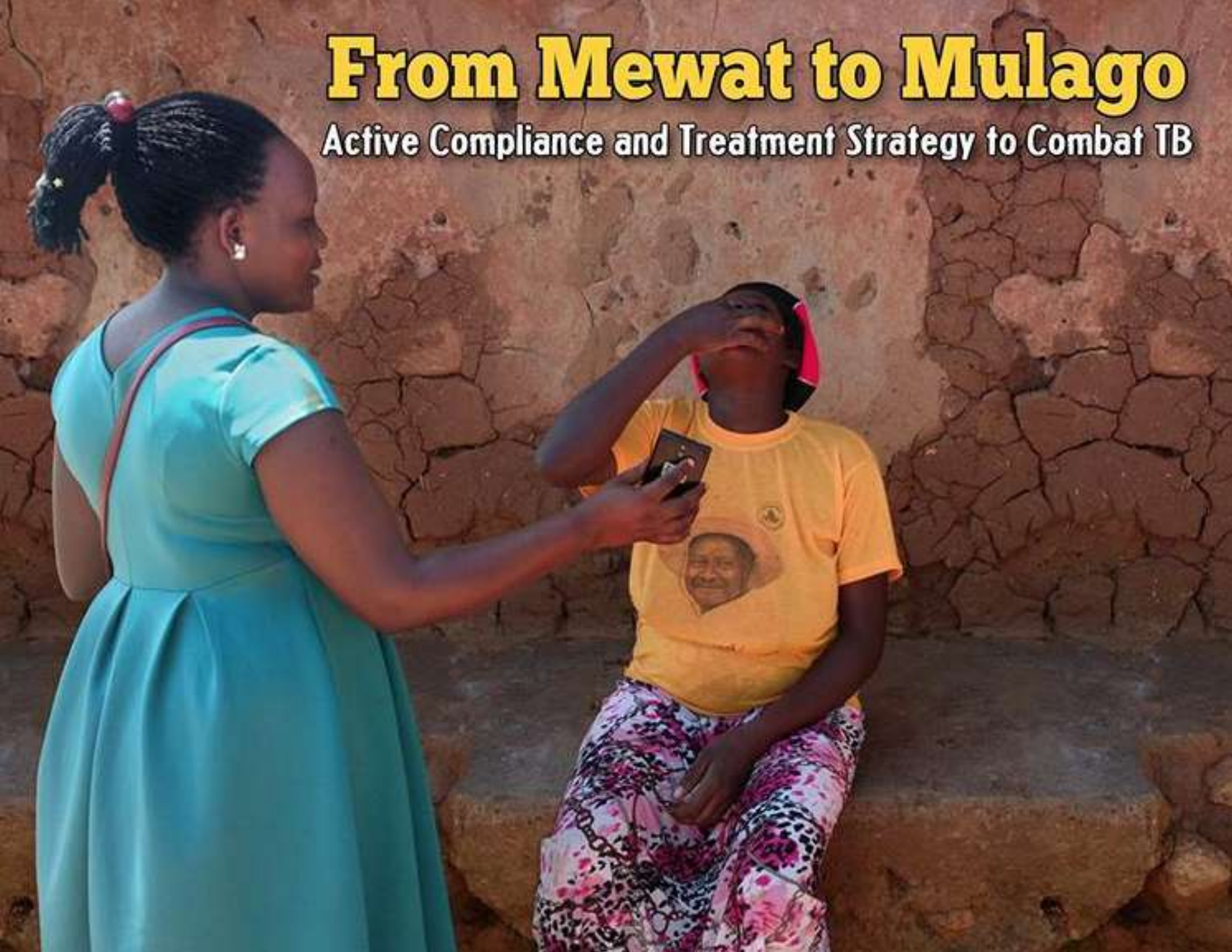
From Mewat to Mulago

Active Compliance and Treatment Strategy to Combat TB



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Active Compliance and Treatment Strategy to Combat TB

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Content

Acknowledgements

This book, From Mewat to Mulago, has been developed by ZMQ as part of their FreedomTBprogramme in India and Uganda. Under FreedomTB, ZMQ has developed an innovative strategy called Active Compliance and Treatment Strategy (ACTS) to improve key TB indicators. The key approach of ACTS is being 'Active' which empowers TB patients by giving them complete control on their treatment using VOT (Video Observed Therapy) along with other compliance reporting, reminders and other information channels. ACTS has empowered tuberculosis patients for self-management of their treatment and but more importantly, has helped in fighting the social stigma attached with this disease by creating a social network of TB survivors as assistive support to new patients. FreedomTB is a low-cost innovation which brings in value for money by impacting large number of beneficiaries with maximized health economic benefits.

FreedomTBprogramme started in 2015 with support from IKP Knowledge Park through Grand Challenges in Tuberculosis Control and has been further supported by USAID and BMGF in India and by DFID in other global regions. We are grateful to our partners in making this mission a reality. We thank the national and state TB programs - National TB and Leprosy Program (Uganda), Revised National TB Control Program (India), Haryana State TB Office, Delhi State TB Office and WHO Office (India). We also thank our implementation partners in Uganda – Ms. Betty Walakira(Executive Director, Health Child) and other local NGOs in the respective countries for their support and enthusiasm in this arduous journey.

With great pride for our core team, we also thank ZMQ FreedomTB team - Ms. Sukriti Nag (Program Manager), Mr. Mohammad Arif (Lead Database Systems), Mr. Faiyaz Alam (Lead Mobile Development), Mr. David Asiimwe (Program Coordinator, Uganda) and Mr. Waseem Akram (Program Coordinator, India) for developing the technology, managing implementation of FreedomTBprogramme and providing technical support in India and Uganda.

We also thank the volunteers, community health workers and health teams in these countries who worked with us unwaveringly for implementing ACTS. Last but not the least, we thank our communities – the TB patients and their families, TB champions (ex-TB patients) and neighborhood volunteers who trusted us as equal stakeholders and adopted our solution for better TB treatment and results.

Testimonials

India has proved yet again, to be a leader in thought and practice on inclusive and frugal Innovations. ZMQ's work using innovative and low cost technology from India on project 'Freedom TB' and its Active Compliance and Treatment Strategy has demonstrated this in Uganda. Freedom TB uses mobile technology to help TB patients stick to their treatment regimen, saving lives and helping people to get back to their work faster. These small investments with big human impacts make us proud and passionate about the role that DFID has been fortunate to play in enabling ZMQ's work with poor communities.

Gavin McGillivray
Head of DFID India

USAID is proud to partner with ZMQ in their drive to find innovative technological solutions that improve access to medical care for those most in need. For their work in Tuberculosis under Freedom TB programme where patient care tools to improve treatment adherence have shown amazing results, ZMQ has succeeded in furthering USAID's mission to build a healthier, more empowered India.

Xerses Sidhwa
Director of the Health Office,
USAID India

IKP is proud to partner with ZMQ on Tuberculosis adherence and treatment for India and Uganda. ZMQ's innovation of mobile based patient reporting through Video Observed Therapy has enabled patients to report their adherence from their homes and villages, far from healthcare facilities. Programme has created immense impact on TB notification and cure rates. It has grown into a holistic bottom-up strategy, Active Compliance and Treatment Strategy, with a built-in environment for active adherence and community participation, reducing overall burden on existing infrastructure. ZMQ has demonstrated a great example of South-South cooperation. The programme has a ripple effect to get replicated in other geographies in the developing world.

Ms. Deepanwita Chattopadhyaya
Chairman and CEO, IKP Knowledge Park

About the Authors

Twin brothers, **Hilmi Quraishi** and **Subhi Quraishi**, are the co-founders of ZMQ, a global 'Technology for Development' social enterprise founded in 1998. With their schooling done in New Delhi, India; they completed their MS degrees in Computer Science from Russia and also began their doctoral studies. But due to unfortunate demise of their father Prof. Zaheer Masood Quraishi, both Hilmi and Subhi returned to India to embark upon a new journey. With staunch Gandhian values instilled by their father, they decided to continue their father's vision of a just society and conceived the idea of an organization which can serve the under-privileged and marginalized, known today as **ZMQ** after their father, as a tribute to him.

Hilmi & Subhi have dedicated 20 years in enabling Digital transformation of poor and marginalized communities, and have brought in a substantial systemic change in addressing critical social issue using digital technologies. They have created numerous people-centric models which are being used successfully across the globe. Along with their passionate ZMQ team, twin brothers have established more than 40 system changing programmes and 120 behavior change communication initiatives using digital strategies. Winners of several international awards like Digital Transformation Award 2018, UNESCO Digital Literacy Award 2017, Schwab Fellowship Finalist 2016 and UNDP World Business Award; they are prominent speakers on social technology forums and their works are regularly published in newspapers and magazines worldwide. Hilmi is also an Ashoka Fellow recognized for his technology based innovations for the world's most urgent social problems. He has also been an Ashoka-Globalizer three times.

'You can capture geographies by waging wars, you can control markets by flooding products, but you can win the hearts of people only by doing social good.'

Subhi Quraishi, CEO ZMQ

'Digital Connectivity has broken all the barriers. It has reached in the hands of remote communities and poorest of the poor. It has enabled human development by building sustainable models. Anymore, no woman should die while giving birth to a child, no child should be left without education, no youth should remain unskilled, no farmer should succumb with their produce and no voice should be left unheard.'

