

Barriers and Facilitators for TB Control in Urban India and Recommendations for an Effective ACSM Strategy – A Review

by
Population Services International/India (PSI)
on behalf of
Improving Healthy Behaviors Program (IHBP)
and
United States Agency for International Development
(USAID)

February 2013



This publication is made possible by the generous support of the American people through the U.S. Agency for International Development (USAID) under the terms of Contract No. AID-386-TO-11-00001. The content is the sole responsibility of IHBP, managed by FHI 360, a North Carolina, U.S.-based global nonprofit organization, and does not necessarily reflect the views of USAID or the United States Government.

Editorial team:

Dr Nayanjeet Chaudhury, Research Director, PSI (nayanjeet@psi.org.in)

Shri Kaliprosad Roy, National Research Manager, PSI (kaliprosad@psi.org.in)

Dr Puspita Dutta, Assistant Research Manager, PSI (puspita@psi.org.in)

Dr Lakshmi Kota, Research Consultant, PSI (lakshmi@psi.org.in)

Dr Santosh Kumar Kaza, Research Assistant, PSI (sanotosh@psi.org.in)

Disclaimer

The comments and discussions presented in this review are those of the editorial team and do not necessarily reflect the opinion of PSI, IHBP, or USAID.

Acknowledgement

Population Services International (PSI) sincerely thanks the Improving Healthy Behaviors Program (IHBP) as well as the United States Agency for International Development (USAID) for the opportunity to conduct this desk review. The review aims to improve understanding of the tuberculosis (TB) scenario in urban India and highlight evidence-based recommendations for an effective advocacy, communication, and social mobilization (ACSM) strategy for urban TB control.

The authors would especially like to thank the IHBP team — Rita Leavell, Sumit Asthana, Subrato Mondal, Lopamudra Paul, Pushpraj Dalal, and Amit Paliwal. It would not have been possible to bring the report to its current form without their valuable suggestions and comments. We also express our gratitude to PSI's senior leadership, particularly Sanjeev Dham, Senior Program Director, for his much cherished guidance and support.

Our special gratitude is due to Dr Venkat Raman from the Faculty of Management Studies, University of Delhi, for his valuable inputs on the situation of TB care in India.

Last but not the least, we thank each member of the editorial team for their hard work in bringing out this report.



IHBP is part of the Health Partnership Program Agreement (HPPA) between USAID and the Government of India. The project collaborates closely with the Ministry of Health and Family Welfare (MOHFW), the Ministry of Women and Child Development (MWCD), and their agencies and counterparts at state and district levels. IHBP focuses on behavior change in four program areas: family planning/reproductive health, TB, HIV/AIDS, and maternal and child health.



Population Services International (PSI) delivers reproductive and other health products, services, and information to enable low-income, vulnerable people to change their behaviors and lead healthier lives. PSI-India, a registered society, began operations in India in 1988. It focuses on improving consumer access to health products, services, and information in 22 states and union territories. PSI programs comprise a full menu of targeted marketing activities in reproductive and child health and prevention of HIV/AIDS, TB, and malaria.

TABLE OF CONTENTS

ABBREVIATIONS	4
EXECUTIVE SUMMARY.....	6
1. INTRODUCTION AND OBJECTIVES.....	8
2. METHODOLOGY.....	10
3. BARRIERS TO TB DIAGNOSIS AND TREATMENT.....	11
3.1 BARRIERS TO EARLY DIAGNOSIS OF TB	11
3.1.1 AWARENESS AND CORRECT KNOWLEDGE ABOUT TB SYMPTOMS AND CAUSES - PERSPECTIVE OF GENERAL POPULATION AND PATIENTS	11
3.1.2 BARRIERS TO EARLY DIAGNOSIS OF TB - PROVIDERS' PERSPECTIVE.....	14
3.2 BARRIERS TO TREATMENT AND COMPLIANCE TO TB TREATMENT	16
3.2.1 DEMAND-SIDE DELAY IN SEEKING CARE – PATIENTS' PERSPECTIVE	16
3.2.2 SUPPLY-SIDE DELAY IN DIAGNOSIS AND TREATMENT INITIATION – PROVIDERS' PERSPECTIVE.....	18
3.2.3 DISCONTINUATION OF TREATMENT – PATIENTS' PERSPECTIVE	20
3.2.4 DISCONTINUATION OF TREATMENT – PROVIDERS' PERSPECTIVE.....	21
4. PREVENTION AND CONTROL OF TB IN URBAN INDIA: POSSIBILITIES	22
5. BUILDING EVIDENCE FROM TRIED AND TESTED INTERVENTIONS IN INDIA AND ABROAD.....	26
6. POTENTIAL STRATEGIES FOR URBAN ACSM.....	33
REFERENCES	37

Abbreviations

ACSM	advocacy, communication, and social mobilization
AYUSH	Ayurveda, Yoga, Unani, Sidda, and Homeopathy
BCC	behavior change communication
CME	continuing medical education
CTD	Central TB Division
DCGI	Drug Controller General of India
DMC	Designated Microscopy Centre
DOTS	directly observed treatment, short-course
DR-TB	drug resistant tuberculosis
GDF	Global Drug Facility
GFATM	The Global Fund to Fight AIDS, Tuberculosis and Malaria
GPS	global positioning system
HBC	high-burden country
ICRC	International Committee of Red Cross
IEC	information, education, and communication
IHBP	Improving Healthy Behaviors Program
IPC	interpersonal communication
KAP	knowledge, attitudes, and practices
LSHG	local self-help group
MDR-TB	multidrug resistant tuberculosis
NGO	nongovernmental organization
NRHM	National Rural Health Mission
NTP	National Tuberculosis Programme

pHCP	private health care provider
PDA	personal digital assistant
PP	private practitioner
PPM	public-private mix
PSI	Population Services International
REACH	Resource Group for Education and Advocacy for Community Health
RMC	RNTCP medical consultants
RNTCP	Revised National Tuberculosis Control Programme
SMS	short message service
TB	tuberculosis
UHIN	Uganda Health Information Network
USAID	United States Agency for International Development
WHO	World Health Organization

Executive Summary

Globally, the burden of TB is estimated to be the highest in India. Of the estimated global annual incidence of 8.8 million TB cases in 2010, nearly 2.2 million cases were reported from India (Kapoor et al., 2012). After the failure of the National Tuberculosis Programme (NTP), the Government of India launched the Revised National Tuberculosis Control Programme (RNTCP) in 1997. The RNTCP was based on the global directly observed treatment, short-course (DOTS). By 2006, the whole (100 percent) Indian population was covered by the DOTS program. However, while huge improvements have been made in cure rates, India is yet to reach its goal of achieving 70 percent case detection and 85 percent cure rate.

The current study reviewed the barriers the Indian government faces in reaching its goal. The barriers were looked at both from patients' perspective as well as providers' perspective. One key reason for the high prevalence of TB is that patients delay in seeking care from a qualified provider. This trend is largely due to poor awareness about TB and its symptoms among patients. Stigma is the other important reason, particularly among married women who are afraid of being abandoned by the spouse and in-laws. From the providers' perspective, mismanagement in case diagnosis is the main factor fuelling this epidemic in India. Underutilization of sputum microscopy, overreliance on chest radiography, and use of suboptimal diagnostics, such as serological tests, are among the main factors resulting in disease mismanagement. With regards to treatment, lack of a uniform treatment regimen followed by private providers and lack of patient-centered approaches that enhance accessibility and acceptability of DOTS are causing hindrance.

This report systematically presents the findings of the literature review under two headings: 1) barriers to early diagnosis of TB and 2) issues related to TB treatment and compliance. The barriers to early diagnosis of TB are further divided into two sections: 1) patient and general population's perspective and 2) providers' perspective. Similarly, issues related to TB treatment and compliance are also discussed from patients' as well as providers' perspectives. Evidence was also sought in the literature about new interventions to improve the current situation.

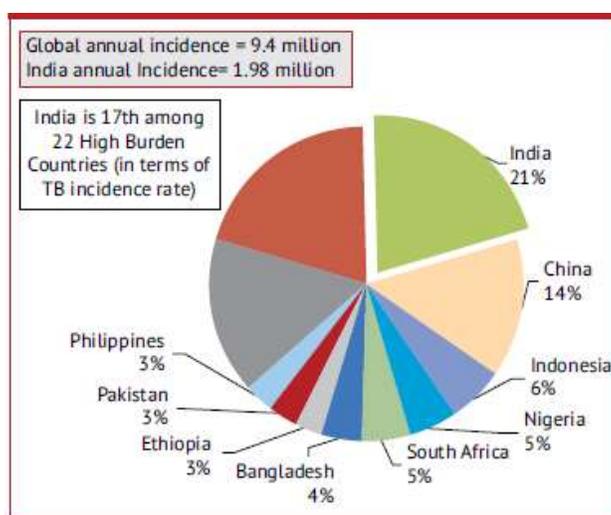
Towards the end of the report, the reviewers make the following recommendations for policy advocacy and pilot experiments:

- A. A comprehensive ACSM strategy, including multiple channels of communication, to raise awareness levels in the general population and use of mid-media and interpersonal communication (IPC) to increase institutional referral for early diagnosis and treatment of suspected TB cases
- B. Use of technology to improve referral linkages, tracking of patients for follow up, and prevention of treatment lapses and drug resistance
- C. Appropriate engagement of private practitioners (PPs) through an effective public-private partnership approach

1. Introduction and Objectives

In 2010, globally there were 8.8 million (range, 8.5–9.2 million) incident cases of TB, 1.1 million (range, 0.9–1.2 million) deaths from TB among HIV-negative people, and 0.35 million (range, 0.32–0.39 million) deaths from HIV-associated TB. India emerged as the country with the highest TB burden, accounting for one fifth (21 percent) of the global incidence. The global annual incidence estimate stood at 9.4 million cases, of which 2 million cases were estimated to come from India. India ranked 17 among 22 high-burden countries (HBCs) in terms of TB incidence rate. (Source: WHO global TB report, 2010).

