



Ministry of Health & Family Welfare  
Government of India



# Guidelines on Engaging Family Caregivers for Supporting Persons with Tuberculosis in India





सत्यमेव जयते  
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# Guidelines on Engaging Family Caregivers for Supporting Persons with Tuberculosis in India

## List of Contributors

- **Dr. Rajendra P Joshi**  
Deputy Director General-TB, Central TB Division, MoHFW
- **Dr. Raghuram Rao**  
Asst. Director General (TB) Central TB Division, MoHFW
- **Dr. Nishant Kumar**  
Joint Director (Public Health), Central TB Division, MoHFW
- **Dr. Varsha Rai**  
State TB officer, Madhya Pradesh
- **Dr. Anuradha Jain**  
Senior Advisor, Health System Strengthening, USAID India
- **Dr. Bhavin Vadera**  
Project Management Specialist (Health), USAID India
- **Dr. Amar N Shah**  
Sr. TB Advisor (Strategy and Innovation), USAID India
- **Dr. Neeraj Agrawal**  
Chief of Party, NISHTHA/Senior Program Director, Jhpiego
- **Dr. Debadutta Parija**  
Country Lead TB, Infectious Diseases and Surveillance, Jhpiego
- **Ms. Krithika Murali**  
Advisor Documentation and Knowledge Management & Coordinator South Asia Regional CPHC, NISHTHA, Jhpiego
- **Dr. Puja Ambule**  
Technical Specialist TB, NISHTHA, Jhpiego
- **Dr. Jyoti Banawari**  
State Team Lead, Jhpiego, Madhya Pradesh
- **Dr. Arjun Rangarajan**  
Senior Director Health System and global Health Strategy, NOORA Health
- **Dr. Jignesh Parmar**  
Senior Program Officer, NISHTHA Jhpiego
- **Ms. Asha Ahuja**  
Documentation Officer, NISHTHA Jhpiego
- **Ms. Sophia Khumukcham**  
National Consultant Community Engagement, WHO-Technical Support Unit, Central TB Division, MoHFW
- **Ms. Sumitha Chalil**  
National Consultant Community Engagement, WHO-Technical Support Network, Central TB Division, MoHFW
- **Dr. Swati Iyer**  
National Consultant Private Sector Engagement, World Health Organization
- **Dr. Charuta Gokhale**  
Technical Officer-Research, CTD, MoHFW
- **Dr. Pooja Tripathi**  
National Consultant for Pediatrics TB & Gender, International Union Against Tuberculosis and Lung Disease (The Union)
- **Dr. Hardik Solanki**  
National Consultant-TB Prevention & LTBI, WHO-Technical Support Unit, Central TB Division, MoHFW
- **Dr. Sivavallinathan Arunachalam**  
National Consultant, WHO-Technical Support Unit, Central TB Division, MoHFW
- **Dr. Deepak Balasubramanian**  
Program Team, Everwell Health Solutions
- **Mr. Sudarshan Saggu**  
Program Team, Everwell Health Solutions
- Community Health Officers of Guna and Khandwa Districts, Madhya Pradesh
- And all District TB officers, NTEP staff and CHOs who have provided valuable inputs to this document in a collaborative manner, especially to the state & district officials.

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## Abbreviations

<b>ANM</b>	: Auxiliary Nurse and Midwife
<b>ASHA</b>	: Accredited Social Health Activist
<b>CHOs</b>	: Community Health Officers
<b>DTO</b>	: District TB Officer
<b>HWCs</b>	: Health and Wellness Centres
<b>IEC</b>	: Information Education and Communication
<b>MDR TB</b>	: Multi Drug resistance Tuberculosis
<b>MOs</b>	: Medical Officers
<b>PPSA</b>	: Patient Provider Support Agency
<b>SoP</b>	: Standard Operating Procedures
<b>STO</b>	: State TB Officer
<b>STS</b>	: Senior Treatment Supervisors
<b>TB</b>	: Tuberculosis
<b>TBHV</b>	: TB Health Visitors
<b>TB-IC</b>	: TB-Infection Control
<b>TPT</b>	: Tuberculosis Preventive Treatment

As we continue to battle global tuberculosis (TB) epidemic, it has become increasingly clear that family caregivers play a crucial role in providing care and support to persons with TB. Family caregivers are often the primary providers of care for persons with TB, and their involvement can have a significant impact on the person's treatment outcomes.

Recognizing the critical role of family caregivers in TB care, it is essential to develop guidelines that provide recommendations and best practices for engaging and supporting family caregivers. These guidelines will help healthcare providers and policymakers to ensure that family caregivers receive the necessary training, support, and resources to provide quality care for persons with TB.

These guidelines are designed to be practical and easy to implement, focusing on the key areas where family caregivers can make a difference in TB care. They provide evidence-based recommendations for engaging family caregivers in the care of persons with TB, including providing education and training, involving them in treatment decisions, and ensuring their physical and emotional well-being.

We hope that these guidelines will serve as a valuable resource for healthcare providers, policymakers, and other stakeholders involved in TB care. By supporting and empowering family caregivers, we can improve the quality of care for persons with TB and ultimately, work towards the goal of ending the TB epidemic.







राजेश भूषण, आईएस  
सचिव  
**RAJESH BHUSHAN, IAS**  
SECRETARY



**FOREWORD**

भारत सरकार  
स्वास्थ्य एवं परिवार कल्याण विभाग  
स्वास्थ्य एवं परिवार कल्याण मंत्रालय  
Government of India  
Department of Health and Family Welfare  
Ministry of Health and Family Welfare

The United Nation's Sustainable Development Goals (SDG) 3, which focusses on "good health & well-being", commits to ending transmission of all communicable diseases, including Tuberculosis (TB). Ministry of Health & Family Welfare (MoHFW), India, is committed to achieving this goal in a time-bound manner. We have been progressing steadily toward the vision of a TB-free India. The Govt. of India, under its flagship National TB Elimination Program (NTEP), has been making significant strides towards effectively combating the disease and associated conditions.

Honorable Prime Minister of India has set a bold target of a TB-free India by 2025, five years ahead of the SDG targets of 2030. Under the NTEP's National Strategic Plan (NSP) 2017-25, the requirements for moving toward ending TB have been integrated into four strategic pillars of Build, Detect, Treat, and Prevent.

While the NTEP takes all possible measures to combat this scourge, it is imperative that the family members of the affected patient are adequately capacitated to provide all necessary physical as well as psychological support to enable the patient to complete entire course of treatment, which can be anywhere between 6 months to 2 years or longer. These operational guidelines are an important step towards engaging with family caregivers and empowering them to provide holistic care and support to the patient as well as other family members throughout the course of the disease.

These operational guidelines provide a framework for the engagement of family caregivers for TB patients to serve as the first point of contact for a range of TB services spanning preventive, promotive, curative, and rehabilitative care to the TB to patients in their families under the NTEP platform.

I would urge all the State and UT governments to utilize these guidelines to bolster TB-related services already offered under the NTEP. I request all the Ayushman Bharat Health and Wellness Centers (AB-HWCs) to lead this initiative and take up a more proactive role in TB care and prevention in their respective catchment areas.

Let us join hands to defeat TB and achieve a TB-free India.

Place : New Delhi  
Date : 21<sup>st</sup> March 2023

(Rajesh Bhushan)





भारत सरकार  
स्वास्थ्य एवं परिवार कल्याण मंत्रालय  
निर्माण भवन, नई दिल्ली - 110011  
Government of India  
Ministry of Health & Family Welfare  
Nirman Bhavan, New Delhi - 110011

रोली सिंह, भा.प्र.से.  
**Roli Singh, I.A.S.**

अपर सचिव एवं मिशन निदेशक (रा.स्वा.मि.)  
Additional Secretary & Mission Director (NHM)



#### Message from AS&MD

Tuberculosis remains a global health emergency and continues to present major public health challenges worldwide. TB can have a significant impact on patients and their families, affecting physical and mental health, family dynamics, finances, and social relationships.

