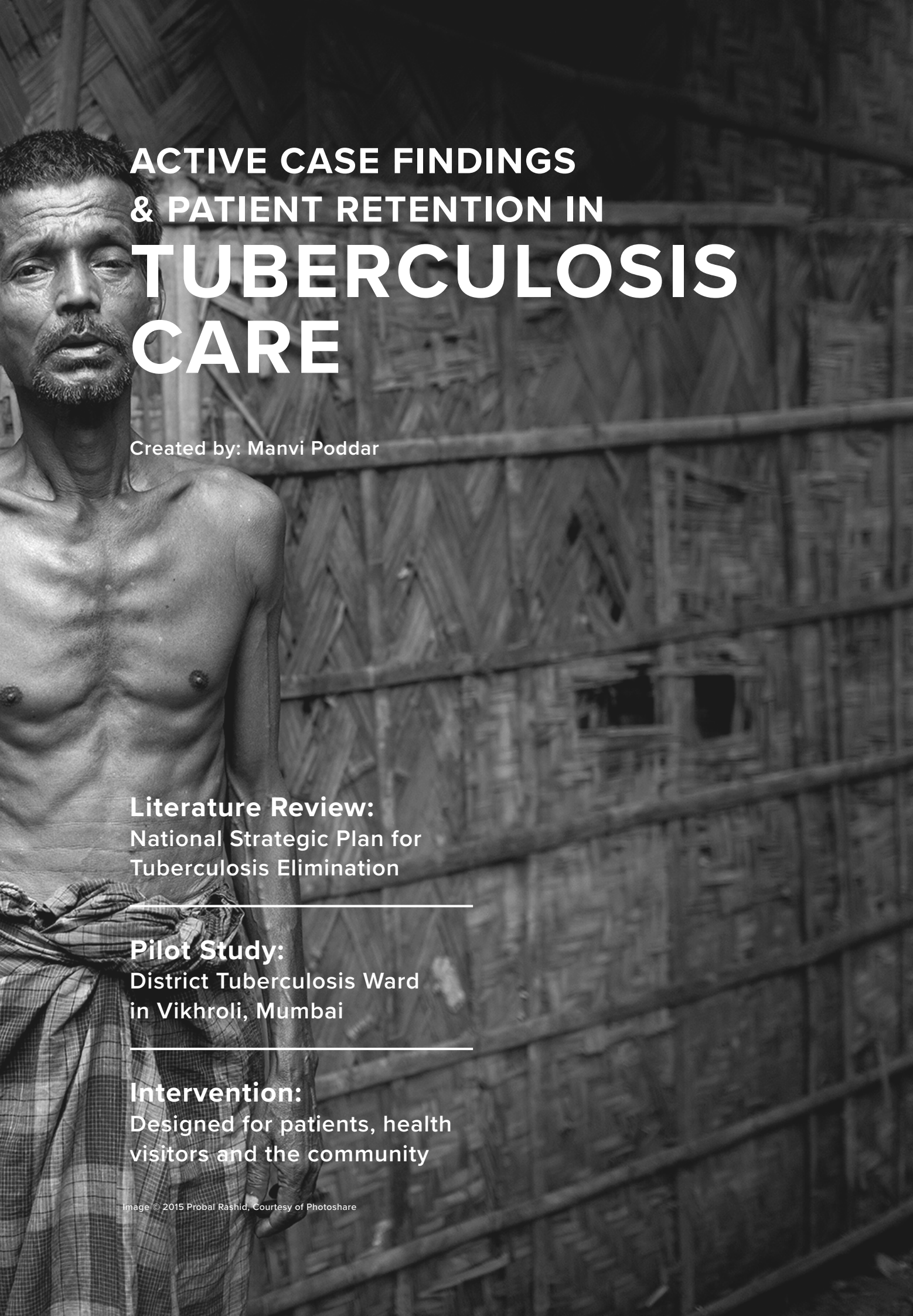




ACTIVE CASE FINDINGS & PATIENT RETENTION IN TUBERCULOSIS CARE

Created by: Manvi Poddar

Literature Review:
National Strategic Plan for
Tuberculosis Elimination

Pilot Study:
District Tuberculosis Ward
in Vikhroli, Mumbai

Intervention:
Designed for patients, health
visitors and the community

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Active Case Findings & Patient Retention in Tuberculosis Care

A thesis submitted in a partial fulfillment of the requirements for the completion of the course in Interior Design, Indian School of Design and Innovation.

To the Department of Product Design May 2019

It is certified that the work contained in the thesis titled
Patient Retention & Tuberculosis

by Manvi Poddar

has been carried out under my supervision and that this
work has not been submitted elsewhere for a degree.

Mr. Bhaskar Bhatt
Program Director: Product Design
and Thesis Mentor
Indian School of Design and Innovation

In mentorship with



HARVARD
T.H. CHAN

SCHOOL OF PUBLIC HEALTH
India Research Center

EXECUTIVE SUMMARY

In response to the growing epidemic of Drug-susceptible and Drug-resistant Tuberculosis (TB) in India, the Harvard T.H. Chan School of Public Health – India Research Center established its project initiative on Patient Retention and Tuberculosis to assess challenges faced by TB health visitors in districts located in Mumbai with the goal of improving TB case detection and patient retention.

The ability of Health Visitors to effectively identify those with TB and ensure that they are completing treatment is a critical component in the attempt to reduce the incidence and prevalence of this disease in India. Through the qualitative assessments, the project aims to gain an understanding of any barriers that health visitor's face in their daily work. The understanding of these barriers will allow for the development of better practices that can improve case identification and treatment retention.

This project book aims to use research findings, as they relate to the role of health visitors in active case findings and patient retention, in order to design an assistive intervention that can help reduce their workload by conducting a systematic analysis of the Revised National Tuberculosis Control Programme 2017 – 2015 and its web enabled patient management system for TB control – NIKSHAY. The intervention proposes the redesign of the features in NIKSHAY; and expands its scope to accelerate a collaborative effort that empowers, educates and facilitates the needs of patients, health visitors, and the community.



Patients sit up in their beds at the Sewri
Government Tuberculosis Hospital in Mumbai,
India.

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ACKNOWLEDGEMENTS

This document was prepared following a capstone project with the Harvard T.H. Chan School of Public Health – India Research Center from January – April 2019, including meetings with stakeholders from Harvard Global Health Institute, Brihanmumbai Municipal Corporation (BMC), Foundation for Medical Research, Medical Aid Films, faculty from the Harvard Chan School as well as visits to BMC's District TB Office in Vikhroli, Mumbai.

The contents of this document represent my perspective and do not represent the recommendations or opinions of any institution, including Harvard T.H. Chan School of Public Health, Harvard T.H. Chan School of Public Health – India Research Center, Harvard Global Health Institute, or the Brihanmumbai Municipal Corporation.

I would like to begin by acknowledging the help of Dr. Sarthak Das, Research Scientist at Harvard T.H. Chan School of Public Health, for his vision and direction as my mentor on this project. A special thanks to Dr. Ananya Awasthi, Assistant Director, Harvard T.H. Chan School of Public Health – India Research Center, for sharing her invaluable inputs throughout the course of my capstone. Dr. K. Viswanath, PhD Lee Kum Kee Professor of Health Communication at Harvard T.H. Chan School of Public Health, for facilitating my capstone project through the India Research Center. I would like to express my gratitude to Professor Bhaskar Bhatt, Program Director Product Design at

Indian School of Design and Innovation, Parsons, for signing on as my academic mentor for the project.

The following key stakeholders without whom this project would not have left the pipeline: Dr. Daksha Shah, City TB Officer, Brihanmumbai Municipal Corporation; Dr. Vinod, Officer, Brihanmumbai Municipal Corporation; and Dr. Mokshada, District TB Officer, Vikhroli Ward, Municipal Corporation of Greater Mumbai.

This project would not have been possible without the time and contribution of the Health Visitors, Senior Treatment Supervisors and Senior TB Laboratory Supervisors, and a TB Patient from the District TB Office, Vikhroli Ward, Mumbai.

Lastly, a sincere thanks to my colleagues at Harvard T.H. Chan School of Public Health – India Research Center: Dr. Aastha Kant, Program Manager; Dr. Nithin Kondapuram, Research Analyst; and Pavitra Madhira, Project Coordinator.

GLOSSARY

ACF:	Active Case Findings
BMC:	Brihanmumbai Municipal Corporation
CTO:	City TB Officer
DMC:	Designated Microscopy Center
DOTS:	Directly Observed Treatment, Short Course
DR-TB:	Drug-resistant TB
DS-TB:	Drug-susceptible TB
DTO:	District TB Officer
FMR:	Foundation for Medical Research
HGHI:	Harvard Global Health Institute
HV:	Health Visitor
IRC:	Harvard Chan India Research Center
LT:	Lab Technician
LTI:	Latent TB Infection
MDR-TB:	Multi Drug-resistant TB
MO:	Medical Officer
MoHFW:	Ministry of Health and Family Welfare
NSP:	National Strategic Plan for Tuberculosis Elimination
RNTCP:	Revised National Tuberculosis Control Programme 2017-2025
STLS:	Senior TB Laboratory Supervisor
STS:	Senior Treatment Supervisor
XDR-TB:	Extensively Drug-resistant TB

ABOUT

A brief description of all partner organizations

Harvard T.H. Chan School of Public Health - India Research Center (IRC)

The overarching mission of the Harvard T. H. Chan School of Public Health is to advance the public's health through learning, discovery, and communication. India has emerged as a focal nation of interest within the School because of the unprecedented social and economic transformation, and enduring partnership, interest and engagement between researchers, students from the School and Indian partners from public, academic and non-profit sectors. The establishment of the Harvard Chan - India Research Center is a natural progression towards creating mutually beneficial collaborations between partners in India and the Harvard Chan School's faculty and students.

The Center aims to provide the physical and intellectual infrastructure to support all public health-related programs and activities of Harvard Chan School faculty, students and staff, and other Harvard Schools. The goals of the Harvard Chan - India Research Center are:

- **Research:** To enable research collaborations on critical public health priorities of India and global health.
- **Training:** To develop training programs in India that will support capacity building in the context of local partnerships, and to provide training and service learning opportunities for Harvard Chan students.

- **Translation & Communication:** To facilitate evidence translation into policy and practice in India.

Harvard Global Health Institute (HGHI)

The Harvard Global Health Institute is committed to surfacing and addressing broad challenges in public health that affect large populations around the globe. They believe that solutions that will move the dial draw from within and beyond the medicine and public health spheres to encompass design, law, policy, and business. They do that by harnessing the unique breadth of excellence within fields at Harvard and by being a dedicated partner and convener to organizations, governments, scholars, and committed citizens around the globe.

To help deliver this mission, all of HGHI's work adheres to 3 strategic principles:

- It will be multi-disciplinary,
- It will involve external partners, whenever possible
- It will systematically measure impact of its work and change course as needed.

Brihanmumbai Municipal Corporation (BMC)

Brihanmumbai Municipal Corporation, also known as Municipal Corporation for Greater Mumbai (MCGM), is the governing civic body of Mumbai, the capital city of Maharashtra. Established under the Bombay Municipal Corporation Act 1888, BMC is responsible for the civic infrastructure and administration of the city.

Foundation for Medical Research (FMR)

The Foundation for Medical Research (FMR),

established in 1975 is a Public trust and a recognized national research organization by the Government of India. FMR works in the fields of biomedical and translation research. Their research focus areas are leprosy, tuberculosis, medicinal plants, environmental health, and malnutrition. Within the area of tuberculosis, FMRs research contributed towards creating a warning about the high levels of multidrug-resistant TB in Mumbai. Their current work aims to reduce TB transmission by airborne infection control practices.^[1]

TEAM



**Dr. Sarthak Das, Research Scientist,
Harvard T.H. Chan School of Public
Health; Senior Advisor, Research
Translation & Global Health Policy,
Harvard Global Health Institute**

Dr. Das is HGHI's Senior Advisor, Research Translation & Global Health Policy; he is also a Research Scientist, Harvard T.H. Chan Dean's Office. Prior to joining HGHI, he served as Chief of Policy & Public Sector Partnerships at Partners in Health, where he led efforts to translate advances in service delivery into sustainable public sector programs with partner Ministries of Health and key multilateral entities such as Global Fund, USAID, and at the UN. He was also engaged in the Ebola response of 2014-15 and the subsequent efforts to rebuild health systems in West Africa. Dr. Das brings over twenty years of experience as both public health scientist and development practitioner. His work is focused amongst the urban and rural poor and includes expertise in program design, delivery, operational research, health policy, and forging strategic partnerships to advance health equity.

He spent eight years working in the Highlands of Papua New Guinea leading a collaborative effort to decentralize HIV treatment and health systems amongst some of the world's most remote communities. He graduated from Harvard College with a joint A.B. in Social Anthropology and Sanskrit/Indian Studies, holds a Master of Public Health from Yale

University and Doctorate in Public Health from the University of North Carolina, Chapel Hill.



**Dr. Ananya Awasthi, Assistant Director,
Harvard T.H. Chan School of Public Health –
India Research Center**

Trained as a Dental Surgeon, Dr. Awasthi began her Public Health career as a consultant in the area of Community Health and prevention of oral cancer. With a Masters in Global Health from the Harvard T.H Chan School of Public Health & Post Grad Diploma in Health Communication from Public Health Foundation of India, she has since worked at the intersection of government, non-governmental organizations and academic institutions to support the development of Public Health programming. Dr. Awasthi is experienced in global health research, management consulting and policy analysis for Public-led Initiatives in Low and Middle-Income Countries. In the past she has worked for various organizations like Deloitte Consulting, the Lancet Commission, Poverty Action Lab- MIT and the National Institute of Physically Handicapped



**Ambika Lall, Research Assistant, Harvard
Global Health Institute**

Ambika recently joined HGHI as a Research Assistant and focuses on the Institute's pandemic preparedness and global health security initiatives. She is a graduate of Wellesley College, from where she received a Bachelor's degree in Psychology



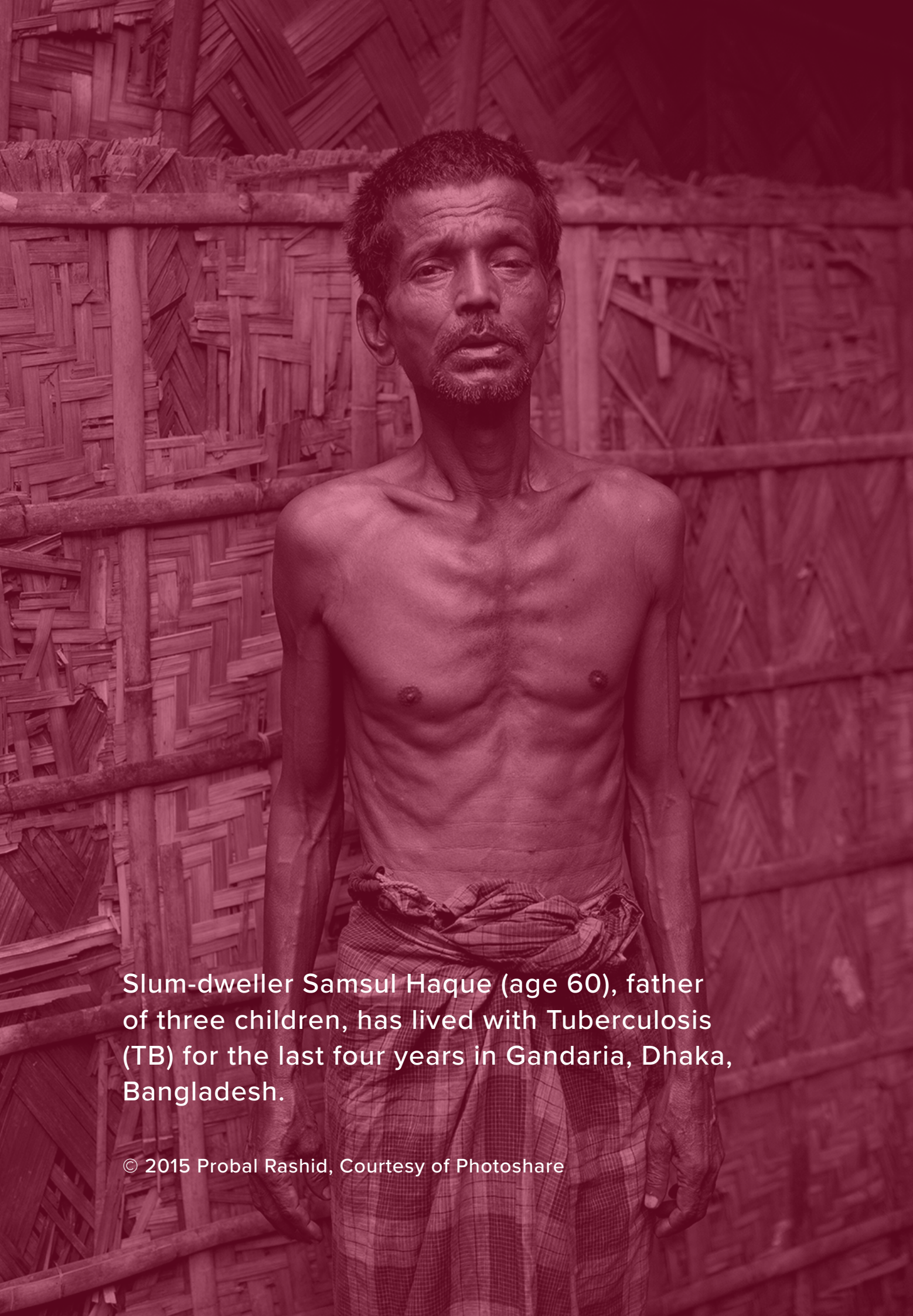
David Jungpa Lee, Master of Medical Sciences and Global Health Delivery'2019, Harvard Medical School

Mr. Lee holds a BA in Public Health from UC Berkeley and is currently pursuing an MD at Harvard Medical School, where he worked with a psychiatrist on a novel group-based mental health intervention for depressed Chinese immigrants. David also trained in community health in India, where he participated in various service projects for urban slums in New Delhi. David hopes to become a physician-researcher who combines quantitative and qualitative methods to deliver creative and effective healthcare to low-resourced communities in the U.S. and abroad.



Dr. Dnyaneshwar Avhad, Surveillance Research Officer, World Health Organization

Dr. Avhad is a medical graduate with a master's degree in Public Health from the Tata Institute of Social Sciences (TISS). Dr. Avhad worked with the Harvard Chan India Research Center as an intern in the spring of 2018. He is currently working with the World Health Organization (WHO) as a Surveillance Research Officer.



Slum-dweller Samsul Haque (age 60), father of three children, has lived with Tuberculosis (TB) for the last four years in Gandaria, Dhaka, Bangladesh.

© 2015 Probal Rashid, Courtesy of Photoshare

CONTEXT OF THE INCIDENCE

Tuberculosis (TB) is a disease that is caused by the bacteria - *Mycobacterium tuberculosis*. TB is curable and preventable. In a majority of cases, the bacterium affects the lungs, and thus makes the disease airborne and contagious. When patients sneeze, cough or spit, they propel germs into the air. A person needs to inhale only a few of these germs to become infected.^[2]

Common symptoms of active lung TB include: **cough with sputum and blood, chest pains, weight loss, weakness, fever, night sweats**

SYMPTOMS

The probability of developing TB disease is much higher among people infected with HIV, and also higher among people affected by risk factors such as under nutrition, diabetes, smoking and alcohol consumption.^[3] The common symptoms of active lung TB are cough with sputum and blood, chest pains, weakness, weight loss, fever and night sweats. One-third of the world's population has latent TB, which means people have been infected by TB bacteria but are not (yet) ill with disease and cannot transmit the disease.^[4]

DETECTION & DIAGNOSIS

There are two kinds of tests that are used to detect TB bacteria in the body: the TB skin test (TST) and TB blood test. A positive skin/ blood test only shows that the person has been infected with the TB bacteria (latent TB). Other tests, such as a chest x-ray and

Since 2000, 53 million lives have been saved through effective diagnosis and treatment.⁶

a sample of sputum, are needed to see whether the person has TB disease.^[5] Figure 1 summarizes this process.

Early detection is one of the major challenges in TB care. Most patients present as asymptomatic for a few initial weeks after having contracted TB disease. This therefore delays the initiation of the treatment regimen.

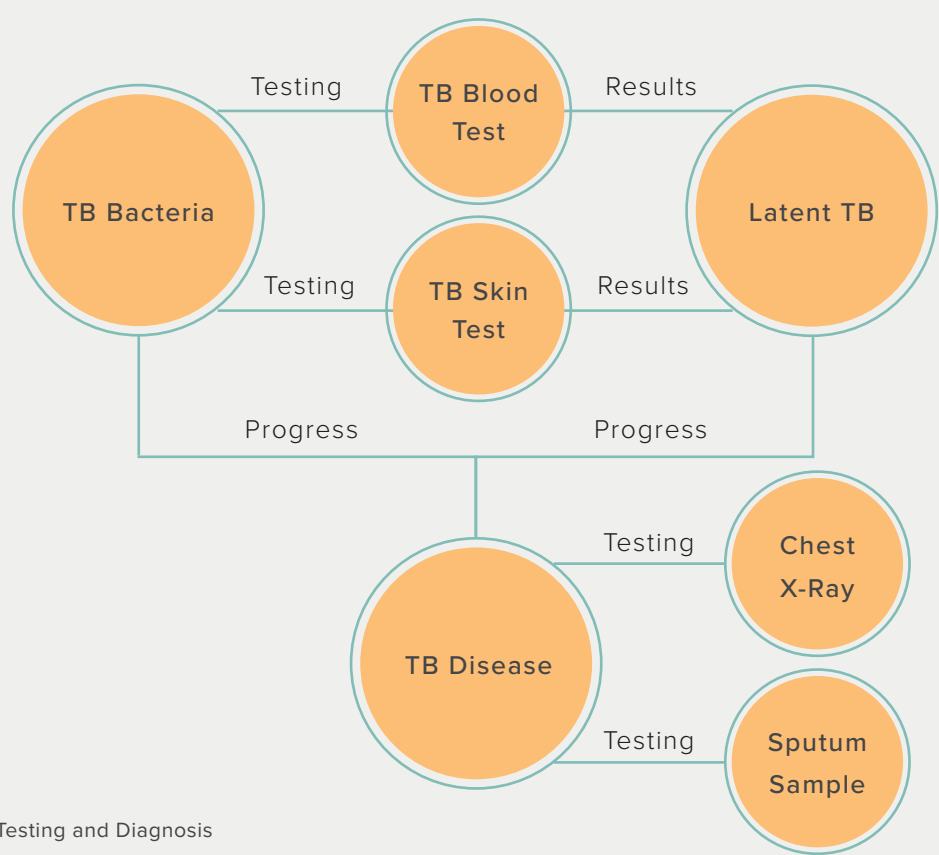


Figure 1: Testing and Diagnosis

TREATMENT

If latent TB is left untreated, it can progress into TB disease. The treatment regimen for latent TB infection can span from 3 months to 9 months. Active, drug-susceptible TB disease is treated with a standard 6-month

Drug-susceptible TB can advance to Drug-resistant TB if it is left untreated.

course of 4 antimicrobial drugs. Multi-drug resistant TB (MDR-TB) is treatable and curable by using second-line drugs. However, second-line treatment options are limited and require extensive chemotherapy (up to 2 years of treatment) with medicines that are expensive and toxic. Extensively drug-resistant TB (XDR-TB) is a more serious form of MDR-TB caused by bacteria that do not respond to the most effective second-line anti-TB drugs, often leaving patients without any further treatment options.