Figure 1: TB incidence by country



Source: WHO Global TB report, 2010

The Government of India's 12th five-year plan envisions a 'TB-free' India, with reduction in the burden of disease until it is no longer a major public health problem. To achieve this vision, the Revised National Tuberculosis Control Programme (RNTCP) has adopted 'universal access' as its new objective to ensure quality diagnosis and treatment of all TB patients in the country. The program plans to achieve this by deploying rapid diagnostics for TB and drug resistant TB (DR-TB), expand services for management of multidrug resistant tuberculosis (MDR-TB), strengthen urban TB control, bolster public-private mix (PPM) initiatives, improve the quality of basic directly observed treatment, short-course (DOTS), and align the initiatives with the National Rural Health Mission (NRHM) supervisory structure.

Objectives

The main objectives of the current situational analysis are to:

- Identify key issues related to TB control scenario in India
- Review existing interventions for TB control in India and globally
- Outline probable urban advocacy, communication, and social mobilization (ACSM) strategies for TB

2. Methodology

There is paucity of in-depth studies in urban India, despite the high risk TB poses for urban areas (1). We initially attempted to find literature related to urban intervention(s) but non-availability of literature required us to include almost all TB-related studies, irrespective of rural or urban interventions. There is an apparent need for empirical studies on TB in urban India.

Our literature search in different databases was conducted using the following keywords in context of TB:

“TB detection”, “TB treatment”, “barriers in TB treatment”, “delay in treatment”, “treatment completion”, “behavioral aspects related to TB and TB treatment”, “urban areas”, “application of advocacy”, “communication, social mobilization”, “ACSM”, “BCC”, “intervention”, “incentives”

The following databases were used for the literature search:

PubMed; ProQuest (peer-reviewed, scholarly journals; English); Academic Search Premier (scholarly, peer-reviewed journals; English); Web of Science; Google Scholar; Websites (grey literature) - WHO Publications; StopTB; MCHIP; PATH; and The Global Fund

Inclusion criteria:

1. Studies that identified issues related to early diagnosis of TB, treatment, and compliance to treatment
2. Studies that proposed or identified interventions for effective control of TB
3. Studies that suggested strategies for ACSM, relevant to TB control in India

We found 78 studies in our preliminary search. The inclusion criteria were applied to all the studies found in the preliminary search. A total of 65 studies and reports were found eligible for the final analysis; this included pieces of grey literature.

3. Barriers to TB Diagnosis and Treatment

3.1 Barriers to Early Diagnosis of TB

3.1.1 Awareness and correct knowledge about TB symptoms and causes - Perspective of general population and patients

A major reason for high TB prevalence in India is that patients delay in seeking care and treatment when they first encounter symptoms. The various reasons for this trend include the following:

- ✓ People's ignorance about TB being a common disease is a major hindrance; most people do not consider themselves prone to TB and thus delay seeking treatment (2, 3, 4, 5). Illiteracy, poverty, and lack of time due to work pressure seem to compound the problem. (6, 7)•
- ✓ There is confusion about the symptoms of the disease, where persistent cough followed by fever is seen as 'a symptom of flu' and coughing up blood as a symptom of TB.
- ✓ Rampant misconceptions and misinformation exist regarding the spread of the disease. For example, the belief that TB spreads through handshaking, sharing food, sharing dishes, and clothing of an infected person; only those living in a congested locality and in unhygienic conditions are prone to TB (8, 9); and that the disease is hereditary or spreads in ways similar to AIDS (such as, through unsafe sex practices).
- ✓ Insufficient perceived severity of symptoms hinders timely diagnosis; few patients regard cough alone as a serious symptom warranting medical attention. Some mistake it for routine illness and tend to seek clinical advice from informal providers first. (10)
- ✓ Many at first take general flu medicines at home or try out herbal and traditional medication for flu; they go to a general practitioner only when they do not get relief from cough and fever.

• The median delay in seeking treatment was 20 days in a study conducted among 531 participants from South India in 2002. (Rajeswari et al.; 2002)

- ✓ Myths about TB among women also abound; many believe TB is caused by mental tension and several precautions are necessary to control the disease.
- ✓ Although people know TB is a curable disease, they still find it difficult to believe so. A common misconception is that TB is incurable and the drugs used for treating TB can harm the patient (even cause impotency and sterility).
- ✓ Women delay treatment for several socioeconomic reasons, including ill health of another family member, perceived high cost of hospital admission, and lack of support from the husband's family. (11)
- ✓ Social stigma attached to TB is one of the most important factors.

Stigma related to TB

- ✓ Persons having TB often experience rejection and social isolation. TB patients are often economic and social outcasts, with poor emotional support and quality of life, low self-esteem, and clinical depression, which may even lead to suicide. Lack of knowledge about the disease and fear of being ostracized often makes people with TB hide their symptoms, thereby failing to receive appropriate treatment.
- ✓ Men affected by TB are forced to quit their jobs or have a reduced capacity to work. Their long leaves/absence from work results in debt and financial burden. (12)
- ✓ Gender differentials also exist in reporting and diagnosing TB, and passive case finding likely leads to failure to diagnose TB in women. The socioeconomic consequences of TB in women are exacerbated by later presentation, which leads to poor prognosis. A WHO report says: *“The fear and stigma associated with TB have a greater impact on women than on men, often leaving them in a more precarious social and economic position. Tuberculosis in women creates orphans, impoverished families and reduces the economic development of society.”* (13) •
- ✓ Research has established that social stigma hampers the genuine efforts made by private and public medical systems to treat TB among women. (13, 14)

• A study by Medindia at the TB ward of the Kasturba Gandhi Government Hospital for Women in Chennai, South India, found that of the 10 women currently at the TB ward, eight were abandoned by their husbands as soon as they were diagnosed with TB and had not seen their children in years.

- ✓ The infectious nature of TB and the social stigma attached to it drive away women, particularly married women, from seeking treatment in the earlier stages when it is easier to cure the disease. They seek help in an advanced stage, where it takes longer and requires more intensive medical treatment to cure TB. Male patients with TB expect their wives to care for them but infected wives rarely receive care. Thus, married women may try to hide their symptoms instead of seeking help. (11, 15)
- ✓ DOTS is successful in curing male TB patients because the womenfolk ensure that their men take medicines regularly and get cured. Similar monitoring for female patients is absent, particularly in rural areas with lower education and awareness about TB. Husbands abandon their wives fearing infection, both during the course of her treatment and even after she is fully cured. While married women avoid treatment because of the fear of being ill treated, abandoned, or divorced by their husbands, single women avoid treatment for fear of remaining unmarried and rejected.
- ✓ TB affects women in their reproductive years, with the greatest burden of TB among those 15–49 years old. For women of reproductive age in developing countries, TB is the third highest cause of morbidity and mortality and leads to more deaths in women than maternal mortality. In high-prevalence countries, women of reproductive age have higher rates of progression to disease than men in the same age group (15). As TB affects the most productive age group, its impact is felt by children and families.
- ✓ In India as elsewhere, prevalence of TB is higher among men than women. One probable reason for this gender gap could be the higher underreporting by women due to social issues and stigma, given that the DOTS treatment requires the patient to visit the DOTS center on alternate days to take the supervised treatment. Unmarried girls and women want the diagnosis of TB to be kept confidential. (16)•

• In a study, 55 percent of the cases wanted the diagnosis of TB to be kept confidential to avoid being labeled as TB patients. A total of 85.6 percent female TB patients had relationship problems with their spouse and family members after they were diagnosed with TB. There was also a lack of health-seeking behavior among women. (Sharma et al., 2010)

Summary: Barriers to seeking treatment for TB - Patients' perspective

1. Ignorance and confusion about TB symptoms, causes, and consequences
2. Misconceptions about the spread of the disease
3. Most people do not consider themselves prone to TB, which indicates people's low risk perception
4. Initially treat at home for flu symptoms
5. Fear of social exclusion and stigma makes people, especially women, hide the disease and not seek treatment
6. Married women hide their symptoms due to fear of abandonment by spouse and in-laws

3.1.2 Barriers to early diagnosis of TB - Providers' perspective

- ✓ Over 80 percent of the TB patients in India, including those living in slums, seek treatment from PPs. (1) Their over-reliance on chest X-rays for TB diagnosis and neglect of sputum examination is one of the key factors for the delay in early diagnosis (2, 3, 5, 17, 18, 19, 20, 21, 22). This trend also reflects the poor availability of quality-assured sputum microscopy services in private laboratories.
- ✓ Absence of uniform protocol to be followed by providers for diagnosis and not prescribing the treatment regimen recommended by RNTCP hinder diagnosis and treatment. (19, 23)•
- ✓ Over-treatment of TB patients by a majority of PPs is contributing to MDR-TB. (19, 23)
- ✓ Abuse of suboptimal diagnostic tests such as serological (antibody-detection) tests for active TB is another major problem. Despite evidence and the lack of any supportive policies, about 1.5 million TB serological tests are estimated to be done in India every year at the conservatively estimated expenditure of US \$15 million per year. (21)

• In a random survey of knowledge, attitudes, and practices (KAP) for TB among 204 PPs in Delhi in 1998, 187 PPs were using 102 different regimens, and only 29.4 percent were using the regimen recommended by RNTCP. The same study found that 51.3 percent of the 187 PPs were over-treating patients. (Singla et al., 1998)

- ✓ Low motivation levels of providers (especially PPs) for referring patients to the TB or DOTS center cause delay in treatment.≠
- ✓ There is lack of a well-networked referral system. (10)
- ✓ Facilities at the DOTS center are often not up to mark.