In order to sustain the efforts towards TB Free India, we need to create systems that provide holistic care and support to the person affected by TB and their family to reduce the impact of disease. For centuries, family members are universally acknowledged as the ideal caregivers and support for patients. Strengthening the role of family members as the primary caregivers, building their capacities in different aspects of care giving, and prevention, and providing need-based support to families for ensuring the successful outcome of patients can go a long way. This intervention will go a long way in empowering patients and their families to minimize the impact of the disease and help in reducing stigma, improving social support and quality of life of people affected by TB, and will ensure equity in TB care.

The National Guidelines on Engaging Family Caregivers for TB Patients highlight the role of family caregivers in improving the health outcome for TB patients, setting up coordination mechanisms between the caregivers and health facilities, sensitizing the health service providers, information education and communication activities, and monitoring mechanism. It also lists out the potential roles and responsibilities of different stakeholders in operationalizing these guidelines. This document will serve as a guiding document for planning, implementing, and monitoring the interventions aimed at strengthening the role of family caregivers in providing holistic care and support to TB patients and their families across the country.

I would like to congratulate all the experts and stakeholders for bringing out these important guidelines which would further help us in improving the social support and quality of life of people affected by TB and ensure successful outcomes and preventing the spread of disease in the community.

Let's Unite to End TB!

  
[Roli Singh]

स्वच्छ भारत - स्वस्थ भारत

Tele : 011-2306 3693, Telefax : 011-2306 3687, E-mail : [asmd-mohfw@nic.in](mailto:asmd-mohfw@nic.in)





भारत सरकार  
स्वास्थ्य एवं परिवार कल्याण मंत्रालय  
निर्माण भवन, नई दिल्ली-110011

GOVERNMENT OF INDIA  
MINISTRY OF HEALTH & FAMILY WELFARE  
NIRMAN BHAWAN, NEW DELHI-110011

डॉ. पी. अशोक बाबू, भा.प्र.से.  
संयुक्त सचिव  
**Dr. P. Ashok Babu, IAS**  
Joint Secretary



**MESSAGE**

The India TB Report 2023 highlights key programmatic achievements over the last year. The National TB Elimination Programme (NTEP) continues to innovate and implement newer strategies like state-of-the-art diagnostic tools, newer drugs and the use of digital technologies including artificial intelligence. But the true spirit of Jan Bhagidari through the engagement and empowerment of the community will be pivotal in making India TB-free.

Our communities provide invaluable support to spread awareness and dispel myths and misconceptions about TB. Patient support groups have been an informal platform for TB patients and their caregivers to share their experiences. State and District TB Forums serve as a formal platform for persons affected with TB and communities to raise their concerns and be an important voice in the decision-making. I am happy to share that TB Forums have been constituted in all States/UTs. These forums help people who have successfully fought the disease to become advocates for TB in the society thereby motivating their peers and providing necessary support. More than 3000 such "TB Vijetas" have been trained physically and around 28,000 have registered for the online self-learning course.

We have prioritized active case finding among vulnerable groups and have made concerted and targeted efforts to reach everybody in the community. The effort to diagnose additional persons affected by TB through this community-based case-finding strategy has been successful in many States and UTs. The programme is committed to ensure that all persons affected with TB receive highest standard for care. Partnerships are key for ensuring high-quality TB care and mitigating the catastrophic costs on account of TB to the affected families. Patient-Provider Support Agency (PPSA) models are being implemented in several high-burden geographies to increase accessibility and affordability to quality diagnostics and treatment for patients in the private sector and improve the treatment outcome.

In addition to routine monitoring mechanisms, the NTEP conducted Joint Supportive Supervision Missions (JSSM) to States/Union Territories (UTs) during the past 2 years for on-site evaluation and provided strategic support for addressing implementation challenges.

I commend the efforts of the TB programme as well as the other stakeholders for working towards a patient-centric health system.

TB Harega, Desh Jeetega !

( Dr. P. Ashok Babu )

टीबी हारेगा, देश जीतेगा—अधिक जानकारी के लिए संपर्क करें 1800-11-6666 (टोल फ्री)  
TB Harega, Desh Jeetega-For more information contact 1800-11-6666 (Toll Free)





**Dr. Rajendra P. Joshi**  
Deputy Director General  
Central TB Division

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आज़ादी का  
अमृत महोत्सव



### MESSAGE

भारत सरकार  
GOVERNMENT OF INDIA  
स्वास्थ्य और परिवार कल्याण मंत्रालय  
MINISTRY OF HEALTH & FAMILY WELFARE  
ROOM NO. G2 (GROUND FLOOR),  
JEEVAN VIHAR BUILDING, 3, SANSAD MARG,  
CONNAUGHT PLACE  
NEW DELHI - 110011  
ddgtb@rntcp.org  
ddgtb-mohfw@gov.in  
011-21400941

The Ministry of Health and Family Welfare in India has demonstrated a strong commitment to achieving the SDGs related to health and well-being. Through various initiatives and policies, the Ministry is working towards ensuring that all citizens have access to affordable, high-quality healthcare services and are able to live healthy and fulfilling lives. At the Ministry of Health & Family Welfare, we are working on a comprehensive plan that seeks to address a wide range of challenges and promote the health and well-being of all citizens.

In our fight against TB, our honorable Prime Minister has set a bold target of a TB-free India by 2025, five years ahead of the SDG targets of 2030. The Ministry of Health and Family Welfare has worked tirelessly to improve the quality of treatment and create comprehensive support systems for TB patients. As a result, we have seen a steady decline in TB incidence and mortality rates over the past few years.

In order to sustain the efforts, we need to create systems that support and empower patients, families, and communities to reduce the impact of the disease. This will help us to improve equity in TB care and can empower the community to take control of their health and the health of their loved ones.

Considering the immense role of families and communities in prevention, providing need-based support to families, providing proper nutrition, reducing stigma, improving social support, and improving the quality of life of people affected by TB for ensuring a successful outcome. I am glad to present National Guidelines on Engaging Family Caregivers for Persons with TB in India. The guideline outlines the detailed technical and operational aspects for strengthening the role of families and communities in the fight against TB.

Let us all work together to build TB Free India!

(Dr Rajendra P Joshi)

## Background

According to Global Tuberculosis (TB) report 2022, India currently accounts for 28.3% of the global TB burden, as well as 26.4% of the global burden of Multi Drug Resistant TB (MDR-TB). While the Government of India (GoI) ensures free diagnostics as well as management of TB across the country, through its robust National TB Elimination Program, the focus on providing care still rests with the health system. While the healthcare system plays an important role in providing treatment for the persons with TB, family members play an even more important role in caring for a person with TB.

For centuries, family members have provided care and support to each other during times of illness. Family members spend the maximum amount of time with the patient and are universally acknowledged as the ideal caregivers and support for the patients. However, family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, and receive little guidance from the formal healthcare providers. Due to inadequate knowledge and skill, family caregivers may be unfamiliar with the type of care they must provide or the amount of care needed. Family caregivers may not know when they need community resources, and how to access and utilize available resources in an optimum way. Secondly, family members are often untapped when it comes to effectively involving them in caregiving, prevention, and recovery at all levels of healthcare. With very limited information or training, families are often ill-equipped to provide support during the recovery process; sometimes resulting in higher rates of relapse and complications.

Researchers have shown that family caregiving enhances caregiver-recipient relationship and caregivers' confidence. Also, caregivers learn to handle difficult situations and derive satisfaction from their caregiving responsibilities which further improves the health outcome of patient. Strengthening the role of family members as the primary caregivers, building their capacities in different aspects of caregiving, prevention and providing a need-based support to families for ensuring the successful outcome of patients can go a long way. This intervention will ensure comprehensive and holistic care and support to the patient and their family members by identifying early signs of complications, preventing complications, and timely referrals throughout the course of the disease. Moreover, it will also support recovery, ensure provision of proper nutrition, follow standard practices thereby improving overall health outcomes of all types of persons with TB. Further, this intervention will help in reducing stigma, improving social support and quality of life of people affected by TB and will ensure equity in TB care.

