

No Time to Lose

Facilitating Person-centred Care for
People with Drug-resistant Tuberculosis



About REACH

REACH, or the Resource Group for Education and Advocacy for Community Health, is an India-based non-profit organisation, established in Chennai in 1999, by a team led by Prof M S Swaminathan (Founder - Chairman) and Dr. Nalini Krishnan (Founder - Director). Over the last 25 years, we have been a key partner and leader in the fight against TB in India, working closely with the TB programme and engaging various stakeholders including the private sector, affected communities, industries, the media, and other important stakeholders in TB elimination.

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About The StopTB Partnership

The Stop TB Partnership is a hosted entity of the United Nations Office for Project Services (UNOPS), with its Secretariat based in Geneva, Switzerland. Established in 2000, the Partnership aligns 1,600 partner organizations (including international and technical organizations, government programmes, research and funding agencies, foundations, NGOs, civil society and community groups, and the private sector) all over the world, leading global advocacy to end TB. TB REACH is a special initiative of Stop TB which provides funding to partners for testing innovative approaches and technologies aimed at improving the diagnosis and treatment success rates.

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About the Project

For a person with **drug-resistant tuberculosis (DR-TB)**, the pathway between diagnosis and treatment initiation is complex. It is a multi-step process spanning several days, involving multiple diagnostic tests and several specialist providers at different facilities.

To tackle this challenge, the **Wave-9 project**—implemented by REACH across eight districts in Bihar (*Bhagalpur, Darbhanga, Gaya, Muzaffarpur, Patna, Saran, Sitamarhi, and Vaishali*) with support from the **Stop TB Partnership** through the TB REACH initiative—focused on streamlining the pre-treatment evaluation (PTE) process and minimising delays. TB Champions, drawing from their own experiences, offered both practical and emotional support to people with DR-TB, enhancing treatment literacy and navigation through the healthcare system.

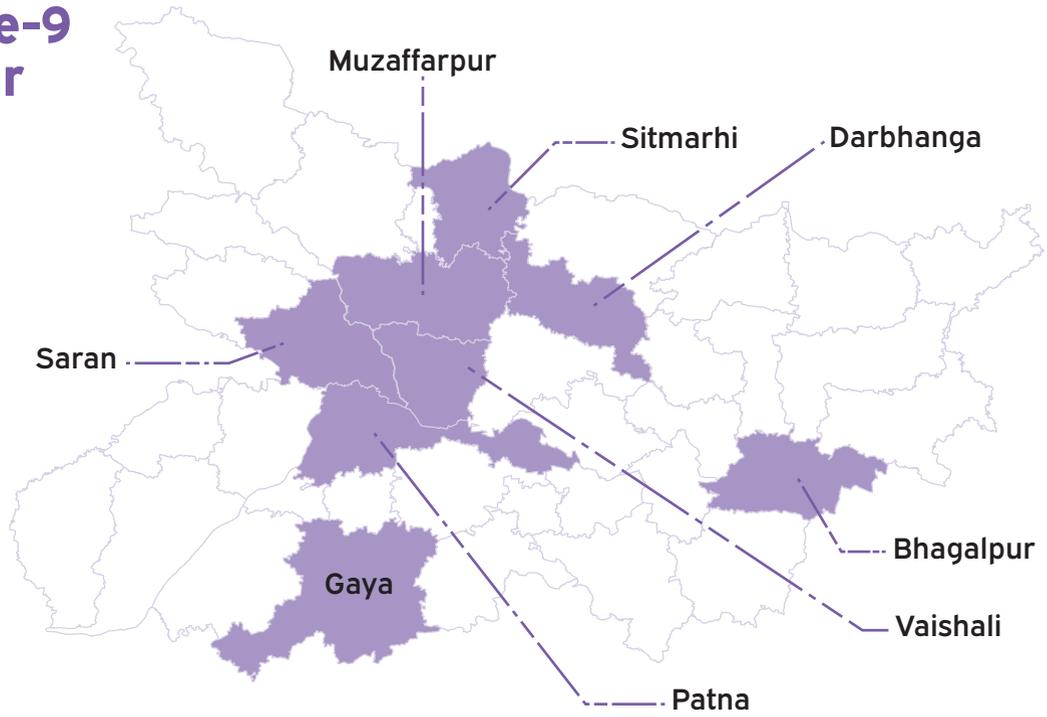
Key interventions of the project included contacting individuals diagnosed with

DR-TB at various Nucleic Acid Amplification Test (NAAT) centres in the implementation districts, facilitating PTEs, and supporting treatment initiation. TB Champions assisted people with LPA sample collection, provided education and counselling, and enrolled them in a digital literacy programme. They also conducted community programmes to raise awareness about TB prevention, diagnosis, and treatment.

