# STORIES OF
# CHANGE

## 2020-2021
### ...
### VOLUME II

Case Studies on
Development Action and Impact

Azim Premji University Publication

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# Stories of Change: Case Study Challenge

## Azim Premji University

Modern India has a history of a vibrant and active social sector. Many local development organisations, community organizations, social movements and non-governmental organisations populate the space of social action. Such organisations imagine a different future and plan and implement social interventions at different scales, many of which have lasting impact on the lives of people and society. However, their efforts and, more importantly, the learning from these initiatives remains largely unknown not only in the public sphere but also in the worlds of 'development practice' and 'development education'. This shortfall impedes the process of learning and growth across interventions, organizations and time.

While most social sector organizations acknowledge this deficiency, they find themselves strapped for time and motivation to embark on such efforts. Writing with a sense of reflection and self-analysis which goes beyond mere documentation and creates a platform for learning requires time and space. As a result, their writing is usually limited to documentation captured in grant proposals or project updates or 'good practices' literature with inadequate focus on capturing the nuances, boundaries and limitations of action.

Recognizing this need, the Azim Premji University launched 'Stories of Change: Case Study Challenge' in 2018 with the objective of encouraging social sector organisations to invest in developing a grounded knowledge base for the sector. In the inaugural year of this challenge (2018 – 19) we received 95 case study submissions, covering a large range of thematic areas.

In the second round of the initiative (2019-20), we received 68 submissions around interventions such as waste management, conservation, livelihoods, sustainable agriculture, reform and rehabilitation, gender, education and teacher development, land rights, child nutrition and community health. The target groups included parents of girl child, prisoners, urban communities, teachers, adivasis, marginal farmers, children, women, youth, among others. Through a two–stage evaluation process, the university selected 3 winners

and 3 special mentions for the 2019-20 Stories of Change Challenge. Together with these, we have selected four additional notable submissions for publication in this compendium. This is the second volume of 'Stories of Change: Case Studies on Development Action and Impact'. [ Readers can download the volume I of the compendium using the link https://azimpremjiuniversity.edu.in/SitePages/pdf/Stories-of-Change_Brochure-2019-20.pdf ]

We hope that educators and practitioners alike find these case studies valuable for influencing policy, building capacity of practitioners, documenting good practices for future learners, providing space to practitioners in teaching, collaborative research and even incubating new ideas for social change.

# Acknowledgements

This compendium is the result of Azim Premji University's 2019 – 20 'Stories of Change: Case Study Challenge'. We thank all organizations who submitted case studies based on their work. We deeply appreciate the time and effort they have spent in developing these cases.

We had a two-stage evaluation process to select the ten submissions included in this compendium. We appreciate the 19 colleagues from Azim Premji Foundation who agreed to review all the 68 submissions and shortlist the best ones. Their names, in alphabetical order, are: Anchal Chomal; Anjor Bhaskar; Annapurna Neti; Arima Mishra; Aravindhan Nagarajan; Ashok Sircar; Chiranjib Sen; Geetisha Dasgupta; Malini Bhattacharjee; Manjunath SV; Nazrul Haque; Puja Guha; Rahul Mukhopadhyay; Rajesh Joseph; Richa Govil; Saswati Paik; Sham Kashyap; Shreelata Rao Seshadri and Sreekanth Sreedharan.

Multiple individuals from the ten organizations selected for this compendium worked closely with the University team to arrive at the final print-ready versions of their cases. All of them took out time from their grassroots work and engaged seriously in this effort. This compendium is a reality only because of each of those individuals. Sanjana Santosh, a former student of M.A. Development program at University, worked with 3 shortlisted organizations to rewrite the cases and make them ready for publishing. We are also grateful to Malini Sood, the copy editor, for her careful language editing.

Throughout the entire initiative – from publicity and outreach to the final design and page layout of this compendium – the University Communication Team supported every step. Thank you, Sachin Mulay, Nanit BS and Sneha Suresh for making this happen.

This compendium would not have been possible without support from Anurag Behar, Vice Chancellor of the University, and Manoj P., Registrar of the University. Manoj's enthusiasm and encouragement led the core team to imagine the Case Study Challenge at a bigger scale than we had originally earlier. We want to thank Anurag and Manoj for their continued support.

We hope this compendium will reach the intended audience – educators, researchers, practitioners, policy makers as well as students of development – and in time will be regarded as a persuasive and authentic account of the Indian social impact ecosystem.

Readers can write to us at case.study@apu.edu.in with their valuable comments, suggestions and reviews so that we can improve our next editions. Thank you for reading and look forward to hear from you.

## Setting the Context
# II. Case studies on Healthcare

This section of the Case Study Compendium includes two case studies that describe health interventions that are very different from one another. Both interventions are critically important given the range of health needs that we face, and they have shown by example that it is possible to address complex issues effectively. The evidence shows that we are in the middle of the 'Health Transition' and are currently facing a double disease burden: there is a continuing burden of communicable diseases such as Tuberculosis, dengue and water-borne diseases; at the same time, there is a growing burden of non-communicable diseases such as heart disease, cancer and stroke.

