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EVALUATION REPORT OF THE PROJECT: BREAKING THE BARRIERS - A COMMUNITY ENGAGEMENT INITIATIVE TO ACCELERATE TB ELIMINATION IN INDIA

Understanding user-feasibility of behaviour change solutions for Persons with Tuberculosis in community engagement programme in the states of Karnataka, Telangana, Bihar and Assam under the USAID funded Breaking the Barriers Project, implemented by KHPT



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An Institute of National Importance
Bengaluru - 560 029, Karnataka State, India**

2024

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ACRONYMS

ACSM	Advocacy Communication and Social Mobilization
ASHA	Accredited Social Health Activist
BCS	Behaviour Change Solutions
BTB	Breaking the Barriers
CS	Community structure
CSG	Care and Support Groups
CTD	Central TB Division
FGD	Focused Group Discussion
FLW	Frontline workers
HA	Health Auto
HCW	Health care workers
IDI	In-depth Interviews
IEC	Information, Education and Communication
JC	Jaanch Coupon
KHPT	Karnataka Health Promotion Trust
MO	Medical officer
NIMHANS	National Institute for Mental Health and Neuro Sciences
NSP	National Strategic Plan
NTEP	National TB Elimination Programme
PwTB	Persons with TB
SK	Starter Kit
TB	Tuberculosis
TBC	TB Champions
TBCHW	TB Champion as Health Worker
TBHV	TB health volunteer
TBMC	TB Mukht Certificate
TU	Tuberculosis Unit

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COMPONENT 1:

QUALITATIVE REPORT

Understanding user-feasibility of behaviour change solutions for Persons with Tuberculosis in community engagement programme in the states of Assam, Bihar, Karnataka and Telangana, under the Breaking the Barriers Project

EXECUTIVE SUMMARY

In alignment with the National Strategic Plan (NSP) of eliminating TB from India by 2025, Breaking the Barriers project was rolled out by KHPT amongst specific vulnerable groups in four Indian states viz. Karnataka, Telangana, Assam and Bihar since 2020, in collaboration with USAID. As part of its community engagement initiative and person centric care models, nine behaviour change solutions (BCS) were implemented in the project geographies. This study is an attempt to understand the influence of BCS on TB awareness, notification, treatment adherence among the vulnerable population groups and explore the feasibility of implementation of the solutions by the communities.

The study used a phenomenological approach and qualitative methods to gain in-depth understanding about the experience of the users (persons with TB & caregivers) and service providers (community stakeholders, NTEP staff and frontline workers). It was conducted by National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore between May-August 2023 in four BTB intervention states – Karnataka, Telangana, Assam and Bihar among a sub-sample of beneficiaries from the tuberculosis units (TUs) where BCS was implemented. This study had resulted in insightful understandings on the behaviours, perceptions, attitudes, motivations which drive the health care seeking among PwTBs and their service providers. Qualitative analysis of the 195 in-depth interviews (IDI) and 11 focus groups discussions (FGDs) highlighted a bundle of intended and additional benefits experienced by the individual users, health system and the community.

The key message from the present study is that, addressing the barriers at the cognitive and behavioural level of persons with TB, and at-risk individuals and groups, could be of foremost importance for achieving the goals of TB elimination programme. The study underscored that over and above the existing IEC and ACSM intervention of TB

programme, the present BCS interventions opens up a range of opportunities to address a multitude of issues and barriers related to TB care-seeking - which otherwise had remained unexplored so far.

The BCS solutions of **Health Auto, Jaanch Coupon and TB soochana** were aimed at enhancing TB case finding. The salient findings emerging out of the study are elaborated below:

Health auto is a free of cost on demand pick-up & drop-off service, aimed to address the hidden costs associated with TB treatment and addressing the decision fatigue experienced by the symptomatic persons that affect their travel to health facility. The intervention rendered an expected benefit for the persons with TB by way of enabling an affordable and accessible ride to the hospital and resulted in improved uptake of services. More significantly, at the behaviour and cognitive level, it was found from the study that, health auto enhanced motivation level, decision making capabilities and entitlement towards TB care seeking. Health auto was able to address additional vulnerabilities within the vulnerable groups, especially housewives, young women, elderly, unemployed and specially-abled. This service successfully bridged the accessibility issues in remote areas. Although, the solution proved to have potential to improve TB case finding in the community, it was not helpful in fighting stigma in the community, rather health auto itself was stigmatized as TB auto, which prevented community members from using the service. Additionally, the auto service being cost intensive sustainability was a point of concern for the programme managers.

Jaanch Coupon is an in-hand copy of a referral slip with the validity and value of the test mentioned in it, intended to be used by individuals having TB like symptoms to visit health facilities and get tested. As a solution this sought to improve TB referral services and diagnosis had resulted in improved uptake of TB services, reduced community resistance, and better health seeking behaviour. This solution also resulted in additional behavioural and cognitive level benefits which included motivation to get tested, decision making for TB care seeking, and improved entitlement to health services at facilities. From the health care provider perspective TB Jaanch coupon had resulted in reduced diagnostic delays, improved health seeking and case finding in the community. However, there were a few caveats regarding the solution. NTEP staff expressed concerns over the quality of referrals being made through jaanch coupon. Communities like migrants, showed a general resistance and apprehensions to use the service.

TB soochana is a set of jingles played at public places intended to generate awareness on TB in the community at large. Findings underscored that TB soochana had resulted in desired awareness and health seeking in the community. More importantly, the intervention which adopted a targeted, consistent, and intensive TB awareness model resulted in reduced community resistance and mitigation of stigma towards TB which is remarkable. The solution led to increased percolation of TB awareness information

in the community, which could be attributed to the novel methods of communication channels which were adopted. All three solutions (health auto, jaanch coupon, and TB soochana) were experienced and perceived to be of importance in ensuring TB services for vulnerable populations. We did not find any major hurdles in implementing TB soochana other than it creating an information overload and not serving well in terms of mitigating stigma at the community level.

The BCS solutions of **TB mukt certificate, starter kit, phone-a-friend, TB buddy** were aimed at enhancing treatment adherence and TB case holding. The salient findings emerging out of the study are elaborated below:

TB starter kit is a TB management guide and calendar to keep records on the TB treatment journey. It was intended to serve as an instrument of support for the TB persons to navigate the complex treatment phase. According to the respondents, this solution had resulted in improved treatment adherence by users, reduced defaulter rates, increased motivation for treatment continuation and effective tracking by health care providers. An additional significant outcome was that the kit reduced the burden of family and health care providers by acting as an instrument of support for both users and providers. Although the solution was well acknowledged by the users and service providers, there were a few caveats such as dependence on project staff and the solution being non-user friendly.

Similar to this, two other person friendly solutions -Phone the friend and TB buddies - had partially resulted in treatment support, psychosocial support, and motivation among the users. These two solutions faced challenges of lack of relatability and lack of clarity among the target population. The presence of conventional caregivers created a lack of felt need and affected the relevance of the solutions.

TB mukt certificate is a physical certificate issued by competent health authorities to the persons who completed treatment successfully. It was developed and intended to enable the transcending process of a PwTB to his routine life post treatment. This solution had resulted in remarkable benefits for the patients and rendered a sense of motivation and ownership towards treatment completion among users and improved community acceptance and mitigation of self- perceived stigma. The solution also proved a motivation for the NTEP workers and gave them a sense of work satisfaction and motivation. However, it was mentioned by NTEP staff that the effects of TB mukt certificate are long term and needs additional counselling and personal support.

The **sharing circle** was implemented to create opportunities for the frontline health workers (ASHA) to share their works experiences and foster a positive attitude & resilience towards their work. The results underscored that, the solution was able to improve knowledge sharing and learning experiences as intended. Notably it also resulted in improved motivation and relationship strengthening among them and in improved work

performances and adaptations towards patient care services. However, lack of incentives for the frontline workers and scopes for sustainability of the solution were two major concerns emerged from the findings. Similar to this, **the TB Champion Health Workers solution** was aimed to cater to the needs of persons with TB and delivering high quality support by involving already recovered persons. This has had additional positive contribution to NTEP programme activities such as contributing to case finding, enabling emotional support and inspiration and alleviating stigma. More importantly the barriers and challenges which was faced by the TB champions was extensively captured during implementation which holds implications for the sustainability of such interventions. However, lack of incentives, difficulty in balancing multiple roles, community resistance and lack of acceptance were some of the practical challenges emerging out of the study.

Most of the Behaviour Change solutions which were implemented and tested in the present study holds potential opportunities for scaling up in other settings. Conversely, the findings indicated a few challenges and also did not find positive responses from the users on Phone a friend and TB Buddy. The solutions which were tested are less resource intensive, accessible, affordable, and person friendly, adding value towards the principle of person centric care emphasized by the National TB Elimination programme. The study provided indications that Health Auto, Jaanch Coupon and TB soochana, TB mukt certificate, starter kit and TBC health worker resulted in a range of tangible benefits at the individual and behaviour level which could incrementally contribute towards the TB elimination goals of the NTEP programme.

1. BACKGROUND

1.1 India's National Tuberculosis Elimination Programme: Addressing the needs of Vulnerable Populations

India bears almost a quarter of the global TB burden, with over 28% of the world's cases¹. India has a National Tuberculosis Elimination Programme (NTEP), led by the Central TB Division (CTD) under the Ministry of Health and Family Welfare. The NTEP envisions the elimination of TB in India by 2025 and recognizes that to detect and treat the missing Persons with TB (PwTB), there must be diverse approaches addressing the different needs of disparate vulnerable populations for increased case notification and improved successful treatment outcomes of both drug-sensitive and drug-resistant TB. Diverse approaches are important because specific vulnerable groups have a higher risk of contracting TB in comparison to others due to factors ranging from occupational hazards and geographical limitations to socioeconomic inequalities and gender-based discrimination.

The National Strategic Plan (NSP) for Tuberculosis Elimination in India 2017-2025² of the Ministry of Health and Family Welfare, Government of India lays down the roadmap for the country's efforts to eliminate TB by 2025. The NSP is aligned with the World Health Organization's End TB Strategy and the Sustainable Development Goals. The National Strategic Plan (NSP) envisions person-centred care and the community's active participation in ending TB. However, there is a complex web of factors that impede timely TB diagnosis, treatment adherence, and even successful TB treatment completion.

1.2 Why does TB remain a Public Health Challenge in India?

The first hurdle is the limited access to poor access to medical support. Vulnerable populations often find themselves in a precarious position, unable to readily access healthcare services. Geographic isolation, limited resources, and economic disparities make it challenging for such populations to access medical care. The stigma associated with TB is another substantial barrier. PwTBs, particularly in vulnerable communities, grapple with discrimination and prejudice. This not only hinders their ability to seek medical attention but also deters them from disclosing their condition and seeking

¹ India TB Report 2022, Coming Together to End TB Altogether, Ministry of Health and Family Welfare, Government of India

² National Strategic Plan to End Tuberculosis in India 2020–25: Accelerating the National Response for Expanded Coverage and Sustained Impact at Scale to End TB in India; June 2020, Ministry of Health with Family Welfare, Nirman Bhawan, New Delhi – 110 108

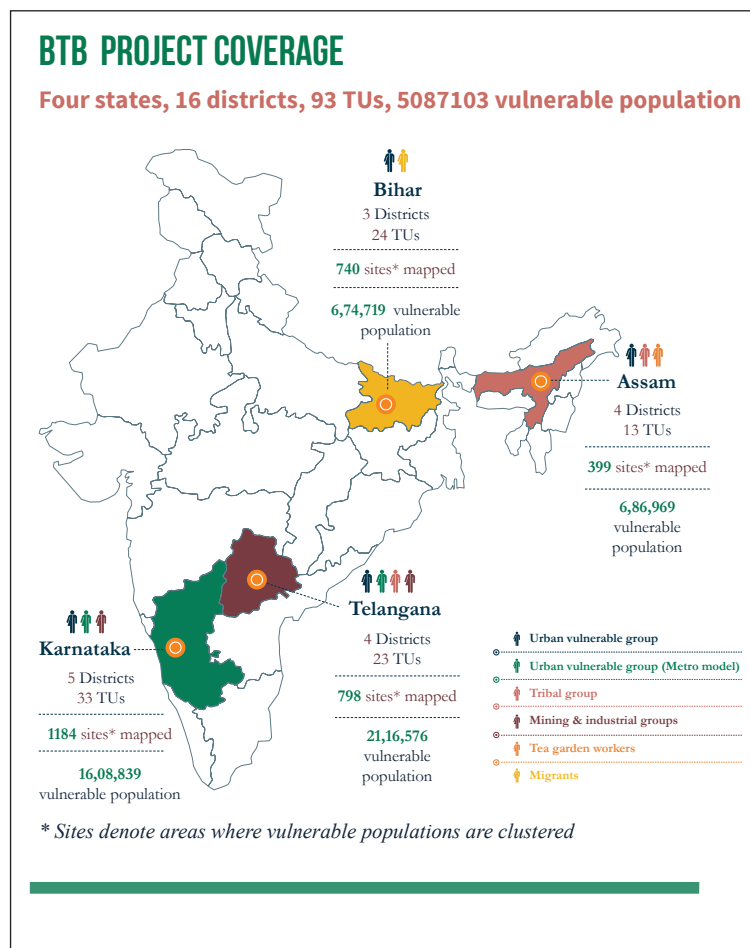
support from friends and family. The lack of a robust support system further complicates matters. When family and friends do not provide the necessary encouragement and understanding, PwTBs are left on their own to navigate a difficult treatment journey.

The significance of empathetic healthcare providers who are sensitive to the needs of vulnerable communities cannot be overstated; without them, effective communication and trust between PwTBs and caregivers remain elusive. Crucial elements in successful TB treatment include psychosocial support and peer groups, which are often missing in the lives of vulnerable populations. The absence of these vital support structures makes it increasingly likely for individuals to stray from their treatment protocols and, in some cases, discontinue treatment altogether.

1.3 About the Breaking the Barriers (BTB) Project

The nuances of the above-mentioned public health challenge became increasingly apparent when KHPT began its intervention across the four states of Assam, Bihar, Karnataka and Telangana as part of its Breaking the Barriers (BTB) project.

Since 2020, KHPT through its USAID supported Breaking the Barriers (BTB) project is covering a total of 5.1 million vulnerable population in 16 districts and 93 TB units (TUs). BTB is a community engagement initiative which is working with different vulnerable populations across the four states namely migrants, urban vulnerable, tribals, mining and industrial workers, and tea-garden workers.



1.4 A closer look at the susceptibilities of vulnerable populations to TB

A closer look at each of these groups helps in better understanding of their vulnerabilities and the critical gaps in addressing TB among them.

Urban vulnerable

In 2011, 65.5 million or 22.5% of the total population lived in slums which are distributed among 2613 towns/cities³. Overcrowding, substandard housing, poor ventilation, poor sanitation, lack of access to safe food and water, and poor nutrition- all facilitate the spread of infectious diseases like TB.

Tribal population

According to the 2011 census, the tribal population in India was 104 million, constituting 8.6 per cent of country's population. The tribal population primarily lives in rural and remote areas and is among the most vulnerable and marginalized sections of society. Moreover, they lag all other social groups in various social, health and developmental indicators⁴. In 2011, 40.6 per cent tribals were below the poverty line and the TB prevalence of tuberculosis (TB) among them is significantly higher at 703 per 100,000 compared to the national average (256 per 100,000)⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6607830/>.

Migrants

As per Census 2011, the number of internal migrants in the country (accounting for inter- and intra-state movement) were 139 million. Some of the most vulnerable populations belong to this group. These include seasonal workers, homeless people, pavement dwellers, street children and those residing in urban slums. A significant section of them live in congregated, crowded settings with poor ventilation and sanitary conditions. Undernutrition, chronic addiction, and unhealthy living further accentuates their vulnerability to TB. Their access to health services and diagnosis of TB including treatment initiation if detected with TB is often hampered in the absence of valid identity documents and residence-proofs whereas their rapid migratory nature acts as a barrier to TB treatment adherence.

Mining and industrial workers

Mining and industrial workers face significant health risks due to harsh working conditions, including extreme temperatures, heat stress, dust exposure, and crowded, poorly ventilated workspaces. They often lack access to basic amenities like drinking water and toilets. Irregular eating habits, driven by work targets and stress result in malnutrition. Workers are at risk of pneumoconiosis, a group of lung diseases caused by

³ <https://www.census2011.co.in/slums.php>

⁴ Office of Registrar General & Census Commissioner India. CensusInfo. Ministry of Home Affairs, Government of India. 2011. Available from: <http://www.censusindia.gov.in/2011census/HLO/HH14.html>

⁵ Thomas BE, Adinarayanan S, Manogaran C, Swaminathan S. Pulmonary tuberculosis among tribals in India: A systematic review & meta-analysis. Indian J Med Res. 2015;141:614–23.

dust inhalation, with silicosis being the most common form due to mineral and metal exposure. In addition, fear of job loss and the associated stigma deter workers from seeking medical care.

Tea garden workers

The same holds true for Assam tea garden workers. An alarming 96% of women workers in tea gardens suffer from anaemia, while malnutrition is pervasive among children, rendering them exceptionally vulnerable to infections. The living and workplace conditions further exacerbate the problem. Overcrowded and unhygienic living conditions in tea garden colonies foster the spread of TB, exacerbated by a lack of awareness. Alcohol abuse is rampant among tea plantation populations, further compromising their health. A considerable gap exists between the appearance of symptoms and the initiation of treatment, as PwTB often lack knowledge about TB symptoms before diagnosis, leading to delayed recognition and treatment.⁶

1.5 The need for developing behaviour change Solutions for Vulnerable Populations

Studies conducted in India, including the National TB Prevalence Survey from 2019 to 2021, reveal that a significant proportion of the symptomatic population (64%) did not seek healthcare services. The primary reason cited for this was that they were ignorant of TB symptoms (68%). While TB control programmes in India and high burden countries have invested in IEC interventions to raise TB awareness at population level, still the levels of health care seeking for TB remains low. In addition, studies have also emphasized that behavioural factors associated with disease could play an important role in driving their health care actions of individuals. In the context of health care seeking actions for Tuberculosis, there is a need for conceptualizing and implementing interventions to specifically address the behavioural dimensions of health care seeking among individuals. In this background we assess the feasibility of implementing behaviour nudges or change solutions to trigger individuals at risk or suffer TB to seek timely healthcare, adhere to treatment regimens, and actively participate in TB response activities.⁷

It was also seen that there were no proven models that credibly and successfully demonstrated addressing TB within the unique socio-cultural and economic contexts of vulnerable populations. This, despite national guidelines identifying urban vulnerable populations, migrants, tribals, tea-garden workers, mining and industrial workers as a sub-group needing additional attention⁷.

⁶ https://www.business-standard.com/article/news-ians/ignorance-leads-to-tb-spreading-in-assam-s-tea-gardens-115011800222_1.html

⁷ National Strategic Plan to End Tuberculosis in India 2020–25: Accelerating the National Response for Expanded Coverage and Sustained Impact at Scale to End TB in India; June 2020, Ministry of Health with Family Welfare, Nirman Bhawan, New Delhi – 110 108

The project has attempted to fill this critical gap by innovating, testing, and demonstrating a set of behaviour change solutions (BCS) designed to address unique context-specific barriers to health. The assumption was that these interventions could play a critical role in accelerating the reduction of the burden of TB in India by empowering individuals, communities, and healthcare providers to proactively engage in early detection, treatment, and prevention efforts. The solutions have been implemented in selected Tuberculosis Units (TUs) in the project states over two years since late 2021.

1.5.1 A multi-state study

The BTB project conducted a behaviour study across 4 states of Assam, Bihar, Karnataka, and Telangana covering all the identified vulnerable groups. In Bihar the study covered migrant population; in Karnataka, it covered mining and mining related industry workers in two districts of Ballari and Hospet. For mining workers, it covered sweepers, welders, machine operators, labourers, security guards, electricians, lorry drivers and housekeeping staff. Three urban cities of Bangalore in Karnataka, Hyderabad in Telangana, and Kamrup in Assam were covered to study the urban vulnerable population. In Mahabubabad district of Telangana the study covered Lambada and Koya Tribes, and Bodo tribes in two districts of Baksa and Kokrajhar, in Assam. The tea garden tribes working in the tea estates were covered in Dibrugarh, Assam.

The study attempted to understand the health-seeking behaviour for general health issues as well as for TB among these groups, culling out the enablers and barriers. Through this, it aimed to find opportunity areas to develop innovative, non-medical interventions to increase the propensity of these vulnerable populations to exhibit the desired health behaviours.

1.5.2 Development of behaviour change solutions to promote psychological changes among vulnerable groups: The Process

KHPT collaborated with the design thinking firm Tinker Labs to conceptualize and develop behavioural solutions. A blended design thinking and behavioural economics approach was used to dissect the treatment journey of PwTBs and caregivers to explore in-depth and uncover the motivations and influences driving their decision-making processes especially towards TB treatment adherence. A mix of qualitative research tools and techniques (in-depth interviews to gain perspectives, observational methods to get a real sense of the living environment, medicine storage, rapid-fire questions to understand instinctive reactions and perceptions towards healthcare) were used to explore and understand the health-seeking behaviours, motivations, drivers, deterrents, and fears of the study population. Given the fact that the behavioural research was undertaken when COVID-19 was at its peak, the implementation was conducted through online and offline mode.

Based on the insights gathered through this exploration, Tinker Labs, and KHPT engaged in a 10-month long ideation and co-creation process, resulting in the formulation of nine innovative behaviour change solutions tailored to the specific needs of diverse vulnerable groups. This immersive approach allows for the design of locally relevant, culturally appropriate intervention solutions that enable communities to make informed decisions aimed at reducing health risks. The acceptance and ownership of these solutions by the communities themselves foster sustained behaviour change.

1.5.2.1 Understanding contexts and consideration

To address the unique behavioural contexts of vulnerable populations, the study considered the following segmented contexts to explore factors which shaped the health seeking behaviour of population under consideration i) "life as usual," ii) "general health seeking," and iii) "TB health seeking." With these three contexts we then mapped the five spheres of influence which the study population was experiencing day to day: self, home and family, work, community, and the healthcare system.

Followed by this exploration, an ideation and co-creation process was undertaken to conceptualize and formulate a set of behaviour change solutions (n = 09) tailored to address the gaps in health care seeking and treatment adherence of diverse population group vulnerable for TB.

To address the unique behavioural contexts of vulnerable populations, the study considered the following segmented contexts to explore factors which shaped the health seeking behaviour of population under consideration i) "Life as usual," ii) "General Health seeking," and iii) "TB health seeking." With these three contexts five spheres of influence were mapped, which the study population were experiencing in day to day life namely, self, home and family, work, community, and the healthcare system.

Followed by this exploration, an ideation and co-creation process was undertaken to conceptualize and formulate a set of behaviour change solutions (n = 09) tailored to address the gaps in health care seeking and treatment adherence of diverse population groups vulnerable to TB.

1.5.3 The intervention: Behaviour Change Solutions

The nine solutions that evolved out of the behavioural study were grouped into case finding (Jaanch coupon, Health auto, TB Soochana) and case holding (starter kit, TB buddy, phone-a-friend, TB mukt certificate, sharing circle, TB champion health worker) solutions. The behaviour change solutions developed from this ideation was categorised as follows:

Table 1: Details of behaviour change solutions

No	Name of BCS	Intervention aimed at	Behaviour change theory/insight underlying the solution
1	Jaanch coupon	Case findings	Diagnostic delay
2	Health auto	Case findings	Decision fatigue
3	TB Soochana	Awareness creation, case finding	Awareness on TB
4	Starter kit	Case holding	Treatment adherence
5	TB buddy	Case holding	Treatment adherence
6	phone-a-friend	Case holding	Treatment adherence
7	TB mukt certificate	Case holding	Treatment adherence
8	Sharing circle	Case holding	Strengthening of service delivery
9	TB champion health worker	Case holding	Treatment adherence

These nine solutions were operationalized as part of a larger population level intervention project – Breaking the Barriers (BTB). The specific BCS solutions have been rolled out on field from October 2021. At the initial stage, it was planned to begin on a pilot basis in selected TUs which were prioritized based on TB case notification rates and treatment success rates. In each district, 2-3 TUs were selected based on low notification, low treatment success rate and logistical feasibilities; one case finding and one case holding solution have been implemented in each TU. After assessing the progress, success stories and feedback from NTEP, the solutions were further scaled up across all project TUs.

1.5.4 Feasibility and acceptability of the BCS: a qualitative exploration

To understand the feasibility of the behaviour change solutions for vulnerable communities, the project partnered with the Department of Psychiatric Social Work, NIMHANS, Bangalore to conduct a user feasibility study. The findings of the study were expected to provide insights into the usefulness and acceptance of the behaviour change solutions to ensure community participation and enhance health seeking behaviours and person-centered care. This would further help the project to generate evidence on the solutions being implemented and support in scale-up by the National TB Elimination Programme (NTEP).

1.6 Objectives of the study:

The primary objective of the study was to understand the potential to scale-up the BCS. The specific objectives were:

- To understand the influence of BCS solutions on awareness, notification of tuberculosis, and treatment adherence.
- To explore the feasibility of implementing the behaviour change solutions

2. METHODOLOGY

2.1 Study setting, population & period:

The study was conducted between May-August 2023 in four BTB intervention states – Karnataka, Telangana, Assam and Bihar among a sub-sample of beneficiaries from the TUs where BCS was implemented as part of the NTEP programme. The districts selected for the present study was also representative of specific vulnerable groups, as outlined in the table below.

Table 2: Study setting: details of vulnerable population groups

Districts	Type of vulnerable population	Population size
Bangalore & Hyderabad	Urban metro population	20,49,232
Koppal & Kamrup	Urban vulnerable	3,31,761
Ballari	Mining & mining related industry workers	1,58,482
Baksa & Mahabubabad	Tribals	4,19,660
Sangareddy	Industrial population	2,51,036
Dibrugarh	Tea-garden population	1,70,125

2.2 Study design:

The qualitative study used a phenomenological approach to gain in-depth understanding about the experience of the users and service providers pertaining to the BCS solutions implemented in the project geographies. This approach aims to link the experiences of users and providers to their actions and motivations which lie beneath the layer of pre-conceived notions and assumptions.

in-depth interviews (IDIs) were conducted to explore the experiences regarding Health auto, Jaanch coupon, TB mukt certificate, TB starter kit, TB buddy and TB champion health worker. focus group discussions (FGDs) were conducted to explore experiences regarding TB soochana and Sharing circle to understand community level thoughts and opinions about the solutions and matters that affect health seeking behaviour and hurdles faced by outreach workers, especially regarding TB related services.

2.3 Study sample:

In total 195 IDIs and 11 FGDs - comprising a total of 112 participants, were conducted. Diagnosed cases under BTB project served as the sampling universe for the PwTBs. People aged 18 years and above, who had used any of the nine BCS solutions were selected for the study. The number of interviews for each stakeholder under each solution was purposively decided, with an aim to attain maximum representativeness. Additionally, in four states together, the total interviews for each stakeholder under each solution were sufficient to attain saturation of the data/information received. The distribution of interviews across states and vulnerable population groups is detailed in tables 3 and 4 respectively.

Table 3: Interviews conducted across the states by behaviour change solutions

IDI sample Solution & state-wise					
IDI	KA	TS	BH	AS	Total
Health Auto	10	15	5	10	40
Jaanch Coupon	12	12	4	12	40
TB MukT Certificate	9	6	3	9	27
TBCHW	9	3	3	3	18
TB buddy	6	6	3	0	15
Ph-a-friend	9	3	3	0	15
Starter kit	12	12	4	12	40
Total	67	57	25	46	195
FGD sample Solution & state-wise					
FGD	KA	TS	BH	AS	Total
Sharing circle	2	1	1	0	4
TB Soochana	3	1	1	2	7
Total	5	2	2	2	11

Note: KA – Karnataka, TS – Telangana, BH – Bihar, AS - Assam

Table 4: Interviews conducted across the vulnerable groups by behaviour change solutions

Vulnerable group wise distribution of interviews								
IDI								
	Mining	Migrant	Urban	Urban M	Industrial	Tea garden	Tribal	Total
Health Auto	0	5	10	10	5		10	40
Jaanch Coupon	4	4	8	8	4	4	8	40
TB MukT Certificate	3	3	6	6	3	3	3	27
TBCHW	3	3	3	6			3	18

TB buddy		3	3	6			3	15
Ph-a-friend	3	3	3	6				15
Starter kit	4	4	8	8	4	4	8	40
FGD								
TB Soochana	1	1	2	1		1	1	7
Sharing circle	1	1	0	2				4

Note: All solutions were not implemented across the intervention geographies uniformly

The study involved various stakeholders for each of the solutions, as mentioned in table 5. The IDIs involved users (PwTB and caregivers), solution providers (auto drivers, TB buddies, community structure leaders) and health service providers (NTEP staff and frontline workers viz. ASHAs). FGDs were conducted among a group of 8-10 participants (separately for males and females) from community. While FGD on the sharing circle comprised of ASHA workers from selected designated microscopy centers (DMCs), for TB soochana it included community structure leaders, persons with TB and family members, and general community members. Findings of the present study are based on users' experience of different solutions, which was further weighed by relevant perceptions from health service providers, solution providers and community structure leaders.

Table 5: Stakeholder mapping - sample size for various stakeholders by behaviour change solutions

Solutions	Types of respondents - IDI						
	Users		Health service provider	Solution providers			
	PwTB	Caregiver	NTEP/FLW	Auto driver	CS leader	TB buddy	TBC
Health auto	16		8	8	8		
Jaanch coupon	20		10		10		
TB mukt certificate	18		9				
Starter kit	20	10	10				
TB buddy	10					5	
Phone-a-friend	15						
TBC health worker							18
TOTAL	99	10	37	8	18	5	18

2.4 Survey tools & trainings:

A stakeholder-wise detailed interview guide was developed for each of the solutions and translated into four local languages. A team of two field investigators, with a minimum qualification of graduate degree, was recruited in each of the states to conduct the interviews and translation. The investigators received two days' extensive training on qualitative data collection methods, tools and protocol of the study, consent forms and ethical processes.

2.5 Data management & analysis:

All the interviews were audio-recorded and the audio files from each intervention geography were coded individually and archived at the organization head office with password protection. A trained research team had prepared a pre-coded analysis matrix based on the research objectives and the interview guide. The audio files along with field notes were translated into the pre-coded matrix and data sorting was done by the trained investigators, under supervision of a dedicated research team.

A deductive approach was used to analyse and code the data by a team of trained researchers to maintain objectivity and ensure quality. Data which was generated for each solution except for sharing circle and TBC health worker, was analysed separately from three perspectives including users (PwTB and caregivers), solution providers (auto driver, TB buddy, CS leader) and service providers (NTEP staff – medical officer, senior treatment supervisor, senior treatment and lab supervisor, TB health visitor; and frontline workers – ASHA).

In view of the array of themes and sub-themes emerging out of the analysis, the findings have been structured under four broad domains and all the themes have been grouped under each domain as relevant – what is the solution (definition and objective), what the stakeholders understood about the solution, usefulness of the solutions (user experiences in terms of various benefits and validation of users experiences through solution and service providers), key concerns, suggestions and conclusion. At the end, a detailed discussion has been incorporated mainly focusing on the key objective of the study – whether the behaviour change solutions were able to facilitate to improve awareness on TB, case finding and treatment adherence and its feasibility for scale up. We also acknowledged few limitations of the study towards the end.

Various themes had emerged through the process of deductive analysis for each of the solutions, ranging from – knowledge and understanding about the solution, usefulness that covered various benefits experienced by the users; perspectives of solution providers in terms of what they perceived about the solution and its usefulness for the community at large, their own experiences of providing the services; perspectives of service providers in terms of their perception of the solution and its usefulness to facilitate TB case finding, creating awareness, TB treatment adherence, and changes in community health seeking behaviour. Both, the solution and service providers' perspectives served as a validation of the users' experiences. Additionally, in the process of analysis, several major key concerns also emerged in different perspectives such as – user friendliness (user perspective), feasibility of implementation (solution and service providers' perspective). Some important suggestions also emerged from the analysis from various stakeholders.