Overall, between January 2022 and September 2024, 4,212 people were diagnosed with DR-TB, and 3,869 (92%) of them were initiated on treatment. The treatment initiation rate was higher among those with INH mono-resistant TB (97%) and those with Pre-XDR/XDR TB (96%) compared to those with MDR-TB (91%). Additionally, 706 people with DR-TB received support for nutrition and travel during this period.



Wave-9 Bihar



#1

Empowering TB Survivors as TB Champions

REACH recognises the role of affected communities and engages them to provide care and support to people with TB. TB survivors from the intervention districts who demonstrated a commitment to supporting people with drug-resistant TB (PwDRTB) were carefully selected and provided with comprehensive training. The organisation's flagship **TB Survivor to TB Champion (TBS to TBC) curriculum**, equipped these survivors with the knowledge and skills needed to contribute to project activities.

The training emphasised the project's objectives and the critical role of TB Champions in reducing pre-treatment loss to follow-up (PTLFU) and improving treatment initiation rates among PwDR-TB in their districts. By empowering TB Champions with technical knowledge and a deeper understanding of their role, the project ensured they were prepared to make a meaningful impact in their communities.



#2

Collecting NAAT Results

In Bihar, TB Champions played a crucial role in ensuring that people diagnosed with drug-resistant TB (DR-TB) received timely care. One of their key responsibilities was visiting NAAT (Nucleic Acid Amplification Test) centres regularly to collect the contact details of individuals newly diagnosed with DR-TB. These labs, established in district TB centres (DTCs), TB units, and medical colleges, diagnose rifampicin resistance in people with TB using advanced molecular techniques like Truenat and CBNAAT. This activity required close coordination with Lab Technicians, DOTS+ supervisors, and the State Treatment Lab Supervisor (STLS).

This process was vital for reducing the time it took for people with DR-TB (PwDRTB) to begin their pre-treatment evaluations (PTE). DR-TB is a complex and aggressive form of TB, and delays in starting treatment can worsen the prognosis for those affected. By minimising waiting times, TB Champions prevented delays between diagnosis and care, enabling PwDRTB to start treatment faster and with fewer obstacles. This intervention played a key role in improving treatment outcomes in a region where logistical barriers often complicate access to healthcare.



#3

Personalised Support for People with DR-TB

After identifying a list of people diagnosed with DR-TB, TB Champions directly reached out to them through phone calls, encouraging them to visit DR-TB nodal centres for their pre-treatment evaluation (PTE). This is crucial for assessing the person's health status and tailoring the most effective and safe treatment regimen for DR-TB.

However, a few of them were unreachable, hesitant, or faced challenges at the family level that prevented them from seeking timely care. In such cases, TB Champions made house visits and provided vital education on the importance of early treatment initiation for DR-TB.

They addressed concerns, dispelled myths, and reassured them about the treatment process. The Champions also conducted a need-based evaluation to identify any barriers to accessing care. For those struggling to reach the DR-TB nodal centres, the Champions arranged travel support, ensuring timely treatment initiation. This personalised, hands-on approach was instrumental in overcoming the many challenges faced by people with DR-TB.





#4

Simplifying Pre-Treatment Evaluations for PwDRTB

Navigating the healthcare system for DR-TB treatment is often a complex and overwhelming task, involving multiple tests and specialist consultations. As part of the Wave-9 project, TB Champions ensured people with DR-TB completed pre-treatment evaluations (PTE), accessed necessary tests, and received timely consultations.

When PwDRTB arrived at the facility, TB Champions expedited the process of obtaining an OPD ticket, provided necessary information, and helped them complete the necessary paperwork. With their deep understanding of the facility's layout and procedures, they streamlined the journey of people with DR-TB through different departments, sparing them unnecessary delays and bureaucratic hurdles. This also prevented PwDRTB from being lost to follow-up or abandoning treatment due to confusion or delays. In cases where specific tests were unavailable in public healthcare facilities, the project provided financial support to ensure the PTE process was completed without delay.



