

**Qualitative Assessment of the Tuberculosis Care System for
Migrant Urban-Industrial Workers Living in Kapas Hera, New Delhi**

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Introduction

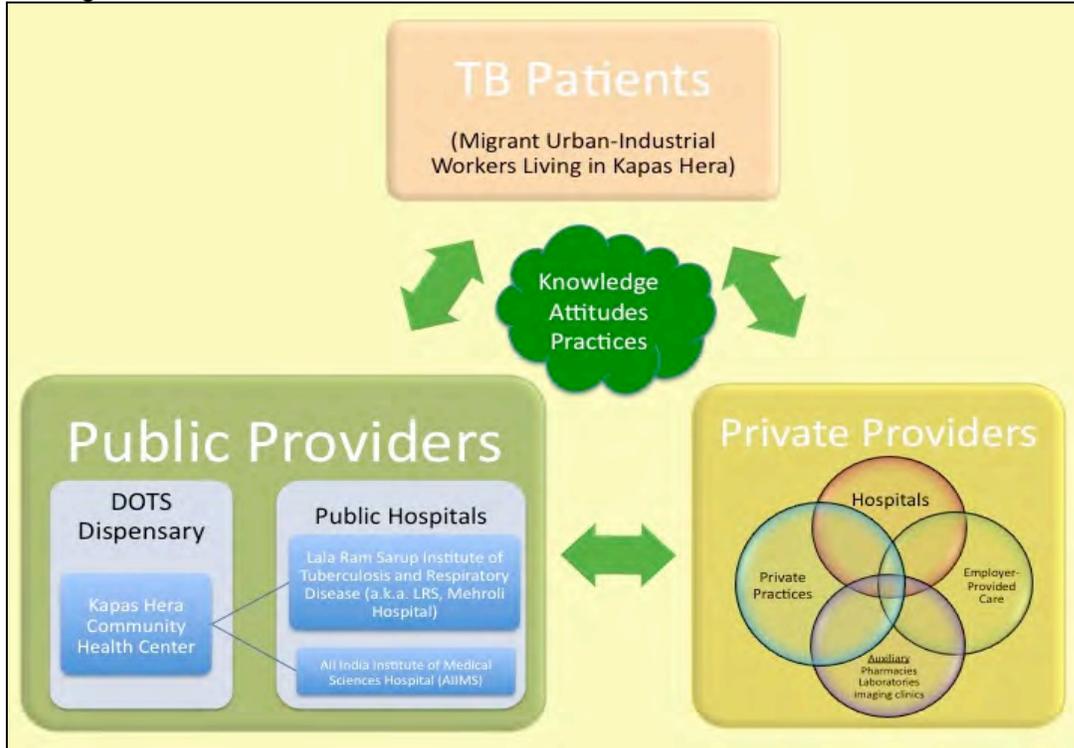
India currently suffers from the highest burden of tuberculosis (TB) in the world, accounting for one-fifth of the entire global incidence.¹ In addition to adopting the World Health Organization's (WHO) Directly Observed Therapy Short-course (DOTS) strategy to combat TB through a national TB control program in 1993, India's Revised National Tuberculosis Control Program (RNTCP) has recently expanded policies fostering Public-Private Mix (PPM) approaches to delivering TB care with the aim of increasing case detection and treatment success rates.

Public-Private Mix approaches are viewed by the RNTCP as cost-effective ways to target populations that continue to have poor TB detection and outcome metrics. Among those that endure some of the worst case detection and treatment success rates are migrant urban-industrial workers (MUIWs). As India transitions from an agrarian to an industrialized country, factories producing export products have boomed in urban and peri-urban regions, bringing with them large communities of industrial workers who are usually migrants from more rural regions of India. The migratory nature of their lifestyle, poor working and living conditions, and their marginalized social status increases a MUIW's risk of developing active TB, while simultaneously decreasing the likelihood that they receive timely and appropriate care.

The current body of knowledge regarding the RNTCPs performance, including their success and challenges, is vast. Communities chiefly composed of MUIWs are a new phenomena, however, and the specific challenges to controlling TB among these communities are likely very different from the general population, though they are not well understood or documented. As the RNTCP seeks to expand DOTS coverage within these communities, very little has been done to assess the feasibility or acceptability of PPM approaches to care amongst the private sector in MUIW communities.

This study attempts to fill this gap in research by assessing the TB care system in a Kapas Hera, a MUIW community in southern New Delhi. A focused ethnography approach was taken to better understand the "Knowledge, Attitudes, and Practices" (KAPs) amongst private providers TB care, public providers of TB care, and MUIW diagnosed with TB while living in Kapas Hera. This study examined each groups' KAPs in an effort to more thoroughly understand how patient and provider KAPs determine the relationship dynamics between private providers, public providers, and patients (Figure 1). This study also examines how these relationship dynamics affect the behaviors of patients and care-providers. The overarching goal of assessing the KAPs and relationship dynamics of these groups is to produce a context-rich assessment of the current TB care system in Kapas Hera, in order to inform future policy advocacy, development, and implementation aimed at improving TB control in this and other MUIW communities.

Figure 1



Methods

The topic of this study was proposed by an Indian non-profit, Center for Health and Social Justice (CHSJ), a policy research and advocacy organization with the mission of improving the health and social status of marginalized populations. In late 2008, CHSJ drafted a list of study topics the organization was interested in developing into a research project, which an intern could then complete. One study topic was regarding the role of the public and private sector in providing tuberculosis diagnostic and therapeutic services to MUIW communities. CHSJ sought to develop an evidence base for future policy research and advocacy aimed at improving the quality, accessibility, and affordability of tuberculosis diagnostic and curative care for MUIWs. CHSJ leadership and the researcher discussed the study topic and determined that a qualitative evaluation would be the most appropriate methodology to develop the knowledge base CHSJ was interested in acquiring. A qualitative evaluation, CHSJ and the researcher agreed, could provide a broad understanding of the TB care system among MUIWs communities in addition to describing the relative roles the private and public sector play in providing TB care. Both CHSJ and the researcher felt that a qualitative evaluation of the KAPs and relationships between patients, private providers, and public providers would best produce the knowledge and information CHSJ desired to generate from this study.

Data were collected over the months of August and September of 2009 through formal and informal interviews of respondents from four categories: *Patients*, *Private Providers* of TB care, *Public Providers* of TB care, and *Key Informants*. The researcher, with collaborating CHSJ staff, determined that formal and informal interviews were the best methods for collecting the richest and most relevant data for addressing the research question. While surveys can capture important components of KAPs, changes in KAPs and relationship dynamics over the period of illness and treatment could not be easily coalesced from a survey methodology and required the more responsive and sensitive approach of formal and informal interviews. Furthermore, collecting data through interview format provided the researcher the flexibility needed to respond to emerging information and experiences. Unlike a uniform survey, the quality of information elicited from interviewees could be improved by modifying the interview questions, techniques, or approaches.

The researcher and collaborating CHSJ staff developed inclusion criteria for *Patients*, *Private Providers*, and *Public Providers* with the aim of capturing the most complete collective description of the TB care system within an MUIW community.

Inclusion criteria for *Patient* subjects were individuals who have been diagnosed with tuberculosis by any type of health care provider within twenty-four months, considered Kapas Hera as their primary place of residence at the time of their diagnosis, received at least a portion of their diagnostic or curative care for their TB in Kapas Hera, and worked in an industrial factory within six months of their diagnosis. CHSJ and the researcher decided that a formal TB diagnosis was an appropriate threshold used to delineate between those who have had a genuine experience with the TB care system and those who may have only had health care experiences tangential to the TB care system. The time parameter requirement for TB diagnosis was made to balance the interest of collecting information that is timely and relevant to recent RNTCP policies against the interest of being able to capture *Patients* who have had a completed TB therapy and can relate a complete account of their illness narrative, start to finish. Because MUIWs change their employer, employment status and current place of residence quite frequently, identifying a bona fide migrant urban industrial worker living in Kapas Hera at any given time becomes subjective. The self-reported primary place of residence and the six-months prior to diagnosis employment status criteria were intended to define whom the researcher does and does not consider a MUIW belonging to the Kapas Hera community.

Inclusion criteria for *Private Providers* of TB care were health care professionals who provide any therapeutic or diagnostic services intended for the treatment or detection of tuberculosis within the defined geographic region of Kapas Hera. The inclusion criteria for *Private Providers* was intended to define which private providers were considered a part of the TB care system in Kapas Hera. Private providers who practice outside of Kapas Hera or do not provide any services related to TB care or diagnosis were not considered relevant to this study.

Inclusion criteria for *Public Providers* of TB care were clinical and administrative staff of either of the two main sources of publicly provided TB care for Kapas Hera residents, the Kapas Hera Community Health Center or the Lala Ram Sarup Institute of Tuberculosis and Respiratory Diseases (L.R.S.) in neighboring Mehrauli. These two facilities represent the two main sources of publicly provided TB care for people living in Kapas Hera. Different levels of clinical and administrative staff relate to and interact with *Patients* and *Private Providers* in different ways. Assessing the KAPs of staff, from all levels from these facilities, is important to understanding how the status and position of the *Public Provider* influences their KAPs.

Inclusion criteria for *Key Informants* were broadly extended to anyone tangentially connected to the TB care system in Kapas Hera without being an eligible *Patient*, *Private Provider*, or *Public Provider*. This umbrella category of respondents was used to capture the perspective of individuals who had privileged experiences with the TB care system of Kapas Hera and could contribute to the overall understanding and assessment of the KAPs of each of other three respondent categories.

Formal, in depth, semi-structured interviews were conducted with five *Patients*, seven *Private Providers*, and six *Public Providers*. Two formal interviews, one *Key Informant* and one *Public Provider*, were conducted in the absence of the researcher by the research assistant, who served as the chief translator during prior interviews. *Patients* were sampled using snowball-sampling methodology due to the difficulty of locating TB patients who were seeking care in the private sector or had already completed DOTS treatment from the RNTCP. Though no gender inclusion criterion was included for *Patients*, all responding *Patients* happened to be males between the ages of twenty-three and thirty. The gender bias of respondents is not surprising because the vast majority of MUIWs are young men. The *Patient* inclusion criteria and sampling methodology may present a bias toward those who have been successful in their TB treatment. MUIWs who have not been successful in their treatment are more likely to return to their town of origin, be unwilling to share their experience, or be consumed by their disease and die.

Public Providers of TB care were purposefully sampled to include respondents from as many levels of clinical and administrative authority within the RNTCP as possible, who also had the greatest influence, expertise, or direct patient-contact experience with TB care amongst MUIWs living in Kapas Hera were. The sampling methodology was intended to sample *Public Providers* whose KAPs were the most relevant to the TB care system in Kapas Hera

Private Providers of TB included pharmacists and clinical care providers advertising themselves as Rural Medical Practitioners (RMPs), Bachelor of Medicine/Bachelor of Surgery (MBBS), or any other certified clinician within Kapas Hera. *Private Providers* of TB care were purposely sampled to maximizing variety in medical training, certification, and geographic distribution within Kapas Hera. The researcher felt that increasing the diversity of education and clinical practice among the *Private Provider* sample population would increase the depth and quality of the assessment of the KAPs of private providers of TB care in Kapas Hera. Some *Private Providers* were also sampled through

snowball sampling methodology by asking *Patients, Key Informants, and other PRPs* where private providers who commonly diagnose and treat TB in Kapas Hera can be found. Like *Public Providers*, this method was used to assess the KAPs of *Private Provides* who were likely to be the most relevant to the TB care system in Kapas Hera.