The idea of building capacity of family members in taking care of persons with TB can be materialized through interventions tailored to identified family members during their interactions with the health care system in person and through other platforms. These exercises can be led and implemented by trained healthcare staff such as Community Health Officers (CHOs), Medical Officers, Senior Treatment Supervisors (STS), TB Health Visitors (TBHV), Auxiliary Nurse Midwives (ANMs) etc. Apart from training, family members can be provided easy access to engaging and informative materials such as videos, animation tools, and information brochures in their own language through various IT and mobile platforms, to act as ready reckoners and reference points. Early evidence from USAID-NISHTHA project initiative, implemented by Jhpiego and NOORA in two





high-burden districts of Madhya Pradesh (Guna and Khandwa) points towards better adherence as well as treatment outcomes for persons with TB, whose family members have been trained as caregivers. In view of this, National TB Elimination Program, Ministry of Health & Family Welfare rolled out guidelines on engagement of family caregiver for persons with TB to provide holistic care and support to the patient and their family members throughout the course of the disease.

## Scope

This document provides guidance on the engagement of family members as trained and skilled primary caregivers for providing comprehensive support and education to family members and caregivers, addressing all aspects of TB treatment and care for improved health outcomes of persons with TB.

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Source: (1\* Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R, Eden J, editors. <https://www.ncbi.nlm.nih.gov/books/NBK396398/>)

## Program Goals and Objectives

### Goal

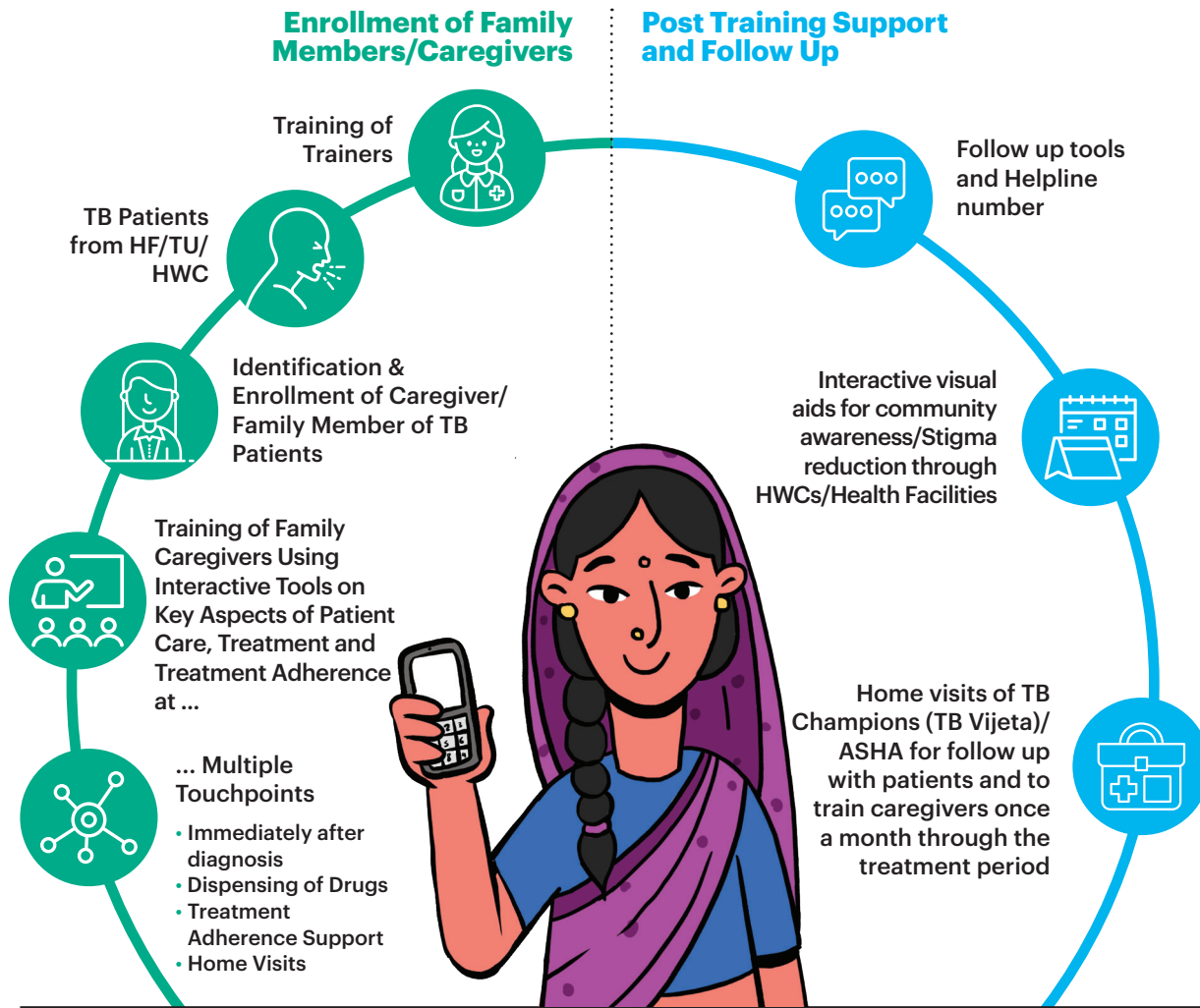
To provide holistic care and support to the patient and their family members throughout the course of the disease, ensuring successful treatment outcomes, and preventing the spread of TB in the community.

### Objectives

-  Engage family members as trained and skilled primary caregivers for improved health outcomes for persons with TB.
-  Enhance self-efficacy and confidence of persons with TB and their family members to practice healthy behaviors, including adherence to treatment regimens.
-  Increase knowledge and awareness about TB among family members and the community.
-  Enhance capacity of the community to expand the scope of their support.

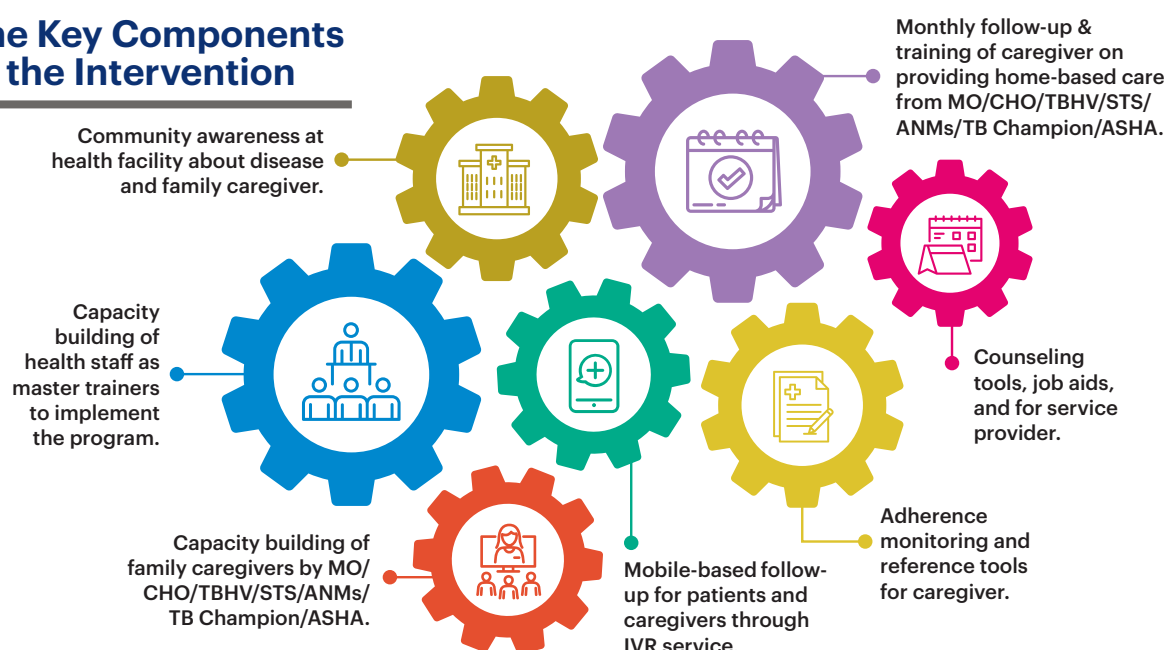


## The Intervention



This initiative of NTEP will majorly focus on empowering family members as primary caregiver of persons with TB to provide holistic and comprehensive care throughout the course of treatment for ensuring successful treatment outcomes and preventing the spread of TB in the community. Under this initiative, one responsible caregiver for every confirmed person with TB will be identified and enrolled in NI-KSHAY by health staff. The identified caregiver will be asked to accompany the person with TB in every visit to the health facility. During each visit, the identified caregiver will be trained by health staff (CHOs/MOs/ANM/ASHA/TB HV/STS) on different aspects of caregiving using interactive tools designed for caregiver. Health staff of current treatment facility will need to ensure that every person with TB and their family caregiver will be followed-up on monthly basis for adherence monitoring and training of caregivers. A set of interactive counselling tools, training materials and job-aids are developed and provided under this initiative for caregivers to capacitate them. An IVR based reminder/follow-up messages/training capsules will be sent to all enrolled caregivers twice a week for ensuring treatment adherence and imparting training to the caregivers.