Hilmi Quraishi, Ashoka Fellow & Co-Founder ZMQ

Introduction

Responding to the pandemic threat of HIV/AIDS in early 2000s in India, ZMQ launched Freedom HIV/AIDS – a strategic awareness building programme with use of mobile games. This innovative programme reached a remarkable number of 42 million subscribers with 10.3 million game sessions downloaded in just three years. It was also replicated in East Africa with support from Hivos (Netherlands) where it recorded 1.2 million downloads of the game sessions. Thus, Freedom HIV/AIDS proved to the first most successful and largest mobile phone game-based behavior change campaign in the world. Since HIV plays as a strong risk factor for onset of Tuberculosis, it was imperative to design a target programme for TB as well. With this realisation ZMQ launched ***FreedomTBprogramme*** in 2010.

Initiated with mobile phone based awareness games on TB for school children and youth, FreedomTB later incorporated capacity building tools for Directly Observed Treatment Short-course (DOTS) providers and Community Health Workers (CHWs). As majority of Low and Middle income countries (LMIC) lack any Health Management and Information System (HMIS) for effective management of TB, ZMQ created TB-HMIS which contains an electronic record of TB patients and enables evidence based TB treatment. TB-HMIS is a crucial component under ACTS - Active Compliance and Treatment System which is developed to address the issues of discontinuation and non-compliance of TB treatment dueto long duration of its procedure. ACTS captures real-time adherence to treatment using video-observed therapy which empowers patients to manage their treatment actively.

FreedomTB and Freedom HIV/AIDS led to creation of Freedom Series by ZMQ which isa series of programmes on communicable and non-communicable diseases. Under communicable diseases, Freedom Polio was a successful programme contributing another such programme which contributed to India's struggle with polio eradication. In 5 years period, Freedom Polio reached to over 1.2 million children under-5 years of age and 21 million children under-15 years of age. ZMQ's series on Non-Communicable Diseases (NCDs) include work in the areas of Hypertension, Diabetes, Cardiovascular diseases and Mental health. These lifestyle diseases, despite being preventable, need to be addressed with a high priority as they not only affect health in urban areas but have started penetrating rural communities as well.

Today, ACTS is globally recognised as an ideal strategy to combat chronic disease like Tuberculosis in Low and Middle Income Countries. Strategies similar to ACTS are now being applied by for management of other diseases. ZMQ is also a member of 'Stop TB Partnership', an initiative set up by World Health Organization (WHO), now managed by UNOPSto eliminate Tuberculosis as a public health problem. ZMQ's CEO, Subhi Quraishi is member of 'WHO Global Task Force on digital health and TB'.

1.Tuberculosis:A Giant Killer

Infecting more than 10.4 million and killing 1.7 million people in 2016, tuberculosis (TB) ranks as one of the ten deadliest diseases of the world. A highly contagious disease, it spreads from person to person through air and affects people with a lower immune system most easily. Over 95 per cent of TB cases are seen to be reported from low and middle income countries which links poor nutrition and poverty with prevalence of TB. In 2016, the largest numbers of TB cases were reported from Asia with 45 per cent new cases, followed by 25 per cent cases in Africa.

A TB infected person does not necessarily feel ill and may remain as a latent TB case. Such cases form about one-quarter of the world's population. Latent TB case may never develop the disease except children and people with a weak immune system, who are at a higher risk of developing active TB. If left untreated each active TB patient can infect 10 to 15 more people every year.

TB patients in Mulago Center in Kampala,

TB patients waiting at the Kasangati TB unit in Wakiso district, Uganda

TB patients waiting for their turns at Gurmandi TB unit in Jahangirpuri, Delhi, India

2. Global Epidemic: A Ticking Time-Bomb

Failure of adherence to treatment of regular TB leads to a severe form of TB called MDR-TB (Multi Drug-Resistant Tuberculosis). Patients with MDR-TB develop resistance to regular first-line medicines prescribed for TB treatment and hence they are moved to a longer treatment where they are put on a more powerful second-line prescription, which are more expensive and toxic. MDR-TB remains a public health crisis and a health security threat.

In 2016, there were around 490,000 new MDR-TB cases reported out of which India, China and Russia together accounted for nearly half of that global MDR-TB cases. In some cases, more severe drug resistance can develop called XDR-TB (Extensively Drug-Resistant tuberculosis), which is an even more serious form of MDR-TB where even most effective second-line anti-TB medicines do not respond to treatment; often leaving patients without any further treatment options. Out of the 490,000 new MDR-TB cases in 2016, 6.2 per cent had XDR-TB. The treatment of XDR-TB is more expensive and has more side-effects on the patients than treating ordinary TB.

TB patients waiting for their turns to take medicine at Kirari TB unit in Mangolpuri, Delhi, India

A slum in Wakiso district, Uganda

A congested slum of Jahangirpuri in Delhi, India

3. DOTS: Current Strategy to Fight TB

DOTS - Directly Observed Treatment Short-course is the internationally recommended strategy for Tuberculosis treatment and is presently practiced in more than 180 countries worldwide. It has been recognized as a highly efficient and cost-effective strategy. The guideline for treatment calls for an observer to monitor patient medication and adherence practices. DOTS consist of an observer/supervisor watching the patient swallow tablets in a way that is sensitive and responsive to the patient's needs. The supervisor helps to ensure the right drugs are taken at the right time for the full duration of treatment.

DOTS protocol is designed as a top-down manual model. It is built with a strong observation strategy because of its nature of design. The system is heavily dependent on the supervisor, where a low-performing supervisor can risk the lives of not only the patients but also affect non-infected members in the vicinity. DOTS emphasises regular intake of TB drugs for a period of six to eight months and regular monitoring of patient's treatment for progress assessment. The data of the patient, dosage and treatment are recorded in registers but are not real-time. The ubiquity of mobile networks and connectivity challenges the DOTS strategy and calls for a newer technologies with real-time data which can facilitate instant decision-making.

Patients waiting outside the health facility to be tested for TB at Mulago centre, Kampala, Uganda

Medicines for TB patients stocked at H-block TB unit in Jahangirpuri, Delhi, India

TB supervisor distributing medicines to TB patients at Sultanpuri TB unit in Mangolpuri, Delhi,India

4. Active Compliance and Treatment Strategy (ACTS)

A New Approach to Combat TB

ACTS – Active Compliance and Treatment Strategy is a new approach devised by ZMQ's Freedom TB programme to tackle Tuberculosis. Unlike conventional DOTS model, ACTS is a bottom-up technology driven approach to control TB. The key approach of ACTS is being 'Active'. It gives control to patients to manage their treatment using mobile phone tools with compliance reporting, reminders and other information channels. It also creates new networks of treated patients as knowledge providers, who serve as peer-educators in communities to provide assistive support to patients, making it as an effective community-led model.

With ubiquity of mobile networks and increasing mobile phone users, ACTS offers a system-change approach in treatment and management of TB. Patients are included as part of the solution design and are empowered to take control of their own treatment with limited supervision. It reduces burden on DOTS providers and brings down costs drastically. ACTS is a fully-technology linked model and has multi-tier technologies at various stages with a built-in environment for active adherence and community participation to reduce burden on existing infrastructures. The stages of ACTS are Active Ground Building, Active Case Finding, Active Patient Compliance, Active Community-led Supervision, Active Treatment Management and Active Ground Assessment.

A patient in Kasangati preparing for video based reporting of his medication in Wakiso district, Uganda

Stages of ACTS

Stage I: Active Ground Building 1

Learning Tools/ Digital Stories/ Interactive Games/ ACSM

Stage II: Active Case Finding 2

Door-to-Door Screening / Testing / Referrals

Stage III: Active Patient Compliance 3

Patient tools for Evidence based Reporting (VOT)

