

# Innovative TB Community Service Delivery During the COVID-19 Pandemic

Best Practices and Lessons  
Learned from Cambodia, India,  
Indonesia, and Kenya



## FOREWORD

The Global Fund TB Strategic Initiative 'Innovative Approaches to Finding Missing People with TB' 2021-2023 aims to support countries to address specific barriers to finding and treating missing people with TB and scale-up innovative health facility and community approaches to accelerate TB case finding and treatment, especially for key populations and vulnerable groups. This includes finding and treating people with drug-susceptible (DS-TB), drug-resistant TB (DR-TB), children, and adolescents.

Globally, over the past decade and in alignment with UNHLM targets, TB programs have demonstrated an increase in TB case notifications. The onset of the COVID-19 pandemic in early 2020 had a tremendous impact on TB programs and, in some cases, reversed gains made over the past period. Despite the challenges imposed by COVID-19, countries have taken bold efforts to address the crisis, adapt their programs to an uncertain environment, and recover lost ground. As a result, a number of innovative approaches have been adopted to find and treat missing people with TB. This report is an effort to document the lessons learned from the implementation of these innovative approaches and to share good practices widely across all countries.

This report was developed by the Global Coalition of TB Advocates (GCTA) with technical guidance and support from the Global Fund TB Strategic Initiative.

**Eliud Wandwalo, Head TB, the Global Fund**

**Daisy Lekharu, Disease Advisor TB, the Global Fund**

## ABOUT THE GLOBAL COALITION OF TB ADVOCATES

The Global Coalition of TB Advocates (GCTA) is a global platform focused on issue-based advocacy, improving governance accountability and representation, and capacity building of TB affected communities and other groups across the globe. GCTA bridges the gap between civil society organizations, communities affected by TB, and other stakeholders in the TB response—including the World Health Organization (WHO), the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), Unitaid, and other global health agencies—ensuring that communities are involved in all TB processes. Its primary mission is to ensure that the communities affected by TB are at the centre of all advocacy efforts and to champion issues identified as a priority by communities affected by TB. Since its inception in March 2013, GCTA has contributed to the global TB agenda through activism on the price reduction of TB technologies, including GeneXpert cartridges, and TB drugs, including bedaquiline and delamanid; capacity building of TB communities; data collection on community perspectives on the impact of COVID-19 on the TB epidemic; and the publication of a report with 20 recommendations towards activating a human rights response to TB. To learn more about GCTA, please find its 2021–2025 Strategic Plan here.

## ABOUT THE TB STRATEGIC INITIATIVE

The TB Strategic Initiative, funded by the Global Fund and implemented by the Stop TB Partnership (Stop TB) and WHO, has been working with national TB programs and partners since 2018 to stop the spread of TB and reach the global goal adopted by world leaders to end TB by 2030. This ambitious joint effort, initially launched in 13 countries, aims to address specific barriers to finding missing people with TB –especially among key vulnerable populations– through a combination of innovative approaches, knowledge-sharing, and best practices. Now in its second phase (2021–2023), the TB Strategic Initiative will catalyze further efforts to find and successfully treat people with TB facing barriers and that are currently missed at different points in the TB care cascade in 20 countries, as well as strategic engagement with 5 countries in West and Central Africa.

**Date of Publication:** December 2022

**Authors:** The report was prepared by the Global Coalition of TB Advocates-led by Dr Fifa A Rahman (consultant), Blessina Kumar, and Archana Oinam.

**Funding Support:** Global Fund TB Strategic Initiative (2021–2023)

All photos by the Global Coalition of TB Advocates.

## ACKNOWLEDGEMENTS

We are grateful to the Global Fund for their support and technical insights into this report. Notably, we would like to thank the following individuals from the organization:

Eliud Wandwalo	Head, TB
Daisy Lekharu	Disease Advisor, TB
Keith Mienies	Technical Advisor, Community Responses and Systems
Gilles Cesari	Senior Advisor, Key Populations and Community Responses
Nicholas Oliphant	Senior Specialist, Community Health Worker Programming

This report was informed by the experience and insights of numerous TB experts, including communities affected by TB. Our thanks to the following (listed alphabetically by surname):