2.6 Ethical approval:

Approval for the study has been obtained from the Institutional Ethics Committee of NIMHANS, Bangalore [IERB no. NIMHANS/40th IEC (BEH.SC.DIV.)/2023]. As per the protocol, all the participants were briefed on the purpose of the study, risks and benefits, and confidentiality issues. Audio recording was done for transcription purpose. Informed consent was obtained before conducting each of the interviews.

2.7 Operational definitions:

Vulnerable population: Vulnerable groups are disadvantaged as compared to others mainly on account of their reduced access to health services and the underlying determinants of health such as safe and potable drinking water, nutrition, housing, sanitation etc. These include those that on the grounds of sex, caste, birth, physical or mental disability, health status (including HIV/AIDS, TB, etc.), sexual orientation and civil, social or other status, which has the effect of nullifying or impairing the equal enjoyment or exercise of the right to health.

Awareness on TB – refers to knowledge about TB disease, its symptoms, diagnosis and treatment related services

TB notification - indicates the number of persons diagnosed with TB over a specified period for a specified population

TB treatment adherence - the extent to which the behaviour of persons under TB treatment- taking medication, following a diet, and/or executing lifestyle changes- corresponds with the agreed recommendations from a healthcare provider. Adherence to treatment is critical for cure, controlling spread of infection, and minimizing the development of drug resistance

TB stigma: Refers to the myths and misconceptions about the origin, transmission and treatment of TB disease. These myths and misconceptions lead people to stigmatize or discriminate a PwTB and/or their family.

Direct/indirect effect of solution: When benefits of a solution directly reach its intended audience it is referred to as direct effect, and when it happens as a by-product of the use of the solution it is indirect.

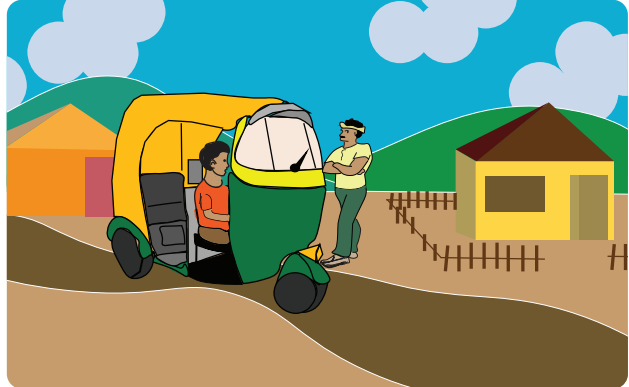
Feasibility of implementation: Refers to whether any solution is user friendly and convenient to implement and scale up.

3. RESULTS

3.1 BCS 1: HEALTH AUTO (HA)

3.1.1 What is Health Auto?

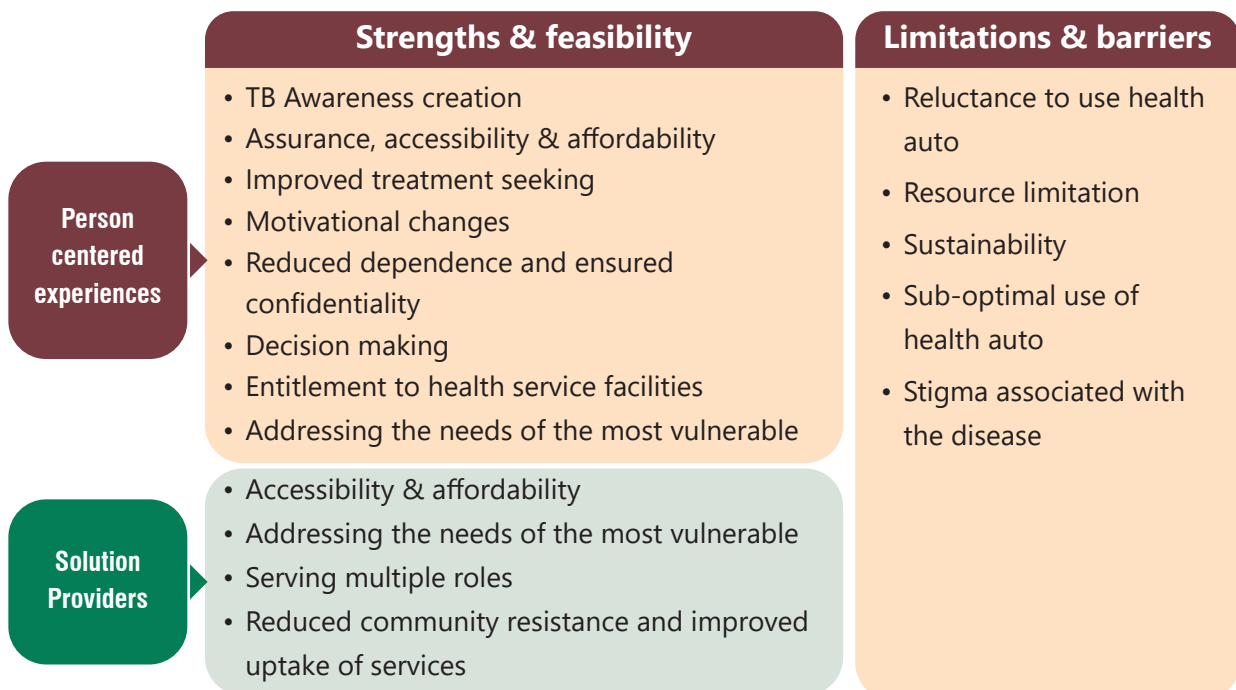
The Health Auto aims to offer a free of cost, on-demand pick-up and drop-off service to healthcare facilities for persons with TB symptoms, and persons on TB treatment. One can book a health auto through a phone call for a range of services- going to the testing centers, medicine collection, follow-up visits, and any other TB hospital visits.



Objective of health auto:

Health auto was developed and intended to address the hidden costs associated with testing, medicine collection, making healthcare easily accessible in terms of proximity, and timing. It was also aimed at addressing the 'decision fatigue' experienced by the presumptive TB persons which hindered their travel o health facility for accessing TB related services.

HEALTH AUTO: a snapshot of the findings



Service Providers

- Accessibility & affordability
- Addressing the needs of the most vulnerable
- Fills the gap in outreach service
- Contribution to TB case-finding
- Opportunity for TB awareness creation
- Active role of auto drivers

3.1.2 What did stakeholders understand about the solution? - Knowledge about the solution, and source of information

According to the users, The Health Auto (HA) solution was also referred to as '*auto*', '*ola auto*' in Karnataka, '*Arogya Auto*', in parts of, Telangana '*tom-tom*' in Assam, and '*tempo*', '*Karnataka wala tempo*' in Bihar.

Most of the users across intervention geographies reported that they have received information about the service from local community structure leaders, frontline health workers, neighbours, and friends, through local awareness, campaigns, and KHPT staff. The users understood that health auto can be used to go to the hospital to seek TB-related services and medications. Some of the users (Karnataka and Assam) were not aware of the purpose of the health auto facility except for the fact that the service is free of cost. There were other users who mentioned that they did not ask, and they were not informed for what purposes health auto can be used. It was only after availing the service that they understood its purpose. However, users from all four intervention geographies have used the health auto multiple times to visit the hospital for testing, follow-up, collect TB medication, and to attend Care and Support Group (CSG) meetings.

"I have used it around 3 times...once I went for checkup, second time for medicines and for report on the third time." (Female, 19 years, user, Kamrup Assam)

"I went in the auto TB test for the first time. I have used three times till now...for medicines and three times and during follow up" (Male, 60 years, user, Baksa, Assam)

3.1.3 The usefulness and feasibility of health auto:

The data regarding the usefulness of the solution has been analyzed from the perspective of the users, community structure members, solution providers such as auto drivers, and service providers such as frontline workers or programme (NTEP) staff. Various themes have emerged from the analysis which were reflective of the strengths or usefulness of the solution, weaknesses in terms of limitations associated with the solution and opportunities for further improvement.

3.1.3.1 Person centered user experiences:

The users shared a range of benefits that they got while using the solution. While in some cases the users spoke about single benefit, others shared multiple benefits, as outlined below:

- **Theme 1 – TB awareness creation:** it was found that few of the users received TB related information from the auto drivers. The information provided included – TB disease and its transmission. According to some of the users of the solution the health auto drivers shared information regarding TB as a disease and its transmission, the testing processes, motivation and encouragement to complete treatment, and importance of consuming nutritious food. According to the users this was an added factor that encouraged them to use the health auto.

“He (auto driver) used to say...You will be ok with these medicines. Keep distance so that others are not affected, family members also have to be taken care of properly. Also, he said don't break (discontinue) treatment dawa torna nahi hai and on the basis of that information I didn't discontinue”. (Male, 35 years, User, West Champaran, Bihar)

- **Theme 2 - Assurance, accessibility and affordability:** Users reported that the availability of health auto resulted in increased ease of accessing health facility without hassle or difficulty and reduced out of pocket expenditures. Health auto resulted in the assurance of a hassle-free travel which in turn had helped to improve visits for treatment-seeking, follow-up, treatment adherence, & attending CSGs

“I used to collect medicines quickly, even when I was sick and not able to collect them myself. The auto driver would go and collect medicines for me. He was very helpful”. (Male, 56 years, User, Mahabubabad, Telangana)

“You have free service, so you don't have to worry. Many came into my auto for testing; after using medicines, they have recovered. You can also recover. He was reliable. He gave me a sense of safety. (Male, 56 years, User, Mahabubabad, Telangana)

“We didn't have money sir so I used to ask for money (chanda) from others, but once this tempo service started then I stopped asking money for transportation. The fare for transportation was also saved”. (Male, 35 Years, West Champaran, Bihar)

- **Theme 3 – Improved treatment Seeking:** Users found the solution helpful as it gave assurance of availability of the service as per their need and requirement. This in turn encouraged treatment continuation.

“It became easier to reach the hospital. If this tempo was not available then I would have to search a tempo for going to hospital, sometimes it may be available and sometime not available and then I must cancel. This tempo (health auto) can take from home and go and after taking medicine return to home”. (Male, 35 Years, User, West Champaran, Bihar)

“I used this service to attend meetings, collect tablets, and make hospital visits”. (Female, 31yrs User, Hyderabad, Telangana)

- **Theme 4 - Motivational changes:**

Users reported that their motivational level to access health facility had improved due to various reasons. One most common factor mentioned by the users was polite and receptive behaviour of the drivers during their journey. Active involvement of auto driver in terms of motivating the presumptive persons, timeliness of services, encouragement & support provided for completing formalities at the health facilities, guiding on issues like cough hygiene etc. gave them courage to get themselves tested, continue treatment and successfully completing the course. In general users expressed their reduced anxiety and discomfort while using the health auto.

"The conversation with the driver was good. He would motivate me to go for a check-up without any fear. He would tell you that it is just a cough; you don't decide if it is TB; just go for testing, and even if it is TB, you have free service, so you don't have to worry. Many came into my auto for testing; after using medicines, they have recovered. You can allso recover. He was reliable. He gave me a sense of safety. (Male, 56 years, User, Mahabubabad, Telangana)

- **Theme 5 - Reduced dependence and improved confidentiality:** Some of the users expressed that the health auto had reduced their levels of dependence on others, especially for treatment-seeking. It also provided a safe and confidential space for the users to maintain a healthy conversation while travelling to the facility. It reduced their fear and acted as a counselling support for them.

"The auto driver would talk to me nicely. They would say, 'this disease spreads from one person to the other. Be brave, take your treatment properly, don't lose your courage. I didn't personally know the auto driver. They didn't face any troubles from me, and they didn't give me any trouble." (Male, 64 years, User, Koppal, Karnataka)

"This auto was reliable. Auto driver, maintained confidentiality". (Male, 56 years, User, Mahabubabad, Telangana)

- **Theme 6 – Decision making:** Availability of the health auto enabled the persons with TB to take quick decisions with regard to their travel plans for health facility. It provided an easy choice for the users to plan their visit to health facility as required.

"It was normal; it was for free. Whenever hospital staff asked to visit, I could go easily and come back home easily. Whenever I do not have money, I don't have to think; when called, he will come". (Female, 21 years, User, Hyderabad, Telangana)

- **Theme 7 - Entitlement to health service facilities:** Users reported that the auto drivers' company to the health facility resulted in a sense of entitlement and privilege at the health facility as compared to their experiences of visiting alone. The users emphasized that health auto drivers wait for them to bring the persons back home.

"It was good; the health staff prioritized me. When I went through this process, hospital staff prioritized me. It didn't take much time for the check-up. It would take a lot of time if I went by myself for treatment. Through this auto hospital staff took extra care of me". (Male, 56 years, User, Mahabubabad, Telangana)

- **Theme 8 - Addressing needs of the most vulnerable:** Vulnerabilities in terms of age, gender, physical challenges was something that health auto was able to address in addition to serving the hard to reach population. It emerged from the analysis that young women, housewives, those who were severely sick, and/or were suffering from adverse side effects explained how the solution was beneficial to them.

"If we are getting such free services, we feel good....as at this age it becomes difficult to go ourselves. We need to thank them. Before there were no such services and now, they have provided us for free...we need to thank them for this " (Male, 60 years, User, Baksa, Assam)

3.1.3.2 Perspectives of solution providers - Health Auto Driver

Inspirations for the auto drivers:

When one considers what inspired the health auto drivers, the data revealed in most cases their personal experiences of being a TB survivor or having seen a TB survivor from close quarters, either within the family, friends or neighbours acted as a motivation to help others. In addition, the health auto drivers also reported personal satisfaction of doing good deed, being respected and appreciated by the larger community. The family support for the person to be a health auto driver was also seen to be an important factor that helped them to decide whether to be a health auto driver or not.

"I learned about TB once my brother got sick. Since my brother got sick, I've taken a lot of delivery patients for free. Doing this service is no problem for me, I feel comfortable doing it. Many patients have told me that HA makes things easier. They often say, "God bless you". It makes me happy." (Male, 45 years, auto driver, Bangalore, Karnataka)

"It gives me satisfaction when I become the health of the driver and help others in transportation who cannot afford it." (Male, 37 years, auto driver, Sangareddy, Hyderabad)

My family always supports this job. I asked my family if they were having any concerns and they agreed with my decision. I didn't overthink about the decision I made". (Male, 52 years, auto driver, Koppal, Karnataka)

Initially My family members thought, this disease may spread to my son, due to the nature of this disease anyone can be afraid. (Male, 33 years, West Champaran, Bihar)

Results from the auto-drivers were reflective of the findings emerging out of the users' experiences, in addition to some more specific insights.

- **Theme 1 - Multiple utilities of health auto:** According to health auto drivers, there were multiple utilities served by the service which included collecting medicines from the hospital, undergoing TB check-ups, and attending monthly support group meetings.

"More number of patients are using this and people waiting for this auto as they can't spend Rs. 40-50. It is easier for patients to go for a test, to buy medicines and all". (Male, 52 years, auto driver, Ballari, Karnataka)

- **Theme 2 - Addressing the needs of the most vulnerable:** In alignment with users' experiences, auto drivers also mentioned that this solution was particularly useful for individuals who could not travel alone due to old age, fatigue, vomiting, or had anxiety about using public transport. They further opined that it was helpful especially for those of lower economic strata, who can't afford to spend money on conveyance.

"Health Auto should definitely continue. Until TB goes away, HA should exist. It is very helpful for poor people, very helpful for the extremely poor. It's not needed for the rich - they will bring their own vehicle. Poor people won't even have a bicycle." (Male, 64 Years, Koppal, Karnataka)

- **Theme 3 - Accessibility and affordability:** The health auto drivers mentioned that this solution was more convenient in comparison to public transport. In case of public transport, one has to spend a lot of time and money making it more challenging for the persons suffering from TB to reach the hospital.

"I usually will wait with a patient in the health centre. Hospital staff accepts my service positively. Care givers check the patient immediately after arrival to health centre." (Male, 52 years, auto driver Koppal)

Community structure leaders:

The themes emerging from the community structure leaders had commonality with that of users and auto drivers, especially in the following two aspects:

- **Theme 1 - Addressing the needs of the most vulnerable:** A member of the community structure pointed out that the health auto is more useful for those who find it very difficult to access transport and find it physically challenging to use other means of transport. And also, mentioned that the health auto facilitated people to get tested.

"This auto will be helpful for the TB patients who are unable to travel to the hospital like whoever feel very tired, vomiting such people can't travel to the hospital alone so,

such people utilize this service I see the changes means earlier no one discusses about this but now if anyone is having a cough, they talk to me and I send them in auto for testing". (Female, 41 years, CS leader, Bangalore, Karnataka)

- **Theme 2 - Accessibility and affordability:** Compared to earlier times, after health auto has been implemented there has been a substantial increase in health facility footfall. People, especially the poor marginalized section, have benefitted the most by this free of cost transportation facility. Further, CS leaders also mentioned that the announcements through the auto was able to create public awareness and people now recognize symptoms and get in touch with the CS by themselves and inquire about testing.

"As it is free of cost people won't reject it if we (CS leader) advise them to go to the health center for testing. The community accepts when we say free service to transport patients to the health center is available. After a bit of motivation, they take it positively". (Female, 31 years, Bangalore, Karnataka)

"Since the introduction of the Health Auto service, people have gained the confidence to come forward for treatment". (Male, 64 years, User, Koppal, Karnataka)

- **Theme 3 - Improved uptake of TB related services:** CS leaders from Assam have mentioned the visible changes in the community as a result of health auto service. Compared to earlier times, after health auto has been implemented there has been a substantial increase in health facility footfall, especially in Baksa. People, especially the poor marginalized section, have benefitted the most by this free of cost transportation facility, especially in Kamrup. Further, CS leaders also mentioned that the announcements through the auto was able to create public awareness and people now recognize symptoms and get in touch with the CS by themselves and inquire about testing.

"...before hardly people used to go to the facility. But after introduction of HA services... the mobility towards facility has increased." (Female, 31 years, CS leader, Baksa, Assam)

"It has been useful for the poor...especially for those who are marginalized. They cannot go on their own. Or give fare so for them it has been a great service." (Female, 44 years CS leader, Kamrup, Assam)

3.1.3.3 Perspectives of health service providers - NTEP staff/frontline workers:

The perspective of NTEP staff/Frontline workers had commonality with that of users and health auto drivers especially with regard to – Theme 1: improved assurance, accessibility and affordability and Theme 2: addressing the needs of the most vulnerable groups.

As pointed out by NTEP staff the solution was most useful for the lower economic strata, and people with restricted mobility, as the solution enables them to access the facility. In the absence of this solution there would be negligence of the symptoms as well as delay in treatment seeking.

“Geographical point of view few pockets particularly which are hard to reach, along with some patient which belongs to Dalit or mahadalit colony where peoples are economically backward, struggling with financial crisis, few patients in such condition don’t want to come even having symptoms of TB. They hold back for a long time (bahut din tak roke hue rakhta hai) Means they are unable to get treatment due to lack of money. These kinds of patients are linked with this health auto service”. (Male, 35 years, NTEP, West Champaran, Bihar)

“The TB patients we have, most of them are economically not sound. And many patients are physically weak as well...so for them it has been very useful....to those who are physically weak...to that kind of patients there are none to bring them to the facility...so these auto services have been very useful to the patients. Because without facing any inconveniences. They have helped the patients reach the facility...and no. 2, there are some patients those who are financially weak. Those who cannot afford for transport fare to reach the hospital. These free auto services have helped them to a great extent.” (Female, 40 years, ASHA, Hyderabad, Telangana)

In addition, four distinct perspectives were also shared by the health service providers pertaining to the impact of health auto interventions.

- **Theme 3 - Fills the gap in outreach services:** Identifying the gap in service outreach in Urban areas where number of ASHAs is less, NTEP identified the significance of the health auto service. It was mentioned that health auto could be useful for different kinds of people in need.

“It’s helpful in places where there aren’t a lot of ASHAs or places where the hospital/ health centre is far away. It’s also helpful for people living alone, and people living in slums who hesitate to come, people who go to duty at odd times, etc.” (Male, Service Provider, Bangalore, Karnataka)

- **Theme 4 - Contributes to TB case finding:** For the NTEP respondents in Telangana and Karnataka, the Health Auto was positively contributing to TB referrals, detection, treatment adherence and follow-up. Given the fact that it helps in ferrying presumptive persons in time, it contributes to early diagnosis & detection; Health auto is used by PwTBs for medicine collection, attending CSG, thus enabling timely follow-ups and treatment adherence. More importantly, for the NTEP Health auto has made healthcare accessible; difficult-to-reach people are coming to get tested.

"TB referral was happening before too, but the coordination with HA has created some improvement. It has made it easier for some cases to be referred." (Male, 52 years, NTEP, Bangalore, Karnataka)

"Yes, through this health auto, in one area the referrals have increased because it is the only mode of transportation and a patient can use this health auto not only for treatment but for routine health check-ups for collecting medicines and diagnosis. This health auto is being very helpful, especially in the villages where autos are not frequent. In 1 trip 2-3 PwTB can visit the hospital". (ASHA, 35 years, Sangareddy, Telangana)

- **Theme 5 - Opportunity for TB awareness creation:** The health auto had also helped in generating awareness among the population, in turn contributing to an increase in demand of health services among the vulnerable groups. NTEP further acknowledged its usefulness, as health auto had been helping hospital staff with sample collection.

"It is helping in early detection, and as awareness is provided, many are coming forward to seek health care if they find themselves symptomatic. They want to get tested and get healthcare, as the auto does not charge them, which saves them money. Most of them are poor, so this free service motivates them to visit the hospital". (Male, 60 years, NTEP, Mahabubabad, Telangana)

- **Theme 6 - Role of auto drivers:** The NTEP staff also suggested that the success of health auto is dependent on the fact that the health auto drivers are aware of the TB disease and are actively playing a role in its prevention and cure.

"This health auto service is helping very much and is useful in my community because not all come forward to work as health auto drivers for TB patients as the disease spreads and is dangerous. But these health-conscious auto drivers are trained, they have knowledge, and they know safety measures. They know how to treat TB patients. So many are utilizing the service and feel it is reliable and safe, and they recommend it to others". (Female, 35 years, ASHA, Sangareddy, Telangana)

3.1.4 Insights on limitations and barriers in using health auto service

- **Reluctance to use health auto:** The data put forth a set of challenges that were identified by the cross-section of stakeholders of the study. The users pointed out their discomfort or hesitancy of using the health auto, when the driver was not known to them.

"When I went for first time, I was doubtful...as in what he would do...whether he will admit me in the hospital." (Male, 45 years, User, Kamrup, Assam)

- **Resource limitation:** The NTEP staff, while recognized the important role being played by the health auto in increasing the uptake of services, testing, treatment adherence, among others; they were concerned about the budgetary limitation of

NTEP to scale up the solution. The NTEP staff went on to add that they are using the opportunity provided by BTB to inform and create awareness about the solution among the frontline workers so that they can communicate about the solution at the community level.

"NTEP side we don't have budget to scaleup, but we are informing the ASHA and ANM and AWW about this facility and they inform the people so, people will utilize this service more" (Male, 38 years, NTEP staff, Koppal, Karnataka)

- **Sustainability:** The continuity of the health auto driver was identified as one of the challenges by a community structure leader. For instance, the health auto service was discontinued in one of the TUs in Bangalore when the health auto driver shifted base.

"Recently the driver's family shifted to some other place. So, there is no health auto nowadays but earlier it was very useful". (Female, 41 years, CS leader, Bangalore, Karnataka)

- **Sub-optimal use of health auto:** It was observed by NTEP staff that, though there is a much higher scope for the health auto to increase number of presumptive tests using the auto service, it is not functioning at the optimal.

"From KHPT side, the number of patients we are supposed to receive, they are not turning up." (Male, 48 years, NTEP staff, Baksa, Assam)

- **Stigma:** The social stigma associated with TB is a serious concern. As is pointed out by one of the health auto drivers, due to concerns about privacy and fear that others will discover their health issues PwTB may not disclose the use of health auto service.

"One beneficiary explained to me saying, my neighbours noticed I was being taken around in an auto and became curious. We hadn't disclosed my TB diagnosis to our neighbours to avoid judgment and a potential breakdown in communication." (Male, 45 years, Auto driver, Bangalore, Karnataka)

"Some of them who have seen me utilize this service ask me about it, and I tell them that it's a free auto service and is helping us visit the hospital for testing and collecting medicines". (Male, 56 years, User, Mahabubabad, Telangana)

Alternatively, it was stated by NTEP staff (in Telangana) that the health auto addressed stigma associated with TB to some extent in the community. According to them, stigma had reduced as people who already use health auto services encourage others to utilize health auto. Further the auto drivers provide the much-needed psychological support too. Inflow of persons for TB testing had increased due to reduction in stigma associated with TB and people who kept away from hospitals owing to financial and accessibility reasons started coming back to the hospitals now.

"Stigma is reduced to an extent; previously, people used to feel hesitant to be with people who had these symptoms, but now they are taking medicines, going for check-ups, and receiving treatment. They are respected in society". (Male, 60 years, NTEP, Mahabubabad, Telangana)

3.1.5 Opportunities for further improvement

- Increase number of Health Autos especially in slums and other remote areas (user, CS leader, FLWs/ NTEP staff)
- IEC inside the Health Auto needs to be strengthened for the general population to be informed of TB (auto driver)
- Timely monetary benefit to auto drivers (CS leader)
- Health auto drivers seek a sense of sustainability/certainty in terms of income from plying the health auto, in the form of regular payments. (auto driver)
- Increase in payment, and a permanent government job. (auto driver)

3.1.6 Summary

Insights from this qualitative study shows that health auto could be considered a potential behavioural change solution to address the multi-layered gaps and barriers at existing within the transportation eco-system of the vulnerable communities.

From the users' perspectives it was found that this particular solution had resulted in significant advantages for the vulnerable population at a psychological level by improving their motivational levels, decision process, confidence, entitlement and reduced feeling of dependence pertaining to their health are seeking actions for TB. At the system level, the solution had resulted in ensuring person centric care by addressing issues of accessibility, affordability, and special needs of vulnerable population. The findings underscored that the solution was most useful for those populations who experienced additional vulnerabilities within the main vulnerable group, such as- younger women, housewives, elderly, men out of work, and specially-abled. This was acknowledged and echoed by the NTEP staff as well. They agreed that the auto was useful for those who have accessibility issues, live in remote areas, and also have different working hours.

The experiences and perceptions shared by the users were also reflected by the solution providers, community leaders and programme stakeholder. However, when it comes to health auto as a medium for creating awareness, it was found that the information dissemination was not uniform across the geographies. This to an extent was dependent on the auto drivers as well. While some auto drivers took the initiative to inform and create awareness among the people he/she was ferrying, there were others who were not as enthusiastic.

In terms of reducing fear/anxiety or social stigma related to TB and its treatment, health auto as a solution does not fight stigma per se. As was shared by health auto drivers, people will not use the same auto if they come to know it helps TB presumptive persons. The auto drivers also refrained from keeping TB related IEC materials in their auto in fear of losing customers. The users did not clearly state the fact that they are using the auto for TB related services; rather they tend to refer to it as a health care service auto. The encouragement provided by the health auto driver in certain cases added a sense of positivity during the commute.

There was not much difference between vulnerable groups in terms of acceptance of health auto or the way the solution has been useful. The role of KHPT and community structures was visible in the narratives of the participants. The data from migrants, revealed that presence of Jeevika sakhi who are able to capitalize their existing relationship with the community to motivate them for utilization of the TB services.

Further, NTEP staff had opined that health autos hold the potential for improving case findings in the community, add to the existing TB outreach services and could result in improved TB awareness in the community. At the same time, they also pointed out the health system challenges that even if the auto service increases the number of referrals to the DMCs, the DMCs themselves lack logistics and human resource support to manage the increased load and conduct timely tests. The role of health auto drivers was positively acknowledged by the NTEP staff and thus highlighted the opportunity for mainstreaming them as a potential community stakeholder for the TB programme.

In conclusion health auto as BCS had resulted in potential benefits for the TB presumptive persons we interviewed at the individual level and also has perceived impacts in improving access and thus notification of TB.

3.2 BCS 2- TB JAANCH COUPON

3.2.1 What is a jaanch coupon?

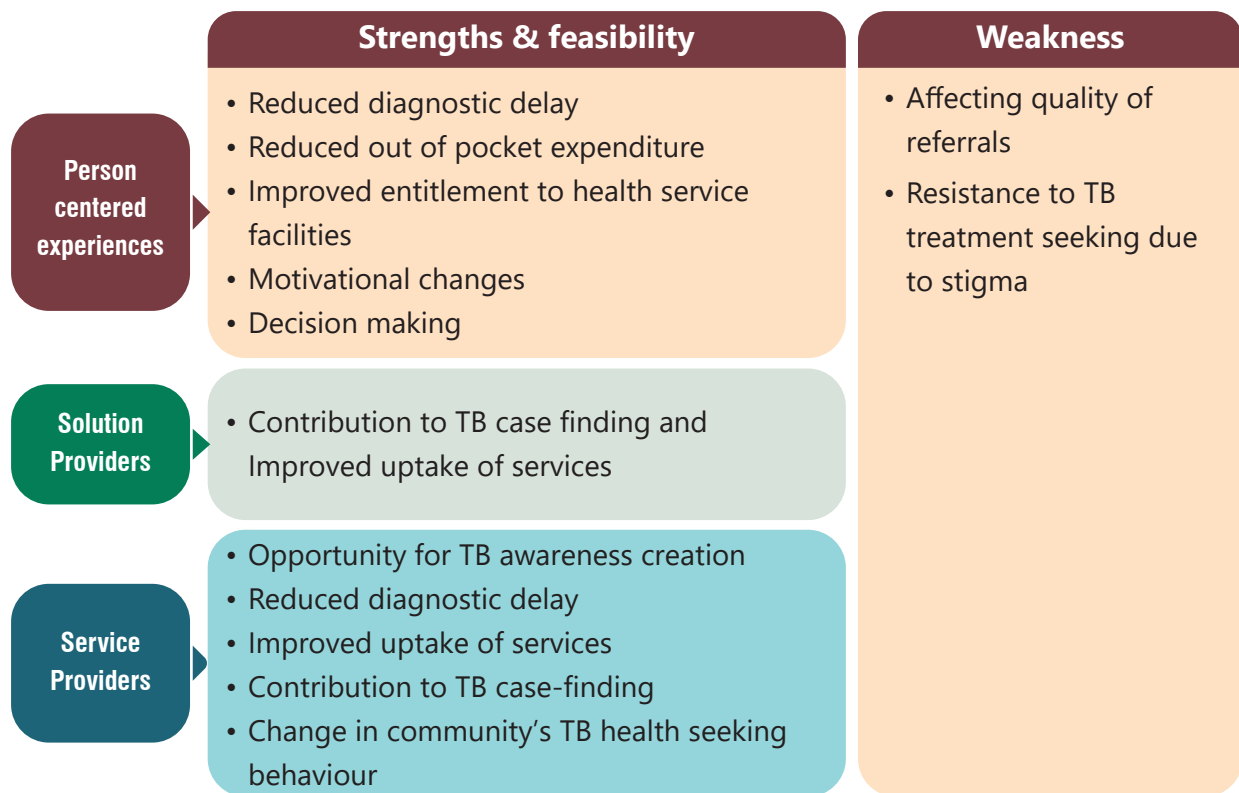
- Jaanch coupon is a physical, in-hand copy, that has cost of test, validity of seven days mentioned. It helps individuals with symptoms suggestive of TB to visit testing facility. The cost acts as a feeling of value gained by the free of cost test at the public health facility. The validity mentioned creates a sense of urgency to visit.
- A coupon that health-workers, community coordinators and community structure members give to individuals with symptoms suggestive of TB to nudge them for testing.



Objective of jaanch coupon:

The solution is intended to provide an appraisal of the value of TB services provided for the persons and caregivers towards the free TB service. This solution is designed to stimulate the health seeking behaviour by using a gain framing approach, encouraging individuals to undergo TB testing.

JAANCH COUPON: A SNAPSHOT OF THE FINDINGS



3.2.2 What did the stakeholders understand about the solution? Knowledge about the solution, and source of information

According to the users, Jaanch coupon was commonly referred to as '*Jaanch Coupon*', '*Jaanch card*', '*card*', and '*ticket*'. Some of the users also called it '*health card*', '*coupon*'. Information about the jaanch coupon was received from the community structures, KHPT staff, NTEP staff, ASHA workers, self-help group members such as the '*jeevika samuh*' meetings and neighbours. Users mentioned that JC helps in early and hassle-free testing and receive the results faster. Some of the users from Telangana also shared that they were given Jaanch coupon during a door-to-door visit by the community structure leaders, accompanied by the community coordinator. One of the users from industrial population in Telangana shared that he was informed about the coupon and its usage mechanisms by a private doctor whom he had consulted.