Summary: Barriers to early diagnosis of TB - Providers' perspective

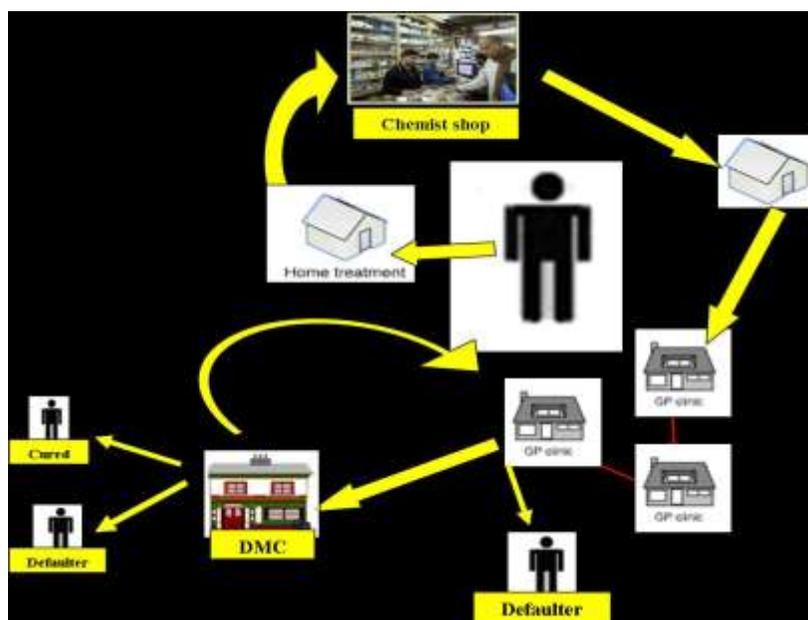
1. Over-reliance on chest X-rays and underutilization of sputum examination by providers, particularly PPs
2. Absence of uniform protocol for diagnosis
3. PPs not following the proper treatment regimen
4. Abuse of sub-optimal diagnostic tests for detecting TB
5. Lack of motivation among PPs for referring patients to DOTS centers

In short, undiagnosed, delayed diagnosed, and mismanaged TB continues unabated in India.

*In a study conducted between May 2004 and January 2005 in Pune, Maharashtra, among 117 new sputum positive patients, it was found that patients had to make multiple contacts with PPs due to the limitations of these providers in diagnosing or directing patients to RNTCP. (Kelkar-Kambete, 2008)

3.2 Barriers to TB Treatment and Compliance

Figure 2: Archetype of a TB patient



3.2.1 Demand-side delay in seeking care – Patients' perspective

- ✓ People have concerns about the efficacy of treatment. (9)
- ✓ There is reduction in the capacity to work as a result of the disease.
- ✓ A common belief is that TB is incurable, and the drugs used for its treatment can harm the patient. Many fear that TB can cause impotency and sterility. (12)
- ✓ The fear of costs to be incurred for the tests and the doctor's fees is a major reason for delay in TB diagnosis, treatment seeking, or sometimes not going for treatment at all. (2)
- ✓ The TB affected may not seek treatment because symptoms are not severe enough. (24)
- ✓ While the DOTS strategy seems to be successful and acceptable, accessibility remains a major concern for many, as very often it takes time and money to get to the DOTS facility. (25)

- ✓ Many patients shop around for care at various health facilities before a correct diagnosis of TB is made. (5) •
- ✓ Many obtain the help of informal providers before seeking treatment at a DOTS facility (10). Recurrence of symptoms after temporary relief drives the patient to seek clinical advice from qualified practitioners.
- ✓ Women fear being deserted by their husband if they report TB symptoms; they delay reporting until it is unbearable. (7, 26)
- ✓ Women lack decision-making power, and the time consumed by an earning member to take the woman to a health facility and the cost incurred in the process of treatment proves a hindrance. (13, 27)
- ✓ Inconveniences related to DOTS include clinic location, timings, and long waiting hours at the centers. (28)
- ✓ For mobile populations, the nature and timing of their work is not suitable for DOTS visits.
- ✓ There is fear of being identified as a TB patient during repeated treatment visits to the DOTS facility.
- ✓ Lack of personal attention and rude behavior of DOTS facility staff may add to the patient's reluctance. (29)•

• A study was conducted in 2008 in selected slums of Bangalore about the health-seeking behavior of 124 persons with pulmonary symptoms. It was found that about 50 percent visited two health facilities before diagnosis, and 87 percent visited two or more facilities before initiating treatment; 42 initiated treatments at government health facilities; and the 5 who initiated treatment at private health facilities were later referred to government health facilities. The majority of persons with pulmonary symptoms had poor knowledge of TB, and most were unaware of the availability of free anti-TB services at government health facilities. (Suganthi et al., 2008)

• Distance from the place of stay (44.5 percent) was cited as the main reason for not visiting a government facility when sick, followed by non-availability of medicines (37.4 percent) and non-availability of health personnel (30.9 percent). In the same study, 60 percent preferred to visit government center for treatment; 44 percent knew that cough for more than two weeks could be due to TB, although 93 percent had heard about TB. Only 15 percent were aware of the existence of a DOTS center. These findings are based on the Impact Assessment of RNTCP – II communication campaign on KAP of the target audience in 12 states of India, conducted by SEDC - Synovate for the Ministry of Health and Family Welfare, Government of India, in 2009.

- ✓ Many are unable to meet the requirement for alternate day attendance at the DOTS center, given the competing priorities and demands of daily life, particularly for those engaged in daily labor and those with children still at school. (30)
- ✓ Loss of earnings for people from low socioeconomic strata is an issue.
- ✓ There are superstitions about the treatment of the disease. (31)≈

Summary: Barriers to treatment and compliance – Patients’ perspective

1. Reluctance to come thrice weekly for drug administration during the intensive phase
2. Superstition about cures for the disease
3. Absence of patient-centric approaches in treatment
4. Discontinuation of treatment as soon as symptoms subside
5. Direct and indirect costs of treatment, such as cost of drugs and loss of earnings during treatment

3.2.2 Supply-side delay in diagnosis and treatment initiation – Providers’ perspective

- ✓ Research suggests that patients who first consult PPs experience a significantly longer health system delay than patients who first consult governmental health services (4, 11, 22) ∇. Rather than screening patients in a systematic manner with the aid of standard guidelines, PPs usually resort to symptom-based treatment, followed by X-ray examination and, infrequently, sputum examination. In addition to the delay in treatment, patients who consulted PPs rather than government health providers also incurred more expenditure.
- ✓ Half of all TB treatment in India occurs in the private sector, and access to standardized, effective short-course regimens is not uniform because of poor treatment practices (17,

≈ In a survey done in slums and resettlement colonies of Delhi, certain superstitions were found to exist regarding the treatment of TB (such as, eating of tortoise meat). Many patients believe that the best treatment is available in the city of Vrindavan (a pilgrimage city situated in North India). There are also myths about the spread of the disease, such as sharing dishes and clothing of an infected person spreads TB. (Sharma et al.,2008)

∇ In four districts of Tamil Nadu prior to the implementation of RNTCP, it was found that the average health system delay in diagnosis was 23 days. Sixty-nine percent of the patients experienced a health system delay of more than a week. The health system delay was significantly longer if patients first consulted a PP (30 days vs. 7 days). (Rajeswari et al., 2002)

20, 30, 32)[∅]. Practitioners of various alternative forms of medicine often prescribe anti-TB drugs without being qualified to do so (1)[•]. This results in prolonged morbidity and increased mortality from the disease. Poor prescribing practices also fuel the emergence and spread of drug-resistant organisms, and are certainly one of the reasons for the MDR-TB burden. (17)

- ✓ There is limited access to treatment regimens for MDR-TB, and continued use of retreatment regimens that are not evidence based.[≈] In spite of RNTCP's DOTS Plus initiative launched in 2006 to deal with MDR-TB patients, less than 1 percent of the estimated number of MDR-TB patients have access to adequate treatment. (17, 23)
- ✓ Lack of patient-centric approaches affects the accessibility and acceptability of the DOTS program. While the DOTS strategy has improved cure rates, many patients still shift from government providers to PPs. Research studies have suggested more patient-centric services, such as confidentiality and consideration of patients' needs, organization of TB services to ensure the patient has treatment as close to home as possible, possible incentives, identification of potential difficulties in advance, accurate address records, and taking action against defaulters. A Cochrane review of 11 randomized controlled trials in 2007 found no significant effect of DOTS vs. self-administration on cure or treatment completion in people receiving TB treatment. (17)

[∅] An article in the *New Yorker* by Spector, published in 2010, and a recent World Report in the *Lancet* paint a serious picture of the diagnostic and treatment ecosystem in the private sector in India, characterized as it is by systematic market failures throughout the value chain. These include dumping useless diagnostics from rich countries into India because of weak regulation, doctors receiving incentives for the tests ordered, over-reliance on useless tests and underuse of good diagnostics, prescription of incorrect treatment regimens, and lack of accountability to ensure that patients complete TB treatment. (Spector, 2010²⁰, p 243)

[•] India has a huge, unwieldy, and poorly regulated private sector with an estimated 10 million registered doctors, with a ratio of 1 doctor per 1,000 population. Around 50 percent of these are qualified and registered non-allopathic doctors practicing alternative systems of medicine, such as Homeopathy, Ayurveda, and Unani. (Pinto and Udwadia, 2010, p2)

[≈] India has the second largest population of MDR-TB in the world. A study conducted in Mumbai in 2009 found MDR-TB prevalence rates to be 24 percent among the newly diagnosed, previously untreated patients, and 41 percent in the first-line drug failures. (Pinto and Udwadia, 2010, p2).