**Drug
Susceptible
TB**

Is treated with a standard course of 6 months with 4 antimicrobial drugs.

**Multi Drug-
Resistant TB
(MDR-TB)**

Is treatable by using second-line drugs. However, second-line treatment options are limited with medicines that are expensive and toxic.

**Extensively
Drug-
Resistant TB
(XDR-TB)**

Is a more serious form of MDR-TB caused by bacteria that do not respond to the most effective second-line anti-TB drugs, often leaving patients without any further treatment options.

GLOBAL BURDEN OF TUBERCULOSIS

During a TEDx Gateway talk, Dr. Zarir Udwadia leading Pulmonologist at Hinduja Hospital, explained that Tuberculosis is responsible for the deaths of 1000 million human beings over the past 200 years. The global incidence of TB exceeds that of Small Pox, Plague, Malaria, Cholera, AIDS, and Influenza, combined.^[7] Tuberculosis persists as a leading infectious killer in India with nearly 1/4th of the worlds TB burden.^[8] In 2016, there were an estimated 10.4 million new TB cases worldwide. It causes ill health for approximately 10 million people each year and is one of the top ten causes of death worldwide.^[9] Seven countries accounted for 64% of the new cases: India, Indonesia, China, Philippines, Pakistan, Nigeria, and South Africa.^[10]

Figure 2: Estimated TB incidence in 2016, for countries with atleast 100 000 incident cases

Source: Global Tuberculosis Report 2017

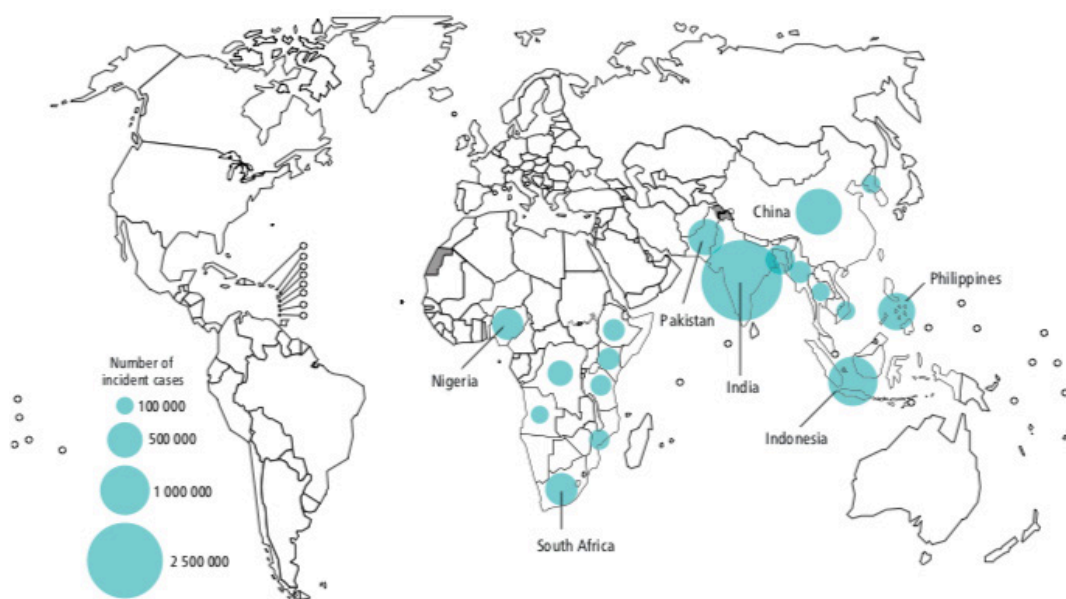


Figure 3: Estimated TB incidence of MDR-TB in 2016, for countries with at least 1000 incident cases
Source: Global Tuberculosis Report 2017

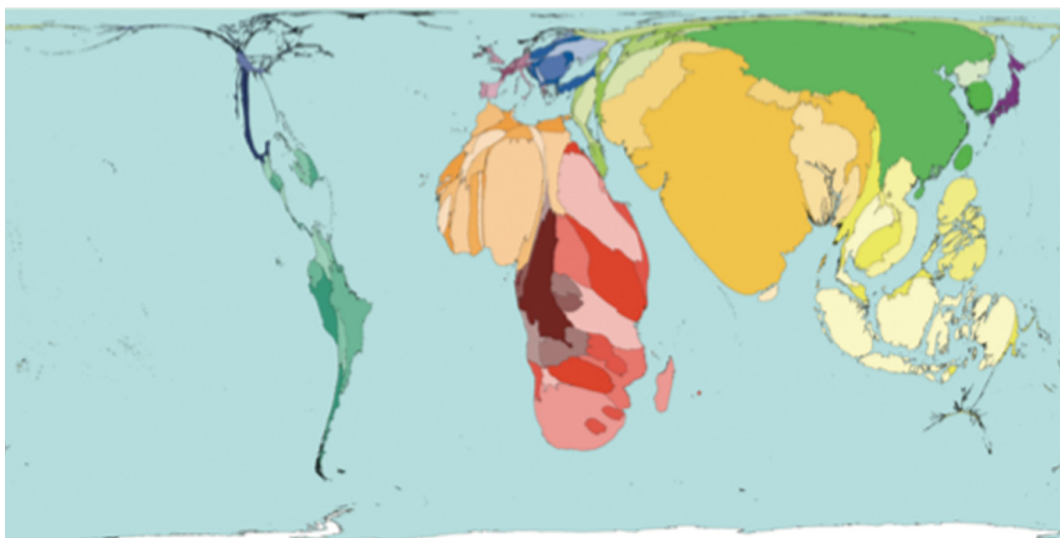


Figure 2 shows the estimated TB incidence in India is the highest with at least 2.5 million incident cases. China, Indonesia, and Philippines come second with at least 1 million incident cases. In 2016, there were an estimated 490 000 new cases of MDR-TB worldwide.^[11] In 2016, 8000 patients with extensively drug-resistant TB (XDR-TB) were reported worldwide.^[12]

Figure 3 displays the global incidence of MDR-TB in 2016. According to this figure, India has 150000 incident cases. Russian Federation and China are second with at least 100000 incident cases.

The map in Figure 4 portrays a visual representation of countries with high numbers of incidence. The Indian sub-continent and the continent of Africa display the largest burden of cases.^[13]

Figure 4: Visual representation of the world with the burden of TB cases
Source: worldmapper.org



INCIDENCE OF TUBERCULOSIS IN INDIA

An approximate of 2.2 million cases in 2014 out of the estimated annual global incident cases of 9.6 million were reported from India. TB kills an estimated 480,000 Indians every year and more than 1,400 every day. India also has more than a million 'missing' cases every year that are not notified and most remain either undiagnosed or unaccountably and inadequately diagnosed and treated in the private sector.^[14] In India, multiple sources of evidence from surveys and surveillance show large underreporting of detected TB cases, especially in the private sector. Three examples of actions that have been taken to close reporting gaps are:

- Mandatory reporting
- A national electronic reporting system that facilitates reporting of cases - NIKSHAY
- Efforts to engage all care providers through PPM (public-public and public-private mix) schemes.

The urban environment, case detection, appropriate diagnosis and loss of patients to follow up are important areas in need of continued support as is preventing the increase of multi drug-resistant TB.

The urban environment, case detection, appropriate diagnosis and loss of patients to follow up are important areas in need of continued support as is preventing the increase of multi drug-resistant TB.

According to the Global Tuberculosis Report 2017 by the World Health Organization, Figures 5 and 6 depict recent treatment outcomes and MDR-TB treatment enrollment, respectively.

Figure 5 compares India's treatment outcomes to the global average. While the percentage of outcomes that result in failure, death and lost to follow-up are almost similar to the global average, the percentage of treatment success is lower in India. Furthermore, a higher percentage of treatment outcomes remain unknown.

Figure 6 shows an increase in the number of patients enrolled to seek treatment with MDR-TB. However, if the number of enrolled patients in 2016 (32,914) is compared to the World Health Organization's estimate of MDR-TB patients in India in 2016 (as shown in Figure 2), there is a large gap with the number of incident cases and enrollment into treatment. This gap highlights the need for improved active case findings in India.

The following section will disseminate India's National Tuberculosis Control Programme and its efforts and protocols placed to combat TB.

Figure 5: Treatment outcomes for new and relapse TB cases in 2015

India in comparison with the global average

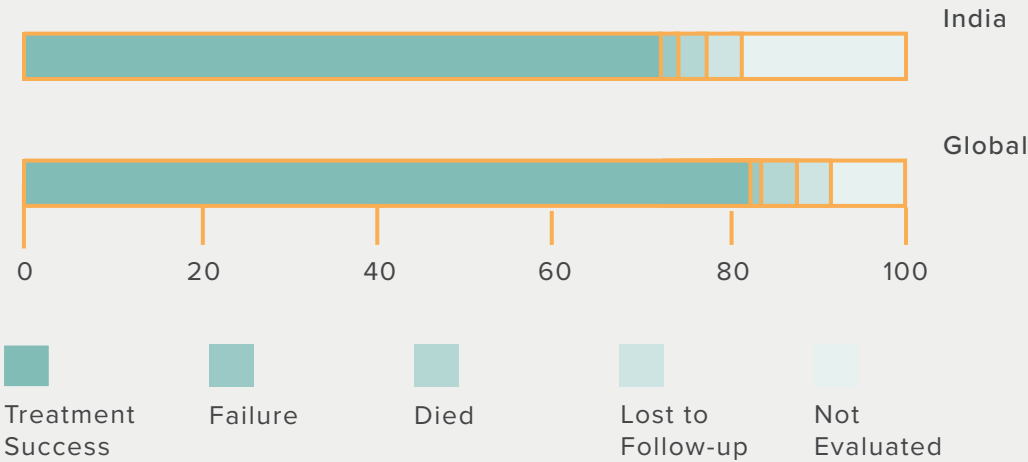
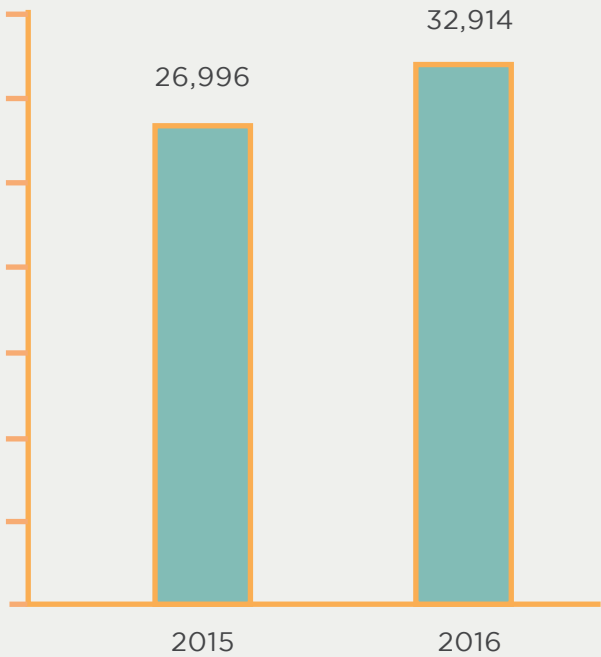


Figure 6: Enrollment into MDR-TB treatment in India



LITERATURE REVIEW

A systematic review of the National Strategic Plan for Tuberculosis Elimination 2017

The Ministry of Health and Family Welfare (MoHFW), Government of India, in its National Strategic Plan (NSP) aims to eliminate the incidence of TB by the year 2025. The NSP is a framework to guide the activities of all stakeholders including the national and state governments, development partners, civil society organizations, international agencies, research institutions and private sector.^[15]

Through the Revised National Tuberculosis Control Programme (RNTCP), MoHFW plans to achieve the goal to eliminate tuberculosis by:

- Mandatory TB notification
- Integration of the programme with the general health service (National Health Mission)
- Expansion of diagnostics services
- Programmatic management of DR-TB
- National drug resistance surveillance.^[16]

THE PROTOCOL

Detection: The guidelines require that sputum smear microscopy for primary diagnosis of drug sensitive TB and rapid molecular test for the diagnosis of drug resistant TB must be used.

Case Findings: Presumptive patients, like family and co-workers, have to be identified and referred to diagnostic facilities for further investigation. Health care providers must systematically screen patients who present symptoms of TB (regardless of private or

public). Enhanced outreach activities must be carried out among key population including clinically, socially and occupationally vulnerable groups of people.

Treatment: All patients that present with cough as a symptom are to be screened for TB in the public sector. According to the RNTCP, the patients must also be screened for resistance to rifampicin or any other additional drugs. Patients who are resistant to any first line drugs are subjected to baseline Kanamycin and Levofloxacin (second-line drugs).

Private Sector: The government has made the notification of all TB patients that seek treatment from the private sector mandatory. In order to facilitate the same, the RNTCP has developed a case-based TB surveillance system - NIKSHAY. NIKSHAY serves as a platform for notification of patients from public and private sectors.^[17]

INTERVENTIONS ADOPTED

RNTCP offers all diagnosis and treatment related to Tuberculosis care free of cost. The Programme uses the World Health Organization's recommended Directly Observed Treatment Short Course (DOTS) Strategy. The DOTS course entails the following:

- Sustained political and financial commitment. TB can be cured and the epidemic reversed if adequate resources and administrative support for TB control are provided.
- Diagnosis by quality ensured sputum-smear microscopy. Chest symptomatic

examined this way helps to reliably find infectious patients.

- **Standardized short-course anti-TB treatment** given under direct and supportive observation helps to ensure the right drugs are taken at the right time for the full duration of treatment.
- **A regular, uninterrupted supply of high quality anti-TB drugs** ensures that a credible national TB programme does not have to turn anyone away.
- **Standardized recording and reporting** helps to keep track of each individual patient and monitor overall programme performance.^[18]

Image 1: Official logo of the RNTCP DOTS programme



Under the DOTS course, the 99Dots Programme is a low-cost approach for monitoring and improving TB medication adherence.

Using 99DOTS, each anti-TB blister pack is wrapped in a custom envelope (Image 2), which includes hidden phone numbers that are visible only when doses are dispensed (Image 3). After taking daily medication, patients make a free call to the hidden phone number (Image 4), yielding high confidence that the dose was “in-hand” and has been taken.

The national programme also rolled out an electronic recording and reporting system (NIKSHAY) with 98% of reporting units sending in case-based reporting of TB patients, including notifications from private providers. NIKSHAY is an app that keeps a track of the missed-calls received through the 99DOTS course. Health Visitors, Supervisors and District TB Officers use the app to record the number of TB patients in an area and track their adherence to the treatment (Image 5). NIKSHAY is developed and maintained by the Central TB Division (CTD), Ministry of Health and Family Welfare, Government of India, in collaboration with

the National Informatics Centre (NIC), and the World Health Organization Country office for India.

NIKSHAY is used by health functionaries at various levels across the country both in the public and private sector, to register cases under their care, order various types of tests from Labs across the country, record treatment details, monitor treatment adherence and to transfer cases between care providers. It also functions as the National TB Surveillance System and enables reporting of various surveillance data to the Government of India.^[19]

Image 2: Capsule wrapping
Source: 99dots.com



Image 3: Dispensing
Source: 99dots.com

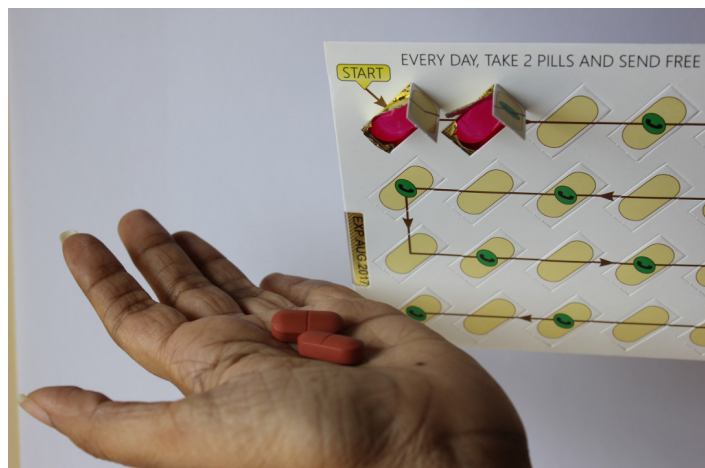
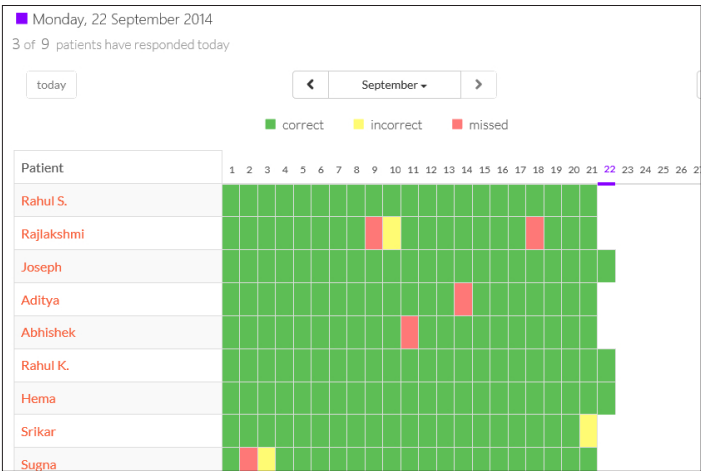


Image 4: Calling
Source: 99dots.com



Image 5: Treatment adherence
as shown on NIKSAY
Source: 99dots.com



AWARENESS CAMPAIGNS

In order to raise awareness and encourage patients to seek treatment, RNTCP launched a nation-wide awareness campaign, “TB Hareha, Desh Jeetega” (TB will loose, the country shall win), with the Indian film actor, Mr. Amitabh Bachchan, as the ambassador.

Simultaneously, the Ministry of Health and Family Welfare’s (MoHFW) social media accounts regularly post awareness campaigns about Tuberculosis. Image 7 shows an example of the latest posts on cough management.

Image 6: TB Harega, Desh Jeetega
Source: Central TB Division, Ministry of Health and Family Welfare

COUGH FOR OVER 2 WEEKS COULD BE TB MEET A DOCTOR NOW

Other Symptoms of Tuberculosis (TB):

- Fever
- Night Sweat
- Loss of Appetite
- Weight-loss

Visit your nearest government health facility for high quality free diagnosis and treatment

Irregular or incomplete treatment may lead to Drug Resistant TB

- TB germs spread through the air
cover your mouth while coughing



TB HAREGA, DESH JEETEGA

Central TB Division • Directorate General Health Services • Ministry of Health and Family Welfare • Government of India



Image 7: Cough Management
Source: Ministry of Health and Family Welfare



Dos & Don'ts

for **TB** patients

Cough Management for Infection Control

✓ Do's

- Cover your mouth while coughing & sneezing.
- Wash your hands with soap & water.
- The patient's room should be well ventilated & with proper sunlight.
- Keep windows open to ensure proper ventilation of the room.

⊘ Don'ts

- Do not cough and spit in the open.



34

PROPOSED INTERVENTIONS

The NSP outlines recommendations for proposed interventions that should be implemented but are not.^[20]

- Active Case Findings:**
- Community screening using mobile facilities
 - Targeting vulnerable demographic groups
 - Institutionalize screening at old age homes, refugee camps, and homeless shelters
- Diagnosis:**
- Capacity building for latent TB infection
 - Promoting and fostering research for new diagnostic tools
 - Ensuring notification through labs from private sector and link the same to lab surveillance
- Treatment:**
- Regular or long-term follow up of all treated patients
 - Promote appropriate treatment adherence mechanism including provision of mobility support to workers, patient enablers and insurance to TB patients, social support systems, nutrition support, and ICT mechanisms
- Prevention:**
- Providing N95 masks to staff in high-risk settings
 - Certifying health facilities with airborne infection control (AIC) compliance
 - Developing cough corners/counters to screen patients with cough symptoms to fast track the process.
 - Periodic screening of all staff members
 - Periodic training and capacity building of staff

Private Sector:

- Free drugs and diagnostic tests for patients in the private sector
- Enhance surveillance and quality improvement through NIKSHAY
- Strengthening regulatory approaches
- Involving medical colleges to facilitate research and treat DR-TB cases

CHALLENGES REMAIN

In 2018, a year after the RNTCP was implemented, according to the Central TB Division in the Government of India, a total of 2158712 cases were reported across the country; 1617784 from the public sector and 540928 from the private sector (refer to Figure 7 for a state wise break-up).^[21]

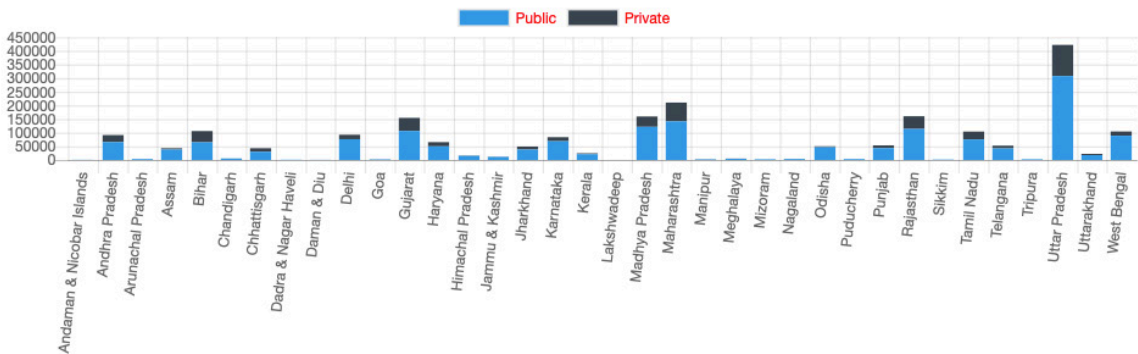
As of May 1, 2019, a total of 725602 new cases have been reported from the public and private sectors. This recent data indicates that the incidence of TB in India is still on the rise.^[22]

Even with the RNTCP protocol and interventions in place, TB control faces daunting challenges in India. Decades of unrestrained transmission have left millions of Indians with latent TB infection, which may re-activate. A significant portion of the population is undernourished, which weakens immunity and drives TB reactivation.^[23]

A larger portion of the population suffers from risk factors for tuberculosis, including diabetes, indoor air pollution from cook stoves, or smoking. Patients with previous, inadequately treated TB are at a risk of suffering from recurrence at any time. TB

The National Strategic Plan highlights the lack of awareness in communities about TB diagnostic and treatment facilities.