The treatment approach to these two categories of disease is quite different: for communicable diseases, usually the symptoms are acute and need immediate medical care. Adherence to the treatment protocol is key to achieving a complete cure. Non-adherence can have serious repercussions, including relapse and (particularly in the case of TB) drug resistance. The consequences of this are debilitating, even life-threatening. In the case of non-communicable diseases (also called 'lifestyle diseases'), the challenge is to get patients to not only take medication for the long-term – sometimes for the rest of their lives – but also to make sustained changes in their diets and lifestyles to support the medical regimen. This requires an effort: to quit smoking or drinking alcohol, or exercise regularly, or eat more vegetables is not easy without a larger eco-system that provides the necessary social support.

The case study on the TB Careline of the Karnataka Health Promotion Trust describes an initiative that goes to the heart of TB care. Despite the longstanding efforts of the Revised National TB Control Program, TB continues to be a serious cause of morbidity and mortality in India. Statistics published by the World Health Organization indicate that almost 2.7 million new cases of TB are detected in India every year, with an estimated 400,000 deaths. TB Treatment is relatively long drawn out, in that it takes a minimum of 6 months. After the first couple of months, patients tend to feel a lot better, and the most obvious symptoms of the disease disappear. The treatment is harsh and takes a toll on the body – loss of appetite, change in skin color and

tiredness are some of the side effects. As a result, patients tend to stop taking their medicines, significantly increasing their chances of becoming resistant to future treatment. Due to the stigma attached to the disease, they have few options for counseling and support that are both private and reliable.

The 'Mitra' TB Careline fills this gap by providing confidential counseling, a way for patients to get back on their treatment regime and loops back to their healthcare provider to give them an update on their patient's status. During the Covid-19 pandemic, when patients were unable to access regular care due to lockdown or other reasons, the helpline was able to reach out to their clients and continue to provide them with services. Leveraging the growing IT capabilities, the TB Careline has shown that technology can be combined with care and compassion to make a real difference in health outcomes. By partnering with the government at the state and central levels, KHPT has been able to integrate their helpline approach into the government's framework, thus creating the possibility of long-term sustainability of their approach.

The second case study describes an intervention that is designed to provide familial support for people suffering from chronic conditions that are not amenable to quick cure. The stress of such conditions on both the patient and their families is tremendous and require guidance on coping mechanisms to help them manage the situation. Non-communicable disease (NCD) burden is growing rapidly in India, and it is estimated that 1 in 4 Indians is at risk of dying before the age of 70 due to NCD. The risk factors for such diseases – rates of high blood sugar, hypertension, tobacco and alcohol consumption, among others – are also showing a growing trend, which does not bode well for the future. Another challenge faced by the health system is the shortage of human resources, whether it is doctors or nurses or outreach workers, who could provide the caregiving support that families need. In their absence, families are left without knowledge or resources on how to deal with the medical condition of the loved ones.

The Care Companions Program (CCP) launched by Noora Health recognizes the important role played by family members in helping patients with such chronic diseases to come to terms with their condition as well as make the changes needed to put them on the road to recovery. Since this is an effort that has to last their lifetime, the need to maintain such sustained effort can take a toll on both the patient themselves and their family. The CCP is designed to allay the fears and anxieties of family members and provide

them with awareness and skills to be proactive and knowledgeable care givers. There is evidence to show that such training contributes to reductions in mortality as well. Using available opportunities, such as hospital waiting rooms, CCP has been able to reach out to an impressive number of people: starting in 2012, they now work with a network of more than 150 institutions and have trained more than a million patients and family members in CCP.

These two examples document interventions that are practical as well as scaleable. In fact, both have been implemented at scale, and can be further replicated widely. Allocations to the health sector continue to be extremely low in India, which affects many aspects of health system functioning. Continuity of care is one of the casualties of the system – whether it is in terms of treatment adherence, or care and support, the health system is not equipped to do it effectively. These two case studies show that it is possible to build both access to and quality of care in the health system even in the face of a resource crunch.

# II.B: Counselling and Care on Call: The Story of the TB Careline

## Karnataka Health Promotion Trust (KHPT)[21]

Tuberculosis (TB) is the top infectious killer in the world, and India accounts for about a quarter of the 10 million cases that occurred in 2017. TB patients are required to take a minimum of six months of treatment. However, due to an abatement of symptoms or uncomfortable side effects, they often stop taking medication, thereby raising the risk of the TB bacteria developing a resistance to drugs and becoming more difficult to treat. While TB patients are offered in-person visits by government facilities to monitor treatment adherence, many do not opt for this service because they fear being ostracized by their neighbours and relatives. Mitra, a free-of-cost phone-based 'TB Careline', provides not only information about TB to patients opting for the service, but also counsels them, links them back to treatment if they discontinue it, and provides feedback to providers about their patients' status. It is staffed

by a team of trained counsellors, and has been operated by KHPT since 2014, reaching out to an average of 500 new patients in Karnataka every quarter. The Careline has reached out to 15,989 patients between April 2014 and September 2020, with 7,647 patients completing treatment.