#5

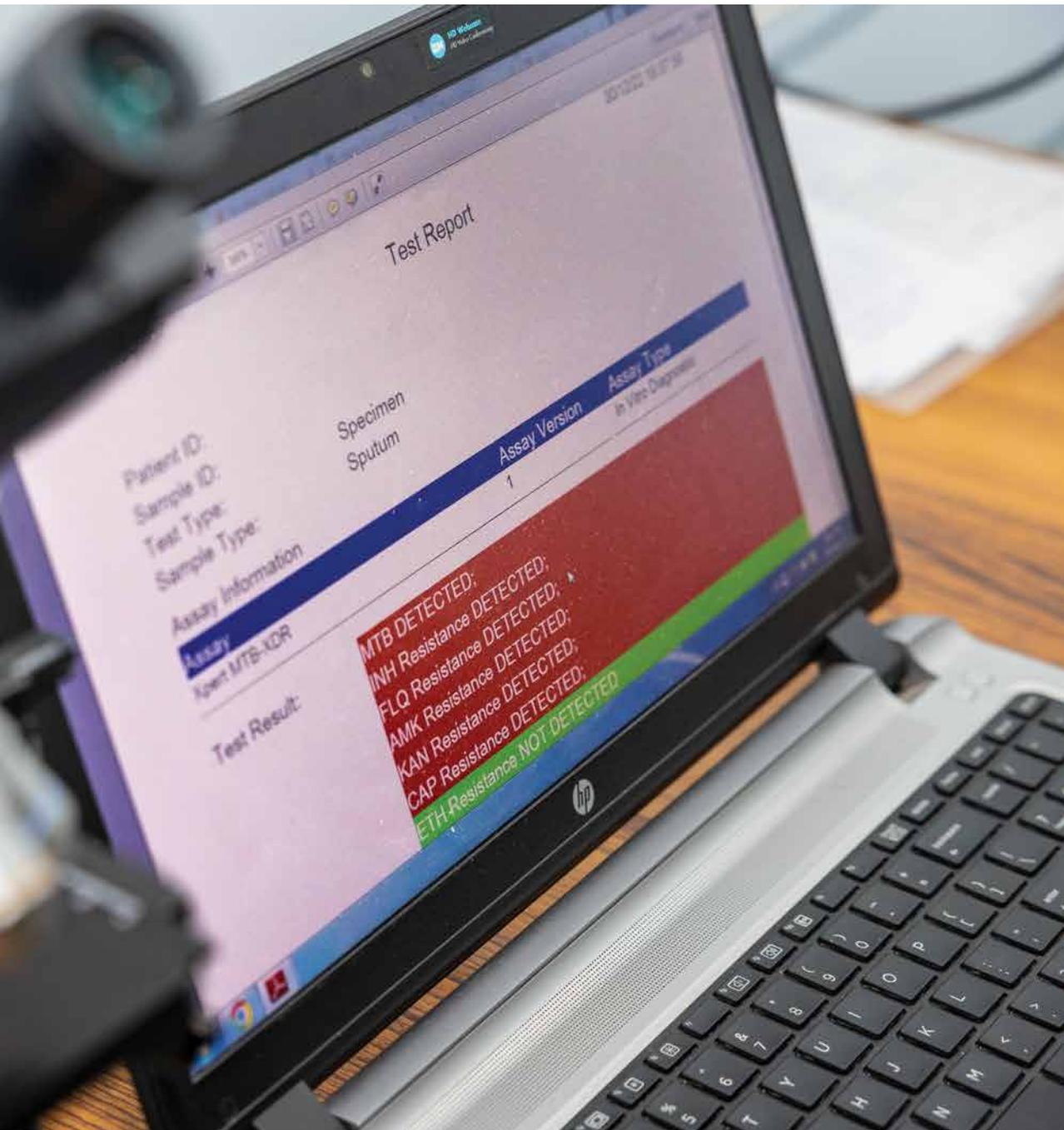
Support for LPA

TB Champions helped PwDRTB with sputum sample collection and ensured timely and accurate testing. They also facilitated the completion of the Line Probe Assay (LPA) test, which plays a critical role in determining the presence of drug-resistant strains of TB.

With only a limited number of laboratories equipped to perform LPA, collecting and transporting samples from various TB Units posed significant logistical challenges. The involvement of TB Champions was instrumental in overcoming these hurdles, ensuring samples reached the labs without delays or errors.