Key informant interviews were largely informal and included interviews with three laboratory worker, a private hospital sales representative, a dentist, a medical imaging technician, three academics focusing on RNTCP or MUIW issues, two family members of *Patients*, a private provider involved in a PPM scheme practicing outside of Kapas Hera¹, approximately thirty MUIWs living in Kapas Hera, and four current or former TB patients who did not meet *Patient* inclusion criteria. All interviews conducted by the researcher were administered in Hindi via an English-Hindi interpreter trained and screened by the researcher and CHSJ staff. The screening consisted of a CHSJ staff member, fluent in English and Hindi and experienced in conducting qualitative research, reviewing the interpreter applicants' written translations of sample interview questions and performance in a mock interview.

Background and Context

Migrant Urban-Industrial Workers

“Most people come here to work.” – MUIW TB patient living in Kapas Hera

Over the last two decades India's economic development has grown rapidly. Export manufacturing has been a major component of this growth.ⁱⁱ On the outskirts of cities throughout India, large areas of land that were once vacant, are now Special Economic Zones (SEZs) containing hundreds of export factories manufacturing everything from automotive parts to clothing. Export factory proliferation and other economic factors caused Indians from poor, rural, agrarian regions of India, poured into urban and peri-urban areas to meet the growing demand for unskilled and semi-skilled labor.

High unemployment in rural regions of India and the opportunity to make 4,000 – 5,000 Rupees (approximately 100 U.S. dollars) per month at an export factory are the main motivating forces driving young people, mostly men, to urban industrial work. While some workers establish permanent residency in the area that they work, most work temporarily, migrating back to their hometown for months at a time to be with family, transport remittances, and rest.

When workers become sick, which they often do because of environmental pressures of poor living and working conditions, they generally have three possible venues for health care within MUIW communities: 1) privately owned pharmacies (also called, “medical stores”), clinics and hospitals, 2) government dispensaries, community health centers, and hospitals, and 3) Employee State Insurance clinics and hospitals. Employees' State Insurance (ESI) is a social benefits program designed to provide certain benefits for employees who experience sickness, employment injury and maternity leave.ⁱⁱⁱ Under ESI, an export factory is legally obligated to offer them ESI insurance, deducting a

¹ There are currently no private providers of TB care involved in a PPM scheme practicing in Kapas Hera.

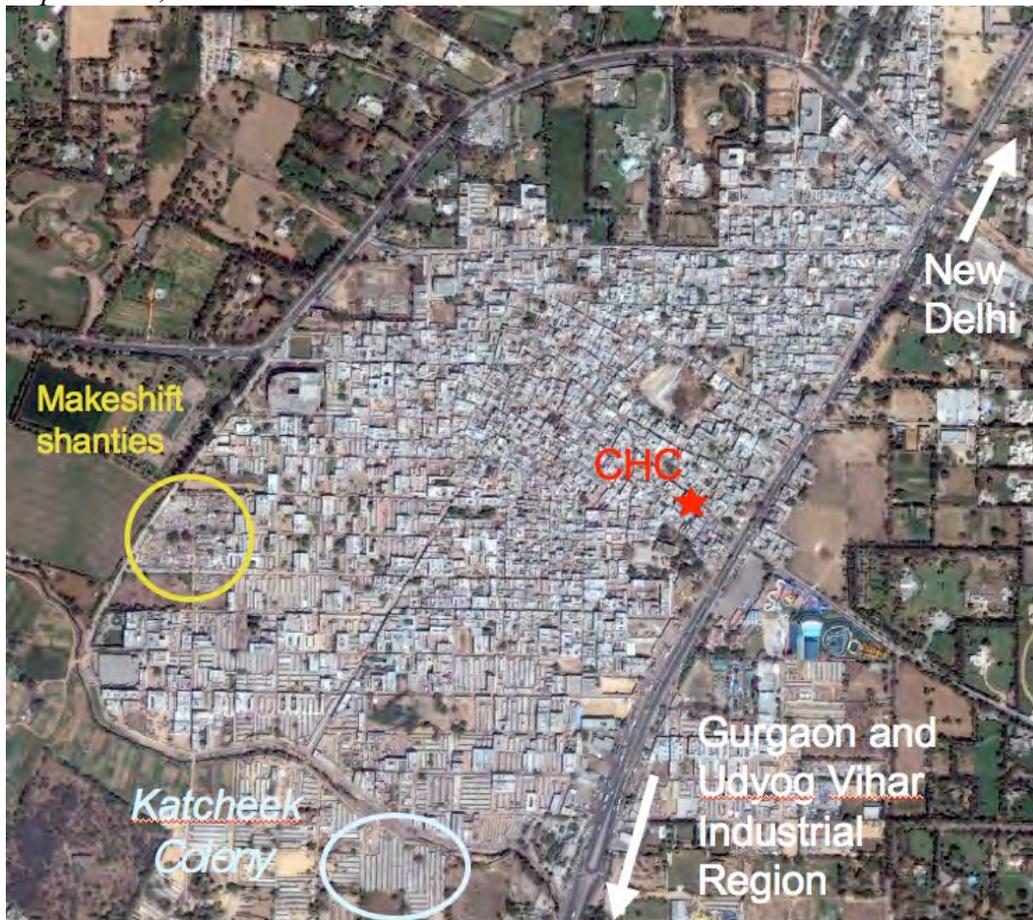
percentage of their monthly salary to contribute to the premium. In return, the worker enjoys a modest benefit package for medical services available at established ESI clinics and hospitals, often located near export factory SEZs.

Characteristics of Kapas Hera

Boarding New Delhi on the northern edge of Haryana State, the city of Gurgaon is covered with current and future SEZs. Within these SEZs are hundreds if not thousands of export factories and call centers. Many of the laborers working in Gurgaon's export factories live in Kapas Hera, just north of the Haryana-New Delhi boarder. Kapas Hera is a densely populated, one-half square kilometer grid of mostly one- and two-story buildings. People who have lived in Kapas Hera their entire lives explained that ten years ago, almost no migrants from other states were living in Kapas Hera, though they now estimate that up to 90% of the population is MUIWs and their families. Kapas Hera has responded to the dramatic immigration poorly, often resembling a refugee camp in terms of public infrastructure and housing conditions.

A prominent RNTCP doctor and official described Kapas Hera's transformation as it swells with MUIWs this way: "Over the years, the area has developed in such a way to cater to the minimum needs of laborers living there."

Kapas Hera, New Delhi



The official 2001 Indian census reports a population of just over 21,000.^{iv} The population of Kapas Hera at any one time is likely to be much greater due to census methodologies that count migrant workers as residents of their hometown, not Kapas Hera, regardless of how long they have lived in Kapas Hera continuously or cumulatively. To establish permanent residency, a MUIW must provide proof of residence when applying for a new Indian voter's identification card. Fearing legal responsibility in the future, landlords refuse to provide any proof of residency to MUIWs. Attaining a voter's identification card anywhere other than your birthplace is virtually unheard of. MUIWs often live in Kapas Hera for decades without a local voter's ID card, excluding them from many social services or benefits.

Among those interviewed, excluding those working for the RNTCP, all estimated the true population of Kapas Hera is between 150,000 to 400,000 people. When asked what the population of Kapas Hera was, those working for the RNTCP claimed that the 2001 census indicated that the population was just fewer than 100,000 people. This, of course, was an inaccurate reference to the deeply flawed 2001 census, which reported the population of Kapas Hera to be 21,000.^{iv} Most *PUPs* would suggest that their personal estimation was much higher than 100,000. They were unwilling or unable to publicly admit this, however, because the RNTCP required a microscopy center for every 100,000 people. Kapas Hera did not have a microscopy center and would not likely be able to get one due to budgetary and facility limitations. So, admitting that they felt the population was greater than the 100,000 would be tantamount to accusing the RNTCP of not complying with its own policy and procedures. To admit this shortcoming to a foreign researcher was not acceptable. Unfortunately, the 2011 Census of India, the largest census in the history of mankind, will, again, fail to accurately record the average number of people living in Kapas Hera at any one time due to the tabulation methodology's inability to account for worker migration patterns.^v

To accommodate the exponential rise in population in a span of approximately ten years, Kapas Hera's landscape has changed dramatically. To reduce living expenses, MUIWs live in the most affordable accommodations possible. Simple, cheaply constructed, and able to house many MUIWs, the two most common housing types are *katcheeks* or *pakkas*. Kapas Hera's transformation into a MUIW community can be most appreciated from satellite images over the years documenting the gradual blotting-out of small, green fields with *pakka* buildings or *katcheek colonies*.

Katcheeks are brick- and concrete-constructed cubes with approximately 100 square feet and corrugated tin roofing. *Katcheeks* are built in back-to-back rows. Several of these two-unit wide rows are built parallel to each other to form a *katcheek colony*. An open sewage line usually runs down the middle of the gullies between each row of *katcheeks*. *Pakkas* are rooms of the same size and characteristics, but are more expensive to rent than *katcheeks* because they have a concrete roof, being just one unit in a two- to four-story building packed with *pakkas*. Both types of housing come standard with a metal door and one bare, hanging light bulb. Some are equipped with fans but extended

blackouts are common during the summer, turning *pakkas* and *katcheeks* into dark, windowless, concrete ovens.

Gully of a katcheck colony in Kapas Hera



The MUIWs are mostly men and save money on housing by sleeping up to four-at-a-time in these size rooms, often sharing rent with other workers who work opposing shifts. Most workers sleep on the concrete floor with a thin blanket. Workers often change units or travel back home for extended periods of time, making beds and other furniture costly and impractical. *Pakka* buildings and *katcheck colonies* often have their own water well and latrine for tenets' community use. However, the water is only quasi-potable and most MUIWs allow the dirt and other sediment to settle to the bottom of a bucket before attempting to drink. No *pakkas* or *katcheeks* have indoor plumbing.

As expected, the municipal infrastructure is even more rudimentary than the MUIW's lodgings. The sewage that runs down the gullies of *katcheck colonies* or out of *pakka* buildings through pipes, collects into concrete channels of open sewage on either side of every road. Besides the concrete channels, roads are constructed with mixtures of dirt and stones. Most roads are more dirt than stones. During the rainy season, sewage channels food into the streets, gushing downhill as small sewage rivers up to two feet deep.

Findings

The Health Care System in Kapas Hera

When asked, all respondents recognized that people living in Kapas Hera tended to become ill more frequently than other people living in Delhi. Most agreed that poor nutrition, unsanitary living conditions, and crowded, sunless living quarters contribute to the higher incidence of illness. When MUIWs or their families fall ill, several sources of care are available within both the public and private sector. MUIWs generally access primary care in the private sector through local “*jholachop*” doctors and pharmacists, while seeking more advanced care at public hospitals and community health centers.