- ✓ Given the rigid DOTS model, program targets can sometimes compete with the needs of patients. One particular study identified the potential dangers of target-driven programs, where support is absent for both frontline workers and patients. (30)[∞]
- ✓ There is existence of a large subgroup of patients who have failed treatment, had relapses, or discontinued therapy. (17)

3.2.3 Discontinuation of treatment – Patients’ perspective

- ✓ Given the low levels of awareness about disease recurrence, there is a tendency to stop treatment once the symptoms disappear. (5, 33)
- ✓ Studies of patients defaulting on treatment in India point to inconvenience of clinic timing resulting in loss of wages, costs of travel to the clinic, lack of provision for continuity of treatment in case a family emergency precludes visit to the clinic, lack of respectful communication between staff and the patient, and inadequate information and poor management of adverse events and toxicity. (5, 17, 28, 30)•
- ✓ Some other factors that contribute to an incomplete treatment regimen are: side-effects of anti-TB drugs, lack of personal attention, and rude behavior by staff (29); inconvenient DOTS services and long waiting hours, alcoholism, and illiteracy (28); and non-relief from symptoms, drug intolerance, migration, and non-willingness to come thrice weekly for drug administration during the intensive phase. For people from low socioeconomic strata, earning was more important than spending time at DOTS center for treatment. This factor becomes even more important if initial treatment alleviates the symptoms. (25)
- ✓ Women find it more difficult to comply with treatment once symptoms subside. (10)

[∞] This study was conducted at two pilot sites in New Delhi from 1996 to 1998. Health workers screened patients to determine their ability to conform to DOTS. The patients who failed in the screening were put on standard TB treatment instead of RNTCP’s short-course treatment. These treatment-denied patients mostly came from the absolute poverty strata and were socially marginalized, itinerant laborers and poorly integrated in the city. Such a patient was recorded as one who refused DOTS. Their TB treatment card was removed from the center and so no record existed of their ‘enrolment’. Hence, the most vulnerable patients were excluded from the best available care. “These workers were working from a programme orientation, rather than a TB-control orientation. Their focus was on the cure rates rather than curing patients.” (Singh et al., 2002, p 700)

• The most important reason given by patients for not accepting treatment under the RNTCP was logistical: they did not feel they could manage to meet the requirement for alternate day attendance at the DOTS center, given the competing priorities and demands of their daily lives. It was perceived as particularly difficult by patients engaged in daily wage labor and those with children still in school. (Singh et al., 2002)

Many of the patients who start receiving therapy, often in secrecy, stop as soon as they start to develop adverse effects, such as orange discoloration of skin (seen with Rifampin, a first-line drug for TB), which may reveal to the community that the individual has TB. Discontinuation of therapy can lead to emergence of MDR-TB and extensively drug-resistant TB, which is difficult to treat and can be fatal. (12)

3.2.4 Discontinuation of treatment – Providers’ perspective

- ✓ Lack of motivation at the provider level and mechanisms for following up with patients for treatment compliance are major causes of treatment discontinuation. (24, 28, 30)
- ✓ A majority of PPs do not maintain appropriate records of TB patient numbers. (34, 35)
- ✓ It is difficult for patients to re-enter the system if they miss treatment. (30)
- ✓ Treatment regimens are not completely standardized, free/subsidized drugs are not being offered, and treatment observation is not undertaken fully. (36)

To summarize the key issues to be addressed for controlling TB in India, we would like to cite the words of Dr Madhukar Pai, internationally renowned TB expert: “poor access to good diagnostic services, poor case detection rates and diagnostic delays, widespread use of inappropriate diagnostics and mismanagement of TB, lack of adequate regulation of TB diagnostics, lack of laboratory quality assurance, inadequate funding for TB control, and barriers to scale-up of new technologies” are the key issues plaguing TB control in India. (36, p 243)

Summary: Barriers to treatment and compliance – Providers’ perspective

1. Absence of a uniform treatment regimen for adherence by PPs
2. Over-treatment of patients, leading to MDR-TB
3. Lack of regulation in prescribing practices; various unqualified practitioners prescribe medication for TB
4. Lack of quality assurance in laboratories

4. Prevention and Control of TB in Urban India: Possibilities

1. Integration of public and private health care systems in controlling TB to provide universal coverage and scale up PPM*

The PPM models in India that emphasize sustained advocacy for DOTS and at the same time allow PPs to retain private patients need to be aggressively pursued and scaled up (11). Enthusiasm in the private sector has not been effectively exploited by RNTCP (37). According to one report published in January 2010, only 19,000 PPs in the entire country are working with the RNTCP, and only 2–3 percent RNTCP case findings and less than 1 percent case management are being reported through PPM projects (17, pg 9). Integration of RNTCP with the private sector is needed not only because a great majority of all TB patients in the country are treated in the private sector (5, 10, 18, 22, 23, 24) but also because audits have found diagnostic and treatment practices in the private sector to be suboptimal and not in compliance with international guidelines for TB care (17, 21). While mismanagement of TB is clearly harmful for patients, it is also a public health issue since every mismanaged TB patient can transmit the infection to others in the community, thus worsening the epidemic. This makes PPM vital for also addressing this issue (36).

The available research has indicated that such models are successful at increasing case detection and cure while maintaining acceptable/good treatment outcomes (38)•. They also prove cost-

* A study was conducted in Bangalore city, India, to assess the cost and cost-effectiveness of PPM for TB care and control when implemented on a large scale. PPM implementation substantially reduced costs to patients, such that the average societal cost per patient successfully treated fell from US\$154 to US\$132 in the four years following the initiation of PPM. The study concluded that PPM implementation on a large scale in an urban setting can be cost-effective and considerably reduce the financial burden of TB for patients. (Pantoja et al., 2009)

In a study conducted between May 2004 and January 2005 in Pune, Maharashtra, among 117 new sputum positive patients, it was found that patients had to resort to multiple contacts with providers due to limitations of these providers in diagnosing or directing patients to RNTCP. Patients who consulted a private provider participating in PPM were more likely to be suspected and referred to RNTCP. Once the patients entered RNTCP, the system's response was rapid, with diagnosis offered and treatment initiated within 7 days on average. (Kelkar-Khambete, 2008)

In a cross-sectional sample survey of private providers in Ujjain district, India, it was found that most providers were aware of RNTCP and were keen to collaborate with it. However, none of them had ever been contacted by RNTCP. (De Costa et al., 2008)

* This study undertook a review of medical literature for PPM projects in India between 1999–2004. Of the 14 selected PPMs, six involved PPs and eight corporates and NGOs. RNTCP provided PPs training on diagnostic and treatment practices. Kannur and Kollam projects provided training and support to private laboratories. Other projects relied on PPs to refer patients for smear microscopy. The major finding of the review was that PPM increased case notification and helped maintain acceptable treatment outcome. (Dewan et al., 2006)

effective for patients since the drugs are provided to them free of charge by the government under RNTCP (39, 40)≈. At the same time, necessary advocacy, training, and supervision can be provided by a strong public sector TB control program. Urban areas tend to have large numbers of PPs, and they need to be targeted for intensified PPM scale up (38, 39).

2. Addressing why patients prefer private health care despite a highly successful DOTS program in India

It appears that RNTCP has had an impact in the community with regard to the availability and accessibility of TB services at government health facilities. However, the relatively high levels of subsequent shifting to private health facilities calls for urgent action to make government facilities more patient-friendly, with quality care and delivery of RNTCP services (24). Care providers can extend support and co-operation to the patient by providing counseling, building good rapport, insisting on treatment regularity, high motivation and empathetic attitude, and timely provision of drugs to ensure treatment regularity (28).

3. Accreditation of laboratories for quality assurance

An overwhelming majority of Indian laboratories have no formal quality accreditation or certification. Lack of quality assurance at laboratories is a major hindrance to improving TB diagnosis in India (17, 21). The country must adopt new tools that are accurate, validated, and WHO-endorsed, and replace suboptimal tests with robust tests that can impact patient outcomes and reduce TB transmission in the community. The Drug Controller General of India (DCGI) must tighten regulation of diagnostics and ensure that suboptimal tests are reviewed and removed from clinical use.

4. Need for greater regulation of TB drugs

Better regulation of the private medical sector by the DCGI is another key improvement needed to halt the current use of misleading serological tests (21). Health care markets in countries like India are complex, involving a wide spectrum of healthcare providers, from the un-qualified practitioners (“quack doctors”) to highly trained specialists, with a wide variation in the quality of medical care, in both public and private sectors (20). Much more research is needed to

≈ A rural TB unit in Chennai, South India, was selected for this study. The objective of the study was to evaluate a rural public-private partnership model (PPPM) within the TB control program (RNTCP). All the 52 PPs who were trained in modern medicine and the 13 private laboratories (PL) in the area were listed. The PPs underwent training on RNTCP, and the PL staff was trained in sputum microscopy. The PPPM included referral of TB suspects to the smear microscopy centers (government or PLs) for diagnosis and treatment of patients as per RNTCP guidelines. Patients were back-referred to the PPs. The DOTS providers and centers were chosen by PPs in consultation with patients. Annual case detection improved from 66 per lakh to 75 per lakh. (Balasubramaniam et al., 2006)

understand provider behavior, variations in practice quality, market dynamics, and incentives that promote mismanagement. A recent analysis of the global private TB drug market estimated that the volume of first-line anti-TB drug sold in India was sufficient to provide a full course of treatment to 117 percent of the estimated incident cases in India (17, pg 9). This scenario underscores the importance of collaborating with the private sector for TB management and the need for greater regulation of TB drugs.

5. A **wider set of surveillance sites** are needed to obtain a more realistic view of the true MDR-TB rates throughout the country. This would assist in planning an adequate response to MDR-TB diagnosis and care. (17, 41)

6. In addition to the focus on early detection and symptomatic and microbiological cure, **psychosocial support** to patients and their families must also be given importance. (13)

7. There is a strong need to **increase the awareness levels** of the wider community on TB and RNTCP services, especially in urban areas (1, 2, 10, 24, 29)•. TB control is possible only if the disease is diagnosed and treated in time, irrespective of the place of diagnosis and treatment. Hence, the current information, education, and communication (IEC) and/or behavior change communication (BCC) strategies need to incorporate messages highlighting the need to visit the DOTS center if they do not get relief from symptoms even though they are visiting health care providers known to them (10).

8. Provision of **incentives to various stakeholders**, including private providers like qualified PPs, chemists, and community health workers, could change their motivation levels. This is vital, as most patients prefer to consult known private doctors first and feel comfortable in seeking treatment from them (5, 24). However, specific selection criteria must be used for PPs' involvement in PPM for the program to be successful: providers who have many TB patients under their care; providers who diagnose and treat patients, provide free drugs (subsidized by the government), and follow up on patients (42).