## The Key Components of the Intervention



## Training of Health Staff

- All general health system staff and different cadres of NTEP should be trained on the family caregiving initiative. A standardized curriculum is enclosed as *Annexure-1* for health care providers.
- The design of the training is to ensure that the health care providers (CHO/TB Champions (TB Vijeta) (TB Vijeta)/TBHV/ANM/ASHA) acquire knowledge and skill and attitude for clinical management, case finding and outreach support to patients, after treatment initiation. Besides this, the team will also learn on how to identify and engage family caregivers in their facilities and communities. All the service providers dealing with TB should be trained on communication and counseling skills which will enable them to ensure better long-term adherence to treatment of persons with TB through family caregivers. Training on soft skills such as attitude, behavior, communication and counseling need to be included as part of the capacity-building modules.
- A pool of master trainers should be created at state level and district level and this pool will ensure the cascade training of the field staff.
- It has to be ensured that the CHOs/MO/STS/TBHV are trained on the NTEP guidelines using the standardized training material shared by the CTD. Self-learning modules for CHOs on TB are also available on the Swasth eGurukul platform of the Central TB Division (<https://www.swasth-egurukul.in/home/myhome>).
- A one-day/half-day sensitization of CHOs/MOs/STS/TBHV/MPW (who are already trained in NTEP) on the standard training curriculum, to be organized by the district on the family care model initiative.

Note\* Family caregiving component will be incorporated in all standard curriculum of TB Champions (TB Vijeta) (TB Vijeta) and Community Health Officers/MOs/STS/TBHV etc.

- Once the CHOs/MOs/TBHV/STS are trained, a two-hour orientation of ASHAs/ANMs/ TB Champions (TB Vijeta) (TB Vijeta) need to be organized on family caregiver tools and collaterals at the facility level.

## Identification & Enrollment of Family Caregiver

- Post training, in order to ensure the delivery of quality TB services, suitable family members should be identified by the health staff (preferably doctor initiating treatment of TB patient) for all the active persons with TB at the time of treatment initiation.
- A family caregiver includes a relative and non-relative (including friends) who provide unpaid care to persons in need of care.
- Family caregiver will be chosen by the person affected by TB.
- The caregiver need not necessarily be a blood relative of the patient.

### Criteria to Choose a Family Caregiver

- Any person who is willing to take the responsibility of caring for the patient and consented to become a family caregiver Any person who is above 14 years of age.
- Any person who stays with the person affected by TB most of the time.
- Any person who is acceptable to the persons with TB are comfortable with caregiver.

Note\* • Caregiving for a person with a TB can be done by any gender identity and sexual identity, including but not limited to cis men, cis women, and LGBTQIA++ persons (lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual etc).  
 • Founded on the principles of inclusiveness, informed consent, and informed choice, the scope of the word 'family member' is broad and, in addition to conventional family structure, may recognize members of a family of choice, found family, kith and kin, close friends and partners."

- Post identification of family caregiver during treatment initiation, family caregivers and patients should be enrolled in NI-KSHAY.
- Treatment initiating facility will further transfer the person in NI-KSHAY to designated Ayushman Bharat Health and Wellness Centre (AB-HWC) for further support and training. The CHO at the HWC will ensure monthly training and follow up of caregiver and patient at the facility or during outreach.
- In urban areas or where there are no AB-HWCs, STS/TB HV/ANM of current treatment facility should be responsible for monthly training of the family caregiver and follow-up of TB patient at the facility or during outreach.

## Follow-up Trainings of the Family Caregiver & Patients

- All persons with active TB (including DR-TB and patients taking treatment from private sector) and caregivers should be followed-up on monthly basis for adherence monitoring and trainings should be imparted to caregivers on different aspects of disease, prevention, and providing home-based care throughout the treatment duration.

- Persons with TB along with the designated family caregivers should visit the current treatment facility/AB-HWC every month for follow-up. During this visit MO/CHO/STS/TBHV/ANM will conduct training sessions for family caregiver using various interactive training tools available in the program.
- If persons with TB are not able to come to the health facility, CHO/TB Champions (TB Vijeta) (TB Vijeta)/STS/TBHV/ANM are expected to reach out to all persons with TB and to train family caregivers on different aspects of TB care on a monthly basis.

### Training Schedule of Caregivers and Topics to be Covered

Sr. No.	Stages	Touchpoints	Purpose (Topics to be covered during interaction)	Responsible Person
1.	Post Diagnosis	Immediately after confirmation of diagnosis or Within one week of treatment initiation	<ul style="list-style-type: none"> <li>• General awareness about disease.</li> <li>• To counsel other family members/ household for contact tracing &amp; TPT.</li> <li>• For treatment literacy including treatment duration, treatment adherence.</li> <li>• Nutrition, Nikshay Poshan Yojana and other incentives.</li> <li>• About myths &amp; misconception about disease.</li> <li>• Prevention of disease at household and Airborne Infection Control (AIC) at home.</li> <li>• Sputum disposal and disposal of waste of Persons with TB.</li> <li>• About services/community support platforms/social protection schemes available for Persons with TB and families.</li> </ul>	<ul style="list-style-type: none"> <li>• Doctor initiating treatment of Patient.</li> <li>• At AB-HWCs or during their outreach.</li> <li>• In Urban Areas (where there are no HWCs) – during the visit of patients and caregiver to health facility or TB Champions (TB Vijeta) (TB Vijeta)/ASHAs/ANMs/TBHV.</li> </ul>
2.		Monthly (till treatment completion)	<ul style="list-style-type: none"> <li>• Treatment adherence support.</li> <li>• Early identification of adverse drug reactions and management.</li> <li>• Screening of other family members for symptom identification.</li> <li>• Importance of nutrition.</li> <li>• Psychosocial Counseling.</li> <li>• About myths &amp; misconception about disease.</li> <li>• Prevention of disease at households and Airborne Infection Control (AIC) at home.</li> <li>• Sputum disposal and disposal of waste.</li> <li>• About services/community support platforms/social protection schemes available for Persons with TB and families.</li> <li>• Stigma reduction and any other issues.</li> <li>• Differentiated TB Care Assessments and its importance.</li> </ul>	<ul style="list-style-type: none"> <li>• At AB-HWCs - CHOs should ensure that all on-treatment persons with TB should visit AB- HWC once in a month with family caregiver to check adherence and assess patients for differentiated TB Care.</li> <li>• TB Champions (TB Vijeta) (TB Vijeta)/ASHAs should conduct household visit to all persons with TB on treatment TB and family caregiver on a monthly basis.</li> <li>• In urban areas or where there are no HWCs – during the monthly visit of persons with TB &amp; caregiver to health facility or TB Champions (TB Vijeta) (TB Vijeta)/ASHAs/ ANMs/TBHV during their outreach.</li> </ul>

Sr. No.	Stages	Touchpoints	Purpose (Topics to be covered during interaction)	Responsible Person
3.	Post Treatment	Monthly for initial 3 months after treatment completion.	<ul style="list-style-type: none"> <li>For symptom screening.</li> <li>To counsel them for vocational and physical rehabilitation.</li> <li>Post treatment care.</li> <li>Getting back to routine life.</li> <li>Psychosocial counseling.</li> </ul>	<ul style="list-style-type: none"> <li>In rural areas – MO, STS, CHO, MPW(M)/ANM, ASHA, TB Champion. In urban areas – MO, STS, TBHV, MPW(M)/ANM, ASHA, TB Champion.</li> </ul>
		At the end of 6 months.		
		At the end of 12 Months.		
		At the end of 18 months.		
		At the end of 24 months.		