*Figure 1 TB Careline*

The service has proved to be flexible and adaptable to the requirements of the health system. The Careline has transitioned from reaching out to patients in the private sector to providing counselling and information about accessing new welfare schemes to all patients registered with the national registry. During the Covid-19 lockdown, counsellors continued to provide outbound call services from their homes in the absence of public transportation, and included updated and accurate information about Covid-19 and its risks to all registered TB patients. The TB Careline has the potential to be scaled up in a

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21 Contributed by Vrinda Manocha and Dr Prarthana B. S.

cost-effective manner while continuing to provide pertinent information and counselling services to TB patients and caregivers, and also adapting to the emerging needs of communities as well as the health department.

# 1. Introduction

The TB Careline is based in a modest office located off a busy road in Dharwad city, Karnataka, 400 kilometres from the state capital of Bengaluru. It is a single room on the first floor of the Karnataka Health Promotion Trust (KHPT) office, a bungalow on a residential street. At first glance, it appears to be the average office set-up, the usual mix of monitors, headphones, and desk chairs that say nothing about what the people who work there actually do each day. It is at 9.00 a.m. when five women arrive, plug in their headphones and pull up long lists of numbers that the place begins to buzz, turning into a hive of activity. For it is from this office that these five women, counsellors of the TB Careline, make calls to over 2,552 TB patients across Karnataka, offering treatment monitoring and counselling services free of cost.

Telephone-based counselling on matters of health is not uncommon; a number of services offer support to people with issues of mental health and addiction. Even more common are telephone helplines that offer one-time information when a patient reaches out for it. However, the success of the latter depends on the patient's initiative, access to phones, and a basic understanding of their condition. TB patients do not always fit the bill.

TB is the top infectious killer in the world today, with India sharing a quarter of the global burden of 10 million TB patients (see Figure 2). Ending TB's run is a top priority of the Government of India, which has pledged to eliminate TB in the country by 2025 through the intensive efforts of the National Tuberculosis Elimination Programme, in collaboration with non-profit partners and the corporate sector. However, even with all the house-to-house campaigns, the provision of free testing and treatment and nutrition support to TB patients, the disease persists, mutating into drug-resistant forms and attacking the poorest and most vulnerable populations living in crowded and badly ventilated parts of the city.

The message that the government has consistently put out is that if a person has a persistent cough for two or more weeks, they should get themselves tested. However, the collection of lung TB symptoms—cough,

fever, joint pain, night sweats—is rarely enough to send people running to the doctor asking for a sputum test. Indeed, a study conducted by KHPT in Bengaluru in 2017 found that the delay between the onset of symptoms and the initiation of treatment, due to a variety of factors, averaged 40 days.
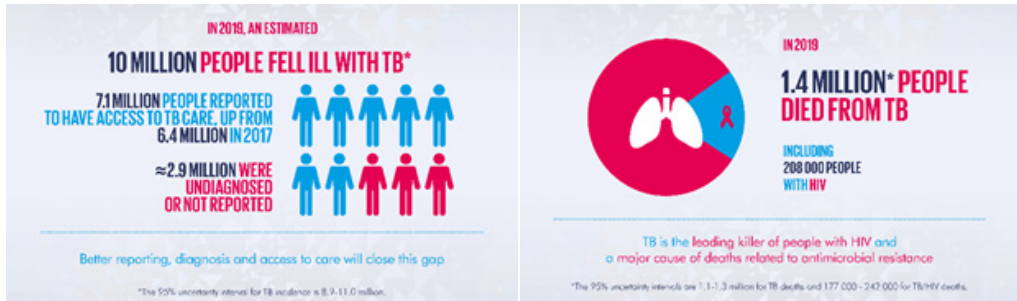


*Figure 2: Global TB statistics. Source: Global Tuberculosis Report 2020, WHO*

That's what happened to Sandeep, a 30-year-old man of slim build, whose active life of yoga and gym-going did not prepare him for the debilitating abdominal pain that hit him in early 2017. Sandeep, who worked at a factory creating parts for construction machines, went to a health provider in his village, who, he says, took little interest in his condition. Sandeep continued to work in an environment thick with dust, refusing to wear a mask because it irritated him. He became weaker and weaker until his employer noticed and took him to another private doctor. Sandeep's abdomen was drained of fluid, and he was given an X-ray. "My lung was white on the X-ray," he remembers. Sandeep was finally diagnosed with TB. His doctor assured him that TB was curable, handing him a green-and-blue card with a toll-free number and a symbol of clasped hands. The card read 'DOTS Mitra'. (DOTS is the treatment strategy of the national TB programme. Putting DOTS Mitra together indicated that Mitra is supporting the national TB programme.)