Stage IV: Community-led Supervision 4

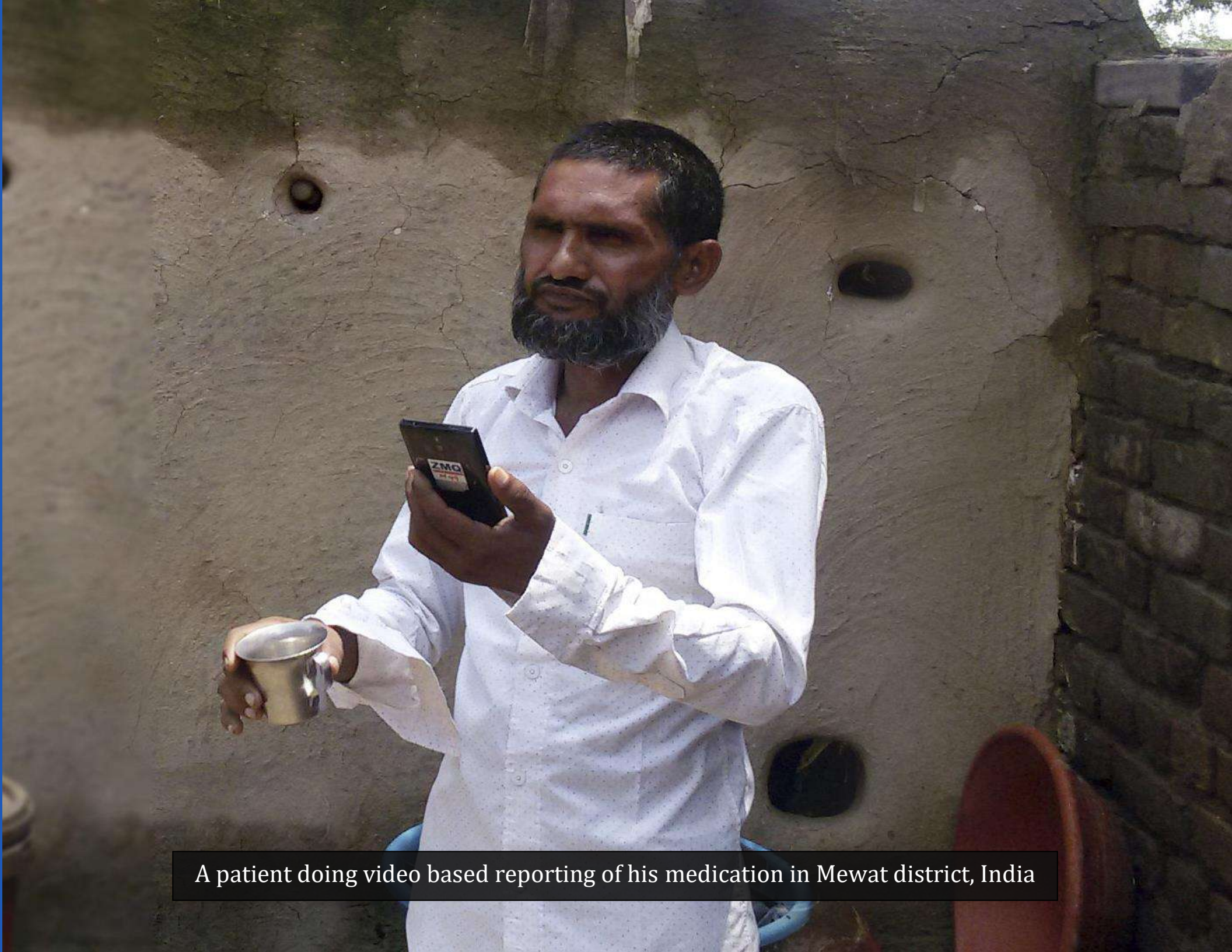
Group Active Compliance/ Family ACTS / Monitoring

Stage V: Active Treatment Management 5

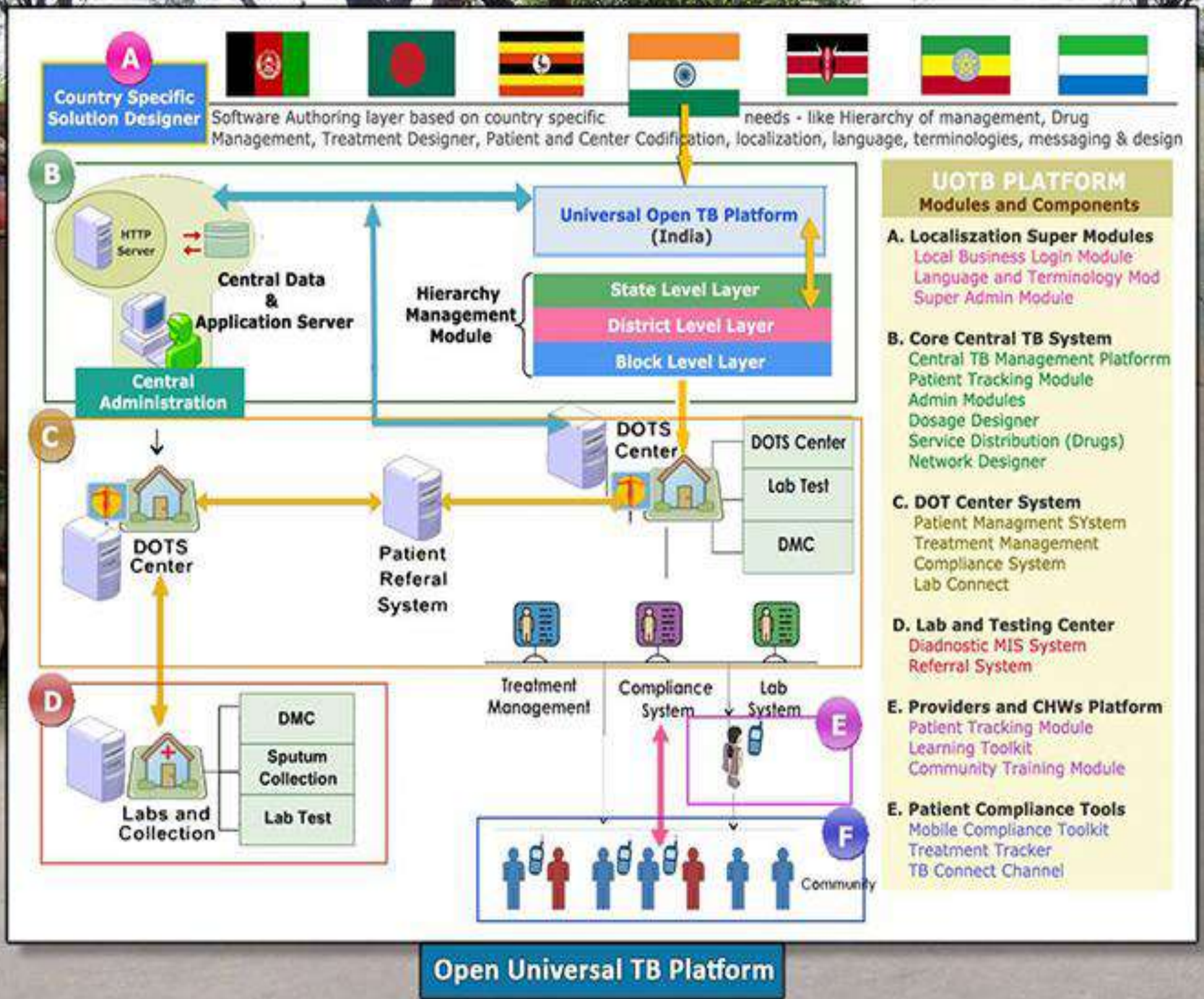
OUTB Platform/DMCs/TB Units/Nikshay Integration

Stage VI: Active Ground Assessment 6

Spatiotemporal Epidemiological Model / e-Predict



A patient doing video based reporting of his medication in Mewat district, India



Open Universal TB Platform

A child assisting his mother in doing video based reporting of her medication in Mewat district, India

5. ACTS Stage 1: Active Ground Building
Door-to-Door Mobilization

Before initiating any intervention for disease management, it is crucial to build an active environment for communities to understand the problem. Hence, Active Ground Building is the foremost step based on the Social and Behaviour Change Communication (SBCC) approach used by ZMQ. This approach not only establishes a strong community engagement process but also ensures a higher degree of participation by diverse local stakeholders throughout the programme. In this strategy, communication interventions play a consistently central role to create awareness on Tuberculosis.

Active Ground Building strategy includes connecting with children in the schools through edutainment based games and activities; out-of-school campaigns to reach to youth through social media and role-play mobile games; and conducting workshop with women Self Help Group (SHG) networks; and specially designed mobilization meetings with TB patients. Active Ground Building exercise deploys some of the most effective channels of communication for a wider awareness on TB such as decision-making digital stories which are disseminated through community radio stations and mobile recharge shops in the rural areas. Trainings are conducted with community health workers and village volunteers to understand severity of TB as a disease and its treatment. ZMQ also mobilises and works with religious leaders, village heads and other local influencers to establish credible channels of information on Tuberculosis in the community.

ZMQ field coordinator meeting the community members in
Nagina village during the active ground building stage in Mewat district, India

स्टॉप टी.बी. कॉरनिवल

मोबाइल पर डाउनलोड करें

http://www.freedomtb.org/mgames/tbcric.wml

स्टॉप टी.बी. मोबॉइल क्रिकेट

कम्प्यूटर / इंटरनेट पर खेलें

http://www.freedomtb.org/awareness.html

स्टॉप टी.बी. लर्निंग ज़ोन

स्टॉप टी.बी. क्रिकेट

स्टॉप टी.बी. क्विज़

- दो हफ्ते से ज्यादा चलने वाली खाँसी टी.बी. हो सकती है।
- टी.बी. से बचाव और इलाज दोनों ही संभंव है।
- टी.बी. नियंत्रण के लिए डॉट्स सबसे प्रभावशाली प्रणाली है।

FreedTBm

ZMQ Technology for Development

National Rural Health Mission

DOTS- Sure Cure for TB.