On the other hand, **NTEP staff** reported that information about the jaanch coupon was typically acquired from KHPT. It was mentioned to be distributed by field workers, community structure leaders and not at the hospital. According to NTEP those eligible for the jaanch coupon were individuals who had been experiencing cough for two or more weeks, along with fever and the presence of blood in the sputum. Some of the NTEP staff from Telangana reported receipt of information about the solution from within NTEP itself.

The community structure leaders were familiar with the jaanch coupon as a card used for free testing at the hospital, specifically for those people who have TB symptoms.

3.2.3 The usefulness and feasibility of jaanch coupon

The data regarding the usefulness of the solution has been analysed from the perspective of the users, community structure leaders and NTEP staff/frontline workers. Various themes have emerged from the analysis which were reflective of the strengths or usefulness of the solution, weaknesses in terms of limitations associated with the solution and opportunities for further improvement.

3.2.3.1 Person centered user experiences

- **Theme 1-Reduced diagnostic delay:** Most of the users of jaanch coupon mentioned that it helped them to access TB testing services immediately. They further shared that the inclusion of a validity period on the coupon helped them to make a quick decision and motivated to reach the testing facility as soon as possible.

"After seeing the jaanch coupon, the hospital staff conducted tests and initiated TB treatment without taking any money. Usually without card hospital staff tend to ask many questions, but with the jaanch coupon, they didn't ask any questions" (Female, 29 years, User, Koppal, Karnataka)

"They took immediate care, testing with efficiency. They didn't do it carelessly." (Male, 21 years, User, Ballari, Karnataka)

"The jaanch coupon in-stills courage in people to consult a doctor otherwise they might hesitate to go. There are people among us who are reluctant seek medical attention but receiving a coupon tends to compel them to go." (Male, 57 years, User, Baksa, Assam)

- **Theme 2 - Reduced out of pocket expenditure:** Concerns of potential extra money demanded for testing were alleviated with the use of the jaanch coupon. Families also expressed support for using the jaanch coupon since it did not incur any additional costs.

"Initially, I had a fear of getting tested for TB, and in private hospitals, as testing was more expensive and required a long waiting time. The jaanch coupon not only saved my money on testing but also significantly reduced the waiting time." (Male, 30 years, User, Ballari, Karnataka)

Further, the jaanch coupon effectively mitigated the cost concerns for non-earning members of the family, or those who were from lower economic strata. One user highlighted its cost-saving benefits, mentioning that it particularly helped her save costs as her husband has a modest income from wages. Some of the users also

shared that the service providers were well aware about jaanch coupon and it was readily accepted.

"I am a housewife, and my husband earns a modest income. Therefore, the jaanch coupon proved highly beneficial by significantly reducing the costs for my tests. (Female, 33 years, User, Ballari, Karnataka)"

"There's no harm in using the jaanch coupon. It's really helpful for poor people, because they may lack the financial means to undergo testing. Without the JC, they may ignore symptoms, thinking it will improve on its own. With the JC, they can easily access free testing, and the medications also provided at no cost, allowing them to manage their health without any financial burden." (Female, 28 years, User, Bangalore, Karnataka)"

- **Theme 3 – Improved entitlement to health service facilities:** The users of the jaanch coupon experienced feeling of happiness and a sense of privilege. They expressed that individuals carrying the coupon were prioritized by the health facility staff, allowing them to avoid long waiting times for testing.

"I found this to be very useful because the process of testing is quick and observing this, I believe the hospital management will try to provide quick services. They spared me from standing in the long queues". (Female, 80 years, User, Mahabubabad, Telangana)"

- **Theme 4 - Decision making:** One of the benefits highlighted by the users was that when there was uncertainty about which doctor to consult or where to seek advice from, the jaanch coupon gave a sense of direction.

"I was tired of receiving treatment at various places (hospitals) like Chanpatiya Betiah etc. Meanwhile, the doctor of Betiah told me that I have TB and prescribed medication. Upon returning home, when I attended a group meeting (samuh jeevika meeting), I shared my situation with one chachi then she provided me with this Coupon. Once I got this coupon, I visited the government hospital where I got free medicines, test and X-ray. Now I am feeling better". (Female, 45 years, User, West Champaran, Bihar)"

- **Theme 5 - Motivational changes:** Data revealed that jaanch coupon was helpful to motivate users to muster the courage to undergo TB testing.

"As it is free of charge, it motivated the participants to undergo testing, knowing that they would not incur any personal costs". (Female, 19 years, User, Hyderabad, Telangana)"

"It saved both time and money. If I had opted for tests and other procedures at a private centre it would have been costly". (Male, 21 years, User, Koppal, Karnataka)"

3.2.3.2 Perspectives of solution providers: Community structure leaders

Contribution to TB case finding and improved uptake of services: According to the community structure leaders, there had been an increase in the number of tests

compared to earlier times when jaanch coupon was not implemented. They further highlighted that jaanch coupon to an extent contributed to the generation of demand for government health services among the marginalized population and instilled renewed confidence on the government health service. This increase in the uptake of services thus positively improved the attitude of the health staff.

"We have referred many people—10–15 members—based on their symptoms. We and ASHAs referred many people through a jaanch coupon".

'Everyone has a good opinion on the Jaanch coupon; now people have the belief that the government will provide good service'. (Male, 41 years, CS leader, Telangana)

"Many are utilizing government facilities after the introduction of jaanch coupons. Patients developed confidence in government facility treatment. Hospital staff are treating the patients well. This is good". (Male, 41 years, CS leader, Mahabubabad, Telangana)

3.2.3.3. Perspectives of health service providers - NTEP staff/Frontline workers

NTEP staff/FLW had to a large extent exhibited commonality with the users and CS leaders' experiences and observations especially in terms of creating awareness, reducing diagnosis delay, improved uptake of services and contribution to TB case finding.

- **Theme 1- Opportunities for TB awareness creation:** According to some of the NTEP staff the coupon system was able to create awareness about TB in the community. For instance, 57 years old service provider from Dibrugarh mentioned with the JC being given by the community structures along with detailed information on its usage, people have become more aware about TB treatment. According to him, it has also improved the treatment seeking behaviour among people.

"...apart from health workers...they (community people) are able to know and understand about it (TB)...that there are also such provisions. So, ...common people also got the opportunity to know as in - why this coupon is provided, its objectives...and they have also tried to understand through Jaanch Coupon...that from this coupon they can also do the treatment...like the way KHPT officials go to the field and make people understand and the way they explain or advise beautifully to ASHA workers ..that way desire to seek treatment has increased I feel".

- **Theme 2 - Reduced diagnostic delay:** The jaanch coupon has also helped in reducing the delay in accessing testing. And it is most useful for the vulnerable population especially those who are economically weak, and those residing in hard-to-reach zones. Those who earlier went to private facilities, are now shifting to government hospitals. The NTEP respondents in Telangana said that the JC has contributed to an

increased TB detection, and has also led to an increase in number of referrals. Since it does not involve spending any money, it motivates people to come forward to get themselves tested.

"After introducing this solution, the number of TBs tested had increased. i.e., more people with TB are getting treated". (Male, 37 years NTEP, Sangareddy, Telangana)

"People coming for diagnosis has increased since introduction of the Jaanch Coupon". (Male, 37 years NTEP, Sangareddy, Telangana)

- **Theme 3 - Improved uptake of services:** Also, it was reported by TBHV (urban) that people especially those in the high-risk areas are changing their perception and shifting from private health sector to public health facilities for TB testing because of the convenience and ease of use of the JC.

"Previously, patients were more inclined to visit private hospitals, but now they are shifting towards public sectors, thanks to the jaanch coupon. The testing rate has increased, primarily due to distribution of coupons". (Female, 33 years, TBHV, Koppal, Karnataka)

- **Theme 4- Contribution to TB case finding:** According to NTEP representatives across the intervention geographies there has been an increase in the number of TB tests compared to earlier or before the jaanch coupon was introduced.

"With the help of the coupon our notification has also increased. The patients whom the RNTCP workers cannot reach, these kinds of organization are reaching through coupons and awareness. Patients who are in hard-to-reach areas or very far from the facilities are also coming here for diagnosis and treatment. Many people were earlier either not able to get their test or went to wrong place for tests. Many of them went to private facilities. Few of them went to village level local Doctors (RMPs)". (Female, 26 years, NTEP staff, West Champaran, Bihar)

"There is more testing because of JC - there's more intensity. Some people might be getting late to the hospital. The idea was that if they had this card [JC], they might get seen faster. It's given to those who get cough tests done. The JC is given through the field workers, not at the hospital. I mostly see the JC being given to poor people. Some elderly people too". (Female, 45 years, NTEP staff, West Champaran, Bihar)

"...having JC is a good idea. Like patients those from rural areas they have not much understood about the TB diagnosis and free treatments...and through that they became aware". (Male, 42 years, NTEP staff, Mushalpur, Baksa)

Apart from the above-mentioned aspects, one distinct contribution, as highlighted by the health service providers, was:

- **Theme 5 - Change in community's TB health-seeking behaviour:** According to the NTEP staff, there had been a noticeable shift in the attitude of the community towards TB, and the jaanch coupon has played a role in addressing the stigma associated with TB. For them, all the awareness-raising activities surrounding the distribution of the jaanch coupon had also contributed to sensitize the healthcare service providers.

"I have noticed a change in their perspective. Previously, individuals with symptoms used to hesitate to visit the public hospital, but now they understand the severity and are actively seeking diagnosis and treatment. The public healthcare staff exhibit respectful behaviour towards the individuals showing TB symptoms and also with PwTB ". (Male, 41 years, NTEP staff, Mahabubabad, Telangana)

3.2.4 Insights on limitations and barriers in using jaanch coupon

- **Affecting quality of referrals:** One of the major concerns raised particularly by NTEP staff was that the extensive use of jaanch coupon by the community structures to refer people for testing at times affected the quality of referrals.

"...as CS leaders, they are supposed to be well informed about individuals with TB like symptoms so the jaanch coupon should be issued only after thorough inquiry...but not to increase the numbers/quantity of the sample; this is my appeal towards them." (Male, 42 years, NTEP staff, Baksa, Assam)

- **Resistance to TB treatment seeking:** Some of the CS leaders mentioned that people ignored TB symptoms despite receiving the jaanch coupon and having information on TB. The primary reason cited was the stigma attached with TB. It was noted by the community structure leaders from Bihar, that the community was hesitant to open up and share about the disease or even health-related matters, and occasionally, there were refusals to accept the jaanch coupon and even if they accept it, sometimes they did not visit the health center for testing.

"What would happen if I get TB...so this belief kept me away from undergoing test immediately...because people may think bad about it" (Female, 35 years, CS leader, West Champaran, Bihar)

3.2.5 Opportunities for further improvement

- Name and details of the person could be mentioned on the jaanch coupon to make it personal
- Continuing the coupon will be helpful as it raises awareness among people and proves advantageous for them. Moreover, the increased testing rate would also assist NTEP staff. (service provider)

- In order to improve the use of jaanch coupon at the grassroot level ASHA and AWWs should be oriented, and they should be in-charge of distributing these coupons. As frontline workers have the best knowledge about the communities they serve, well-placed to make informed decisions about the distribution of the coupons to the individuals who would benefit the more.
- The gram panchayats too should be oriented about the use of the jaanch coupon; this will lead to greater awareness and increase in referral, treatment access and adherence.

3.2.6. Summary

Insights from this qualitative study shows that jaanch coupon could be considered a potential behavioural change solution to address the behaviour and cognitive level barriers which impede TB health care seeking.

From the users' perspectives, it was found that jaanch coupon had resulted in significant advantages by improving their motivational levels, decision-making processes, and a sense of entitlement pertaining to their health care seeking actions for TB. Users found the coupon beneficial, as they felt prioritized by the health facility. The fact that they did not have to pay for testing also served as an encouragement for the users.

Users of the solution have conveyed that those who have used the 'jaanch coupon' were more likely to share their positive experiences and actively encourage others with similar symptoms about the use of the solution. Many users reported that with the coupon in hand, they feel motivated and obliged to visit the health facility within the stipulated time and they are less afraid now to visit a hospital and get tested. The use of the coupon also appears to have reduced diagnosis delays, with users pointing out that upon receipt, either sought medical attention immediately the following day or within a period of two to seven days. One user shared her experience, stating that she first learned about the coupon during a SHG meeting. Subsequently, in the second meeting, held one month later, she seriously considered the information and decided to avail the coupon facility. Furthermore, the fact that Lab Technicians conduct sample collection and tests without extensive questioning, help in reducing the fear of associated with the testing processes.

The implementation of jaanch coupon has been noted to result in a sustained increase in its demand over time. This was pointed out by TBHV and community structure leaders. The CS leaders in Telangana indicated that the coupon distribution takes place under diverse settings, including community meetings, SHG meetings, and awareness camps, targeting individuals with symptoms suggestive of TB. Hence, the distribution of coupons has been viewed as an activity intricately linked to awareness generation and subsequent follow-up actions.

The data from users and community structures does not indicate whether jaanch coupon effectively addressed issues related to stigma. However, according to NTEP staff from Telangana, it has helped to reduce stigma specifically associated with TB testing rather than addressing the broader stigma related to TB as a disease. The analysis of the data further reveals that the JC has been equally beneficial across vulnerable groups, including those in urban metro areas, urban settings, or the mining population. The findings demonstrate that the introduction of the JC has led to an improvement in the attitude and quality of care at public health facilities, both in terms of testing and treatment. Jaanch coupon shows potential for a positive shift in community perceptions regarding the responsiveness of public health facilities to the needs of vulnerable groups. People now perceive health staff as being politer and more responsive to their needs.

3.3 BCS 3 - TB MUKT CERTIFICATE (TBMCT)

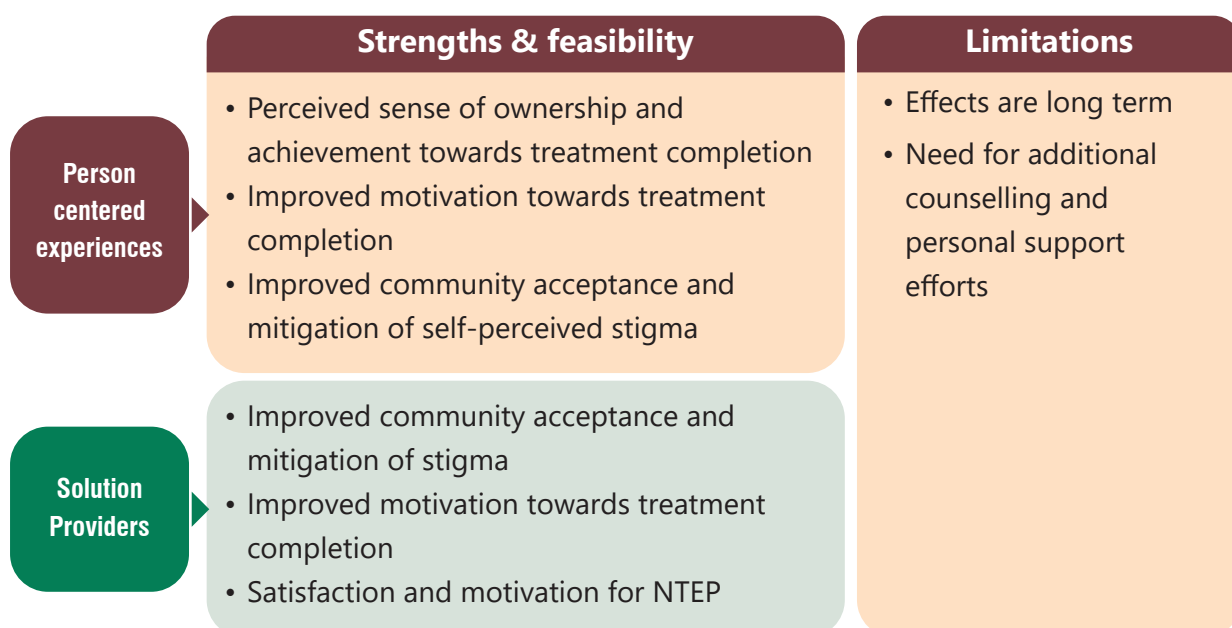
3.3.1 What is TB MukT Certificate?

TB-free or MukT certificate is a physical certificate issued by the health authorities to persons with TB to declare that (s)he had completed treatment successfully.

Objective: TB MukT certificate solution was developed and intended to facilitate the transcending process of a TB patient back to their routine life after completing treatment. Also, the certificate was aimed to create a documentation of the treatment completion in a timely manner and reduces any ambiguity and concerns related to test results.



TB MUKT CERTIFICATE: A SNAPSHOT OF FINDINGS



3.3.2 What did stakeholders understand about the solution? – knowledge about the solution and source of information

According to the users, TB mukt certificate (TBMC) was commonly known in different nomenclature across the states: such as 'TB certificate' in Karnataka, 'kagaj' (paper) in Bihar. According to the data, users were able to comprehend that the TBMC was provided at the local health facility after successful completion of TB treatment and it can be used as a proof, everywhere and might be helpful in terms of getting back to job etc. While, most of the users had seen/heard about the TBMC in the CSG meetings, while it was being issued to other fellow PwTBs, some of them heard about the certificate at health camps. Few of them had not heard about the certificate until they themselves received it post treatment.

"In 3rd CSG meeting I got to know about TBMC, when one PwTB was about to get the certificate after getting cured. So, they told me that I will also get TBMC." (Female, 35 years, User, Kamrup, Assam)

"Yes, I was informed about the TB Mukht certificate in the chest examination camp, where a chest examination was done, and I was asked to take medicines for one month and to give feedback on whether I was experiencing vomiting, diarrhoea, or loss of appetite" (Male, 36 years, User, Sangareddy, Telangana)

"...certificate is like a proof that we got cured as people tend to discriminate and so if need arises we can show the certificate. If they see that they will take us normally." (Male, 51 years, User, Baksa, Assam)

On the other hand, **NTEP staff** reported that certain details in the certificate like Nikshay ID, type of TB, dates of treatment initiation and completion, history of PwTB, were important and useful information. They acknowledged that TBMC was an authentic recognition and proof of treatment completion.

3.3.3 The usefulness and feasibility of TB mukt certificate:

The data regarding the usefulness of the solution was analyzed from the perspective of the users i.e. PwTB who had received the certificate and NTEP staff/frontline health workers. Various themes have emerged from the analysis which were reflective of the strengths of the solution, weaknesses in terms of limitations associated with the solution and opportunities for further improvement.

3.3.3.1 Person centered user experiences:

It was observed that the TBMC held significant practical value and, in certain cases, intrinsic value. Users highlighted various benefits of the TBMC, which are outlined below:

- **Theme 1- Perceived sense of ownership and achievement towards treatment completion:** Completing TB treatment and obtaining the certificate introduced a profound sense of achievement for some individuals. To the extent that they emphasized newfound confidence in freely navigating various spaces without fear of discrimination. The certificate played a crucial role in creating awareness about the full recoverability of TB, empowering users to advocate for ongoing medication, adherence to doctor's advice, and fostering courage within community.

"When encountering other patients, we can share our own experience by saying I had also TB, and as you can see, I received a certificate... its curable condition...just take the DOTS treatment...there is no need to be afraid. I have already suggested one patient nearby...so whenever someone have TB symptoms, we guide them to seek for treatment." (Male, 51 years, User, Kamrup, Assam)

"Those patients who were present there at the time of TBMC issuing, expressed positivity about my recovery. I told them that they too would recover soon and inquired about their medication adherence. My successful treatment brought them a sense of satisfaction" (Male, 54 years, User, Kamrup, Assam).

- **Theme 2- Improved motivation towards treatment completion:**

The analysis revealed that TB-mukt certificate has been useful for most of the users in different ways. While witnessing others getting the certificate in meetings, motivated them to complete the treatment, this certificate also helped some of them to assimilate back to social life and resume work.

"Yeah, upon witnessing others getting the certificate, we were inspired, and we believed that once we complete the treatment course of treatment, we will also obtain it." (Male, 51 years, User, Baksa, Assam)

"During my treatment, after observing people receive this certificate, motivated me to complete my treatment promptly." (Male, 39 years, User, Sangareddy, Telangana)

- **Theme 3 – Improved community acceptance and mitigation of self-perceived stigma:**

The solution had two-fold advantage in the context of addressing uncertainty and stigma at the personal and at the level of community. It was mentioned that the issuance of this certificate by competent authorities/Government helped dismiss fear and stigma, motivating individuals to encourage other people in the community not to be afraid and to continue their treatment.

"Yeah, when I had TB, there was a sense of fear and uncertainty about what might happen. Now, I don't have any fear." (Female, 26 years, User, Dibrugarh, Assam)

The TB mukt certificate helped reduce stigma and discrimination toward the affected person from the community or the workplace. The certificate helped at the time of marriage, served as a useful document for traveling, getting a new job, re-joining work and helps to get back to social life.

"Earlier, people did not come near me... fearing that I have TB and they will contract the disease. Even those from my own caste (biradar) avoided visiting my house, I reciprocated by refraining from visiting their house. I didn't go anywhere outside. However, once I completed the treatment and received this certificate, they now visit my house without hesitation. I have also started visiting everyone else's houses. People now talk to me nicely. Those who are educated understand the situation once they read the certificate. I show this document to those who may still harbour doubts". (Female, 45 years, User, West Champaran, Bihar)

"...to resume a normal life and assimilate with society like before, it has definitely helped. When I had TB, perhaps the way people, especially neighbours, were supposed to treat me, they might not have treated me that way. But, now they stay in touch with me, and there has been a positive change in how they interact with me. This extends to my work environment as well, where my co-workers also treat me well." (Male, 28 years, User, Dibrugarh, Assam)

Those who did not directly talk about usefulness, they still indirectly mentioned how community and colleagues at work had accepted them back and behave better after they complete TB treatment meaning that it helped reduce stigma and discrimination in the community. Most of them used the certificate as a proof of treatment completion/cure which they can show to their friends or neighbours. The way the word 'proof' was used also indicates that they needed to justify to the community and/or at workplace that they no longer suffer from TB.

"Now people tend not to discriminate as I got TBMC. Earlier I could sense that a little." (Male, 51 years, User, Baksa, Assam)

"Before getting TBMC, no one used to talk to me properly. People thought that if they talked to me, they might contract TB. After receiving the certificate discrimination was reduced from community, friends, and neighbourhood." (Female, 33 years, User, Bangalore, Karnataka)

"For people who work as employees, this certificate serves as tangible proof. Those who have recovered from TB can present this certificate, affirming that they were once TB patients but are now fully recovered." (Male, 39 years, User, Sangareddy, Telangana)

3.3.3.2 Perspectives of health service providers -NTEP staff/Frontline workers

NTEP staff/FLW exhibited commonality with the users' experiences to a large extent especially in terms of nudging treatment completion, mitigating stigma,

- **Theme 1- Improved community acceptance and mitigation of stigma:** The NTEP staff also reiterated that TBMC was useful for schools and for people who are looking to rejoin their work. Comparing implementation in urban and rural areas, one NTEP staff from Karnataka pointed out that in comparison to rural geographies, TBMC was more useful in rural areas as people are generally involved in daily wage works or agricultural work.

"There is stigma in society. Awareness is less here in rural areas. Providing certificates in city might be helpful. I don't know whether it will be helpful in rural locations." (Male, 38 years, NTEP staff, Koppal, Karnataka)

"Patient starts expressing that they feel completely fine. The effectiveness of this is evident when the patient, upon receiving the certificate, starts actively tell people around him that by adhering to medications promptly, others can achieve recovery and obtain this certificate". (Male, 40 years, NTEP staff, West Champaran, Telangana)

- **Theme 2- Improved motivation towards treatment completion:** The same was reflected by NTEP staff from across intervention geographies, who had expressed that TBMC was an effective mechanism to boost confidence and motivate the PwTBs. According to NTEP staff, when PwTB are informed during CSG meetings that after completing 6-9 months of treatment they will get a certificate, it encouraged them to continue the treatment till the end. They also mentioned that it works as proof that they have recovered from TB, bringing them joy, and can also help them addressing stigma and discrimination within the community.

"It's also beneficial for our work. During meetings, we invite TB champions who have received certificates to share their experiences. When new patients see these TB champions, they are inspired to complete their treatment." (Male, 56 years, NTEP staff, Ballari, Karnataka)

Apart from the above-mentioned aspects, couple of additional contributions as highlighted by the NTEP staff, are as follows:

- **Theme 3- Satisfaction and motivation for NTEP:** The solution had a surprising impact on NTEP staff, as they expressed feeling a sense of satisfaction when handing over the TBMC to individuals who have completed their treatment.

"We are also delighted because of TBMC. Providing TB completion certificates to patients brings us satisfaction in our work. These certificates serve as an inspiration to new patients". (Female, 48 years, NTEP staff, Bangalore, Karnataka)

Additionally, NTEP staff mentioned that along with the certificate, identifying the PwTB who completed treatment successfully as TB champions also is a great motivation as they can play a big role to mitigate stigma and indirectly, increases the number of tests and aids in the final goal of ending TB.

"...if we provide the TBMC after completion of treatment, it will motivate individuals to finish their treatment completion, and more people will be encouraged to seek TB treatment. With increased testing, we can better achieve our goal of eliminating TB." (Male, 34 years, NTEP staff, Kamrup, Assam)

"...as they received treatment and completed after maybe 6 months or 9 months. Then they can get certificate and when they are designated as TBC and called for meeting to talk to patients. More than us the patients become more motivated for treatment completion. And they tend to express themselves more fully." (Male, 34 years. NTEP staff, Kamrup, Assam)

3.3.4 Insights on limitations and barriers in using TB mukt certificate

The TBMC received widespread acknowledgement from users and health service providers for its ability to harness benefits. However, there were a few specific concerns and alternate views regarding the solution.

- **Effects are long term:** A user from Telangana revealed that the solution had not really been helpful in addressing the stigma instantly rather it's a gradual process that needs to be implemented at a scale in the community.

"Even after receiving the TB Mukt Certificate, the situation remains unchanged: whenever I try to engage in a conversation, people just walk away. I believe that with time, perception will change". (Male, 50 years, User, Hyderabad, Telangana)

"When we talk about the overall acceptance of this certificate in this society its then I would like to say we are still in early stages. We have not distributed many certificates yet so it will take time to understand this but the reliability of all staff and in this facility is very high in this area". (Male, 40 years, NTEP staff, West Champaran, Bihar)

One of the NTEP staff in Telangana, who sees its utility more on the personal level rather than community level.

"The TB Mukt certificate is for individuals for their personal use. It is to certify that a particular patient is now free from TB and is ready for community participation. So, I don't think a TB medical certificate will help in the elimination of TB. We have initiated this to change PwTB's behaviour. To eliminate TB, we need people to come forward for screening, testing, and diagnosis, followed by medication". (Female, 53 years, NTEP staff, Sangareddy, Telangana)

- **Need for additional counselling and personal support efforts:** the NTEP staff from Telangana expressed that the certificate alone may not be sufficient in motivating people; rather, several rounds of counselling that the health care staff provide coupled with the certificate act as a nudge and brings about some behaviour change among PwTBs.

“Yes, I have observed a noticeable change in the patient’s behaviour. Providing counselling them initially in their treatment journey, and consistent y follow-ups for the initial 2 months, along with a prescribed medication regimen for the subsequent 6 months, are very essential. This is not a brief one-month course, rather, it requires ongoing commitment. Even after completing the 6 months medication phase, regular hospital visits for some more follow-ups remain necessary. So, after so much encouragement during this period, there is definitely a change in PwTB”. (Female, 53 years, NTEP staff, Sangareddy, Telangana)

3.3.5 Opportunities for further improvement

- Scaling up as part of NTEP, it would be beneficial (NTEP)
- The certificate may be made smaller in size so that it is easy to carry (User)
- The certificate may not be made digital (PwTB/NTEP)
- TBMC can be given to those PwTBs who want (NTEP)
- The issuance of TBMC should be demand-based rather than universal, and its promotion should be advocated through specific events and social media activities

3.3.6 Summary

The Findings underscored the valuable role of the TB mukt across various dimensions, benefiting patients, their peers and health care providers identically. The physical certificate not only enhanced a sense of ownership and achievement for patients who completed treatment but inspired them to become advocates in the fight against TB. Moreover, the certificate served as a powerful motivational tool for other PwTB in the community, viewed as a tangible reward attainable through their own efforts.

The solution emerged as a crucial tool in mitigating self-stigma, enhancing community acceptance, and consequently having a possibility of addressing enacted stigma. Both ASHA & NTEP staff reiterated that the most crucial aspect about the solution lies in terms of how it can work as a motivator for people to complete treatment, more than anything else.

Additionally, the findings suggest that TBMC served as a valid proof of treatment completion, particularly in various situations such as the workplace and when resuming social activities. This indicate that TB MukT certificate was accepted not only by the PwTB or family but also the community at large. Similarly, the fact that TBMC was widely used to validate treatment completion also indicate that there is perceived as well as enacted stigma in the community and hence, this documentary proof successfully deals with stigma and discrimination in the community or workplace.

In summary, the solution played a key cognitive role in addressing the inherent stigma and promoting better community acceptance of TB patients. The solution had also emerged as a motivating tool not only for other TB patients but also for the NTEP staff. Feedback from NTEP staff also reinstated the fact that TBMC was able to serve its desired objectives and therefore, there was acceptance at the health system level. Suggestions to implement the solution on a larger scale clearly highlight the positive impact of TBMC and the potential scope of scale-up especially in Karnataka, Assam and Telangana.

3.4. BCS 4 - TB STARTER KIT

3.4.1 What is TB starter kit?

- TB starter kit comprises of three components, a TB management guide with information on basics of TB, a calendar to record the treatment journey and a user's guide to inform users on how to use the kit.
- It helps newly-diagnosed persons with TB and caregivers to understand and prepare for their treatment, as well as create a sense of ownership of their treatment journey.
- The kit helps in 'calendarization of the treatment journey' and prepares those on TB treatment for the entire treatment duration.
- It addresses the barriers of ambiguity and confusion about TB treatment protocols.

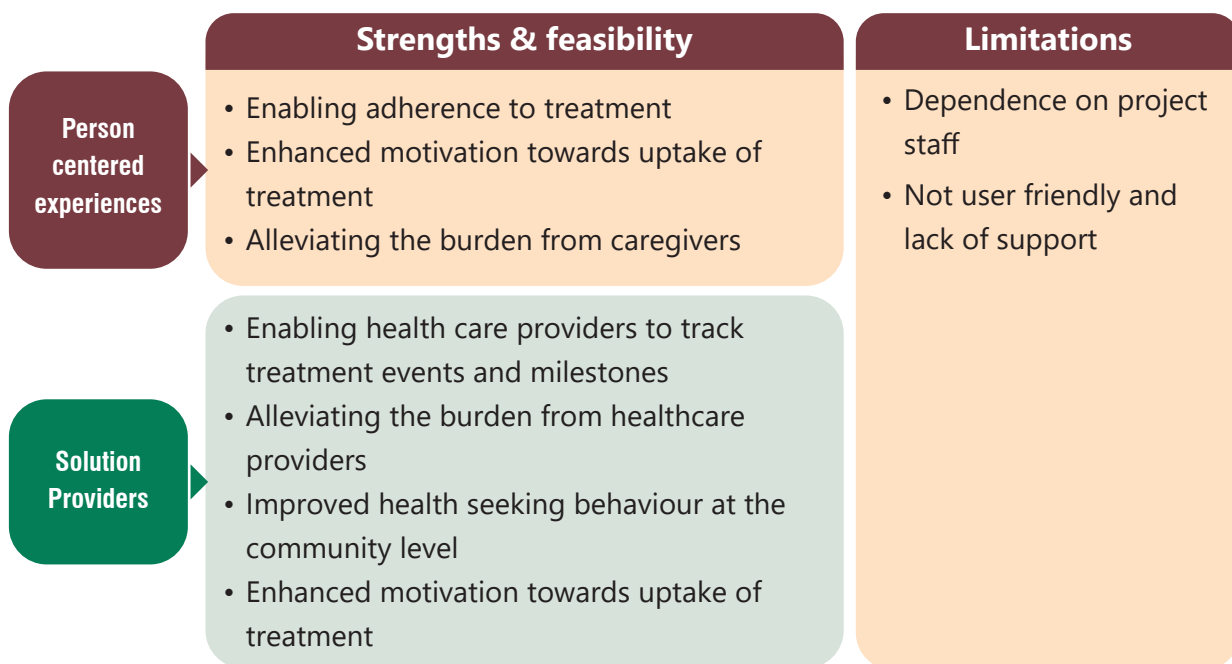
MONTH 6
"Believe in yourself!"