Figure 7: State wise total notification from January - December 2018.
Source: Central TB Division, Ministry of Health and Family Welfare



A major challenge in TB care is delayed diagnosis and inadequate treatment, particularly amongst patients seeking care from private providers.

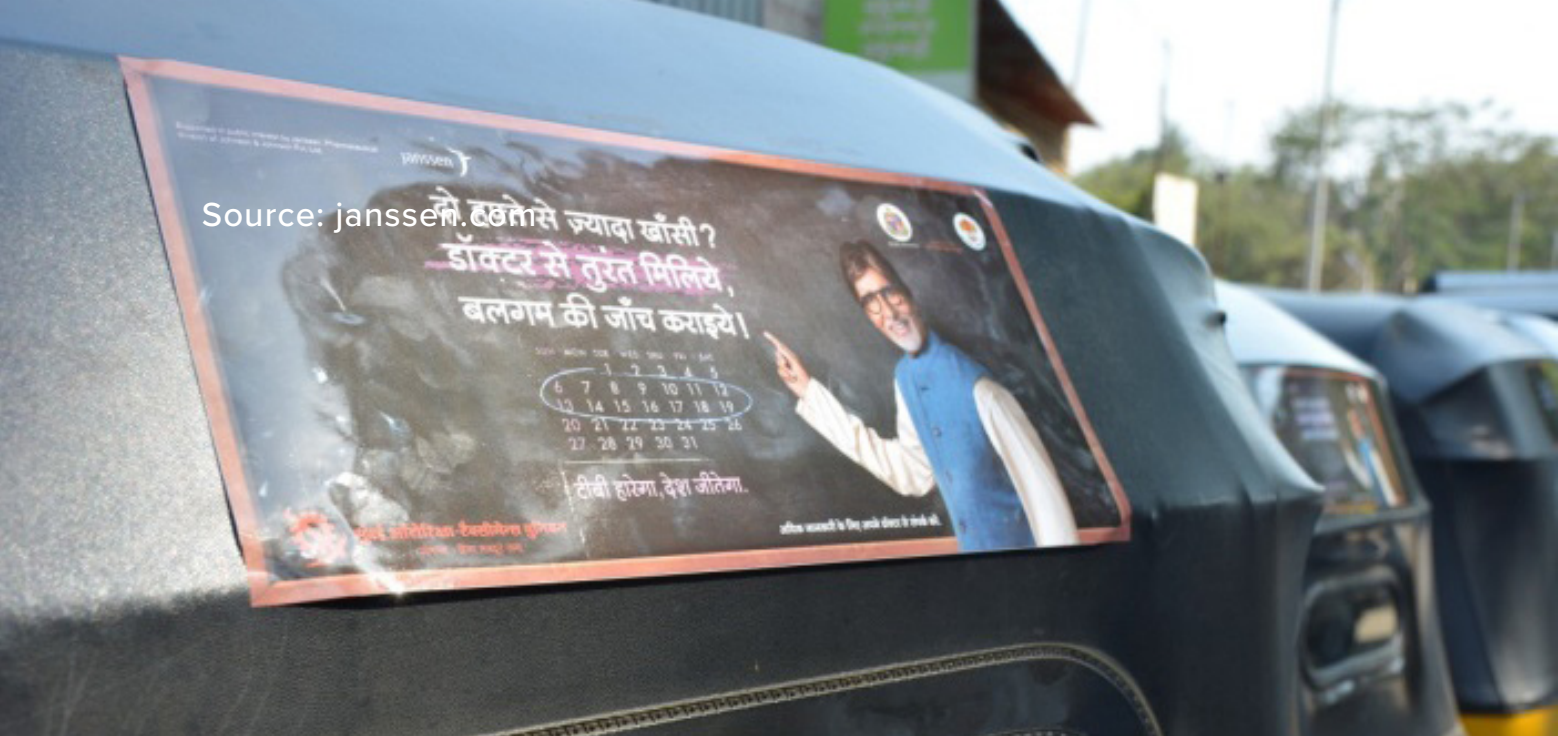
patients spread the bacteria to their families and communities, perpetuating the age-old cycle of transmission and risk. Social habits and behavioral habits like following cough etiquettes, and spitting and sneezing without a mask are factors that feed the problem of transmission.

A major challenge in TB care is delayed diagnosis and inadequate treatment, particularly amongst patients seeking care from private providers. Private providers are ill equipped to sustain their patients on prolonged, costly treatments. Currently, the government has little information on the treatment practices, adherence and outcomes from the private sector.

Patients spread the bacteria to their families and communities. Social and behavioral habits like following cough etiquettes, spitting, and sneezing without a mask are factors that feed the problem of transmission.

The NSP also highlights the lack of awareness in communities about TB diagnostic and treatment facilities. Furthermore, it is also difficult to keep track of the transmission and treatment in the migrant and tribal population.

Source: janssen



To raise awareness and encourage patients to seek treatment, RNTCP launched a nation-wide awareness campaign, “TB Hareha, Desh Jeetega” (TB will loose, the country shall win), using the Indian actor - Mr. Amitabh Bachchan.



PILOT STUDY

A look into the structure, protocol and incidence of Tuberculosis in a district ward located in the city of Mumbai.

Drawing a focus to the state of Maharashtra, situated in western India, it is the second largest state in India, with a population of 118 million. There are 79 district-level reporting units under the Revised National TB Control Programme (RNTCP), which has its headquarters in Mumbai, the city with the highest burden of MDR-TB in India. With a population of approximately 14 million, 50–60% of whom live in overcrowded slums with extremely poor hygiene, sanitation and ventilation, Mumbai (along with Pune) has emerged as a major center for multi and extensive drug resistant TB in the country. This has been documented by numerous studies in the last decade.^{[24][25]} Mumbai remains a major hub for TB in India with 45,675 new cases of drug-sensitive TB and 4,891 cases of multidrug-resistant TB reported between 2015 and 2017 by Brihanmumbai Municipal Corporation (BMC).

Given the protocols and interventions the RNTCP follows and the challenges it highlights, in order to move forward with the research and to gain a first-hand understanding of TB care under RNCTP, it was important to speak with the front line health workers on the field.

The scope of the project is to conduct research and design a capacity building intervention for the TB care setting in Mumbai, Maharashtra. BMC is the municipal body in-charge of the city. Given the high population of the city, in order to serve better, it has been divided into 23 wards. Each ward has a BMC head office.

The District Head Office is responsible for all duties that the BMC fulfills in a given ward.

The District TB Office exists under the District Head Office of the BMC. Every District TB Office has the organizational structure outlined in Figure 8.

The District TB Officer (DTO) is responsible for all facilities, patients and staff in their district. The Medical Officer (MO) is the only officer who is a clinician with a medical degree. The MO looks after the complex cases

Figure 8: Organizational structure at district TB offices in Mumbai

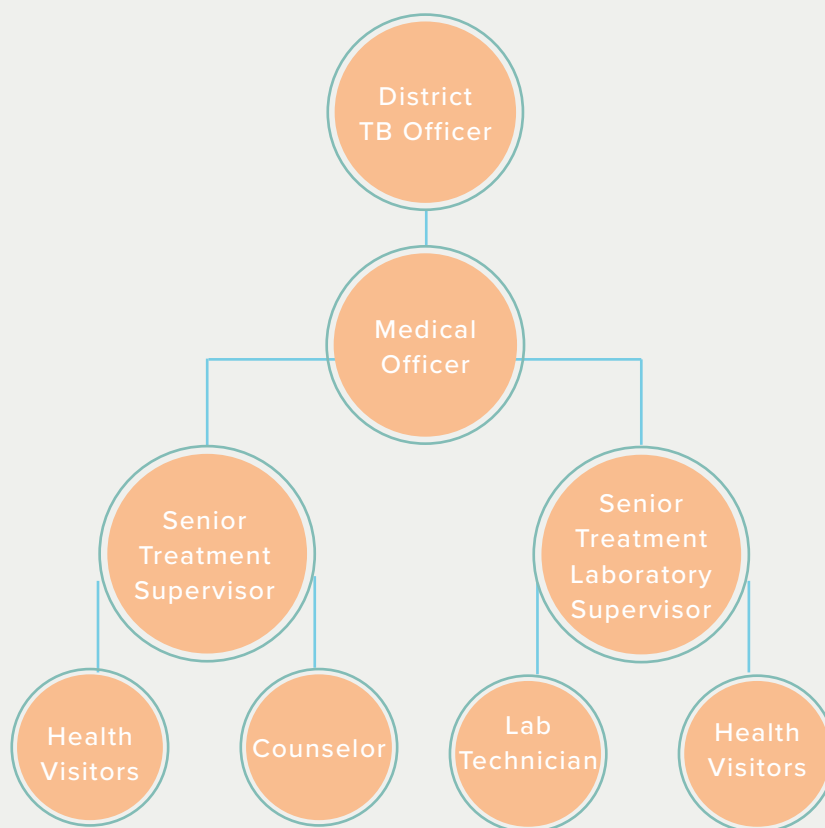
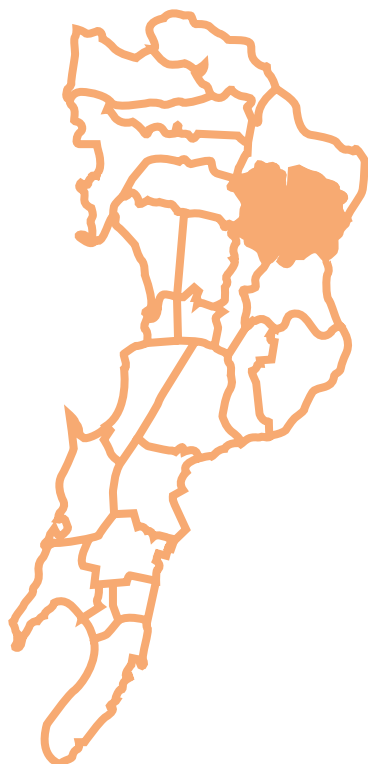


Figure 9: Map of Mumbai divided by Ward/Districts



An approximate of 1 million people reside in Vikhroli. According to the City TB Officer, Vikhroli has one of the highest incidences of TB in the city.

and counsels the health visitors and patients if they face medical emergencies or troubles. The Senior TB Laboratory Supervisors (STLS) oversee and are in-charge of all Lab Technicians (LT) who conduct various tests to diagnose patients. Senior Treatment Supervisors (STS) are directly in-charge of Health Visitors, who actively work on the field to retain patients, find new incident cases, dispense medicines, and follow-up with patients. Lastly, the Counselors, trained from the Tata Institute of Social Sciences, offer mandatory counseling to MDR-TB and XDR-TB cases.

As a pilot to Harvard Chan India Research Center's project, the City TB Office granted permission for qualitative data collection from the Vikhroli (S) Ward in Mumbai. The focus of the pilot study is to better understand the organizational structure, roles, responsibilities and challenges faced by the staff members.

An approximate of 1 million people resides in Vikhroli. According to the City TB Officer, Vikhroli has one of the highest incidences of TB in the city. Vikhroli has two high-risk/burden areas - both around and inside encroached settlements. Figure 9 shows the map of Mumbai and highlights Vikhroli's geographical location in the city. The area is prone to migrant population coming in from the East.

Vikhroli also houses two lakes that hold a majority of the city's water supply. Surrounded by mountains and hills, the area is prone to landslides, making settlements around these areas a hazard. Figure 10 shows the geographical representation of the same.

Figure 10: Geographical representation of Vikhroli

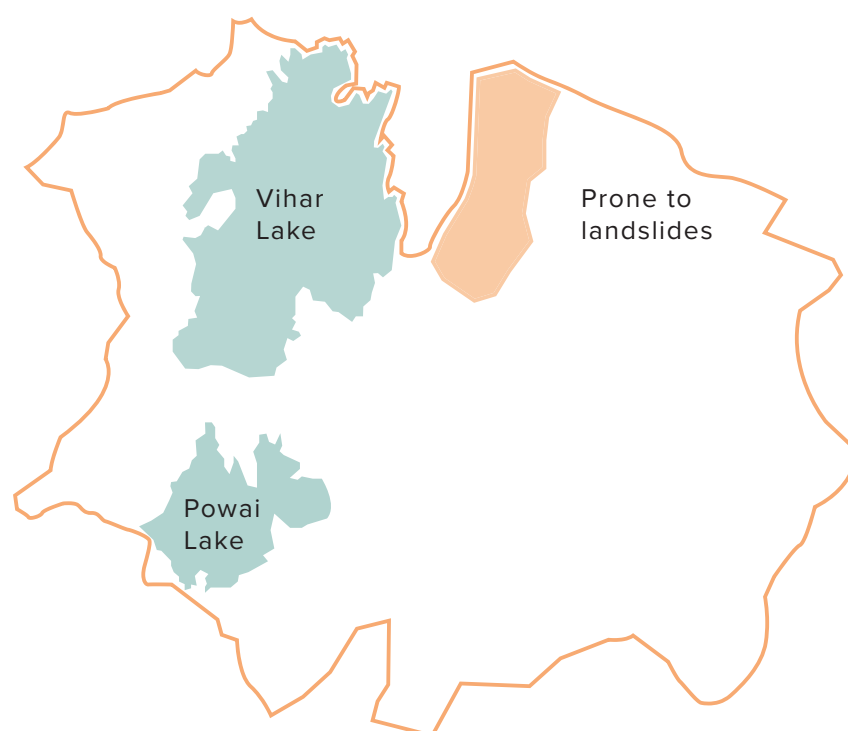


Figure 11 highlights all the crucial facilities that the BMC provides and their locations within the boundaries of Vikhroli. These facilities include public transport (buses and trains), law enforcement, fire department, schools and shelters, and hospitals. After understanding the geographic landscape of Vikhroli and the facilities that the BMC provides, the next step involved mapping the TB care facilities that are a part of the RNTCP. Vikhroli has a total of three DOTS centers (dispensary) and three microscopy centers (diagnosis) as shown in Figure 12. The District TB office houses one DOTS center.

The TB care system in Vikhroli includes 2 STLs, 3 STSs, 10 HVs, 1 MO and 3 Counselors

The Vikhroli TB care system includes 2 Senior Treatment Laboratory Supervisors, 3 Senior Treatment Supervisors, 10 Health Visitors, 1 Medical Officer, and 3 Counselors. With only 10 Health Visitors to cater to a

Most of the facilities and TB care centers are placed alongside the railway line. Even though this placement might provide easier access to patients/health visitors travelling along the line, it does not provide easy access for people who reside away from this linear line.

population of over 1 million people, accessibility and patient follow-up are key challenges. In order to understand the accessibility of the DOTS/Microscopy centers for the population and the challenge of visiting patient homes and communities, the three maps were combined onto one (Figure 13).

The map in Figure 13 shows that most of the facilities and TB care centers are placed alongside the railway line. Even though this placement might provide easier access to patients/health visitors travelling along the line, it does not provide easy access for people who reside away from this linear line. Though accessibility may be a challenge, a larger question that looms is - are people aware of the programs and facilities available, how to avail them, and where these health facilities in the public sector are located?

Figure 11: BMC facilities in Vikhroli

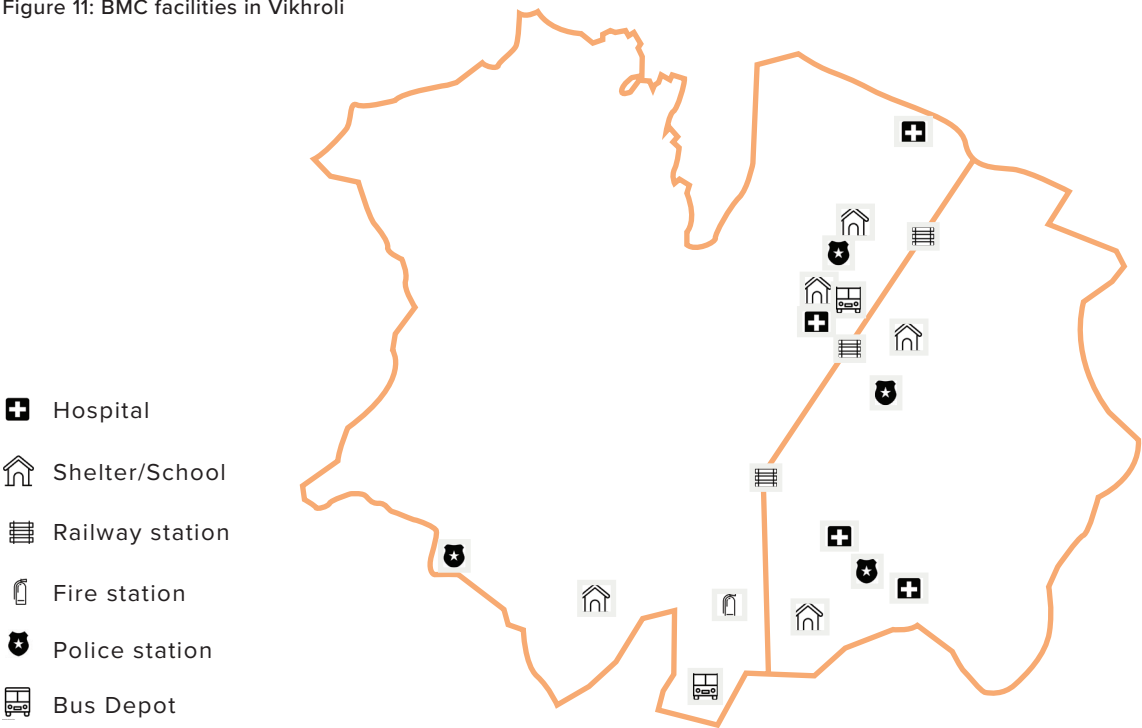


Figure 12: TB facilities in Vikhroli

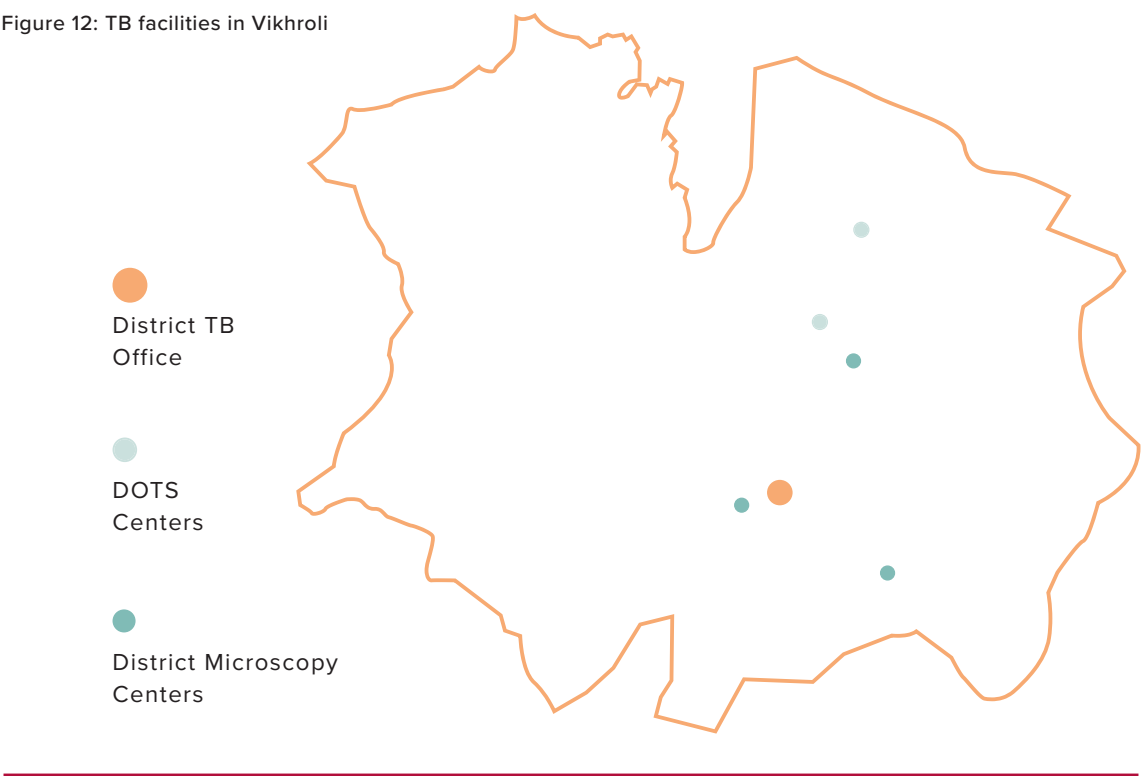
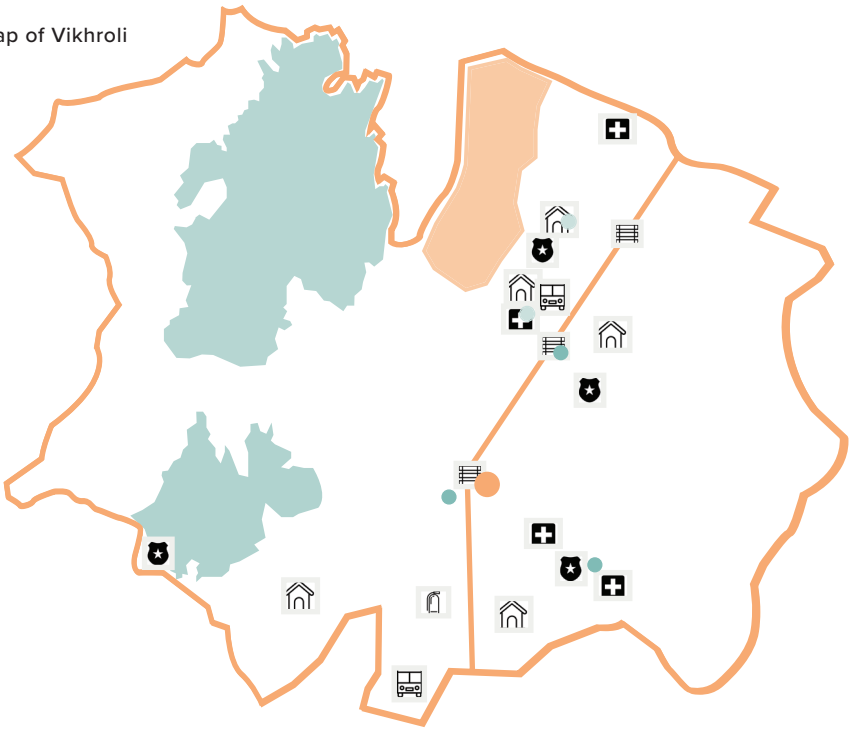
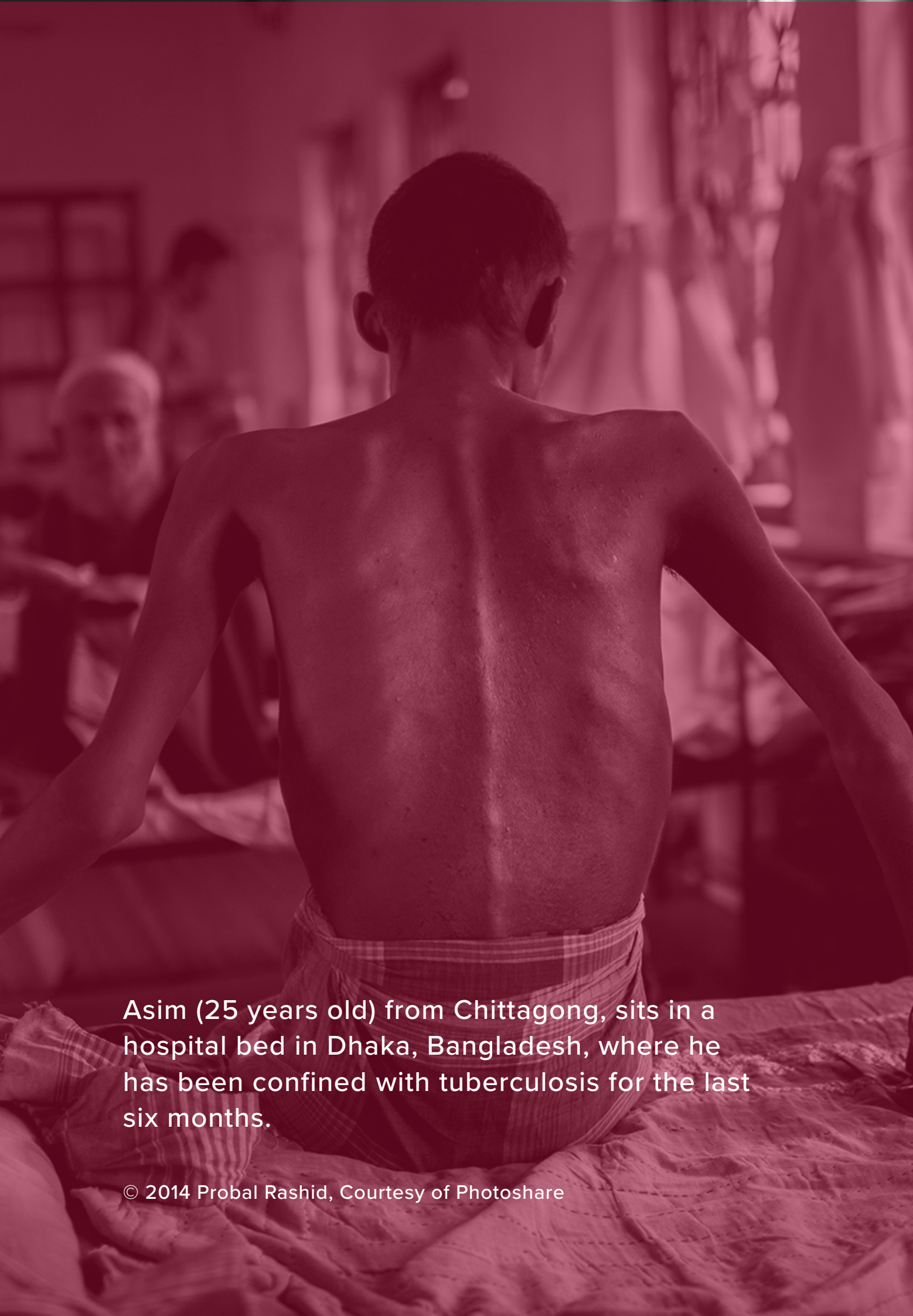