Bhagidari

Delhi Government Team Delhi-making things happen

The Lilly MDR-TB Partnership

Edutainment based campaign being conducted in a school in Jahangirpuri, Delhi, India

Conducting TB awareness campaign in the community in Wakiso district, Uganda

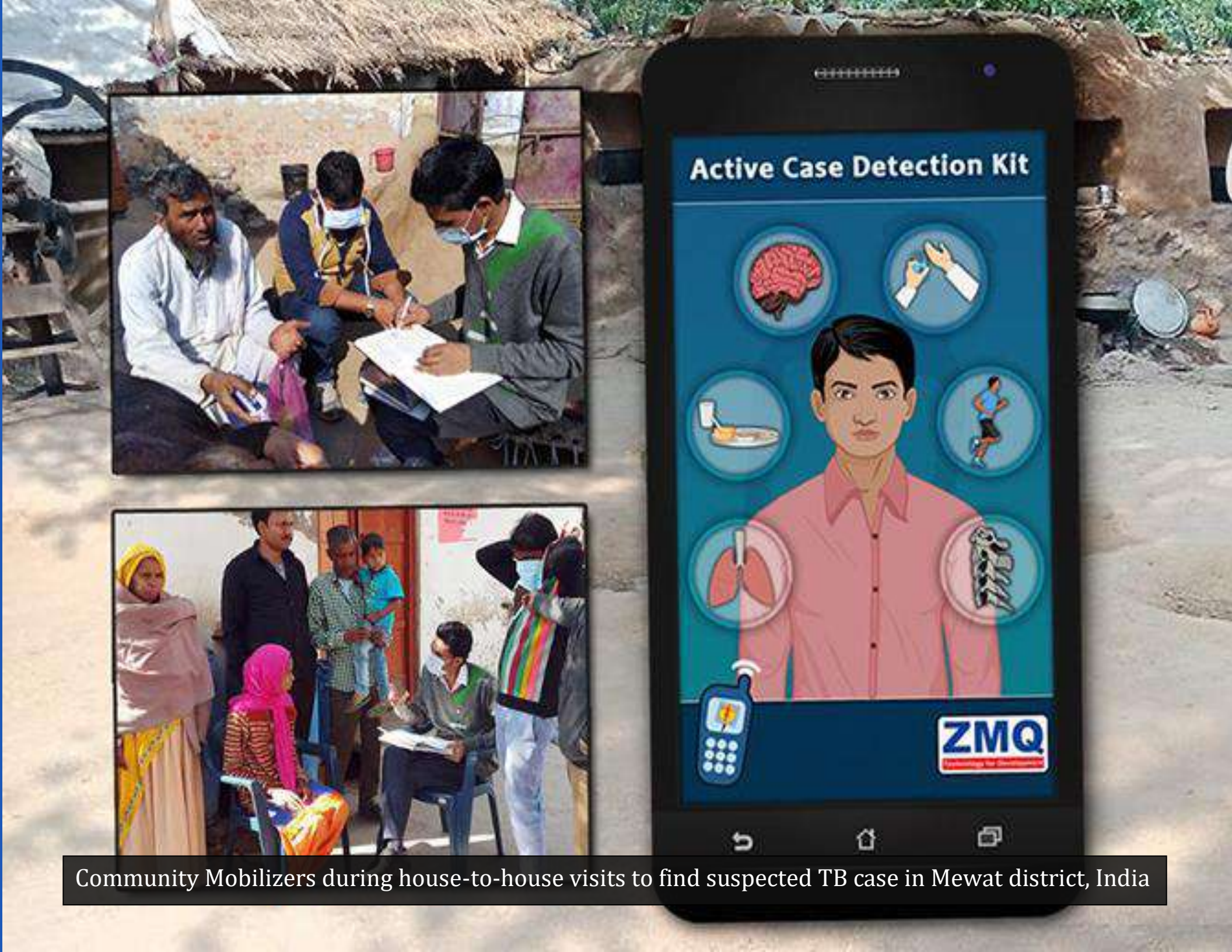
TB Awareness campaign with TB patient and their families outside the Kasangati TB unit, Wakiso, Uganda

6. ACTS Stage 2: Active Case Finding
Searching the Missing Million

Every year almost 10.4 million people in the world get infected with TB, but a more unsettling fact is that almost 40 percent of this huge number goes missing by the health systems; failed to be reported, diagnosed or treated. These people mostly belong to the vulnerable groups of society which are difficult to reach and are often deprived of right services such as migrants, miners, refugees, children and people living with HIV. As a result, many of these die or continue to suffer desolately and, more dangerously, transmit the disease to other people. If some of them get treatment with improper drugs, they contribute to the growing threat of drug resistant TB.

As part of ACTS, ZMQ conducts systematic screening of people suspected with active TB in a predetermined target group. Initially, this is done by conducting workshops at different levels – rural, peri-urban slums and urban areas to create awareness on Tuberculosis. The group is then asked to identify whether similar symptoms exist in their family or neighbourhood. In addition to this, household visits are conducted in these areas to talk more about TB and identify the symptoms. Once the symptoms are identified, ZMQ's Active Case Finding mobile toolkit captures the data of the suspected person and sends it to the nearest designated microscopy centre and lab for immediate testing. Screening in other selected risk groups is also done after a careful assessment of epidemiological relevance and health system preparedness based on WHO guidelines.

Health worker (VHT) using Active Case Finding toolkit to find suspected TB cases in Wakiso district, Uganda



Community Mobilizers during house-to-house visits to find suspected TB case in Mewat district, India

Community Mobilizers taking to a TB suspect in Mewat district, India

7. ACTS Stage 3: Active Patient Compliance

Gaining Full Control

Active Patient Compliance System is a toolkit for TB patients to report their compliance to treatment using mobile phones. It enables patients to report their adherence from their homes and/or villages, which are far flung from healthcare facilities, using a mobile phone. Neither the patients are required to visit the health centre for taking medicine nor do the DOTS providers need to visit their homes to directly observe them taking the medicine. The patients report their compliance by sending a video, audio or text, among which video 'selfies' (Video Observed Therapy) are the most popular. The system has a 'Real-time' dashboard which monitors each and every patient on a daily basis. The mobile toolkit has other components as well like patient information, scheduler, test reports, referral dates and other knowledge channels to keep updated with TB awareness.

This method strengthens the health system as it reduces the burden on DOTS providers from constant policing for treatment adherence to limited supervision. Active Patient Compliance empowers the patients and gives them full control of managing their treatment. Majority of the TB patients are physically weak and financially poor. They are unable to travel long distances to the heath facility to pick their medicine and also cannot afford to miss their wages. A lot of stigma is also attached when a patient is seen regularly coming to the facility for treatment, moreover if it is a woman. Hence, *Active Patient Compliance* method is a proven strategy for TB treatment and adherence overcoming all these challenges.

TB patient reporting her dosage using Active Patient Compliance toolkit in Mulago, Uganda


Patient Info
Report
Compliance
Upload
Schedule
Partners
आज आप अपनी वीडियो भेज कर दवाई के सेवन की सूचना करेंगे।
Message
Audio
Video
Observer
Dots Provider
Active Compliance
Patient Toolkit
Login
TB Learning
ZMQ

TB patient reporting his dosage using Active Patient Compliance toolkit in Mewat district, Haryana, India

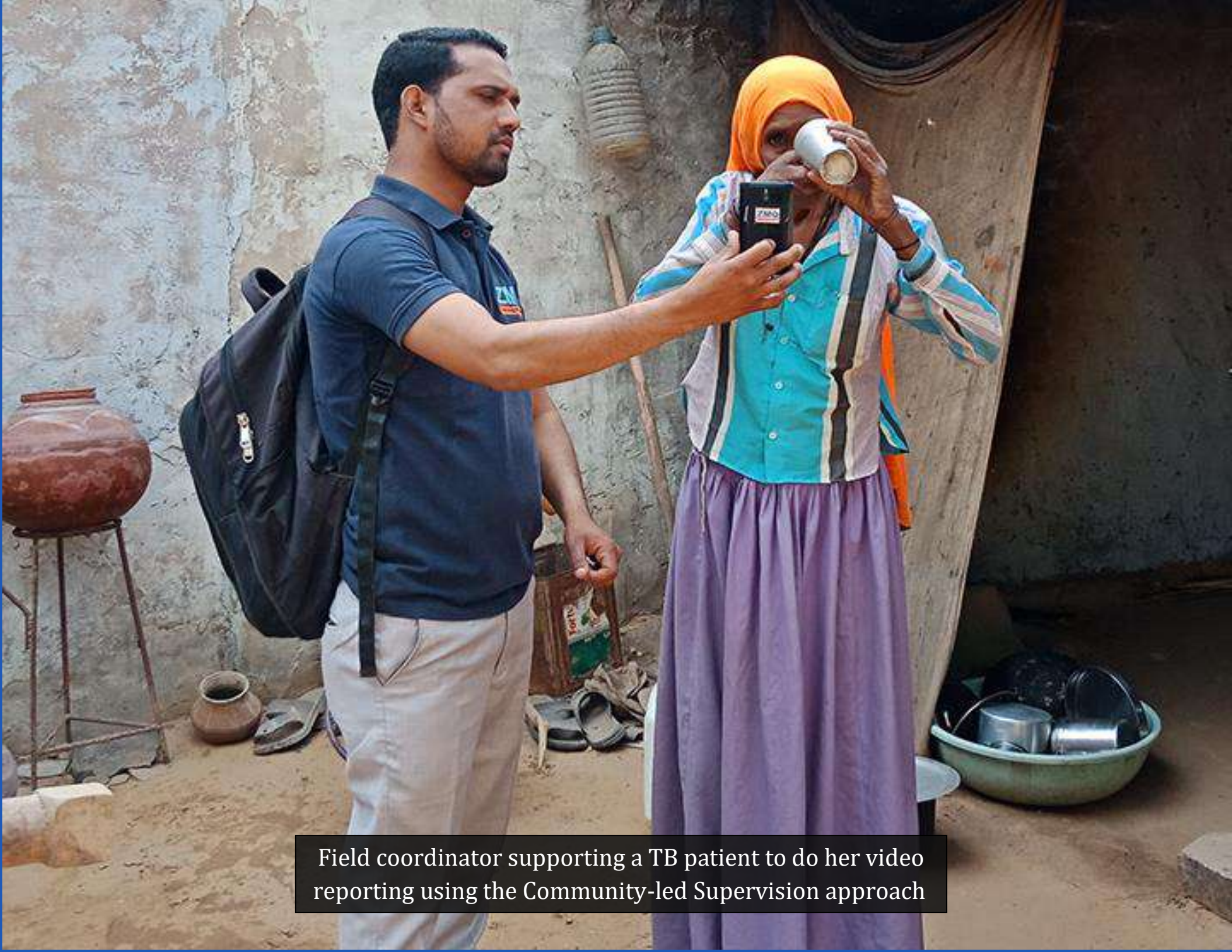
TB patient reporting his dosage using Active Patient Compliance toolkit in Wakiso, Uganda