Did I take my medication today?

How am I feeling today?

1	2	3	4	5	6	7
y n	y n	y n	y n	y n	y n	y n
😊	😊	😊	😊	😊	😊	😊
😐	😐	😐	😐	😐	😐	😐
😞	😞	😞	😞	😞	😞	😞

Objective: The kit is designed to serve as a supportive instrument for the PwTB to navigate the complex treatment journey. It is intended to facilitate this journey by acting as a comprehensive tool for recording, tracking and managing the day-to-day treatment regardless of their significance. The kit was aimed as a simple one-stop solution to benefit PwTB, their families and health care providers in enabling a favourable treatment journey.

STARTER KIT: A SNAPSHOT OF FINDINGS**3.4.2 What did stakeholders understand about the solution? – Knowledge about the solution and source of information**

According to the users, they were oriented on the use of TB starter kit (TBSK) by health facility staff or KHPT staff or frontline health workers during care and support group (CSG) meetings or house visits. Many users across intervention geographies referred to it as a “calendar” or “diary”. It was mentioned that health staff visited once or twice a month to check on them and during their visits they explained about using the calendar. Most of the users were well aware about the detailed usage of the kit.

“This calendar made it easy to track the medication and the condition. If we miss the dosage in the morning, I was able to take medication another time on the same day after referring to the calendar. Because of the calendar, I didn’t miss any doses”. (Male, 34 years, User, Bangalore, Karnataka)

“When I was detected with TB, I visited Chest hospital in DTC Hyderabad, where Jhansi ma’am introduced me to this calendar”. (Male 33 years, User, Hyderabad, Telangana)

“We call it the TB calendar; I learned about it through the TB supervisor.” (Female, 49 years, User, Sangareddy, Telangana)

According to the NTEP staff, they received information and orientation about the starter kit from KHPT staff. They also reported that before initiating the treatment process, they provide PwTB with the TB starter kit, explain its purpose and usage. They further mentioned that TBSK serves as a valuable tool to monitor the progress of PwTB.

3.4.3 The usefulness and feasibility of starter kit

The data regarding the usefulness of the solution was analysed from the perspective of the users i.e. PwTB & their caregivers who had used the starter kit and NTEP staff/ frontline health workers. Various important themes emerged from the analysis reflecting the experiences of both users and providers.

3.4.3.1 Person centered user experience

- **Theme 1 – Enabling adherence to treatment:** Users across various intervention geographies mentioned that starter kit played a crucial role in preventing confusion and ensuring proper dosage. It was also mentioned that it helped in tracking the side effects and duration of treatment. Furthermore, the majority of users affirmed that the tool contributed to their medication adherence by preventing the omission of doses.

"I could monitor my health issues, including headaches, pain in my hands and legs, allergies, or any other concerns. I could also track whether it was the first month or the second month of treatment" (Male, 62 years, User, Bangalore, Karnataka)

"In the beginning, I was a little scared, wondering what it was! Because it was given to my husband. He explained how to mark. community Coordinator (CC) also explained it. I like it because it ensures I am taking medicine regularly. If it's not there then I might forget one dose". (Female, 30 years, User, West Champaran, Bihar)

"It is like looking at regular calendar and this calendar (SK) is the same. I usually keep this calendar near the TV, so soon after taking the medicine, I put a tick mark." (Male, 32 years, User, Koppal, Karnataka)

"At first, with SK, there is no chance of forgetting to take the medicines...it stays in your head when you see the calendar that you have to take the medicines...and even pictures are provided, and seeing them feels goodit helped me not to miss medicines, and secondly, how did you feel that one you can know from it...through the calendar I got to know the days that are left ..and how many days I have undergone treatment so far." (Female, 24 years, User, Dibrugarh)

They also mentioned that though it is similar to the calendar at home, the starter kit helped them track their medication. The solution has been useful irrespective of gender of the user.

"If starter kit was not there, I would have to monitor and remind about taking medicines. If you had asked about a situation... like 10 days before, if patient had vomited or not... when you skipped the medicine... remembering those dates and details can be challenging.....like in this week you can say that you vomited 2 times and in this week you had a headache. With SK, every experience is recorded in the calendar, making it easy. Otherwise, normally it's hard to remember...what happened post that...in that way it has been useful." (Female, 51 years, caregiver, Kamrup, Assam)

- **Theme 2- Enhanced motivation towards uptake of treatment:** According to the users, SK served as a source of motivation, giving the PwTB a sense that they are making gradual progress towards completing the treatment and providing a feeling of achievement.

"When I look at the calendar...and it is approaching the end of the month...so after seeing it I feel happy because my treatment is nearing completion." (Female, 18 years, User, Kamrup, Assam)

- **Theme 3 - Alleviating the burden from caregivers:** Experiences from the caregivers revealed the benefits of using the tool, which included the ability to track medicine dosage and timings, track & manage side effects, monitor psychosocial status of the PwTB and keep a record of pill counts. One caregiver expressed that SK alleviate the burden by reducing the need for care givers to remember every detail and providing better support for PwTB. Another caregiver also pointed out, along with helping in tracking the treatment journey, the calendar ensures that individual avoids any overdose of medication. Some of the users mentioned that they had used SK with the help of someone else like, family members (son, daughter, wife etc.) and others like ASHA and AWW.

"One more thing is that some individuals have tendency to forget and accidentally take medicine twice a day. This overdosage can lead to potential side effects. However, with the habit of looking at the calendar, such instances of overdosage can be prevented". (Male, 23 years, caregiver, Sangareddy, Telangana)

I can't write and read, so I took help from Anganwadi teacher, once in 2 or 3 days usually mark. (Female, 60 years, User, Koppal, Karnataka)

Not received any orientation. I was informed to tick in the calendar every day after taking tablets; rest all, I do not understand, as I am not that educated. It would be better if I received the calendar in Telugu. I would have understood better since it is in English and I don't know the other benefits of it I did not know what these emojis represented. I asked my wife to help. (Male, 32 years, User, Hyderabad, Telangana)

3.4.3.2 Perspectives of health service providers: NTEP staff/frontline workers

Themes emerging from the healthcare providers revealed commonality with that of the users in the following two aspects:

- **Theme 1 - Enabling health care providers to track treatment events and milestones:** The SK enabled PwTB keep track of their treatment journey, medicine dosage, side-effects, and personal feelings on a daily basis. Service providers mentioned that PwTB can determine the number of days left to complete their treatment by checking the calendar everyday it can also ensure they haven't missed a tablet. Additionally, the calendar shows the remaining days to take the medicines

that can motivate PwTB to complete treatment. Maintenance of daily treatment records through SK had actually helped Doctors and other health staff to monitor the particular PwTB better and prescribe the next steps or counsel them accordingly. There was a consensus that it helps the PwTB in adhering to their treatment.

"We can't monitor every patient on a daily basis, and even our ASHAs can't do that. In this regard, the starter kit is very helpful. It allows us to monitor their medicine consumption and understand how they are feeling during their treatment". (Male, 28 years, NTEP staff, Koppal, Karnataka)

"Few years ago, the number of cases was higher. Now they have reduced treatment relapse, treatment failure, and recurrent cases to an extent". (Male, 38 years, NTEP staff, Mahabubabad, Telangana)

- **Theme 2 - Alleviating the burden from healthcare providers:** ASHAs and TBHV also mentioned that PwTB can take their own responsibility and as such there is a reduced burden of responsibility on them. TBHVs mentioned that the follow-up has become easier for them owing to the starter kit. They can rely on the starter kit to know what the PwTB has been through physically and emotionally. It helped PwTB in taking responsibility for consistently adhering to their medication schedule and they can easily use happy or sad faces to show the emotions that they might be experiencing.

"It has made follow-up easier for us, and patients have experienced mental stress. They reflect on why they marked "sad" the previous day and strive to be happier. Additionally, we provide counselling based on their chart when we visit their homes once every two weeks." (Female, 46 years, NTEP staff, Bangalore, Karnataka)

In addition to the abovementioned two themes, data from healthcare providers also reflected the following benefits of the solution:

- **Theme 3 – Improved health seeking behaviour at the community level:** The importance of SK solution in the context of TB treatment adherence and follow up was also reflected by the NTEP staff. NTEP/FLW from Assam revealed that SK has proven highly useful for their communities. They specifically pointed out that over last two years, there has been a noticeable change among those who used the solution. Users became increasingly aware of medicine dosage, timings, side-effects, and management of emotional turmoil associated with the disease, treatment, and medicines. As a result, there has been a substantial decrease in defaulter/drop-out rate among the users. The SK effectively served as a day-to-day guide.

"It is very useful to the patients. Since we don't get to meet patients quite often, SK becomes like a companion for them, always with them...like they feel that we are with them...when they have SK with them. Also, when we meet them, checking the SK enable us to provide more effective counselling. As in why it has happened, why not, what to

be taken next, and improve the counselling process in that way.” (Male, 34 years, NTEP staff, Kamrup, Assam)

“Previously we had to explain a lot...but now they have good understanding about TB, treatment, dietary requirements etc. The default rate previously was very high, but now we observe a declining trend since the introduction of SK. Many patients have told us that the SK has been very useful.” (Male, 38 years, NTEP staff, Baksa, Assam)

- **Theme 4 – Enhanced motivation towards uptake of treatment:** As one Medical Officer pointed out, the progress of the treatment can motivate the PwTB to complete the treatment. The chances of missing medication are reduced because of using the starter kit as it ensures a visual confirmation of medication taken.

“Tracking motivates the patient. The calendar indicates since when they are having the disease and the remaining days to finish the medications. Consistent medications intake allows them to notice the changes and hence, work is half done by that. Marking on the smiley faces shows their general condition during the different phases of the treatment. We can see the emotional state of the patient and respond accordingly. Previously, they used to miss taking their medicines. But with the help of calendar, it ensures regular medications intake”. (Male, 35 years, NTEP staff, Bangalore, Karnataka)

3.4.4 Insights on the limitations and barriers in using starter kit

- **Dependence on project staff:** As per implementation plan, the SK has to be provided ideally by the doctor (MO) or the NTEP staff and to explain the details of how to use it to the PwTB. However, users mentioned that they received the starter kit from other stakeholders like frontline workers, or KHPT staff, which was not as per implementation plan.

“I am aware of the starter kit. KHPT staff has told and explained the details about it. They distribute this kit to PwTB. During a meeting, they provided explanations to the patient and I was also present.” (Male, 35 years, User, West Champaran, Bihar)

“I received training on the use of SK, and the BTB Community coordinator told clear instructions on how to use the starter kit (Male, 21 years, User, Hyderabad, Telangana)

- **Not user friendly and lack of support:** Those who are not literate often find it not user-friendly, citing difficulties in reading, and emojis may not always make clear sense.

“I think it would be more beneficial if the calendar were prepared in the local language. Since now it is in English, if local language version of the calendar was available, it would have been better”. (Male, 33 years, User, Hyderabad, Telangana).

3.4.5 Opportunities for further improvement

- It would be useful to include dietary recommendations, such as which vegetables, fruits, eggs, and pulses to consume, in the calendar (User)
- Should be implemented in all states, in both rural and urban areas. (NTEP staff)
- Language options may be increased (Assamese, Hindi, Telugu, Urdu) (Caregiver)

3.4.6 Summary

The kit played an important role by serving as an easy and effective instrument for documentation and tracking interactions between the PwTB and caregivers. In addition to the pill intake, the kit helped to track minor but important events related to side effects, psycho-social aspect of the PwTB and other outcomes, which might have otherwise been overlooked as trivial. The kit, which was visually present alongside the PwTB, also played an important cognitive role in reinforcing the PwTB's motivation to follow and continue treatment. The data suggests that the starter kit helped reduce the cases of treatment failure to an extent. It also provided a sense of control over the situation the PwTBs are experiencing. It also contributes to creating awareness about TB treatment journey.

3.5 BCS 5 - TB BUDDY

3.5.1 What is a TB buddy?

- It is a caregiver, community member or TB Champion assigned or nominated by the person with TB as a buddy to provide holistic support during each stage of the treatment.
- The solution helps PwTB to find absolute, undoubted support within and outside their homes on medical and non-medical issues such as emotional support while keeping TB a secret.

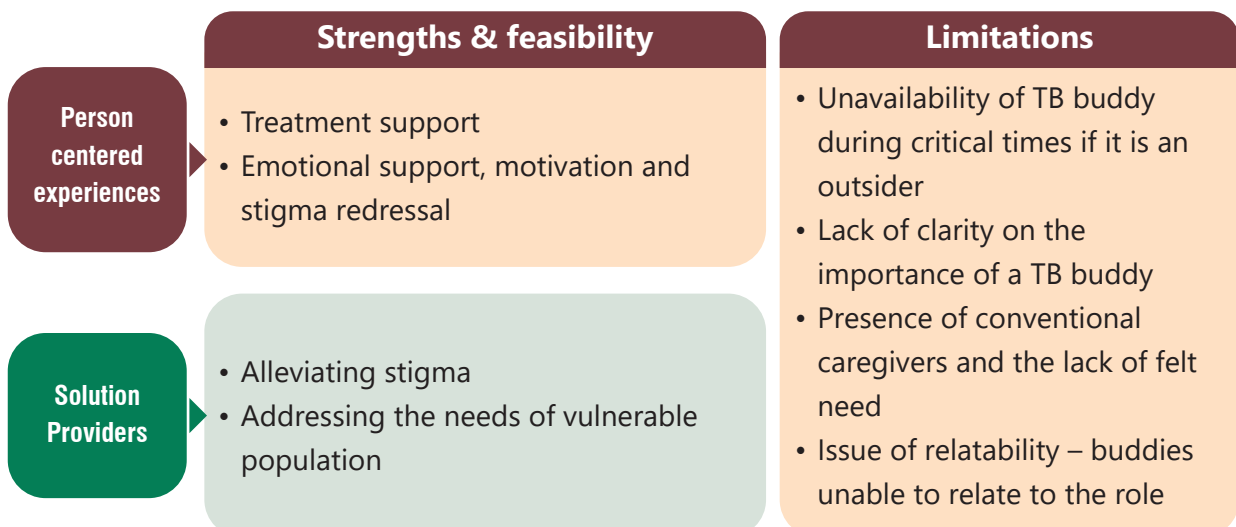
Objectives

The solution was intended to establish a trusted and friendly relationship for PwTB, enabling them to seek timely emotional, social and treatment related support without hesitation.

BUDDY HEALTH GUIDE



TB BUDDY: A SNAPSHOT OF FINDINGS



3.5.2 What did stakeholders understand about the solution? – Knowledge about the solution and source of information

According to the **users** TB buddy is a friend or family member who provides care for persons with TB. The users perceived TB buddy more as a family member or care giver than as an assigned person playing the role of TB buddy. Though it was clear to users that this person could be outside the family too and help in their TB treatment journey, for majority of them family members/their care givers turned TB buddies as their caregivers. These included husbands, daughter, mother, sister, etc.

According to the **solution providers (TB Buddy)**, TB buddy receives information from KHPT staff during meetings. They are informed of responsibilities through orientation and trainings. Their responsibilities include helping PwTBs keep track of food and medicine, ensuring their emotional well-being.

"I was given orientation initially when I joined as the TB buddy. To be there for a PwTB as a friend and support them, to encourage them to continue medicine". (Female, 40 years, TB buddy, Hyderabad, Telangana)

3.5.3 The usefulness and feasibility of TB buddy

The data regarding the usefulness of the solution was analysed from the perspective of the users i.e. PwTB and the solution providers i.e. TB buddies. Various important themes emerged from the analysis reflecting the experiences of both users and providers.

3.5.3.1 Person centered user experience

- **Theme 1 - Treatment support:** For the users, the TB buddy served as a reliable support, available whenever they needed any. For some PwTBs, TB buddies extended their support to the entire family. According to the users, there were multiple aspects in which TB buddies proved efficient and helpful like their ability to maintain confidentiality, assisting in various ways such as providing diet & nutrition support and accompanying the users to the hospital during the treatment journey.

"She helped me significantly by ensuring timely medication and maintaining a proper nutritious diet. If I ever forgot to take my medicine, she would remind me and insist I take it in her presence". (Male, 65 years, User, Koppal, Karnataka)

"She was like a friend; she would visit me at the hospital, and occasionally, she would come to my home. She inquired about my health, how I was doing, and whether I was adhering to my medication. She also asked if I needed financial help". (Female, 32 years, User, Hyderabad, Telangana)

In some cases, the support went beyond psychosocial assistance; the buddies helped by personally procuring medicines for PwTBs and even offering financial support.

"No one knew that I had TB, not even my family members. This TB buddy would come like everyone else to collect milk from my house and would give me suggestions. So, I didn't have any other opinion or doubt about why she was visiting my house. Only me and my wife knew about this". (Male, 46 years, User, Mahabubabad, Telangana)

- **Theme 2 - Emotional support, motivation and stigma redressal:** Community still associates TB with stigma; hence, as per the users, having a TB buddy somewhat alleviated the burden for them. Their compassionate, sensitive, and thoughtful nature also played an important role in encouraging PwTBs to complete their treatment.

"My TB buddy was very polite and conversed with me in a friendly manner. While some people tend to keep a distance from TB patients, she sat very close to me. When talking to her, I felt a sense of relief; I did not feel like I was suffering". (Female, 32 years, User, Mahabubabad, Telangana)

"I was very scared, uncertain about what would happen... but, my sister and the community coordinator provided me with courage. They advise me to eat well, take my medicine, and stay involved. It gave me a sense of reassurance, knowing that someone would be there to help us". (Female, 34 years, User, Koppal, Karnataka)

3.5.3.2 Perspective of the solution providers -TB buddies

Who became TB buddies?

TB buddies were individuals who were either family members, had personal experience as a TB survivor or had a close connection with someone who had survived TB. Alternatively, they could be frontline health workers as well, including ASHA and 'jeevika'. According to health care providers, this solution is helpful for PwTB, and can also contribute to reducing stigma associated with the disease.

TB buddies mentioned about their opinion about the usefulness of the solution:

- **Addressing needs of vulnerable population:** According to some buddies, this intervention will be more effective when providing support to vulnerable population, such as the elderly people, those residing in remote areas, those with limited mobility, etc.

"This buddy system is beneficial, but for many people facing economic hardships, it is difficult to access hospitals and avail themselves of the benefits. Some may not be able to manage travel on their own, so for patients in such situations, I wish that additional

assistance can be provided to help them with transportation, making it more beneficial and helpful. I wish doctors could extend their support in this regard". (Female, 60 years, TB buddy, West Champaran, Bihar)

One female buddy explained how this solution is able to address the stigma among PwTB and in the community at large - *"I'm very happy to be a TB buddy. I am spreading awareness about TB. In the past, people were scared of TB. If they found themselves positive, they would be hesitant to come out of their house. but, now, as I assure them that with medication, recovery is possible, and they gain confidence to come out and feel encouraged. I feel good about being able to help others. They cooperate with me, and though there was initial stigma, they now perceive themselves as normal. They also openly share their feelings and personal problems with me". (Female, 32 years, TB buddy, Mahabubabad, Telangana)*

3.5.4 Insights on limitations and barriers in using TB buddy

- Practices of isolation of the PwTB by both the family, and the person himself/herself kept away
- Unavailability of TB buddy during critical times if it is an outsider
- Lack of clarity on why someone needs to be assigned as a TB buddy
- Presence of conventional caregivers like family members and the lack of felt need to assign anyone for such a role and name.
- Though assigned with the role of TB buddy individuals in this role unable to self-identify as such.

3.5.5 Opportunities for further improvement

- There was a strong suggestion to extend it to the remote areas where healthcare access is a challenge.
- The TB buddy solution has successfully promoted treatment adherence and psychosocial well-being to an extent. Given that no financial investment is required, as anyone familiar within the family or outside can serve as a TB buddy, it proved to be a feasible solution for implementation.

3.5.6 Summary

The TB buddy solution received a mixed response from both the users and providers. It provided essential treatment related and emotional support for the persons on treatment, helping them overcome various difficulties. While it successfully addressed

stigma from provider's perspective, users did not share the same. Some questioned the necessity of a treatment buddy when a family caregiving system was already in place. Users suggested that the solution could be more beneficial for vulnerable population like elderly, rural patients and those with disabilities. There was ambiguity in explaining the necessity of TB buddy for treatment purpose, especially in comparison to family caregivers. Many users referred to TB buddies as visitors or family member, and not everyone was aware of TB buddy programme as a distinct treatment support solution. In most cases TB buddies were often people with direct experience of TB, either frontline health workers or as survivors themselves or had close relationships with someone who had survived TB (spouse, child, parent, friend).

3.6 BCS 6 - TB CHAMPION AS HEALTH WORKERS

3.6.1 What is TB Champion Health Workers (TBCHW)?

On boarding persons who have been successfully completed their treatment for tuberculosis as health-workers, providing them with training to offer effective treatment support to other PwTBs, and accrediting their efforts and roles through institutionalisation.

Objective:

- To explore avenues to involve persons who have successfully overcome TB, referred to as (TB) Champions, and providing them with training to collaborate with NTEP staff in delivering high-quality support for the persons undergoing TB treatment.
- The proposed solution seeks to train and involve cured persons as health workers, thereby addressing the current gaps in NTEP human resources and enhancing their capacity to meet the specific needs of individual TB patients.

TBCHW: A SNAPSHOT OF FINDINGS

Strengths & feasibility	Limitations
Contribution to programme: <ul style="list-style-type: none">• Contribution to TB case finding• Enabling emotional support for PWTB• TB awareness and source of inspiration• Alleviating stigma	<ul style="list-style-type: none">• Lack of incentives• Difficulty in balancing multiple roles• Community resistance and stigma• Lack of trust and acceptance• Demotivating negative experiences
Positive self-experiences: <ul style="list-style-type: none">• Sense of entitlement and social status• Perceived and experienced satisfaction• Source of self-motivation	

3.6.2 What did the TBCHW understand about the solution? - knowledge on the roles & responsibilities

The data revealed that selected TB champions were aware of their roles and responsibilities and could articulate them clearly. They were aware that they had to conduct house visits

and during these visits, educate community people about TB disease and its symptoms, diagnosis & treatment, necessary measures to be taken and the importance of consuming nutritious foods.

"Earlier there was uncertainty among them (PwTB) regarding where to go for check-up, what to do, whom to discuss with. But now, through regular visits and discussions we are making them aware and as a result of our rigorous work there is change... they know me as a TB specialist, they trust me and are more open. They even call over phone and clarify doubts." (Male, 24 years, TBCHW, West Champaran, Bihar)

"We visit patients' homes to inquire if they are experiencing any side-effects after taking their medicines. In case of existing side-effects, we try to change their medications. Additionally, we motivate patients to ensure they complete their treatment." (Female, 27 years, TBCHW, Bangalore, Karnataka)

3.6.3 Usefulness and feasibility of TBCHW

The data regarding the usefulness of the solution was analysed from the perspective of TB champions who had been selected and trained as health workers. TBCHW reported usefulness of the service in terms of how it contributes largely to the programme activities and secondly, their positive self-experiences.

- **Theme 1- Contribution to TB case finding:** TBCHWs mentioned about facilitating various services that encompassed screening, supporting symptomatic individuals in getting tested, and enhancing awareness about TB through various community outreach activities. They actively participated in care & support group meetings, where the doctors would give a platform for TBCHWs to share personal experiences, encouraging others undergoing treatment. Most respondents noted an increase in TB referrals since they started working as health workers. Some TBCHWs conducted awareness activities, and engaged in one-to-one interaction with people undergoing TB treatment.

"I am required to refer to 15 patients each month. In the last round, 5 people tested positive for TB. Fortunately, all of them are currently undergoing treatment and are in good health." (Female, 40 years, TBCHW, Koppal, Karnataka)

"I actively attend CSG meetings, discuss about TB and also personally meet with patients to educate them about proper nutrition and medication. People understand the importance of medication, continue their treatment and successfully recover". (Male, 35 years, TBCHW, Hyderabad, Telangana)

"We did screening of symptomatic patients at the start...and out of this we find some patients. We also do announcements by going to villages...by renting a vehicle and also when we meet someone when they ask we explain.... we also conduct awareness programmes, meetings in villages." (Male, 26 years, TBCHW, Baksa, Assam)

- **Theme 2- Enabling emotional support for PwTB:** The TBCHWs highlighted the critical role they play in offering emotional support to the persons on treatment. This included both managing adverse drug reactions to addressing mental agony stemming from potential stigma or discrimination associated with being a PwTB.

"Having successfully overcome TB myself, my involvement as a TBCHW inspires others with the courage to complete their treatment. Fellow TB patients draw motivation from– my example, witnessing my recovery through adherence to TB medicines. By noticing my path to restored health, they recognize the importance of pursuing a n d maintaining wellness through proper treatment." (Male, 45 years, TBCHW, Bangalore, Karnataka)

"We provide emotional support to patients, assuring them that TB is not an insurmountable problem, and treatment is readily available. We encourage them not to hide their symptoms; unlike HIV, TB is manageable". (Female, 33 years, TBCHW, Bangalore, Karnataka)

The TB champions further reported that they provided support to the PwTB and their families. One of the TBCs highlighted that PwTB and their families have become more open and comfortable with them because of their consistent visits, follow-ups, counselling, especially during difficult emotional phases.

"...as we ourselves were TB patient and now got certificate from govt... they tend to believe us as we became totally cured and it motivates them when we share our experiences with them." (Male, 39 years TBCHW, Baksa, Assam)

- **Theme 3 - TB awareness and source of inspiration:** It was also noted that when PwTB and their family members realized that TBCHWs had personally triumphed over TB, it served as inspiration for them to be persistent in their own journey. Thus, TBCHW can become a source of wide range of information about TB, and its treatment in the community.

"I am not sure if referrals and demand have increased, but actively I provide awareness to everyone". (Female, 27 years, TBCHW, Bangalore, Karnataka)

"I haven't made any referrals so far, but I do advise patients to cover their mouths while coughing and sneezing". (Female, 38 years, TBCHW Bangalore, Karnataka)

- **Theme 4 – Alleviating stigma:** Some TBCHWs mentioned about their enhanced role within the community because of their personal experiences. Most of them agreed that being TB survivors themselves, can significantly impact the community, with PwTB and their families increasingly relying on them. TBCHWs helped reducing fear among community members, especially PwTB and their families. The relatability of TBCHWs allows individuals with TB to easily connect with them, facilitating more effective guidance for those undergoing treatment compared to others.

"Normally, patients often experience adverse effects at the beginning of treatment, leading to a desire to dropout. Having someone to guide them during this critical period can make a significant difference. Continuous guidance throughout the treatment process is beneficial, especially when frequent visits from healthcare professionals might not be feasible. TBCHWs, being close to the patients, play a crucial role in providing consistent support". (Male, 26 years, TBCHW, Baksa, Assam)

"To understand people in rural areas, or in SHG/women meetings, or discuss with those groups of people who are helpless, those who are unaware about TB or support for those who have this disease but are unable to go the Hospitals, unable to seat, unable to walk. In such situations, I visit and guide them, initiating conversations about the disease and offering support.". (Male, 48 years, TBCHW, West Champaran, Bihar)

3.6.4 What motivates the TB champion to become health workers? Positive self-experiences

- **Theme 1- Sense of entitlement and social status:** As per the data, the participants commonly used words like satisfaction, self-worth, self-confidence, happiness, recognition, and respect while explaining what the role meant to them. The TBCHWs associated their work with a great sense of achievement, and they felt that they received respect not only from the community but also from the doctors and other health staff at the facilities. Further, in certain instances, TBCHWs, as TB survivors themselves, successfully combated stigma and discrimination, and emerging as post-recovery examples.

"I have just completed SSLC, curing even one patient gives us a sense of self-worth and value within society". (Female, 27 years, TBCHW, Bangalore, Karnataka)

"At first, I did not get any recognition, especially from people those who still perceive tuberculosis as a stigma. I emphasize to them that I, too was once a TB patient. When I had TB, I didn't get the respect. As a TB champion health worker, I have earned respect and attention from everyone, including doctors, health staff all". (Female, 30 years, TBCHW, Hyderabad, Telangana)

- **Theme 2- Perceived and experienced satisfaction:** The TBCHW believed that they made a significant impact in changing the perspectives and behaviours of both PwTB and their caregivers about TB. Moreover, the TBCHWs have a sense of pride for being able to contribute to the journey of PwTBs and positively influencing behaviours. According to them, they were successful in enabling PwTBs, caregivers and families to combat stigma associated with TB.

"I feel good and proud of myself for working as a TBCHW. Many of the individuals were hesitant to access health care. Due to my suggestion, few people accessed health care and availed treatment. Some of them who feel it as a stigma, after attending CSG

meetings, understood that it is very common and nothing to be stigmatized and it is fine to share experiences about TB and how they feel being TB positive with other persons in CSG meetings. I could also change the mindset of the PwTB family. Few felt it was harmful and isolated themselves at the house instead of getting treated. As a TBCHW, I was able to get a few of them for diagnosis. Witnessing this shift in mindset gives me hope that in coming years, more people will receive timely treatment. Hopefully we will eradicate TB.” (Female, 30 years, TBCHW, Hyderabad, Telangana)

- **Theme 3- Source of self-motivation:** The fact that TBCHW themselves and even some of their family members had undergone TB treatment and faced discrimination in community, they felt especially motivated to contribute towards the community and it was easier for them to relate to this work.

“As both me and my brother was infected with TB and we both faced stigma and discrimination. This personal experience motivated me to work on breaking these negative thought processes and making a positive interest to work as a TBCHW” (Male, 26 years TBCHW, Baksa, Assam)

“As the government has targeted to eliminate TB, and as myself was TB patient, I felt I should work at village level and contribute to the goal of the government’s TB elimination.” (Male, 39 years, TBCHW, Baksa, Assam)

“I saw it in my own family, and I got cured. My neighbours started talking to me after I was cured. They abandoned me when I tested positive, and two of my family members died because they didn’t take it seriously and didn’t take proper medication. This motivated me, I thought I should do something to eradicate TB. Only because of this, I became TBCHW”. (Female, 38 years, TBCHW, Hyderabad, Telangana)

“I think that, whether I get money or not if a patient gets cured with my little effort then if the person ever meets me in the future and says because of you I got a new life due to your effort today I am here. That is enough for me”. (Male, 48 years, TBCHW, West Champaran, Bihar)

3.6.5 Insights on limitations and barriers in using TBCHW

- **Lack of incentives:** The TBCHWs say they are satisfied with the work they are doing; however, they seek better incentives to carry on the work.

“The government provides incentives for our work, but the amount is quite minimal. Since we use our own vehicles for transportation, we believe the incentive amount should be increased”. (Male, 45 years, TBCHW, Bangalore, Karnataka)

“it is very good work. Payment should be increase for Champions” (Male, 24 years, TBCHW, West Champaran).

- **Difficulty in balancing multiple roles:** As it is not a full-time job, many TBCHWs had reported that it becomes somewhat difficult for them to balance their role as TBCHWs with other professional and personal commitments.

"As a student, I need to attend college and classes, which doesn't allow me to dedicate full time to this work. I'm managing both responsibilities by creating a scheduled meeting a patient and attending a meeting on the same day. Balancing my college commitments with TBHW work can be challenging". (Female, 21 years, TBCHW, Bangalore, Karnataka)

- **Community resistance and stigma:** According to TBCHW the stigma associated with remains high in the community, especially concerning unmarried young people, often hinders the level of acceptance towards the services provided by the TBCHWs among people

"But there is still fear in the minds of some people. People feel ashamed to tell others about it. If any unmarried, newly married girl or boy, or unwell individuals who experience TB symptoms, they hesitate to share it. They think that if others find it, then it might lead to the postponement or cancellation of their marriage. Whenever I understand about such cases, I visit their home and reassure them, that there is no need to fear or to be ashamed of this disease" (Male, 48 years, TBCHW, West Champaran, Bihar)

"I received information about a patient with this disease. She was an unmarried girl, and when I went to meet her mother to refer her to the appropriate hospital. she became very angry and started scolding me. She wanted to hide the disease, fearing it might create problems for her daughter's marriage in future" (Male, 24 years, TBCHW, West Champaran, Bihar).