Ganesh Acharya	TB advocate, Mumbai, India
Dorothy Adongo	Community TB Advocate and Focal Champion for Western Kenya
Ramya Ananthkrishnan	Director, REACH, India
Siva Anggita	Policy Advisor, National TB Programme, Ministry of Health Indonesia
Huot Chanyuda	National Center for Tuberculosis and Leprosy Control (CENAT), Cambodia
Aarti Chauhan	TB champion, Touched by TB, New Delhi, India
Raghavan Gopakumar	National TB Coordinator, Touched by TB, New Delhi, India
Tejaswini Hiremath	Project Lead, Karnataka Health Promotion Trust (KHPT), Karnataka, India
Heng Hoeun	Peer Support Group Leader, Sa Ang, Kandel Province, Cambodia
Thea Hutnamon	Manager, Stop TB Partnership, Indonesia
Evaline Kibuchi	Chief National Coordinator, Stop TB Partnership, Kenya
Joseph Kilomo	TB champion, Nairobi County, Kenya
Jacqueline N Kisia	National TB Programme Manager, Division of National Tuberculosis and Lung Disease, Ministry of Health, Kenya
Vat Lida	Chair, District Network of People Living with and Experienced TB, Sa Ang, Cambodia
Endang Lukitosari	National TB Programme Working Group, Ministry of Health, Indonesia
Prabha Mahesh	Founder and Board Member Touched by TB, New Delhi, India
Allan Maleche	Executive Director, Kenya Legal & Ethical Issues Network on HIV & AIDS (KELIN), Kenya
Jacinta Musumba	TB champion, Bungoma County, Kenya
Jamin Nasuti	TB champion, Sirisia, Bungoma County, Kenya
Uswatun Nasyifah	TB patient, Serang, Banten Province, Indonesia
Stanley Nyerere	TB champion, Bungoma County, Kenya
Clarity Okibo	TB champion, Kanduyi Sub-County, Bungoma County, Kenya
Emmaculate Aniolo Omolo	TB champion, Siaya County, Kenya
Maurice Otieno Oudia	TB Link Assistant, Siaya County Referral Hospital, Bungoma County, Kenya
Tiffany Tiara Pakasi	Acting Director, Disease Prevention and Control, Ministry of Health, Indonesia
Vikas Panibatla	CEO TB Alert India (TBAI), Hyderabad, India
Phong Chanthorn	Senior Coordinator: Policy, Partnership and Networking, KHANA, Cambodia
Laxmi Rautela	TB champion, TB Alert India (TBAI), New Delhi, India
Delano Reynaldo	Program Coordinator, Sub-Sub-Recipient, Penabulu Consortium, Jakarta, Indonesia
Stephen Shikoli	National Coordinator, Network of TB Champions, Kenya
Permata Silitonga	Penabulu Consortium Indonesia
Pom Sopheap	Lay Counsellor, Sa Ang, Kandel Province, Cambodia
Anupama Srinivasan	Assistant Director, Resource Group for Education and Advocacy for Community Health (REACH), Chennai, India
Timothy Wafula	Program Manager HIV and TB, Kenya Legal and Ethical Issues Network on HIV & AIDS (KELIN), Kenya
Washadi	Patient Supporter, Persahabatan Hospital, Jakarta, Indonesia
Joyce Wairimu	TB champion, Nairobi County, Kenya
Gladys Awino Wanga	TB champion, Siaya County, Kenya
Meera Yadav	TB advocate, Mumbai, India

# TABLE OF CONTENTS

Foreword .....	2
About the Global Coalition of TB Advocates .....	3
About the TB Strategic Initiative.....	3
Acknowledgements.....	4
Abbreviations .....	6
Executive Summary .....	7
Introduction.....	9
Methodology .....	9
Findings .....	10
A. The Impact of COVID-19 on TB Detection and Treatment .....	10
Anxieties around the pandemic .....	10
Limited access to TB service delivery .....	10
Reduction in TB testing, treatment, and outreach services .....	11
Loss of income and limited government support .....	13
Doubling of stigma from both COVID-19 and TB.....	14
B. Best Practices in TB Community Service Delivery during COVID-19 .....	14
Cambodia .....	14
India.....	16
Indonesia .....	18
Kenya.....	20
C. Human Rights and Gender Barriers faced by TB Communities .....	23
Gender-based violence .....	24
Gendered implications of COVID-19-related lockdowns .....	24
Arbitrary arrests, extortion, and COVID-19-related police violence.....	26
Stigma, discrimination, and ostracization.....	28
Delayed and/or conditional TB care during the pandemic .....	29
Fraudulent procurement practices affecting supply of COVID-19 and TB medical supplies.....	29
The digital divide and the right to information.....	30
Poor remuneration of TB community health workers .....	30
Lessons Learned .....	33
Conclusion and Recommendations.....	35