### Follow-up by CHO at SHC-HWC

Every person with TB in the catchment area has to be followed up on a monthly basis preferably by CHOs. Follow-up can be done either at the facility or through household visits. Persons with TB should be followed-up till the completion of the treatment on a monthly basis and at mentioned frequency after treatment completion. This will ensure the training of family members on different aspects of caregiving along with supportive supervision of the patient for a successful treatment outcome.



### Follow-up by TB Champions (TB Vijeta)/ASHAs

For those persons with TB who are not able to come to the facility on a monthly basis for follow-up. TB Champions (TB Vijeta) will visit the households of these patients to ensure treatment adherence and train their family members by using the tools and collaterals. This follow-up exercise would be undertaken on a monthly basis. If required, TB Champions (TB Vijeta) can refer the person with TB and the caregiver to nearest AB-HWC for further assessment and consultation or teleconsultation.

### Follow-up of Patients in Urban areas

In urban areas identification and engagement will be done by a MO and further follow-ups of persons with TB and their caregivers will be done by ANMs/STS/TBHV/ASHA on a monthly basis.

Note\* The list of persons with active TB (on treatment TB patient) in the area of the AB-HWC is available and can be readily downloaded from the Ni-kshay current treatment register. All AB-HWCs have their own Ni-kshay login credentials. If CHOs are not able to download the reports, the same can be generated from Ni-kshay portal at the block/urban ward level by the corresponding TB unit and shall be shared with the concerned AB-HWC for further follow-up of TB patient and caregivers. The list contains all persons with TB who are notified (as per the current facility), and whose treatment outcome is not assigned.



## Family Caregiver Model for Patients Taking Private Treatment

Engagement of family members as trained and skilled primary caregivers for providing comprehensive support and education to family members and caregivers will be done for the persons seeking TB care, irrespective of the sector the patient belongs to. Although conceptually, the idea of implementation of the guidelines would remain unchanged, operationally it would differ in the following manner:

- It would be of utmost importance to sensitize the private healthcare provider about the model.  
**For districts where there are PPSAs:** Sensitization of the providers can be done through the existing PPSA staff in addition to the DTO/MOs/PPM co-ordinator/Programme coordinator. The providers may also be reached by systematic engagement of professional bodies like IMA, IAP FOGSI, consortiums etc.
- **For districts where there are no PPSAs:** The providers may be sensitized by DTO/MO/PPM Co-ordinator/Programme coordinator and by engagement with professional bodies like IMA, IAP FOGSI, consortiums etc.
- Training of the PPSA staff will be done in addition to the existing NTEP staff (CHOs/MO/MO urban PHC/MO Urban HWC/STS/TBHV/MPW) on the family caregiver model. Once the CHOs/MOs/TBHV/STS/PPSA staff are trained, they will organize a two-hour orientation of ASHAs/ANMs/TB Champions (TB Vijeta) on Family Caregiver tools and collaterals at the facility level.
- The caregiver will be chosen by the person with TB and the criteria will remain the same as mentioned above.
- Post identification of family caregiver during treatment initiation, family caregivers and persons with TB will be enrolled in NI-KSHAY by either the provider himself/his staff/PPSA/CHOs/MO/MO Urban PHC/MO urban HWC/STS/TBHV/MPW.
- In case the private providers volunteer, they may continue further support in training and follow-up of caregiver and patient at the facility. They may be assisted by their own staff or PPSA.



- If they do not volunteer, the provider may also transfer that case in NI-KSHAY to designated and nearest AB-HWC for further support and training and CHO/PPSA staff/MO/STS/TBHV/MPW staff will ensure monthly training and follow-up of caregiver and patient at the facility or during outreach.
- In urban areas or where there are no AB-HWCs, PPSA staff/MO urban PHC/MO urban PHC/TBHV/STS/ANM of the current treatment facility/current private health facility will be responsible for monthly training of the family caregiver and follow-up of person with TB at the facility or during outreach.
- Person with TB along with the designated family caregiver will visit current treatment facility/AB-HWC every month for adherence monitoring, during this visit MO/CHO/STS/TBHV/ANM will conduct training sessions for family caregiver using various interactive training tools available in the program.
- If persons with TB are not able to come to the health facility, PPSA staff/CHO/TB Champions (TB Vijeta)/STS/TBHV/ANM are supposed to reach out to all persons with TB to train family caregivers on different aspects of TB care on monthly basis.

## Family Caregiver Tools and Collaterals

### Tools for Service Provider

**Standee:** At health facility IEC materials may be displayed which have information related to symptoms of TB and importance of family caregiving. This will help the patients improve health-seeking behavior and avail TB services related to diagnosis and treatment.

**TB Care Tool:** This tool is developed for MOs/Health staff/CHOs/TB Champions (TB Vijeta)/TBHV/STS to orient persons with TB/family members regarding information related to TB such as signs and symptoms of TB, diagnosis available at health facilities, free treatment and treatment adherence, follow-up, Nutritional support, stigma related to TB, myths and misconceptions etc. This will ensure active participation from caregivers from the family of persons with TB.



**Training Manual:** Training manual includes technical details about the disease, National TB Elimination Program, and family caregiving. This manual will serve as a ready reckoner for Health staff/CHOs/TB Champions (TB Vijeta)/STS/TBHV.

**Job-Aid:** A job-aid for health staff will be kept at all health facilities for ready reference for the service provider.

## Tools for Family Caregiver

**IVR Service for Families and Patients:** An IVR service will be made available specially for family caregiver wherein an automated message will be sent out to patients and families (opt-in based) to reinforce health behavior messaging, give reminders to patient and caregiver for TB treatment adherence. Using the IVR service family member can report any adverse drug reactions using IVR service. At the time of enrollment family caregiver will share the phone number, after which caregiver can enroll themselves by placing a missed call. Tailored messages will be sent to the family caregiver for checking adherence of the patient, and educate caregiver on providing home-based care twice a week.

**Pragati Register:** The Pragati register will help persons with TB/caregivers to track treatment adherence, weight monitoring, nutritional support etc. In this register Persons with TB/caregivers will mark their adherence on the daily basis till treatment completion which will help in adherence monitoring. At the end of the month, caregivers can mention the weight of the patient. This Pragati register also has some basic information about the importance of nutrition and helpline numbers, myths and misconceptions and early signs of Adverse drug reactions.

**Visual Cards for Caregivers:** Visual cards will be made available to caregivers with key messages on the identification of ADRs, home-based caregiving, prevention of disease, nutrition etc.

## Roles and Responsibilities

Sr. No.	Cadre	Roles & Responsibilities
1.	<b>Caregivers</b>	<ul style="list-style-type: none"> <li>• Take care of persons with TB as instructed by Doctor/CHO/TB Champions (TB Vijeta).</li> <li>• Support patients for treatment compliance.</li> <li>• Marking treatment adherence in pragati register.</li> <li>• Facilitate patients for regular follow-ups/checkups at HWCs/health facilities.</li> <li>• Provide nutritional support/dietary monitoring of patients.</li> <li>• Facilitate TB Champions (TB Vijeta) for contact tracing activities.</li> <li>• Ensure initiation and adherence to TB preventive treatment for other eligible household contacts.</li> <li>• Identify and monitor adverse drug reactions and report.</li> <li>• Ensure AIC in house to keep others safe.</li> </ul>
2.	<b>TB Champions (TB Vijeta)/ASHA/ ANM</b>	<ul style="list-style-type: none"> <li>• Identify Presumptive cases from community and their potential caregivers.</li> <li>• Refer presumptive cases and caregivers to HWCs for sample collection.</li> <li>• Visit persons with TB and their families at least once a month for preparing families as caregivers, address issues around stigma and motivate household contacts to undergo TB screening and treatment.</li> <li>• Train caregivers at multiple touchpoints during household visits.</li> <li>• Identify contacts of index TB cases with symptoms of TB and refer them to HWCs for sample collection/testing.</li> <li>• Personally, accompany people to facilities to ensure they get tested promptly.</li> <li>• Provide psychological support to Persons with TB and their caregivers.</li> <li>• Motivate persons with TB who dropped out of treatment to resume taking their medication and complete treatment successfully.</li> <li>• Update CHOs/MOs about the status of treatment adherence of all persons with TB.</li> </ul>