Figure 13: Comprehensive map of Vikhroli



The next section is a collation of all qualitative primary research collected to a gain first-hand insight into the public sector system of TB care and understand the challenges it faces.

**Are patients aware
of all the services &
facilities that the
Revised National
Tuberculosis Control
Programme offers?**



Asim (25 years old) from Chittagong, sits in a hospital bed in Dhaka, Bangladesh, where he has been confined with tuberculosis for the last six months.

© 2014 Probal Rashid, Courtesy of Photoshare

PRIMARY DATA COLLECTION

A collection of qualitative inputs gathered throughout the project with stakeholders working in the area of Tuberculosis care.

This section will disseminate qualitative inputs gathered throughout the course of this project. All inputs listed in this section are subjective opinions. They are not facts. No organization/stakeholder mentioned in this section is to be held accountable for their responses.

PANEL DISCUSSION

In August 2018, the Harvard Chan India Research Center held a Panel Discussion on Patient Retention and Tuberculosis. The aim of the discussion was to facilitate a dialogue between key stakeholders working in the area of tuberculosis care such as officers and health visitors from Brihanmumbai Municipal Corporation, Foundation for Medical Research, PATH and other research and implementation organizations.

The panel constituted of Dr. Sarthak Das, Research Scientist at Harvard T.H. Chan School of Public Health, Dr. Rati Godrej, Advisory Council Member of Harvard Chan India Research Center, Dr. Daksha Shah, City TB Officer from Brihanmumbai Municipal Corporation, and Dr. Nerges Mistry, Director of Foundation for Medical Research. The panelists disseminated their research and findings related to TB care and encouraged the participants to draw from their experiences as experts and recommend interventions in the following three

categories:

- Active Case Findings
- Patient Retention
- Private Sector Engagement

All the participants were divided into smaller groups to discuss these three areas and were given the chart in Figure 14 to record their inputs. The points below summarize the inputs/recommendations from the groups.

Figure 14: Chart distributed amongst working groups



**HARVARD
T.H. CHAN**

SCHOOL OF PUBLIC HEALTH
India Research Center

Patient Retention & Tuberculosis

Suggest 1 - 3 interventions under each category

01 Active Case Findings

02 Patient Retention (Along Cascade)

03 Private Sector Engagement

- Active Case Findings:**
- Community Awareness/Preparedness
 - Identify hotspots/clusters of high burden cases
 - Reducing stigma
 - Workplace education
 - Detection programs should be comprehensive
 - Patient counseling
 - Community engagement
 - Special TB OPDs - 1 stop center
 - Health visitors should dedicate time for ACF
 - Identify and engage different stakeholders
 - Better resource allocation

- Patient Retention:**
- Comprehensive knowledge on all aspects of TB care
 - Build a connection with the patient
 - Involve the family. Establish a buddy system.
 - Develop strategy for migratory population
 - Multi-sectorial approach - stakeholders should not exist in silos
 - One stop service/center
 - Patient oriented approach
 - Patient education
 - Identify high burden centers
 - Motivate patients
 - Case discussion with other Health Visitors

- Private Sector Engagement:**
- Regulate treatment practices in private facilities through legal compulsion
 - Free diagnosis and treatment in private sector
 - Supply the private sector with generic government issued drugs to discourage the use of branded ones
 - Must be made to follow WHO guidelines
 - Educate and engage medical schools



These images were taken during the panel discussion.

The image on the top shows a panelist presenting her research findings to the participants. The image below captures the participants discussing their inputs.

It was apparent from the initial research and inputs from the panel discussion that the front line workers are the key to understanding the TB cascade.

It was apparent from the initial research and inputs from the panel discussion that the front line workers are the key to understanding the TB cascade. The goal of the project is to design an intervention that would help the health visitors with case management and patient retention, and as a part of the baseline assessment, focus group discussions were held with supervisory staff members from the Vikhroli ward; along with a semi-structured interview with one health visitor. In order to gain a deeper understanding of the workers daily work routines and burdens, questionnaires were drafted keeping the entire TB cascade of care in mind. The questionnaires were then reviewed by the Foundation for Medical Research during a focus group discussion.

FOCUS GROUP DISCUSSION WITH FOUNDATION FOR MEDICAL RESEARCH - A STAKEHOLDER WALKTHROUGH

The Foundation for Medical Research (FMR), established in 1975 is a Public trust and a recognized national research organization by the Government of India. FMR works in the fields of biomedical and translation research. Their research focus areas are leprosy, tuberculosis, medicinal plants, environmental health, and malnutrition. Within the area of tuberculosis, FMRs research contributed towards creating a warning about the high levels of multi-drug-resistant TB in Mumbai. Their current work aims to reduce TB transmission by airborne infection control practices.^[26]

As a collaborative partner organization to

the larger project on Patient Retention and Tuberculosis with Harvard Chan India Research Center, for the purposes of the pilot phase, the team at FMR provided invaluable insights and examples to the questionnaires drafted for Health Visitors and Supervisors. Their team drew from their previous experiences of working in the area of tuberculosis, helped contextualize, and draw attention to important foci within each set of questionnaires.

The following is a list of inputs the team from FMR provided for the questionnaires:

Inputs for supervisors:

- What does the word “supervision” mean to the supervisors?
- How do they manage the HVs that work under them?
- Do they hold team building exercises or informal peer meetings to improve motivation among HVs?
- Can they provide an example of a case where they were successful and unsuccessful in supervising HVs?
- What are some of the challenges they face as Supervisors?
- How is an HV hired? What is the induction training like?
- Do the HVs have the option of career progression within RNTCP?

Inputs for health visitors:

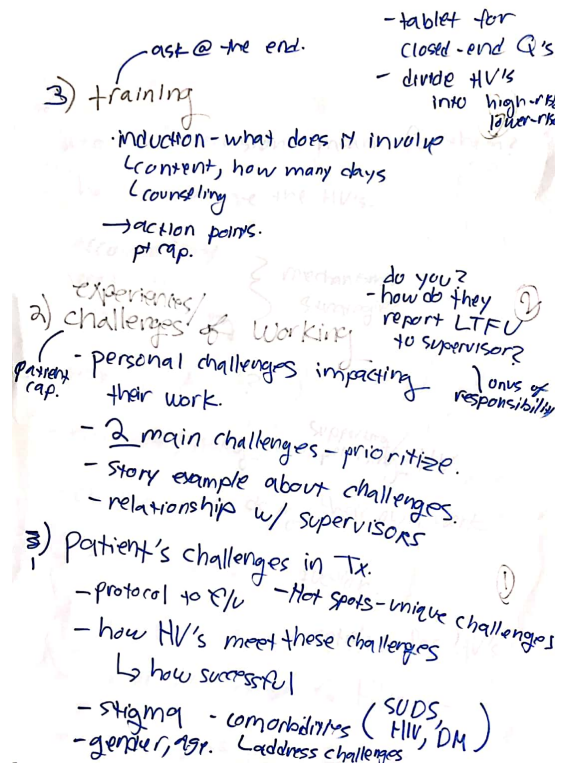
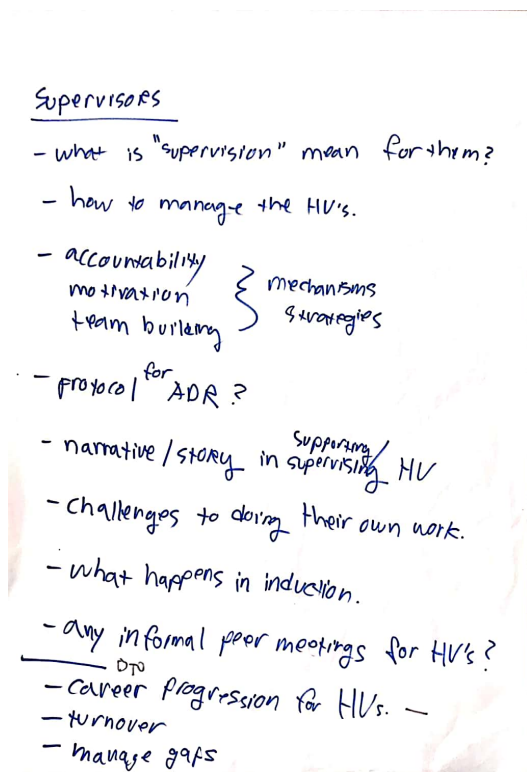
- What are the personal challenges they face as health visitors?
- How do they meet/curb these challenges?
- What is their relationship like with their supervisors?
- What is their strategy when dealing with patient and communities from high-

burden areas?

- A valuable input involved re-ordering the line of questions in the draft. It was suggested that questions related to experiences and challenges of working as health visitors should be asked first. The second set of questions should focus on protocols and challenges with patient retention. To conclude, the third set of questions should be designed around the training they have received as HVs.

Keeping these inputs in mind, the questionnaires were modified. The full questionnaires and summaries of the responses can be found in the following sections.

The images show the raw inputs enumerated during the discussion.



FOCUS GROUP DISCUSSION – SUPERVISORS

Three team members conducted the focus group discussion with a group of six supervisors (STS and STLS). A team member enumerated all responses. The participants who signed the consent forms were a part of the discussion. All participants will remain anonymous.

Opening Question

I would like you to take a couple of minutes to think about your experience in supervising the health visitors and caring for TB patients in this ward. Would anyone like to share his or her experience?

Discussion Questions

1. I would like to learn about your experience in supervising health visitors.

- What do you perceive to be the three main challenges that health visitors face in doing their job?
- What does supervision of Health Visitors mean to you?
 - What supervisory support do you provide the health visitors to help them effectively accomplish their job?
 - Do you regularly interact with them?
Do you have regular review meetings?
- Are health visitors able to regularly reach out to you for help?
 - What are the common issues and/or complaints that arise?
 - Give an example of when a health visitor reached out to you for support?
What did you do?
- What additional support and resources do you believe health visitors need to more effectively accomplish their work?
 - Are there specific skills or content areas that you believe need further strengthening?

2. I would like to now learn about your experience in training health visitors.

- What are the current methods of training the health visitors?
 - Who is responsible for training the health visitors?
 - Are the trainings conducted on a one on one vs. group basis?
 - When do the trainings take place and how often?
 - What are the specific content and skills covered in this training?
- Are there any challenges in providing effective training to the health visitors?
- In what ways do you think that the trainings can be improved?
- Do you feel that you have enough support and resources to provide these trainings?
 - Do the trainings compete with your other tasks and responsibilities?
- How do you monitor the quality of the health visitors?
 - Are there any accountability mechanisms in place to ensure quality?
 - Do you provide any follow-up training sessions to refresh material and/or provide new material to ensure quality?
 - How do you address the challenges related to difference in caseload within health visitors? What kinds of support do health visitors need and then are delivered for the same? How does it comprise the quality of care that is delivered?
 - How often do you meet health visitors? What kind of complaints usually received from the health visitors? Would you report complaints and challenges faced by health visitors in Monthly TB Review Meeting with District TB Officials?
 - Tell us an example of how successfully

fixed a problem raised by the Health Visitors in management of TB patients in the field.

3. Now, I would like to learn your perspective regarding patient retention in TB care.

- What do you perceive to be the main challenges that patients face in completing TB treatment?
 - Are these challenges different for DS-TB vs. DR-TB patients?
 - What are the major comorbidities (Alcohol, diabetes, HIV)? How do these affect TB treatment?
 - Are the challenges different for high-risk vs. low-risk areas?
- How do you strategize to meet these challenges?
- What further support do you need as supervisors to meet these challenges?
- What further support do the patients need in completing their treatment?
- How do you track whether patients are regularly taking their medications?
 - When patients are not adhering to treatment, what is the follow-up strategy?
 - Can you please share an experience where you retrieved a defaulted TB patient (lost to follow-up) back into the system?

Concluding Question

Of all the things we had discussed today, what would you say are the three main ways to support Health Visitors? What is your role as a supervisor to facilitate this?

Responses:

The discussion started off with a round of introductions where each participant shared the number of years they have been working in TB care. Some participants were health visitors and lab technicians when they started work, and were later promoted in their current supervisory role after gaining 12-15 years of experience.

1. Experiences of supervising health visitors

Health visitors face major challenges while making field visits in Vikhroli because of the geographically large area with multiple slum pockets - which are difficult to access. Their quality of work, including quality of administrative tasks, differs due to the inconsistent HV to patient ratio. Drug availability is another major challenge. Some of the participants claimed that they receive untimely distress calls from health visitors often.

2. Training of health visitors

Health visitors are first trained during initiation. They receive a refresher-training course every two/three years or every time there is a new protocol in place. Health visitors have to report to their respective supervisors every 15 days without fail. The amount of work that the health visitors are tasked with is daunting. There is a desperate need for additional staff members. Health visitors also need to be motivated and empowered to carry out their tasks. In any given situation the focus is always the patient, but what about the people who treat these patients? A lot of people are scared of patients with TB. They fear contraction. HVs are always in close contact with patients. It is important that they are regularly screened for TB as well.

3. Perspective on patient retention

It is important to diagnose patients as early as possible so that their treatment can be initiated. Patients have more faith in large hospitals

like KEM or Tata Memorial. They do not trust the local health center. A one-stop center in each ward would fast track the entire process of diagnosis and treatment initiation. Another possible intervention is creating a 24-hour Out-patient Department in each ward that will be open to patient queries, grievances, and concerns. This would be particularly helpful for patients who present side effects of the drugs - and thus stop treatment. However, both these interventions might further stigmatize patients and those around them. On another note, patients with problems like alcoholism should be counseled more often.

In conclusion, when the supervisors were asked about ways in which health visitors can be better supported, they had the following suggestions:

There is a need for grassroots motivation. Health visitors should be recognized for the work they do. Their work should be incentivized. They should be provided with better information, education and communication. Health visitors should also be regularly screened for TB. In order to reduce their workload, every patient should have a patient profile - so that they are easy to track. The Direct Bank Transfer for monetary support could involve the use of TB ATM Cards - this again would reduce the workload of Health visitors. Lastly, non-governmental organizations should engage with the public sector in order to help reduce the burden of cases.

In order to reduce their workload, every patient should have a patient profile - so that they are easy to track.

SEMI STRUCTURED INTERVIEW – HEALTH VISITOR

One health visitor was interviewed. As per the permissions granted by the BMC, all responses were enumerated. The participant will remain anonymous.

Questionnaire

1. I would like to learn about the experiences you have had during your training to become a health visitor

- Why did you decide to become a health visitor?
 - How did you get this job?
 - How did you apply for it?
- What kind of training did you receive when you first joined the job?
 - How equipped did you feel after these trainings?
 - Where and how were these trainings delivered?
 - Have you been able to apply the skills learnt?
- Do you want to give any feedback on the trainings you received?
- How would you improve the training you received?

2. I would now like to learn about your experiences of working here

- What does a typical working day look like for you?
 - Timings
 - Working conditions
 - How much of your time do you spend on doing clerical work, making house visits, and in the lab?
- How many cases do you manage on a daily basis?
 - Do you think the caseload is proportionate to the resources and time available?
 - If not, does the excessive caseload compromises the quality of care or

3. I would like to understand your perspective and experiences with patient retention in Tuberculosis care

- infection control being provided?
- Do you have enough resources/ support to reach all your patients?
- What kind of support do you need to care of all the patients? If so, how is it difficult for you to reach the patients?
- What are some of the challenges you face as a health visitor?
 - Do you feel supported by your supervisors?
 - Whom do you go to when you run into trouble?
- What is rewarding about this job?
 - Are you satisfied with the work that you are doing?
 - What can the facility do to better support your work?
- What would you say are the main barriers/challenges that patients face in taking treatment consistently?
 - What are the cultural barriers in patient retention?
 - Are there any challenges that only a specific demographic group faces?
- Can you tell us about a time when one of your patients were lost to follow up?
 - What are some of the main reasons for patient drop out in Tuberculosis care?
 - What strategies did you use to get them back on their treatment regimen?
 - What could you do prevent this from happening again?
 - Is it difficult to retain patients from the high-risk areas (slums & red-light areas)?
- Describe your relationship with your patients?

- What are the attitudes of the patients to wards you?
- How are you respected or disrespected during your visit?
- What is your interaction and relationship with the patient's family?
- Are they under pre-cautionary medication/protocol to avoid getting infected?
- What is their relationship with the patient?
- Do you counsel them as well?

Responses:

The participant has been working as a Health visitor for the past 12 years. She has a total of 102 patients under her care - 44 of which suffer from MDR-TB.

Typical Working Days:

- The health visitor begins a typical working day by overviewing the adherence status of all her patients through the NIKSHAY app. Throughout the day, she follows up with 10-15 patients who have been irregular with their treatment.
- On designated Out-Patient Department (OPD) days, the health visitor refers new patients for diagnostic tests (X-ray and Gene Expert) to the District Microscopy Centre. Patients who are enrolled on the 99DOTS program come to collect the next course of pills from the participant. Lastly, the health visitor follows-up with patients who did not collect their next course of the pills on this given day.

Private Practitioner:

- All government hospitals like KEM and Tata Memorial often refer patients to her because she has been working as an health visitor for over 12 years; most

The challenge with private practitioners is that they prescribe medicines but do not follow-up with the patient.

In the public sector, if someone presents with cough symptoms, the HV immediately screens for TB; but private practitioners prescribe cold and cough medicines for 4/5 days.

private practitioners and hospitals in the area know her personally.

- The challenge with the private sector, she explained, is that private practitioners treat patients but do not follow-up. More often than not, when they cannot handle a particular case or cannot make a diagnosis, they refer the patient to the health visitor. Furthermore, she has observed that private practitioners do not always explain the severity of the disease to the patients. The relay of information is not constant.
- In the public sector, if someone presents with cough – the participant immediately screens for TB; but PP prescribes cold/cough medicines for 4/5 days and ask the patient to follow up – this delays diagnosis and treatment.
- As an example to further elaborate these challenges, the participant spoke about the case of a young college girl. The girl's Gene expert and sputum microscopy tests were negative. Only after scanning her lungs with an X-ray they discovered that she had TB. In order to start her on the treatment, the health visitor needs the Medical Officer and District TB Officer to sign off. The health visitor asked the girl to visit the health center on particular days when both the Medical Officer and District TB Officer were present. The girl would almost always come on the days when both these individuals were not present. After regular insistence and follow-ups with the girl, the participant was informed that she had started her treatment with a private practitioner. After 6 months of treatment with the private practitioner, the girl developed MDR-TB.