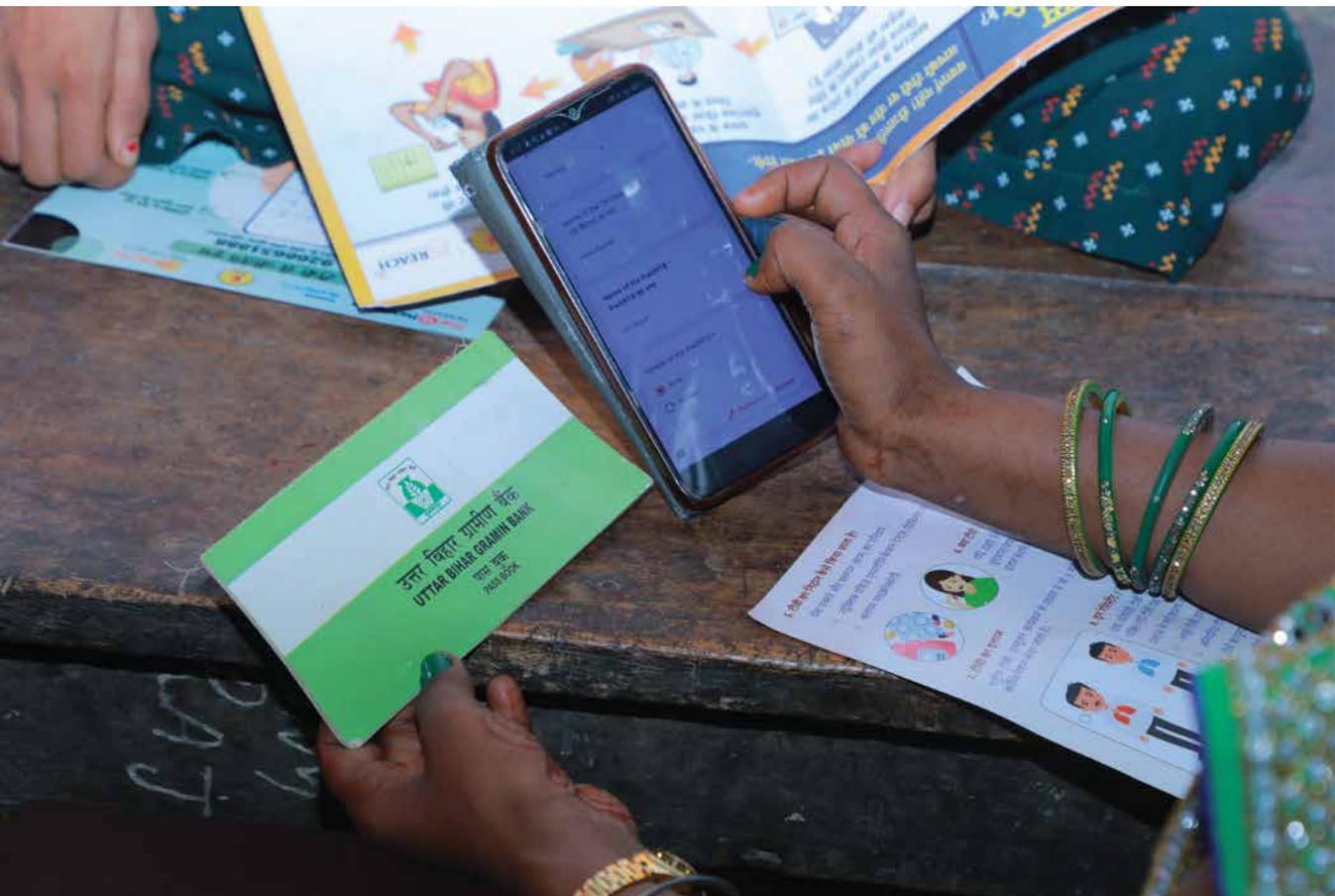
Their efforts not only enabled accurate and early diagnoses but also ensured that PwDRTB were promptly started on the appropriate treatment regimens, improving their chances of recovery and reducing the risk of further complications.





#6

Facilitating Early Treatment Initiation



TB Champions facilitated treatment initiation at DR-TB nodal centres and helped them with enrollment for Ni-kshay Poshan Yojana by obtaining bank account details and coordinating with DOTS+ supervisor, which helped meet their nutrition needs.

They also supported their transfer to nearby Treatment Units (TUs) for easy access to medication ensuring treatment adherence by reducing travel.