In Kapas Hera, the vast majority of health care is provided privately. Within Kapas Hera’s municipal perimeter is only one public Community Health Center (CHC), compared with the estimated one hundred private care providers and twenty pharmacies in addition to several laboratories and imaging centers.² Amongst health care providers practicing in Kapas Hera who refer to themselves as “doctors,” qualification and experience is highly variable. Care providers advertise medical credentials on the storefronts of their one-room outpatient clinic ranging from MBBS to RMP. In reality, the authenticity of providers’ purported medical credentials is dubious. *Key informants, Patients, Public Providers, and Private Providers* agreed that most *Private Providers* practicing in Kapas Hera have not completed a formal medical degree, instead garnering medical training as apprentices and understudies to other health care providers. Though all private “doctors” interviewed advertised themselves as holders of at least one medical degree or certificate, none recounted completing any type of formal degree or certificate program when describing their medical training and no physical degrees or certificates were presented.

Providing medical care with illegitimate credentials is illegal in India, but these laws are not enforced in Kapas Hera. Confident in his own competency, one private provider claimed, “They [referring to other “doctors” in Kapas Hera] are not qualified and have not completed degrees. They must go to urban slums to hide in the masses because they are illegal.” The slang and somewhat derogatory word, *jholachop*, is used for these types of “local-doctors,” who have little medical training. Never the less, *jholachops* are widely utilized for primary care because they are accessible, affordable, and often the only medical care available in an area.

In addition to *jholachops*, privately owned and operated businesses provide auxiliary medical services in Kapas Hera, such as medical imaging, laboratory services, and pharmaceuticals. *Jholachops* almost always maintain a formal or informal commission-based referral system with auxiliary medical service providers. Some *jholachops* keep a small cache of common medications on-hand and refer patients to the nearest pharmacy for most of the prescribed medications. Pharmacies are often the first point of professional health care for MUIWs in Kapas Hera and are usually seen as competitors to *jholachops*. Because of this, commission-based referral systems are not as common

² There is no official record of providers or pharmacies because many, if not most, are practicing illegally. Estimates based on interviewee responses and researcher’s tabulation and estimation.

between *jholachops* and pharmacies. With even less medical training than *jholachops*, pharmacists will sometimes keep a stethoscope and thermometer on hand to diagnose and prescribe to afflicted MUIWs seeking relief at their pharmacy's window.

Employee's State Insurance is a third category of health care available to MUIWs living in Kapas Hera. It is a publicly administered health insurance and delivery scheme funded by payroll deductions from qualifying employees of private industries. Sadly, the ESI Act is loosely enforced. Many factories engage in practices that exclude most of their employees from being eligible for ESI, such as hiring on a contract-basis, only employing workers for a portion of the year, firing them, then rehiring them again, and suppressing and retaliating against those who demand ESI benefits. Consequently, utilization and knowledge of ESI among MUIWs is low. Of all of the community members, key informants, and patients interviewed, very few of those who worked in factories have ever had ESI benefits, many did not know of anyone who had ESI benefits, and some did not have any knowledge of such a scheme, whatsoever. Low knowledge and utilization of ESI was common among all MUIWs, regardless of the workers' age, experience level, or number of years working in export factories. Some MUIWs who were interviewed have worked over a decade in export factories without ever having ESI.

Compared to the private sector and government CHCs and hospitals, MUIWs rarely utilize ESI for minor illnesses or symptoms, if they seek care through ESI at all. On the whole, the role ESI plays in providing TB care to the average MUIW seems to be considered negligible.

Publicly provided health care represents a significant component of the health care services available to MUIWs in Kapas Hera. The one CHC in Kapas Hera is an approximately 1,500 square feet, two-story building on the northern edge the town. There, two doctors and a handful of support staff provide childhood immunizations, prenatal care, direct observation for DOTS therapy, and general medical care for acute illnesses. The CHC opens at 8:00am and closes at 2:00pm every weekday for DOTS and general medical care, but the staff doctors often do not arrive until 9:00am and usually leave around 1:00pm. The CHC's hours of operation present a significant barrier to most MUIWs who begin work in the morning and do not return until late in the evening. In spite of this barrier, the cramped quarters of the CHC are commonly packed with a line of the MUIWs or their families from the time the doors open to the time they close.

In addition to the CHC, Gurgaon General Hospital, the All India Institute of Medical Sciences (AIIMS), and L.R.S. (also referred to as "Mehroli Hospital") are three neighboring public hospitals frequently utilized by MUIWs and their families. Private hospital care is unaffordable for the average MUIW, making these public hospitals the primary source of tertiary care for MUIWs. From Kapas Hera, the fastest way to the nearest hospital is an hour-long auto-rickshaw ride for a fare of 120-180 Rupees. This is beyond the budget of most MUIWs, however, so a cheaper, longer journey on a private commuter bus is the preferred mode of transportation. There, like in the case of the Kapas Hera CHC, MUIWs pay for their care in the hours spent in queues instead of from their pocket.

Knowledge, Attitudes and Practices

Patients

The following section documents the KAPs of *Patients* throughout their TB illness history as they navigate the health care system. Throughout their illness, *Patients* utilize available knowledge and resources to make health behavior decisions that make sense to them. This section explores *Patients'* KAPs within the framework of understanding how their relationships with the private and public sector health care delivery systems inform their health behaviors relating to their experience with TB.

The illness narratives from *Patients* all have very similar beginnings. When symptoms of fever, fatigue, coughing and weightless arise, all *Patients* and key informants who have had TB sought medical care at a pharmacy first for immediate relief from their ailments. There, *Patients* with some health knowledge or experience with treating these symptoms in the past will ask for specific medicines, but many simply describe their symptoms to the pharmacist who then dispenses a couple days' worth of over-the-counter medication to reduce fever or alleviate cough. This transaction will typically cost between five and twenty-five Rupees, a fraction of what the same diagnostic and treatment services would cost at a *jholachop*.

The relative abundance of pharmacies or medical stores gives *Patients* the opportunity to select their primary source of medications. When workers are in search of a pharmacy, they select the one closest to their home. After convenience, *Patients* evaluated their pharmacies by comparing prices. Once the price is determined to be reasonable and comparable to other pharmacies, an ill worker will experimentally test the effectiveness of the pharmacist's medicine – the most important evaluative criteria. When asked how he determined the quality of a medicine, one *Patient* replied, “We know it through our experiences. It doesn't matter if it is cheap or not. Before you eat the medicine, you do not know!”

Once a convenient pharmacy with effective medicines is found, it is common for a *Patient* to develop a certain level of fidelity to it. The bond is generally weak, however. This is because, in spite of a few cases where *Patients* felt they were given “bad medicine” from a pharmacist, most feel that the variation between pharmacies is small and one pharmacist can usually substitute for another. Fidelity to a particular pharmacy is strongest when an MUIW has had a long experiential history of receiving “good medicine” from that pharmacist.

In addition to a positive track record of selling effective medicine, certain pharmacist practices gain the confidence and trust of MUIWs. When asked about how one particular *Patient* developed his trust and faith in a pharmacist whom he was very faithful to, he revealed that refraining from trying to influence a customer's purchasing decisions was a major factor:

“He gives good medicine. Whatever specific medicine I ask for, he will give the same one and he won't change or give his own opinion and whenever I bring a prescription, he gives it to me”

Prescribing or selling drugs with impartiality is viewed as an indicator of the pharmacist's professional integrity. *Patients* reported pharmacists commonly push medications that are more expensive or earn the pharmacist more income because of manufacturer kickbacks or discounts.

Of the few MUIWs who have ESI benefits, some seek relief from mild symptoms at ESI hospitals or clinics. The cough suppressants and fever medications are usually provided for free by the ESI facilities, compared to the few Rupees the MUIW would otherwise spend at a private pharmacy. The amount of faith MUIWs have in care received in ESI facilities was variable. Many questioned the quality of the medicines available through ESI, claiming that ESI employees would sell the good medication for personal profit and only give the cheapest and poorest quality medication to the workers. In contrast, one *Patient* stated, "ESI medicine is definitely better than the medicine in the local market. I have taken both and know from experience." And yet another said, "When I got ill, I didn't show it to the company doctors because their medicine was not right."

Unlike the medications, MUIWs largely trusted the quality of care provided by ESI doctors. However, most felt that private care provides a more patient-centered experience because ESI providers have no personal financial incentive. One *Patient* stated, "With a private doctor, if you pay more you are going to get more attention, and, obviously, the ESI doctor is okay, but after a while they will start to neglect and maybe overlook things." Overall, ESI plays a very small role in providing health care for the majority of MUIWs because it is only utilized for over-the-counter medicines for symptomatic relief that is free or far cheaper than if purchased in a local pharmacy. Believing that ESI services are not useful for anything else, MUIWs do not seek care at ESI facilities for illnesses that they perceive as being more serious.

After the cough and fever remedies fail to alleviate the *Patients'* symptoms of TB, all interviewed *Patients* reported visiting a *jholachop*. The decision to visit a *jholachop* is almost always at the behest of concerned family members. Throughout the year and especially during holidays, MUIWs will often visit their hometown to be with their family. They also return home when prolonged illness hinders their ability to work making their stay in Kapas Hera unaffordable. During this time, many *Patients* succumb to the pressure of concerned family and visit their families' local *jholachop*. The combination of being with concerned family and near a trusted *jholachop* lead to many of the interviewed *Patients'* first experience seeking care beyond a pharmacist for an illness episode. Though one of the *Patients* participating in this study received the majority of their TB care while in their hometown, the sampling methodology of this study is biased against those who receive care outside of Kapas Hera or never return to Kapas Hera after returning home because of their illness. When attempting to recruit *Patient* participants for this study from MUIW community members, many would say that they knew of someone who had been diagnosed with TB, but they had returned home soon after being diagnosed.

When a MUIW decides to seek the care of a *jholachop* while still in Kapas Hera, the criteria for selection are much the same as choosing a pharmacist. However, the

competencies of *jholachops* are considered to be highly variable from one *jholachop* to another, because most MUIWs understand that no two *jholachops* have the same level of training or experience. Consequently, MUIWs heavily favor seeking care from a *jholachop* who has proven their ability. Personal referrals from family, friends, or neighbors living in Kapas Hera become extremely important at this time. Because the illness has grown severe enough to need a “doctor,” the consequences for choosing a low quality *jholachop* are greater than choosing a low quality pharmacist. This is why experimenting with the most convenient *jholachop*, as done with pharmacies, without a personal referral is rare. This is especially true when the illness in question is perceived to be severe or potentially fatal.