## ABBREVIATIONS

C19RM	COVID-19 Response Mechanism, Global Fund
CENAT	National Center for Tuberculosis and Leprosy Control, Cambodia
CHW	Community Health Worker
CLM	Community-led monitoring
CSO	Civil society organization
DR-TB	Drug-resistant TB
FGD	Focus group discussion
GBV	Gender-based violence
GCTA	The Global Coalition of TB Advocates
IPC	Infection, Prevention, and Control
KELIN	Kenya Legal and Ethical Issues Network
KEMSA	Kenya Medical Supplies Agency
KHPT	Karnataka Health Promotion Trust
ILO	International Labour Organization
MDR-TB	Multidrug-resistant tuberculosis
NCD	Non-communicable diseases
NTP	National TB Programme
PETA	<i>Pejuang Tangguh</i> (Indonesian acronym, patient organisation in Jakarta)
PLHIV	People living with HIV
PPE	Personal protective equipment
PwSTB	People with drug-susceptible TB
PwT	People with TB
REACH	Resource Group for Education and Advocacy for Community Health
TB	Tuberculosis
WHO	World Health Organization



## EXECUTIVE SUMMARY

The emergence of the global COVID-19 pandemic in 2020 overwhelmed health systems and resulted in an unprecedented shift of public health resources away from tackling other disease areas to COVID-19 response. Tuberculosis (TB) services have been particularly affected, with TB referrals falling by 59% globally in the second and third quarters of 2020, compared with the same period in 2019.<sup>1</sup> In 2021, the impact was particularly acute. Disrupted access to TB services and reduced resources due to the pandemic contributed to an increase in TB deaths for the first time in a decade.<sup>2</sup>

Community cadres have become increasingly recognised in recent years and have played a crucial role in mitigating pandemic-related effects on TB service delivery. In the TB response, community cadres consist of several types of workers—including community health workers (CHWs) either formally or informally contracted by the public health system or CBOs. They also include individuals from the community and community-led or community-based organisations, like former TB patients, TB survivors, and TB champions. In many contexts, CHWs are recognised as an occupational group by the International Labour Organization (ILO) and the World Health Organization (WHO) and are a part of the public health and care workforce.<sup>3</sup> A growing body of evidence suggests that CHW-led interventions can enhance the TB response in several areas, including improving TB treatment outcomes and psychosocial support to patients and families affected by TB; supporting household contact tracing; and facilitating access to TB services, including referral of persons with presumptive TB.<sup>4</sup>

<sup>1</sup> The impact of COVID-19 on HIV, TB and malaria services and systems for health. Global Fund, 13 April 2021. <https://www.theglobalfund.org/en/updates/2021/2021-04-13-the-impact-of-covid-19-on-hiv-tb-and-malaria-services-and-systems-for-health/>.

<sup>2</sup> Global Tuberculosis Report 2021. WHO, 14 October 2021. <https://www.who.int/publications/i/item/9789240037021>.

<sup>3</sup> Community champions: A rapid scoping review of community champion approaches for the pandemic response and recovery. Public Health England, August 2021. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1011854/A\\_rapid\\_scoping\\_review\\_of\\_community\\_champion\\_approaches\\_for\\_the\\_pandemic\\_response\\_and\\_recovery\\_V8.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1011854/A_rapid_scoping_review_of_community_champion_approaches_for_the_pandemic_response_and_recovery_V8.pdf); WHO guideline on health policy and system support to optimize community health worker programmes. WHO, 6 August 2018. <https://www.who.int/publications/i/item/9789241550369>; International Standard Classification of Occupations. ISCO-08, vol. 1. 2012. ILO, 2012. [https://www.ilo.org/wcmsp5/groups/public/@dgreports/@dcomm/@publ/documents/publication/wcms\\_172572.pdf](https://www.ilo.org/wcmsp5/groups/public/@dgreports/@dcomm/@publ/documents/publication/wcms_172572.pdf).