Patient Initiation:

- The health visitor follows a protocol when it comes to initiating patients on treatment.
- All new patients need to be registered within the RNTCP programme.
- The health visitor visits the patients home to map the exact geographic location.
- The following information is relayed to the patient:
 - The duration their treatment will last (usually 6/8 months in DS-TB cases)
 - The importance of taking the pills regularly, and that if stop the treatment midway, they will still continue to live with TB and will develop MDR-TB – where the treatment lasts for 2 years.
 - Explaining that even though taking these pills might result in a few side effects, they should continue to take them because the side effects can be treated.
 - The health visitor also encourages the patient to contact them if they run into any problem during the course of the treatment. If the case grows complicated, the health visitor refers the patient to the Medical Officer.
 - Patients are told to eat foods with higher protein values to boost their immunity.
 - If the patient qualifies for the nutrition supplement program and monetary incentive program, the health visitor explains the protocol of both these systems.
 - The patient must wear a mask to prevent transmission of the disease, especially when sleeping at night. The patient is also asked to sleep in a ventilated room with open windows.

The patients are told to continue their medication even if they develop side effects to the drugs because their side effects can be treated.

- 2/3 weeks after initiation, the health visitor will visit the patient's home again to assess whether anyone within close proximity to the patient has been infected with the disease.

99DOTS Program:

- Only DS-TB patients are eligible to enroll in the 99Dots program. These patients visit the health center to collect the medicine once in every 28 days.
- DR-TB patients are enrolled in the 99DOTS Plus program – where they have to visit the health center to collect medicines once every 10 days.
- Before the DOTS program, patients would have to come to the health center every single day to collect the pills.

NIKSHAY - Application:

- NIKSHAY is used a platform to monitor treatment adherence. The app shows each patients name and treatment history.
- The color red shows that the patient has not taken the medicine. Dark green reflects that the patient has given a missed call on the toll-free number. Light green is reflected when the HV follows up with a patient personally to ensure that they have taken the pill – and then feeds the confirmed yes into the treatment calendar.
- The patients do not have access to this app
- About 10% of the patients do not have phones. However at least one other member in their families does.

Patient Retention:

- The health visitor explained that guiding the patient is extremely important. The patient is educated about problems with side effects and transmission to others.

It is important to change a patients mentality towards seeking and adhering to treatment.

- In her experience, the health visitor has observed that the private practitioners do not inform patients about wearing a mask to prevent transmission.
- Some of the major challenges the health visitor faces when it comes to patient retention are:
 - The patients need to be persuaded and convinced to adhere to treatment
 - Due to the influx of patients on OPD days, the health visitor would manually write down the names of the patients who have visited to collect the next batch of medicines, however their supervisors (STS) do not refer to the manual notes and need everything to be digitized into the NIKSHAY app. The health visitor therefore spends more time finishing clerical tasks.
- According to her, it is important to influence and change a patient's mentality towards treatment.
- When following up with patients, if they do not answer the participants call, she has to make a house visit. The health visitor needs to be 100% certain that the patient has taken the pill for the day in order to feed this data into her app.

- Family:**
- During initiation, when the health visitor visits the patient's home, she counsels the family to keep an eye out for symptoms amongst them. If anyone of them develops a symptom, they should inform her immediately.
 - Family counseling sessions are held twice a month.
 - Irrespective of adherence follow-ups through the NIKSHAY app, the health

visitor holds a meeting with every patient once a month.

- Community meetings are also organized in high risk or high burden areas.

Nutrition:

- If the patient is eligible for nutrition supplementation, they receive staple foods like lentils, rice and jiggery among others.
- Unhealthy eating habits weaken the immune system. The health visitor advises all family members to eat healthy along with the patients.

Training:

- The health visitor has been trained 5/6 times over the course of 12 years.
- She has gone through training during initiation as a health visitor and had to write an exam to qualify as a health visitor.
- Each time a new protocol is implemented, the health visitor received specific trainings. These include:
 - DOTS program training when the protocol was implemented.
 - Personality development training in 2008
 - 99DOTS + training for MDR-TB cases
 - Training for XDR-TB
 - She went through a round of trainings when Bedaquiline (tablet) for MDR-TB patients was introduced. This pill is known to have severe side effects like side effects include nausea, joint pains, headaches, chest pain, and liver dysfunction.
 - Using the digital tablet
- When she first started work as a health visitor, ANMs/Health Post staff would do most of the work that an HV does today. ANMs and health post staff member trained the participant.

Challenges Faced:

- Though she wears a mask while interacting with patients, the health visitor is not screened for TB.
- Every time the health visitor wishes to take a leave, she must inform all her patients and ask them to collect their pills before she leaves.
- Clerical work has increased. A health visitor role would only involve finding defaulter patients and initiating them back on treatment. They are now tasked with: dispensing pills, counseling, patient follow-ups, initiation, provide nutrition supplements, initiate direct back transfers for monetary support (take back account details) and go for house visits.
- Constantly remind patients to collect their money/supplements

Access To Health Center:

- Patients have trouble finding the health center. A lot of patients who have been referred by private sector claim that they only approached a private practitioner because they did not know where the public health center was located and what kind of treatment/diagnostic services they provide.
- Community health visitors (CHV) visit high-risk areas frequently. Potential patients ask the CHVs for the location of the nearest health center.
- Some of the health visitor's long-term patients diagnose others with similar symptoms and refer them to her.

A large number of patients claim that they approached a private practitioner because they did not know where the public health center was located and the kind of diagnostic/treatment services they provide.

In conclusion, the health visitor claimed that the number of MDR-TB cases is rising. Even though, she doesn't feel as respected as a private practitioner, she is dedicated and committed to her work.

SEMI STRUCTURED INTERVIEW – PATIENT

*One patient was interviewed for the pilot.
The patient is a 21-year-old male, who will remain anonymous.*

Questionnaire

1. **I would like to start by understanding your journey as an individual and how you were diagnosed with TB**
 - When were you diagnosed with tuberculosis? What was your diagnosis?
 - How and why did you decide to approach a healthcare provider? What were your symptoms?
 - Do you know how you contracted the bacteria? Which part of your body is the bacteria affecting?
2. **I would now like to know how you were initiated into the treatment regimen by your health care provider**
 - Are you currently seeking care from the private sector or the public sector, and why?
 - Were you aware about the public sector's program that provides diagnostic and treatment facilities to patients at no cost?
 - Did your healthcare provider educate you about tuberculosis, the side effects of the drugs, and the requirement for your treatment regimen?
 - Did the healthcare provider counsel your family/friends?
3. **Now, I would like to gain a deeper understanding of your treatment regimen**
 - What is your current treatment regimen?
 - How long have you been on this treatment?
 - Do you see an improvement in yourself?
 - Do you remember to take your pills everyday?
 - Does your healthcare provider remind you?
 - Have you forgotten to take your medicine on a particular day? What was the reason behind this?

- Are you enrolled on the 99DOTS program?

4. Challenges faced

- To conclude, what would you say are the three major challenges you continue to face as a patient?

Responses:

Diagnosis: The patient was diagnosed in May/June 2018 with tuberculosis. The patient first noticed a drastic loss in his body weight even though his diet remained the same. The patient's limbs started losing muscle fat. Furthermore, he felt a few lumps in his neck. When patient consulted his mother about these changes, he was offered home remedies such as applying turmeric on the lumps. When the home remedies did not show any improvement, they consulted a healthcare provider in a private hospital. After completing the initial tests, it was found that the bacteria were attacking the patient's neck and not his lungs. The patient was diagnosed with Tuberculosis Lymphadenopathy.

Treatment Initiation: The patient was seeking care from the private sector. He has switched two private practitioners since his diagnosis. Both these healthcare providers did not educate him about the side effects of the drugs. Currently, due to the side effects of the drugs, the patient faces stiffness in his joints (knees, knuckles and lower back). His family used online sources to educate themselves on tuberculosis.

The patient is now in the process of switching to the public sector to seek treatment. With his current treatment

regimen, he spends Rs.20,000 every month to purchase the drugs. These same drugs are available free of cost in the public sector. Now in the public sector, he is going through the microscopy tests again. The patient is not enrolled in or aware of the 99DOTS program.

Treatment: The patient was started on the four first-line antimicrobial drugs. After 4 months of adhering to this treatment, he grew resistant to the drug called rifampicin. Though he showed improvements during this period, eventually the drugs stopped working on him due to the resistance. The patient is now on a new set of medication that includes taking pills after every meal along with an injection everyday. To be injected, he needs to visit his doctor everyday. He also follows a strict diet and exercise plan that comprises of consuming foods that are high in protein and energy. His yoga instructor devised this diet plan. His current treatment regimen will continue for the next two years.

The patient almost never forgets to take his pills on the current treatment. There have been instances when the medication was unavailable to purchase due to a nation-wide shortage. Due to this, the medication had to be imported and resulted in the patient missing a few days of treatment.

He, however, did forget to take his pills regularly before he developed resistant to rifampicin. The patient was not aware about the importance of taking the drugs every day. Furthermore, due to the continuous nature of the treatment, the patient thought missing a day or two of the treatment would

The patient was not aware about the importance of taking the drugs every day.

Due to the continuous nature of the treatment, the patient thought missing a day or two of treatment would not cause any major problem

not be a problem.

When travelling, the patient needs to carry his medication with him and find healthcare providers in the location he is travelling to, in order to receive the injection.

Challenges: When the patient first started his treatment, a year ago, he would feel dizzy, sleepy and lazy. He also faced significant challenges with his locomotive skills. However, one of the major challenges that he has faced so far and continues to face is not being able to devote his time and mind to his work. He has to constantly juggle between following his diet routine, medication and work.

BODY STORMING

After conducting the focus group discussion and semi-structured interview with the supervisors and health visitors, respectively, I wanted to approach a health center from a new patient's perspective. The pilot study was only conducted in one of the twenty-three districts in Mumbai. I decided to locate the health center in the district that I reside in – Andheri West (K West Ward). I started by asking strangers where the District TB Office or health center is located in Andheri West. Unfortunately, I did not get an answer. As an alternative, I searched the BMC ward distribution online. While the BMC website displayed multiple facts about each ward, it did not have an address for the health center.

Every district/ward in Mumbai houses a BMC Headquarters for that area. I used Google Maps to find the headquarters in Andheri

The location of the public health centers is not easily available on the Internet.

West. Once there, I navigated through the building and went to the Health Department. I asked one staff member where the District TB Office in Andheri was. She handed me an address. Once I reached the address (Image 9), I realized that I drive by this building almost every day. I then asked a staff member where the nearest DOTS Center was. Again, I was handed an address. I was sent to a building across from the BMC Headquarters, where I was earlier. (Image 8)

While my judgment may be biased, through this experiment, I learnt that the location of these facilities is not easily available on the Internet. As an outsider, I had to travel to multiple locations before I reached a DOTS center. Even then, I would have to approach a Health Visitor in order to understand the protocols and facilities available under RNTCP.

Image 8: View of the DOTS center
from the BMC headquarters



Image 9: District TB Office

ACCESS TO HEALTH CENTERS

QUALITY OF SERVICES

What are the major challenges faced by all

stakeholder

groups?

RETENTION
ADHERENCE
RELAY OF INFORMATION

What can be done

to combat these

challenges?

DELAYED DIAGNOSIS &

TREATMENT

ACTIVE CASE
AWARENESS FINDINGS

CONTINUOUS
MEDICATION

STIGMATIZATION

PRIVATE SECTOR

AWARENESS ABOUT THE PROGRAM

INSIGHT GENERATION

A synthesis of the information gathered from primary and secondary sources such that they offer valuable insights.

SYSTEMS MODEL

With the data collected through primary and secondary sources, in order to gain a holistic picture, a systems model of the data was created. The model is divided into three main groups:

- Levels of tuberculosis – Symptoms, diagnosis and treatment options for each stage.
- RNTCP – Facilities offered by the public and private sector under RNTCP.
- Stakeholders involved – the roles of each stakeholder group in the system

The first category summarizes the key features of RNTCP for the public and private sectors. In the public sector, RNTCP offers all drugs and diagnosis facilities free of cost, engages with patients through regular follow-ups and counseling sessions, offers nutrition and monetary support to eligible patients, and conducts active case findings; however, there is a general lack of awareness about the program and its facilities. Under the private sector, even though, patient notification is mandatory, it is not followed religiously. Furthermore, treatment and diagnostic facilities are expensive, private practitioners do not follow-up or counsel patients, and the treatment practices are not regulated.

The second section on levels of tuberculosis outlines the different stages of TB starting from Latent TB Infection. A person with latent TB has only been infected with the

bacteria and is not contagious to others around them. People with compromised immune systems (diabetics, alcoholics, and smokers) are at a higher risk of getting infected. With Drug-susceptible TB (DS-TB), the patient presents with cough, chest pains, and weight loss as symptoms of the disease. DS-TB can be treated with a standard 6-month course of 4 antimicrobial drugs. If DS-TB is left untreated, it can progress into Multi Drug-resistant TB – which can be terminal. Lastly, Multi Drug-resistant TB can be detected with a sputum sample or x-ray. The treatment regimen can last for 2 years with expensive and toxic drugs.

The third and final category outlines the various stakeholders involved in Tuberculosis care under RNTCP. These stakeholders include patients, patient families, the community, health visitors, senior treatment supervisors, district TB officers, city TB officers, Government of India, and the society at large. The sub-category under each group outlines their roles and responsibilities in the system. For instance, a health visitor is responsible for dispensing medicines, patient counseling and follow-up, active case findings, patient initiation, house visits, and maintaining clerical records.

The first category summarizes the key features of RNTCP for the public and private sectors.

The second section outlines the stages of tuberculosis starting from Latent TB Infection.

The third category outlines the roles of the various stakeholders involved in TB care under RNTCP.

[Open the page to view the model](#)



Stakeholders

- Patients
- Patient's family
- Community
- Health visitors
- Senior Treatment Supervisor
- District TB Officer
- City TB Officer
- Government
- General Population

RNTCP

- Public sector
- Private sector

Levels/stages of TB

- Latent TB Infection
- Drug-susceptible TB
- Drug-resistant TB

STAKEHOLDER MAP

Given the large number of stakeholders involved and varied number of tasks each group is assigned with, a stakeholder map was developed (Figure 15). This chart outlines the relay of information between various stakeholders involved in the public sector program in Vikhroli.

As shown in the map, the health visitor is a vital member who is in contact with almost all other groups. The health visitor maintains relationships with:

1. Patients
2. Family
3. Local Community
4. Lab Technician
5. Counselor
6. STS
7. DTO
8. MO

The health visitor is vital stakeholder who is in contact with almost all other stakeholder groups

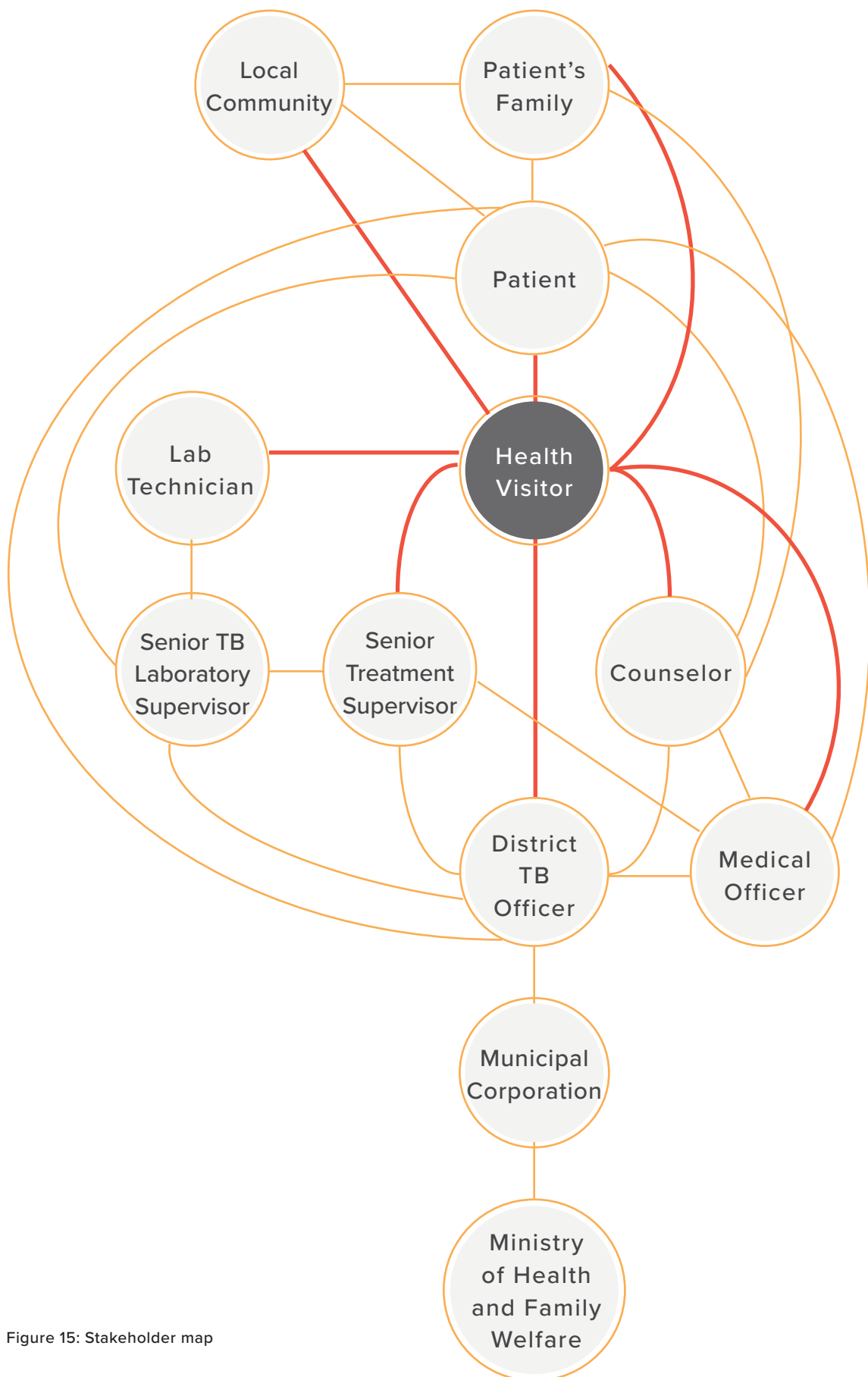


Figure 15: Stakeholder map

MENTAL MODEL

Health visitors and patients are two important stakeholders in sector of tuberculosis care. The following model outlines behavioral patterns of patients who present with symptoms and suspect they are infected with TB; and patients enrolled in the treatment program. The model also highlights the thoughts and behaviors of health visitors, as they relate to active case findings, and patient retention.

The blue blocks at the top of the diagram represent a behavior, emotion, or belief. These showcase what people are thinking, doing, and feeling in a given scenario. For instance, patient behaviors like denial, lack of awareness, neglect and fear have been mapped to understand the rational behind these thoughts.

The bottom half of the diagram represents the features, services, or products offered in the current system. For patients presenting with symptoms, the RNTCP has facilitated community engagement activities, active case findings, and communication campaigns to combat the feelings of denial, lack of awareness, and neglect.

[Open the page to view the model](#)



A TB health center in Bandra East, Mumbai

Patient Presents Symptoms

Denial

Scared to acknowledge

It's all in the mind

Alternative Medicine

Home remedies

Religious/Spiritual Interventions

Lack of awareness

Doesn't know what to do

Whom to consult

How to seek diagnosis/treatment

Proactive

Extensive Testing

Actively seeking healthcare providers

Patient on Treatment Regimen

Neglect

Laziness

Busy schedule

Forgot to take pills

Fear

Side effect of drugs

Scared of getting worse

Over-confidence

Feeling better after a few weeks

It is okay to miss treatment for a couple of days

RNTCP communication campaign

Community engagement

Active case finding

RNTCP communication campaign

RNTCP communication campaign

Community engagement

Active case finding

Online information

Private sector

Public sector

Free drugs/ diagnosis

99DOTS

Follow-up

House visits

Counseling

Initiation Information

Follow-up

Counseling

Follow-up

Health Visitor - Active Case Findings

Fear

Scared of contracting the bacteria

Time available

Clerical work

Scale of Operations

Geographically large areas

Fewer HVs

Access to slums

Health Visitor - Patient Retention

Time

Other duties

Clerical work

Forgot to take pills

Communication

Migrant Population

Unable to contact patient

HV-Patient ratio

Transfers from private sector

Walk-ins

Influx of patients

Wear masks

Designated OPD days

Allot time for ACF

Location mapping during house visits

Community engagement

99DOTS based prioritization

Home visits

Call to follow-up

99DOTS

INSIGHT GENERATION

The insights in this section have been derived from the systems model, mental model and stakeholder map. They have been clustered into three separate groups:

- Awareness – insights that are related to the general awareness amongst patients, health visitors, and the society.
- Behavior – Insights related to the stimulus reaction caused by behavioral patterns; or need better behavioral habits.
- Systemic – Insights related to nation-wide and system-wide challenges and opportunities.

The design of the chart is similar to a Venn diagram because it also presents insights that overlap between the three categories.

It is evident through the research gathered that a change in patient behavior, increased awareness about tuberculosis in various stakeholder groups, and improved systemic interventions would help health visitors with active case findings, patient retention, and a reduction in their workload. Keeping the scope of this project in mind, the following actionable insights were selected:

- People approach the private sector because there is a lack of awareness about the facilities and programs available in the public sector.
- Patients are unaware of the step-by-step progress they make by taking their medication everyday.
- Even with regular counseling and relay of information, patients do not realize the severity of their condition.
- A general lack of awareness in the

society regarding Tuberculosis has resulted in stigmatization of patients

- Patients stop their treatment when they start feeling better after a few weeks of treatment
- Patients stop their treatment if they start showing side effects to the medication.

It is evident through the research gathered that a change in patient behavior, increased awareness about tuberculosis in various stakeholder groups, and improved systemic interventions would help health visitors with active case findings, patient retention, and a reduction in their workload

Open the page to view the diagram



INTERVENTIONS DESIGNED FOR HEALTH VISITORS

Following the generation and selection of actionable insight statement, design interventions with similar foci were studied via secondary sources. The examples below are interventions designed to raise awareness, build capacity and inculcate behavior changes in health visitors.

Assisting community health workers in India – Dimagi's CommCare (Image 10)

Global Health experts have recognized the need for expanded and improved community health programming in order to reach vulnerable people. There exists a shortage of well-qualified health workers in India, particularly in rural areas. Less-skilled health workers must be mobilized for these efforts. ASHAs (accredited social health activists) contribute to improvements in maternal, newborn and child health outcomes. Similar to Health Visitors working in Tuberculosis care, ASHAs face challenges like increased workload, insufficient training, community engagement, and little feedback on performance.^{[27] [28]}

CommCare supports ASHAs by facilitating better data collection, decision support, tracking case management in real time, communications with clients and health center, and access to educational training material. CommCare has also been shown to increase the retention of health-related knowledge among ASHAs and to help them keep up with their scheduled visits.^[29]

Medical Aid Films (Image 11)

Medical Aid Films grew out of the experiences of Midwife Fiona Laird, working in a refugee camp in Darfur in 2006. Seeing babies dying needlessly from tetanus due to their cord being cut with a dirty knife, she sought a way to share simple but life-saving information with health workers and mothers in the community. They create collaborations between health experts and filmmakers to create engaging and accessible films. The films empower health workers and communities with vital knowledge and skills about women's and child health.