## 2. Background and Evolution

The TB Careline was initially christened 'Mitra', meaning a friend or confidante who would provide helpful information about the disease and send reminders to take the medication, but, more importantly, be a source of emotional support to people who may not have understood their condition completely, or grasped why it was important to take medication.

Mitra was born out of an intervention conducted under the Strengthening Health Outcomes through the Private Sector (SHOPS) initiative, a project funded by USAID to improve access to, and increase the use of, health services through market-based models.

Encouraged by the results of a telephone counselling initiative for the consistent use of injectable contraceptives in 2010, SHOPS TB decided to expand the model to tuberculosis patients and healthcare providers (see Figure 3). In April 2014, SHOPS established the TB Careline, a phone-based counselling service for patients, which helped monitor their treatment adherence, provided them accurate information about the disease, and also counselled patients and caregivers throughout the treatment period, and for two years after the completion of treatment.

The SHOPS project created a network of private healthcare providers, and it was this network of 1,149 providers that handed out Careline cards to their newly diagnosed or returning patients, asking them to give the number a missed call. In some cases, the private providers would provide the patient details to the Careline counsellors, with the latter initiating calls to offer services to the patient. The Careline service also proved particularly useful for the private providers, who lacked the bandwidth to follow each of their patients individually; they received monthly updates from the counsellors on the treatment status of their patients.

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When the SHOPS initiative ended in 2015, it was continued through KHPT, which had established the TB Careline in Dharwad, Karnataka. With the trained team of counsellors in place, KHPT began to look for external funding to secure the future of the Careline, which was receiving calls from networked providers even after the closure of SHOPS. In 2016, Indegene Lifesystems Pvt. Ltd, a healthcare technology company, began to support the Careline operations as part of its corporate social responsibility (CSR) activities. KHPT brought Careline under the ambit of the Tuberculosis Health Action Learning Initiative

(THALI), a four-year project that began in 2016, aiming to facilitate access by vulnerable populations to TB care and support services from a healthcare provider of their choice, largely in urban slum areas. The project had aimed to continue engaging with private healthcare providers and registering their patients for follow-up and counselling. However, in September 2017, due to policy changes within the funding agency, USAID, a strategic shift put an end to private provider engagement in THALI.



*Figure 3. The Careline number was earlier toll-free under the SHOPS project and patients were given the Careline card (first row), encouraging them to give a missed call to the number. The number is currently a mobile number (second row). The cards are also available in Telugu.*

While the direction of the THALI project changed to facilitating TB prevention and care services through the government, the focus on patient-centred care and support remained the same. The Careline could no longer be promoted through private providers, but the awareness of such a service would be created through THALI's cadre of community health workers, who worked in the urban slums in 24 districts in Karnataka and Telangana. Nevertheless, the networked providers continued to refer patients to the Careline even after engagement with private providers ceased, accounting for 500 new patients each quarter.

In March 2019, Karnataka state requested the Careline to call up patients in the private sector whose treatment outcomes were not known to enable linkage to nutrition benefits provided to public-sector patients. The counsellors were given a retrospective list of 14,312 patients to work through in two months; these patients had been registered with Nikshay, the national registry, in 2018. The counsellors managed to contact 8,476 patients of which 4,605 could not be tracked due to a lack of contact numbers, wrong numbers, or unreceived calls.

The accomplishment of this task and the feedback provided on the treatment outcomes of the patient reinforced that the Careline objectives aligned well with those of the national programme, and the Karnataka state government began to provide a list of private sector patients registered with the national registry every month. In 2019, the Careline counsellors attempted to track 7,866 private sector patients. The counsellors have followed up an additional 500 new cases each quarter with the provision of the patient list from the government.

The feedback the counsellors provided, not just on treatment outcomes, but also on the number of patients who could not be tracked, has helped the state authorities contact the individual private providers and encourage them to do a better job of collecting patient details. The counsellors have followed up an additional 500 new cases each quarter with the provision of the patient list from the government. In addition to counselling patients and monitoring their treatment adherence, counsellors have started telling patients that they are eligible for Rs. 500 per month from the government through the Nikshay Poshan Yojana towards nutrition support and asking them if they had availed of it. Some districts in Karnataka, based on the information provided, have registered these patients for the Nikshay Poshan Yojana Direct Benefit Transfer (DBT) scheme.

# 3. TB Patients and the Need for Follow-up

After his TB diagnosis, Sandeep was deeply disturbed. As a healthy, active person, he could not understand why he had developed TB. His parents, with whom he lived, were very upset to see their son bedridden and too weak to move. Sandeep would spend four months at home, unable to go to work, or even to move very much. He wanted to give up treatment, because he didn't think it was making him any better.