Sr. No.	Cadre	Roles & Responsibilities
3.	<b>Community Health Officers</b>	<ul style="list-style-type: none"> <li>Identify and train TB Champions (TB Vijeta) at their facility (if not identified/trained yet).</li> <li>Orient HWC team including ANMs, ASHAs and TB Champions (TB Vijeta) about family caregiver initiative.</li> <li>Generate list of all on-treatment Persons with TB from NI-KSHAY.</li> <li>Screen individuals for symptoms of TB in family and ensure they all eligible family member started on TPT.</li> <li>Identify potential family caregivers for all presumptive and confirmed cases.</li> <li>Train &amp; counsel family caregivers at different touchpoints.</li> <li>Plan and ensure follow-up/training of all Persons with TB and family members along with TB Champions (TB Vijeta).</li> <li>Ensure all logistics including recording &amp; reporting formats, consumables, IEC etc. are available at AB-HWCs.</li> <li>Ensure enrollment of Persons with TB and family caregivers in NI-KSHAY platform.</li> <li>Overall monitoring of family caregiver initiative at AB-HWCs.</li> </ul>
5.	<b>Medical Officers (MO)</b>	<ul style="list-style-type: none"> <li>Identify and facilitate training of TB Champions (TB Vijeta) at their facility (if not identified/trained yet).</li> <li>Orient team including ANMs, ASHAs and TB Champions (TB Vijeta) about family caregiving Initiative.</li> <li>Screen individuals for symptoms of TB.</li> <li>Identify potential family caregivers for all presumptive and confirmed cases.</li> <li>Train &amp; counsel family caregivers at different touchpoints.</li> <li>Plan and monitor awareness and community mobilization activities.</li> <li>Plan and ensure follow-up/training of all Persons with TB in consultation with STS and TB Champions (TB Vijeta).</li> <li>Ensure all logistics including recording &amp; reporting formats, consumables, IEC etc. are available at facility.</li> <li>Ensure enrollment of TB patients and family caregivers in NI-KSHAY platform.</li> <li>Overall monitoring of initiative at the facility level.</li> <li>Provide need-based support to linked SHC-HWCs for implementing family caregiving initiative.</li> </ul>
6.	<b>STTs/ TBHVs</b>	<ul style="list-style-type: none"> <li>Overall coordination and monitoring of activities at the SHC-HWC level.</li> <li>Conduct monthly supportive supervisory visits to AB-HWCs.</li> <li>Mentor linked SHC-HWC staff for family caregiver initiative.</li> <li>Generate list of current Persons with TB from NI-KSHAY and share it with SHC-HWC.</li> <li>Facilitate training of CHOs/TB Champions.</li> <li>Conduct follow-up training for all family caregivers and patients.</li> <li>Handhold HWC team for implementing family caregiving initiative.</li> <li>Ensure all caregivers are enrolled a in NI-KSHAY.</li> </ul>
7.	<b>PPSA</b>	<ul style="list-style-type: none"> <li>Identify potential family caregivers for all presumptive and confirmed cases</li> <li>Train &amp; counsel family caregivers at different touchpoints</li> <li>Plan and ensure follow-up/training of all Persons with TB and family members along with TB Champions (TB Vijeta)</li> <li>Ensure all logistics including recording &amp; reporting formats, consumables, IEC etc. are available for private providers</li> <li>Screen individuals for symptoms of TB in family and ensure they all eligible family member started on TPT</li> <li>Overall coordination and monitoring of activities at the private provider level</li> <li>Conduct monthly supportive supervisory visits to Private providers</li> <li>Advocate and brief private provider for implementing family caregiving initiative</li> <li>Ensure all caregivers of private sector patients are enrolled a in NI-KSHAY</li> </ul>
8.	<b>DTOs</b>	<ul style="list-style-type: none"> <li>Issue guidance to the district for implementation of family care giver initiative.</li> <li>Ensure training of NTEP, NHM staff, and TB Champions (TB Vijeta) on NTEP and Family Caregiver initiative.</li> <li>Ensure availability of all tools and collaterals at AB-HWCs.</li> <li>Overall monitoring and supportive supervision of the district for effective implementation of the initiative.</li> <li>Ensure data reporting and recording in NI-KSHAY.</li> </ul>

Sr. No.	Cadre	Roles & Responsibilities
9.	STOs	<ul style="list-style-type: none"> <li>• Issuance of necessary guidance to districts for effective implementation of initiatives in field.</li> <li>• Ensure availability of IEC documents, tools &amp; collaterals.</li> <li>• Overall guidance and support districts on the implementation.</li> <li>• Create pool of master trainers at state and district level for cascade training of CHOs and TB Champions (TB Vijeta).</li> </ul>

## Recording and Reporting Mechanism

A robust mechanism for reporting and monitoring of TB services under the family caregiver model will be in place. All health facilities should use NI-KSHAY for the recording of information for family caregivers and their training. Feature to enroll family caregivers at the time of patient enrollment is developed in NI-KSHAY. Details about the enrolled caregiver, sessions conducted for the caregiver at identified touch points and patient follow-ups done will be recorded in NI-KSHAY. Pragati register will be made available at each health facilities for onward dissemination with patients and their caregiver and treatment adherence monitoring. Based on changes in programmatic guidelines and local needs, additional records can be maintained.

A monthly reporting format for tracking of key components of the programmatic activities from health facilities/HWCs and treatment facilities implementing the family caregiver model is in place. A suggestive list of monitoring indicators is mentioned below:

- No. of confirmed Persons with TB in the catchment area of health facility.
- No. of confirmed Persons with TB for whom caregivers have been identified.
- No. of caregivers identified and enrolled in NI-KSHAY for confirmed cases.
- No. of confirmed cases whose caregivers are trained.
- No. of patients for whom contact tracing was done by health staff.
- No. of contacts of Persons with TB referred for testing in reporting month by CHOs/ASHAs/TB Champions (TB Vijeta).
- No. of Patients and caregivers followed-up in reporting month.
- No. of patients and caregivers followed up after treatment completion.
- No. of patients with ADR referred to a facility by a caregiver.
- No. of patients whose family member initiated on TPT.

A suggestive monthly reporting format for the health facility implementing family caregiver model is provided in *Annexure I*

## Expected Outcomes

- Improvement in treatment adherence and case completion (treatment success) and TPT completion
- Improved knowledge and practice of healthy behaviors to prevent TB-related complications and hospitalizations
- Reduced stress and anxiety among family caregivers and patients and boost in the