Mobile Kunji (Image 12)

Community health workers are crucial human resources to promote maternal health and reduce maternal and infant mortality. A major challenge that the health workers face across the state of Bihar is the lack of proper tools that can be used to convince the rural families on health prevention and treatment issues. In order to improve their role in healthcare service delivery, an innovative job aid called 'Mobile Kunji' was introduced. Mobile Kunji is an audio-visual aid that can be used to learn, share and practice 9-life saving maternal and child health behaviors. The aid includes a pack of 40 illustrated cards on a ring that communicate important messages related to health in rural settings. Each card has a unique number that can be used to access a pre-recorded audio message.^[30]



Image 10: Features and usability of CommCare

Source: World Health Organization

Image 11: Video still from a film on “Caesarean section 1 – Introduction and preparation for surgery”
Source: medicalaidfilms.org

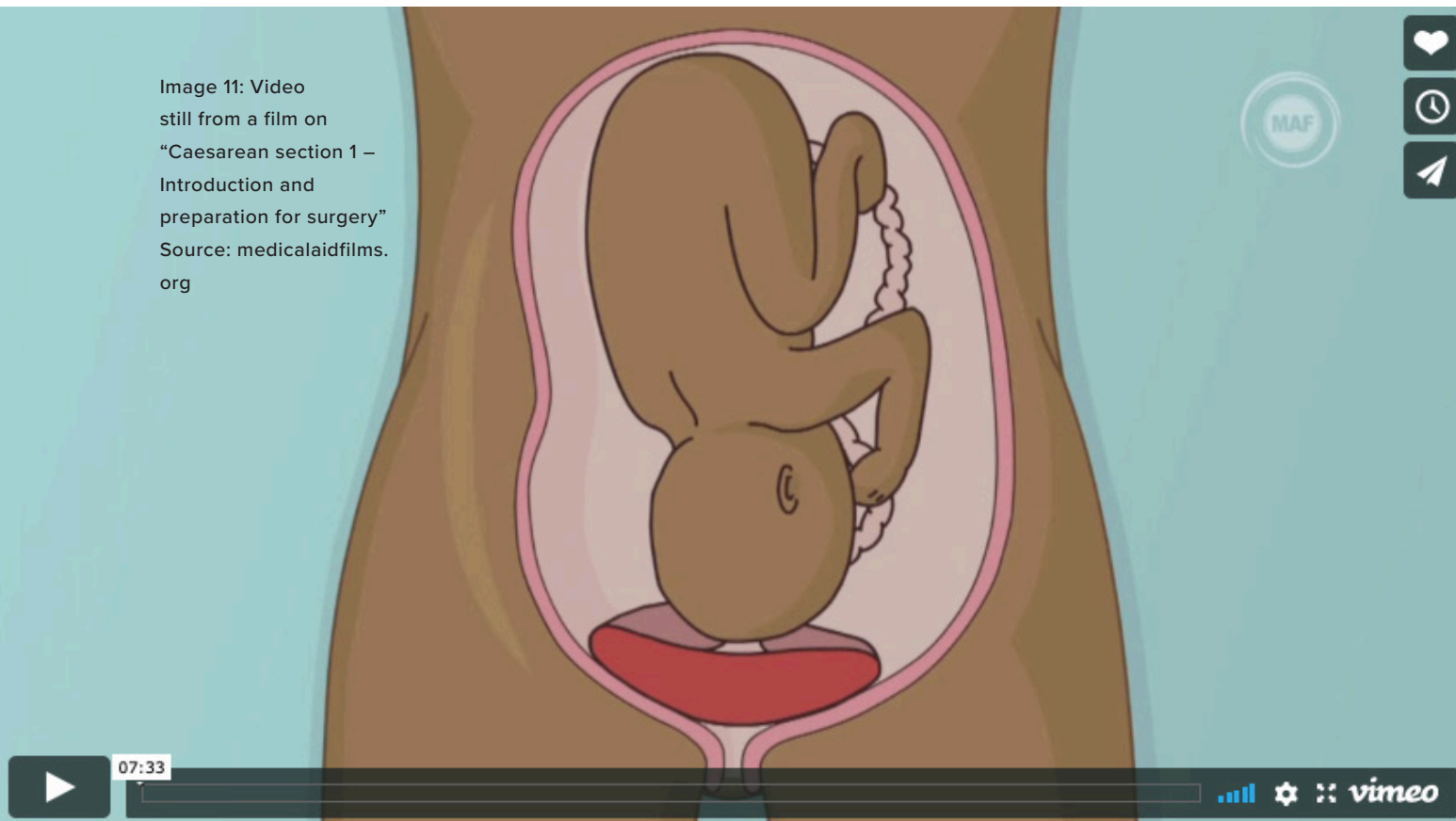
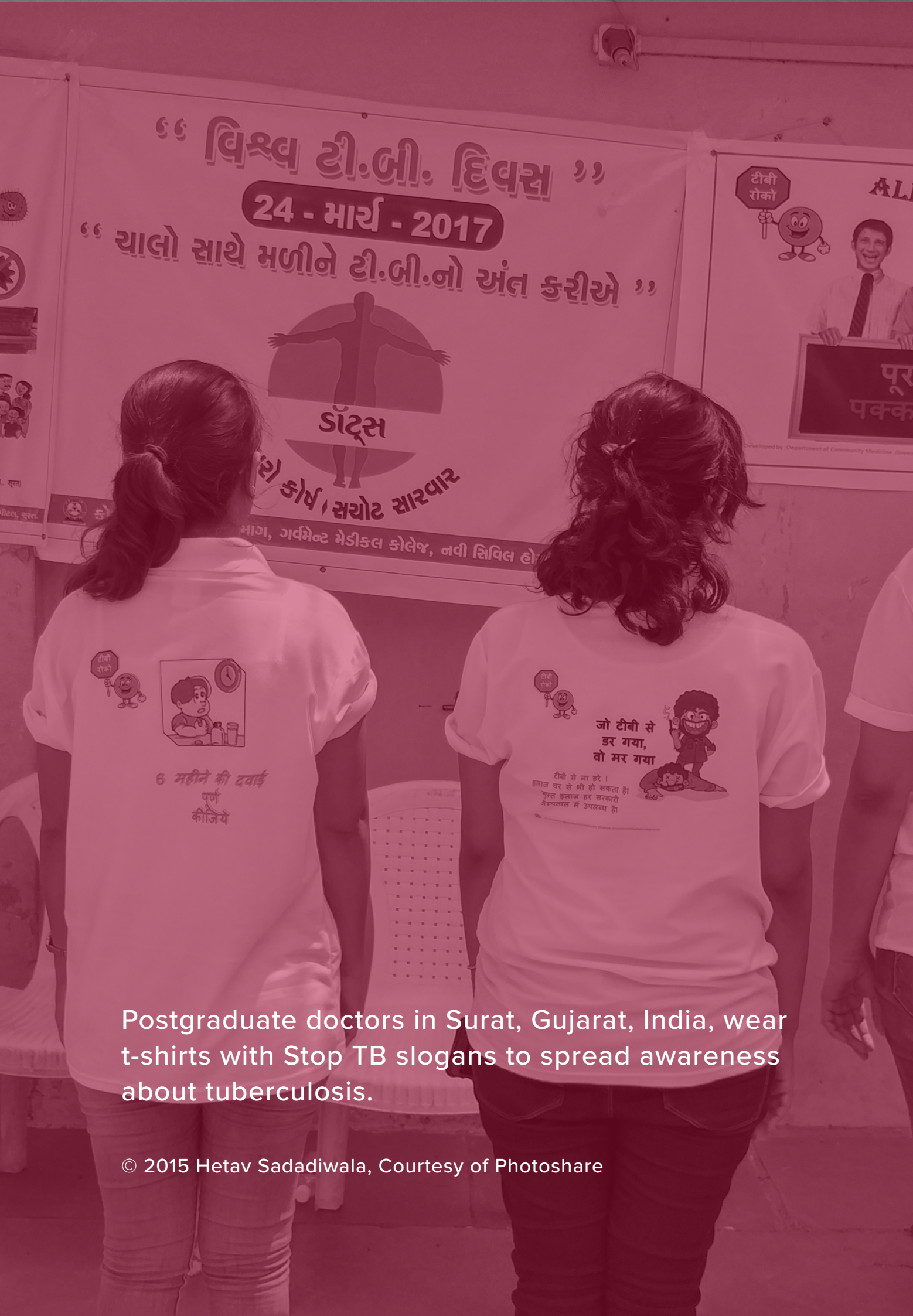


Image 12: Mobile Kunji cards in use

Source: BBC





“ विश्व टी.बी. दिवस ”

24 - मार्च - 2017

“ ચાલો સાથે મળીને ટી.બી.નો અંત કરીએ ”



સંદેશ, સચોટ સારવાર

માગ, ગવર્નમેન્ટ મેડિકલ કોલેજ, નવી સિવિલ હોસ્પિટલ, સુરત

टीबी
रोको



ML

पूर
पक्क

Developed by : Department of Community Medicine, Government Medical College, Surat



6 महीने की दवाई
पूर्ण
कीजिये



जो टीबी से
डर गया,
वो मर गया

टीबी से ना डरे !
इलाज घर से ही हो सकता है।
भारत इलाज हर सरकारी
अस्पताल में उपलब्ध है।



Postgraduate doctors in Surat, Gujarat, India, wear t-shirts with Stop TB slogans to spread awareness about tuberculosis.

© 2015 Hetav Sadadiwala, Courtesy of Photoshare

DESIGN INTERVENTION

CONCEPT MAPPING

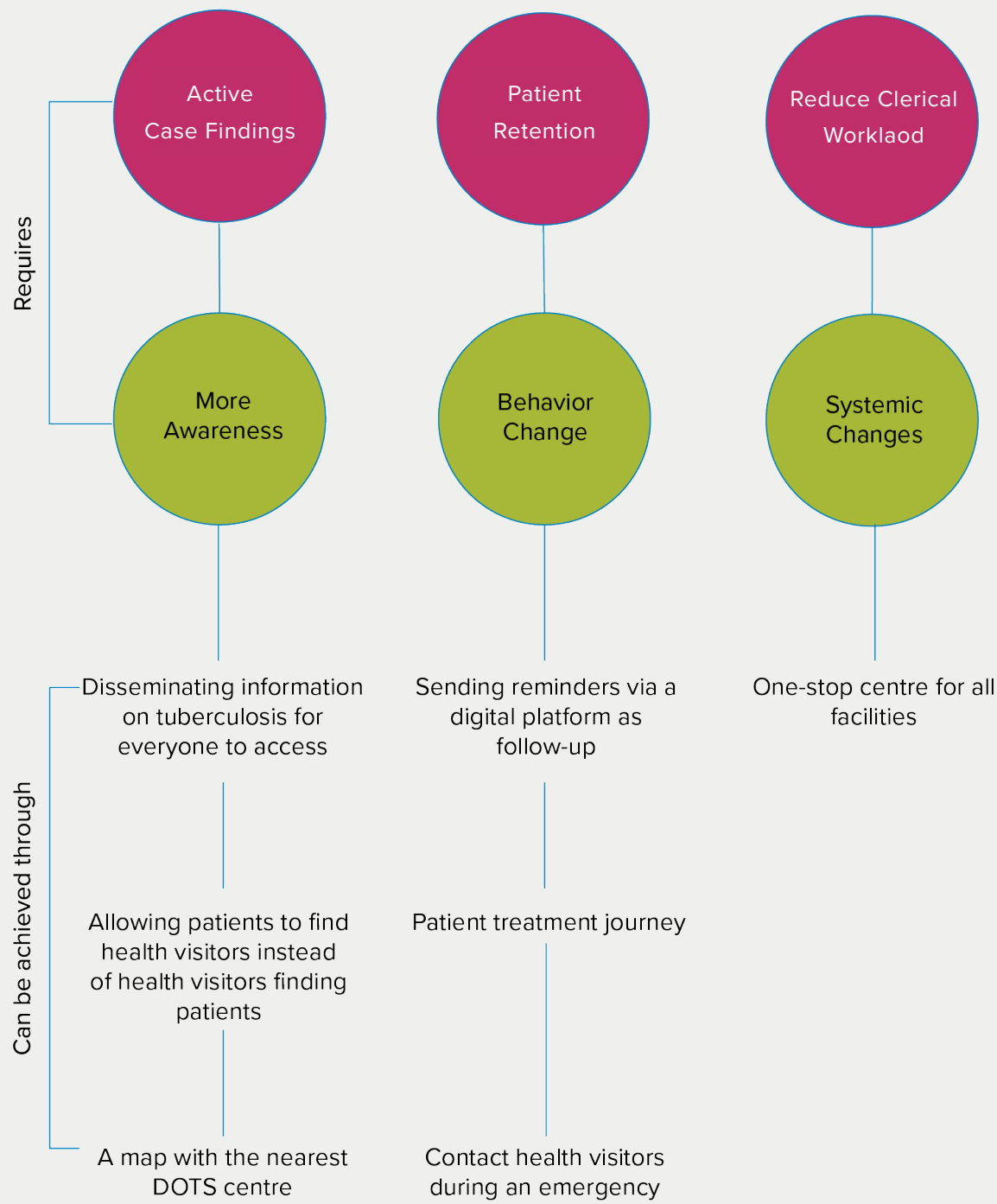
In this step of the process, possibilities for design interventions were explored; keeping the selected insights in mind. The concepts mapped in Figure 16 aim to change patient behavior towards seeking treatment, increase awareness about tuberculosis in various stakeholder groups, and improve systemic interventions to help health visitors with active case findings, patient retention, and a reduction in their clerical workload. It is important to address the role of patients and the community at large in combating these challenges.

Through the features listed in the concept map, the solution proposes a one-stop cohesive digital interface designed for health visitors, patients and the community; that can disseminate information about tuberculosis, allow patients to locate health visitors and centers, outline the patient's treatment progress and work as an online forum for health visitors and patients to contact one another.

Given that the RNTCP uses its web enabled patient management system for TB control called NIKSHAY, after conducting a systemic analysis of NIKSHAY, the design intervention proposes the redesign of the features in this application. The recommended intervention expands the scope of the existing features in NIKSHAY to accelerate a collaborative effort that empowers, educates, and facilitates the needs of patients, health visitors, and the community.

The intervention proposes a redesign of the features in NIKSHAY - the web enabled patient management system for TB control under RNTCP.

Figure 16: Concept map



INFORMATION ARCHITECTURE

NIKSHAY

The chart in Figure 17 outlines the elementary information architecture for NIKSHAY. The application is designed for and operated by supervisors and health visitors working across health centers in Mumbai. It is now mandatory for private practitioners to use this platform to report patients.

Figure 17: Information Architecture of NIKSHAY

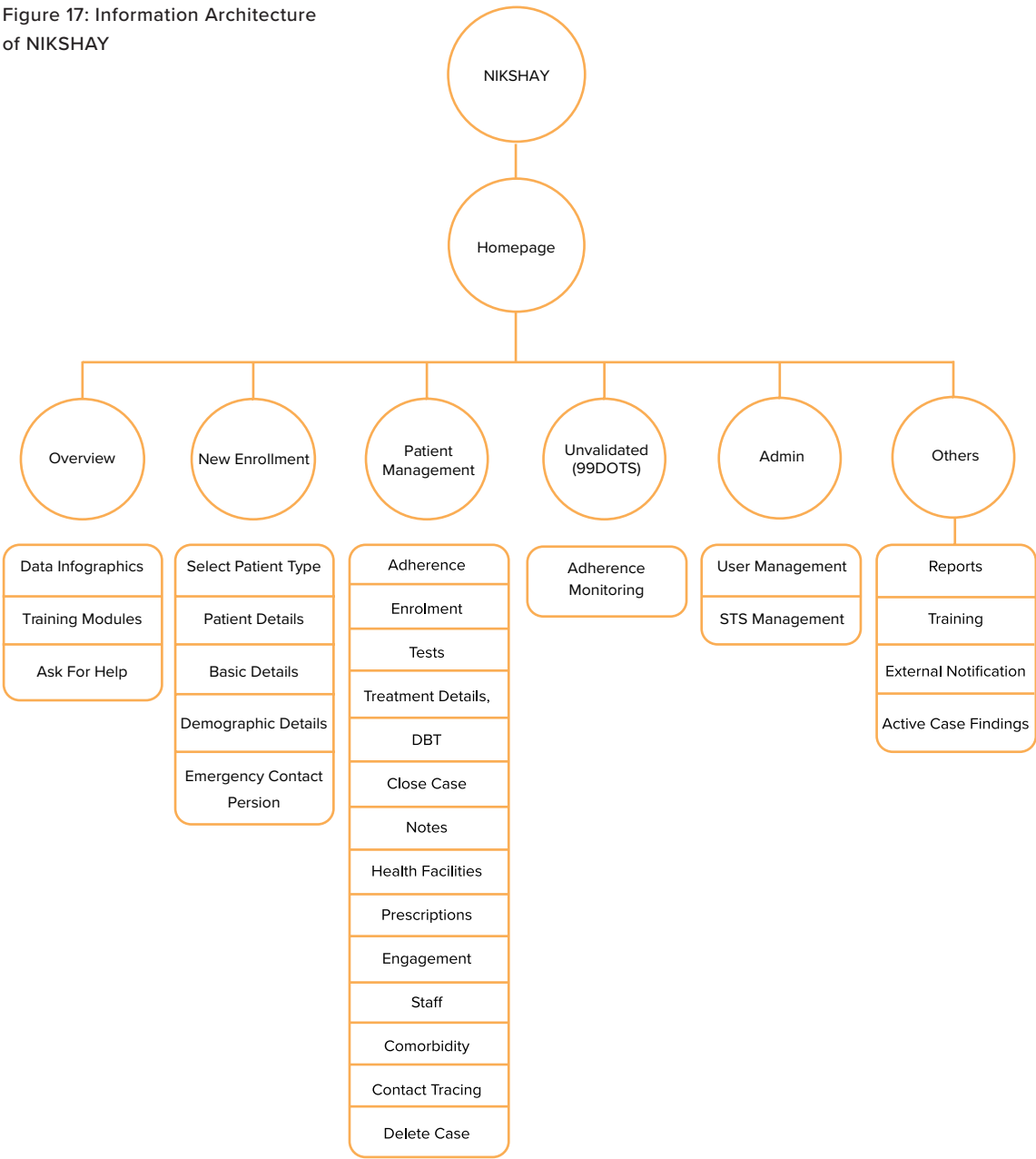


Image 13: Patient Summary

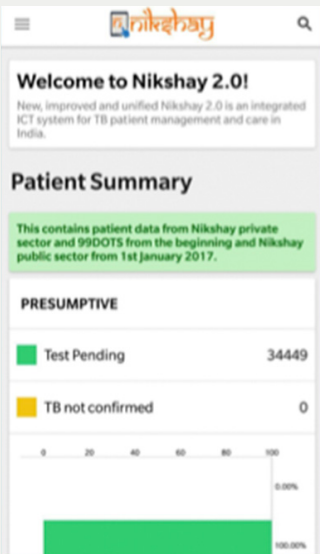


Image 14: Categories & Tabs

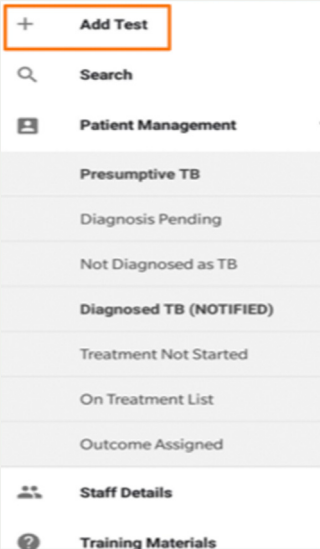
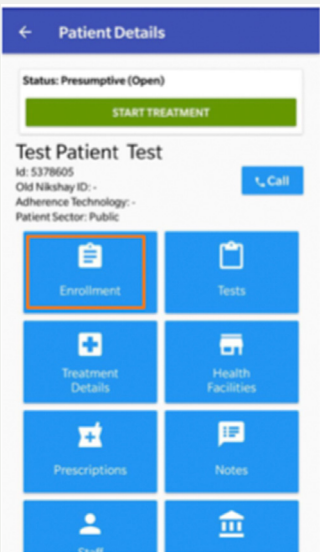


Image 15: Action Buttons



All of NIKSHAYs six categories are related to patient management, enrollment and user management. The training modules incorporated disseminate information that can help users navigate through the application's interface.

A few examples of NIKSHAYs current interface are shown in Images 13, 14 and 15. The interface outlined in Image 13 provides the HVs with a patient summary that presents details about the patient in their treatment regiment - tests pending, test results, diagnosis, and a summary of their treatment adherence. Image 14 outlines the various categories and tabs incorporated in the application (as shown in Figure 17). Image 15 highlights the various action buttons in the interface of the application.

Using the established features of the application, the following section explains the features of and drafts the information architecture for the proposed features.

The application is designed for and operated by supervisors and health visitors. The application includes features related to patient management and monitoring treatment adherence.

Proposed additions to NIKSHAY

Currently, NIKSHAY's user groups are limited to health visitors and their supervisors. One of the major areas of opportunity is to expand the user group to include patients and the society at large.

Additional features for the health visitors will include an online forum to contact and learn from other health visitors, a messaging platform to contact patients, and a learning forum to build their capacity using resources from the MoHFW and WHO.

The section for patients will include features such as viewing treatment progress, receiving motivational or caution messages, request to contact health visitors, receive reminders from health visitors, get involved in community awareness and engagement activities, and learning more about the disease.

Lastly, members of the society will be able to use the app to gain information about tuberculosis, find health centers near them (if that they have TB), and get involved in community engagement and awareness activities near them.