<sup>4</sup> Health policy and system support to optimize community health worker programmes for HIV, TB and malaria services: an evidence guide. WHO, 2020. <https://apps.who.int/iris/bitstream/handle/10665/340078/9789240018082-eng.pdf?sequence=1>.

Despite the monumental impact CHWs have played and continue to play in detecting missing people with TB (PwT), supporting medication adherence, and providing psychosocial support to improve TB outcomes, at the inception of this report, there was no illustrative overview of how innovative community service delivery models sustained TB responses during the COVID-19 pandemic. Through peer-to-peer dialogue; in-depth interviews with CHWs working on TB (including TB champions),<sup>5</sup> National TB Program Coordinators, and technical partners; and focus group discussions in four countries, we sought to fill this gap in the literature. Community service delivery mechanisms implemented during the COVID-19 pandemic in four high-burden countries—**Cambodia, India, Indonesia, and Kenya**—were documented, along with human rights, gender-related, and other barriers. Key insights and recommendations for reversing COVID-19-related effects on TB mortality, morbidity, and on the livelihoods of TB communities were then compiled.

Here is what we found:

- CHWs innovated by delivering TB drugs to homes, conducting online counselling, and jointly conducting COVID-19 and TB awareness activities.
- Ministries of Health innovated by allowing longer take-home doses of TB medications and facilitating medicines pick-up if individuals were locked down in different states.
- CHWs' TB duties included home delivery of medications, referral to testing, psychosocial support, counselling, supply of food, advocacy with local authorities, and other duties. Some worked at night to avoid individuals being marked by neighbours as potentially having COVID-19, and work was mostly done by foot. In all countries, CHWs worked unpaid or for minimal stipends. The majority of CHWs interviewed were women. In several cases, CHWs spoke of the need to spend their own money to provide food to TB communities so they could remain on TB medication. (Cambodia, India, Indonesia, Kenya)
- Lockdowns prevented individuals with TB visiting out of state from accessing medications from their regular facility. Before COVID-19, a referral letter from one's regular facility would be obtained in order to access TB medicines from a different county. However, during the pandemic, national directives were that hospital facilities were only to be accessed in emergencies, and thus were closed to all other enquiries. (Kenya)
- Frequent deviations and deprioritisation of rights-based, gender-sensitive, and patient-centric care occurred, including rude and abrupt behaviours by clinicians and nurses towards CHWs and PwT (exacerbated by the fear of COVID infection), arbitrary arrests of CHWs and PwT who were not wearing masks, and extortion by police in exchange for release from jails. Experiences with authorities resulted in negative effects on health-seeking behaviour. (Kenya)
- Lockdowns increased risk of gender-based violence (GBV). CHWs were at the frontlines in assisting women, including in negotiations with husbands for periods of sexual abstinence. (India)
- Loss of income during lockdown affected TB patients' abilities to purchase food and worsened mental health outcomes. As a result, TB outcomes also worsened and CHWs worked overtime to tackle social and environmental factors influencing TB adherence. (Cambodia, India, Indonesia, Kenya)
- Due to the door-to-door nature of the work, CHWs were particularly vulnerable to police harassment, violence, arrests, and extortion during COVID-19 lockdowns and curfews. This included arrests due to non-masking, despite some CHWs stating that they could not afford masks. CHWs also reported having insufficient supplies of personal protective equipment (PPE) in the initial stages of the pandemic. (India, Kenya)
- Poor communication skills and incivility by nurses and other health staff compromised TB health-seeking behaviour. While these may have been partly due to pandemic stresses, they must be rectified through consultative meetings with TB communities and a long-term commitment to improving interpersonal and communication skills. (Kenya)

Overall, future pandemic responses must incorporate rights-based, gender-sensitive, and patient-centric approaches for vulnerable populations such as TB communities. Violations of these result in worse TB outcomes and worse financial outcomes for communities—affecting overall prosperity and wellbeing.