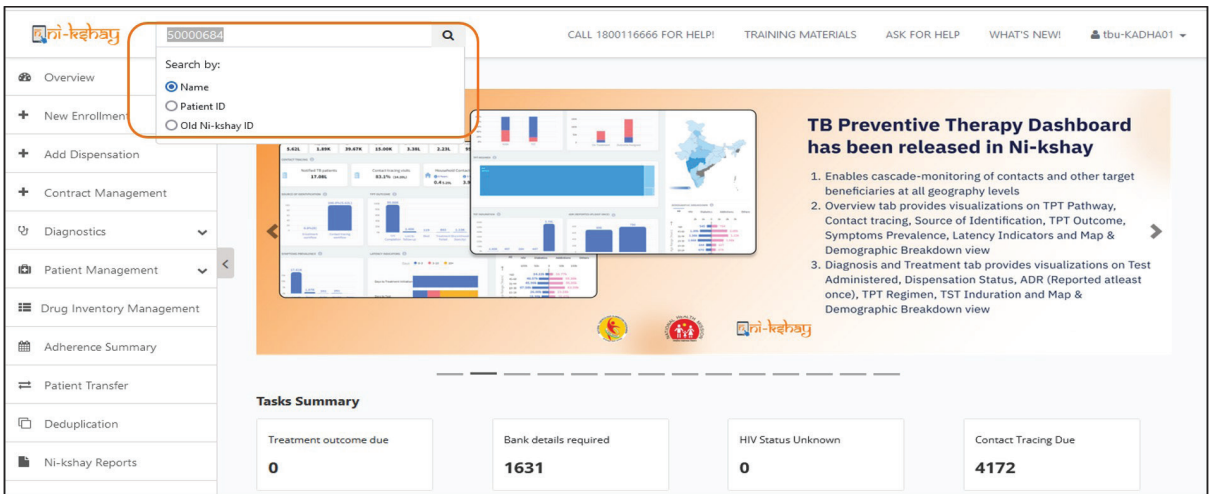
# Annexures

## Annexure I: Ni-kshay Workflows

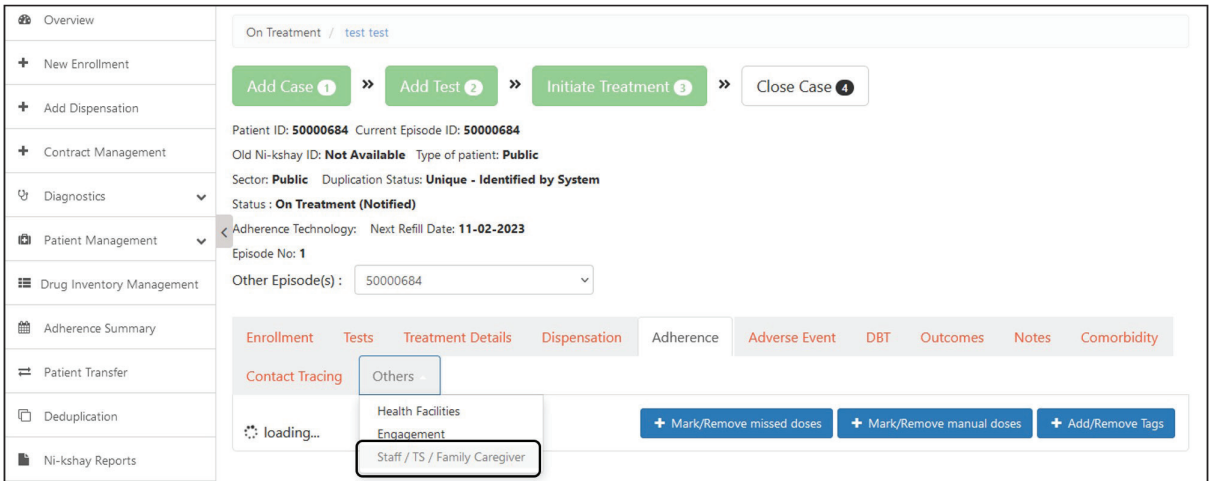
Ni-kshay will enable health staff to enroll a family caregiver and tag linked patients to them. While the enrollment of family caregiver is accessible through the Staff/TS Management Module, tagging patients is accessible either through Staff/TS Management Module or through the 'Staff/TS/Family Caregiver' tab in the patient management module. The details steps are enumerated below:

### STEPS TO ENROLL FAMILY CAREGIVER AND LINK PATIENTS VIA STAFF/TS MANAGEMENT MODULE

#### Step 1: Login to Ni-kshay using the credentials of the Health Facility



#### Step 2: Click on 'Staff/TS Management' under the Admin Section



### Step 3: Click on the 'Add Staff' Button

The screenshot shows the 'Add Staff' interface. The 'Staff' section displays a table with the following data:

No staff assigned				
IndiaTbPrivate	Fam	- - -	+ Add Staff	Cancel

The 'Fam|' dropdown menu is highlighted with a red box, and the 'Family Caregiver Demo Family Caregiver (DHARWAD)' option is visible below it.

### Step 4: Enter the name of the Family Giver and select 'Family Caregiver' from the 'Designation' Dropdown option.

(Data fields that are not relevant to the Family Caregiver will have defaulted values)

The screenshot shows the 'Add Staff' interface with the following data:

No staff assigned				
IndiaTbPrivate	Family Caregiver Demo Family Caregiver (DHARWAD)	x	Family Caregiver	8787878123

The 'Add Staff' button is highlighted with a red box.

The screenshot shows the 'Basic Details' form for adding staff. The 'Designation' dropdown is highlighted with a red box, and the 'Family Caregiver' option is selected. The 'Add Staff' button is also highlighted with a red box.

**\*This page can be used for adding staff at TU level only**

**Basic Details**

Name \* Test

Staff Type \* PublicAndPrivate

Designation \* Multi Purpose Worker  
Multi Purpose Health Assistant  
ASHA  
Aanganwadi Worker  
NGO Volunteer  
Other Community Volunteer  
Private Practitioner  
Others  
Accountant  
Medical Officer  
Family Caregiver

Primary Number \* This field is required

Secondary Number

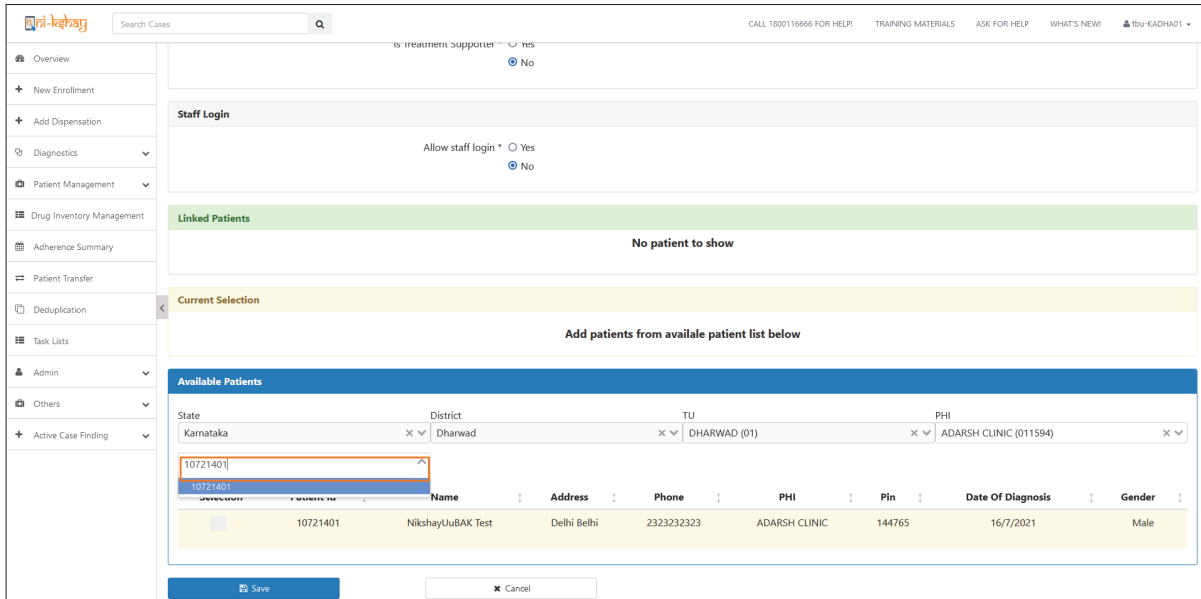
Email

Is Treatment Supporter \*  Private Practitioner  
 Others

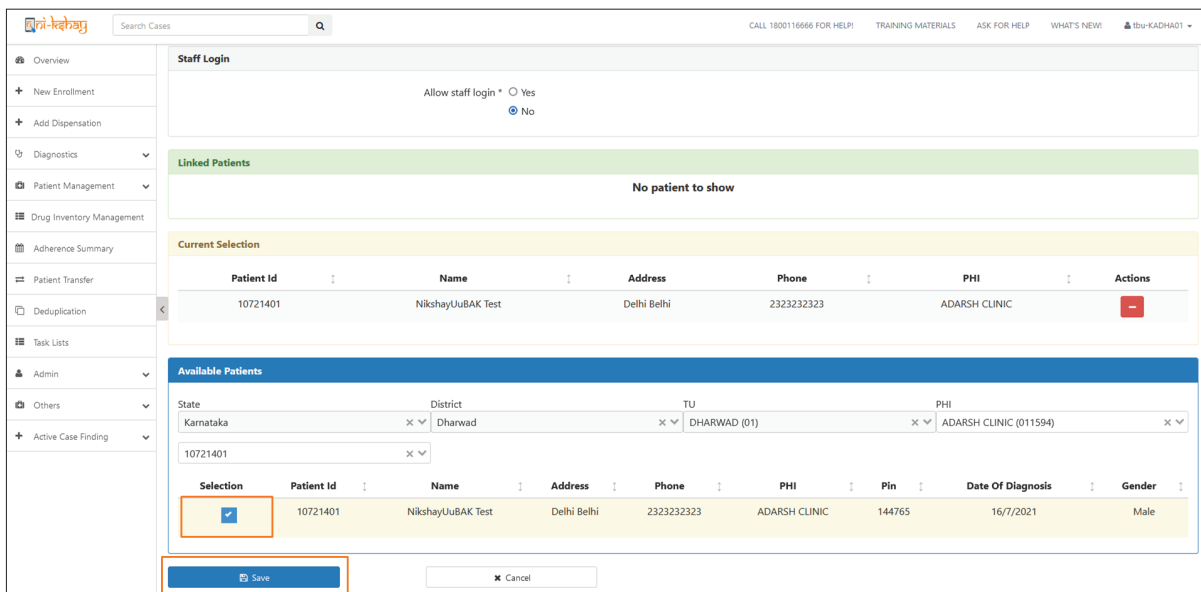
Save Cancel

**Step 5: If the patient has been registered, the newly added Family Caregiver can be tagged to the patient by entering the Ni-kshay ID of the patient in the 'Available Patients' section.**