According to a few TBCHWs, despite their efforts to encourage people to get tested, they tend to ignore their advice.

"Nowadays, people have become increasingly careless about getting tested, often don't pay attention even when we offer advise". (Female, 38 years, TBCHW, Bangalore, Karnataka)

"Some people have a negative attitude towards TB, and when we contact them, they scold us". (Male, 60 years, TBCHW, Koppal, Karnataka)

- **Lack of trust and acceptance as health worker by the community in initial stages:** Although there were several benefits associated with the solution, TBCHWs from the migrant vulnerable group mentioned that there was initially less acceptance in the community. Nevertheless, with repeated visits and interactions, persons with TB gradually started approaching TBCHW for different purposes.

"Earlier when we visited for this work then those who are un educated were thinking that, he perhaps joined some organization and getting money for the work he is doing like this". (Male, 48 Years, TBCHW, West Champaran, Bihar)

"Initially, community members did not accept me. While some of them trusted me, others faced restriction from their families in accessing health services. I went to motivate their family members, managing to convenience some of them. However, for some, still see this as stigma...some viewed TBCHWs as a government initiative and did not trust." (Female, 30 years, TBCHW, Hyderabad, Telangana)

"Initially, many patients used to scold us. Unfortunately, a majority of the patients were heavy drinkers. During house visits, some would even be intoxicated and direct their anger towards us". (Female, 24 years, Koppal, Karnataka)

- **Demotivating negative experiences:** Even though they are identified as TBCHWs, a few participants mentioned their inability to perform their designated role. It was also observed that TBCHWs, at times, feel that despite their contributions, there is considerable mortality among persons with TB.

"One patient passed away because he didn't take medicines regularly. He got infected three times and was an alcoholic. Despite my efforts, including providing food from my home, he didn't heed my advice and eventually changed". (Female, 34 years, TBCHW, Koppal, Karnataka)

3.6.5 Opportunities for further improvement

1. we are working here with limitation we are a few persons here, so we have to reached all of their home .so my suggestion is that number of TBCHW has to be increases, so that we able to cover 'whole area quickly... it may be through Asha, AWW, PRI members etc.
2. it is very good work. Payment should be increase for champions.
3. "having and ID would help to work better as sometimes we face issue in identifying ourselves

3.6.6 Summary

The study identified that the contribution of TBCHW in creating awareness, and case-finding efforts, including screening, referrals for testing, was acknowledged and deemed significant. Secondly, TBCHWs functioning as health workers served as a great source of motivation for the PwTB and their families, as well as the larger community. TBCHWs emphasized their capacity to alleviate stigma, discrimination, and ensure

treatment adherence within community. They highlighted the potential to leverage their own experiences during the TB treatment journey. There are instances TBCHWs are unaware whether their efforts have led to referrals. However, they are confident in their contribution towards motivation and wellbeing of PwTB. The solution and its evaluation provided valuable insights into the challenges faced by TB champions while performing their tasks. TBCHWs highlighted key barriers, including -community resistance, lack of incentives, work burden, and demotivating experiences. Which needs to be addressed to mainstream the role of TBCHWs in programme settings in a sustainable way.

3.7 BCS 7 - PHONE-A-FRIEND

3.7.1 What is phone-a-friend?

- It is a telephonic call system for on-demand counseling and consulting
- Tackling emotional, social and medical issues.
- Enables persons with TB who are worried about being stigmatized to independently access counseling services.
- Addresses the barriers of accessibility of health care services, and the need for confidentiality among persons with TB.

Objective:

The solution is intended to provide a trusted and friendly relationship tie for the PwTB with whom they could timely reach out via phone for any emotional, social, and treatment related support without hesitation.



PHONE-A-FRIEND: A SNAPSHOT OF FINDINGS

Strengths & feasibility

- Treatment information support
- Psychosocial support and motivation

Limitations

- Issues with relatability
- Lack of clarity on who PwTB speak with
- Higher turnaround time
- Lack of felt need

3.7.2 What did stakeholders understand about the solution? - Knowledge about the solution and source of information

The users of the solution mentioned that during the monthly CSG meetings held at the hospital, they received information about phone a friend from health staff, doctors at the facility, ASHA workers, and some users through KHPT staff. Users mentioned that they had the option to give a missed call to a helpline number if they experienced any symptoms or side effects after taking medicines or if they had any questions or doubts about their treatment. The helpline would then call them back and address their concerns and queries.

3.7.3 The usefulness and feasibility of Phone-a-friend

3.7.3.1 Person centered user experiences

The following thematic insights emerged from the PwTBs who utilised this intervention mainly in terms of treatment information support and psychosocial support and motivation

- **Theme 1 – Treatment information support:** The data reveals that users primarily sought information on maintaining a nutritious diet, along with guidance on managing the side-effects of TB medication. Users mentioned that counsellors were polite and responded with patience.

"Yes, they were highly informative and always advised not to worry about the situation. By taking medicines regularly, I can recover. With this encouragement, I am able to tackle all the problems; previously, I was unable to work. Now I go to my workplace every day, even if I do not have much work. I go to my workplace to engage in casual conversation with others to feel normal". (Male, 41 years, User, Hyderabad, Telangana)

- **Theme 2- Psychosocial support and motivation:** Users pointed out that Phone-a-friend offered the psychosocial support they needed, which they could not get from their families. The assurance of confidentiality and the option to remain anonymous gave users with a sense of comfort. The call back service not only provided emotional comfort to some users but also made them feel that someone cares for them.

"They made me feel comfortable, and I felt free to talk openly with them. There are many issues related to this (TB) that we cannot discuss with anyone else, so I found it comfortable to speak with them. Even though they are unknown to me, they would listen to me politely." (Male, 21 years, Hyderabad, Telangana)

"I gave a missed call once, and they promptly returned the call. Just two days ago, they contacted me, inquiring about the status of my treatment and whether I am still taking my medications." (Male, 32 years, User, Koppal, Karnataka)

Phone-a-friend also played a crucial role in boosting the confidence, emphasizing that TB can be cured, and there is life beyond the challenges posed by TB.

3.7.4 Insights on limitations and barriers in using phone-a-friend

- **Issues with relatability:** From the data, it was clear that the term “phone-a-friend” was not easily remembered or understood. According to the users, it was difficult to relate to the name of the solution.
- **Lack of clarity on who PwTB speak with:** There was a lack of clarity on the utilization of the solution. The phone-a-friend solution was often confused with calls made by the KHPT programme team and/or health facility staff. As information and support are already being provided by ASHA/KHPT/TBHV, there was limited perceived need to contact Phone-a-friend. Additionally, there were instances where a family member initiated a missed call, and the user, upon receiving the call back, was uncertain about the reason for the call.

“The first time my daughter was talked over the phone because I went to Betiah that time. They received the call- back stating that it is a call from TB centre” (Female, 45 years, User, West Champaran, Bihar)

- **Higher turnaround time:** Users reported that the timely response was a constraint in the use of the solution. The gap between giving a missed call and receiving the call back reduced the sense of urgency and the need to engage in conversation. The users frequently reported the need for immediate response to the missed call.

“The community coordinator provided me with the number and instructed me to give a missed call. I followed the instruction, and I received a call back after four or five days. Locally, I refer to it as ‘Karnataka wala phone.” (Male, 19 years, West Champaran, Bihar)

“They returned the call two days after I had given a missed call”. (Female, 28 years, User, Koppal, Karnataka)

- **Lack of felt need:** Some of the users did not feel the need for using the solution.

“Initially, I was not aware of phone-a-friend. During my hospital visit, I communicated with them over the phone, but I didn’t initiate the call myself as I didn’t feel the need to use it.” (Male, 67 years, User, Bangalore, Karnataka)

“I didn’t call them; they were the ones who called me. Since I work in the field, I seldom have the time to initiate calls. Furthermore, I haven’t considered reaching out to them again as I currently feel normal”. (Male, 50 years, User, Bangalore, Karnataka)

3.7.5 Summary

While the solution was able to provide some positive support for the patients, still the challenges and issues faced by the patients were considerable. The urgency or the immediate needs with which the calls were made were not timely responded to and thus led to dissatisfaction among the users. Even amongst the users who found phone-a-friend useful, there was hesitation to encourage others to use the solution due to disclosure stigma. Owing to the stigma associated with TB, users were hesitant to encourage others to use the service. The fear of potential discrimination if others discover they have/had TB influenced their decision to not to talk about the solution with others. Overall, there was a mixed response towards the benefits of the solution, with some citing it as useful and others expressing the opposite view.

3.8 BCS 8 - TB SOOCHANA

3.8.1 What is TB Soochana?

- It is a set of TB jingles played at public places to generate awareness of TB among a large number of people at one go.
- TB Soochana is intended to encourage appropriate behaviors amongst people towards TB.
- TB Soochana helps in combating stigma around TB, making TB seem like a conquerable disease and in generating awareness around TB disease.

Objectives

The solution is intended towards creating awareness and literacy about TB through targeted community outreach interventions involving novel modes of information designs.

TB SOOCHANA: A SNAPSHOT OF FINDINGS

Strengths & feasibility	Limitations
<ul style="list-style-type: none"> • Consistent and intensive information about TB • Improved TB awareness • Improved health seeking behaviour • Stigma mitigation 	<ul style="list-style-type: none"> • Limited reach • Information overload • Persistent stigma

3.8.2 What did the stakeholders understand about the solution?

Participants of the focus group discussion were aware about the public announcements taking place in their communities. Across the states the announcements were made mainly in the morning hours through waste collection vehicles, at public events, rallies, and in religious spaces like mosques and churches. The community members who had heard TB soochana mentioned a range of topics covered in the announcements such symptoms of TB and need for test, free treatment availability at the government hospitals, importance of immediate treatment seeking, cough hygiene, and importance of cleanliness. It was mentioned that the timing of the announcement was community

specific. For instance, in Kamrup, Assam announcements happened in the mid-morning time by auto and 1-2 times a month. Whereas, in tea-garden it happened during the late afternoon when tea-garden work ends and workers go back home.

3.8.3 Usefulness and feasibility of the solution

- **Theme 1 - Consistent and intensive information about TB:** Participants in the group mentioned that through TB Soochana, they received information about TB symptoms, diagnosis, and details of testing and treatment, including information about the duration and place of the treatment. They also reported that while this information is not new to them, it is now more recurrent. Additionally, some of the participants mentioned that recently they have been receiving information through waste collection vehicles.

"Yes, we have had knowledge about this disease for 20 years. But, nowadays, we hear these announcements more frequently in the past, we used to come across message related to TB on TV and in some movies" (Community member, FGD, Ballari, Karnataka)

- **Theme 2 – Improved TB awareness:** The participants mentioned that knowledge about TB in the community has increased. They also acknowledged the challenge of reaching every household door-to-door for spreading awareness. Alternate methods, such as the current approach could effectively reach a wider geographic area and enhance awareness. This could ultimately create a stigma free environment for PwTBs.

"Through TB Soochana, people have gained a deeper understanding of TB symptoms. Previously, they did not focus much on their health, but now they show increased interest. If they find any health issues, they promptly reach out to ASHA for clarification. People know that if a PwTB regularly takes medicines for 6 months, he is no longer infectious. Misconceptions have been disappeared, and now the community treats PwTB as normal, mingling them into the community". (Community member, FGD, Mahabubabad, Telangana)

- **Theme 3 - Improved health seeking behaviour:** Narratives also indicate that when TB soochana was comprehended, persons with symptoms prompted to seek testing on their own initiative. There is a belief that regular announcements can make people to contemplate and not ignore their symptoms. Participants shared examples of individuals being motivated to undergo TB tests when experiencing symptoms.

"After hearing TB Soochana, our neighbor Lakshmi and another woman, both exhibiting symptoms, independently visited the government hospital and underwent testing, but the results came back negative" (Community member, FGD, Ballari, Karnataka)

- **Theme 4 – Stigma mitigation:** According to the respondents the TB Soochana as a targeted awareness campaign exercise has helped in addressing stigma and improving access to healthcare services. People are coming forward to get themselves tested. The recurrent TB announcements have helped people overcome fear and they have been able to move beyond preconceived notions of TB and are now more open to avail services.

"A greater understanding is established among people through this TB Soochana, now they are aware of TB symptoms, previously they did not focus much on their health but now they are showing interest, if they are finding any health issues they immediately come in contact with ASHA to find out what it is. People know that if a PwTB takes medicines for 6 months he is no more infectious, they have overcome all their misconceptions and now treating PwTB as normal, they are including PwTB in the community". (Community member, FGD, Mahabubabad, Telangana)

"Now, when a person experiences symptom, they proactively approach ASHA before the situation escalates, seeking guidance on what steps to take. There is a growing trend among people getting tested, and the community has become more compassionate, refraining from discriminating against PwTB. There is general understanding that a person, upon undergoing a 6-month medication course, can recover from TB." (Community, FGD, Koppal, Karnataka)

"In the past, there was a practice of using separate glass and utensils, but attitudes have changed, and now there is willingness to engage in conversations with and visit the homes of TB patients". (Community, FGD, Soochana, Koppal, Karnataka)

3.8.4 Insights on limitations and barriers in using TB soochana

- **Limited reach:** In geographies with vulnerable populations, where most of the people dependent on agriculture, people typically go to work early in the morning. Many have reported that they were unaware of the announcement. Furthermore, those who have heard the announcement tend not to share the information with those who have miss it.

"It would be more beneficial if the announcement is made in Bhojpuri language Older people, who may not be highly educated, often rely on their children for assistance in understanding the messages., However, if the information is announced in Bhojpuri language, it ensures that everyone, regardless of education level and age, can understand it equally". (Community, FGD, West Champaran, Bihar)

"Some people who gone for agricultural work don't hear about it and even the family members who listen to it don't share this information with others". (Community, FGD, Koppal, Karnataka)

- **Information overload:** TB is among the announcements made alongside other announcements pertaining to waste segregation and disposal, making it not always easily obvious to listeners.

"Along with information about TB, information about keeping the surroundings clean, segregating waste, minimizing plastic usage, and refraining from spitting outdoors is also shared in the garbage collection vehicle." (Community member, FGD, Koppal, Karnataka)

- **Persistent stigma:** Despite consistent messaging people who get tested do not share their status with others, there is stigma regarding disclosure.

"It is noticeable when a person with TB arrives, people did not allow them into their house, people would ask them to stand outside, in his house he was asked to use separate utensils and remain isolated. But now if a person is having symptoms, before it gets worse he comes to ASHA and ask what he should do? He goes for testing and people are now more sensitive, they are not discriminating PwTB. They have understood that if a person takes medication for 6 months, he will recover from it". (Community member, FGD, Mahabubabad, Telangana)

3.8.5 Opportunities for further improvement

To ensure broader outreach, TB Soochana should continue with increased frequency, delivered in local and relatable language to effectively reach all concerned communities, in addition to the general population

3.8.6 Summary

While TB awareness interventions have been widely implemented by NTEP programme since decades, the present behaviour change solution a simple way of imparting the same with additional benefits. The data indicates that TB soochana has resulted in improved health-seeking behaviour due to the targeted, consistent and intensive way with which TB awareness was imparted to the community. The intervention was also able to percolate within the community due to the unconventional mode of communication it had adopted. Importantly, the data shows that repeated and consistent messaging on TB has probably alleviated the community resistance and stigma towards TB. Community enacted stigma towards TB has remained as a structural challenge for the TB programme to address so far in any country. But this simple solution has shown a visible impact in decreasing this form of stigma leading to community acceptance towards TB and subsequent behaviour change which deserves importance.

The participants' understanding of TB Soochana was not limited only to the jingles. They also considered the awareness programmemes that were conducted in the community.

These awareness programmes, including house-to-house surveys, gram sabha, mahila sabha meetings, led by community structures also had TB champions participate and speak to the larger community about TB symptoms, diagnosis, treatment and availability of treatment facilities.

TB Soochana has been able to create awareness, and it has shown propensity to positively impact the community and there has been a shift in the community's perception about TB. The community on its own now approaches a health worker (ASHA) in case a person notices any TB symptoms. Such a shift in attitude also demonstrates a growing understanding of the importance of health care within the community, and resultantly leading in improved health-seeking behaviour. Further, with TB Soochana being a targeted awareness campaign that is customized in some cases according to the schedule of the local community, it has helped in addressing stigma, and people are coming forward to get themselves tested. Given that announcements or TB Soochana have been made using existing public platforms such as waste collection vehicles, religious institutions, etc. it is a feasible solution that can be implemented in partnership with other government and non-government stakeholders with similar interests.

3.9 BCS 9 - SHARING CIRCLE

3.9.1 What is sharing circle?

- It is primarily for health workers, it has a set of 10 cards, that act as triggers for the health workers to initiate discussion and share their experiences.
- It creates a space for frontline health workers to bond, share and learn from each other's experiences and seek support from their colleagues.
- Addresses the barriers of feeling unsupported and overburdened.

Objective: The solution aims to create opportunities for the frontline health workers (ASHA) of PwTB to share their knowledge, experiences, challenges and issues in a safe and supportive environment and to nurture a positive attitude and works resilience.



SHARING CIRCLE: A SNAPSHOT OF FINDINGS

Strengths & feasibility

- Sharing and learning platform
- Relationship building and motivation
- Improved work performance and adaptation to challenges

Limitations

- Lack of incentives and motivation
- Sustainability of the intervention

3.9.2 What did stakeholders understand about the solution?

All the frontline users who were part of the sharing circle exercise are aware of the initiative, and reported that the meeting is conducted every month, either in the Anganwadi centre, or in the primary health centres (PHCs). The users have been part of this exercise ranging from three months to two years.

3.9.3 Usefulness and feasibility of the solution

Analysis of user experience revealed the following themes:

- **Theme 1 - Sharing and learning platform:** ASHAs expressed that the sharing circles were a useful initiative, providing them with much-needed space to learn new strategies from each other. This learning extended beyond TB and related services, encompassing personal development such as learning soft skills like empathy, building trust, and actively listening to the people while understanding their challenges. During these meetings, they openly discuss not only work-related matters but also aspects of their personal lives. This serves as a safe space where they can both seek and provide moral support to each other.

“First of all, we do not have an idea on how to talk to people. However, when we gather in a sharing circle, we engage in discussion about everyone’s job, so that we get new ideas and insights. These meetings leave us with a renewed sense of motivation”. (ASHA, FGD, Hyderabad, Telangana)

“ This was very useful to us, we were able to learn valuable insights that are enhancing our ability to fulfil our responsibilities more effectively. In the sharing circle, we have the opportunity to discuss various topics and more aware of TB, current government health benefit schemes, and learn strategies on initiating conversation as ASHA workers with patients to build trust. Additionally, we receive tips on educating people with no knowledge about specific schemes and encouraging their utilization.” (ASHA, FGD, Hyderabad, Telangana)

- **Theme 2 – Relationship building and motivation:** According to all the ASHA workers, the sharing circle meetings are motivational. Some ASHAs also expressed hesitation about sharing their own problems on other platforms, whereas this sharing circle gives them with an opportunity to be open and encourages them, thereby boosting their confidence.

“We discuss many topics that we might not share with our families. Topics would be about being cautious, being happy or being encouraged” (ASHA, FGD, Bangalore, Karnataka)

“Initially, I used to think that I was alone in facing challenges. But, when I attend the sharing circle meeting, I listen to others and realize that we all have our own problems. Understanding that everyone goes through difficulties gives me with a sense of support and encouragement to keep moving forward”. (ASHAs, FGD, Hyderabad, Telangana)

It was also mentioned that the sharing circle strengthens the relationship between the ASHAs.

"This platform is very helpful for sharing both our challenges and successes, supported by relevant examples. Generally, we hesitate to express our own problems, but this platform encourages openness and has also contributed to strengthening our relationships with other ASHA workers". (ASHA, FGD, Koppal, Karnataka)

- **Theme 3 – Improved work performance and adaptation to challenges:** Most of the frontline workers (ASHAs) expressed that the topics discussed during the meetings are helpful to them for effectively handling the tasks related to TB. They share their field experiences, including both successful and unsuccessful case stories, discuss strategies for ensuring treatment adherence and completion of treatment for PwTB, and highlight the challenges they encounter.

"During the meetings, we discuss our field experiences, including both successful and unsuccessful TB cases, and share insights into our approaches" (ASHA, FGD, Ballari, Karnataka)

ASHA workers further mentioned that, post the meetings the ASHA workers say they have become more adept at responding to PwTBs.

"It was helpful for us when someone shared a success story of completing TB treatment. We would adopt their approach to treating patients in our area. And there was a noticeable difference before and after the introduction of the sharing circle. We gained insight into the challenges and obstacles faced while treating TB. This helped us support each other and increase our confidence" (ASHA, FGD, Ballari, Karnataka)

3.9.4 Insights on limitations and barriers in using sharing circle

- **Lack of incentives and motivation:** In spite of sharing circles, they feel their efforts are not adequately recognized by the government, despite their substantial work on the ground.

"I strongly believe that ASHA workers lack recognition from the government; nobody seems to care if something happens to us. While there is a constant expectation for ASHAs to work at the ground level during elections and health campaigns, our efforts go unrecognized". (ASHA, FGD, Hyderabad, Telangana)

- **Sustainability of the intervention:** The ASHAs pointed out that KHPT supports in conducting the sharing circle. However, in the absence of project staff and incentives, the continuity of sharing circles becomes uncertain.

"We are not getting any incentives for this, so there should be a provision to give incentives in order to participate with more motivation. Providing, some refreshments would be beneficial...KHPT is helping in organizing these meetings". (ASHA, FGD, West Champaran, Bihar)

3.9.5 Opportunities for further improvement

- According to the ASHA workers every village should have a sharing circle, as it will enable them to talk about common concerns and work out ways to address these concerns in a consensual manner.
- ASHAs reported that sharing circle meetings should be continued and extended to the community level
- They mention that the meetings should be incentivized.

3.9.6 Summary

Insights from this qualitative analysis highlighted that the intervention was able to create a conducive safe environment for ASHA workers to share their work experiences, facilitating mutual learning, strengthening relationships, and fostering personal motivation. It was evident that the respondents experienced improved work performance in delivering services to patients, ensuring treatment adherence and completion of treatment. The findings underscored the importance of providing the frontline health workers with a regular space and platform for experience sharing during their work routine, as this has the potential to improve their knowledge, work satisfaction and improved service delivery.

4. DISCUSSION

The present study explored the feasibility of the nine behaviour change solutions (health auto, jaanch coupon, TB soochana, starter kit, TB buddy, phone a friend, TB mukt certificate, TBC health worker and sharing circle) which were being implemented as part of the project's community engagement approach, in four states viz. Karnataka, Telangana, Bihar and Assam amongst specific vulnerable population groups – urban vulnerable, tea-garden workers, tribals, migrants, mining & mining related industry workers and industrial workers. The study has explored the role that these set of solutions can play in improving awareness on TB and related services, TB case finding, treatment adherence and stigma associated with tuberculosis which altogether lead to improved treatment seeking behaviour amongst the vulnerable groups. There is evidence suggesting that TB treatment outcomes can be efficiently improved by use of adherence specific interventions such as patient education and counselling, incentives and enablers, psychological interventions, reminders and tracers, and digital health technologies (Alipanah et.al. 2018). Social and behaviour change (SBC) communication strategies and interventions have been used widely in the fields of HIV/AIDS, family planning etc. to promote positive health behaviour and outcomes (Snyder et.al, 2004; LaCroix et.al. 2024; Vermund et.al.,

2017). Although literatures suggest that, use of SBCC in TB has been increasing specially to deal with treatment delays (Luis et.al. 2011; Bello et.al., 2019), there is little evidence especially in Indian context. Here lies the strength of the present study which explored the efficiency and feasibility of behaviour change solutions to contribute to the national TB elimination programme.

Results from the present study indicated that while some of the solutions like health auto, jaanch coupon, TB soochana, starter kit, TB mukt certificate and TBC health worker were able to serve the desired roles, in some cases inadequate understanding of the users regarding the purpose of the solutions, lack of felt need and overlap with existing services limited the fulfilment of the intended objective, especially for phone-a-friend, TB buddy, and sharing circle. Overall findings suggest that from implementation perspective, we need to keep in mind the unique socio-cultural contexts of the vulnerable groups and the solutions need to be based on their specific requirements, especially from health point of view.

4.1 Creating awareness: This analysis looks at awareness as dissemination of information on TB symptoms, diagnosis, treatment and side-effects at the community and at the individual levels (PwTB and their families). Findings underscored that solutions namely TB soochana, Jaanch Coupon generated awareness at the community level. TB soochana was aimed to create mass awareness, the TB and treatment related information imparted during the distribution of jaanch coupon by the community structure members helped people become increasingly informed about the disease. While TB Soochana directly created awareness through the public announcements, reaching out to the masses at once. Solutions such as – health auto, jaanch coupon and phone-a-friend indirectly contributed to TB awareness generation though that was not the intended objective. TBCHW, and health auto created awareness at an individual level, as for these three solutions, interaction with the users were mainly one to one, where PwTBs and their immediate family member, friends or caregivers were informed of their dietary choices, side effects of medication, and emotional well-being.

4.2 Facilitating notification: It was found that Three of the solutions namely health auto, Jaanch coupon, and TB Champion health worker contributed directly to TB case notification across the intervention geographies. Jaanch coupon nudged symptomatic persons to get tested immediately, and thus indicated the possibility of reduced diagnostic delay. As informed of the free of cost test facility, it can substantially reduce out of pocket expenditure and motivate people to take timely decision for undergoing test for TB. In turn the uptake of treatment services also improved. On the other hand, health-auto addressed the accessibility barrier successfully by ferrying presumptive people or sputum samples to the facilities for timely testing. Stakeholder accounts suggested that health auto made testing facilities more affordable, especially for the most vulnerable social groups such as

women, unemployed people, persons with disabilities, elderly etc. and reduced their dependence. Subsequently, the auto service addressed the gap in health service outreach and motivated communities, which in turn is believed to have contributed to increased test and case identification. Furthermore, TBC health workers supported door-to-door screening and referrals of symptomatic persons, supporting them to get tested through various community outreach activities.

4.3 Supporting treatment adherence: Findings revealed that starter kit, TB mukt certificate, TBC health worker, and health auto, played a key role in supporting treatment adherence across intervention geographies. TB starter kit was able to ensure uninterrupted medication, with reduced defaulter rate. It had enhanced motivation for treatment uptake among persons with TB and reduced the burden on caregivers and health care providers to track the PwTBs during treatment. On the other hand, TB mukt certificate motivated PwTBs to complete treatment and ensured improved acceptance at different levels like family, community, workplace, and educational institutions. In turn this had created a sense of achievement and satisfaction among the PwTBs for fighting a disease like TB. There were a few solutions like Phone-a-friend and TB Buddy which were found to be effective in specific geographies like Telangana for supporting treatment adherence, wherein trained counselors or a person selected by the PwTB provide support during treatment phase.

4.4 Addressing TB related stigma: The solutions were designed to address a critical element of alleviating social stigma related to TB disease. The most important of them all was TB mukt certificate which by the virtue of being issued by competent authorities addressed social stigma/discrimination and motivated people on TB treatment not to be afraid and complete their treatment. The fact that TB mukt certificate was a physical proof of treatment completion, it was universally accepted at schools, colleges and by employers which helped people get back to their social life. TB champion health workers, being TB survivors themselves, significantly impacted the communities by helping reduce their fear, prejudices regarding TB. The PwTBs and their family could easily relate to the TBCHWs and connect with them efficiently. Similarly, TB buddies, to some extent, with their compassionate approach helped the PwTBs navigate the challenges of treatment journey and alleviated the burden of fear & stigma. On the other hand, while TB soochana was intended to address social stigma, it did so partially. The health auto solution faced a backlash from the community. People were reluctant to use an auto that ferried presumptive persons, for fear of being infected. The health auto drivers themselves were scared of being identified as an auto that catered to PwTBs. These solutions were unable to help PwTBs overcome the challenge of disclosure stigma.

4.5 Sharing circles: While other solutions were mainly focused on the demand generation, sharing circle targeted the frontline health workers i.e. ASHAs, to address the supply side of healthcare and enhance outreach services. As part of strengthening ANC through community intervention programme, a similar model was piloted in the state of Karnataka during 2011-2014, viz. the concept three sisters' model where all three pillars of frontline health workers i.e. ASHA, ANM and Anganwadi workers at the sub-center level, utilized a platform called Arogya mantappa, once in a month to review their progress through a series of various other peer group activities. This purpose was to address their challenges and provide support for personal development. This model was successfully scaled up by the central government (KHPT, 2014). The solution brought together all ASHA workers on a common platform where they learned from each other and applied the same while responding to the TB and related health needs of the community. The sharing circle also provided a safe space for the workers where they could discuss concerns; it also motivated them to deal with difficult situations. Sharing circle was accepted by ASHAs as part of their routine activities. There was voluntary involvement in the sharing circles to some extent. The solution was used extensively in Telangana, followed by Karnataka and to some extent in Bihar. However, sustainability of the solution could be affected by the expectations of incentivization by ASHAs and involvement of project staff.

4.6 Way forward: For further implementation and adaptation of the solutions, certain concerns, as emerged from the findings, need to be acknowledged and addressed. The solutions should have names that resonate with users. Solution names such as TB buddy or phone-a-friend, were not helpful in fostering a sense of familiarity and connection. Incentivizing was found to be crucial for initiatives like sharing circles and TB buddy for sustainability. Even though participation is voluntary, as it involves dedicating time, energy, and resources, there was expectation associated with the solutions. The motivation of individuals to engage and persist in solutions such health auto or TB buddy is significant, particularly considering the involvement of solution providers. Unless there is intrinsic motivation, presence of the solution would not necessarily mean involvement of the solution providers. Being embedded in the treatment-seeking ecosystem, solutions like TB buddy or phone-a-friend did not elicit a strong perceived need from users for utilization. Cost-intensive solutions like health auto could hinder their scalability and implementation on a larger scale. Apart from that, there were concerns over quality of presumptive referrals. Although it was indicated that solution such as jaanch coupon was able to improve TB case notification, there is a need to consecutively ensure quality of screening and resulting referrals for test in order to avoid load on the health facilities and resultant delays.

5. STUDY LIMITATIONS

The findings and conclusion of the study are based on users' experiences, who were purposively selected from a sample of users identified through the project. All the nine solutions were not implemented across the intervention geographies uniformly. There are also possibilities that some narratives were socially desirable responses. However, the research team took utmost care to eliminate subjectivity of any sort while analysing the data.

6. CONCLUSION

The study aimed to explore the feasibility of implementing BCS and feasibility was looked at from two dimensions. Firstly, from the users' perspective - i.e. to what extent the solutions were user friendly; secondly, in terms of acceptance by the service providers i.e. NTEP for possible scale up.

Looking at the case finding solutions, it can be concluded that health auto as a solution was feasible for the users across the intervention geographies as it rendered support in transportation during test and treatment phase. However, the same was not reflected by the service providers mainly because it was cost-intensive. On the other hand, jaanch coupon was found to be feasible both by the users and the service providers as this motivated and encouraged people to get tested on time, thus reducing the delay in diagnosis. In similar lines the users wanted TB Soochana to be continued as repeated messaging helped people to be aware of the symptoms of the disease and got themselves tested. The TB Soochana or announcements related to TB were made using existing public platforms such as waste collection vehicles, religious institutions etc. Hence it is a feasible solution that can be implemented in partnership with other government and non-government stakeholders with similar interests.

The case holding solutions - the TB mukt certificate and TB starter kit had acceptance among the users and the service providers; and NTEP expressed interest in scaling up these solutions. This holds true for TBCHWs as well. The NTEP's interest in involving TB survivors in the programme, can be leveraged as an opportunity to mainstream the TBCHW solution.

Overall, one barrier that the solutions have not been able to address adequately is that of stigma. Solutions are geared to address specific/stand-alone objectives like treatment adherence or notification. Chances of understanding the solutions could be better with relatable names.