<sup>5</sup> TB champions are individuals who have been cured of TB and have dedicated their time and resources to serve as advocates in their communities. They work to spread information on TB in order to get persons who might exhibit signs and symptoms of TB to get tested and if positive be enrolled on TB treatment. Ending Tuberculosis in Ghana: Contribution of TB champions in community case identification. Rede-TB, 11 November 2020. <https://redetb.org.br/ending-tuberculosis-in-ghana-contribution-of-tb-champions-in-community-case-identification/>.



# INTRODUCTION

## BACKGROUND AND CONTEXT

COVID-19 affected all aspects of social and economic life, leaving no corner of the globe untouched. However, evidence quickly showed that the pandemic did not affect everyone equally. Data from around the world consistently indicated that the crisis exacerbated inequalities, with major consequences for the world's poor and vulnerable. Moreover, as a result of the unprecedented and evolving nature of the pandemic, resources were quickly rerouted from other health and social services to COVID-19 response. Disruptions to TB services were particularly acute, threatening to reverse decades of progress. In June 2020, WHO estimated that TB services disrupted due to COVID-19 could result in an additional 6.3 million TB cases and an additional 1.4 million TB-related deaths between 2020 and 2025.<sup>6</sup> Lockdowns and physical distancing requirements required that health and social service providers, especially those working at the community level, quickly reconfigure supports to patients. In many cases, innovations in service delivery were an urgent imperative. In this way, the pandemic served as a catalyst, with a number of innovative solutions and approaches emerging within TB communities. Despite the challenges imposed by the pandemic, countries have tackled the situation and adapted their programs to enhance outcomes and cover lost ground. This includes adopting innovative approaches in finding and treating missing people with TB through meaningful community engagement. The lessons learned from the implementation of these innovative community approaches should be shared widely across all countries.

## PURPOSE AND OBJECTIVES

To support this effort and scale up community action in all Global Fund supported countries, GCTA reviewed and documented best practices and innovative approaches in finding, diagnosing, and treating missing people with TB in four countries: Cambodia,

India, Indonesia, and Kenya. The purpose of this review was to document and share what has been done within TB communities and to enhance learning for countries to activate and innovate TB programs—including improving TB prevention, case finding, and treatment through community response.

**Specific objectives included identifying and documenting:**

- Innovative approaches and best practices in integrated community-based TB service delivery in the context of the COVID-19 pandemic;
- Human rights and gender-related barriers;
- Community-led monitoring (CLM) and country experiences;
- Innovative models on community engagement in TB along the TB case cascade; and
- COVID-19 pandemic and community engagement practices.

# METHODOLOGY

A semi-structured questionnaire tool was developed to gather information from partners in four countries (Cambodia, India, Indonesia, and Kenya). In-depth key informant interviews and focus group discussions (FGDs) were carried out in-person with community health workers (also known as TB champions/patient supporters/lay counsellors/peer support groups in different contexts) in all four countries. Interviews and discussions were facilitated by the GCTA in India, Indonesia, and Kenya, and in-person by KHANA in Cambodia. Additional in-depth interviews were carried out with TB civil society organisations (CSOs), managers/coordinators of the National TB Programmes within each country's Ministry of Health, WHO Country Team staff, and human rights organisation staff. These insights were audio-recorded and auto-transcribed by Otter.ai, with the exception of

<sup>6</sup> Martin-Hughes et al., "Impacts of COVID-19-Related Service Disruptions on TB Incidence and Deaths in Indonesia, Kyrgyzstan, Malawi, Mozambique, and Peru: Implications for National TB Responses." PLOS Global Public Health, 30 March 2022. <https://journals.plos.org/globalpublichealth/article?id=10.1371/journal.pgph.0000219>

Cambodia where interviews were conducted in Khmer and manually translated by KHANA staff members. From transcriptions, responses were organised into themes and elaborated below.