With a treatment period of at least six months and a mandate to not miss a single dose in case this lapse creates drug-resistance, TB patients often struggle to take their medication every day (see Figure 4). Patients may have to swallow two to six tablets at the same time each day, and then have to deal with debilitating side effects, which include nausea, fatigue, vomiting, jaundice, itching, rash, tremors in the hand, and red-coloured urine. The side

effects can put a person off treatment entirely, or it may result in days-long delays that prevent their recovery. On the other hand, the treatment may ease symptoms enough after the initial few weeks for the person to feel that they have recovered, and therefore believe that they do not need to take treatment any longer. In both these situations, patients can relapse, and if they are off treatment for more than a month, they will have to begin from scratch all over again.

The road to recovery can be long and gruelling, made more difficult by socio-economic factors like poverty, malnutrition, and stigmatization. TB is an isolating disease; patients have been stigmatized by their own families, co-workers, and friends for having the disease. This stigma continues even after they have completed treatment. Families, who do not understand that the patient is non-infectious shortly after treatment begins, often place the patient in a different room, with different plates and bedding. During the THALI project, it was not uncommon for field staff to come bearing tales of



*Figure 4. A course of TB medication lasts for at least six months, making adherence difficult for patients (image is only for illustrative purposes).*

women abandoned by their husband and his family, and separated from their children for fear that they would infect their families with TB, and that other people would get to know about it. These circumstances are enough to pull patients off their course of treatment and send them into depression.

The fear that the neighbours will find out that they have TB also prevents patients from seeking healthcare. TB patients do not want to be visited at home for fear that people will see a government healthcare worker and start speculating about why she is there. That is partly why they seek private sector care. Careline was instrumental in providing support to those who would not receive in-person care, but also needed follow-up. All they needed to have treatment support on the go was a mobile phone, or even know someone who did.

# 4. The Careline Call Process

Sandeep knew very little about TB at the time of his diagnosis. "(I thought) I had never had bad habits. So why did I get it?" he says. Sandeep had no mobile phone and his friend called the number on the Careline card. He would bring his phone over whenever the counsellor called, so that she could speak to Sandeep, giving him correct information about his condition and counselling him.
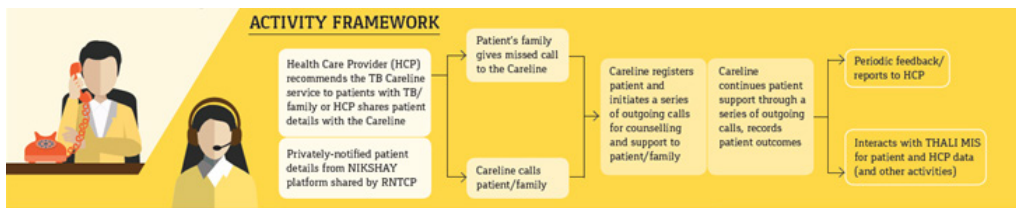


*Figure 5. The Careline call flow*

A patient given the Careline card is instructed to give a missed call to +91 73497 78223 (see Figure 5 for the Careline call flow). A Careline counsellor returns the call, and, based on the patient's language preference, allots the patient to one of the counsellors, keeping in mind the existing call load of the counsellor and the counsellor's experience. Each counsellor on the team is generally a graduate, and much of the training is done on the job. Counsellors are hired on the basis of their interest in engaging with patients. They are given a one-month trial period to understand their motivation and to see if they can handle long hours of talking to patients without ever meeting them. The TB Careline has five counsellors as of November 2020, and between them, they are fluent in Kannada, English, Hindi, Telugu, Urdu, Konkani, and Marathi. The first call to the patient is an introductory one; the counsellor says that she is calling from the Careline, explaining the purpose of the Careline, and registers the patient's consent to be followed up by phone call. The next day, she calls the patient for the first session of post-diagnosis counselling, asking them if they have disclosed the disease to others, and if any of their friends or family members are showing symptoms.

Counsellors generally encourage TB patients to disclose their condition to family members, to avoid the stress of keeping the condition secret from their family and to enlist their support in taking treatment and in handling side

effects. The verbal screening of the patient's close contacts by counsellors is an important component of Careline services; the counsellor instructs the patient to direct their close contacts to a healthcare provider if they show TB symptoms. The first call generally takes five to ten minutes.