TB patient reporting her dosage using Active Patient Compliance toolkit in Mewat, India

8. ACTS Stage 4: Active Community-led Supervision
Involving the Peers

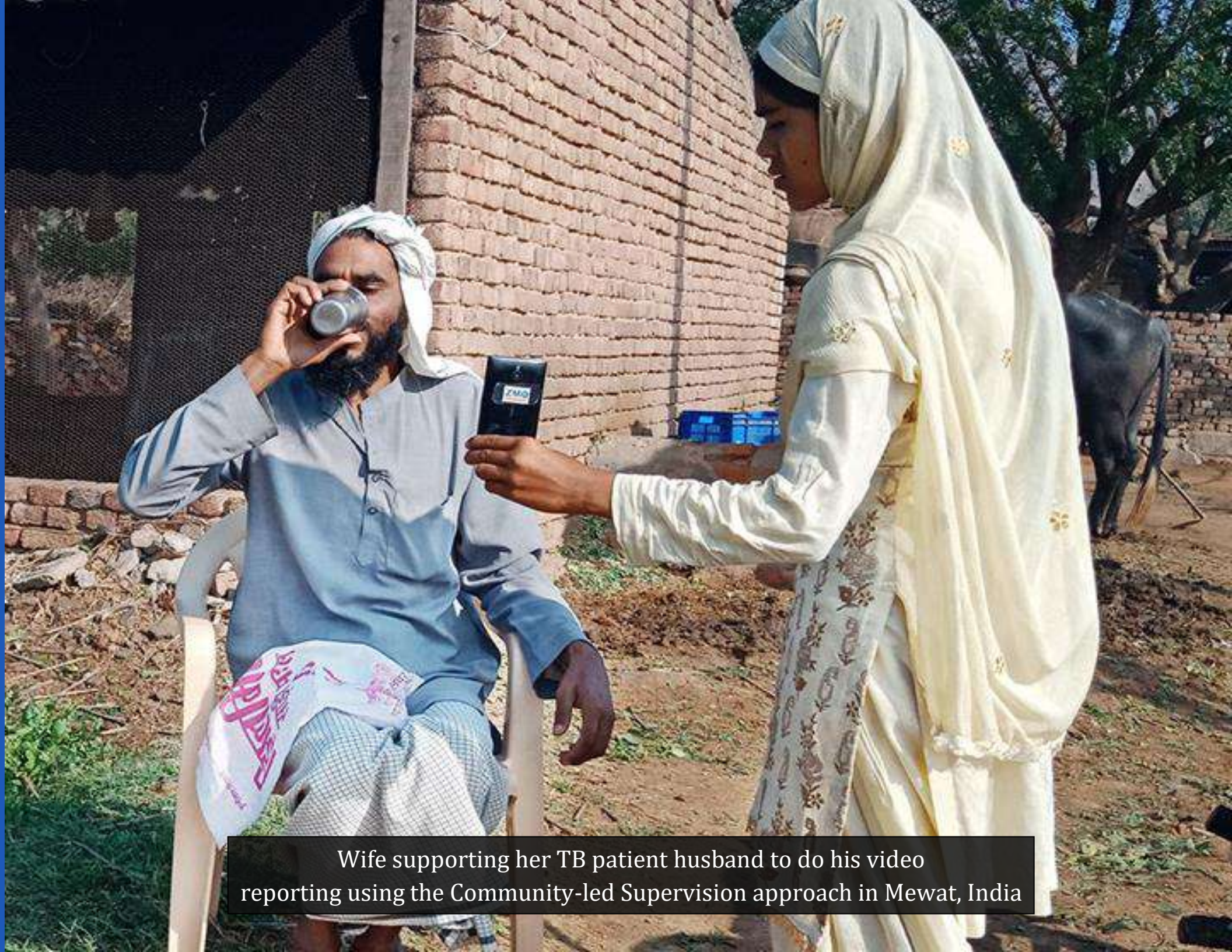
Active Community-led Supervision is a strategy to engage community members of the TB patient observing his/her treatment. A community member can be someone from the family, neighbourhood, village volunteer or a treated patient (TB survivor). This approach leads to creation of a new network of treated patients as knowledge providers, who are ready to serve as peer-educators to their communities for providing assistive support to new TB patients. This makes ACTS a *Community-led Supervision* model.

ZMQ has devised a strategy for TB patients; such as women, children, elderly, lower literate and poor who either don't have access to mobile phones or don't know how to operate a mobile phone; to enable reporting using group-based video-observed therapy. It helps in reducing the stigma and keeps patients away from isolation. Community volunteers are identified who are willing to report compliance for a group of patients using a single mobile phone, referred as *Group Active Compliance*. This method has tremendously reduced the burden of community health workers in India and Uganda, and has created a new set of volunteers ready to share the burden.



Field coordinator supporting a TB patient to do her video reporting using the Community-led Supervision approach


NOKIA
Community Observer
Mobile Active Compliance System
Toolkit
1 qo
2 abc
def 3
4 ghi
5 jkl
mno 6
7 pqrs
8 tuv
wxyz 9
0
TB Learning
Community Observation
Active Mode
Observer Mode
DOTS Mode
Missed Patients
Refresh Device
Upload Data



Wife supporting her TB patient husband to do his video reporting using the Community-led Supervision approach in Mewat, India

Field coordinator and mother supporting their TB patients to do their video reporting using the Community-led Supervision approach in Wakiso, Uganda

Neighbour supporting a TB patient to do his video reporting using the Community-led Supervision approach in Mangolpuri, Delhi, India

9. ACTS Stage 5: Active Treatment Management

An Integrated Partnership

Active Treatment Management is a start-to-end fully-technology linked framework where all the stages of TB treatment are knitted together as an integrated solution. The backbone of the framework is based on OUT-TB platform (Open source Universal Technology-based TB platform), which empowers the community health workers, field coordinators, DOTS providers, supervisors and lab technicians to manage treatment of TB patients in an efficient way. The framework is not dependent on any specific technology used by different TB programmes but works with a larger objective to introduce technology at all the layers of TB system such as mobilisation, case finding, diagnosis, address verification, initiation of treatment, reporting, follow-up testing and completion of treatment. If all these layers in the TB system start using technology at their levels; TB treatment will get revolutionised.

For instance, putting patients to treatment after finding them positive usually takes 4-6 days. With this strategy, putting a patient to treatment takes just 24-48 hours (1-2 days). Similarly, address verification of patients has been brought down from 3 days to just a few hours. All of these technology-linkages help in drastically reducing patient drop-out rates, efficiently tracking the follow-up cases and accelerating transitioning of patients from Phase I to Phase II. This framework needs to be integrated with the government infrastructure to improve treatment and management.

Mobile Active Compliance Method for TB Treatment

ZMQ team demonstrating the ACTS model to TB staff in Jinja, Uganda

TB testing lab in Mulago, Kampala, Uganda

TB Patient being trained to do video-based reporting in Nagina TB unit in Mewat, India