While their health literacy is generally low, MUIWs understand that the *jholachops* are not qualified doctors, and they should be skeptical of a *jholachops*’ competency. “We go to private providers for small diseases, like fever, cold and cough, but not for big diseases,” one *Patient* stated. MUIWs do not see *jholachops* as a source for comprehensive care, but rather as a first-aid dispenser and gatekeeper for more specialized care if needed. MUIWs feel that when they are not able to alleviate their symptoms from treatment found at the pharmacies, a *jholachop* can usually be trusted to determine if patient’s condition is severe enough to refer to a hospital or is mild enough to be treated by the *jholachop*. To a MUIW, a good *jholachop* is someone who can diagnose and cure most conditions, but is able to quickly identify a disease that is beyond their scope of practice and refers them to a hospital. After several diagnostic tests, usually including some combination of blood, sputum, x-ray and tuberculin sensitivity tests, and some times several days and experimental treatment regimens, the *jholachops* delivered on each *Patients*’ expectations and either diagnosed all of them with TB, or confirmed they likely had TB and referred them to more advanced care.

Patients, and MUIWs in general, have a complex relationship with local *jholachop* doctor. *Patients* are not naïve to *jholachops*’ low level of medical education and training and are constantly skeptical of their competence. *Patients* also report having a general distrust in *jholachops* because they feel that many are overtly exploitive of workers. *Jholachops* are often accused of wasting patients’ time and money by performing superfluous diagnostic procedures to increase their profit margin, only to refer them to a hospital. One *Patient* paid a Kapas Hera *jholachop* a months’ salary on daily saline drip therapy to treat his TB. The *jholachop* claimed that the saline was providing the *Patient*’s body with needed nutriment. The belief that therapies administered with a needle are most effective, common among MUIWs, surely contributed to the *jholachop*’s ability to profit from a therapy with no real therapeutic benefit. *Jholachops*’ exploitive practices go beyond selling costly, but ineffective saline drips. In Kapas Hera, it is widely known that in addition to their service fee, *jholachops* make a commission on diagnostic imaging and laboratory lab referrals as well as referrals to private hospitals. One *Patient* stated plainly, “Commission is common, but who tells it on its face? Commission is common with every doctor.”

The community-based referral system among MUIWs acts as a governing mechanism for unscrupulous and ineffective *jholachops*. *Jholachops* who frequently refer to private

hospitals or charge high prices and perform many tests without curing a reasonable portion of their patients quickly gain a poor reputation in the community and lose business. The information costs of personally evaluating a *jholachop* and the risk of choosing a bad *jholachop* are very high for a MUIW, underscoring the importance of referrals from community members. Even with a positive referral and a history of providing acceptable care, MUIWs are constantly evaluating a *jholachop*'s performance, adjusting their confidence in them accordingly. When asked about his level of trust regarding the *jholachop* he first visited for his TB symptoms, one *Patient* said, "When his medicine worked, I had trust. But, when his medicine didn't work, I looked forward to going to the government hospital."

A government hospital is, in fact, where all of the interviewed *Patients* reported going after consulting with a *jholachop*. Before visiting a *jholachop*, many *Patients* explained that they suspected their disease was very serious and would be beyond the scope of practice of their *jholachop*. Even those who knew of TB and suspected they had TB and were aware that they could receive free TB treatment at a government hospital reported seeing a *jholachop* first. When *Patients* were asked about this counterintuitive care seeking pattern, it became clear that even when a *Patient* was very worried about how serious their condition was, they trusted their *jholachop* to deliver a convenient, affordable, and reliable assessment of how serious their condition was. To them, the expense of time and travel costs required to reach a public health care facility, including the typical opportunity cost of missing a day's work, and the wait required to be seen by a public doctor was greater than the price they expected to pay at the conveniently located *jholachop*. The government hospital seems to be a last resort for sick MUIWs, no matter how severe they may think their illness is.

For some *Patients*, their *jholachop* was confident enough in their TB diagnosis and knowledge of TB treatment to prescribe a few days' worth of anti-tuberculin medications for the *Patient* to begin right away. Following diagnosis, each *Patient* was directly referred to a nearby government hospital by their *jholachop*. *Patients* reported that this direct referral from their *jholachop* had a significant influence on their decision to seek care at a public facility. While MUIWs may know the name and location of the closest CHC or public hospital in their hometown, knowledge of what public facilities are available near Kapas Hera and where they are located is very low among MUIWs. A referral from a *jholachop* is not only an endorsement of quality, but also key information that the *Patients* can use to make future care-seeking decisions. *Jholachops* can be found on every major street of Kapas Hera, while the only CHC is tucked in a remote alleyway on the edge of town, and the nearest hospital is miles away.

Without this referral from a *jholachop*, many MUIWs will never know what public options for care are available in Kapas Hera. Not knowing where the public facilities are delays care and complicates diagnosis and treatment as ill MUIWs visit pharmacies and *jholachops* for weeks in a trial-and-error attempt to relieve their illness. One *Patient* explained this trial-and-error process plainly:

"Well, I thought 'I'll go to the medical store first and see, if it didn't work out, I would go to the doctor.' So, when I went to the medical store, it didn't work out

and I still had the same complaints. Then, I went to the local doctor. That didn't work. Then I went home.”

In his case, the crucial referral from the *jholachop* never came. After exhausting his known health care options, the *Patient*, now very ill after weeks of inappropriate care, returned home for support. Luckily, this *Patient's* personal, hometown *jholachop* did refer him to the local government hospital to begin DOTS. Poor awareness among MUIWs and *jholachops* of available public services and how to access them, delays appropriate care.

In addition to being poorly advertised and inconvenient to access, public facilities are usually avoided because MUIWs do not develop a relationship of trust with a *PUP* as they would with a *jholachop*. MUIWs view *PUPs* as competent, but not as personally invested or interested in a patient's health as a *jholachop*. *PUPs* are seen as civil servants fulfilling a duty, instead of concerned and interested care providers. The sentiment among *Patients* and MUIWs was in near unanimous agreement with one *Patient's* opinion that, “The behavior [of *PUPs*] is okay, but not as good as you would get in a private clinic.”

Positive prior experience with publicly provided health care or personal referrals played a strong role in forming expectations and perceptions of publicly provided care as it does for *jholachops*. A *key informant*, who had depleted his family's savings after more than four years of off-and-on treatment for his TB from the private sector, swore to never return to a government hospital after he felt the medicine he was given at one almost killed him. Conversely, a *Patient*, who had received effective care for a bout of Dengue Fever in a government hospital as a child was more than willing to return to a government hospital for TB care, in spite of the long distance or waits in queues required.

MUIWs often reported that the time and resources to travel to government facility and wait in queues present a significant barrier to accessing care at a government facility. Going to the government hospital is usually a daylong event, requiring workers to take a leave from their jobs. MUIWs are often not allowed sick days and are fired and replaced if they do not work their given shift. For MUIWs who are allowed unpaid sick leave, the prospect of losing a day's wage will prevent them from going to the government hospital until absolutely necessary. “I wasn't willing to quit my work or take a day off and go to the hospital, the big hospital in Delhi, and that's why I was postponing it,” one *Patient* explained. Though the local CHC can diagnose TB for most people with active pulmonary TB³, MUIWs who know of the Kapas Hera CHC feel that the CHC is only used for minor ailments and going there for suspected TB is a waste of time.

Once *Patients* seek care at a public facility, their confidence in public TB care remains low as they complete a lengthy, three-day process of diagnosing TB per RNTCP guidelines.^{vi} Those who have not had confidence-inspiring personal experiences with publicly provided care or reliable personal references have the lowest confidence. *Patients* sometimes cited the long queues of people receiving TB care as an indicator of

³ Some diagnoses require an x-ray. The Kapas Hera CHC does not have an x-ray machine and refers those needing an x-ray to private imaging centers or the nearest government hospital.

quality and a source of confidence in the public sector. *Patients* reasoned that if other people were willing to wait in line several days a week for medicine for months at a time, the medicine must be “good medicine.” Some *Patients* explained that they were forced to trust the publicly provided care simply because they had no other options. While these indicators of quality facilitated initiating DOTS, personal confidence in publicly provided TB care did not develop for most *Patients* until the treatment began to alleviate their symptoms. When asked, one *Patient* explained the process of initiating care developing his confidence in publicly provided TB care this way:

“I did not have faith, as such. But, there were other people who were taking this course so I went along and took the course. You know, if given a chance, I would have taken the private course...But, once I took the government medicine, now I have faith.”

Ultimately, *Patients* viewed publicly provided TB care as a last resort. As such, concerns about *Public Providers’* bedside manner, the time it took to diagnose or treat TB on DOTS regimen, or the difficulties associated with traveling to public facilities to receive directly observed therapy were not as important as the medicine’s ability to cure their TB. Generally, *Patients* reported very high levels of satisfaction with care they received from the public sector, mostly because the therapy was effective. While they admitted to feeling that private doctors provided more patient-centered care than a salaried public provider, this was only a minor component of their total perception of publicly provided care. *Patients* desperate enough to seek public care were chiefly concerned with the public sector’s ability to identify and cure their illness. Desperate to be cured and motivated by the belief that one day of missed treatment would necessitate re-starting the entire six to nine-month regimen, *Patients* reported strict adherence to DOTS once enrolled.

Patients frequently complained that publicly provided DOTS treatment regiment of six to nine months was too long and TB patients should be allowed to take their medicine home with them. A common belief among *Patients* is that the DOTS treatment is administered three times per-week instead of every day because of staff shortage issues. If they had enough staff to observe all TB patients take their medicine, *Patients* reasoned, the total length of the treatment regiment for most TB patients could be halved from six months to just three.

Once the DOTS treatment alleviate the majority of a *Patient’s* symptoms, inconvenience and the length of treatment regimen become the most important deterrents to completing the therapy. This is especially relevant to MUIWs who travel between Kapas Hera and their home every few months. For those who are enrolled in DOTS at one of the government hospitals neighboring Kapas Hera, these barriers are somewhat mitigated by transferring their directly observed therapy to the Kapas Hera CHC. However, work shifts prevent many, if not most, MUIWs from accessing the CHC during operating hours between 8:00am and 2:00pm.

Many *Patients* enroll in DOTS at a public dispensary, community health center, or hospital in or near their hometown. Though they may desire to return to Kapas Hera to

work before their therapy is complete, transferring their treatment from a public facility near their hometown to the Kapas Hera CHC is not considered as a realistic option by the *Patient* and never offered as an option from the *Public Providers*. Though possible, such a transfer has never been performed because of the administrative burden it imposes on RNTCP staff, according to a senior staff member of the Kapas Hera CHC. Two *Patients* were, however, able to accommodate their migration between Kapas Hera and their hometown through less formal means. The first began private treatment in his hometown for three months before returning to Kapas Hera. On referral from his friend, he went to the public Gurgaon General Hospital near Kapas Hera when he neared the end of his privately purchased TB medicine. There, a *Public Provider* took the *Patient's jholachop's* diagnosis on good faith, approved the *Private Provider's* treatment, and gave the *Patient* his 'DOTS' medicines to take at home without direct observation. The second *Patient* to accommodate their migration began DOTS at a public hospital near his hometown. The hospital then transferred his therapy to a *Private Provider* participating in a PPM scheme, who lived closer to the *Patient's* hometown residence. The *Patient*, wanting to return to Kapas Hera to work, convinced the *Private Provider* to give him the remaining two months of treatment to take in Kapas Hera independently in exchange for Rupees 500 the next time he returned to his hometown.