## Treatment adherence in two minutes: A call transcript

*Counsellor:* *Namaste. How are you?*
*Patient:* *I am fine. How are you?*
*Counsellor:* *Are you taking your medicine?*
*Patient:* *Yes, I am.*
*Counsellor:* *Are you able to eat well?*
*Patient:* *I am able to eat three times a day, timely.*
*Counsellor:* *Don't worry about anything now, as you are able to eat well and you are taking your medicine regularly. Do you have any other problems now?*
*Patient:* *I have no problems now. I am feeling fine.*
*Counsellor:* *I am glad you are feeling fine, okay, okay . . . As you have planned, go back to your provider on the 4th because you're completing nine months of treatment.*
*Patient:* *Bye. I'll disconnect now.*
*Patient's husband:* *Excuse me, madam.*
*Counsellor:* *Yes, sir?*
*Patient's husband:* *We are going there [to the provider] anyway. But she is feeling perfectly fine and has no complaints now.* *Counsellor: Yes, I realize that she's doing well now, but you should finish your follow-up with the doctor and stop your medication only when he asks you to.*

*For the full translation of the audio recording, see Appendix A.*
*Please note that names have been removed to protect patient privacy.*

After the second call, the counsellor speaks to the patient once a week for the first two months of treatment (the intensive phase) and once in two weeks during the next four months (the continuation phase). Counsellors

ask patients how they are feeling, if they are taking treatment regularly, and if they are eating a healthy diet. If the patient says that they have missed treatment doses, the counsellor talks to the patient about how important it is to stay on course with the treatment and to reduce the risk of a relapse. When patients complain about side effects such as nausea, the counsellors tell them about simple home remedies such as drinking kashaya (a herbal health drink), and eating small meals a few times a day rather than one big meal, all the while encouraging them to stay active. If the side effects are severe, they instruct them to visit the doctor. Counsellors also remind them about routine visits for follow-up testing, and continually check that none of their close family members and friends have developed symptoms. Once patients have completed the treatment, the counsellors call them once a month for up to two years to check that they remain TB-free. Follow-up calls generally take two minutes per patient, seven to eight minutes if the counsellors advise them on coping with side effects.

## Contact screening: Excerpts from a call

*Counsellor:*  *How many people are there at home?*
*Patient's father:*  *We are a large family, around 15–20 people.*
*Counsellor:*  *Is there anyone over 60 years of age?*
*Patient's father:*  *Yes, there is.*
*Counsellor:*  *Do they have diabetes or any other disease?*
*Patient's father:*  *Yes, they have diabetes.*
*Counsellor:*  *Are they healthy or do they have any complaints?*
*Patient's father:*  *They have no complaints.*
*Counsellor:*  *Do any of them have symptoms like cough, fever, or not being able to eat properly?*
*Patient's father:*  *Yes. They complain about not being able to eat properly.*
*Counsellor:*  *Go to the nearest government hospital to get him/her checked.*

*For the entire translation of the audio transcript, see the appendix.*
*The patient's name and details of the hospital have been*
*removed to protect patient privacy.*

The calls are made through a tablet computer, which has replaced the earlier system of using smartphones to make calls; the smartphones were overheating because of extensive daily use. While the calls to patients are not recorded, an earlier Excel-based monitoring system gave way in 2019 to a software programme that brings up their daily call schedules and allows them to track whether patients are taking treatment.

*However, the counsellors do not provide medical advice, and if symptoms resurface or side effects worsen, patients are told to visit their healthcare providers immediately.*

Careline counsellors are often asked for medical advice by patients who lack access to doctors or do not have the time to visit the doctor themselves. However, the counsellors do not provide medical advice, and if symptoms resurface or side effects worsen, patients are told to visit their healthcare providers immediately. TB counsellors are also mindful of not disclosing a patient's TB status if a caregiver or friend picks up the phone. It's a lot to remember, but with experience, exercising caution has become second nature to the counsellors. "The problems that patients have can't be shared with everybody. We are not doctors, but people open up to us," says Vijayalakshmi, a senior counsellor who has been with Careline since 2014.

## 5. Adapting Careline to Patients' Needs

The call flow, which specifies call frequency and procedures, may appear straightforward, but it must mould itself to the needs of each patient. Although the Careline functions between 9:30 a.m. and 5:30 p.m., six days a week, the Careline counsellors make and receive calls long after working hours, averaging about 50–70 calls per day. A TB patient may only get access to her husband's phone in the evening after he returns from work, and that is when the counsellors will have to call her. Patients may call to hear a friendly voice if they feel that they have no one to turn to (see Figure 6). "I have a patient with multidrug-resistant TB who lives alone in a big city," Sirisha, a counsellor who has been with Careline for two years, says. "Her ears are ringing because of the treatment, and she has reached a stage where she isn't convinced that she will be cured, even though she has had 16 months of treatment. She hasn't told her family that she is ill and is depressed." Sirisha has told the patient to call her at any time, and her phone rings twice or thrice every week with worried calls from the young woman.

Patients have called the counsellors even at 10:30 p.m., and the counsellors have never said no. Their families, too, have understood the importance of their work and do not have any objections to these late-night phone calls.If the patients are very young, or elderly, the Careline counsellors talk to caregivers about the patient's treatment adherence and often counsel the caregivers themselves for whom dealing with a close family member's illness is difficult. Elderly patients often have long conversations with counsellors, because they have no one else to speak to.