9. To strengthen the role of the private sector, PATH proposed the following program objectives (43):

• There are gaps in public awareness about DOTS. In a study, even among the cohort of economically productive, educated Indians, only one patient (0.5 percent) could expand the DOTS abbreviation, and five patients (2.5 percent) were vaguely aware of what DOTS entailed. Only 30 of the 200 patients (15 percent) were even aware of the government using a strategy called DOTS in the fight to control TB in India. (Pinto and Udwadia, 2010¹)

- ✓ Increase referral system from private chemists to Designated Microscopy Centers (DMCs)
- ✓ Increase TB case detection and reduce diagnostic delays for appropriate TB treatment
- ✓ Improve access to quality DOTS service for PPs
- ✓ Discourage the sale of TB drugs without prescription
- ✓ Enhance PPs' access to quality diagnostic services free of charge
- ✓ Provide free continued education and association with a reputed government program

5. Building Evidence from Tried and Tested Interventions in India and Abroad

Various interventions have been undertaken in India and other countries to increase the cure rates of TB. Some of them are briefly discussed below:

1. Financial incentives for patients: Although most public services provide TB tests and drugs free of charge, other direct and opportunity costs pose barriers to accessing TB services and treatment, especially for poor rural and marginalized urban patients (such as slum dwellers, migrants, and the homeless). While aggregate costs for the poor tend to be lower than for the non-poor, costs as a proportion of income are much higher for the poor. In many cases, patients resort to borrowing money or selling assets as a result of their illness. Many of the performance-based financial and material incentive schemes targeted at patients are designed to help compensate for these direct and opportunity costs. Financial incentives, including cash, vouchers, lottery tickets, or gifts for patients, are designed to overcome the direct and indirect costs incurred by patients. Studies show improvement in patient compliance with the use of financial incentives (44). Financial incentives for TB control also prove cost-effective because treatment benefits accrue not only to the patient but also to the society by preventing the spread of the disease (45).[~] •

2. Food incentives like free nutrition for patients: Given the well-established link between malnutrition and TB, the World Food Program has advocated offering different nutritional supplements in various settings. Studies have been conducted to assess the impact of food incentives on patients. Both patients and providers view food as a means to offset indirect costs

[~] The Urban Poverty Alleviation Department (UPAD) and the Cochin municipality initiated an incentive program for the urban, poor TB patients in Cochin. Monetary support was provided to them to enable travel and food purchase. In return, patients were expected to attend the clinic for treatment. Results of program evaluation found that case detection increased from 16 during the pilot phase in 1996 to 791 during the first 3 years of the scheme. (Beith et al., 2008)

• In another study on migrants with TB in the U.S., treatment compliance of two groups of TB patients was compared. The first group was provided with a financial incentive, which was a mixture of cash, tokens, and vouchers. An incentive of US\$5–10 value per appointment was given. A further US\$20–40 was offered if the treatment was completed without a missed appointment. Patients in the second group were only reminded of their appointments, without any financial payment. The results indicated that treatment compliance was higher in the first group compared to the control group. (cited in Giuffrida & Torgerson, 1997)

of treatment, improve nutrition, reduce stress, and contribute to a positive patient experience. Cured patients and their families emerge as powerful communicators and promoters of TB treatment seeking (46, 47, 48, 49, 50, 51).

3. Performance incentives for private providers: In India and the Philippines, National Tuberculosis Control Programs (NTPs) provided free anti-TB drugs to PPs on the condition that patients are not charged for the drugs. PPs can only charge consultation fees from patients to add to their (providers') income. This enables the patients, particularly the poor, to refrain from defaulting and completing the treatment program without worrying about the cost of medicines. In addition, the private providers who become known to cure TB patients gain a strong reputation as healers, which can result in increased client demand for all services (52).

The World Health Organization (WHO) researchers reviewed 15 PPM models in TB control, involving NTPs in partnership with private care providers or with not-for-profit umbrella organizations that worked with individual providers. They examined the nature of contractual relationships and the quality of care and results. In nearly all the models studied, private providers received no formal financial payments although they did enter into contracts that enabled the providers to receive public-sector TB drugs for free distribution to patients, enabled them to receive continuing education, associated their work with a "reputed" national program, and, lastly, ensured that they followed national guidelines and reported results to the NTP. Treatment success rates were above 80 percent in 13 of the 15 initiatives and on par or better than overall NTP averages. TB case detection rose by 10–36 percent.

The key conclusions drawn here are: 1) high treatment success rates can be achieved for patients receiving treatment from PPs who follow international standards of TB care, are linked with a national DOTS-based TB program, and provide TB drugs free of charge to patients; 2) engagement of PPs can increase TB case detection rates, one of the measures of performance in TB control; and 3) it is possible to use informal but well-defined "drugs-for-performance contracts" (without direct financial payments) with individual PPs in TB program implementation. These do act as incentives for participation in TB control programs and are associated with good performance and improved patient and public health outcomes (34).

The Resource Group for Education and Advocacy for Community Health (REACH) developed and implemented a PPM program in partnership with the Chennai local health authority and the

Tuberculosis Research Centre, Chennai, India. PPs were sensitized to RNTCP and DOTS through one-on-one or group meetings and were assisted in referring patients. Surveys were carried out at baseline and at the completion of the study to assess changes in attitudes and practices. The PPM model emphasized sustained advocacy for DOTS and allowed PPs to retain private patients (53). In this experiment, 600 PPs underwent sensitization about RNTCP, after which the proportion of PPs adopting DOTS increased significantly, and the majority (72.8 percent) used sputum testing for TB diagnosis. The proportion of PPs who used X-ray alone for diagnosis declined to 16.0 percent, down from a baseline of 45.4 percent.

4. Incentives to community health workers: Provision of incentives to community health workers promotes extension of DOTS services beyond public facilities through outreach, ensures greater patient access, and increases adherence. Performance-based incentives targeting individual public health workers include direct payments, food packages, vouchers, and other material goods such as briefcases, bags, watches, soaps, T-shirts, and hats (54, 55, 56, 57). Evidence from evaluation studies conducted in India, Pakistan, and Nepal shows that involving community health workers in the treatment of TB produced the best results for increasing cure rates. These studies compared cure rates of programs involving different groups, such as a) DOTS with direct observation by health workers at DOTS centers, b) DOTS with direct observation by community health workers, c) DOTS with direct observation by family members, and d) DOTS without direct observation. While research has indicated that community-based approach to DOTS is more effective than government facility-based DOTS, no studies have been found in the literature that evaluated the impact of incentives.

5. Establishing support groups: The Russian Red Cross Society in the Republic of Khakassia, Siberia, has established a social club (called “White Camomile”) for TB patients. Here, patients are provided comprehensive information about the disease and its treatment, and they can share their feelings and support each other. Those who fully recover are invited to share their experience, thereby boosting the current patients’ confidence. The former patients have established a team of volunteers to provide regular psychosocial support to TB patients, who are prone to defaulting on treatment. This support promotes positive attitude toward TB treatment among patients and reduces default (58).

6. Community education: The national health communication strategy approved by the Central TB Division (CTD), Government of India, in 2005 encouraged health-seeking behaviors and treatment adherence through improved patient and community education and by strengthening patient-provider interpersonal communication (59).

7. Improving diagnostics: A small pilot study on sputum collection, transportation of samples, and test reports was conducted in Gangavathi town (Koppal district) in Karnataka from November 2011 to February 2012. The participating private health care providers (pHCPs) collected sputum samples at their clinics. The samples were picked up by a private *courier* the same day and taken to the DMC, which is an accredited government health facility for sputum smear microscopy. Results were collected by the service provider in the afternoon the same day and transported back to the pHCP. Results reached on the same day or the next. The monthly cost of the activity came to INR 3,000 and involved 11 pHCPs (5 active). Sixty-eight sputum sample sets were transported and tested, and 14 chest symptomatic were sputum positive. Patients were happy they did not need to go to a DMC (saving of time, cost, and effort), while providers were happy as they did not risk losing their patients and got quick results (60).

8. Capacity building in TB care: Project Axshya (meaning “TB-free”) was implemented by The Union and World Vision International through their partners and sub-recipients in India. PSI was one of the organizations selected to carry out the intervention on Ayurveda, Yoga, Unani, Sidda, and Homeopathy (AYUSH) providers. A key objective of the project was to engage AYUSH providers to improve TB screening, diagnosis, and care, especially for the marginalized and vulnerable populations. As part of the program, 1,050 such providers in six states (Punjab, Haryana, Rajasthan, Maharashtra, Karnataka, and Bihar) were trained in screening suspected TB cases and referring them to DMCs. Results of the study were evaluated, and it was found that overall only 35 percent of the AYUSH providers recommended their patients to undergo a sputum test, and 45 percent suggested their patients to come back to them with test results (61).