The BTB project placed community engagement at its core, recognizing the crucial role communities play in tackling TB. By building strong connections between the community and TB services, the project aimed to empower individuals and inspire behaviour change.

BTB adopted a socio-ecological approach, targeting interventions across individual, interpersonal, community, and societal levels. This framework positioned individuals, especially persons with TB (PwTBs), at the centre, nudging them and their networks towards better aspirations. Recognizing the different barriers faced by PwTBs at the individual level such as lack of awareness, decision fatigue, lack of treatment adherence the project developed tailored behaviour change solutions. Furthermore, the BTB engaged with formal and informal community structures (CS) like savings groups, youth groups, and panchayat representatives, enhanced their understanding of TB and their roles in elimination efforts through perspective building workshops, and enabled them to use and implement the behaviour change solutions. In doing so, the BTB project demonstrated the power of collaborative action, empowerment, and community-driven solutions in tackling complex health challenges, such as TB.

COMPONENT 2:

QUANTITATIVE REPORT

PSYCHOSOCIAL ASSESSMENT STUDY

EXECUTIVE SUMMARY

Tuberculosis is a potentially serious infectious disease that mainly affects the lungs of the human beings. The bacteria that cause tuberculosis are spread from person to person through tiny droplets released into the air via coughs and sneezes (Mihimbira et al., 2017; Sathiyamoorthy et al., 2020)). Most people infected with the bacteria that cause tuberculosis do not have symptoms and when symptoms do occur, they usually include a cough (sometimes blood-tinged), weight loss, night sweats and fever (Lohiya et al., 2020; Mihimbira et al., 2017; Sathiyamoorthy et al., 2020; Thomas et al., 2015; Yasobant et al., 2021). Treatment is not always required for those without symptoms. Persons with active symptoms will require a long course of treatment involving multiple antibiotics (Lohiya et al., 2020; Mihimbira et al., 2017; Sathiyamoorthy et al., 2020; Thomas et al., 2015; Yasobant et al., 2021):

TB remains a major disease entity causing millions of deaths annually across the world, with higher rates of mortality in the developing nations like India, where the pooled prevalence has been found to be 296 individuals per lakh population. TB ranks as a deadly disease resulting in millions of deaths worldwide (Aggarwal, 2019; Sathiyamoorthy et al., 2020; Sreeramareddy et al., 2014). However, the effect of TB on the psychosocial status of patients and interventions to improve treatment outcome is neglected, especially in underdeveloped and developing countries (Samal, 2016; Sreeramareddy et al., 2014; Subbaraman et al., 2016).

Psychosocial assessment in many clinical conditions including TB has gained importance in recent years. Based on several studies, it is widely believed that psychosocial problems are evident in TB patients throughout the world (Lohiya et al., 2020; Thomas et al., 2015; Yasobant et al., 2021). Depression and Anxiety rates that contribute to psychological stress were found to be high in TB patients compared to the general population and this trend is more evident in the developing and underdeveloped nations (Chandra et al., 2019; Samal, 2016).

Psychosocial problems such as feeling anxious, sadness, irritation, anger outburst, sleep disturbance, family issues, lack of support from others have a negative impact on patients' livelihood and successful treatment completion (Lohiya et al., 2020; Thomas et al., 2015; Yasobant et al., 2021). WHO's global 'End TB Strategy' promotes "integrated, patient-centred care" (which includes 'patient support' and 'management of co-morbidities') as one of the three pillars of TB treatment (Endalamaw et al., 2022). However, its implementation is a challenge for National Tuberculosis Programmes (NTPs), particularly in low-income countries, where the focus is on the bio-medical aspects and much less attention is paid to addressing the psychosocial needs of patients. There are few studies testing psychosocial interventions for TB patients, despite the acknowledged importance of patient-centred care and psychosocial support (Krishna et al., 2019)

Summary of Key Findings

The overall data indicates that the majority (52.6%) of the sample were male and (47.4%) were females. The average age of the female participants was 32.5 years and their male counterparts were 41.6 years. From the overall socio demographic background of the participants, the vast majority (83.2%) belong to the low economic status. The participants were approximately equally distributed as rural (49.6%) and urban (50.4%) domiciles with the majority (72.3%) of the participants were married. As for literacy levels of the participants, it can be identified that a larger group had completed higher secondary education (25.54). The average duration of treatment for TB among the participants 215.6 days among females and 212.9 days among males.

The participants' overall scores indicate no signs of anxiety and depression which reflects within each states' anxiety and depression scores. A possibility of extended periods of TB treatment may have contributed to these results. The increased levels of social support may have played a vital role in the overall reduction of the levels of anxiety and depression among the participants. This could reflect on the influence of marital status, community awareness and the agency's contribution in the treatment-awareness of the participants.

2.1 BACKGROUND OF THE STUDY

KHPT is a non-profit organisation that actively contributes to the awareness, prevention, treatment and rehabilitation of health and illness. The organisation focuses on various areas of healthcare including childcare, maternal care, HIV/AIDS and TB (Home | KHPT - Engage, Innovate, Empower, n.d.). Working with various marginalised communities across India, the organisation lays emphasis on scientific approach to their community engagement with a detailed focus on research and exploration to rigorously improve the community's health. The present study falls under the scientific contribution of KHPT in their interventions to treatment, awareness and rehabilitation of patients with TB, namely, within the communities in the states of Karnataka, Telangana, Bihar and Assam.

The current project is proposed to assess the psychosocial aspects such as anxiety, depression, perceived social support, and stigma and discrimination of persons with TB, as well as impact of the behaviour change solutions implemented as part of the community project. This assessment encourages the patients and the caregivers to enhance the access to health system and treatment adherence, implemented by KHPT (Karnataka Health Promotion Trust), Bengaluru, Karnataka State, India.

The data from the community members does not entail any specific medical treatment from NIMHANS or any medical institution/ professional. Any minimal risk to their psychosocial problems was addressed on one-to-one basis and referral services were made available for those who need; was brought to the attention of the agency as well as mental health professionals of NIMHANS as and when required.

2.1.1 Research Objectives

The core objectives of the study were:

- a. To assess the psychosocial changes amongst persons with TB who received the solutions across the TB continuum of care.
- b. To assess the support network for persons with TB in the project catchment areas.

The study intended to explore the following aspects specifically:

1. The levels of Anxiety, Depression, Stigma and Discrimination of persons with TB in the catchment areas.

2. The impact of behaviour change solutions, implemented by KHPT as part of community-based programmes, on persons with TB in the project catchment areas.
3. The social support for persons with TB in the project catchment areas.
4. To provide referrals to mental healthcare services to persons with TB in the project catchment areas on need-basis.

2.2 METHODOLOGY

Research Design

The research design for the present study was descriptive research design and applied a cross-sectional approach. The participants were beneficiaries of the TB awareness initiative. Through the correlational inquiry, the relationship between TB and mental health status of the participants were evaluated.

Sampling

The sampling technique applied for the study was purposeful sampling. As participants were members of the group accessing and seeking support. The participants were provided with the measures and assisted by the investigators if any participant was illiterate. The data was collected from May, 2023 to September, 2023.

Inclusion and exclusion criteria

The following were the inclusion criteria: persons with tuberculosis who have been beneficiaries of the programme and beneficiaries within the programme implementation catchment area.

The following were the exclusion criteria of the study: persons not in conscious state or having altered sensorium, who may not be able to cooperate during the data collection. Persons with developmental disorders of severe and profound categories as diagnosed previously by a physician. Persons with speech and language issues.

Ethical considerations

Ethics approval for the present study was obtained from the NIMHANS Institute Ethics Committee (Ref. No. NIMHANS/40th IEC (BEH.SC.DIV.)/ 2023, Dated 20.03.2023). Observation and interaction with human subjects was a core component in the study. Hence, best clinical and research practices with WHO and ICMR guidelines were followed to avoid any risk of harm. Participants were briefed about the study and their voluntary participation following which Informed Consent was obtained prior to the process of data collection.

Tools for the study

1. **Socio-Demographic Data Sheet:** The socio-demographic data sheet was constructed to record the data pertaining to necessary details and medical history necessitated for analysis; which included age, gender, marital status, educational and occupational background and the duration of treatment for TB.
2. **Hamilton Anxiety Rating Scale:** The Hamilton Anxiety Rating Scale (HAM-A) was developed by Hamilton M in 1959. It is a 14-item clinician rating scale to assess the severity of anxiety in the domains of psychic and somatic anxiety. Each item is rated in a 5-point Likert, with 0 (not present) to 4 (severe). Total range is of 0-56, where 25-30 falls within the moderate-severe category. It has been widely used in India (Lanka & Anand, 2013)
3. **Hamilton Depression Rating Scale:** The Hamilton Depression Rating Scale (HDRS) was developed by Hamilton M in 1960. It is a 17-item clinician rating scale to assess the severity of anxiety in the domains of melancholic and physical symptoms. Each item is rated in a 5-point Likert, with 0 to 4 indicating specific responses. Scores above 20 fall in the moderate-severe category. It has been widely used in India (Dhiman et al., 2022).
4. **Multidimensional Scale of Perceived Social Support:** The Multidimensional Scale of Perceived Social Support (MSPSS) was developed by Zimet GD, Dahlem NW, Zimet SG and Farley GK in 1990. It is a 12 item scale and has domains of family, friends and significant others based on the sources of support. Each item is scored 0-7 between 'Very Strongly Disagree' to 'Very Strongly Agree' and summed up for total score. Higher scores in the scale indicate greater perceived social support. It is widely used in India (Subramanian et al., 2021)
5. **Stigma and Discrimination Attitude Questionnaire:** The Stigma and Discrimination Attitude Questionnaire was developed by Sagili KD, Satyanarayana S and Chadha SS in 2016. The 13 item questionnaire has been widely used as a survey tool for assessing the attitudes towards persons with tuberculosis (TB). There are two domains- stigmatising beliefs and discriminatory attitudes. Each item-response is recorded in agreement to somewhat disagree; and also Yes, No and Don't Know/ Can't Say. It has been widely used in India (Sagili et al., 2016).

2.3 RESULTS

2.3.1 Part A: Overall results from four states

The data was analysed through r-software and excel to assess the current trends within the study. The collected data was analysed on the basis of their states namely: Karnataka, Telangana, Bihar and Assam; along with an overall data analysis. The following Tables and Figures detail the results from the study.

The results of the overall sociodemographic details revealed that of the 137 participants; 52.6% (72) females and 47.4% (65) males were the final sample of the study. The average age of the females in the sample is 32.5 years and 41.6 years for males. Out of the 137 participants, 99 participants were married, 35 were single or unmarried, one divorced and one widowed participant. The majority (72.3%) of the sample were married. The majority (35) of the sample had completed higher secondary educational programmes, 33 participants were from high school educational background and 32 participants were illiterate, 19 participants were from primary school and 18 participants had a graduate school educational background.

In terms of occupational background, 40 participants were daily wage labourers or coolies; 31 participants were homemakers and 15 participants owned local small businesses, 26 participants were students and 14 were unemployed. With regards to socioeconomic status, 114 participants were lower economic background and 22 participants were from the middle economic background and one participant belonged to upper economic background. At the same time, the majority of the participants 69 were from urban areas and 68 belonged to the rural areas. Of the 65 females in the sample, the average duration of treatment for TB was identified as 215.6 days and of the 72 males, the average duration of treatment for TB is 212.8 days.

Table 1 Overall socio demographic details of the participants

Socio Demographic categories		Female (N= 65)	Males (N=72)	Total (N=137) (%)
Age (mean)		32.54	41.64	-
Marital Status	Married	40	59	99 (72.23%)
	Single	24	12	36 (26.27%)
	Widowed/divorced	1	1	2 (1.45%)

Socio Demographic categories		Female (N= 65)	Males (N=72)	Total (N= 137) (%)
Education	Illiterate	14	10	24 (17.52%)
	Primary School	6	13	19 (13.86%)
	High School	20	13	33 (24.08%)
	Higher Secondary	17	18	35 (25.54%)
	Graduate	8	10	18 (13.13%)
Occupational background	Daily wages/ coolie	10	30	40 (29.19%)
	Farmer	1	10	11 (8.03%)
	Homemaker	24	7	31 (22.62%)
	Small business	7	8	15 (10.94%)
	Student	17	9	26 (18.97%)
	unemployed	6	8	14 (10.21%)
Economic status	Low	55	59	114 (83.21%)
	Middle	10	12	22 (16.05%)
	Upper	0	1	1 (0.13%)
Domicile	Rural	26	42	68 (49.63%)
	Urban	39	30	69 (50.36%)
Avg, duration of treatment for TB	(in days)	214.35	212.7	-

Figure 1 Overall Anxiety Scores of the Respondents (N=137)

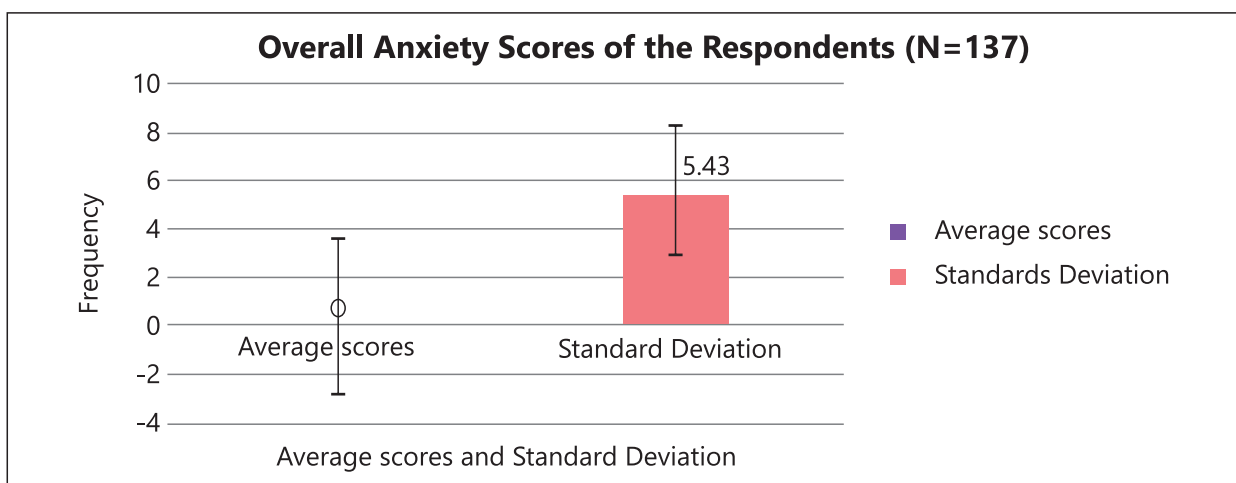


Figure 1 shows the overall total scores of the respondent's anxiety. The average scores of the participants were 0, indicating that there was no anxiety among the participants. However, the standard deviation scores 5.43 implies that less than 7 participants had high scores in anxiety.

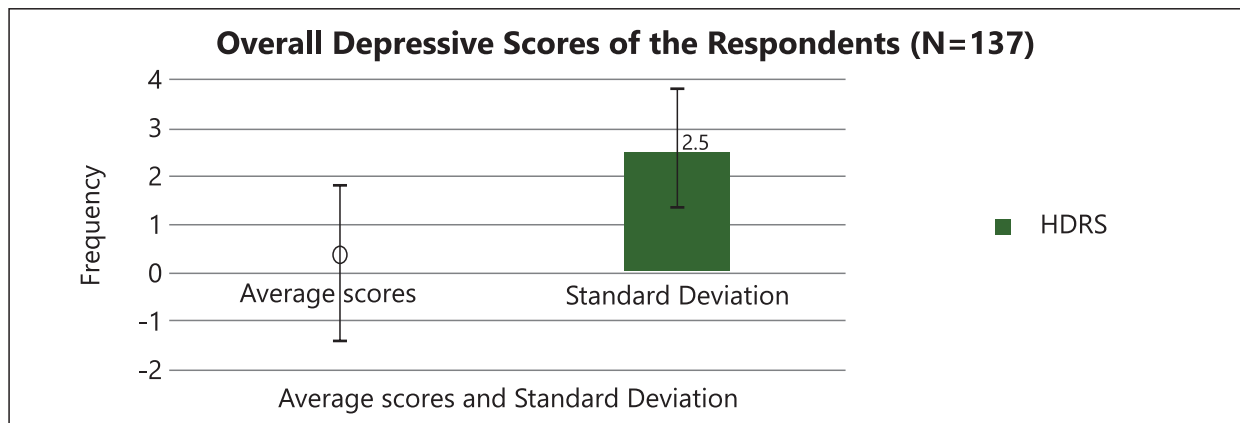
Figure 2. Overall Depressive Scores of the Respondents (N=137)

Figure 2 indicates the overall scores of the participants in depression. The average scores of the participants in depression is 0, indicating that there was no depression. However, the standard deviation scores 2.5, implies less than 4 participants have high scores in depression.

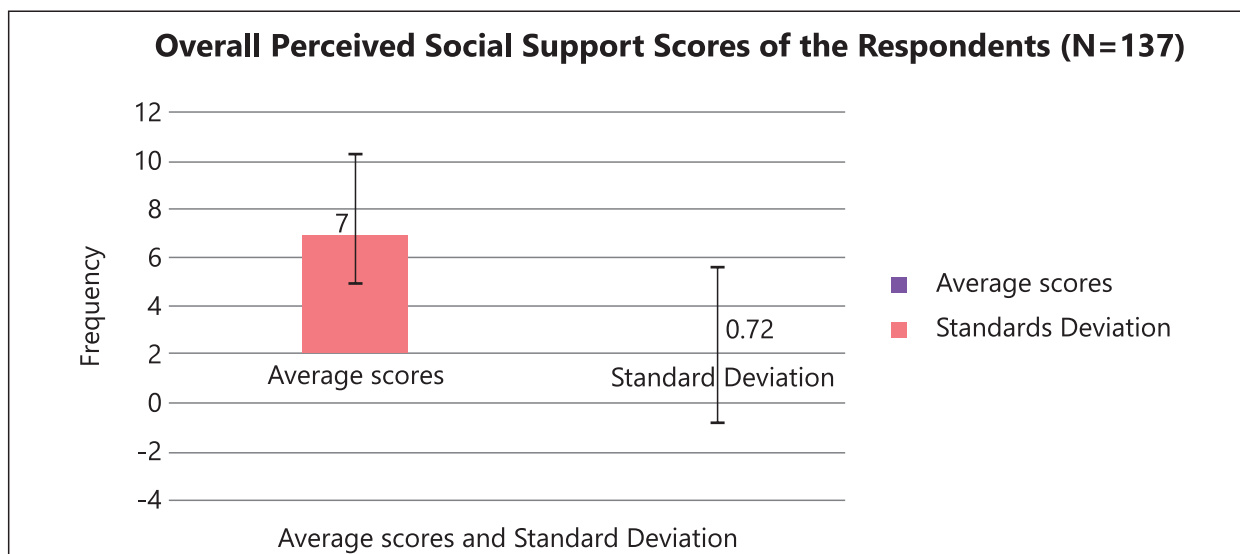
Figure 3. Overall Perceived Social Support Scores of the Respondents (N=137)

Figure 3 indicates the overall total scores of the participants in the perceived social support. The average scores of the participants are 7, indicating that there were high levels of perceived social support among the participants. However, the standard deviation scores 0.72, implies that less than 2 participants have low scores in perceived social support.

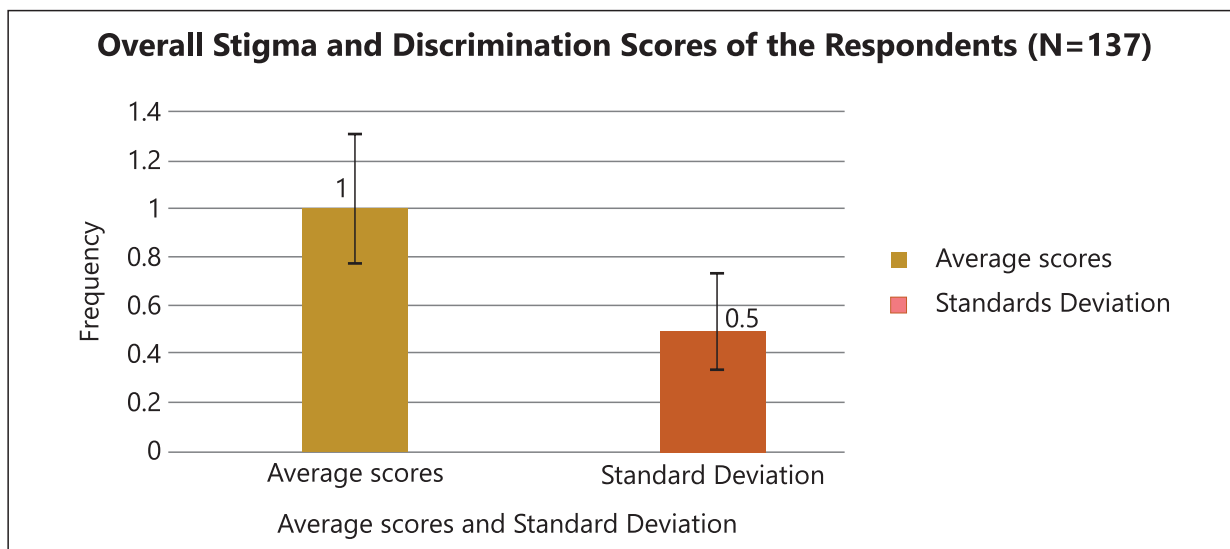
Figure 4. Overall Stigma and Discrimination Scores of the Respondents (N=137)

Figure 4 indicates the overall total scores of the participants in their stigmatising and discriminatory attitudes. The average scores of the participants in depression is 1, indicating that there were low levels of stigma and discrimination with a standard deviation of 0.5 indicating less than 2 participants have moderate scores in stigmatising and discriminatory attitudes.

2.3.2 Part B: Key findings from the States

2.3.2.1 Karnataka

The results of the sociodemographic details revealed that of the 38 participants, 19 (50%) were male and 19 (50%) were female participants in the final study. The average age of the females in the sample is 31.68 years and 40.57 years for males. With regards to marital status, 23 participants were married, 15 were single or unmarried. The majority (11) participants were from higher secondary background, 10 participants were from high school educational background and 6 participants were illiterate, 6 participants were from primary school and 5 participants had a graduate school educational background.

Occupational status of the samples reveals that of the 38 participants, the majority (13) of the participants were homemakers, 8 participants were daily wage labourers or coolies, and one participant was engaged in social services, 6 participants owned local small businesses, 10 participants were students and one was unemployed. With regards to economic status, the majority (23) of the participants were from low income backgrounds and 15 participants were middle economic status. Regarding domicile background, 33 participants resided in urban areas of Karnataka and 5 participants were from the rural area of the state. With regards to treatment duration, of the 19 females in the sample, the average duration of treatment for TB was identified as 182.63 days and of the 19 males, the average duration of treatment for TB is 164.42 days.

Table 2. Socio-Demographic details of the respondents (N=38)

Socio Demographic categories		Female (N=19)	Males (N=19)	Total (N=38)
Age (mean)		31.68	40.57	-
Marital Status	Married	10	13	23 (60.5%)
	Single	9	6	15 (39.5%)
Education	Illiterate	2	4	6 (15.8%)
	Primary School	2	4	6 (15.8%)
	High School	8	2	10 (26.3%)
	Higher Secondary	6	5	11 (28.9%)
	Graduate	1	4	5 (13.2%)
Occupational back-ground	Daily wages/ coolie	5	3	8 (21.1%)
	Homemaker	6	7	13 (34.2%)
	Small business	3	3	6 (15.8%)
	Student	5	5	10 (26.3%)
	Unemployed	0	1	1 (2.6%)
Economic status	Low	13	10	23
	Middle	6	9	15 (39.5%)
Domicile	Rural	0	5	5 (13.2%)
	Urban	19	14	33 (86.7%)
Mean duration of treatment for TB (in no. of days)		182.6	164.4	-

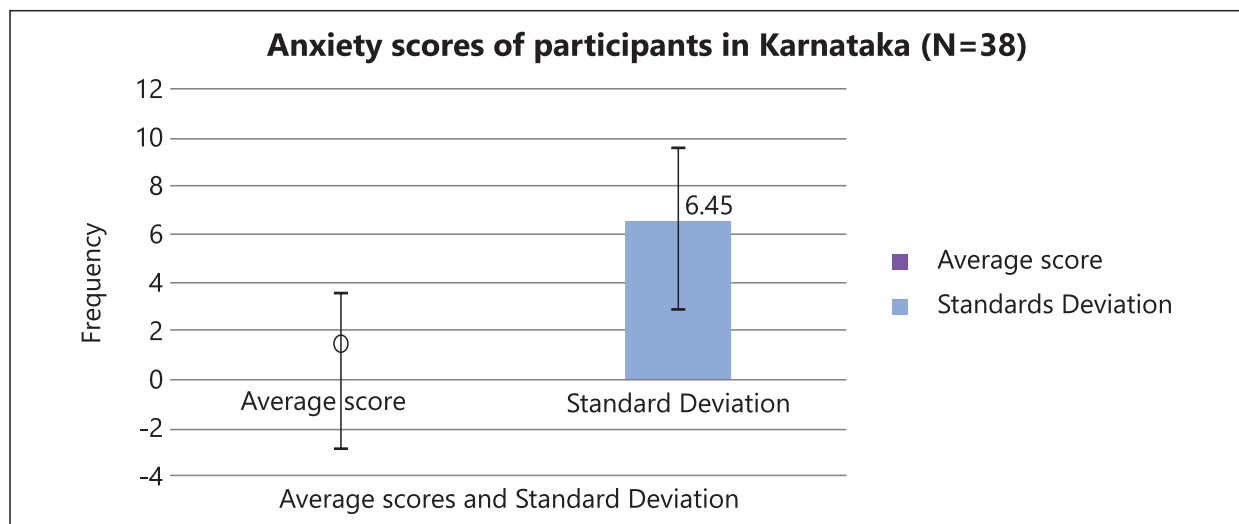
Figure 5. Anxiety scores of participants in Karnataka (N=38)

Figure 5 shows the total scores of anxiety from Karnataka. The average scores of the participants were 0, indicating that there was no anxiety among the participants. However, the standard deviation scores indicate that 6.45 implies less than 4 participants have high scores in anxiety.

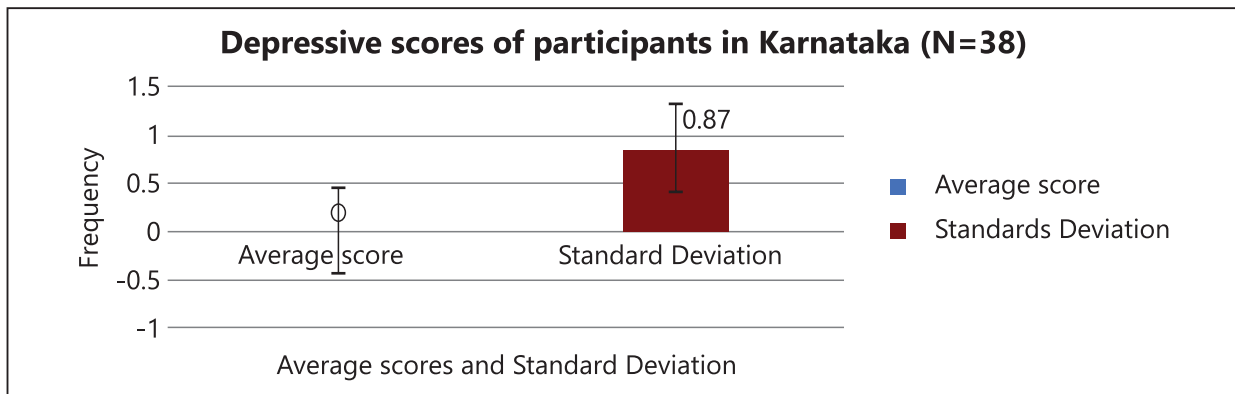
Figure 6. Depressive scores of participants in Karnataka (N=38)

Figure 6 indicates the average scores of the participants in depression. The average scores of the participants in depression is 0, indicating that there was no depression among the respondents. However, the standard deviation scores indicate that 0.87 implies less than 2 participants have moderate to high scores in depression.

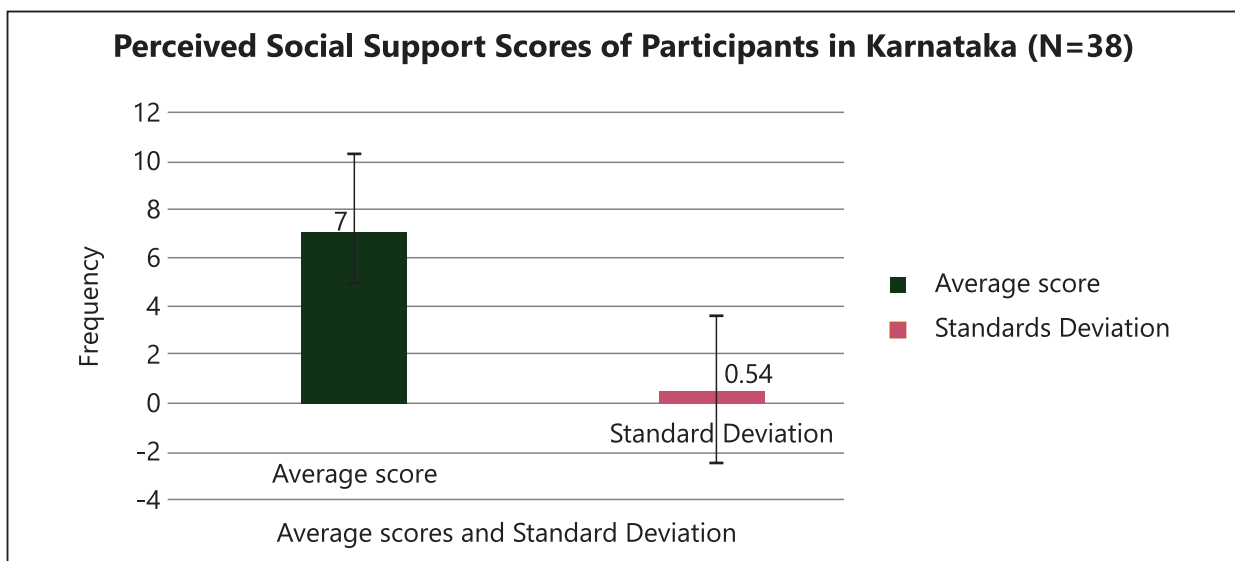
Figure 7. Perceived Social Support Scores of participants in Karnataka (N=38)

Figure 7 indicates the average scores of the participants in the perceived social support. The average scores of the participants were 7, indicating that there were high levels of perceived social support among the participants. However, the standard deviation scores of 0.54 indicate that less than 2 participants have low scores in perceived social support.

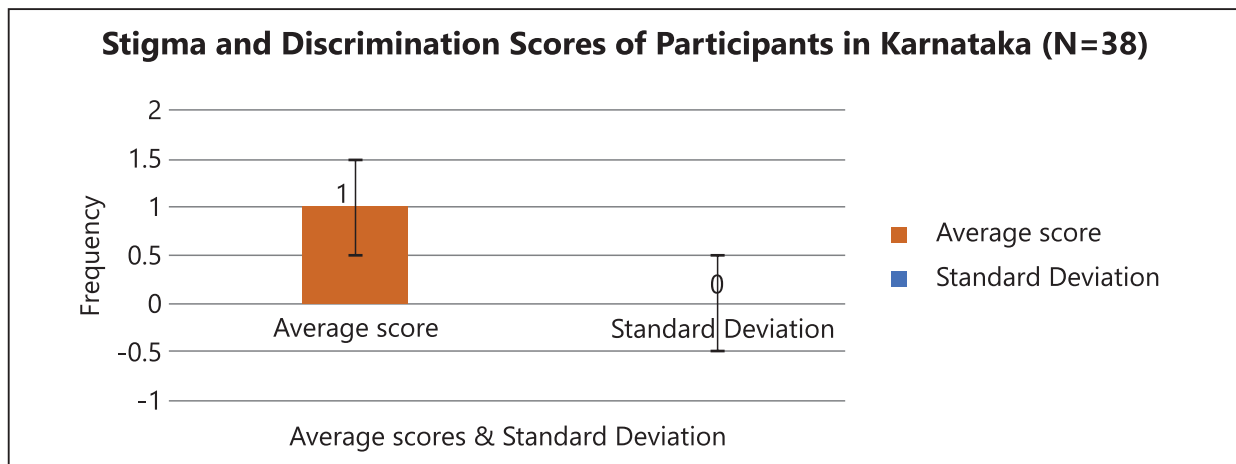
Figure 8. Stigma and Discrimination Scores of participants in Karnataka (N=38)

Figure 8 indicates the average scores of the participants in the stigma and discrimination. The average scores of the participants is 1, indicating that there were low levels of stigma and discrimination with no variation in standard deviation.