It is not known how often these types of exceptions are made to accommodate the migratory habits of workers, but what is clear is that each of these *Patients* were committed to completing their medications and needed very badly to work. Without these sorts of flexibilities, the likelihood that these two *Patients* would have completed their full six-month regimen is unclear. Observing key points along each *Patients'* TB illness history, other variations of TB care are more easily appreciated.

Table 1, below, diagrams these key events among each *Patient's* TB care history. This table is not intended to represent common or typical TB care patterns among MUIWs. Instead, it should be used as a tool to appreciate the variation in TB care patterns that were observed in this evaluation, as *Patients* transition back and forth between private and public care.

Table 1. Pivotal TB care events among *Patients*

	<i>Patient 1</i>	<i>Patient 2</i>	<i>Patient 3</i>	<i>Patient 4</i>	<i>Patient 5</i>
Care History Before TB Diagnosis	Hometown pharmacy (visiting family)	Kapas Hera Pharmacy	Kapas Hera Pharmacy	Kapas Hera Pharmacy, then <i>jholachop</i>	Kapas Hera Pharmacy, then <i>jholachop</i>
Initial TB Diagnosis	Hometown <i>jholachop</i> , (visiting family)	Kapas Hera <i>jholachop</i>	Kapas Hera <i>jholachop</i>	Hometown <i>jholachop</i> (returned home due to illness)	Kapas Hera <i>jholachop</i> ⁴
Anti-TB Therapy Before DOTS	Hometown <i>jholachop</i> (3 months)	None	Kapas Hera <i>jholachop</i> (2-3 days)	None	Same hometown <i>jholachop</i> from previous TB episode
TB Diagnosis from Public Institution and DOTS enrollment	None ⁵	LRS	LRS	Government hospital near hometown	Government hospital near hometown
DOTS Initiation	Gurgaon General Hospital	Kapas Hera CHC	Kapas Hera CHC	Government hospital near hometown (2-months)	Community DOTS provider in hometown
Continuation of DOTS	-Gurgaon General Hospital -Not directly observed -DOTS medicines given to patient one-month at a time to take independently	Kapas Hera CHC	Kapas Hera CHC	-PPM <i>Private Provider</i> in patient's hometown directly observed (2 months) -PPM <i>Private Provider</i> then sold DOTS medicines to <i>Patient</i> to complete independently in Kapas Hera (2 months)	Community DOTS provider in hometown
Therapy Termination and Final Screening	Gurgaon General Hospital	LRS ⁶	LRS	Kapas Hera <i>jholachop</i>	Government hospital near hometown

Each patient navigated the available health care options available to them in a way that was most reasonable to them, based on their resources of money, time, and knowledge. In the early stages of their TB illness, risk and severity of the illness are perceived as low, and *Patients* initially rely on convenient and affordable symptomatic relief from a pharmacy. As the severity of the illness increases and many are forced to return to their

⁴ This patient had two episodes of TB. After being diagnosed by a hometown *jholachop*, the *Patient* completed three of the nine recommended months of treatment from that *jholachop* before returning to Kapas Hera to work. The treatment stopped prematurely because of cost and brief symptomatic relief. The table above reflects the events of second TB episode.

⁵ Doctor at Gurgaon General Hospital relied on the *Patient's* hometown *jholachop's* diagnosis and therapy regimen.

⁶ Tentatively scheduled two weeks from time of interview

hometowns, a *jholachop*, who has proven themselves as effective health care gatekeepers to the *Patient* or a trusted personal referral, is consulted for care. If the *jholachop* suspects or diagnoses TB, most *jholachops* will refer to a public hospital after assuring a profit for their services. By then, a very ill and frightened *Patient* will tolerate the distance, time, and patients required to be diagnosed and comply with direct observation guidelines, no matter how disruptive it may be to their normal life.

Throughout this process, *Patients* are constantly evaluating each health care provider's cost, convenience, and confidence in effectiveness throughout the escalation of care from pharmacist to government TB specialist. Severity of disease greatly effects how *Patients* prioritize these three evaluation metrics, favoring convenience and cost in the initial stages of illness until they grow disparately ill and effectiveness becomes their only concern. Though the specifics of each *Patient's* TB experience varied, these common themes were constant throughout each *Patient's* illness narrative, governing their relationships with *Private Providers* and *Public Providers*, and influencing their care seeking behaviors.

Private Providers

The knowledge, attitudes, and practices of *Private Providers* are not well understood or documented. As the most common source of health care in India, evaluating the KAPs of *Private Providers* is crucial to developing their potential to contribute to TB control efforts.^{vii} Their relationship with *Patients* and the public sector informs their diagnosis, treatment and referral behaviors, which, in turn, affect a TB patient's likelihood of receiving timely and appropriate care. While most *Private Providers* in Kapas Hera are practicing illegally, they play a significant role in determining the outcomes of MUIWs who develop TB in Kapas Hera. The following section describes the KAPs of *Private Providers* practicing in Kapas Hera as they relate to TB care within the framework of their relationships with *Patients* and *Public Providers*.

Reflecting the general population of Kapas Hera, most *Private Providers* are migrants from the poorer Indian states neighboring New Delhi, like Uttar Pradesh and Bihar. Most pharmacies or *jholachop* offices are concrete rooms between 100 and 200 square feet, facing a busy road. In *jholachop* offices, a small exam room is created by boarding or curtaining off the back wall of the room, while the front of the room has a desk and at least one bench for waiting patients to sit. Because most MUIWs work during the day, pharmacies and *jholachop* offices are not usually open until the afternoon and remain open until late in the night, unlike the local Community Health Center.

The pharmacists conduct business and interact with MUIWs through a large window facing the street. People rarely linger near pharmacies, while *jholachop* offices are sometimes active social scenes. Patients who are familiar with the *jholachop* may stop by on their way home from work to "pass the time" in the doctor's waiting room area. Nine people in one popular *jholachop's* office were observed socializing one evening, while the only patient in the office was having his wound dressing changed. These socializing habits serve a greater purpose for both *Private Providers* and *Patients* than

merely passing the time, however. Establishing their office as a welcoming hangout, *jholachops* are able to build the community relationships needed to advertise his services and make his practice more visible in the community. One *jholachop* explained that while he lives outside of Kapas Hera and does not maintain any close friendships with MUIWs, active social engagement with community members is an important part to building and maintaining the success of his practice.

Medicinal icons, credentials and degrees are brightly painted on *jholachops*' office windows and sandwich boards in the streets. *Jholachops* may also advertise their town or state of origin along with their dubious credentials. Being born and raised in the same town or state as a MUIW is often the initial commonality that is used to develop social ties to the people in the Kapas Hera community.

For MUIWs, socializing in a *jholachop*'s office is an opportunity to gather information. While enjoying the company of others, MUIWs observe how *jholachops* treat patients and develop a more informed opinion of their skill level and qualification. By becoming more familiar with a *jholachop* on a personal level, MUIWs are also able to cultivate a trusting relationship with a certain *jholachop*, as they relate to each other by reminiscing about hometowns, discussing politics and religion, or sharing a pot of chai tea.

Most *jholachops*, pharmacists, or other auxiliary medical service providers in Kapas Hera begin their careers as apprentices in Kapas Hera or their hometown. The only interviewed *Private Provider* that reported completing any training was a pharmacist, who had completed a formal certificate for x-ray imaging and completed only some pharmacological training. The rest usually had some combination of fragmented formal training preceding an apprenticeship, later developing their medical skills and abilities through practice and experience.

The majority of *jholachops* who were interviewed have practiced in Kapas Hera for more than three years. According to some who have been practicing in Kapas Hera for more than a decade, the growth of *jholachops* has reached a plateau in the last three to five years. Beginning a new practice, *jholachops* would say, is much harder today than only a few years ago because there are now many *jholachops* to choose from and competition is fierce.

Though their disciplines and practices are different, the account of how *jholachops* and pharmacists came to practice in Kapas Hera followed a similar narrative. When family, friends and neighbors would return home from living and working in Kapas Hera for visits, they would tell *Private Providers* and *Private Providers-to-be* about the shortage of health care providers in Kapas Hera. Seeking an increase in income that an undiscovered market of patients promised, *Private Providers* would strike out for Kapas Hera. Depending on their experience level, they would either begin as an apprentice or *compounder* for a *jholachop* or pharmacist or open their own office. If beginning a new practice, *Private Providers* would start by providing care for people they already knew living in Kapas Hera and people living near their new business, growing their practice by word of mouth.

To build and maintain a successful career, *jholachops* must earn and maintain the confidence of their patients. Patients will only continue to pay twenty to one hundred Rupees per visit to a *jholachop* if they feel that the medical expertise is worth that amount. The livelihood of the *jholachop*, therefore, depends on maintaining a monopoly on any medical knowledge they possess that is beyond the level of the common MUIW. In terms of their behavior during medical visits, this means that the *jholachop* maintains an air of confidence and unquestionable authority while examining and communicating with patients. During a medical examination, for example, the questions *jholachops* ask are formal, terse, and direct. After an assessment, the *jholachop* will rarely explain what he has diagnosed as the illness, instead plainly telling the patient the next step that must be done in order to be healed, whether it be further testing, a trip to the pharmacy for medication, or an immediate injection or intravenous saline drip.

Additional testing at a local laboratory or an x-ray at a medical imaging clinic is common, regardless of the symptoms the patient presents. This is because there is a financial incentive to provide a greater quantity of medical services created by the fee-for-service payment system. When a *jholachop* refers a patient to a laboratory or imaging center, he does not directly charge a fee for the referral, however, but rather earns a commission from the auxiliary medical services providers. The commission arrangements are largely informal and arranged on an individual basis between each auxiliary medical service provider and *jholachop*. The details of these arrangements are kept very private because *jholachops* do not want to appear to have an incentive to perform medically unnecessary diagnostic procedures for profit. Once the results of the tests are available, they are rarely interpreted to the patient. Instead, the *jholachop* will simply prescribe a therapy and assure the patient they should not worry and they will be fine if they take their medicines as instructed.

Educating the patient about what illness they have, how they likely developed it, or how to prevent it in the future is rare because this sort of health empowerment would directly undervalue the expertise of the *jholachop*. The *jholachop* is only expected to do what is necessary to rid the patient of the illness or know what steps must be taken to do so. Unlike *jholachops*, pharmacists are not expected to diagnose and prescribe therapy, so pharmacists are not compelled to stage a performance of unwavering confidence and authority. This allows pharmacists to have a less formal and usually more personal relationship as near-equals with their patients and customers compared to the paternalistic relationships that exist with *jholachops*. No financial incentive to maintain a monopoly on medical knowledge and information means that pharmacists are more willing than *jholachops* to educate their patients and customers regarding their illness. Commonly, pharmacists become *de facto* primary care providers, educating, diagnosing and treating patients with minor ailments at their pharmacy window for no additional cost. Pharmacists will rarely treat anything they perceive to be more severe than a common cold or fever, instead referring them to a near-by or trusted *jholachop*.