9. Use of technology: Technology has been used to monitor compliance to treatment and to educate the community. Three examples on the use of technology in public health are presented below:

i. SIMpill in South Africa

SIMpill, an ordinary pill bottle with an attached device that includes a SIM card and a transmitter, was used to monitor and improve compliance to treatment among TB patients in South Africa. Two pilot studies among patients using SIMpill were conducted in Northern Cape Province in 2005 and another in Khayelitsha, Western Cape Province, in 2007. The results indicated that use of the pill bottle significantly increased compliance/treatment adherence rates. (62)*

ii. PDAs used by Uganda Health Information Network

The Uganda Health Information Network (UHIN) used personal digital assistants (PDAs) to collect relevant information, such as drug usage and drug stocks, from community centers and convey it to the district health offices, who then took the necessary remedial action. PDAs were also used to regularly communicate health information to health professionals like doctors, senior nurses, and senior clinical officers. The evidence gathered by independent consultants in 2004–2005 indicated 24 percent savings per unit of spending over the traditional manual data collection and transmission approaches. (63)

iii. Educational SMS by PSI

PSI and the National Tuberculosis Center, Lao People's Democratic Republic, in conjunction with a local mobile phone company, devised a successful program to target remote and vulnerable populations. These high-risk groups were sent educational short message service (SMS) messages carrying details of the locally available, PSI-supported, trained and equipped network of social franchise clinics (Sun Quality Health) in their respective areas. The clinics offered services like family planning and childhood illness management. Since the launch of the Sun Quality Health network at the end of 2010, PSI Laos has enrolled over 40 private clinics. (64)

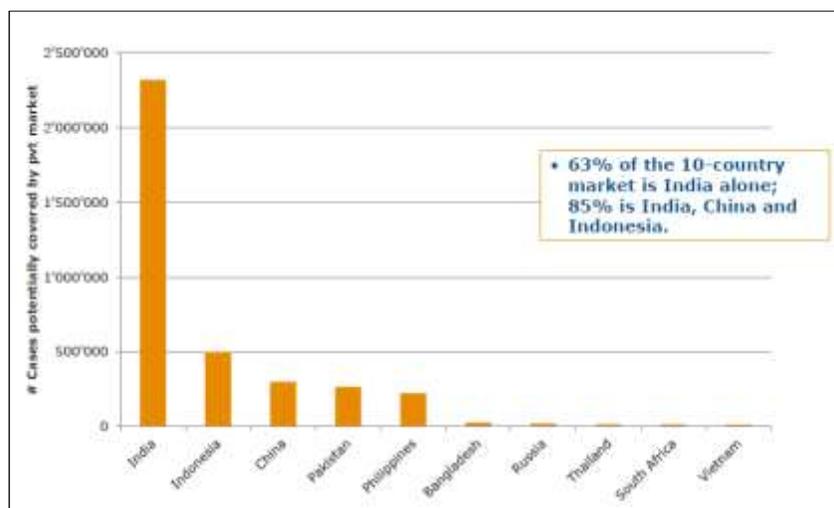
Some Key Questions:

* SIMpill is an ordinary pill bottle with an attached device that includes a SIM card and a transmitter. Each time the bottle is opened, it sends an SMS message to a central SIMpill server, which records the date and time of the event. When this does not occur at the prescribed time (or within a set tolerance period), the SIMpill computer sends a treatment reminder message to the patient, family member, and/or caregiver. If the patient still does not take his/her medication after the reminder, then the clinic or the DOTS health worker is alerted so they can telephone or visit the patient personally.

1. Can we apply total market approach to RNTCP?

According to a study conducted to estimate the size and usage patterns of private TB drugs markets in high-burden countries (HBCs), India shares 63 percent of the private market for anti-TB drugs and 35 percent of the total TB disease burden of HBCs[~]. Diversity of drug strengths for loose drugs and fixed dose combinations is reported to be the highest in India. (65)

Figure 3: Number of TB cases covered by private markets



(Source: Wells et al., 2011)

The average drug price is higher in private markets of HBCs than the price prescribed by the Global Drug Facility (GDF)[€]. The coverage of first-line private sector drugs to treat all incident TB cases in India was 117 percent but only 1.5 percent of the incident cases were covered by PPM. The first-line drug market is fragmented in all countries, and only three of the top 12 first-line drug manufacturers sell products in more than one country. The anti-TB drug market in India is huge, and the private sector thrives on it. Therefore, the Government of India needs to consider negotiating with both the private sector providers as well as the pharmaceutical industry to arrive at a mutually beneficial strategy for supply of essential TB medicines at a cost

[~] HBCs with data on private market share is available for India (1); China (2); Indonesia (3); South Africa (5); Bangladesh (6); Pakistan (8); the Philippines (9); Russia (11); Vietnam (12) and Thailand (18).

[€] The GDF provides a unique package of services, including technical assistance in TB drug management and monitoring of TB drug use, as well as procurement of high-quality TB drugs at low cost. For more information, visit <http://www.stoptb.org/gdf/>.

acceptable to both the providers and the consumers, while regulating the quality of drug manufacturing as well as of the care provided through the private sector.

2. What does the consumer (patient) need?

From the available research, it is clear that some of the consumer requirements include:

- ✓ Reducing the direct and indirect costs of treatment
- ✓ Expanding access to treatment (possibly by involving community health workers)
- ✓ Improving the quality of TB diagnosis

Patients also require more flexible clinic hours, respectful communication with health care staff, and monitoring of drug side effects.

3. What does the provider (doctor) want?

In addition to involving private providers through PPM, they can also be provided financial and other incentives that will increase the treatment success rate. These have been discussed earlier in this document.

4. What does the industry want and need to innovate in TB care and control?

Greater engagement of the private sector is needed to effectively deliver innovative products and services. For example, due to the phenomenal growth and potential of private service laboratory networks in India and the recent introduction and WHO endorsement of breakthrough technologies (such as Xpert MTB/RIF, c18, a 2-hour molecular test for TB and drug-resistance), opportunities are now emerging for private sector laboratories to not only contribute to improved case detection but also ensure financial viability because of economies of scale. (23)

It is also a matter of concerted efforts by different stakeholders, such as the Department of Biotechnology, Indian Council of Medical Research, Centre for Scientific and Industrial Research, etc., to define their role in TB care in India and assist the government in carving out a strategic plan for eliminating the disease from the country.

6. Potential Strategies for Urban ACSM

Three major strategies have been identified by PSI to address the gaps in India's TB control program. These are presented below:

1) **Multichannel communication:**

Communication programs are more effective when consistent messages are conveyed through a mix of communication channels targeted at different sectors of the population. The communication channels selected for the TB control program should be able to meet a specific need or engage a specific audience. For example, messages to the public should stress that clinical services are free, thereby encouraging low-income people to seek care. Similarly, patients are motivated and encouraged to go to a medical facility when persons who were previously infected tell them about how they were treated and cured of TB; such persons should also be involved in TB control programs (29). The general population's health education by community health programs to dispel the myths and stigma surrounding the disease and its treatment is another key issue that must be addressed to strengthen India's progress in TB control. Special population groups, such as migrant laborers, urban slum dwellers, and occupationally marginalized workers, can be targeted as special groups to address their higher vulnerability; both mass media and IPC campaigns can be accordingly generated. The role of mid media — street plays, group meetings, etc. — cannot be overemphasized, particularly for raising awareness among women and children about TB symptoms and access to free diagnostic and therapeutic services.

Potential strategies for urban ACSM - Multichannel communication

Strategy	Ways to implement	Target group	Probable outcome
Multichannel communication	- Mass media informs channels for access to services	Vulnerable populations; urban slum dwellers	-Reducing stigma, beliefs about TB and TB curability
Mass media (awareness)	-Group meetings, community activities, street plays, puppet shows, <i>melas</i>	Mobile populations, Occupationally marginalized groups	-Increase in self-risk perception
Mid media (stigma/discrimination)	- Community volunteers for IPC;	Women, children, elderly	-Awareness about treatment
IPC (compliance)	Former patients can be community volunteers (vicarious experiences)	TB patients	-Early diagnosis; treatment compliance

2) Use of technology by TB programs in India

Technology can be fruitfully utilized for patient and provider database management, improved tracking system for referral and treatment adherence, and linkage of TB registry and patient database. A few examples of successful programs in which technology has been used to monitor patients' treatment compliance and increase cure rates have been presented earlier. Essentially, the following areas can be part of a strong m-health strategy in India, especially by engaging private providers, DMCs, DOTS providers, and patients.

- ✓ Database of TB service providers and patients
- ✓ Helpline services
- ✓ Dynamic referral linkages
- ✓ TB notification
- ✓ Identification of nearest DOTS providers
- ✓ Treatment reminders
- ✓ Defaulter notification
- ✓ Cross referrals

Potential strategies for urban ACSM – Use of technology

Strategy	Ways to implement	Target group	Probable outcome
Use of technologies	<ul style="list-style-type: none"> - m-health for providers - Database of TB service providers and patients - Helpline services - Dynamic referral linkages - TB notification - Identification of nearest DOTS providers - Treatment reminders - Defaulter notification - Cross referrals 	Private providers; DMCs; DOTS providers; patients	<ul style="list-style-type: none"> - Database maintained - Improved tracking system for referral and treatment adherence - Linkage of TB registry and patient database

3) Engaging private providers for TB control in India

Most of the health care in India is predominantly sought from the private sector. A large majority of PPs are individual providers who are both formal (qualified) and informal (non-qualified) providers. Most poor and socially marginalized communities, in both rural and urban areas, usually seek health care from informal providers.

Various studies of PPMs have been discussed in this document before. It would be appropriate to refer to one specific market-based partnership model for the health program conducted by PSI in the state of Karnataka.●

Potential strategies for urban ACSM – Involving private providers

Strategy	Ways to implement	Target group	Probable outcome
Engage private providers	<ul style="list-style-type: none"> - Incentives (CCT) for diagnosis and treatment completion - Accreditation/empanelment under RNTCP as “one-stop-shop” for all TB care services - Subsidized lab facility - DOTS - Supporting follow up - Supporting manpower 	Formal providers of TB care; MBBS; AYUSH; private labs; NGOs; corporate sector	<ul style="list-style-type: none"> -More engagement of PPs in TB care -Improvement in overall quality of TB care services -Increased case detection and cure rate
Engage chemists	<ul style="list-style-type: none"> - Capacity building for referral - Incentive for smear positive case 	Private pharmacists; front-line salesmen in chemists shops	-Increased early case detection
Expand DMC services	<ul style="list-style-type: none"> - Conduct mobile diagnostic camps for vulnerable populations - Collaborate with PPs in community diagnostic camps; offer lab services - Dynamic diagnosis and reporting mechanisms 	DMCs in thickly populated urban areas like slums, industrial belts	<ul style="list-style-type: none"> -Early detection -Minimizing delay in diagnosis and treatment
Collaborate with industry	<ul style="list-style-type: none"> -Tie up with the pharma sector for innovation in diagnosis/treatment 	Pharma and biotech industry	<ul style="list-style-type: none"> - New tools for faster diagnosis - New drugs for effective and acceptable management of TB

● PSI implemented a program for TB referrals in Karnataka state. Forty-nine towns in 13 districts were covered. The project was based on the social franchise model – to create and expand a pool of allopathic private providers to diagnose and treat TB cases as per the International Standard for TB Care (ISTC) by World Health Organization. In total 489 PHCPs were networked by the program. A total of 1,087 (16 percent) suspects were detected to be sputum positive (PSI Unpublished, 2012).