Then there are the difficult cases that require the counsellors to find ingenious ways to prevent the TB patients from putting the phone down permanently. Gracy, who has been with the Careline for just three months, has been dealing with a tough situation with a family living in central Karnataka. "The mother and one-year-old child have TB," she says. "The husband is blaming the wife for giving it to his son. His son is with him, and the wife is at her mother's place. He is not giving me her number." Gracy has been speaking to the husband, reassuring him that TB is curable and that many people have recovered completely. On just one occasion was she able to speak with both husband and wife on a conference call, where



*Figure 6. The treatment period can be isolating for a patient, who may be stigmatized by the family and blame themselves for getting TB.*

she reassured them both that the wife would recover if she took treatment. "He [the husband] is comforted when he talks to me, but he is still angry. I am working on changing his mind." Gracy hopes for a breakthrough that will allow the wife to come home to her family, a message that is sought to be delivered through repeated conversations on the phone.

Shivamma remembers a case where she had to be inventive and resourceful in order to drag one of her patients out of depression. "She was just 20 years old. She was bedridden for two months, surviving on just juice. Her husband had had an affair and left her," she recalls. "She didn't think she would survive." Shivamma had to coax the patient to take her treatment and eat, while simultaneously trying to build her self-confidence and strengthen her will to live. "Her parents would call me, and I would say that I would

not talk to her until she had walked to her plate." Once the young girl had struggled out of bed and walked across the room to take a bite of food, her parents would hand Shivamma the phone.

# 6. Challenges and Limitations

Having to be just a faceless voice on the phone presents significant limitations, and the first barrier in the path of the counsellors is securing the patient's consent. "Refusals have been low, but sometimes patients are afraid to share that they have the disease and are worried others will find out," says Shivamma. "Some people are busy with work and tell us they will not be allowed to pick up their phone during work hours." Counsellors have only one or two chances to convince patients that follow-up and counselling services could help them on a months-long journey to recovery. However, if they choose to ignore their advice, the counsellors must respect their wishes.

The lack of face-to-face contact also takes a toll on the counsellors themselves. Gracy may have been able to convince the man in Chitradurga to let his wife come home immediately had she met him, but she has to be content with having conversations over the phone. Counsellors thus have to strike the right balance of patience and persistence in their efforts to change the behaviour of TB patients.

> *"The thread of communication is very delicate. We can break it by saying one wrong word. Since we don't have direct communication, our very 'hmms' and 'aahs' are non-verbal communication and they can tell if we are listening,"*

Counsellors have also lost patients because of changed mobile numbers, with no way to track them. In addition to following the call protocols, which involve calling patients lost to follow-up once in 15 days for three months, the counsellors have developed an informal protocol. "We follow up once in 15 days if a number is out of service, but we try the number weekly if it is ringing," says Shivamma.



*Figure 7. The Careline counsellors have discussions with the technical team on their experiences and difficult cases.*

There is no linkage between the Careline counsellor and the government health staff, partly in the interest of maintaining patient confidentiality, and thus there is no further support system to help enforce the counsellors' recommendations. Tina, one of the newer counsellors on the team, is struggling with a case of a 15-year-old girl in central Karnataka who has lost her eyesight to TB, and is being shuttled between public and private providers by her parents. Her parents have asked the counsellors for medical help, which they cannot provide. Tina seeks the advice of the technical team at THALI (see Figure 7), but this is hard to do for all but the most difficult cases. Counsellors have sometimes been confronted by patients asking why they are even interested in their health. "We say it is our work. We get no benefit from it, and even if you scold us, we want you to feel better. We want no one else to be affected by the disease," Sirisha says.

At other times, counsellors have called patients, only to find out that they have passed away. "I find it difficult to say anything to the family, but I have to find something comforting to say," says Shivamma. The counsellors have undergone training in bereavement counselling, which has helped them to comfort caregivers about the loss of the individuals they had become close to themselves. Every six months, even after a patient's death, the counsellors call the deceased's family members to ensure that no one in the family has symptoms.

Dealing with patient deaths, losing cases to follow-up (due to a change in phone numbers, disconnected numbers, unanswered calls, or when contact can no longer be established with the patient for various reasons), and handling difficult cases have taken an emotional toll on counsellors, but they have developed their own coping strategies to deal with their feelings. Gracy and Sirisha say they feel very bad when they hear about patient deaths, imagining themselves in the position of the bereaved family, but Shivamma tries to be pragmatic. "There's no use in feeling bad," she says. "I just have to remember my satisfaction in having helped patients in the private sector who do not go regularly for check-ups." The counsellors also draw on each other's experience, taking two-minute breaks from the call to discuss what to say to the patient or caregiver before calling them back.