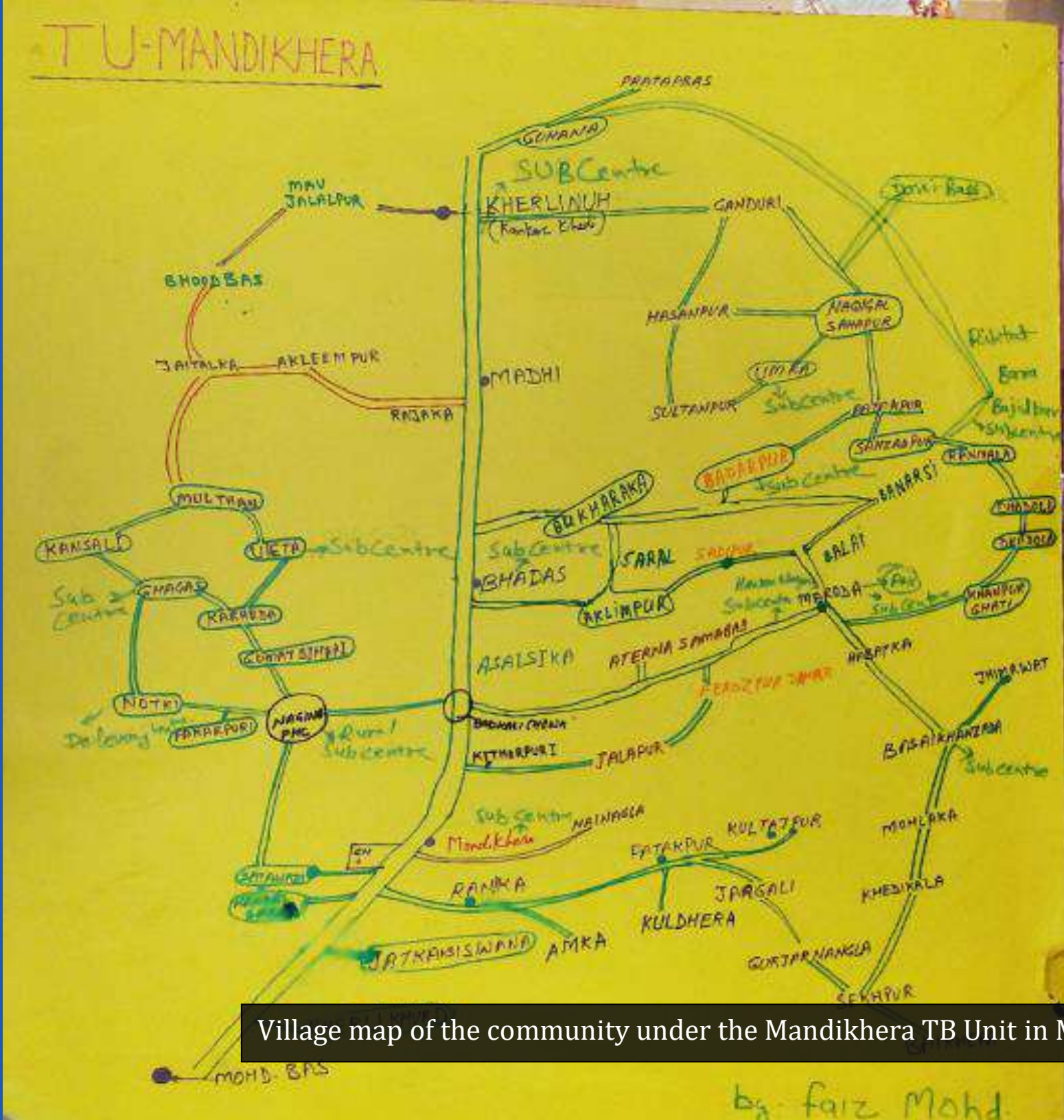
Ground team operational at TASO Entebbe unit in Wakiso, Uganda

10. ACTS Stage 6: Active Ground Assessment

Keeping a Close Watch

Active Ground Assessment is a ZMQ model for persistent stimulation and endemic prediction of Tuberculosis. It is derived based on multiple factors of TB epidemiology and community based social networking parameters. ZMQ's ACTS (Active Compliance and Treatment System) help in generating these predictive models up to the level of village and community. In every community, the records of Tuberculosis epidemiological indices such as the prevalence of infection, incidence of infection (annual infection rate), prevalence of disease (case rate), new cases, prevalence of suspect cases and case detection rate are noted. With the help of the collected data, we design customized interventions and strategies to combat Tuberculosis for those areas.

ZMQ and its FreedomTBprogramme have been using the Active Ground Assessment model for prediction of Tuberculosis in intervention areas in India - Mewat, Jahangirpuri and Mangolpuri; and Uganda - Wakiso and Mulago (Kampala). ZMQ has mapped high risk zones in the intervention area and have deployed a squad of field coordinators who are constantly also engaged in active case finding. The suspected cases are immediately referred to the nearest center for testing.



Village map of the community under the Mandikhera TB Unit in Mewat, India

ZMQ Field Coordinator with the vulnerable communities during the Active Ground Assessment campaign in Mewat, India

ZMQ Field Coordinator interviewing a woman during
the Active Ground Assessment campaign in Wakiso, Uganda

11. Strategy for Implementation

Building Partnership with the Government

For implementing ACTS at national level in both India and Uganda, its integration with the government interventions is an imperative step. It was mandatory for us to take permission from the Ministry of Health in the respective countries to implement ACTS. We approached the ministries and got the approvals from RNTCP (Revised National TB Control Program) in India and NTLP (National TB and Leprosy Program) in Uganda to use ACTSas an effective strategy to combat Tuberculosis. For efficient implementation of ACTS in the regions, we had built successful partnerships with local government authorities in all the intervention regions. We brought on board the state TB authorities from Haryana and Delhi in India, and Wakiso and Mulago in Uganda.

We started working with all the 5 blocks of Mewat district, primarily a rural areain the Haryana state with 5 TB Units and 13 PHCs. In Delhi, we commenced our work in 2 districts - Jahangirpuri (BJRM) and Mangolpuri (SGMH), both of which are two of the largest slums in Delhi. In Uganda, we started working in Wakiso district which has a large population in urban slums and in Mulago (in Kampala district) which is the largest TB unit of the country. We trained all the DOTS providers and Voluntary Health Team (VHTs) workers in TB Units in India and Uganda for using ACTS as a strategy in treating TB patients.

ZMQ team discussing the implementation strategy with district TB team in Wakiso, Uganda

ZMQ Field team at Al Afia Hospital at Mandikhera TB unit in Mewat, India

ZMQ team visiting the Entebbe hospital in Wakiso, Uganda

12. Diversified Stakeholder Engagement
Involving Local Partners

ZMQ's Active Compliance and Treatment Strategy (ACTS) is a multi-tier approach to tackle Tuberculosis with a bottom-up approach. It recognizes different stakeholders ranging from community health workers, field coordinators, paramedics, lab technicians and doctors to communities, TB patients along with their families and neighborhood as an inherent component of ACTS. One of the initial challenges was the poor mobile connectivity which came up both in India and Uganda. ZMQ identified the most suitable mobile carriers and signed with them to get the best connectivity in the region. This also enabled us to secure low-cost data packages for transferring data of video based compliances. In Uganda, the content and messages were contextualized for local needs in Lusoga and Luganda languages.

In Uganda, we partnered with a local NGO called Health Child. Together with the local partner and NTLP, we identified heavily loaded TB units which were working with patient from slums, nearby rural areas and serving population from the islands. Patients who were living at a distance were put on Active Compliance mode as for them to come down daily to the TB center was a challenge. The units where we operated in Wakiso were Kasangeti, Entebee IV, TASO Entebee and Kisubi. Later we opened another unit Mulago in Kampala, which is the largest TB center in Uganda with large population, both rural and urban slums. In Mewat and Delhi in India, we directly worked with the government teams. We also recruited local volunteers from the community and trained them to use Group Active Compliance as a strategy to combat Tuberculosis.

ZMQ team discussing with the TB staff at the Kasangati TB unit in Wakiso, Uganda

ZMQ team conducting workshop with different stakeholders in Punhana village, Mewat, India

Post workshop discussion of various stakeholders in Kansangati TB unit in Wakiso, Uganda

13. Training and Capacity Building

Creating New Cadres

ZMQ recruited a team of 13 field coordinators who were placed at different PHCs and sub-centers spread over 5 blocks of Mewat. Similarly, 11 field coordinators were recruited in Delhi, in Jahangirpuri and Mangolpuri TB centers. The teams were given awareness training on Tuberculosis, in-depth training on DOTS strategy, the dosage regimen and complete cycle of treatment – from diagnostics, putting patient on treatment, follow-up and completion of treatment. The teams were trained on different aspects of ACTS with a specific focus on Active Patient Compliance so that they can train patients to report their intake of dosage using Video Observed Therapy (VOT). Specific training manuals for providers, field coordinators and patients were developed. Reporting registers for providers and field coordinators were also developed. The teams were also trained on community mobilization for social and behaviour change communication (SBCC), which came out as the most effective strategies under ACTS. This activity was able to bust the myths among community, de-stigmatizing Tuberculosis and increased the number of TB cases (from the missing ones).

In Uganda, we identified the 5 TB units - 4 in Wakiso and 1 in Kampala for implementing the Freedom TB programme. Three days training programme on using the new approach of ACTS was conducted with VHTs (community health workers) from these 5 centers. Regular refresher trainings were conducted every 3 months to keep the teams updated with anything new coming up in the technology tools. Community mobilization was also a very effective strategy in Uganda.

ZMQ Supervisor conducting awareness campaign with communities to create new cadres as TB volunteers.

Training women on TB awareness in the Self Help Groups in Mangolpuri, Delhi, India

ZMQ donor team attending a training workshop at Entebbe hospital, Wakiso, Uganda

14. ACTS in Rural Area
Mewat in Haryana

Mewat is a district in the south of Haryana state in India with a population of over 1.1 million. It has five rural blocks with 431 villages. Muslims comprise 82% of the population, and the majority of the people in the rural part of the district are farmers. The female literacy rate in the district is 36.6%. In an otherwise well-performing state, Mewat has a high focus due to its poor heath indicators on Tuberculosis and Maternal & Child Health.

ZMQ started working in Mewat with a small pilot on Mobile based Active Patient Compliance in 2014-15 with 20 patients. The response was overwhelming with an extremely successful pilot. Subsequently, ZMQ's Freedom TB programme got scaled up to whole of Mewat, five blocks namely Tauru, Nuh, Punhana, Nagina, and FirozpurJhirka. ZMQ reached to 2,500 patients in one and a half year years of intervention. With support from USAID, DFID and BMGF, ZMQ got another scale-up of the project Mewat to cover 3,000 patients in 2016-17 with holistic ACTS strategy. The programme has helped in substantially improving the key TB indicators – treatment completion rates, cure rates and lowering the re-lapse rates. The subsequent scale-ups in Mewat helped us to test and build all the stages of ACTS, which has led to evidence based change in the behaviours of the Meo community.