Furthermore, they followed up with those initiated on treatment to support them through the long treatment period. This comprehensive support reduced logistical barriers and improved treatment adherence.



Education on DR-TB Treatment Adherence

One of the main challenges of DR-TB treatment is its complexity, with PwDRTB needing to take multiple drugs over a long period. TB Champions have been instrumental in educating them about the importance of sticking to the prescribed schedule. Missing even a single dose can lead to further drug resistance or complete treatment failure, which is why consistent adherence is crucial.

They also addressed the psychological aspect of the treatment by preparing PwDRTB for potential side effects like nausea, fatigue, or joint pain. Understanding that these side effects are part of the process helps maintain their commitment to the treatment. TB Champions have provided practical strategies for managing these symptoms and knowing when to seek medical help.

Additionally, TB Champions gave them clear guidance on lifestyle adjustments—what to avoid, how to maintain a healthy diet, and how to stay active despite the challenges. Their support isn't just about managing medication but about fostering a positive mindset and empowering PwDRTB to take control of their health.

#8

Individual Counselling

TB Champions delivered person-centred care to people with DR-TB, providing a holistic approach to treatment. They guided PwDRTB on proper nutrition, emphasising its role in strengthening immunity and aiding recovery. TBCs also highlighted the importance of avoiding substances like alcohol and smoking, which can hinder treatment and overall health.

Their counselling extended beyond medication to include vital infection control practices, such as mask use, hand sanitising, and managing co-morbidities that could complicate treatment. They also helped them enrol in the Direct Benefit Transfer (DBT) programme under **Nikshay Poshan Yojana**, ensuring access to crucial nutritional support.

But the support didn't stop there. TB Champions acknowledged the emotional and psychological challenges of DR-TB, offering personal stories and coping strategies. They provided a safe space for PwDRTB to voice concerns, clarified treatment-related doubts—including fears about side effects—and delivered emotional encouragement, helping them stay motivated and focused on their path to recovery.





#9

Family-Centered Care





TB Champions worked closely with families, highlighting their crucial role in the recovery of a person with DR-TB, and encouraged them to be a source of emotional strength and confidence for their loved ones. They stressed the importance of maintaining a routine, from ensuring that the PwDRTB takes their medication regularly to providing proper, nutritious food to support the treatment process. They also stressed the need for contact screening for TB and preventive treatment, ensuring families were informed and proactive in managing the disease within the household.

But it's not just about managing medication or treatment regimens. TB Champions helped caregivers understand their role extends beyond tasks—it's about being a steady presence, providing emotional support, and ensuring the person with TB feels empowered, valued, and motivated throughout their treatment journey.

#10

Using IVRS for Accessible Treatment Literacy

Drug-resistant TB can be an overwhelming experience, and those diagnosed need information and emotional support at every step of the care cascade. The Wave-9 project leveraged Interactive Voice Response System (IVRS) technology to disseminate crucial information to people with DR-TB and their families, making the learning process accessible and convenient.

During counselling sessions, TB Champions introduced PwDRTB and their families to the IVRS platform, explaining how it worked and providing them with pamphlets containing a phone number and instructions. With just a feature phone—no smartphone or internet connection needed—they could listen to pre-recorded bite-sized explainers or access the next episode at their convenience. This tech-driven approach made essential information more readily available, reaching PwDRTB who might otherwise struggle to access resources due to technological or geographic barriers.

Through a package of messages designed to ensure treatment literacy, people with DR-TB learned about various aspects of the treatment, including adherence, potential side effects, dietary recommendations, and the importance of completing the entire treatment course. The IVRS system also allowed PwDRTB and their families to record their questions and receive responses, addressing any concerns they had regarding the treatment process.





#11

Community Awareness Programmes





Timely TB diagnosis leads to better treatment; it reduces the burden of advanced TB cases on health systems and facilitates targeted public health interventions to control the spread of the disease. Besides other activities, the Wave-9 project also focused on improving public understanding of the disease by conducting awareness programmes in hospitals, villages, schools, and other community settings.

By delivering targeted awareness sessions, TB Champions educated

communities about the symptoms of TB, the importance of early testing, and the available treatments. TB Champions, trusted voices within their communities, could connect with residents personally, encouraging open conversations and addressing their concerns directly. Their efforts not only reduced the stigma around the disease but also encouraged people to seek medical help sooner, improving the chances of successful treatment.