2.3.2.2. Telangana

The results of the sociodemographic details revealed that of the 38 participants; 20 (52.6%) were males and 18 (47.4%) were female participants in the study. The average age of the females in the sample is 32.34 years and 42.1 years for males. With regards to marital status, 28 participants were married and 10 were single. With regards to educational background, the majority (15) of the sample had completed higher secondary educational programmes, 10 participants were illiterate, 5 participants were from primary school and 8 participants had a graduate school educational background.

The occupational status reveals that 6 participants were daily wage labourers or coolies; 5 participants were homemakers, 8 participants owned local small businesses, 10 participants were students and 5 were unemployed. With regards to the economic status, the majority (31) of the sample belonged to the lower economic status and 7 participants were of middle economic status. The domicile background reveals that the majority (20) of the participants resided in urban areas and 18 participants were from the rural area of the state. With regard to treatment duration, of the 18 females in the sample, the average duration of treatment for TB was identified as 119.4 days and of the 20 males, the average duration of treatment for TB is 108.9 days.

Table 3. Socio-Demographic details of the respondents

Socio Demographic categories		Female (18)	Males (20)	Total (38)
Age (mean)		32.38	42.1	-
Marital Status	Married	11	17	28 (73.7%)
	Single	7	3	10 (26.3%)

Socio Demographic categories		Female (18)	Males (20)	Total (38)
Education	Illiterate	5	5	10 (26.3%)
	Primary School	0	5	5 (13.2%)
	Higher Secondary	8	6	14 (36.8%)
	Graduate	5	3	8 (21.1%)
Occupational background	Daily wages/ coolie	0	6	6 (15.8%)
	Farmer	0	8	8 (21.1%)
	Homemaker	5	0	5 (13.2%)
	Small business	4	0	4 (10.5%)
	Student	7	3	10 (26.3%)
	Unemployed	3	2	5 (13.2%)
Economic status	Low	15	18	33 (86.8%)
	Middle	3	2	5 (13.2%)
Domicile	Rural	6	12	18 (47.4%)
	Urban	12	8	20 (52.6%)
Mean duration of treatment for TB	(in no. of days)	119.4	108.9	-

Figure 9. Anxiety scores of participants in Telangana (N=38)

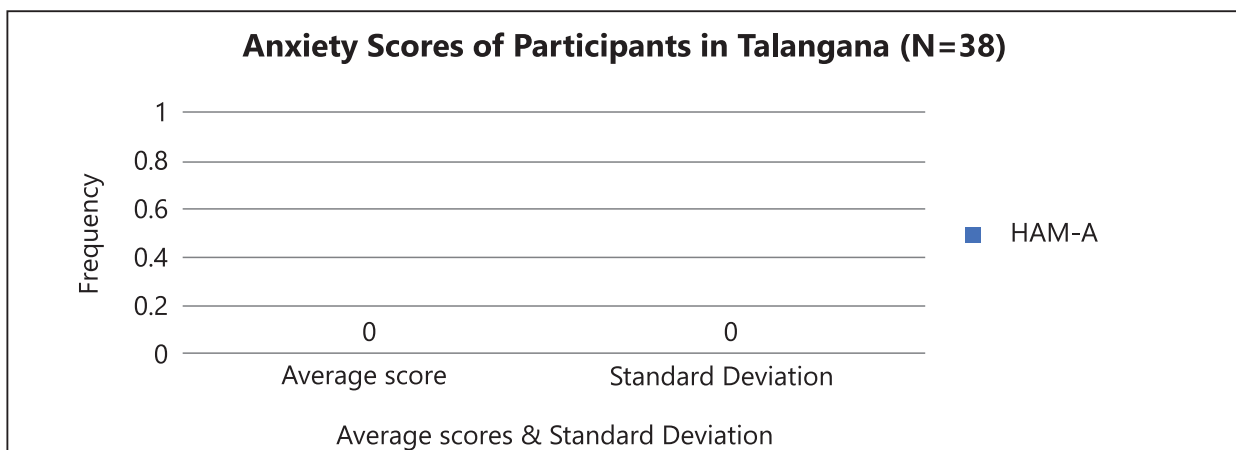


Figure 9 shows the total scores of anxiety from the participants. The average scores of the participants were 0, indicating that there was no anxiety among the participants with no variation in standard deviation

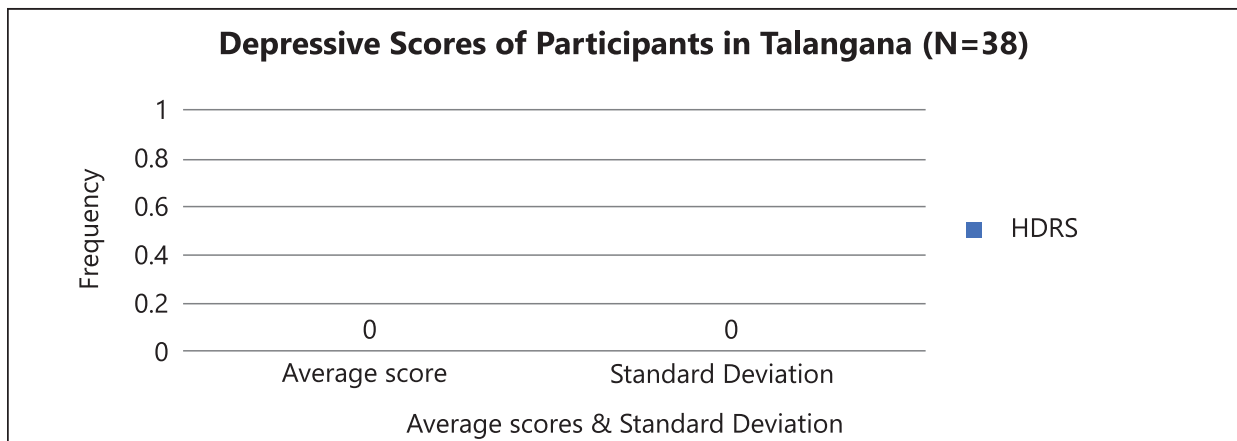
Figure 10. Depressive scores of participants in Telangana (N=38)

Figure 10 indicates the average scores of the participants in depression. The average scores of the participants in depression is 0, indicating that there were no signs of depression with no variation in standard deviation.

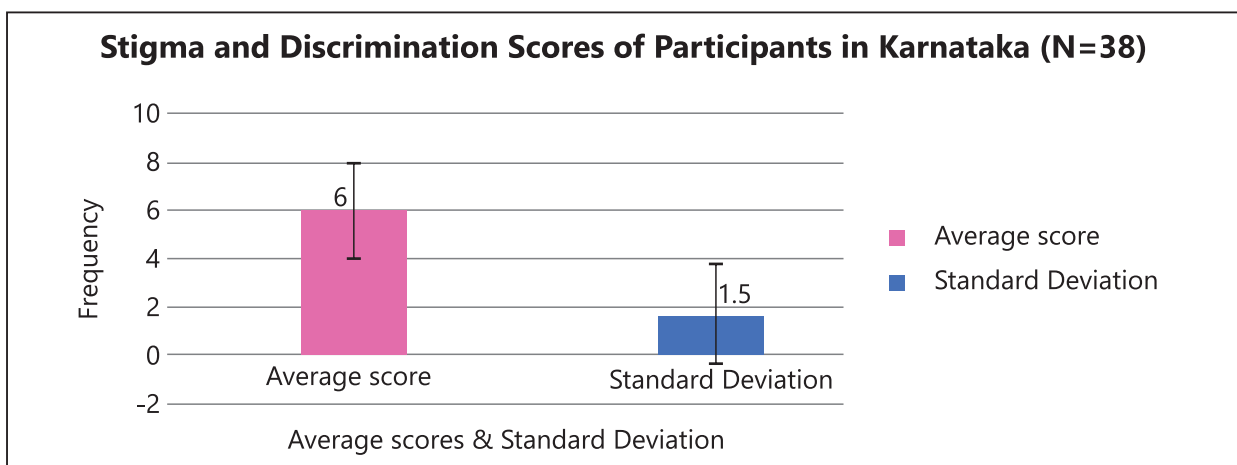
Figure 11. Perceived Social Support Scores of the participants in Telangana (N=38)

Figure 11 indicates the total scores of the participants in the perceived social support. The average scores of the participants are 6, indicating that there were high levels of perceived social support among the participants. However, the standard deviation scores 1.5 implies less than 3 participants have low scores in perceived social support.

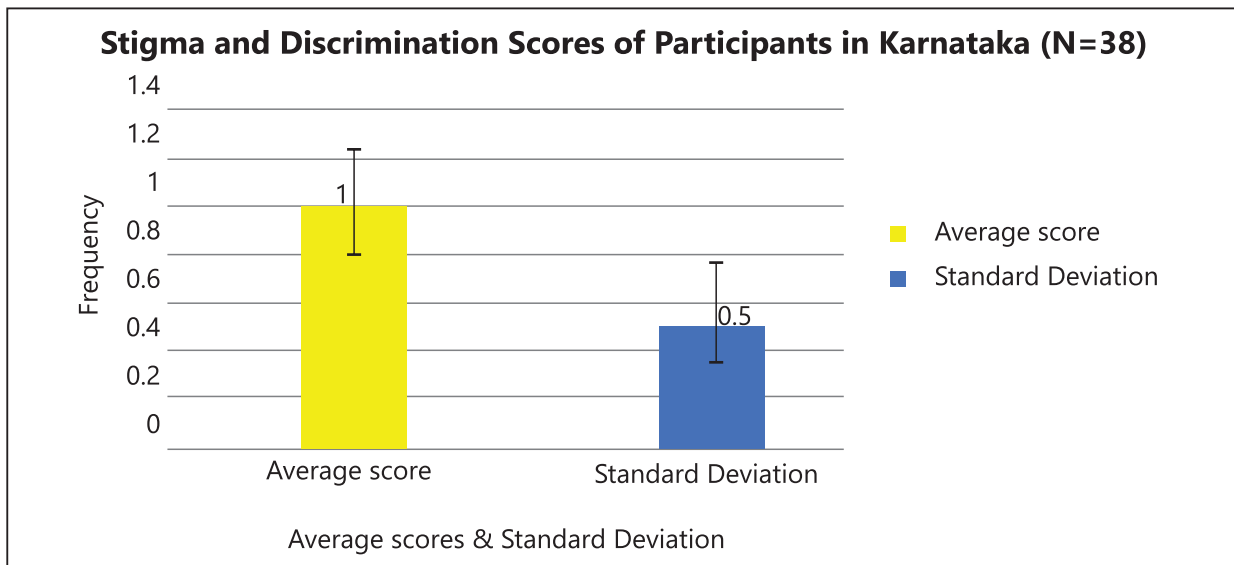
Figure 12. Stigma and Discrimination scores of the participants in Telangana (N=38)

Figure 12 indicates the total scores of the participants in the stigma and discrimination. The average scores of the participants is 1, indicating that there were low levels of stigma and discrimination; 0.5 variation in standard deviation implies less than 2 participants have moderate/high scores in stigma and discrimination.

2.3.2.3 Bihar

The results of the sociodemographic details reveals that of the 21 participants; 13 (62%) were male and 8 (38%) were female participants in the study. The average age of the females in the sample is 39 years and 42.2 years for males. With regards to marital status, 18 participants were married, 2 were single and one participant was divorced. Regarding educational status, the majority (9) of the samples were illiterate, 2 participants were from higher secondary background, 5 high school background participants, 3 participants were from primary school and 2 participants had a graduate school educational background.

The occupational status reveals that 8 participants were daily wage labourers or coolies, 7 participants were homemakers, one participant was a student, one participant owned local small businesses, 3 participants were farmers and one was unemployed. The economic status of the respondents reveals that the majority (18) participants belonged to the lower income status, 2 participants were from middle income and 1 participant was from an upper income background. The domicile background shows that 21 participants resided in rural area. The treatment duration indicates that of the 8 females in the sample, the average duration of treatment for TB was identified as 235.1 day and of the 20 males, the average duration of treatment for TB was 255.5 days.

Table 4. Socio-Demographic details of the Respondents (N=21)

Socio Demographic categories		Female (8)	Males (13)	Total (21)
Age (mean)		39.0	42.2	
Marital Status	Married	8	10	18 (85.7%)
	Single	0	2	2 (9.5%)
	Widowed/divorced	0	1	1 (4.8%)
Education	Illiterate	3	6	9 (42.9%)
	Primary School	1	2	3 (14.3%)
	High School	3	2	5 (23.8%)
	Higher Secondary	1	1	2 (9.5%)
	Graduate	0	2	2 (9.5%)
Occupational background	Daily wages/ coolie	0	8	8 (38%)
	Farmer	1	2	3 (14.3%)
	Homemaker	7	0	7 (18.4%)
	Small business	0	1	1 (4.8%)
	Student	0	1	1 (4.8%)
	Unemployed	0	1	1 (4.8%)
Economic status	Low	7	11	18 (85.7%)
	Middle	1	1	1 (4.8%)
	Upper	0	1	1 (4.8%)
Domicile	Rural	8	13	21 (100%)
	Urban	0	0	0
Mean duration of treatment for TB	(in no. of days)	235.1	255.5	

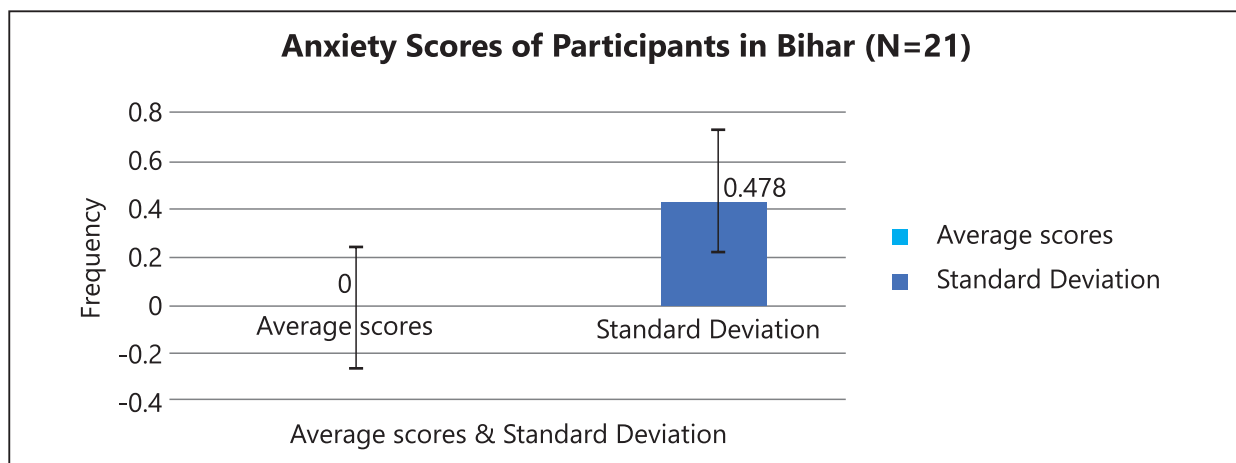
Figure 13. Anxiety Scores of participants in Bihar (N=21)

Figure 13 shows the total scores of anxiety among the participants. The average scores of the participants were 0, indicating that there was no anxiety among the participants. However, the standard deviation score 0.478 indicate that less than 1 participant have moderate scores in anxiety.

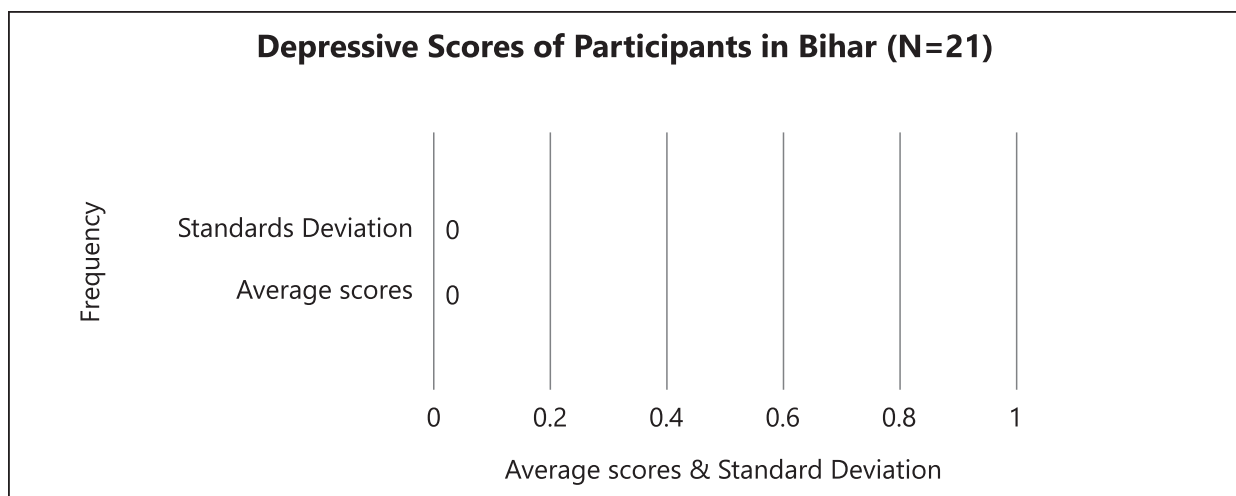
Figure 14. Depressive Scores of the participants in Bihar (N=21)

Figure 14 indicates the total scores of the participants in depression. The average scores of the participants in depression is 0, indicating that there was no depression. The standard deviation scores indicate the same.

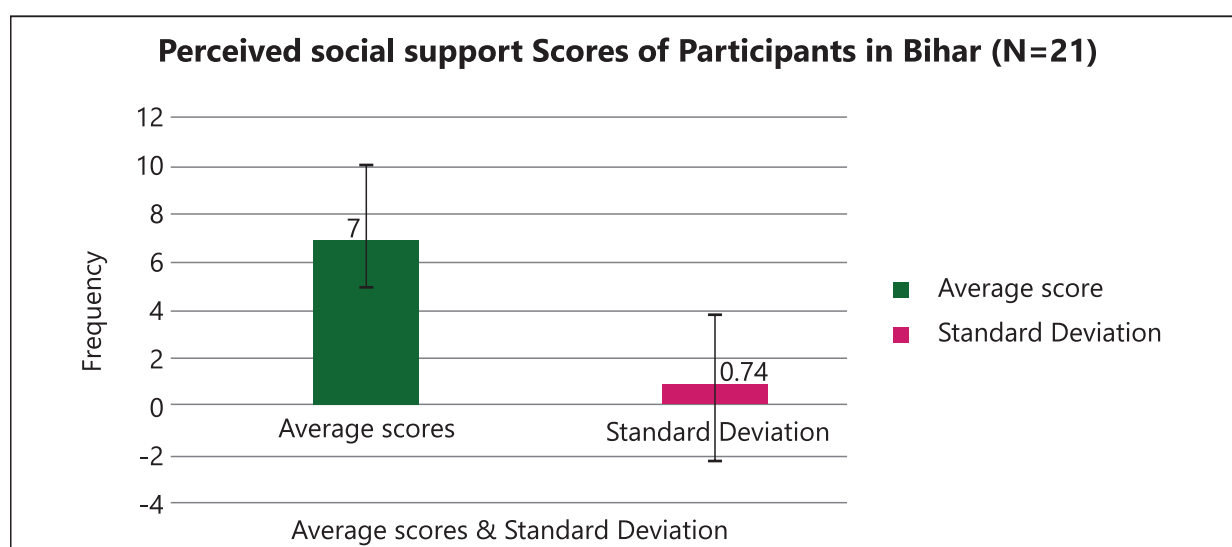
Figure 15. Perceived Social Support scores of participants in Bihar (N=21)

Figure 15 indicates the total scores of the participants in the perceived social support. The average scores of the participants was 7, indicating that there were high levels of perceived social support among the participants. However, the standard deviation score 0.74 indicate that less than 2 participants have low scores in perceived social support.

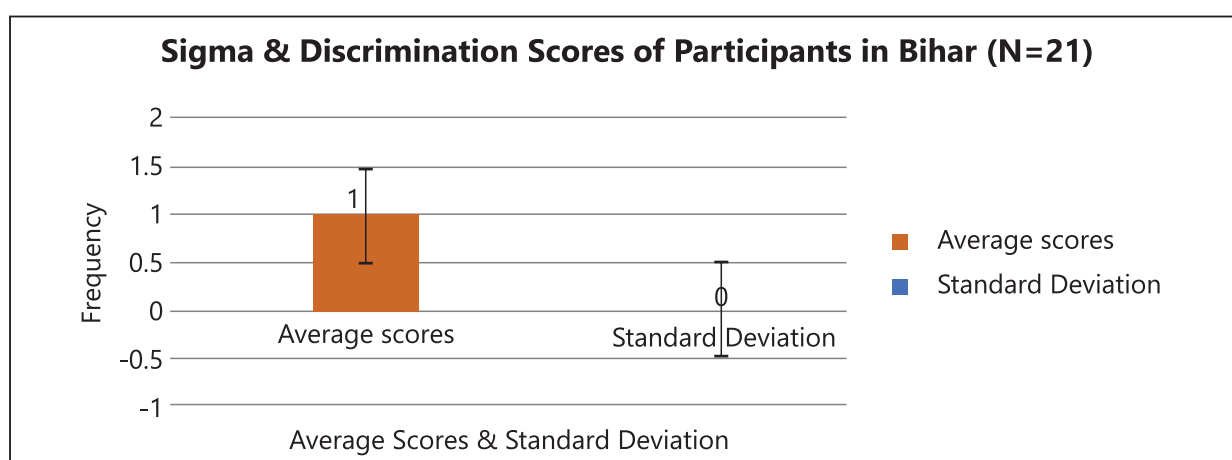
Figure 16. Stigma and Discrimination scores of participants in Bihar (N=21)

Figure 16 indicates the total scores of the participants in the stigma and discrimination. The average scores of the participants in depression is 1, indicating that there were low levels of stigma and discrimination with no variation in standard deviation.

2.3.2.4 Assam

The results of the sociodemographic details revealed that of the 40 participants; 20 (50%) were male and 20 (50%) were female participants in the study. The average age of the females in the sample is 30.9 years and 41.9 years for males. With regards to marital status, out of the 40 participants, the majority (30) participants were married, 9 were single and one participant was widowed. Regarding educational

status reveals that, of the 40 participants, the majority (18) of the samples had completed high school educational programmes, 7 participants were from higher secondary background, 7 participants were illiterate, 5 participants were from primary school and 3 participants had a graduate school educational background. The occupational status of the participants indicates that the majority (18) participants were daily wage labourers or coolies, 6 participants were homemakers, one participant was engaged in social services, 3 participants owned local small businesses, 5 participants were students and 7 were unemployed. The economic status of the participants indicates that the majority (40) of the participants belonged to the lower economic status. The domicile background shows that the majority (24) of the participants resided in rural areas and 16 participants were from the urban areas. The duration of treatment reveals that of the 20 females in the sample, the average duration of treatment for TB was identified as 337.9 days and of the 20 males, the average duration of treatment for TB is 334.9 days.

Table 5. Socio-Demographic details of the Respondents (N=40)

Socio Demographic categories		Female (20)	Males (20)	Total (40)
Age (mean)		30.9	41.9	-
Marital Status	Married	11	19	30 (75.0%)
	Single	8	1	9 (22.5%)
	Widowed/divorced	1	0	1 (2.5%)
Education	Illiterate	4	3	7 (17.5%)
	Primary School	3	2	5 (12.5%)
	High School	9	9	18 (45.0%)
	Higher Secondary	2	5	7 (17.5%)
	Graduate	2	1	3 (7.5%)
Occupational background	Daily wages/ coolie	5	13	18 (45.0%)
	Homemaker	6	0	6 (15.0%)
	Small business	0	6	6 (15.0%)
	Student	5	0	4 (10.0%)
	Unemployed	4	3	7 (17.5%)
Economic status	Low	20	20	40 (100.0%)
Domicile	Rural	12	12	24 (63.2%)
	Urban	8	8	16 (42.1%)
Mean duration of treatment for TB	(in no. of days)	321.6	334.9	-

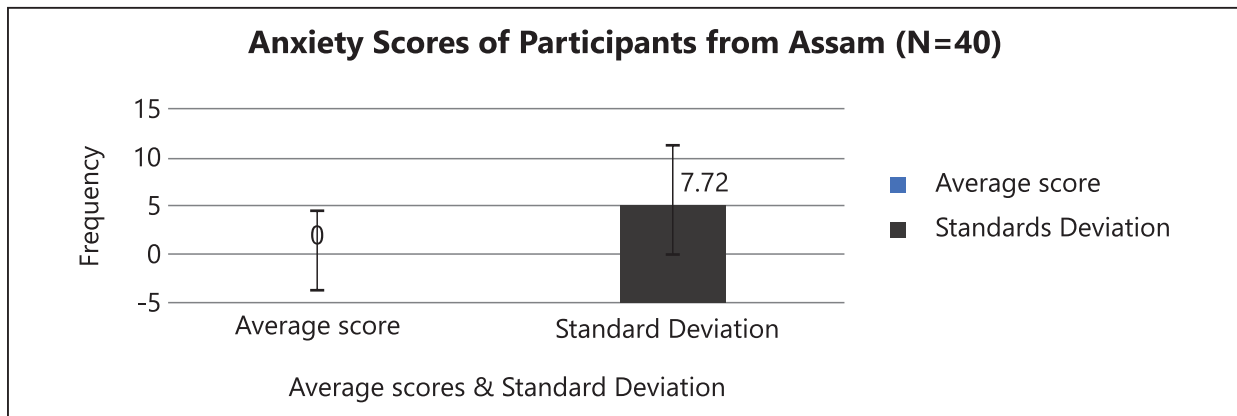
Figure 17. Anxiety Scores of participants in Assam (N=40)

Figure 17 shows the total scores of anxiety among the participants. The average scores of the participants were 0, indicating that there were no signs of anxiety among the participants. However, the standard deviation scores 7.72 implies less than 4 participants have moderate/high scores in anxiety.

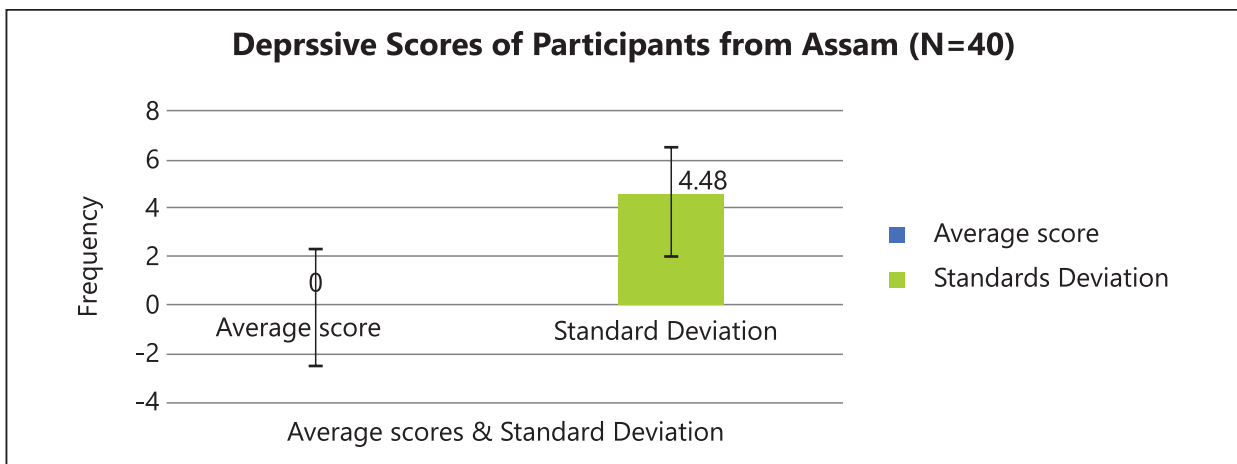
Figure 18. Depressive scores of participants in Assam (N=40)

Figure 18 indicates the average scores of depression among the participants. The average scores of the participants in depression was 0, indicating that there were no signs of depression. However, the standard deviation scores 4.48 implies less than 3 participants have moderate/high scores in depression.

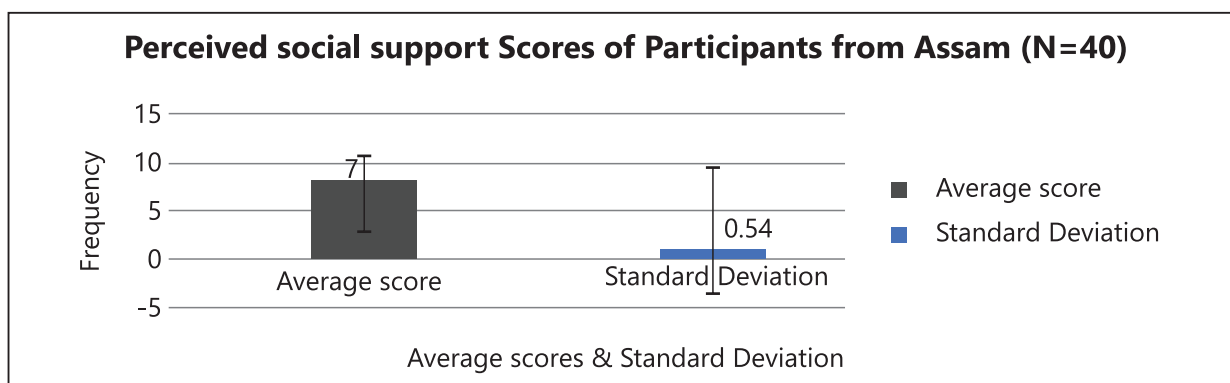
Figure 19. Perceived Social Support scores of participants in Assam (N=40)

Figure 19 indicates the total scores of the participants in the perceived social support. The average scores of the participants were 7, indicating that there were high levels of perceived social support among the participants. However, the standard deviation scores 0.54 implies less than 2 participants have low scores in perceived social support.

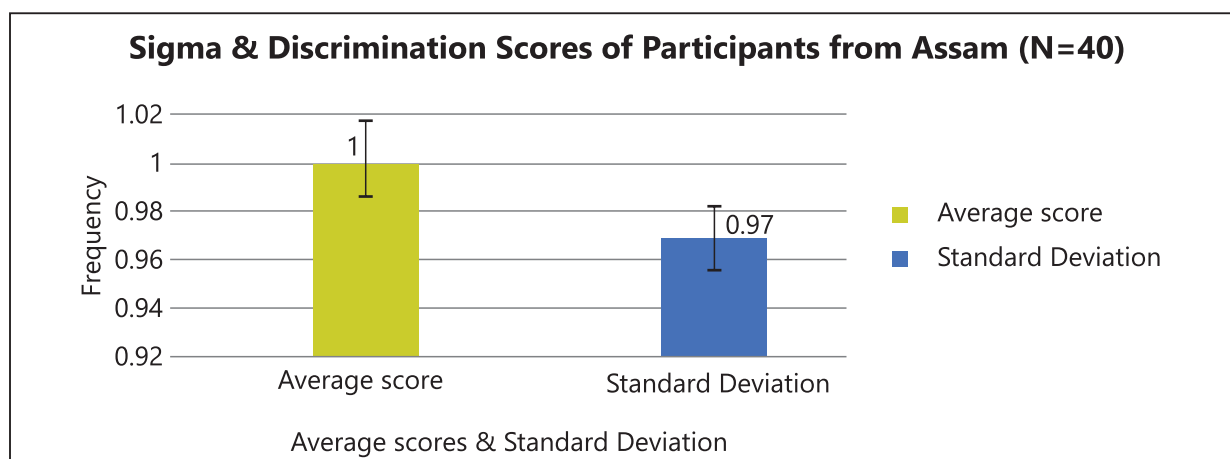
Figure 20. Stigma and Discrimination scores of participants in Assam (N=40)

Figure 20 indicates the total scores of the participants in the stigma and discrimination. The average scores of the participants in stigma and discrimination was 1, indicating that there were low levels of stigma and discrimination. However, the standard deviation score 0.97 indicate that less than 3 participants have low scores in perceived social support.