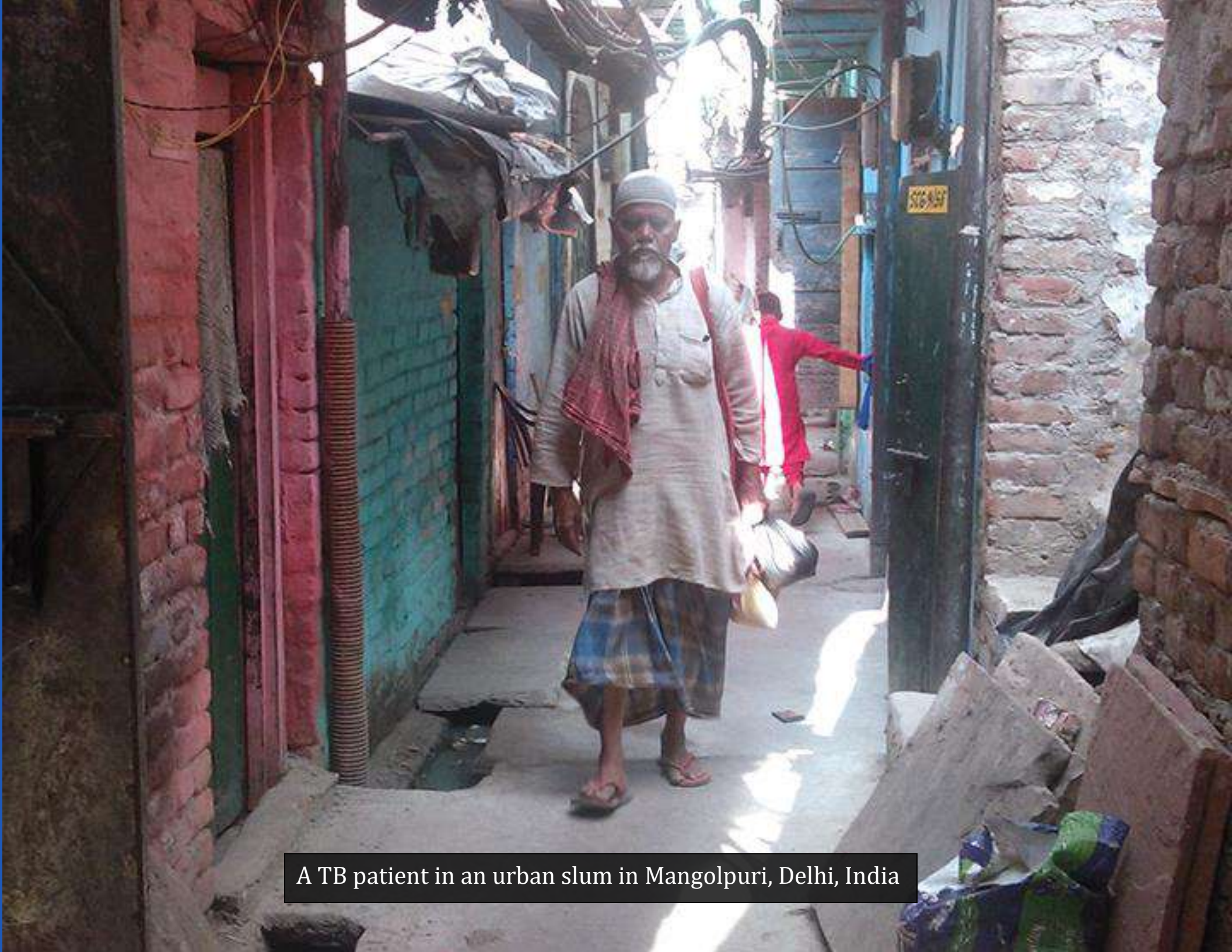
ZMQ team visiting a TB patient during a household visit in Mewat, India

ZMQ team with suspected TB patients in Mewat, India

ZMQ field coordinator conducting TB trainings with rural communities in Mewat, India

15. ACTS in Urban Slums
Jahangirpuri and Mangolpuri in Delhi

With poor statistics and high prevalence rate of Tuberculosis in the slums of Delhi, ZMQ approached the Delhi State TB office in 2016 to do pilot in the two Northern districts of Delhi to see the acceptance of ACTS in the urban and semi-urban settings. ZMQ got the permission to work in two district namely Jahangirpuri (BabuJagjeevan Ram Hospital) Mangolpuri (Sanjay Gandhi Memorial Hospital). Both the districts are semi-urban slums with a very high immigrant population, living in unhygienic settlements and majority of them are below poverty line. Still the area has high penetration of mobile phones. In 2016, ZMQ ran the first pilot with 100 patients collectively from B block and H block of Jahangirpuri and later scaled to five dispensaries namely B block, H block, Azadpur, Indranagar and RajpuraGurmandi. Later, ZMQ scaled the programme to two dispensaries in Mangolpuri namely - Sultanpuri and Kirari Village under Sanjay Gandhi Memorial Hospital. In last two years, the programme has touched upon over 1700 patients and the success of programme is overwhelmingly exciting.



A TB patient in an urban slum in Mangolpuri, Delhi, India

Training patients at Indira nagar TB unit in Jahagirpuri, Delhi, India

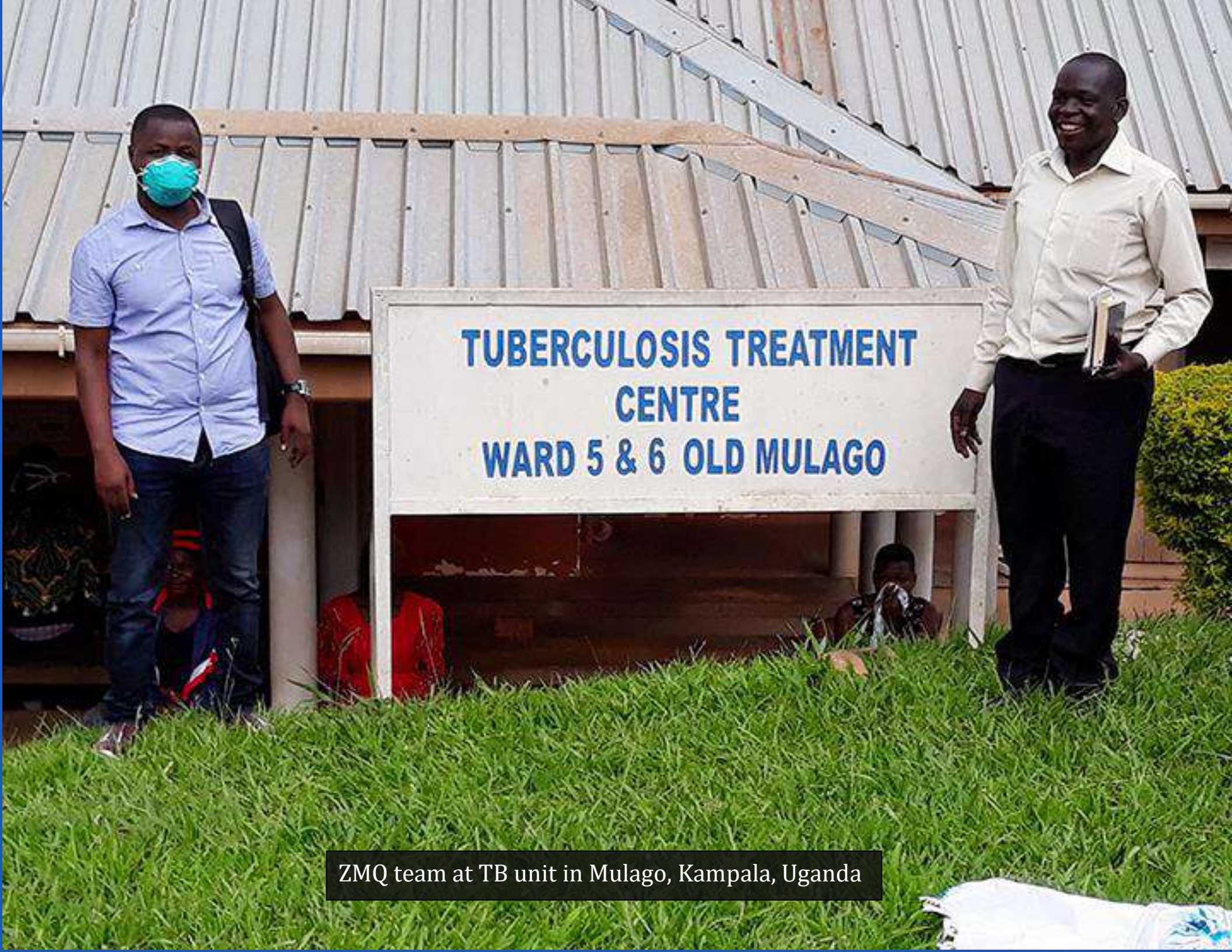
A neighbour supporting a TB patient to do video-based reporting in Kirana village in Mangolpuri, Delhi, India

16. ACTS in Africa
Wakiso and Mulago in Uganda

Uganda, a landlocked country in East Africa, has high prevalence of Tuberculosis with 253 per 100,000 people. HIV is the leading risk factor for development of TB in Uganda, and is the leading cause of death among people with HIV/AIDS. Under the South-South collaboration, ZMQ was given the challenge to take FreedomTB's ACTS (Active Compliance and Treatment Strategy) to Uganda. ZMQ approached National TB and Leprosy Program (NTLP) of the Ministry of Health, Uganda and shared the results from the India's pilot programme. Experts from the ministry granted permission to commence a large pilot in two districts of Uganda after their due diligence procedure. With its own team on the ground, ZMQ engaged with a local NGO, Health Child in Uganda.