Jholachops must also be sensitive to practicing medicine within their range of clinical expertise and knowledge. While their clinical judgments must appear sound and

unwavering up to a point, successful *jholachops* understand the limits of their clinical capacity and must refer patients to more advanced care when necessary. One *jholachop* who had been practicing in Kapas Hera for five years explained,

“If I have a sick patient and try to treat him by experimenting on him, he may die. I have my limitations to the degree of treatment I can provide. When I know that the condition of the patient is critical, it is my need to send him to AIIMS. I cannot risk losing my patient”

Mismanaging a patient with a severe illness can result in a devastating loss of confidence among the community. To increase their practice’s profitability and competitiveness with other *jholachops*, a *jholachop* has an incentive to continually expand his scope of practice by practicing on the margins of their abilities. The consequences of mismanaging a patient with severe illness are dire enough, however, to reduce the pace at which a *jholachop* expands their scope of practice to a crawl.

Most *Private Providers* in Kapas Hera will not attempt to cure a case of active pulmonary TB because it is considered too risky. *Jholachops* will, however, commonly perform and profit from the diagnostic procedures and experimental therapies they use to rule out other diseases. However, once TB is determined to be the most likely diagnosis or the TB patient’s tolerance for ineffective treatment evaporates, *Patients* will usually be given a prescription for few days’ worth of anti-tuberculin medicine and referred to a hospital. When and if the patient with suspected TB is tested at a RNTCP site, it is unclear how initiating anti-tuberculosis therapy can affect the sensitivity or specificity of TB diagnosis through sputum microscopy.

However, few *jholachops* are confident enough to firmly diagnose TB and manage a TB patient’s therapy throughout their illness. Those who do, profit handsomely from their willingness to risk a poor patient outcome and the potential consequences to their practice. Of those who reported treating TB patients with anti-tuberculosis medication, no private provider reported following the TB diagnostic or therapeutic guidelines put forth by the RNTCP, largely due to a lack of knowledge. This misuse and overuse of anti-tuberculosis medication in the private market can contribute to the rate of resistant strains of TB circulating in the community. Most *jholachops* are aware of resistance and encourage their patients to complete the therapy they have been prescribed. However, *jholachops* report that even if they begin a TB patient on a six- to nine-month therapy regimen, the TB patients often do not complete their regimen because they cannot afford it, they return home during their treatment, or they lose interest in completing the therapy after becoming symptom free.

The majority of *jholachops* do not risk treating a TB patient and claim to always refer them to a neighboring hospital. The need to refer a patient for TB or other illness occurs frequently enough that a successful *jholachop* must be very familiar with local sources of secondary and tertiary care. *Jholachops* often refer to many different hospitals, private and public, depending on the specific circumstances surrounding the patient and their illness. Like auxiliary medical services in Kapas Hera, a commission system exists between many local private hospitals and *jholachops*. Most workers are too poor to afford private hospital care, however. For those patients, *jholachops* must be willing to

refer them to a public hospital or the patient will lose confidence in the *jholachop's* ability to provide feasible and acceptable care options to the patient. The majority of *jholachops* interviewed reported referring patients with diagnosed or suspected TB to a public hospital because they understand that treating TB takes many months and the price of private treatment is unaffordable to nearly all MUIWs living in Kapas Hera. Due to the financial barriers to private hospital care, the majority of MUIWs who are in need of care beyond the *jholachop's* scope of practice are referred to public hospitals.

While *Private Providers* are very familiar with the names and locations of private hospitals because of their referral needs and practices, some *Private Providers* did not even know where the Kapas Hera CHC was. *Jholachops* and pharmacists view the CHC as a competitor. *Jholachops*, feeling that they provide medical services comparable to the CHC, are not compelled to refer to the local CHC, and therefore have no interest in being familiar with the CHC or the services that are available there. If a *jholachop* feel compelled to refer a patient, they will refer to a hospital. Community Health Centers are viewed as only appropriate for minor illnesses, so if a *jholachop* were to refer a patient to the local CHC, they would be viewed as under qualified and a waste of time and money.

Jholachops understand that they fill a market demand for easily accessible, convenient, and patient-centered care in Kapas Hera that the public sector is failing to meet. When asked about their views of public care, their perceptions are largely negative and focused on the gaps that *jholachops* see themselves filling. Public care, *jholachops* would claim, is extremely inconvenient and the absolute last resort for care when no other affordable options are available for a patient. *Private Providers* continue that *Public Providers* are unsympathetically fulfilling a duty of their job when caring for patients and are often corrupt, selling publicly provided medications in the private market for profit.

While they publicly criticize public health care operations and providers, *jholachops* do believe in the ability of public sector to cure patients, in spite of the inconvenience and alleged corruption. *Jholachops* demonstrate this trust in the public sector's effectiveness by continuing to refer patients to public hospitals. *Jholachops* understand that patients hold *jholachops* as accountable for the value of their referral as they do the care they directly provide. If a patient does not feel the public hospital is effectively treating their illness, their confidence in the *jholachop* diminishes and they may find a new *jholachop*. So, while *jholachops* criticize many aspects of publicly provided health care, they largely trust the quality of care provided at public hospitals and frequently refer patients who present with illnesses outside of their scope of practice

Knowledge of the RNTCP and DOTS is generally low among *Private Providers*. Though all interviewed *Private Providers* were familiar with a government program that offered free diagnosis and treatment of TB, most knew very little beyond that. Like other publicly provided health care, *Private Providers* trust the quality of TB therapy offered by the RNTCP, but criticize the organization and delivery of care. Most *Private Providers* understand that the DOTS strategy used by the government to treat TB requires directly observed therapy. *Private Providers* are sensitive to the living and working conditions of MUIWs that make adherence to directly observed therapy difficult and

recognize how impractical it is for most MUIWs in Kapas Hera. *Private Providers* are confident that the inconvenience of directly observed therapy is the primary reason why MUIWs do not initiate or complete DOTS therapy. A private provider practicing outside of Kapas Hera and very familiar with the RNTCP through his involvement in Public-Private Mix scheme was interviewed as a *Key Informant*. Though he practices outside of Kapas Hera and is, therefore, not defined as a *Private Provider*, his summary perception of DOTS and the RNTCP closely matched the sentiment expressed by all of the *Private Providers* interviewed for this study. This *Key Informant* said,

“Patients always prefer to go for private treatment. This is not because the quality of medicines is poor. In fact, the quality of DOTS medicine is very good. But people prefer private treatment because they don’t have to come to the clinic or DOTS center every other day...coming to the center every day means they have to skip work or be late.”

The KAPs of *Private Providers* in Kapas Hera are only superficially exposed and critiqued in this report, but the general findings can be reduced to the following summary. One of the least understood or appreciated *Private Providers* in Kapas Hera, in terms of their impact on TB patient outcomes, is the pharmacist. Pharmacists are active in the initial stages of a patient’s illness and often play a critical role in transferring health knowledge regarding disease, treatment, and local health care options. As the effects of TB on a *Patient’s* body become more devastating and the *Patient* seeks care that is more advanced than what the pharmacist is able or prepared to offer, the *jholachop* becomes the most influential person in determining the *Patient’s* course though the TB care system in Kapas Hera.

Jholachops are very familiar and close with the MUIW community. *Jholachops* put a concerted and deliberate effort into socializing with the MUIW community because the success of their practices depends on how well they understand and respond to MUIWs’ health care needs, expectations, and preferences. In their practice, *jholachops* balance their immediate interest of maximizing the profitability of each patient against their long-term interest of building a reputation of quality care and sound clinical practices. Because each individual *jholachop* strikes this balance according to their personal ambition and risk-aversion, some *jholachops* are willing to treat TB cases. The majority of *jholachops*, however, are reluctant to assume the risk of failing to cure a TB patient. In stead, they will make a small profit from testing, experimentally treating, and possibly diagnosing TB before referring an MUIW to a public hospital for free, albeit inconvenient, advanced care. *Jholachops* are quick to criticize the lack of consideration for the patient within the public sector, but trust and rely on the effectiveness of publicly provided care, including DOTS. Because the majority of MUIWs are unable to afford private hospital care when needed, *jholachops* frequently refer patients with suspected or diagnosed TB to the public sector for care. Though effective, *jholachops* know that free TB care available in the public sector is difficult for most MUIWs to begin and maintain and are deeply skeptical of the DOTS strategy for controlling TB in MUIW communities.

Public Providers

Within the private sector, the treatment experience and health outcomes of a patient greatly affected by how a health care provider perceives, understands and interacts with their patient. The same is also true in the public sector. Unlike *Private Providers*, however, *Public Providers* do not have a direct monetary incentive structure to practice their medicine in a way that is preferred by their patients. Top-down flows of guidelines and practice regulations from the RNTCP hierarchy are designed to ensure that treatment of TB patients within the DOTS program is uniformly good. The personal biases and preconceptions do, however, affect the behaviors of public providers of TB care. Recognizing the importance of the KAPs of front-line *Public Providers* of DOTS, the RNTCP has already dedicated research efforts to explore and understand how *Public Provider* KAPs affect the outcomes of TB patients from vulnerable and marginalized populations in New Delhi, including “itinerate labourers.”^{viii} Understanding and documenting the KAPs of public providers of TB care is essential to ensuring access to high quality TB diagnostic and therapeutic services in the public sector for the most vulnerable populations.

While, RNTCP leadership recognizes the importance of public providers’ KAPs toward patients, the importance of public providers’ relationships with private providers has not been recognized. Currently, no literature is available regarding the KAPs of any level of RNTCP official in terms of their relationships with the private health sector. The RNTCP has recently created several PPM schemes to collaborate with the private sector in combating TB, especially within poor and marginalized population groups, though the process of implementing PPM scheme policies has been slow. While a specific Urban Slum Scheme is aimed at developing PPMs in communities like Kapas Hera, the RNTCP has no formal relationships with any private providers in Kapas Hera. Understanding the KAPs of *Public Providers* regarding *Private Providers* in Kapas Hera may explain the factors that affect the PPM implementation process.

The following section explores the KAPs of *Public Providers* of TB care at several clinical and administrative levels of the RNTCP at the Kapas Hera CHC and the most commonly reported hospital used by MUIWs for TB care, Lala Ram Sarup (LRS).⁷ The KAPs of *Public Providers* were examined within the context of their relationships with *Patients* from the MUIW community of Kapas Hera and *Private Providers* of TB care in Kapas Hera. Additionally, through the course of the investigation, the researcher discovered that the *Public Providers*’ KAPs of DOTS and the RNTCP also contribute to TB patient outcomes and are, therefore, included in this report as well. The narrative below describes the observed KAPs of *Public Providers* within the framework of these relationships.