#12

Participation in District Review Meetings



Every month, district review meetings were held across the eight intervention districts, under the supervision of the District Programme Coordinator (DPC). These meetings served to assess progress and ensured continued support for people with DR-TB. TB Champions provided detailed updates on the individuals they are following, offering insights into each PwDRTB's diagnosis, treatment progress, and any challenges they may be facing.

This helped the team stay informed about the on-ground realities, from treatment

adherence to any emerging challenges that individuals were facing. TB Champions brought attention to any issues that require additional assistance, whether it's addressing side effects, navigating social or financial difficulties, or managing other barriers to treatment. If a PwDRTB became lost to follow-up (LTFU), TB Champions flagged it during these discussions, ensuring that timely interventions can be made to re-engage them into the healthcare system.

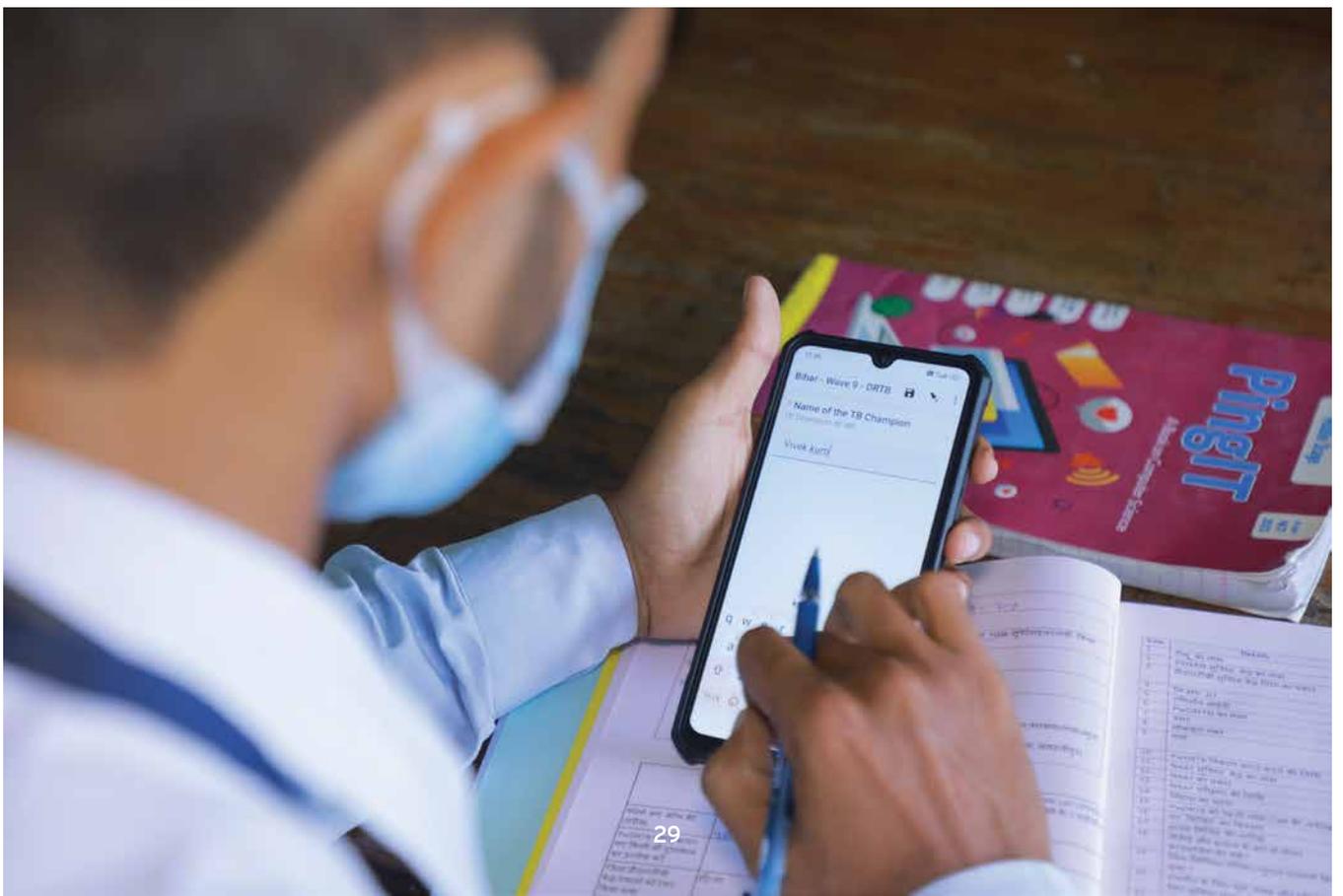


Digitising Data

An essential component of ensuring streamlined care for individuals with drug-resistant TB (DR-TB) was accurate and efficient data management. TB Champions played a critical role in this by capturing PwDRTB details—ranging from diagnosis and pre-treatment evaluations (PTE) to treatment initiation—using the KOBO Collect platform, an open-source digital tool designed for real-time data collection and monitoring.