In view of the above, a PPM model can be piloted in select sites by the government to explore the involvement of PPs in a mutually complementary role with DMCs. A DMC can enroll high potential PPs in its area (urban and per-urban), based on certain qualifying criteria (such as high patient load, quality of care, and availability of skilled manpower, etc.), and offer support for appropriate referral linkages with DMCs so that patients referred by a PP to the DMC for sputum microscopy go back to the same PP, thus maintaining trust with the provider. DMCs can provide supportive supervision in order to maintain quality of services, besides offering free DOTS packages for the diagnosed patients. DMCs can also help PPs set up sputum collection centers or even other relevant laboratory services depending on the resources available with a PP, thereby ensuring that patients do not feel the stigma of having to go to a nearby DMC, which is usually avoided by most patients. DMCs may have to play a more active role in patient tracking than what exists today, so that the defaulter rate can be substantially minimized. Empanelment of PPs by DMCs may go a long way in this endeavor. In such partnership models, while the DMCs can ensure early diagnosis of suspected patients and their full DOTS coverage through PPs, the providers not only retain their patients but also prevent revenue losses. In fact, accreditation of successful PPs engaged in active patient referral and successful follow up may help in motivating more PPs in this collaboration. More work is needed on such models, especially to strengthen efforts to combat TB in urban India.

Models to study - Innovations in other sectors

Demand-side financing of TB patients could be useful where public health services are meager/not available and patients need to go to private sector for treatment.

- ✓ Chiranjeevi Yojana (2005–2006), Gujarat: An innovative scheme covered through PPP for emergency obstetric care and emergency (66)
- ✓ Janani Suvidha Yojana, Haryana (67), and Voucher Schemes for Institutional Delivery, Uttar Pradesh (68): Increased access to services for urban BPL women through private health providers and referral arrangements with government institutions through vouchers
- ✓ Immunization drive, Kerala: Intensive IEC/BCC campaign through district, sub-district, and school level, involving health, education, social welfare, local self-help groups (LSHGs), opinion and religious leaders, and NGOs (69)
- ✓ Community Health Insurance for BPL, Uttarakhand (70), and health insurance in Mizoram (71): Schemes tried to enhance accessibility to care through the private sector

References

- ¹ Pinto LM, & Udwardia ZF. Private patient perceptions about a public programme; what do private Indian tuberculosis patients really feel about directly observed treatment? *BMC Public Health*. 2010;10:357
- ² Baseline KAP Study under RNTCP Programme, Central TB Division, 2003 <http://www.tbcindia.org/pdfs/Baseline%20KAP%20Study%20under%20RNTCP%20Project%20-%20CMS.pdf> [accessed on June 12, 2012]
- ³ PSI Unpublished. Market Based Partnership for Health in Karnataka – PSI Experience in TB Referral.2012
- ⁴ R. Rajeswari, V. Chandrasekaran, M. Suhadev, S. Sivasubramaniam, G. Sudha, G. Renu, Factors associated with patient and health system delays in the diagnosis of tuberculosis in South India, *The International Journal of Tuberculosis and Lung Disease*, 2002;6(9):789–795
- ⁵ Suganthi P, Chadha VK, Ahmed J, Umadevi G, Kumar P, Srivastava R, Magesh V, Gupta J, Sharda MA. Health seeking and knowledge about tuberculosis among persons with pulmonary symptoms and tuberculosis cases in Bangalore slums. *The International Journal of Tuberculosis and Lung Disease* 2008 Nov;12(11):1268-73
- ⁶ Kaulagekar A, Radkar A, Social Status Makes A Difference: Tuberculosis Scenario During National Family Health Survey – 2, Inter-Disciplinary School Of Health Sciences, University Of Pune, 2006
- ⁷ Ganapathy S, Thomas BE et al., Perceptions of Gender and Tuberculosis in a South Indian Urban community. *Indian Journal of Tuberculosis*. 2008; 55:9-14
- ⁸ Atre SR, Kudale AM, Morankar SN, Rangan SG, Weiss MG. Cultural concepts of tuberculosis and gender among the general population without tuberculosis in rural Maharashtra, India. *Tropical Medicine and International Health*. 2004 Nov;9 (11):1228-38
- ⁹ Dinesh M Nair,L Annie George, and K T Chack, Tuberculosis in Bombay: new insights from poor urban patients, *Health Policy Planning*. (1997) 12 (1): 77-85. [Downloaded from <http://heapol.oxfordjournals.org/> by guest on June 12, 2012]
- ¹⁰ Kapur SL, Raman AV, Sachdev KS, Satyanaraya S. How Did the TB patients Reach DOTS Services in Delhi? A Study of Patient Treatment Seeking Behavior. *PLoS ONE* 2012 Vol 7 (8) 1-5
- ¹¹ Kelkar–Khambete A, Kielmann K, Pawar S, Porter J, Inamdar V, Datye A, et al. India’s Revised National Tuberculosis Control Programme: looking beyond detection and cure. *International Journal of Tuberculosis Lung Dis*. 2008 Jan;12(1):87–92
- ¹² Anita S. Mathew and Amol M. Takalkar., Living with Tuberculosis: The Myths and the Stigma from the Indian Perspective. *Clinical Infectious Diseases*. 2007 Volume 45, Issue 9, Pp. 1247

- ¹³ MedIndia TB Stigma Still Haunts Indian Women <http://www.medindia.net/news/interviews/TB-Stigma-Still-Haunts-Indian-Women-66759-1.htm> [accessed June 12, 2012]
- ¹⁴ Khan KB. Understanding the gender aspects of tuberculosis: a narrative analysis of the lived experiences of women with TB in slums of Delhi, India. *Health Care Women International*. 2012;33(1):3-18
- ¹⁵ Connolly M, Nunn P. Women and tuberculosis. *World Health Statistics Quarterly*. 1996; 49(2):115-9
- ¹⁶ Sharma PP, Kumar A, Singh, P. A study of gender differentials in the prevalence of tuberculosis based on NFHS-2 and NFHS-3 data. *Indian Journal of Community Medicine*. 2010 35 (2) 230-237
- ¹⁷ Bhargava A, Pinto L, Pai M “Mismanagement of Tuberculosis in India: Causes, consequences and the way forward”, *Hypothesis* 2011 9 (1) 1-13
- ¹⁸ Jaggarajamma K, Balambal R, Muniyandi M, Vasantha M, Thomas B, Nirupa C, Sudha G, Chandrasekaran V, Wares F. Perceptions of tuberculosis patients about private providers before and after implementation of Revised National Tuberculosis Control Programme. *Indian Journal of Tuberculosis*. 2009 Oct;56(4):185-90
- ¹⁹ Singla N, Sharma PP, Singla R, Jain RC. Survey of knowledge, attitudes and practices of tuberculosis among general practitioners in Delhi, India. *International Journal of Tuberculosis Lung Dis*. 1998 May;2(5):384–9
- ²⁰ Specter M. A deadly misdiagnosis. Is it possible to save the millions of people who die from TB? *The New Yorker*. 2010:48–53
- ²¹ Pai M. Tuberculosis Control in India: Time to get dangerously ambitious? *National Medical Journal of India* 2011; 24(2):65-68
- ²² Uplekar MW, Juvekar S, Parande DB, Dalal DB, Khanvilkar SS, Vadair AS, and others. 1996. “Tuberculosis Management in Private Practice and Its Implications.” *Indian Journal of Tuberculosis* 43 (1): 19–22
- ²³ Udwardia ZF, Pinto LM, Uplekar MW. Tuberculosis management by private practitioners in Mumbai, India: has anything changed in two decades? *PLoS One* 2010;5(8):e12023
- ²⁴ Charles N, Thomas B, Watson B, Raja Sakthivel M, Chandrasekaran V, Wares F. Care seeking behavior of chest symptomatics: a community based study done in South India after the implementation of the RNTCP. *PLoS One*. 2010 Sep 20;5(9)
- ²⁵ Katiyar K, Bihari S, et al, An Analysis of Failure of Category II DOTS Therapy, *Indian Journal of Community Medicine*. 2008 April; 33(2): 129–130
- ²⁶ http://www.stoptb.org/assets/documents/countries/acsm/TB_Corr.pdf [accessed on June 12, 2012]
- ²⁷ Courtwright A, Turner AN Tuberculosis and Stigmatization: Pathways and Interventions. *Public Health Reports / 2010 Supplement 4 / Volume 125*