In the early phase, ZMQ established ACTS in four health centers of Wakiso district namely Kasangati, TASO Entebbe, Entebbe IV Hospital and Kisubi Hospital. Later, it scaled to Mulago health facility in Kampala district. Since Uganda was following daily dose regime, ZMQ's ACTS system was modified accordingly and also adapted in local language Luganda/Lusoga. A team of field coordinator and VHTs were setup to register the patients, put them on ACTS within two days of diagnosis. ACTS has been widely accepted by the patients as well as the NTLP. In a span of 18 months, the programme treated 980 patients with the compliance rating as high as 83.09%. ZMQ has just commenced a new scale-up in three more districts in Uganda namely Mbarara, Kabarole and Mbale. Two new components are being added in the new scale-up of ACTS – nutrition and holistic health which is non-invasive therapies to improve adherence to treatment.

‘FreedomTB’ poster established at KasanagtiTB unit in Wakiso, Uganda



ZMQ team at TB unit in Mulago, Kampala, Uganda

ZMQ team at Mulago TB unit in Kampala, Uganda

Ground team at TASO Entebbe in Wakiso, Uganda

Ground team at Entebbe IV hospital in Wakiso, Uganda

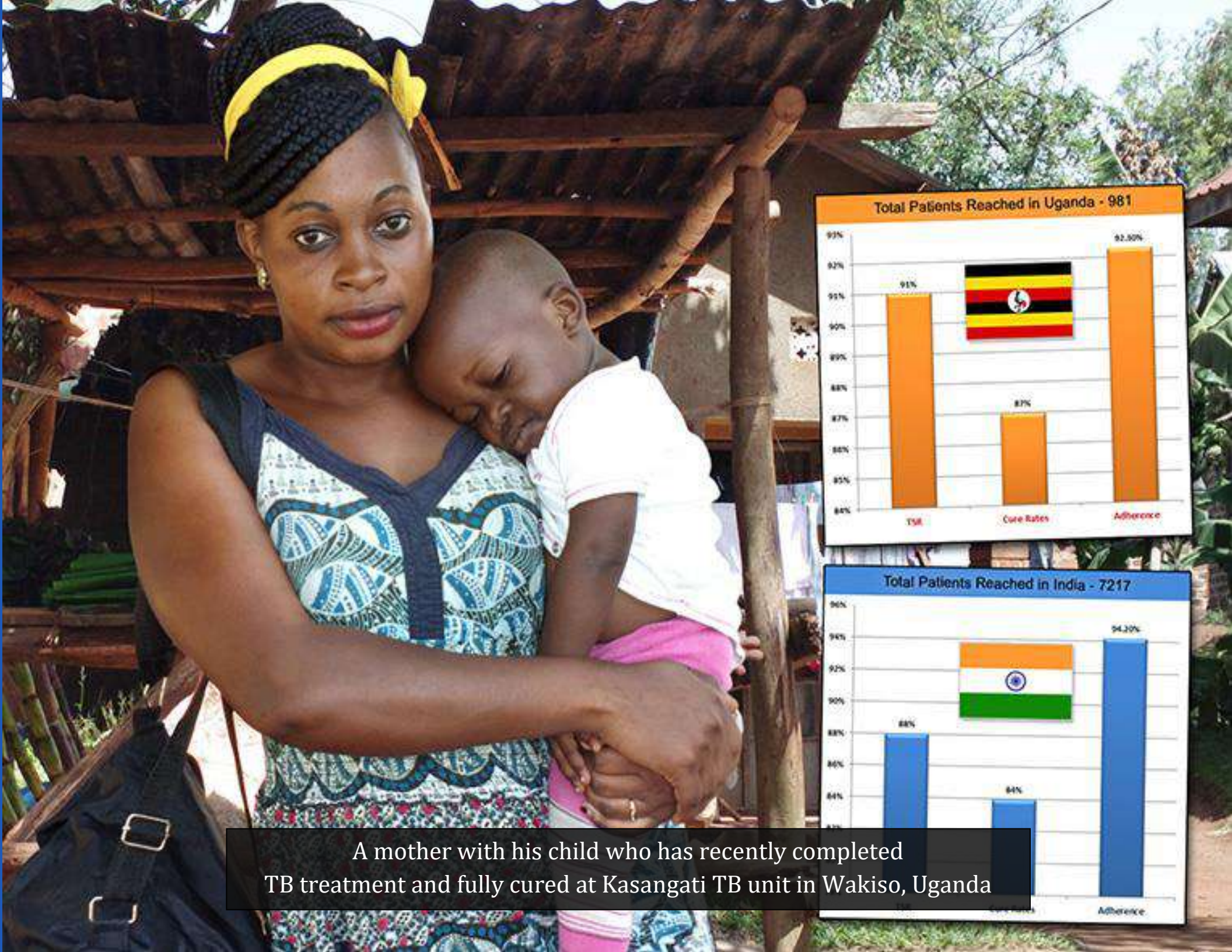
Ground team at Kisenyi TB Unit in Wakiso, Uganda

Donor team meeting the TB patients at KasangatiTB unit in Wakiso, Uganda

17. ACTS Impact: Bringing Back the Smiles

ZMQ devised Freedom TB programme to combat Tuberculosis. Under FreedomTB, ZMQ devised a multi-pronged strategy called ACTS – Active Compliance and Treatment Strategy, a bottom-up model to take control of Tuberculosis using technology. The pilot started with 20 patients in 2014 which got scaled to three districts in India – Mewat, Jahangirpuri and Mangolpuri; with almost 7,200 patients completing their treatment in three years. The programme was also piloted for almost two years in Uganda – Wakiso and Kampala with almost 1,000 patients. The programme got an overwhelming acceptance both from RNTCP (India) and NTLP (Uganda) and has been able toimprove the key TB indicators substantially – treatment completion rates, cure rates and lowering the re-lapse rates. The compliance rating has gone as high as 83.09 %.

ACTS is now going for a new round of scale-up in India and Uganda, in the newer districts. ACTS is soon commencing a pilot in Rwanda. Seeing the remarkable results of ZMQ's programmes, WHO has invited Mr. Subhi Quraishi, CEO ZMQ as a founding member of WHO's Task Force on mHealth and TB to advise Global TB Programme on use of ICTs for Tuberculosis prevention, care and control; in-line with the objectives of End TB Strategy. ZMQ has also been invited by NITI Aayog (National Institution for Transforming India), a policy think tank of Government of India, to establish ACTS in some of the aspirational districts (low-performing districts identified by the government) to eradicate TB by 2025, fulfilling the vision of the Prime Minster of India.



A mother with his child who has recently completed
TB treatment and fully cured at Kasangati TB unit in Wakiso, Uganda

TB survivors after treatment completion

TB survivors after treatment completion

18. ACTS: A Way Forward

Tuberculosis is a top killer worldwide, ranking alongside HIV/AIDS. It places its heaviest burden on the world's most poor and vulnerable, aggravating existing inequalities. Due to TB, people incur high health expenditure or suffer income loss equivalent to approximately more than 50 per cent of their income. ZMQ is in sync with the WHOs strategy of a world free with TB - zero deaths, zero disease and zero sufferings due to TB.

"In the end, we must remember that the war against TB will not be won at meetings in Moscow, Delhi or New York. It will be won in communities. It will not be won with declarations. It will be won by nurses, doctors, community health workers and others at the frontlines. Our job is to give them the resources they need to find every last person with TB, to diagnose them, to treat them, and to cure them. That's the measure of success." - Dr. Tedros Adhanom Ghebreyesus, WHO Director-General.

ZMQ's ACTS – Active Compliance and Treatment Strategy with its multi-pronged holistic approach is the answer to the world free of TB. We are scaling up in India. We have already acted on the call of the Prime Minster of India to eradicate TB by 2025. Under the South-South Cooperation model, we have taken Freedom TB to Uganda with a great success. NTLP of Ministry of Health Uganda is ready to scale Freedom TB to 3 more districts of Uganda and then go for a national adoption. Most of the countries in Africa have high levels of HIV and limited access to treatment. They are sitting on a drug-resistant tuberculosis time bomb, which can explode anytime. ZMQ has set up *FreedomTBCenter of Excellence* in Uganda to serve as a model for other African countries to learn from and take ACTS in their countries which will help in eradicating TB from Africa and the whole world by 2030.


FreedomTB and ACTS - Changing lives for a happier tomorrow

ZMQ team with children in a slum outside Kampala


ACTS
FREEDOMTB
Programme by:
ZMQ
Technology for Development
ZMQ
Supported by:
BILL & MELINDA GATES foundation
UKaid
from the British people
Central
TB Division
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