## FINDINGS

### A. THE IMPACT OF COVID-19 ON TB DETECTION AND TREATMENT

#### ANXIETIES AROUND THE PANDEMIC

The COVID-19 pandemic saw TB services heavily disrupted across the globe. In countries where there is heavy reliance on community health workers to refer patients to TB diagnosis and treatment, such as Kenya, the panic and confusion that ensued with the emergence of a highly transmissible novel virus made responding in communities particularly difficult. Joseph Kilomo, a CHW in Nairobi County, Kenya described these sentiments in early 2020:

*When COVID-19 came, everybody was in panic, because it was a new pandemic. I was reading so much (sic) information online – and the information was so scary to accept. And then we saw that the symptoms for TB and for COVID-19 which were the same, so we missed many opportunities (to recruit patients for testing and treatment) because there was confusion on which is which.*

**(Joseph Kilomo, TB champion, Nairobi County, Kenya)**

Panic and confusion also emerged from the fear of being diagnosed with COVID-19 and thus being stigmatised due to a positive COVID-19 diagnosis. According to Tejaswini Hiremath, Project Lead, Karnataka Health Promotion Trust (KHPT) in India:

*People were not even able to differentiate whether based on the symptoms that they*

*were having (they) had to go for a COVID test or TB test. Whenever we spoke about going for the TB test, even at that time, people were scared, because what if it is COVID? There was a huge 'no' from the communities' side. Even when the symptoms were there, we had a very hard time to convince them that this is not a COVID test, this is a TB test.*

**(Tejaswini Hiremath, Project Lead, KHPT, Karnataka, India)**

Fear of getting diagnosed with COVID-19 has been discussed in the literature as related not just to "disease contraction and dying, but also associated socio occupational stress."<sup>7</sup> The 'hard time' experienced by CHWs and NGOs points to key considerations for the next pandemic. These include the need for messaging strategies around engagement in TB services and for governments to actively reassure communities of protection and support in case of diagnosis with the relevant pandemic pathogen.

#### LIMITED ACCESS TO TB SERVICE DELIVERY

In many countries, due to both COVID-19 and TB being respiratory illnesses, TB specialist centres were often converted to COVID-19 centres. In **Indonesia**, where TB remains one of the top four causes of death, Persahabatan Hospital in Jakarta, which also houses the National Respiratory Centre, was converted to a national referral centre for COVID-19, alongside other facilities.

According to Pak Borky, a patient supporter based at Persahabatan Hospital, prior to the pandemic, consumption of TB medication was observed by a peer supporter in-person at the health facility. During COVID-19, this practice was replaced by the provision of one weeks' supply of take-home medications for TB patients, with family members observing treatment. While this reduced infection risk, Pak Borky shared that family members sometimes found it difficult to see their family members experience the side effects of their TB medications and thus advised them not to finish it. He also said that his role during the COVID-

<sup>7</sup> Arora A, Jha AK, Alat P, Das SS. Understanding coronaphobia. *Asian J Psychiatr*. 2020 Dec;54:102384. doi: 10.1016/j.ajp.2020.102384. Epub 2020 Sep 6. PMID: 33271693; PMCID: PMC7474809. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7474809/>.

19 pandemic shifted to virtual peer support through video calls with patients to encourage the completion of regimens.

In addition, the conversion of TB facilities into COVID-19 facilities meant that patients did not want to go to health facilities as they considered them high risk. In the words of Lusiana Aprinawati, a member of the TB Working Group in Jakarta:

*Many people are saying they don't want to go to the hospital or health services, especially for TB patients, because they said, they "akan dicovidkan" (will contract COVID). They afraid to be pointing (identified) as Covid patients. So, many people refuse to go there, and I heard this from many people and TB patients.*  
(Lusiana Aprinawati, Member of TB Working Group, Jakarta)

At the start of the pandemic, mobile services had yet to be established or were operationally limited. As a result, in numerous geographies, TB communities did not access testing, treatment, and other care services. In **India**, Meera Yadav, a TB advocate based in Mumbai, described how the TB community wasn't sufficiently informed about the reasons for closure of certain health facilities:

*After lockdown some of the labs and private health clinics didn't not open. They were completely shut down and we don't know the exact reason behind it. (Perhaps) some of the doctors died due to COVID. We had to find a different health care centre for those who were taking medicines. Some of them were not ready to go to a different centre and had to be counselled.*  
(Meera Yadav, TB Advocate, Mumbai, India)

Lay counsellors played an essential role in acclimatising communities with TB to chaotic and often uncertain circumstances during peak moments during the COVID-19 pandemic.

## REDUCTION IN TB TESTING, TREATMENT, AND OUTREACH SERVICES

All four countries in this study experienced a reduction in TB testing due to the shift in priorities toward COVID-19. In India, for example, despite best efforts by the government to release guidelines on TB and COVID-19 bidirectional screening,<sup>8</sup> lockdowns made it difficult to keep testing rates up.