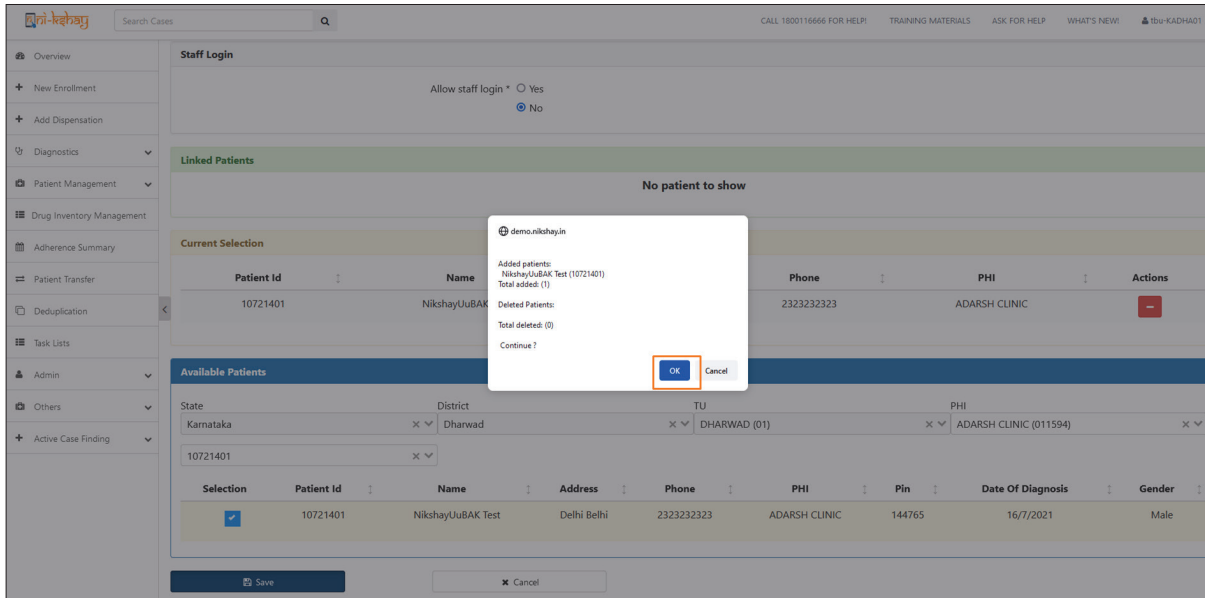
(If the patient ID has not been added, you can click 'Save' to complete addition of the Family Caregiver and tag the patient either through the patient page or through the Staff Module)



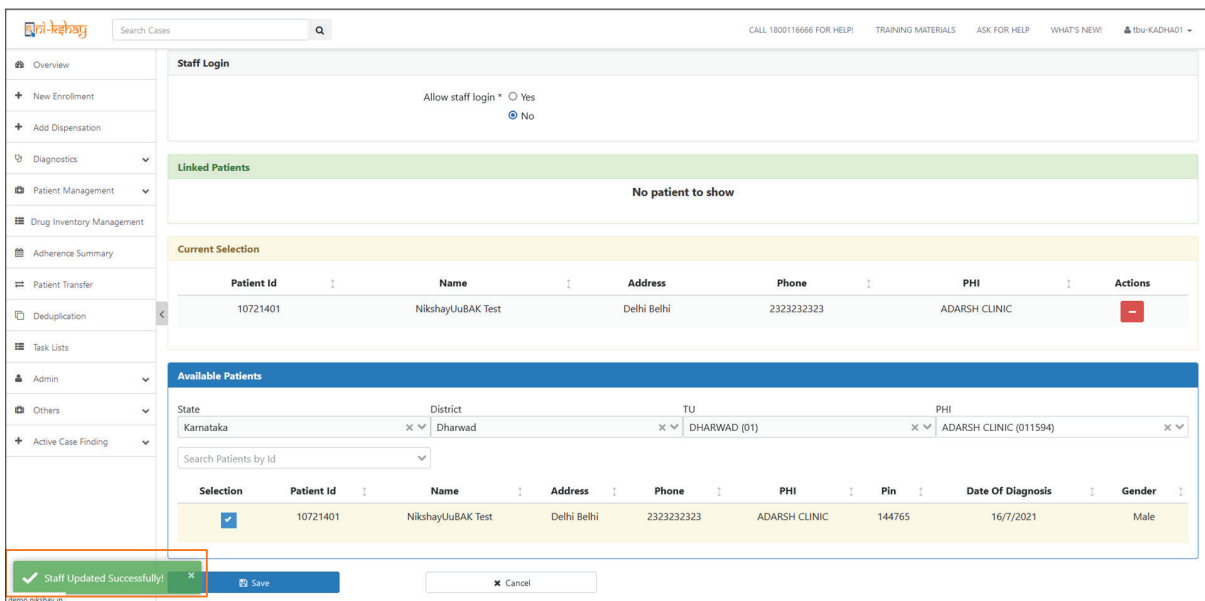
**Step 6: Upon finding the patient record, click the Checkbox selection and the 'Save' button.**



**Step 7: Select 'Ok' on the popup displayed.**



**Upon successful addition of the Family Caregiver, a success message is displayed on the screen.**





## STEPS TO LINK PATIENTS IN PATIENT MANAGEMENT MODULE

**Step 1: Login to Ni-kshay and search for the Patient who is to be tagged to an already enrolled Family Caregiver.**

**Step 2: Click on the ‘Staff/TS/Family Caregiver’ tab available under ‘Others’**

The screenshot shows the Ni-kshay patient management interface. The patient ID is 40962696. The 'Others' dropdown menu is open, showing options: Health Facilities, Family Caregiver (highlighted), and Engagement. The interface also displays an adherence chart for February and March 2023, showing 0% overall adherence.

**Step 3: Select the Family Caregiver from the list of added Family Caregivers in Staff section.**

The screenshot shows the Ni-kshay patient management interface for patient ID 10767036. The 'Family Caregiver' dropdown menu is open, showing a list of caregivers including 'test (NGO Volunteer)', 'test asha (Pharmacist/Storekeeper)', 'testling tbu (ASHA)', 'Shankar (ASHA)', 'Test (ASHA)', 'Supporter for treatment (ASHA)', 'Kishor T test (Senior treatment Supervisor)', 'sam test (NGO Volunteer)', 'testpatient (STS)', 'test (Senior Tuberculosis Laboratory Supervisor)', 'treatment supporter (ASHA)', 'hamisa (ASHA)', 'Test (Pharmacist/Storekeeper)', 'Radha (ASHA)', and 'test ts (Other Community Volunteer)'. The 'Add Staff' button is visible at the bottom.

**Step 4: Click on ‘Add Staff’ Button to tag the patient to the Family Caregiver.**

## Annexure II: Reporting Format

Sr. No.	Indicator	In Reporting Month	Cumulative Numbers
1	No. of confirmed TB patients in the catchment area of the health facility		
2	No. of confirmed TB patients for whom caregivers have been identified		
3	No. of confirmed cases whose caregivers are trained		
4	No. of confirmed patients provided with Pragati Register for adherence tracking		
5	No. of patients followed-up in reporting month		
6	No. of caregivers/contacts who were referred for TB testing by		
8.	No. of caregivers who received follow-up post-treatment completion in the reporting month		
9	No. of patients whose family member initiated on TPT		