The relationship between *Public Providers* and *Patients* varies depending on the job function and title of the *Public Providers* as well as their primary location of work. *Public Providers* working in Kapas Hera have significantly different KAPs towards

⁷ In order to protect the anonymity of the *Public Providers* interviewed within the narrowly defined geographic region of Kapas Hera, the title or position of respondents will not be disclosed or linked to any statements used in this report

MUIWs and TB patients than the *Public Providers* working at LRS, largely due to relative differences in their familiarity with and knowledge of the MUIW community in Kapas Hera that are a result of their relative locations. The CHC is within Kapas Hera, while LRS is several miles away. The *Public Providers* working at the Kapas Hera CHC do not live in Kapas Hera, however, commuting to the CHC on the northern edge of town without being exposed to the poorer, southern half of Kapas Hera. Even without being familiar with the poorest parts of Kapas Hera, the *Public Providers* working at the CHC are in daily contact with MUIWs and their families crowding into the undersized facility seeking care. Accordingly, *Public Providers* working at the CHC are far more familiar with living and working conditions of MUIWs than the *Public Providers* working at LRS.

CHC providers were more personally connected to the MUIW community and sympathized with the hardships of MUIWs' lives to a greater degree than observed in *Public Providers* at LRS. The difference in relative perception of MUIWs between the staff of LRS and the local CHC permeated how each *Public Provider* understood the issues of TB care in Kapas Hera. For example, the major causes for MUIWs with TB not initiating or adhering to DOTS were largely systemic socioeconomic barriers to accessing and maintaining public care, according to CHC *Public Providers*. In contrast, *Public Providers* working at LRS, with less personal contact with MUIWs or their living conditions, were more likely to attribute poor initiation and adherence behaviors to personal shortcomings. *Public Providers* at LRS claimed that people do not adhere to DOTS therapy because, "they are not motivated enough" and sometimes RNTCP staff may need to "threaten" or "intimidate" patients who they suspect are not properly motivated to complete their full course of anti-TB therapy. This attitude was not observed among the *Public Providers* at the CHC.

The RNTCP leadership puts a considerable amount pressure on its administration and staff to meet or exceed TB Case Detection and Treatment Success rate targets.⁸ This pressure creates an institutional incentive to not enroll people who are perceived to have a high risk of defaulting on their treatment. In 2002, a qualitative operational research of front-line *Public Providers*' KAPs in New Delhi found that "itinerate labourers" and other vulnerable groups were likely to not be registered for DOTS and receive substandard TB care from the public sector based on *Public Providers*' perceptions of how likely a TB patient will adhere to treatment.^{iiiiv} Though high ranking RNTCP *Public Providers* maintained that "a field officer's judgment should not matter," and no one is ever denied enrollment in DOTS based on their perceived risk of default, one *Public Provider* admitted that this is not always the case. This *Public Provider* claimed to use their "intuition" to judge if a potential DOTS patient was likely to adhere to treatment or not and would not enroll people whom he felt would not "focus on the rules" adequately.

⁸ Case Detection is the proportion of new sputum smear positive cases detected to the total estimated incidence of active pulmonary TB in a given population per year. Treatment Success is the proportion of registered patients who were cured or completed therapy to all registered patients in a given population per year.

All *Public Providers* who were interviewed understood that MUIWs regularly return home when they become ill and therefore pose a significant risk of defaulting and are therefore denied enrollment in DOTS while living in Kapas Hera. While this report is, of course, unable to quantify the frequency that MUIWs are denied DOTS therapy or intimidated and threatened by *Public Providers*, it affirms that the perceptions and practices of *Public Providers* leading to poor TB patient outcomes described by 2002, were observed being practiced in 2009.

The belief that patients will not adhere to therapy unless observed and compelled to do so by *Public Providers* is more common among higher-ranking RNTCP staff and officials than those working on the frontline. One high-ranking RNTCP official explained that they understood the hardship of adhering to DOTS while working, but concluded that TB patients simply cannot be trusted to adhere on their own:

“I would say it’s very difficult for them [MUIWs] to adhere to DOTS. Coming in thrice a week to the center for doses is very difficult when you have to go to work every morning and work long hours to make money. We can’t make the treatment once a week or let them take it home. They may not take it on time or not take it at all.”

This distrust of a TB patient’s ability to do what is best for their own health is fundamental premise driving directly observed therapy campaigns.

The *Public Providers* at the Kapas Hera CHC reported that caring for MUIWs and their families gave them a great amount of personal satisfaction because they felt their work was meaningful and purposeful. One CHC *Public Provider* stated that they enjoyed their work because it gave them the “opportunity to change lives.” The fulfilling sense of satisfaction described by CHC *Public Providers* seemed to inform their personal interactions with patients. In the presence of the researcher, the clinical staff appeared to treat patients with dignity, respect, and attentiveness comparable to the treatment from a *jholachop*, though lacking the showmanship of confidence common among *jholachops*. Acknowledging that poor treatment from *Public Providers* is a common criticism of publicly provided care, one CHC *Public Provider* assured the researcher that the Kapas Hera CHC staff were much more “patient-friendly” and “courteous” than the staff of other CHCs.

Ensuring that a TB patient is comfortable and confident with the public care they receive is largely the responsibility of the TB Health Visitor. Health Visitors are frontline *Public Providers* of DOTS responsible for directly observing therapy, visiting patients at their homes to verify residence and make recommendations to facilitate a successful recovery from TB and minimize risk of transmitting TB further, and attempting to contact registered TB patients who have missed therapy doses. Health Visitors know many patients by name and have casual conversations with them as they spend an average of about ten minutes to swallow seven⁹ pills in one sitting. The difference in socioeconomic status between a patient and a Health Visitor is small compared to the difference between

⁹ Most patients being observed ingest seven pills during each directly observed therapy session. Others ingest fewer pills depending on their category of treatment and if they are in the continuation phase of therapy.

a patient and a public doctor, allowing for a more casual socialization environment between a patients and Health Visitors. Similar to *jholachops*, Health Visitors' social interactions with patients can greatly influence a patient's confidence in publicly provided TB care and publicly provided care, generally.

While Health Visitors reported enjoying the nature of their work, turnover is high and the salary is low. Health Visitors have the most direct contact with TB patients and arguably the largest impact on a patient's perception of the RNTCP and DOTS, yet Health Visitors are among lowest in RNTCP hierarchy and salary. Turnover and salary dissatisfaction undermine the process of building trusting, positive relationships between the patient and the Health Visitor. During the period of data collection, dissatisfaction with compensation reached a point where Health Providers throughout southern New Delhi were preparing for a collective strike in order to demand higher wages from the RNTCP. Low wages was a common complaint among all but the highest administrative levels of the RNTCP. Low wages and tensions between clinical staff and RNTCP administration likely contribute to the alleged corruption. *Public Providers* would claim selling medicines or charging TB patients for free treatment was common but did not admit to participating or personally witnessing these acts. Salary dissatisfaction may also play a role in *Public Providers* tendency to arrive to work late and leave work early. When they leave early, many *Private Providers* travel to their second job they have to supplement their income. Even doctors working in public hospitals and clinics will practice medicine in a private clinic in the afternoons. One *Public Provider* was observed referring a patient they saw at a public facility to his private practice later that afternoon for a diagnostic procedure that required equipment that was not available at their facility.

The Kapas Hera CHC does not have an x-ray or any other expensive medical equipment. When an x-ray is needed, a patient at the CHC is more likely to be referred to a private medical imaging center in Kapas Hera than the nearest public facility with an x-ray machine. For 100 to 200 Rupees a private imaging center will charge for a chest x-ray, a patient can return to the CHC with a developed x-ray film in a couple of hours. The alternative is to spend hours of travel and wait time to have the x-ray taken at LRS, then spend hours of travel and wait time three days later to pick up the film. For the referring *Public Providers*, the optimal choice is obvious and most patients agree. *Public Providers* referral to private imaging centers is common enough to suspect a commission system exists between the *Public Provider* and the imaging centers, though the evidence for this is merely circumstantial.

The *Public Providers* at Kapas Hera are deeply critical of the Ministry of Health leadership. The staff at the Kapas Hera CHC resent that they have not been provided the resources to expand facilities and services needed to meet the booming population of Kapas Hera. Resources are allocated based on census data, *Public Providers* explained, not the requests and complaints of the *Public Providers* on the ground. Experiencing the recent surge in population in Kapas Hera firsthand, the CHC staff was more willing than RNTCP administration and leadership to criticize the Ministry's over-reliance on census data.

The CHC leadership expressed even deeper distrust and frustration with RNTCP. The CHC leadership understands that the number one barrier to MUIWs seeking TB care at the Kapas Hera CHC is the conflict between common work hours for MUIWs and the CHC's hours of operations. The CHC leadership claims to have requested that the RNTCP leadership address this issue, but nothing has been done and the CHC leadership lacks the authority to modify operation hours. *Public Providers* working for the RNTCP commonly complain that the RNTCP leadership is completely unresponsive to the frontline clinical staff's requests or suggestions.

In addition to being critical of the RNTCP leadership, CHC *Public Providers* are deeply skeptical of the DOTS drugs. One CHC *Public Provider* claimed that the DOTS medicine is "substandard" and described a conspiracy theory in which a pharmaceutical company likely bribed the RNTCP and World Health Organization to secure the contract to produce DOTS medicine, but produces low quality drugs in order to lower their production costs and make more profit. This *Public Provider* went so far as to say that if a close friend of his developed TB, he would recommend that he seek treatment in the private sector if he can afford it, because one could "never be sure of the medicines" from the RNTCP. Lack of confidence among *Public Providers* clearly affects their willingness to enroll TB patients in DOTS and may also result in lower confidence in DOTS among the MUIW community. RNTCP leadership are far less critical of public TB care, admitting that though the RNTCP experiences challenges to combating TB in certain communities, DOTS is working very well in India. *Public Providers* who were further removed from central RNTCP leadership, hierarchically or geographically, were more willing to openly criticize the RNTCP and DOTS.

The KAPS of *Public Provider* toward MUIW TB patients and RNTCP can have dramatic effects on the accessibility, timeliness, and quality of TB care a *Patient* will receive from a public facility. As the RNTCP continues to expand Public-Private Mix approaches to combat TB in urban slums, the KAPS of *Public Provider* toward the private health care sector in Kapas Hera may also affect the experience of MUIWs suffering from TB. This evaluation found that *Public Providers* largely underestimate the private sector's role in providing tuberculosis care in Kapas Hera, undermining current and future efforts to harness the private sector's capacity to control TB in MUIW communities. The first indication of *Public Providers'* unfamiliarity with the private health care system is their gross underestimation of the number of *jholachops* or pharmacies in Kapas Hera. One high level RNTCP official estimated that only ten to fifteen *jholachops* are working in Kapas Hera when, in reality, more than fifteen *jholachops* practice on only one of Kapas Hera's main roads.

The estimates that *Public Providers* who worked at the Kapas Hera CHC versus neighboring public hospitals were much higher than ten to fifteen *jholachops*, but uniformly lower than the estimates that *Private Providers*, themselves, offered. *Public Providers* working in Kapas Hera were also more inclined to have a positive view the quality of privately provided TB care from *jholachops*, compared to *Public Providers* working outside of Kapas Hera. When asked about the quality of TB care in the private market, a high ranking *Public Provider* will quickly cited recent publications research

indicating that TB diagnostic and treatment strategies are heterogeneous and substandard. A front-line *Public Provider* in the Kapas Hera CHC, on the other hand, casually said that, “Yes, of course private providers prescribe TB medicine and seventy percent of treatment in the private sector is good.” While lower level *Public Providers* working in Kapas Hera may have positive perceptions of *jholachops* and other *Private Providers*, the negative attitudes of high ranking *Public Providers* toward the private health care sector in Kapas Hera likely hinders public-private collaboration the greatest.