**In southwestern India**, it was reported that not only did testing halt, but that community health workers had to take on numerous COVID-19-related duties, including convincing communities of the efficacy of vaccinations alongside transmitting TB awareness messaging. These COVID-19-related duties were also undertaken in Delhi and Mumbai, and throughout the country occurred without payment or COVID-19-specific training. According to Tejaswini Hiremath, Project Lead, KHPT:

*There was absolutely no testing happening. Because every government facility turned every (bit of) attention towards COVID. Virtually every facility turned towards COVID. So in those few months, TB testing stopped. When the question of immunising with the vaccine came, there was a huge situation from the community that "no, we don't want vaccines" and so people had certain notions about the vaccination across India. Our community structures had to take leadership in organising the camps for COVID vaccine awareness (in conjunction with) TB awareness activities.*  
(Tejaswini Hiremath, Project Lead, KHPT, Karnataka, India)

Raghavan Gopakumar, National Coordinator, Touched by TB—the national coalition of people affected by TB in India based in New Delhi—further stated, "Whatever sputum we transported was just lying there because all the lab technicians were transferred to work on COVID."

Testing and treatment interruptions were also reported **in Kenya**. One respondent noted that per-

<sup>8</sup> Guidance note on Bi-directional TB-COVID screening and screening of TB among ILI/SARI cases. Ministry of Health India, 2020. <https://www.mohfw.gov.in/pdf/1TBCOVIDscreeningguidancenote.pdf>.

sons with TB who were in town from other states at the time lockdowns were announced could not secure medicine supplies from the facilities where they were registered, resulting in interrupted treatment.

*When COVID came, TB services were distracted, because some facilities were closing down because of fumigation activities. So, at that point when somebody had cough and wanted to come for testing, they got there and there were no services at the facility. And the other thing was because of lockdowns, some of our clients were locked down in other counties. As a result, some people who were on TB treatment had to interrupt treatment due to lockdowns.*

**(Stephen Shikoli, National Coordinator, Network of TB champions, Kenya)**

In **Indonesia**, two years after the pandemic first began, respondents have noted that the effects of service delivery disruptions remain unresolved, with the situation only now returning to normal (as of July 2022) and depletions in service quality still evident. Budi Hermawan, Executive Director of POP TB Indonesia, National Organisation of Drug-Resistant (DR-TB) Survivors explained:

*During the COVID-19 pandemic, we saw a lot of tuberculosis services turning into COVID-19 services, so the needs of TB patients could not be served properly. But now that we see that it's starting to get resolved. Services have been active again, but we need to make improvements so that these services can be better, easier to access and more patient oriented. Quality services are a human right. It is our duty as the TB community to ensure and encourage the availability of quality services so that they are easy and accessible for tuberculosis patients, so that TB elimination in 2030 can be achieved.*

**(Budi Hermawan, Executive Director, POP TB, Indonesia)**

Overall, the shift in TB services towards COVID-19 saw drastic reductions in TB detection, consistent with global statistics that over 1.4 million fewer people received TB care.<sup>9</sup>

TB community outreach activities were also disrupted during COVID-19. In **Cambodia**, respondents described how individuals with presumptive TB were reluctant to undergo TB screening because of a fear to be tested for COVID-19. As the fear of COVID-19 spread, regular community outreach activities became impossible as people affected by TB and their families were reluctant to have contact with TB peer support group leaders due to concerns about contracting COVID-19. The lack of ability to engage communities and follow-up on TB (and COVID-19) symptoms had devastating effects. In one anecdote from Cambodia, a peer support group leader shared that an individual with presumptive TB died as he tested positive for COVID-19 and was required to undergo COVID-19 treatment before he was allowed to receive TB treatment. Similar prerequisites were imposed for testing as well, with individuals required to undergo COVID-19 testing first before receiving TB testing.