With the use of these additional features, the data generated can be analyzed to gain a deeper understanding of the challenges faced by the three user groups. The analysis of this data can then be used to further design interventions that can combat larger systemic issues. For instance, if a member of the community has viewed a health center near him repeatedly, NIKSHAY

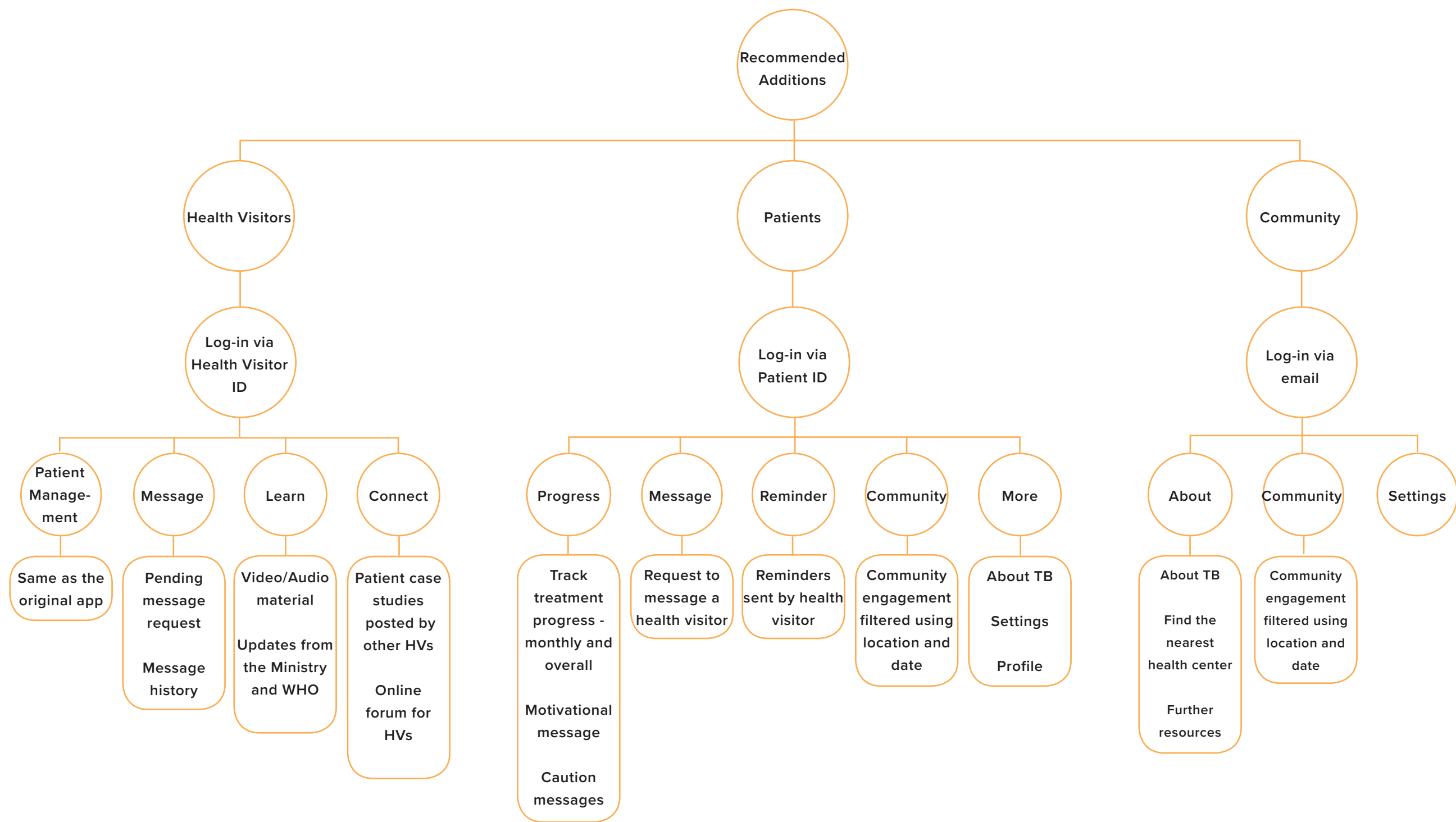
will prompt the health visitor working in the said health center about the repeated views by this individual; the health visitor can then choose to contact the individual and encourage him to visit the center.

The next section explains all the proposed features with the help of a mock-up for the interface. It also lists a range of data analysis that can be generated and used to further achieve the goal of active case findings and patient retention.

Currently, NIKSHAY's user groups are limited to health visitors and their supervisors. One of the major areas of opportunity is to expand the user group to include patients and the society at large.

[Open the page to view the architecture](#)

Information architecture for the recommended additions



Colour Palette



CMYK - 0, 65.2, 100, 0



CMYK - 80.9, 48.6, 0, 0

PROTOTYPE

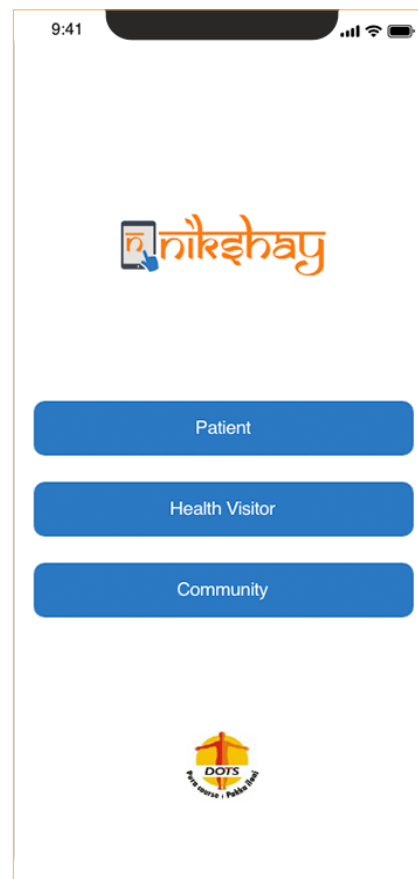
The prototype created outlines the various features added under each of the three user groups. The prototype has been created using the following specifications:

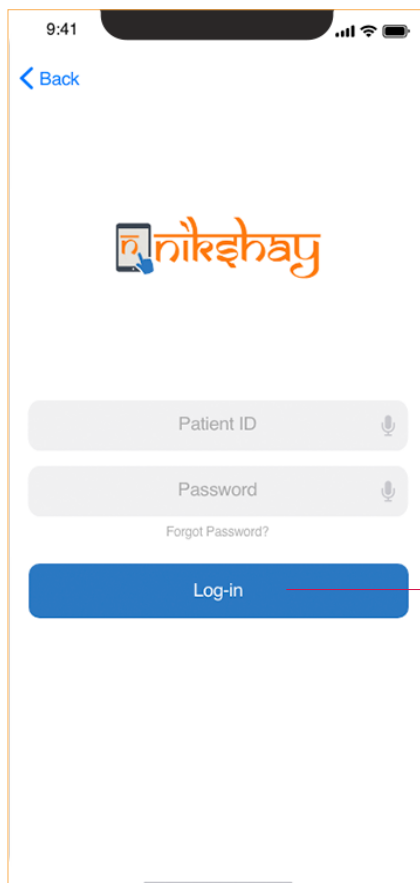
- Operating System: iOS
- Colours: Orange and Blue (used from the original application)
- Typeface: Proxima Nova and San Francisco

The application opens to a user log-in page (Image 16), where one will need to select either patient, health visitor, or community, depending on the group they belong to.

The following pages outline the key features of the application with the help of the interface designed.

Image 16: Log-in screen

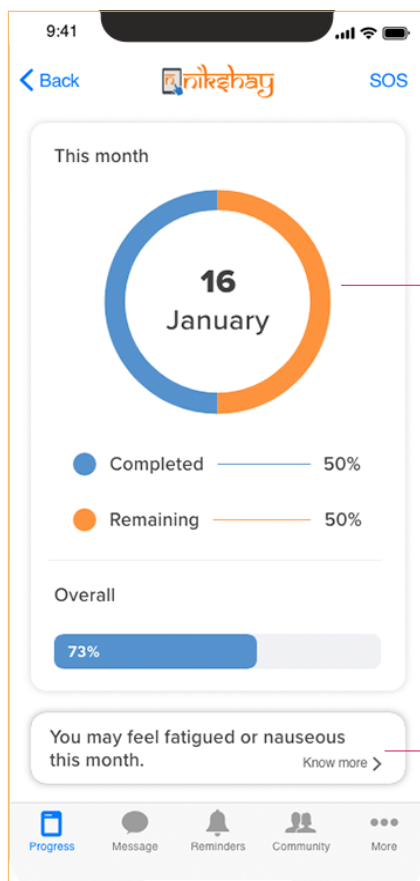




Designed for patients: To help them monitor their treatment progress, contact health visitors in case of emergencies, learn more about tuberculosis, and participate in community engagement activities.

Patient Log-in

Patients can log-in to the application using their unique Patient ID that is generated when they initiate treatment.

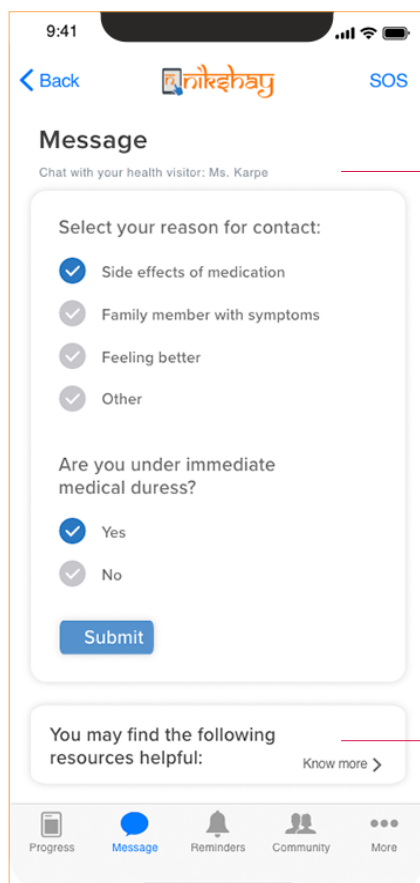


Treatment Progress

Using the 99DOTS program, the patient can see a visual representation of their treatment progress. This screen highlights the percentage of medication remaining for the month as well as an overall estimate.

Warning/Motivational Messages

The section highlighted provides the patient with either warning messages or motivational messages. For instance, “you may develop side effects to the medication this month” or “you have only 3 days of medication left!”

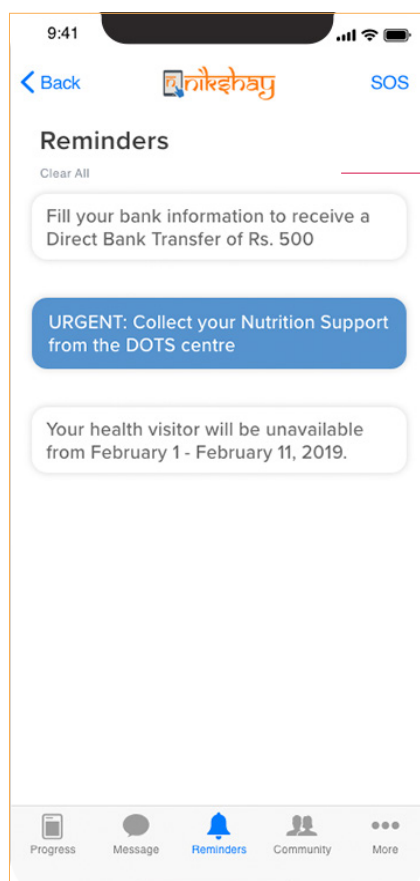


Messaging Health Visitors

If the patient needs to contact their health visitor, they can send a message request stating their reason for contacting the health visitor.

Based on the reason, the health visitor can choose to accept or reject the request. If accepted, the patient can chat with the health visitor.

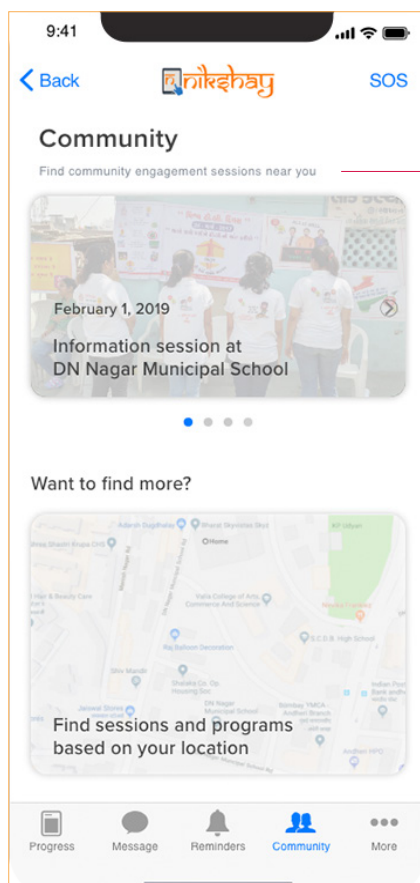
The screen also prompts the patients towards a few resources that might answer the patients queries, as an alternative.



Reminders

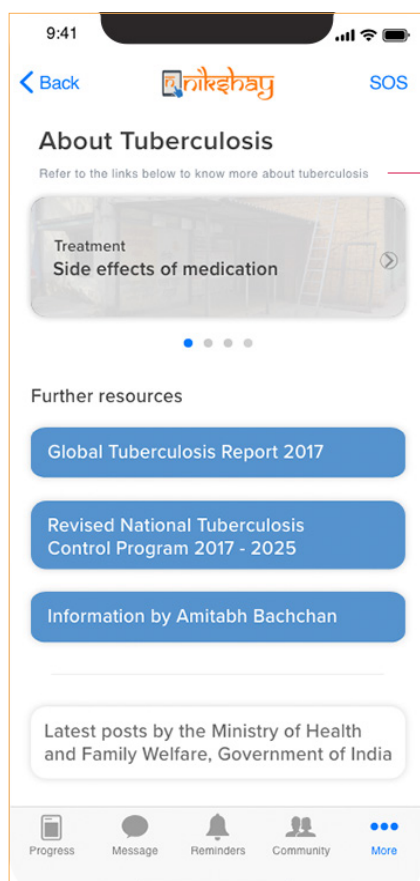
The health visitor can choose to send the patient reminders like “Collect your nutrition support for the month of January” instead of sending reminders via calls.

The application itself can generate messages based on the data collected and algorithms fed. For instance, if by the end of the day, the patient fails to give a missed call through the 99DOTS program, the application can generate a message reminding them to do so.



Community Engagement

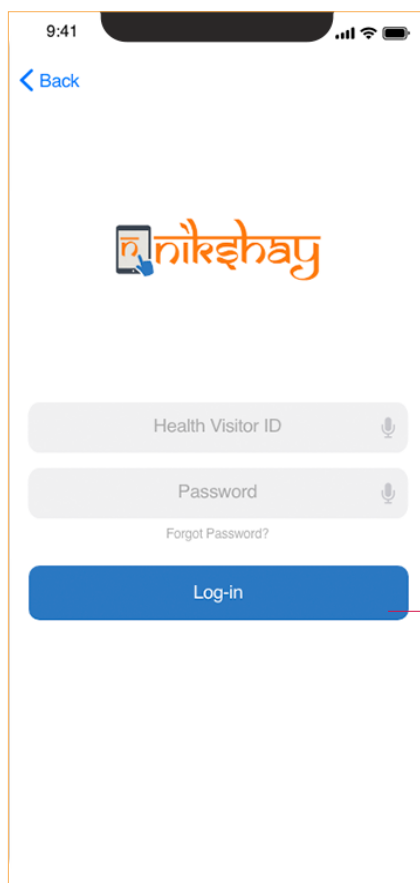
The patient can view community awareness programs and activities scheduled near them, and can choose to attend the same.



Information On Tuberculosis

The application will serve as a one-stop information portal where patients can have access to verified and authenticated information about TB and RNTCP.

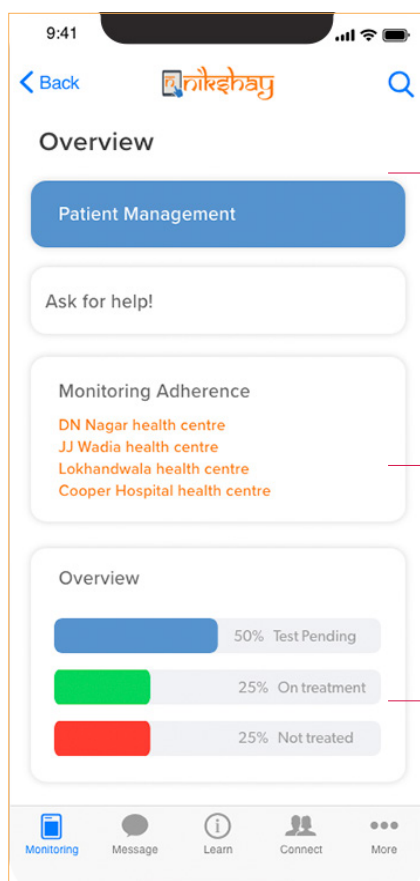
This screen will also highlight the latest posts and notes by MoHFW.



Designed for health visitors:
To help them monitor treatment adherence, patient medical history, contact patient for regular follow-ups, expand their own knowledge and skills, and connect with fellow health visitors via an online forum.

Health Visitor Log-in

Health visitors can log-in into NIKSHAY using their unique IDs. This feature is the same as in the original application.



Patient Monitoring & Overview

The HV is directed to the overview page after logging in. The page houses the 'Patient Management' tab - which houses the features from the original application.

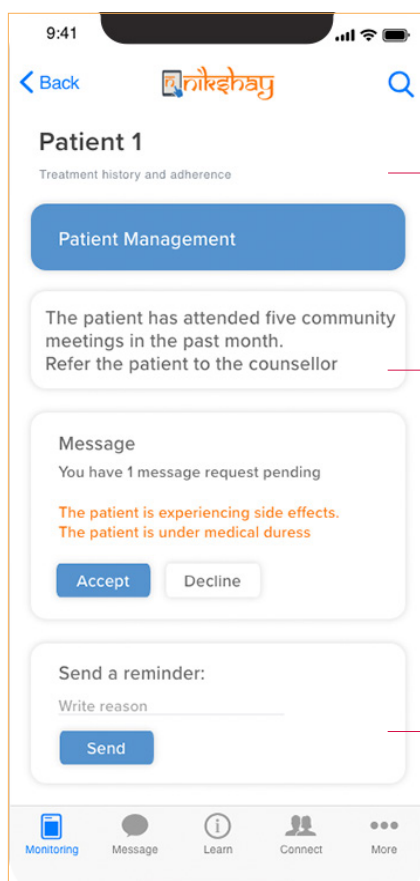
The HV can use health centers as categories to find information on individual patients quicker. As opposed to scrolling through hundreds of patient names.

The page provides an overview of the status of all the patients they are responsible for.



Monitoring Patient Adherence

Using the data from 99DOTS, this screen outlines daily treatment adherence for each patient registered under the selected health center.

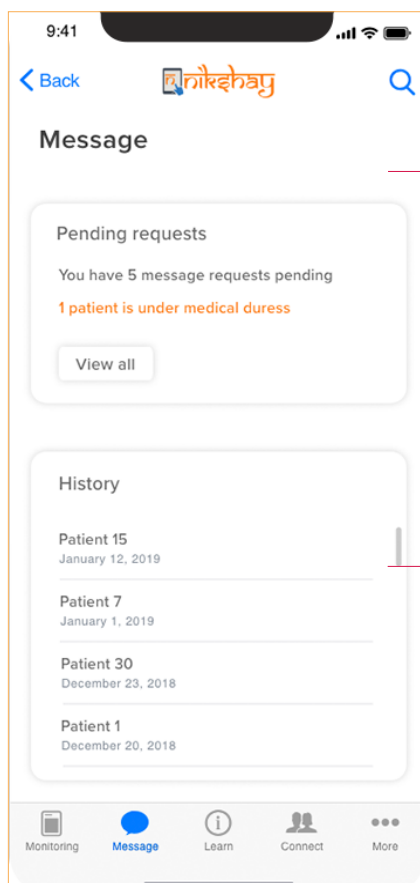


Patient Information

If the HV wishes to look further into a patient's diagnosis/treatment details, by clicking on their name, the HV can find their test results, pending tests, and pending messages

The application itself can use the patient's app history to recommend interventions specific to the patient. For instance, if a patient has accessed resources related to drug side effects, the HV can then plan their next counseling session on side effects.

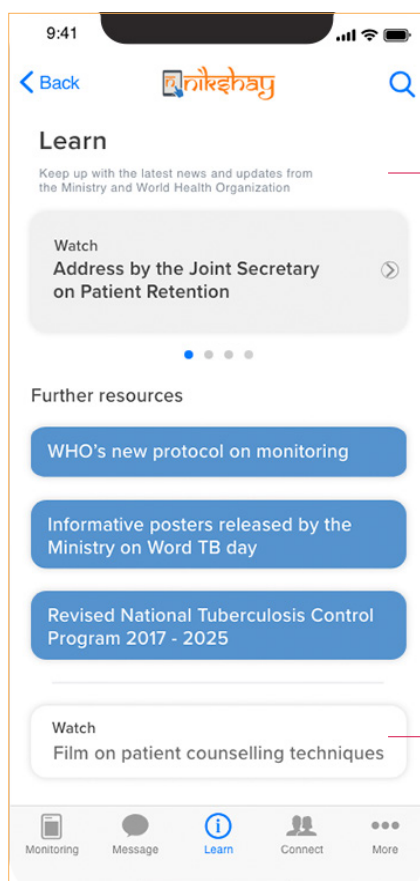
The HV can also send a reminder to the patient through this page



Messaging Patients

The HV can view all the pending message requests they have from various patients. They can prioritise their responses by viewing if any patient is under medical duress.

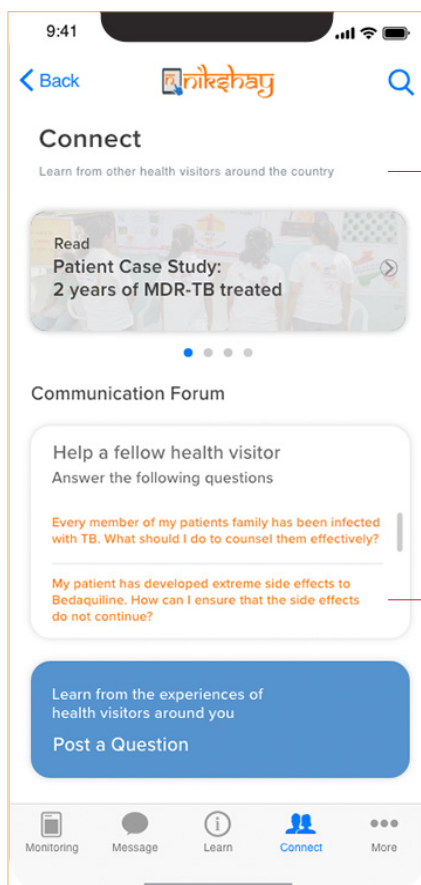
The HV can also view their chat history with all patients.



Helpful Resources

Similar to the patient, the HV also has access to verified and authenticated information about TB and RNTCP protocol. Other capacity building resources can be accessed as well.