2.4 Discussion and Conclusion

The above results suggest that multiple factors play a significant role in identifying the prevalence of psychosocial factors in the intervention, prevention and treatment of TB. Literature suggests that patients with Pulmonary Tuberculosis (PTB) had significant rates of depression and anxiety (Amreen & Rizvi, 2016; Liu et al., 2022; Ruiz-Grosso et al., 2020; Wang et al., 2018). Further, the patients coming from lower economic backgrounds had higher risk of anxiety and depression- predominantly the physiological manifestation of the symptoms (Wang et al., 2018; Yilmaz & Dedeli, 2016). Contrary to the existing literature, the present study has identified that there was no prevalence of anxiety and depression among the participants.

Within the overall anxiety scores of the participants of the current study, less than 7 participants have reported having moderate scores of anxiety and less than 4 participants having reported moderate levels of depression. Synthesising the data of each state, there is a similarity with the overall results. Karnataka and Assam reported comparatively higher standard deviation in the anxiety and depression scores while Telangana and Bihar had reported no significant standard deviation. While reviewing the data we can identify that the highest literacy was within Karnataka and Assam states, this could have impacted awareness-based anxiety. Various literature suggests that within individuals who have greater awareness of the illness and emotional awareness have greater levels of anxiety and depression (Lee & Lee, 2019; Nezlek, 2002)

In a systematic review, the tendency to seek medical assistance was low among the female population, who often resort to home remedies and quick solutions. At the same time their male counterparts have greater tendencies of visiting health care professionals for various health related concerns. Women were identified to either miss their treatment or discontinue medication against medical advice (Sreeramareddy et al., 2014). The present study identifies a similar pattern in the increased number of males diagnosed with TB in comparison to the number of females. Within the overall results, one can identify similar patterns where the females diagnosed with TB were students which could indicate the prevalence of awareness and early diagnosis among the younger population. Greater number of homemakers and students have been diagnosed with TB.

Financial limitations, lack of extreme overt symptoms and social stigma plays a significant role in delaying the treatment by 2 weeks (Samal, 2016; Sreeramareddy et al., 2014). In states such as Bihar and Telangana, occupational background and literacy along with the rural residential background, could have impacted the access to adequate healthcare, support and awareness of the illness. The present study indicates that the levels of perceived social support were significantly high among participants with TB. This could relate to the increased number of married participants in the study. It shows that 114 participants were married out of which the vast majority reported feeling well

supported during the period of treatment. It must be noted that a large majority of the married participants were males. The increasing acceptance of TB as an infectious disease has increased the levels of stigma and discrimination against patients with TB (Yilmaz & Dedeli, 2016). A poor quality of life and management of comorbid conditions are significant contributors to the acceleration of TB among patient populations (Santos et al., 2016).

While exploring further data on the basis of the four states, one can identify that while the vast majority of the participants do not report feeling anxious and depressed; the standard deviation within each state represents the smaller subgroup within the participants that report feelings of anxiety and depression of moderate levels. The same participants have reported having low perceived social support within their family groups. An important factor in the prevention and treatment of TB is the levels of awareness among the participants. While studies suggest that a significant contributor to the stigma among East Asian countries is the association of TB with HIV/AIDS (Samal, 2016; Yasobant et al., 2021), the present study identifies that all participants had no discriminatory practices among the community whereas some stigmatising beliefs persisted. In Karnataka, a larger group of participants were homemakers and from low economic backgrounds, living in the urban areas of the state. These factors, including the results that indicate a large majority had at least completed high school education, may have contributed to the faster recovery from the illness in comparison to other states. Bihar and Assam have the longest period of treatment which may align with the domicile and economic backgrounds.

Conclusion

The present study identified that there were no significant psychosocial contributors in limiting the awareness, treatment and management of TB within the four states where the intervention was applied. There were no signs of anxiety and depression among the vast majority. The larger group felt well supported by the primary caretakers and community and had no discriminatory attitudes or stigmatising beliefs among them. Some long-standing reasons for the present study's contradictory results with reference to the prior literature may be the implementation of interventions by KHPT. Since the data collection took place after the interventions were conducted by the organisation, there's a possibility that the access to information, screening and awareness may have impacted the results produced by the study. A second reason could be the duration of the treatment for the participants was approximately 200 days. As the study was conducted towards the end of the treatment the possibility that their severity of their illness decreased may have contributed to the positive outlook toward the support and illness itself.

2.5 Recommendation and policy implication

Research

While the present studies observed the relationship between psychosocial factors in lieu of the treatment intervention provided by the organisation, future studies could prioritise the implementation of screening, assessment, intervention and rehabilitation of TB patients for a wider array of mental health conditions. Future studies could focus on comparative groups and Randomised Control Trials (RCTs) that could provide richer data that would generate detailed impact on the overall wellbeing of the participants. Ultimately future studies could evaluate the impact of long-term treatment outcomes on community and individual's physical and psychological health.

Future study could further discuss inquiry into gender-based health-seeking behaviours among participants along with possible cultural influences in the study. Coping with mental and psychological distress among patients with TB could be further explored. Studies can be conducted on different age groups with a larger, concentrated sample population that would provide greater insight into trends within specific age groups and the awareness of illness and ability to seek and access support from the community and healthcare providers.

Programme

The programme could lay focus on effective ways to maintain long-term health of the patients along with continued awareness of TB among the communities they engage with through community gatherings, festivals and role-modelling. The programme could focus on methods to increase the speedy recovery rates within communities, as the sample population would not have the economic capacity to sustain a long course of treatment. Additionally, increased sensitization of females and their family members encouraging them to seek medical support and familial cooperation could be key to community wellness. Continuity of care shall be made available to manage the psychosocial problems in the community by connecting the mental health institutions like NIMHANS.

Advocacy

The programme could continue its on-going strategies to break the barriers against the spread of TB. Widening the outreach to other communities via creative approaches such as street plays, mass media and through community leaders could amplify the scope and advocacy for persons with TB in prevention, treatment and rehabilitation within the country. Involving community healers, adjacent healthcare units, social workers, bureaucrats and mental health providers could encourage sustained outcomes of the programme.

References

- Aggarwal, A. N. (2019). Quality of life with tuberculosis. *Journal of Clinical Tuberculosis and Other Mycobacterial Diseases*, 17, 100121. <https://doi.org/10.1016/j.jctube.2019.100121>
- Alipanah N, Jarlsberg L, Miller C, Linh NN, Falzon D, Jaramillo E, et al. (2018) Adherence interventions and outcomes of tuberculosis treatment: A systematic review and meta-analysis of trials and observational studies. *PLoS Med* 15(7): e1002595. <https://doi.org/10.1371/journal.pmed.1002595>
- Amreen, & Rizvi, N. (2016). Frequency of Depression and Anxiety among Tuberculosis Patients. *Journal of Tuberculosis Research*, 04(04), Article 04. <https://doi.org/10.4236/jtr.2016.44021>
- Bello S, Afolabi RF, Ajayi DT, et al. Empirical evidence of delays in diagnosis and treatment of pulmonary tuberculosis? Systematic review and meta-regression analysis. 2019; 1-11.
- Canty-Mitchell, J. & Zimet, G.D. (2000). Psychometric properties of the Multidimensional Scale of Perceived Social Support in urban adolescents. *American Journal of Community Psychology*, 28, 391-400.
- Chandra, M., Rana, P., Chandra, K., & Arora, V. K. (2019). Tuberculosis - Depression syndemic: A public health challenge. *Indian Journal of Tuberculosis*, 66(1), 197–202. <https://doi.org/10.1016/j.ijtb.2019.02.007>
- Dhiman, S., Subodh, B., & Chakrabarti, S. (2022). Course and outcome of bipolar I disorder among Indian patients: A retrospective life-chart study. *Indian Journal of Psychiatry*, 64(5), 510–517. https://doi.org/10.4103/indianjpsychiatry.indianjpsychiatry_129_21
- Endalamaw, A., Gilks, C. F., Ambaw, F., Chatfield, M. D., & Assefa, Y. (2022). Satisfaction of tuberculosis patients to healthcare services at the global level: A systematic review. *Health & Social Care in the Community*, 30(6), e3435–e3446. <https://doi.org/10.1111/hsc.13953>
- Hamilton, M. (1959). The assessment of anxiety states by rating. *The British Journal of Medical Psychology*, 32(1), 50–55. <https://doi.org/10.1111/j.2044-8341.1959.tb00467.x>
- Hamilton, M. (1960). A rating scale for depression. *Journal of Neurology, Neurosurgery, and Psychiatry*, 23(1), 56–62. <https://doi.org/10.1136/jnnp.23.1.56>
- Home | KHPT - Engage, Innovate, Empower. (n.d.). KHPT. Retrieved February 6, 2024, from <https://www.khpt.org/>

- Karnataka Health Promotion Trust. Improving Management and Delivery of Outreach Services, Shaping Demand and Strengthening Accountability: An overview of Sukshema's community intervention. Unpublished report; Benagluru, Karnataka 2014. https://www.khpt.org/wp-content/uploads/2022/01/Community-interventions_documentation_MNCH.pdf
- Krishna, A., Mini, G., & Aravind, L. (2019). Evidence based interventions and implementation gaps in control of tuberculosis: A systematic review in low and middle-income countries with special focus on India—PubMed. <https://pubmed.ncbi.nlm.nih.gov/31151496/>
- LaCroix JM, Snyder LB, Huedo-Medina TB, et al. Effectiveness of Mass Media Interventions for HIV Prevention, 1986–2013. *J Acquir Immune Defic Syndr.* 2014; 66: 329–340. doi:10.1097/QAI.0000000000000230
- Lanka, U., & Anand, B. (2013). A controlled study of psychopathology, life events, personality and sociodemographic factors in irritable bowel syndrome. *Archives of Mental Health*, 14, 124–133.
- Lee, E., & Lee, H. (2019). Disaster awareness and coping: Impact on stress, anxiety, and depression. *Perspectives in Psychiatric Care*, 55(2), 311–318. <https://doi.org/10.1111/ppc.12351>
- Liu, X., Bai, X., Ren, R., Tan, L., Zhang, Y., Lan, H., Yang, Q., He, J., & Tang, X. (2022). Association between depression or anxiety symptoms and immune-inflammatory characteristics in in-patients with tuberculosis: A cross-sectional study. *Frontiers in Psychiatry*, 13, 1–8. <https://doi.org/10.3389/fpsy.2022.985823>
- Lohiya, A., Suliankatchi Abdulkader, R., Rath, R. S., Jacob, O., Chinnakali, P., Goel, A. D., & Agrawal, S. (2020). Prevalence and patterns of drug resistant pulmonary tuberculosis in India-A systematic review and meta-analysis. *Journal of Global Antimicrobial Resistance*, 22, 308–316. <https://doi.org/10.1016/j.jgar.2020.03.008>
- Luis SF, Kamp N, Mitchell EMH, et al. Health-seeking norms for tuberculosis symptoms in southern Angola: Implications for behaviour change communications. *Int J Tuberc Lung Dis.* 2011; 15(7): 943–948. doi:10.5588/ijtld.10.0588
- Mihimbira, F., Cuevas, L., Dacombe, R., Mkopi, A., & Sinclair, D. (2017). Interventions to increase tuberculosis case detection at primary healthcare or community-level services—PMC. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5721626/>
- Nezlek, J. B. (2002). Day-to-day Relationships Between Self-awareness, Daily Events, and Anxiety. *Journal of Personality*, 70(2), 249–276. <https://doi.org/10.1111/1467->

6494.05005

- Ruiz-Grosso, P., Cachay, R., Flor, A. de la, Schwalb, A., & Ugarte-Gil, C. (2020). Association between tuberculosis and depression on negative outcomes of tuberculosis treatment: A systematic review and meta-analysis. *PLOS ONE*, 15(1), e0227472. <https://doi.org/10.1371/journal.pone.0227472>
- Sagili, K., Satyanarayana, S., & Chadha, S. (2016). Is Knowledge Regarding Tuberculosis Associated with Stigmatising and Discriminating Attitudes of General Population towards Tuberculosis Patients? Findings from a Community Based Survey in 30 Districts of India | *PLOS ONE*. <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0147274>
- Samal, J. (2016). Health Seeking Behaviour among Tuberculosis Patients in India: A Systematic Review. *Journal of Clinical and Diagnostic Research : JCDR*, 10 (10), LE01–LE06. <https://doi.org/10.7860/JCDR/2016/19678.8598>
- Santos, A. P. C. dos, Lazzari, T. K., & Silva, D. R. (2016). Health-Related Quality of Life, Depression and Anxiety in Hospitalized Patients with Tuberculosis. *Tuberculosis and Respiratory Diseases*, 80(1), 69–76. <https://doi.org/10.4046/trd.2017.80.1.69>
- Sathiyamoorthy, R., Kalaivani, M., Aggarwal, P., & Gupta, S. K. (2020). Prevalence of pulmonary tuberculosis in India: A systematic review and meta-analysis. *Lung India : Official Organ of Indian Chest Society*, 37(1), 45–52. https://doi.org/10.4103/lungindia.lungindia_181_19
- Snyder LB, Hamilton MA, Mitchell EW, et al. A meta-analysis of the effect of mediated health communication campaigns on behavior change in the United States. *J Health Commun*. 2004; 9: 71-96. doi:10.1080/10810730490271548
- Sreeramareddy, C. T., Qin, Z. Z., Satyanarayana, S., Subbaraman, R., & Pai, M. (2014). Delays in diagnosis and treatment of pulmonary tuberculosis in India: A systematic review. *The International Journal of Tuberculosis and Lung Disease: The Official Journal of the International Union Against Tuberculosis and Lung Disease*, 18(3), 255–266. <https://doi.org/10.5588/ijtld.13.0585>
- Subbaraman, R., Nathavitharana, R. R., Satyanarayana, S., Pai, M., Thomas, B. E., Chadha, V. K., Rade, K., Swaminathan, S., & Mayer, K. H. (2016). The Tuberculosis Cascade of Care in India's Public Sector: A Systematic Review and Meta-analysis. *PLoS Medicine*, 13(10), e1002149. <https://doi.org/10.1371/journal.pmed.1002149>
- Subramanian, A., Mohan, A., Nandi, P. K., & Rajeshwari, K. (2021). Perceived social support, depression and their impact on quality of life of people living with HIV in India. *AIDS Care*, 33(10), 1329–1334. <https://doi.org/10.1080/09540121.2020.1810620>

- Thomas, B. E., Adinarayanan, S., Manogaran, C., & Swaminathan, S. (2015). Pulmonary tuberculosis among tribals in India: A systematic review and meta-analysis. <https://doi.org/10.4103/0971-5916.159545>
- Vermund SH, Mallalieu EC, Van Lith LM, et al. Health communication and the HIV continuum of care. *J Acquir Immune Defic Syndr*. 2017; 74: S1-S4. <http://www.embase.com/search/results?>
- Wang, X., Li, X., Zhang, Q., Zhang, J., Chen, H., Xu, W., Fu, Y., Wang, Q., Kang, J., & Hou, G. (2018). A Survey of Anxiety and Depressive Symptoms in Pulmonary Tuberculosis Patients With and Without Tracheobronchial Tuberculosis. *Frontiers in Psychiatry*, 9, 1–10. <https://doi.org/10.3389/fpsyt.2018.00308>
- Yasobant, S., Bhavsar, P., Kalpana, P., Memon, F., Trivedi, P., & Saxena, D. (2021). Contributing Factors in the Tuberculosis Care Cascade in India: A Systematic Literature Review. *Risk Management and Healthcare Policy*, 14, 3275–3286. <https://doi.org/10.2147/RMHP.S322143>
- Yilmaz, A., & Dedeli, O. (2016). Assessment of anxiety, depression, loneliness and stigmatization in patients with tuberculosis. *Acta Paulista de Enfermagem*, 29(5), 549–557. <https://doi.org/10.1590/1982-0194201600076>
- Zimet, G.D., Dahlem, N.W., Zimet, S.G. & Farley, G.K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52, 30-41.
- Zimet, G. D., Powell, S. S., Farley, G. K., Werkman, S., & Berkoff, K. A. (1990). Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 55(3–4), 610–617. <https://doi.org/10.1080/00223891.1990.9674095>

ANNEXURE

Annexure-1

Table. Socio-Demographic details of the participants

Socio Demographic categories		Female	Males	Total
Age (avg)				-
Marital Status	Married			
	Single			
	Widowed/divorced			
Education	Illiterate			
	Primary School			
	High School			
	Higher Secondary			
	Graduate			
Occupational background	Daily wages/ coolie			
	Farmer			
	Homemaker			
	Small business			
	Student			
	unemployed			
Economic status	Low			
	Middle			
	Upper			
Domicile	Rural			
	Urban			
Avg, duration of treatment for TB	(in days)			-

Annexure-2

Hamilton Depression Rating Scale (HDRS)

Reference: Hamilton M. A rating scale for depression. *J Neurol Neurosurg Psychiatry* 1960; 23:56–62

Rating Clinician-rated

Administration time 20–30 minutes

Main purpose To assess severity of, and change in, depressive symptoms

Population Adults

Commentary

The HDRS (also known as the Ham-D) is the most widely used clinician-administered depression assessment scale. The original version contains 17 items (HDRS₁₇) pertaining to symptoms of depression experienced over the past week. Although the scale was designed for completion after an unstructured clinical interview, there are now semi-structured interview guides available. The HDRS was originally developed for hospital inpatients, thus the emphasis on melancholic and physical symptoms of depression. A later 21-item version (HDRS₂₁) included 4 items intended to subtype the depression, but which are sometimes, incorrectly, used to rate severity. A limitation of the HDRS is that atypical symptoms of depression (e.g., hypersomnia, hyperphagia) are not assessed (see SIGH-SAD, page 55).

Scoring

Method for scoring varies by version. For the HDRS₁₇, a score of 0–7 is generally accepted to be within the normal

Hamilton Depression Rating Scale (HDRS)

range (or in clinical remission), while a score of 20 or higher (indicating at least moderate severity) is usually required for entry into a clinical trial.

Versions

The scale has been translated into a number of languages including French, German, Italian, Thai, and Turkish. As well, there is an Interactive Voice Response version (IVR), a Seasonal Affective Disorder version (SIGH-SAD, see page 55), and a Structured Interview Version (HDS-SIV). Numerous versions with varying lengths include the

HDRS₁₇, HDRS₂₁, HDRS₂₉, HDRS₈, HDRS₆, HDRS₂₄, and HDRS₇ (see page 30).

Additional references

Hamilton M. Development of a rating scale for primary depressive illness. *Br J Soc Clin Psychol* 1967; 6(4):278–96.

Williams JB. A structured interview guide for the Hamilton Depression Rating Scale. *Arch Gen Psychiatry* 1988; 45(8):742–7.

PLEASE COMPLETE THE SCALE BASED ON A STRUCTURED INTERVIEW

Instructions: for each item select the one “cue” which best characterizes the patient. Be sure to record the answers in the appropriate spaces (positions 0 through 4).

- | | |
|--|---|
| <p>1 DEPRESSED MOOD (sadness, hopeless, helpless, worthless)</p> <p>0 <input type="checkbox"/> Absent.</p> <p>1 <input type="checkbox"/> These feeling states indicated only on questioning.</p> <p>2 <input type="checkbox"/> These feeling states spontaneously reported verbally. Communicates feeling states non-verbally, i.e. through facial expression, posture, voice and tendency to weep. Patient reports virtually only these feeling states in his/her spontaneous verbal and non-verbal communication.</p> | <p>2 FEELINGS OF GUILT</p> <p>0 <input type="checkbox"/> Absent.</p> <p>1 <input type="checkbox"/> Self-reproach, feels he/she has let people down.</p> <p>2 <input type="checkbox"/> Ideas of guilt or rumination over past errors or sinful deeds.</p> <p>3 <input type="checkbox"/> Present illness is a punishment. Delusions of guilt.</p> <p>4 <input type="checkbox"/> Hears accusatory or denunciatory voices and/or experiences threatening visual hallucinations.</p> |
| <p>3. SUICIDE</p> <p>0 <input type="checkbox"/> Absent.</p> <p>1 <input type="checkbox"/> Feels life is not worth living.</p> <p>2 <input type="checkbox"/> Wishes he/she were dead or any thoughts of possible death to self.</p> <p>3 <input type="checkbox"/> Ideas or gestures of suicide.</p> <p>4 <input type="checkbox"/> Attempts at suicide (any serious attempt rate 4).</p> | <p>7. WORK AND ACTIVITIES</p> <p>0 <input type="checkbox"/> No difficulty.</p> <p>1 <input type="checkbox"/> Thoughts and feelings of incapacity, fatigue or weakness related to activities, work or hobbies.</p> <p>2 <input type="checkbox"/> Loss of interest in activity, hobbies or work – either directly reported by the patient or indirect in listlessness, indecision and vacillation (feels he/she has to push self to work or activities).</p> <p>3 <input type="checkbox"/> Decrease in actual time spent in activities or decrease in productivity. Rate 3 if the patient does not spend at least three hours a day in activities (job or hobbies) excluding routine chores.</p> <p>4 <input type="checkbox"/> Stopped working because of present illness. Rate 4 if patient engages in no activities except routine chores, or if patient fails to perform routine chores unassisted.</p> |
| <p>4. INSOMNIA: EARLY IN THE NIGHT</p> <p>0 <input type="checkbox"/> No difficulty falling asleep.</p> <p>1 <input type="checkbox"/> Complains of occasional difficulty falling asleep, i.e. more than ½ hour.</p> <p>2 <input type="checkbox"/> Complains of nightly difficulty falling asleep.</p> | <p>8. RETARDATION (slowness of thought and speech, impaired ability to concentrate, decreased motor activity)</p> <p>0 <input type="checkbox"/> Normal speech and thought.</p> <p>1 <input type="checkbox"/> Slight retardation during the interview.</p> <p>2 <input type="checkbox"/> Obvious retardation during the interview.</p> <p>3 <input type="checkbox"/> Interview difficult.</p> <p>4 <input type="checkbox"/> Complete stupor.</p> |
| <p>5. INSOMNIA: MIDDLE OF THE NIGHT</p> <p>0 <input type="checkbox"/> No difficulty.</p> <p>1 <input type="checkbox"/> Patient complains of being restless and disturbed during the night.</p> <p>2 <input type="checkbox"/> Waking during the night – any getting out of bed rates 2 (except for purposes of voiding).</p> | |
| <p>6. INSOMNIA: EARLY HOURS OF THE MORNING</p> <p>0 <input type="checkbox"/> No difficulty.</p> <p>1 <input type="checkbox"/> Waking in early hours of the morning but goes back to sleep.</p> <p>2 <input type="checkbox"/> Unable to fall asleep again if he/she gets out of bed.</p> | |

9. AGITATION

- 0 ☐ None.
- 1 ☐ Fidgetiness.
- 2 ☐ Playing with hands, hair, etc.
- 3 ☐ Moving about, can't sit still.
- 4 ☐ Hand wringing, nail biting, hair-pulling, biting of lips.

10. ANXIETY PSYCHIC

- 0 ☐ No difficulty.
- 1 ☐ Subjective tension and irritability.
- 2 ☐ Worrying about minor matters.
- 3 ☐ Apprehensive attitude apparent in face or speech.
- 4 ☐ Fears expressed without questioning.

11. ANXIETY SOMATIC (physiological concomitants of anxiety) such as: gastro-intestinal – dry mouth, wind, indigestion, diarrhea, cramps, belching cardio-vascular – palpitations, headaches respiratory – hyperventilation, sighing urinary frequency sweating

- 0 ☐ Absent.
- 1 ☐ Mild.
- 2 ☐ Moderate.
- 3 ☐ Severe.
- 4 ☐ Incapacitating.

12. SOMATIC SYMPTOMS GASTRO-INTESTINAL

- 0 ☐ None.
- 1 ☐ Loss of appetite but eating without staff encouragement. Heavy feelings in abdomen.
- 2 ☐ Difficulty eating without staff urging. Requests or requires laxatives or medication for bowels or medication for gastro-intestinal symptoms.

13. GENERAL SOMATIC SYMPTOMS

- 0 ☐ None.
- 1 ☐ Heaviness in limbs, back or head. Backaches, headaches, muscle aches. Loss of energy and fatigability.
- 2 ☐ Any clear-cut symptom rates

14. GENITAL SYMPTOMS (symptoms such as loss of libido, menstrual disturbances)

- 0 ☐ Absent.
- 1 ☐ Mild.
- 2 ☐ Severe.

15. HYPOCHONDRIASIS

- 0 ☐ Not present.
- 1 ☐ Self-absorption (bodily).
- 2 ☐ Preoccupation with health.
- 3 ☐ Frequent complaints, requests for help, etc.
- 4 ☐ Hypochondriacal delusions.

16. LOSS OF WEIGHT (RATE EITHER a OR b)

a) According to the patient: b) According to weekly measurements:

- 0 ☐ in No weight loss. 0 ☐ Less than 1 lb weight loss week.
- 1 ☐ Probable weight loss associated with in week. 1 ☐ Greater than 1 lb weight present illness.
- 2 ☐ Definite (according to weight in week) loss to patient. 2 ☐ Greater than 2 lb weight loss.
- 3 ☐ Not assessed. 3 ☐ Not assessed.

16. INSIGHT

- 0 ☐ Acknowledges being depressed and ill.
- 1 ☐ Acknowledges illness but attributes cause to bad food, climate, overwork, virus, need for rest, etc.
- 2 ☐ Denies being ill at all.

Total score: ☐☐☐

Annexure-3

Hamilton Anxiety Rating Scale (HAM-A)

Reference: Hamilton M. The assessment of anxiety states by rating. *Br J Med Psychol* 1959, 32:50–55.

Rating Clinician-rated

Administration time 10–15 minutes

Main purpose To assess the severity of symptoms of anxiety

Population Adults, adolescents and children

Commentary

The HAM-A was one of the first rating scales developed to measure the severity of anxiety symptoms, and is still widely used today in both clinical and research settings. The scale consists of 14 items, each defined by a series of symptoms, and measures both psychic anxiety (mental agitation and psychological distress) and somatic anxiety (physical complaints related to anxiety). Although the HAM-A remains widely used as an outcome measure in clinical trials, it has been criticized for its sometimes-poor ability to discriminate between anxiolytic and antidepressant effects, and somatic anxiety versus somatic side effects. The HAM-A does not provide any standardized probe questions. Despite this, the reported levels of interrater reliability for the scale appear to be acceptable.

Scoring

Each item is scored on a scale of 0 (not present) to 4 (severe), with a total score range of 0–56, where <17 indicates mild severity, 18–24 mild to moderate severity and 25–30 moderate to severe.

Versions

The scale has been translated into: Cantonese for China, French and Spanish. An IVR version of the scale is available from Healthcare Technology Systems.

Additional references

Maier W, Buller R, Philipp M, Heuser I. The Hamilton Anxiety Scale: reliability, validity and sensitivity to change in anxiety and depressive disorders. *J Affect Disord* 1988;14(1):61–8.

Borkovec T and Costello E. Efficacy of applied relaxation and cognitive behavioral therapy in the treatment of generalized anxiety disorder. *J Clin Consult Psychol* 1993; 61(4):611–19

Address for correspondence

The HAM-A is in the public domain.

Hamilton Anxiety Rating Scale (HAM-A)

Below is a list of phrases that describe certain feeling that people have. Rate the patients by finding the answer which best describes the extent to which he/she has these conditions. Select one of the five responses for each of the fourteen questions.

0 = Not present, 1 = Mild, 2 = Moderate, 3 = Severe, 4 = Very severe.

1	Anxious mood	0	1	2	3	4
	Worries, anticipation of the worst, fearful anticipation, irritability.					
2	Tension	0	1	2	3	4
	Feelings of tension, fatigability, startle response, moved to tears easily, trembling, feelings of restlessness, inability to relax.					
3	Fears	0	1	2	3	4
	Of dark, of strangers, of being left alone, of animals, of traffic, of crowds.					
4	Insomnia	0	1	2	3	4
	Difficulty in falling asleep, broken sleep, unsatisfying sleep and fatigue on waking, dreams, nightmares, night terrors.					
5	Intellectual	0	1	2	3	4
	Difficulty in concentration, poor memory.					
6	Depressed mood	0	1	2	3	4
	Loss of interest, lack of pleasure in hobbies, depression, early waking, diurnal swing.					
7	Somatic (muscular)	0	1	2	3	4
	Pains and aches, twitching, stiffness, myoclonic jerks, grinding of teeth, unsteady voice, increased muscular tone.					
8	Somatic (sensory)	0	1	2	3	4
	Tinnitus, blurring of vision, hot and cold flushes, feelings of weakness, pricking sensation.					
9	Cardiovascular symptoms	0	1	2	3	4
	Tachycardia, palpitations, pain in chest, throbbing of vessels, fainting feelings, missing beat.					
10	Respiratory symptoms	0	1	2	3	4
	Pressure or constriction in chest, choking feelings, sighing, dyspnea.					
11	Gastrointestinal symptoms	0	1	2	3	4
	Difficulty in swallowing, wind abdominal pain, burning sensations, abdominal fullness, nausea, vomiting, borborygmi, looseness of bowels, loss of weight, constipation.					
12	Genitourinary symptoms	0	1	2	3	4
	Frequency of micturition, urgency of micturition, amenorrhea, menorrhagia, development of frigidity, premature ejaculation, loss of libido, impotence.					
13	Autonomic symptoms	0	1	2	3	4
	Dry mouth, flushing, pallor, tendency to sweat, giddiness, tension headache, raising of hair.					
14	Behavior at interview	0	1	2	3	4
	Fidgeting, restlessness or pacing, tremor of hands, furrowed brow, strained face, sighing or rapid respiration, facial pallor, swallowing, etc.					

Annexure-4

Multidimensional Scale of Perceived Social Support

(Zimet, Dahlem, Zimet & Farley, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**

Circle the "2" if you **Strongly Disagree**

Circle the "3" if you **Mildly Disagree**

Circle the "4" if you are **Neutral**

Circle the "5" if you **Mildly Agree**

Circle the "6" if you **Strongly Agree**

Circle the "7" if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).

References

- Canty-Mitchell, J. & Zimet, G.D. (2000). Psychometric properties of the Multidimensional Scale of Perceived Social Support in urban adolescents. *American Journal of Community Psychology*, 28, 391-400.
- Zimet, G.D., Dahlem, N.W., Zimet, S.G. & Farley, G.K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52, 30-41.
- Zimet, G.D., Powell, S.S., Farley, G.K., Werkman, S. & Berkoff, K.A. (1990). Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 55, 610-17.

Annexure-5

Stigma and Discrimination Attitude Scale (Sagili et al, 2016)

References:

Sagili KD, Satyanarayana S, Chadha SS. Is Knowledge Regarding Tuberculosis Associated with Stigmatising and Discriminating Attitudes of General Population towards Tuberculosis Patients? Findings from a Community Based Survey in 30 Districts of India. PLoS One. 2016;11(2):1–11.

Stigmatising and Discriminating Attitudes:

Stigmatising Attitudes	Now I will make some statements about people suffering from TB. Please let me know How much you agree to these?	Strongly Agree	Somewhat Agree	Disagree
1	Family of persons with TB should not be allowed to participate in any social function.			
2	Women with TB who are married should be sent off to her parent's house.			
3	Children with TB should not be allowed to go to school.			
4	Children of persons with TB should not be allowed to go to school.			
5	Persons with TB engaging in daily wage labour should not be allowed to work.			
6	Persons with TB are threat to community.			
7	Persons with TB should be left isolated in the community.			

Discriminating Attitudes	Which of the following you would agree to do?	Yes	No	Don't Know / Can't say
1	Share a meal with person you know had TB			
2	Take a Woman with TB to hospital if you suspect TB			
3	Marry your daughter to a boy knowing he had TB			
4	Isolate your family member having TB in the house			
5	Marry your son to a girl who you know had TB			
6	Send your daughter in law to parent's house if she had TB in order to protect other family members from TB			



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