By transitioning from paper-based to electronic records, TB Champions helped reduce errors, improve data accessibility, and enable faster decision-making by healthcare providers. Details such as the date of diagnosis, type of drug resistance, PTE completion status, and treatment initiation milestones were recorded. This digital format ensured that the records were centralised and readily available to the larger team, enabling better tracking of individual progress and identifying delays or challenges in the treatment pathway.

Furthermore, this also allowed for the generation of valuable insights from aggregated data. This helped in assessing the effectiveness of interventions and identifying gaps in service delivery. By leveraging technology for data management, TB Champions contributed to building a more responsive and efficient healthcare system for people with DR-TB.



#14

Continuous Support to PwDRTB

The first few months of treatment for drug-resistant TB are often the most challenging, requiring strict adherence to a complex regimen and frequent visits to healthcare facilities. During this critical phase, TB Champions maintained regular contact with people with DR-TB to help them stay on track with their treatment. Through these interactions, they assessed the specific needs of each individual and facilitated additional support to address barriers that could hinder adherence.

For many PwDRTB, this support included assistance with nutrition to counter the debilitating effects of TB and the demanding treatment regimen. TB Champions also arranged travel support for those unable to afford transportation to nodal centres for medicine collection or follow-up lab investigations. This personalised and holistic approach extended beyond medical care, addressing the socioeconomic challenges that often accompany DR-TB.





#15

Supportive Supervisory Visits

TB Champions received consistent support through regular supervisory visits by the programme team to intervention districts. The programme team provided hands-on guidance during house visits and retrieval of lost-to-follow-up (LTFU) people with DR-TB. TB Champions were also trained in real-time advocacy techniques, equipping them to engage with NTEP officials to address systemic barriers. Additionally, they received continuous support in capturing and entering accurate data, ensuring reliability in tracking treatment progress.

These visits were instrumental in ensuring smooth operations, verifying their work with people with DR-TB, and addressing any challenges they encountered. This ongoing supervision enhanced their capacity to perform and ensured that district-specific challenges were tackled effectively, fostering better outcomes for PwDRTB.





#16

Advocacy in Action

TB Champions played a pivotal role in strengthening TB care in Bihar by actively monitoring and reporting the availability of NAAT test kits and drugs to project teams at the district and state levels. This real-time reporting supported advocacy efforts with the State TB Officer (STO) of the National TB Elimination Programme (NTEP) in Patna, Bihar.

Alongside the project team, TB Champions participated in monthly NTEP review meetings across intervention districts. These meetings provided a platform to highlight individual and health-system-level barriers observed during routine follow-ups with PwDRTB. Key advocacy efforts included addressing the inadequate supply of NAAT kits and drugs, improving the timely transportation of samples for Line Probe Assay (LPA) testing, and pushing for earlier treatment initiation at nodal centres. When patients reported drug shortages, TB Champions liaised directly with DOTS+ supervisors to procure medicines and maintain treatment adherence.

In many instances, TB Champions went above and beyond their roles. They engaged with Panchayati Raj Institution (PRI) members and collaborated with TB survivor-led networks in Bihar to secure additional nutritional support for patients. These efforts reflected their unwavering commitment to improving patient outcomes and ensuring that systemic barriers did not hinder access to timely and effective TB care.





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This photo essay book is a collection of photographs that describe the '*Peer-led, Personalised, and Person-centred support model for people with drug-resistant TB (PwDRTB)*', implemented across eight districts in Bihar from January 2022 to September 2024. The project, implemented by REACH in collaboration with the National TB Elimination Programme and with support from the Stop TB Partnership through the TB REACH mechanism, aimed to reduce pre-treatment loss to follow-up by streamlining pre-treatment evaluations and minimising delays between diagnosis and treatment initiation.