Public Providers who are higher ranking and work outside of Kapas Hera are not oblivious to the role of *Private Providers* in providing general health services, however. One high ranking *Public Provider* had a firm grasp on the importance of *jholachops* in Kapas Hera as a source of primary care, hospital referral, and care for “basic” disease because of their low cost and relative convenience. Other *Public Providers* interviewed also understood the importance of *jholachops*, though the *Public Providers* who were interviewed struggled to conceptualize or articulate where *jholachops*’ should fit within the operational framework and policies of the RNTCP.

Public Providers know that a cooperative relationship with *jholachops* would contribute to the RNTCP’s TB control efforts, but *Public Providers* also understand that a formal public-private mix collaboration between *jholachops* and the RNTCP is not bureaucratically feasible. This is because a formal arrangement between the RNTCP and *jholachops*, for example, would condone and legitimize their illegal private practice. Many *Public Providers* expressed deep frustration with this dilemma and are uncomfortable with making any statements that could be interpreted as policy recommendations that are counter to existing practices. One high-ranking *Public Provider* demonstrated this paradox by explaining that many people with TB in Kapas Hera are “going for private treatment to one of the many unqualified doctors present in that area. In all of Mahlpapur, Kapas Hera, and Rajokri, there are no TB specialists. They don’t even have qualified doctors with proper MBBS degrees.” Later on in the interview, however, the same *Public Provide* concedes that, “We need a larger workforce to reach out to communities and get them involved in eradicating TB. Even if we get these *jholachops* into the system, we will be able to cater to a larger population.” Though they are an important *de facto* source of TB care in Kapas Hera, the RNTCP do not recognize the role of *jholachops*, and therefore do not view them as potential resources for PPM expansion.

Recommendations

The purpose of evaluating the KAPs of *Patients*, *Public Providers*, and *Private Providers* of TB care in Kapas Hera is to create an evidence basis to guide future research, policy development and policy advocacy. Though the scope of the research was broad, several future opportunities for the RNTCP, MUIWs and advocacy groups, and private health care providers to enhance the TB control efforts in Kapas Hera can be gleaned from the findings in this evaluation.

The recommendations below are opportunities to improve the TB care available to MUIWs in Kapas Hera the researcher has identified for each of these three groups.

While several specific recommendations are presented, these recommendations are based on conclusions the researcher's interpretations of the findings. Individuals and organizations may derive equally legitimate conclusions and subsequent recommendations from the findings in this evaluation that differ from the researcher's. The intended value of this report should be measured in its usefulness to the individuals and organizations that affect TB control efforts in India's vulnerable populations. In that interest, the researcher encourages readers of this report to interpret, understand and relate with the presented information and analysis in a way that is most relevant and productive to their unique role in TB control.

Opportunities for the RNTCP

Centralized decision making and insufficient engagement with the MUIW population in Kapas Hera appear to be the greatest impediment to controlling TB among the MUIW community in Kapas Hera. Therefore, the greatest opportunities the RNTCP has to improve the TB care system in Kapas Her are to 1) decentralize many operational authorities to local *Public Providers* and 2) develop stronger public awareness of and confidence in DOTS and the RNTCP.

While *Private Providers* are familiar with local public and private hospitals, MUIWs are poorly informed of available health care options. Health knowledge, including information about local health care resources, is disseminated verbally through social networks. In fixed communities, social networks can accumulate and distribute health information very efficiently. Because the population of Kapas Hera is in constant flux, however, workers living in Kapas Hera have a difficult time locating the CHC and an even harder time finding local public hospitals. When workers fall ill, *jholachops*, on the other hand, are highly visible and always available. Lack of knowledge in the community regarding available public TB services often leads to a MUIW afflicted with TB wasting time and monetary resources at a *jholachop*, while growing increasingly ill and possibly developing resistance through inappropriate anti-TB therapy.

Creating signage and advertisements publicizing where and how workers can access public services can overcome this information barrier. Printed publicity is a way to create permanent, public sources of information, overcoming the weaknesses in social network-based knowledge sharing that frequent migration exposes. Well-designed and located billboards, for example, can provide permanent and easily accessible information regarding where and how public TB diagnostic and therapeutic services can be accessed. Reducing the information barriers to access public TB care through effective signage may be a very cost effective measure for the RNTCP to increase case detection rates and decrease delays in accessing appropriate TB care in Kapas Hera.

Decentralizing operational decisions to front line *Public Providers* can increase engagement with the MUIW community and foster innovative and adaptive strategies to controlling TB in populations with unique demographics and behaviors. Front-line *Public Providers* are more sensitive to the needs and preferences of the community they serve than high-ranking and far-removed *Public Providers*. However, front-line providers are not granted the authority or capacity to adapt or innovate their practices to

fit the community they serve. For example, *Public Providers* working at the CHC recognize that the CHC's hours of operation are inappropriate for workers' needs, professional relationships with *jholachops* can benefit TB control efforts, and migrant populations require flexibilities to adhere to directly observed therapy. Never the less, *Public Providers* at the CHC are institutionally powerless to respond to these opportunities and improve public TB care in Kapas Hera. Their frustration leads to inefficient and ineffective delivery of TB services within their community as well as poor morale and resentment of RNTCP bureaucracy among front-line providers. Because of the importance of personal experiences and referrals in guiding MUIW care-seeking behavior, poor morale among *Public Providers* can devastate the MUIW community's confidence in DOTS and the RNTCP. Decentralizing operational decisions to on-site facility leadership is essential to improving the quality and accessibility of public TB care in Kapas Hera.

Opportunities for Civil Society groups advocating on behalf of MUIWs

Civil society groups, such as non-governmental organizations, labor union, and MUIW community groups, have several opportunities to strengthen many of the TB care system weaknesses in Kapas Hera that this evaluation highlights. Civil society groups have the greatest capacity and opportunity to improve TB care in Kapas Hera in three ways: 1) generating and disseminating information, 2) organizing individuals and groups for the purpose of collective action and collaboration, 3) advocating for public policy to improve the TB care system in Kapas Hera and the general living and working conditions of MUIWs.

Civil society groups with a research capacity must continue to expand the body of knowledge regarding TB MUIW communities. This evaluation only begins to describe many of the problems impeding TB control in Kapas Hera, including the shortcoming of the RNTCP in providing accessible and acceptable public TB care to the MUIW community. Future research quantifying the struggles, challenges, and failures of the TB care system in MUIW communities will be an important next step to fully understanding the scope and scale of the issues observed and described in this evaluation. Civil society groups best fill this research role because they are able to investigate issues and generate information that the public sector is unwilling or unable to sufficiently explore.

Civil society groups can also improve the TB care system among MUIWs by distributing currently available information within the MUIW community. Like the RNTCP, civil society groups can empower the MUIW community with accurate and relevant health information. Increasing health literacy regarding the signs and symptoms of TB, the diagnosis and treatment process for TB, and where and how to access appropriate and affordable TB care, will enable MUIWs experiencing TB and TB-like symptoms to make more informed care-seeking. Civil society groups can also reduce the medical harm and waist associated with inappropriate care from under-qualified health care professionals by equipping MUIWs with the health knowledge needed to properly evaluate medical therapies. The prevalence of treating serious medical illnesses, including TB, with inappropriate therapies will decrease if more MUIWs in the community are informed enough to recognize ineffective and potentially harmful treatment.

This evaluation describes several opportunities for improving the TB care system in Kapas Hera that remain unrealized because of poor organization and cooperation among stakeholders. Civil society groups can act as a liaison between potential partner institutions or a catalyst for collective action movements in a capacity that the public or private sector is unable to achieve. For example, the relationship between *jholachops* and the RNTCP is weak, if present at all. Civil society groups can be the bridge between these two groups, educating and informing each of the potential benefits that a closer relationship would provide to each of their interests.

Civil society groups can also facilitate the creation of organized labor movements and support their success. A strong, organized, and influential labor union can achieve fairer compensation, just employment practices, and adherence to existing labor laws and regulations, such as those pertaining to ESI benefits. Increasing access to care and standard living and working conditions among MUIWs is an indirect way to alleviate the burden of TB and other causes of poor health. Additionally, Civil society groups can support the organization of community members to fight exploitation from landlords and advocate local officials for a more feasible process to obtain local identification cards needed to procure local public services.

Lastly, civil society groups can act as direct representatives of MUIW communities to advocate for more favorable public policy, specifically within the realms of public health services and labor policy implementation and enforcement. As an unorganized, socially and politically marginalized population, MUIWs lack the influence or political capital to advocate for themselves. Civil society groups have the opportunity to intervene and advocate on behalf of this vulnerable community for public policy to address the immediate and long-term health and social needs of MUIWs throughout India. Using the available research, civil society groups can hold public institutions and officials accountable for not adequately addressing the TB care needs of MUIWs or ensuring a humane level of living and working conditions of MUIWs. Such advocacy is essential to improving the health and wellbeing of MUIWs overall.

Opportunities for Private Providers

A significant finding of this report is the importance and influence *jholachops* and other *Private Providers* have in determining the outcomes of MUIWs with TB. *Private Providers* have two main opportunities to improve the health outcomes of their TB patients, while simultaneously increasing the success of their practice: 1) actively build stronger ties with the RNTCP, and 2) provide TB and general health information to the community.

If *Private Providers* build stronger ties with the RNTCP, MUIWs who seek them for TB care will benefit from *Private Provider's* increased knowledge of the RNTCP's standard of practice for TB diagnosis and therapy as well as the *Private Provider's* increased willingness to refer TB patients to public TB care. In exchange, *Private Providers* will benefit from an improved public reputation as a qualified health care provider with TB

expertise. Strengthening the relationships between *Private Providers* and local *Public Providers* and the RNTCP will also increase RNTCP's willingness to establish formal schemes with financial rewards to participating *Private Providers*.

Private Providers may also benefit from increasing health literacy in the MUIW community. *Jholachops* should fight the impulse to guard health information as a trade secret and, instead, promote health literacy in the MUIW community. *Jholachops* who strive to educate the community through public forums, enhanced patient-provider communication and distribution of print material can establish themselves as a beneficent and competent provider in the community. Because community reputation and referral systems are very important to the care seeking behaviors of MUIWs, demand for health services from the *jholachop* who strives to educate the public will be greater than for his competitors. The increased demand will assure the provider constant business and possibly allow them to charge patients a premium for their services.

In summation, many factors contribute to impeding or delaying appropriate care for MUIWs diagnosed with TB in Kapas Hera. The relationship dynamics between *Patients*, *Public Providers*, and *Private Providers* of TB care evaluated in this study can describe and explain many of the characteristics and trends of the TB care system in Kapas Hera. The RNTCP, civil society groups, *Private Providers* and other groups are encouraged to utilize the knowledge generated from this study to improve TB control efforts in MUIW communities and the living and working conditions of MUIWs generally.

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