For many patients, that call tips them from despair to hope. At a time when he was depressed, as were his mother and father, Sandeep said he felt good when the calls came. "It was nice to know that someone cared about my

treatment." He dragged himself out of bed and focused on getting healthy, and by the time his treatment ended in August 2017, he was already back at work, doing small jobs.

# 7.  Careline's Impact and the Way Forward

## 7.1 Value addition by the TB Careline

i.   The TB Careline maintains the privacy of patients who may not wish to receive in-person care.

ii.  Each call is tailored to the patient's needs, offering a personalized approach to prevention, care, and support.

iii. Counsellors are also trained to address specialized issues of bereavement as well as paediatric, geriatric, and drug-resistant TB.

iv.  Careline is a system that uses technology without removing the human connect from patient care, making it acceptable to the patient and the caregivers, while at the same time increasing the efficiency of the counsellors.

v.   The Careline is a flexible system that can be adapted to the needs of the government health system (supporting treatment notification and linkages to patient benefits) or the private sector (providing feedback on the patient's treatment status).

> *The Careline counsellors have managed to convince about half of the patients who stopped taking treatment to resume their medication.*

The TB Careline has registered 15,989 patients between April 2014, when it began operations, and September 2020. In this period, 7,241 patients have completed treatment, 2,552 are under active care, and 605 patients have died. The Careline counsellors have managed to convince about half of the patients who stopped taking treatment to resume their medication. In total, 7,866 patients who have been notified to the state TB programme from January–September 2020 are being tracked currently to ascertain their treatment status. These numbers are a testament to the dedication of the team of five counsellors, who work well past their office timings to ensure that no patient feels isolated, confused, and afraid of what is happening to them. Even during the Covid-19 lockdown, the counsellors worked from home, in the absence

of public transport, to ensure that their call schedules weren't disrupted and that TB patients would not feel isolated in an uncertain time. They calmly explained the risks of Covid-19 and provided accurate information to TB patients at a time where rumours and inaccurate information were rife on social media.

The TB Careline has enormous potential, combining as it does a technological process with the human touch. Not only does it have the ability to reach thousands of patients and follow them for up to two years after treatment, but it also does this in a discreet manner that is respectful of the patient, is convenient to the patient, and, mostly importantly, maintains the patient's privacy.

The Careline is a flexible and scalable system that has the potential to cover every state and district in India. Since its inception as a service for private sector patients, it has expanded to involve a greater number of counsellors with a wider range of language capabilities to cater to both public and private sector patients. The state government has also asked KHPT to provide information on DBT payments under the Nikshay Poshan Yojana scheme, which provides TB patients Rs. 500 per month for nutrition support during the treatment period.

*With a larger team and greater language capabilities, the Careline would be a valuable weapon in the government's arsenal to fight TB and eliminate it in India by 2025.*

The government has established a TB information service called Nikshay Sampark, which offers callers information on TB treatment and patient services that are available through the national TB programme. Its call centre is staffed by 100 agents speaking 14 languages, who have handled 8.95 lakh calls from patients and healthcare providers across the country since May 2018. Nikshay Sampark does not currently offer counselling services to TB patients, but with its infrastructure and geographical coverage, it has the potential to integrate counselling as a function in its services.

The KHPT team visited the offices of Nikshay Sampark in Gurgaon in May 2019 to share learnings from the work of the TB Careline with the team. KHPT suggested that a part of the Nikshay Sampark system be dedicated to a counselling service and shared the Careline call schedule and workflows

as samples upon which Nikshay Sampark could build their own schedules, workflows, and protocols. KHPT continues to advocate with the national TB programme to integrate the Careline into Nikshay Sampark within two years, with the aim of ensuring that for every TB patient, no matter where he or she is located, support is just a phone call away.

# 9. Acknowledgement

We wish to acknowledge, first and foremost, the Careline counsellors working in Dharwad, Karnataka, who have for many years been friend, counsellor, and guide to TB patients and caregivers across the state. The support of Indegene Lifesystems Pvt. Ltd and the United States Agency for International Development (USAID) has been invaluable to the Careline's operations. KHPT works in collaboration with the Government of Karnataka as we move towards achieving India's goal of eliminating TB in 2025, and we acknowledge the support of the programme staff of the National Tuberculosis Elimination Programme.

# About KHPT

*KHPT is a not-for-profit entity founded in 2003 that aims to reduce inequalities in health by building responsive systems through evidence-driven approaches. KHPT works in over 20 states of India, primarily in the fields of Maternal, Neonatal & Child Health (MNCH), Tuberculosis (TB), Adolescent Health (AH), HIV/ AIDS, and Comprehensive Primary Health Care (CPHC).*

*KHPT envisions a TB-free India, with a focus on scaling innovations on prevention, detection, treatment, and care for patients through building the capacities of communities and health systems. The organization is working in collaboration with the National Tuberculosis Elimination Programme to end TB in India by 2025.*