- ²⁸ Vijay S, Kumar P, Chauhan LS, Vollepore BH, Kizhakkethil UP, Rao SG. Risk factors associated with default among new smear positive TB patients treated under DOTS in India. *PLoS One*. 2010;5(4):e10043
- ²⁹ Impact Assessment of RNTCP – II communication campaign on Knowledge, Attitude and Practice (KAP) SEDC - Synovate for the Ministry of Health and Family Welfare, Government of India in 2009
- ³⁰ Singh V, Jaiswal A, Porter JDH, Ogden JA, Sarin R, Sharma, Arora VK, Jain RC. TB control, poverty, and vulnerability in Delhi, India. *Tropical Medicine and International Health*. 2002;7(8): 693–700
- ³¹ Sharma N, Nath A, et al, A Qualitative Evaluation Of The Information, Education And Communication (IEC) Component Of The Tuberculosis Control Programme In Delhi, India . *The Internet Journal of Tropical Medicine*. 2008 Volume 4 Number 2
- ³² Sudha G, Nirupa C, Rajasakthivel M, Sivasusbramanian S, Sundaram V, Bhatt S, et al. Factors influencing the care-seeking behaviour of chest symptomatics: a community-based study involving rural and urban population in Tamil Nadu, South India. *Tropical Medicine & International Health*. 2003;8(4): 336–41
- ³³ <http://www.tbcindia.org/pdfs/draft%20social%20assessment%20exec-summ-fnl.pdf> [accessed on June 12, 2012]
- ³⁴ Lönnroth, Knut, Mukund Uplekar, and Léopold Blanc. 2006. “Hard Gains through Soft Contracts: Productive Engagement of Private Providers in TB Control.” *Bulletin of the World Health Organization* 84 (11): 876–83
- ³⁵ Solomon A Yimer, Carol Holm-Hansen, Gunnar A Bjune. Assessment of knowledge and practice of private practitioners regarding tuberculosis control in Ethiopia, *Journal of Infectious Dev Ctries* 2012; 6(1):13-19
- ³⁶ Pai M. Improving TB diagnosis: difference between knowing the path and walking the path. *Expert Rev Mol Diagn*. 2011 Apr;11(3):241–4
- ³⁷ De Costa A, Kazmi T, Lönnroth K, Uplekar M, Diwan VK. PPM: 'public-private' or 'private-public' mix? The case of Ujjain District, India. *The International Journal of Tuberculosis and Lung Disease*. 2008 Nov; 12(11):1333-5
- ³⁸ Dewan P, Lal SS, Lönnroth K, Wares F, Uplekar M, Sahu S, Grsnich R, Chauhan LK. Improving Tuberculosis through public-private collaboration in India: Literature Review. *BMJ* 2006.Vol 332 574-577
- ³⁹ Balasubramian R, Rajeswari R, Vijayabhaskara RD, Jaggarajamma K, Gopi PG, Chandrasekaran V, Narayana PR. A rural public-private partnership model in tuberculosis control in south India. *International Journal of Tuberculosis Lung Dis* 2006 10 (12) 1380-1385
- ⁴⁰ Pantoja A, Lönnroth K, Lal SS, Chauhan LS, Uplekar M, Padma MR, Unnikrishnan KP, Rajesh J, Kumar P, Sahu S, Wares F, Floyd K. Economic evaluation of public-private mix for tuberculosis care and control, India. Part II. Cost and cost-effectiveness. *The International Journal of Tuberculosis and Lung Disease*. 2009 Jun;13(6):705-12

- ⁴¹ D'souza DT, Mistry NF, Vira TS, Dholakia Y, Hoffner S, Pasvol G, Nicol M, Wilkinson RJ. High levels of multidrug resistant tuberculosis in new and treatment-failure patients from the Revised National Tuberculosis Control Programme in an urban metropolis (Mumbai) in Western India. *BMC. Public Health*.2009 Jun 29;9:211
- ⁴² Saw S, Manderson L, Bandyopadhyaya M, Sein TT, Mon MM, Maung W. Public and/or private health care: Tuberculosis patients' perspectives in Myanmar. *2009 Health Research Policy and Systems* 7-19
- ⁴³ PATH Report of USAID, Evaluation of Tuberculosis Program in India: March, 2011
- ⁴⁴ Giuffrida A, Torgerson DJ. Should we pay the patient? Review of financial incentives to enhance patient compliance. *BMJ* 1997 Sep 20; 315 (7110):703-7
- ⁴⁵ Beith A, Eichler R, and Weil D. Performance-Based incentives for Health: A Way to Improve Tuberculosis Detection and Treatment Completion? April 2007. Centre for Global Development Working Paper #122
- ⁴⁶ Cegielski JP, McMurray DN. The relationship between malnutrition and tuberculosis: evidence from studies in humans and experimental animals. *International Journal of Tuberculosis and Lung Disease* 2004; 8:286-98
- ⁴⁷ Papathakis P, Piwoz E. Nutrition and tuberculosis: a review of the literature and considerations for TB control programs: USAID Africa's Health in 2010, 2008
- ⁴⁸ Nelson Martins, Peter Morris, Paul M Kelly, Food incentives to improve completion of tuberculosis treatment: randomized controlled trial in Dili, Timor-Leste, *BMJ*. 2009; 339: b4248.(doi:10.1136/bmj.b4248)
- ⁴⁹ Mohr, Tom, O. Rajobov, Z. Maksumova, and R. Northrup. 2005. "Using Incentives to Improve Tuberculosis Treatment Results: Lessons from Tajikistan." Millwood, Va.: CORE Tuberculosis Case Study and Project HOPE
- ⁵⁰ An IFRC and Stop TB Partnership advocacy report/Towards a tuberculosis-free world, March 2011
- ⁵¹ Mookherji, Sangeeta, Diana Weil, M. T. Eang, and H. Mory. 2003. "Enabling TB Treatment Seeking and Completion through Food Support to Patients in Cambodia: A Case Study Approach." Paper presented at the Thirty-Fourth World Congress. International Union Against Tuberculosis and Lung Disease, Paris, October 29–November 2
- ⁵² Beith, Alexandra, Rena Eichler, J. Sanderson, and Diana Weil. 2001. "Can Incentives and Enablers Improve the Performance of Tuberculosis Control Programs? Analytical Framework, Catalogue of Experiences, and Literature Review." Paper presented at the workshop Incentives and Enablers to Improve Performance of TB Control Programs, Paris, November 5–6
- ⁵³ Krishnan N, Ananthkrishnan R, Augustine S, Vijayalakshmi NK, Gopi PG, Kumaraswami V, Narayanan PR. Impact of advocacy on the tuberculosis management practices of private practitioners in Chennai City, India. *The International Journal of Tuberculosis and Lung Disease*. 2009 Jan;13(1):112-8

- ⁵⁴ Singh, A. A., D. Parasher, et al. (2004). "Effectiveness of urban community volunteers in directly observed treatment of tuberculosis patients: a field report from Haryana, North India." *International Journal of Tuberculosis and Lung Disease* 8(6): 800-802
- ⁵⁵ Khan, M. A. M., J. D. J. Walley, et al. (2002). "Costs and cost-effectiveness of different DOT strategies for the treatment of tuberculosis in Pakistan. Directly Observed Treatment." *Health Policy Planning* 17(2): 178-186
- ⁵⁶ Mathema, B., S. B. Pande, et al. (2001). "Tuberculosis treatment in Nepal: a rapid assessment of government centers using different types of patient supervision." *International Journal of Tuberculosis and Lung Disease* 5(10): 912-919
- ⁵⁷ Mookherji, Sangeeta, and Alexandra Beith. 2005. "Evaluating Tuberculosis Control Incentives and Enablers in the Context of Scale-up: Evidence and Experiences." Draft document for review. Arlington, Va.: Rational Pharmaceutical Management Plus Program, Management Sciences for Health
- ⁵⁸ Jakubowiak WM, Bogorodskaya EM, Borisov SE, Danilova ID, Lomakina OB, Kourbatova EV. Social support and incentives programme for patients with tuberculosis: experience from the Russian Federation. *International Journal of Tuberculosis and Lung Disease* 2007 Nov; 11(11):1210-5
- ⁵⁹ CTD. "A Health Communication Strategy for RNTCP. CTD, New Delhi," Nov 2005, pg. 180.
- ⁶⁰ USAID India(2012). Initiative to Enhance Participation of Private Healthcare Providers in the Revised National Tuberculosis Control Program Tuberculosis Control & Care Initiative <http://mbph.in/pdf/tbcc-pr/TB-Program-Report.pdf> [accessed on Jan 17, 2013]
- ⁶¹ An unpublished report on PSI intervention with AYUSH providers for capacity building in TB care, Feb.- Mar. 2012
- ⁶² SIMpill® Medication Adherence [Available at <http://www.SIMpill.co.uk> ; accessed on Feb 21, 2013]
- ⁶³ The Uganda Health Information Network (UHIN). [Available at <http://mhealthinfo.org/project/uganda-health-information-network-uhin> ; accessed on Feb 21, 2013]
- ⁶⁴ PSI (2010). On The Move Against Tb In Laos. [Available at <http://www.psi.org/move-against-tb-laos>; accessed on Feb 21, 2013]
- ⁶⁵ Wells WA, Ge CF, Patel N, Oh T, Gardiner E, et al. (2011) Size and Usage Patterns of Private TB Drug Markets in the High Burden Countries. *PLoS ONE* 6(5):e18964
- ⁶⁶ UNFPA, Rapid Assessment of Chiranjivee Yojana in Gujarat, 2006, New Delhi, 2006
- ⁶⁷ Ministry of health, Haryana (2007). Janani Suvidha Yojna Promoting Institutional Deliveries in the Urban Slums Initially in Eight Districts of Haryana. [Available at http://www.researchgate.net/publication/23777474_Janani_Suvidha_Yojna_Promoting_Institutional_Deliveries_in_the_Urban_Slums_Initially_in_Eight_Districts_of_Haryana]

⁶⁸ Donaldson, D., H. Sethi, and S. Sharma. 2008. Vouchers to Improve Access by the Poor to Reproductive Health Services: Design and Early Implementation Experience of a Pilot Voucher Scheme in Agra District, Uttar Pradesh, India. Washington, DC: Health Policy Initiative, Task Order 1, Futures Group International

⁶⁹ National Rural Health Mission Kerala. [Available at <http://arogyakeralam.gov.in/docs2/immunizationpip200910190209.pdf>]

⁷⁰ U health smart card. Uttarakhand Health & Family Welfare Society. [Available at <http://ukhfws.org/cms/detail.php?progID=11>]

⁷¹Gupta A (August 2008). Evaluation of Mizoram Health Care Scheme. [Available at http://mizofin.nic.in/file/ecobranch/EXTERNAL%20ASSISTANCE%20&%20LOAN/ASIAN%20DEVELOPMENT%20BANK/ADB%20SAL/Evaluation%20of%20Mizoram%20Healthcare%20Scheme%20_Final_.pdf]