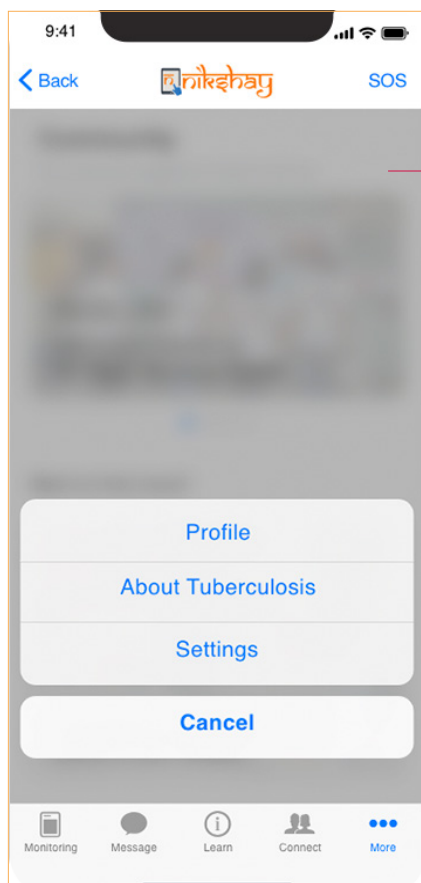
As shown, the HV can watch a video patient counseling techniques.



Connect With Fellow Health Visitors

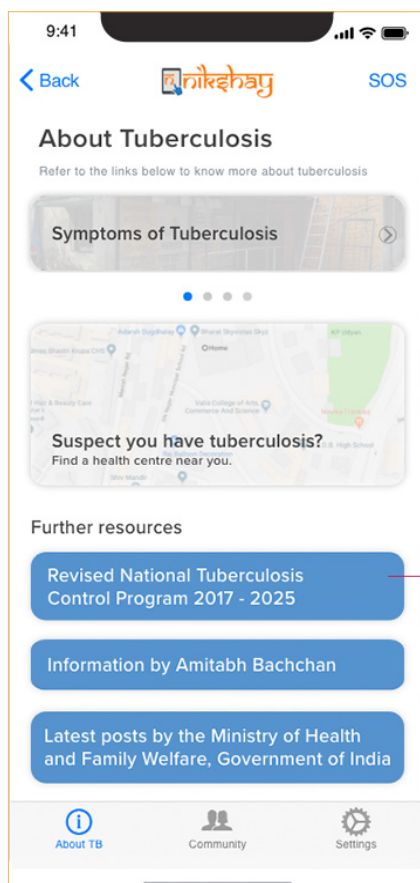
HVs can read about and learn from the experiences of their fellow HVs by accessing published case studies.

For HVs, the application also serves as an online forum where HVs can connect with their fellow HVs and learn from one another. It allows the HV to post a question when in doubt, to which other HVs can respond.



Additional Features

HVs can view their own profiles and general information about TB.



Designed for the community:
To raise awareness about tuberculosis, help suspected patients find a health centre based on their location, and engage in community engagement activities

Information On Tuberculosis

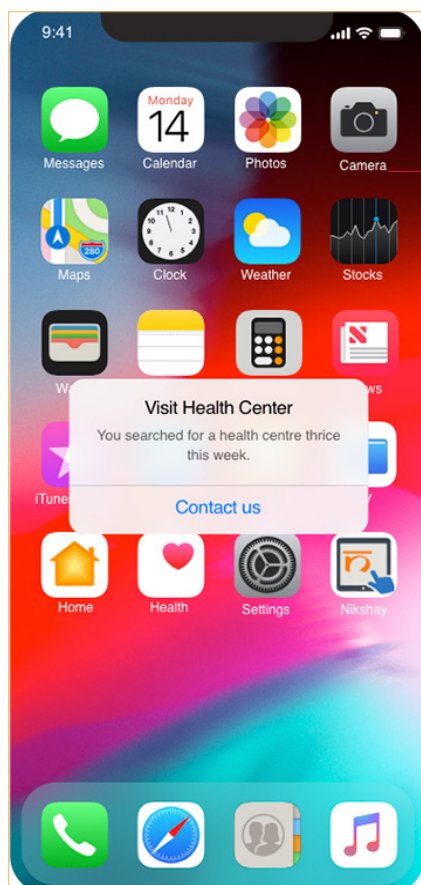
For the community, NIKSHAY can serve as an information application that disseminates information on TB, RNTCP and other facilities provided in the public sector



Nearest Health Center

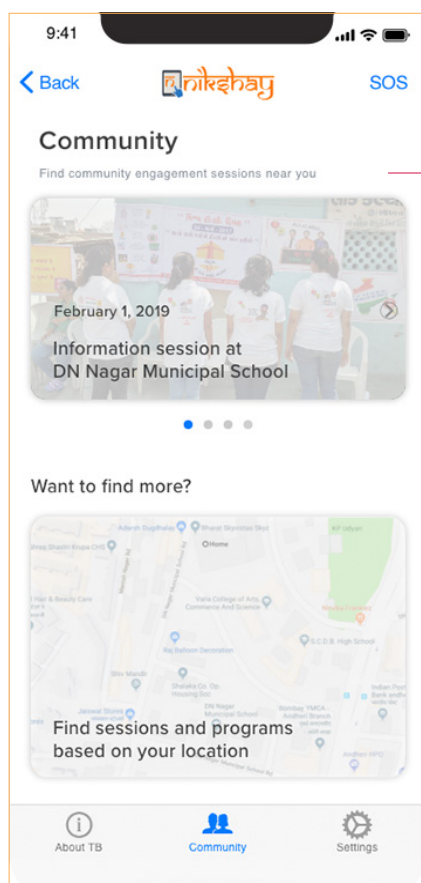
The application can help an individual find a health center near them if they suspect themselves of having contracted TB.

The application uses the individuals location to recommend health centers near them



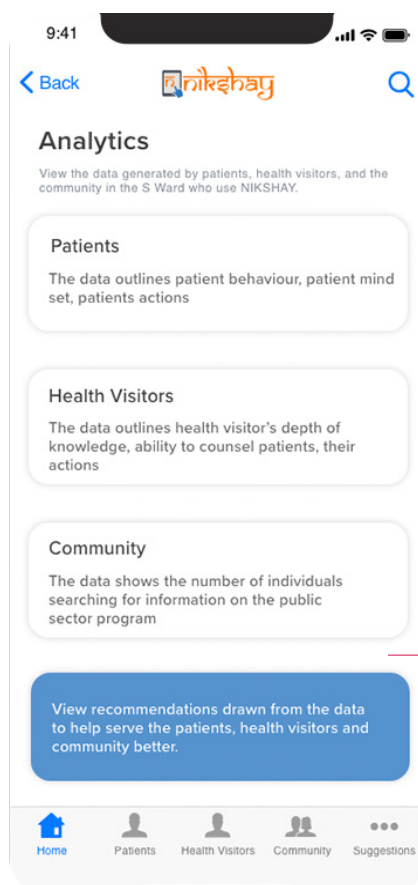
Visit Health Center Notification

Using the search history of finding health centers, the application can send notifications to the individual encouraging them to reach out to a HV or a health center.



Awareness and Engagement

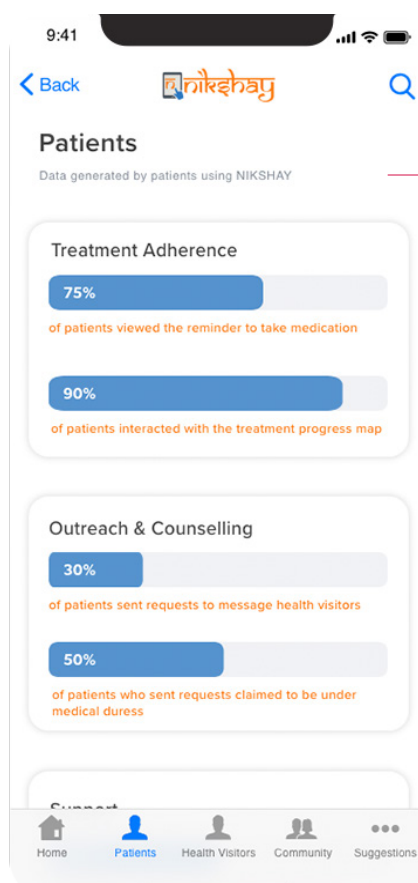
Individuals can also choose to be a part of the community awareness programs the HVs conduct if they wish to learn more about TB and the services provided under RNTCP.



Designed to identify and address systemic challenges in TB care: With the data generated from all three user groups, policy makers and supervisors can gain a deeper understanding of patient and HV behavior in order to solve some of the systemic challenges.

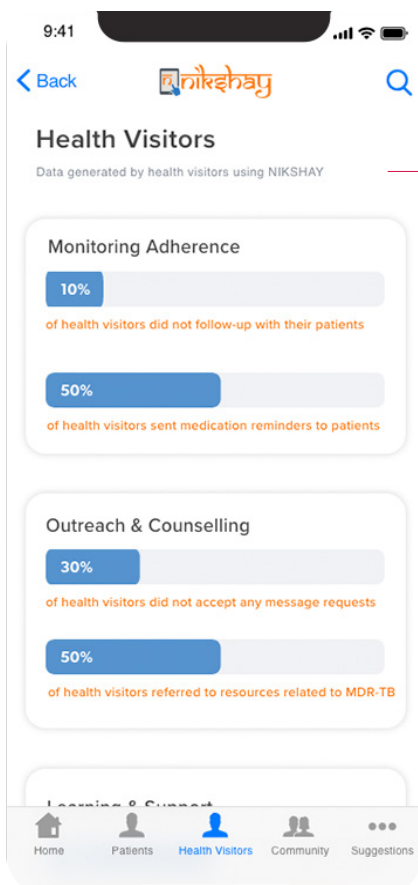
Data Generated

Policy makers and supervisors (CTO, DTO, STS) can analyse the specific data generated to inform their studies and develop re-iterated interventions to curb TB.



Patients

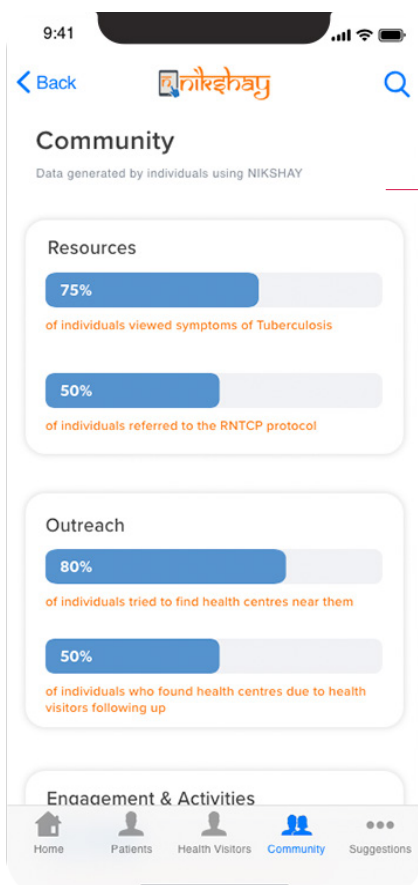
Data gathered from patients in a particular district/ward. HVs and supervisors can use these data points as insights to better cater to patients. For example, the percentage of patients who do not collect their nutrition support from the health center can help policy makers assess if this facility adds value to the RNTCP program or not.



Health Visitors

With the data generated by all health visitors in a district or a city, supervisors and the CTO can plan, for example, capacity building activities and trainings.

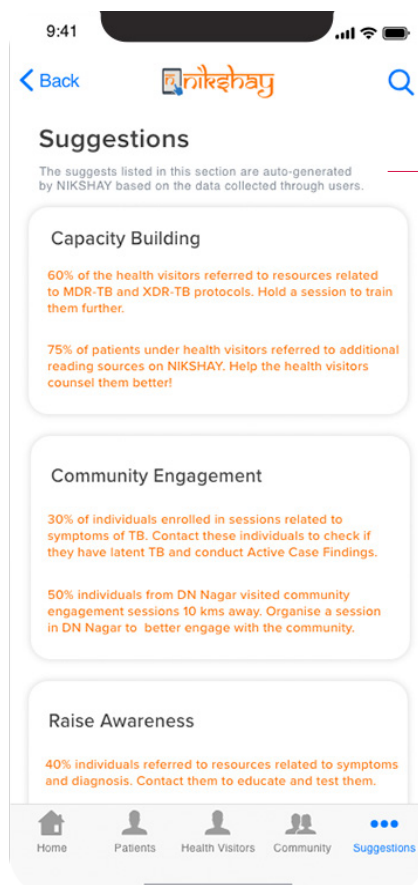
For instance, if a percentage of HVs have viewed resources related to counseling, CTOs and DTOs can hold training sessions on patient counseling.



Community

Generating and collecting data from individuals in the community can assist with active case findings and raising awareness about TB.

If a percentage of individuals tried finding health centers in a particular district, it could indicate that the district is a high-burden/ high-risk area.



Suggestions

Based on the data generated and analysed, the application can recommend interventions.

For example, if a majority of people in a community enrolled for a session on symptoms of TB, the application can prompt the HV working in that district to conduct active case finding.

ACCEPTANCE TEST

Acceptance tests were carried out with a Health Visitor from the Vikhroli ward and a patient in order to assess the importance and verify the concept generated.

Health Visitor: There has been an increase in the incidence in people under the age of 25. Students and children are vulnerable groups because their immunity level is not as good as adults. Students do not eat healthy; this is another factor that contributes towards their weakened immunity. With their busy and erratic schedules, they forgot to take their medication and give long gaps between their meals. Students also refer to multiple online sources in order to educate themselves about their condition and treatment regimen. Since the proposed portal will provide information on the disease, the health visitor can be sure that the information is authenticated and accurate.

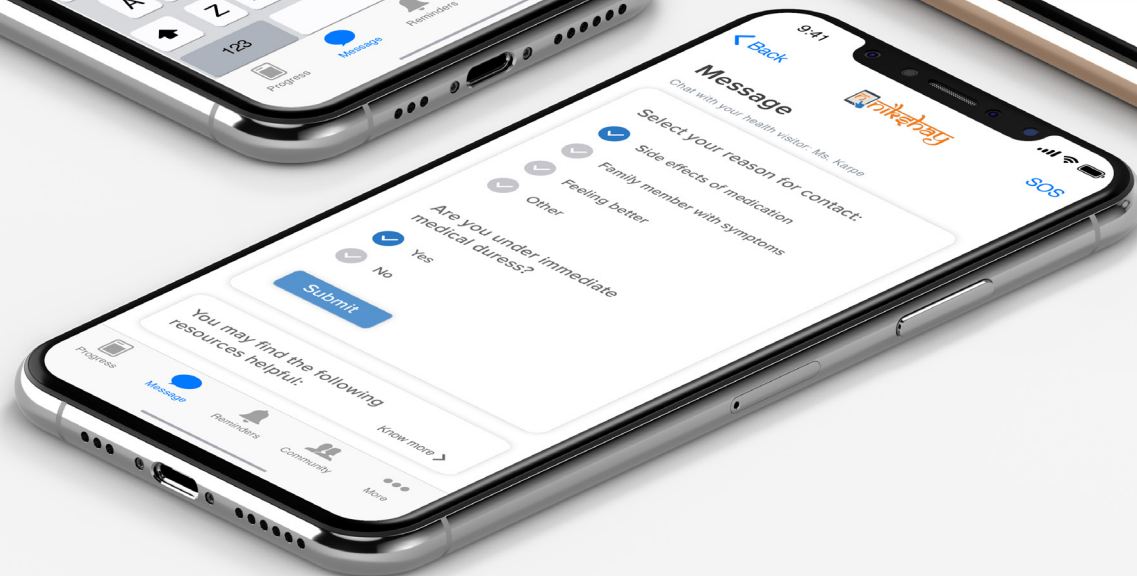
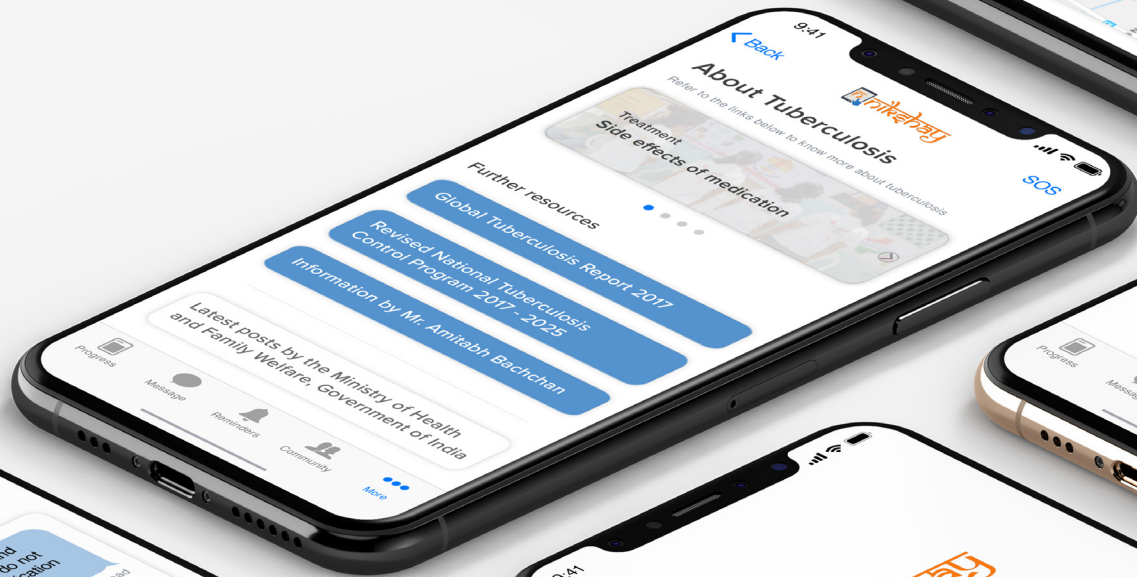
Furthermore, the health visitor highlighted that the ability of the portal to remind patients to take their pills everyday would be beneficial. It would add an additional layer of reminders that the patient receives. The health visitor appreciated that the portal will also send notifications to the patients about collecting the pending nutrition support and filling forms for Direct Bank Transfers.

Patient: There is an abundance of information on tuberculosis available on the Internet. All these sources list contradicting symptoms, diagnosis procedures, and treatment regimens. One can never know how

There is an abundance of information on tuberculosis available online. All these sources list contradicting symptoms, diagnosis procedures, and treatment regimens. One can never know how accurate this information is.

How accurate this information is. The ability of this proposed portal to collect and relay accurate information for all possible scenarios would be extremely helpful for the patient and his family. The valuable addition to the portal of being able to contact health visitors during an emergency would also make the process of treatment easier. Given that the patient is currently in the process of switching from the private sector to the public sector, a map with the nearest health centers would be extremely helpful. The map will act as a starting point to seeking help.





IMPACT & CHALLENGES

An evaluation of the potential impact of the intervention and the possible challenges it may face in the system.

Through the analysis of the data that will be generated by the three user groups, supervisory staff and policy makers can use these insights to modify the program for better efficiency.

The extended information architecture of NIKSHAY works towards achieving the goal of active case findings and patient retention. By expanding the user group to include patients and the community, it proposes to take the responsibility of reaching out to patients/community from the health visitors and places it on patients and individual members of society. In doing so, the application ensures that patients are in control of their treatment with an abundance of verified information available digitally. Patient and individuals can choose to broaden their knowledge of tuberculosis and the facilities available in the public sector, which would enable a percentage of the community to reach the public sector effectively.

The extended features are minimal interventions that do not majorly interfere with the currently features of the app or the 99DOTS program. Instead, the features facilitate the current qualities of the program in order to better serve the purpose of active case findings and patient retention.

Through a back door analysis of the data that will be generated by these three groups of users, supervisory staff and policy makers can use this analysis to modify the program for better efficiency. This data will highlight the numerous challenges faced by patients, health visitors and individuals in the society; through which larger systemic issues may be addressed. In addition, new interventions can be tested through the app, and their impact can be quantified using the data

The extended list of features comes with set challenges. If these are overlooked, the impact of the intervention might suffer.

generated.

However, the extended list of features comes with set challenges. If these challenges are overlooked, the impact of the intervention might suffer. The app is designed to include members of the society as individual users who can use the app to gain information about tuberculosis and find health centers based on their location.

This set of features will only prove successful if NIKSHAY is advertised amongst the masses. Extensive advertisement campaigns will need to be carried out to inform individuals about the existence of the application.

Furthermore, one of the foci of the initiative on Tuberculosis for the Harvard Chan India Research Center was to empower and motivate health visitors. In order to achieve this, the number of tasks that health visitors are burdened with must be reduced. The extended features proposed in this intervention may not contribute towards that goal. They do however, work towards ensuring that symptomatic patients contact health visitors in order to seek treatment; and are therefore enrolled into the treatment program.

REFLECTIONS

As I begin to write my reflections, I am reminded that four years of my undergraduate program have come to an end. This section will, therefore, be a compilation of experiences and reflections from the past four years, and not just the past four months.

My introduction to and understanding of the word 'design' was not easy. I always perceived 'design' to be of beautiful and aesthetic value. However my three years in Product Design has changed that perception. To me, design is something much more. It is logical reasoning, it is functionality, and most importantly, it is a way of thinking. It encourages the mind to challenge and question every fiber of being and every wheel in a system.

In my second year, when I selected my major as product design, I was exposed to the physical aspect of design. I was forced to translate my vague thoughts and ideas into physical form. My thoughts turned into ideas and raw material turned into usable products. However, I would always wonder whether my products were adding to the world? Was I creating products because I believed in them? Or was I creating them because I had been asked to?

My progression into junior year helped me answer these questions. I was suddenly aware of my creations and constantly questioned the need for their existence. This is when I discovered the need for de-

signing for social good. Throughout the year I chose to work on projects spanning from medical devices, emergency-care systems, and design for disability. Not once did I stop and question my motive for creating products for social good. But again, did the world really need another product that targeted the same set of problems?

My senior year at ISDI has been a rollercoaster of events. Along with my classes and assignments, I was fortunate to be working with the IRC throughout the year. I was introduced to the words ‘public health’ – a world where design struggles to exist. Public health interventions rarely call for interventions through product innovation. During my time at IRC, I realized that design interventions don’t always have to have a physical form. Interventions that target complex challenges, like Tuberculosis, can involve policy changes, strategy proposals or capacity building exercises. What was glaringly clear, though, was that the field of public health could use design thinking and design interventions to combat some of the most multifaceted challenges that the world faces today.

My experience working in the field of public health during my capstone was different. During the course of this project, public health was forced to collide with the world of design. I was fortunate to be able to learn research methodologies from my mentors and colleagues at IRC, and use that data to create an intervention that is not the norm in public health. Working with public health experts, I was shown the intricacies of systems that I design for; and that any intervention I create, will directly or indirectly, have an impact on every single stakeholder in that system.

ENDNOTES

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A look back at some of the most memorable experiences at Harvard Chan India Research Center.



