Have you ever missed a dose? If yes, how many? If yes, did a DOTS provider check on you each time?
51.	Did they call or visit you?
52.	Would you prefer a call or visit?
53.	Did you know that you were under a DOTS treatment regimen?
54.	Were you provided information on DOTS?
55.	If given the option, would you have preferred a private treatment regimen? [might have to explain that private treatment regimens rely on self-compliance to medication, but it offers convenience of not having to visit a DOTS center every other day]
56.	Were you provided information on the drugs?
57.	Did you find going to DOTS every other day to be a burden?

**Patient Survey**

58.	Did DOTS fit well into your schedule?
59.	Did you feel that there was a stigma against you? If yes, what did you encounter?
60.	What could be improved about the treatment process?
61.	Would you recommend this health care facility to others?