Similar disruptions to community outreach work occurred in **Kenya**, with community health workers in Siaya County (approximately 400 kilometres west of Nairobi) reporting being met with aggression from communities who feared COVID-19. A respondent explained:

*Visiting the house during the COVID-19 period, people were really suspicious. So, when you go to somebody's home, you're not welcome. Because they fear. If you're coming from the hospital, and you've come to visit them, you'll find the fear of stigmatisation from other people who think they have COVID, because these are patients we keep following and there are fears that you have come for other reasons such as COVID instead of TB. So especially during that time, when you come to a home and you're from the health facility,*

<sup>9</sup> Impact of the COVID-19 pandemic on TB detection and mortality in 2020. WHO, 22 March 2022. <https://www.who.int/publications/m/item/impact-of-the-covid-19-pandemic-on-tb-detection-and-mortality-in-2020>

*you are not welcome to visit. Most of us were met with aggression, lots of it. To the point some people had to withdraw from taking drugs. Pulling them back (into treatment) was not such an easy task.*

**(Gladys Wanga, TB champion, Siaya County, Kenya)**

Communities also feared that CHWs providing TB services would report them to COVID-19 authorities, and they would then be required to remain in quarantine facilities. According to one respondent:

*(Communities) were saying: 'What if you're trying to do a COVID test to me? Because I'm coughing? I just know you want to go and report me and tell these people to come pick me up.' They were practically refusing all (our help), even if it was somebody you know who has presumptive TB.*

**(Dorothy Adongo, Community TB Advocate and Focal champion for Western Kenya)**

### LOSS OF INCOME AND LIMITED GOVERNMENT SUPPORT

Many TB communities work in the informal sector, requiring daily work to bring home food and money to support their families. In all four countries surveyed, TB communities working in the informal sector (e.g., market stall keepers, laundry washers, house cleaners, and labourers) lost income during lockdowns as they weren't allowed to leave their homes and had no way of generating other income. Furthermore, in most instances, there was limited or no government support for lost incomes. Given that TB medications must be taken with food, the loss of income directly impacted TB adherence.

TB community health workers worked together to find income for people affected by TB. In **India**, a TB champion spoke about efforts to engage politicians to find money to provide to affected communities:

*During lockdown, TB patients from villages who were working as labourers didn't have money to buy food or to pay their rent. They*

*faced lots of problems. We got together and advocated with our local MLA (Member of Legislative Assembly) to provide food for them.*

**(Aarti Chauhan, TB champion, Touched by TB, New Delhi, India)**

In some cases, individuals had lost income but were ashamed to communicate this, requiring active follow up by community health workers to ensure that families had enough food to consume their medicines. In **Kenya**, a respondent shared:

*We would go to houses, bringing the drugs but not sure what condition you are going to find the family in. You're not even sure whether the drugs you have delivered, are they going to swallow them or not? And maybe it is the wife or even a child who will tell you the situation, saying "Auntie, Auntie, you know, Dad has not told you we have not eaten for two days."*

**(Dorothy Adongo, Community TB Advocate and Focal champion for Western Kenya, Bungoma County, Kenya)**

The same was found in **Cambodia**, where community health workers described how reduced incomes due to lockdowns affected many TB communities working in the informal economy that did not have income protection.

In **India**, some communities that had been given money via direct bank transfers as welfare support reported not receiving these funds. According to one TB champion:

*DBT (direct bank transfers) of 500 rupees are not received regularly and some patients really need this money to buy nutrition (food). Nutrition support should be provided in kind along with the medicines.*

**(Shabana, TB champion, Touched by TB, New Delhi, India)**

This was corroborated by another TB champion, Saba, who said that many patients were not getting the direct bank transfers.



Saba, a TB champion, talks about income losses during COVID-19 and how direct bank transfers to TB communities were irregular, with many halting altogether.

These findings underscore the vulnerabilities faced by TB communities and other marginalised populations and shed important light on considerations for future pandemic response, including the need for financial support and cash injections during lockdown circumstances.

### DOUBLING OF STIGMA FROM BOTH COVID-19 AND TB

TB community health workers in all four countries reported that people with TB faced elevated levels of stigma, due largely to the fact that both were lung-related infectious diseases and had overlapping symptoms (e.g., cough). Stigma due to COVID-19 or TB was noted as a barrier to accessing TB services. Dorothy Adongo, a TB champion from Bungoma county in **Kenya**, spoke about how stigma manifested when she accompanied people with presumptive TB to facilities for diagnosis, noting that:

*There was stigma coming from the COVID-19 disease itself. The way that people with COVID-19 were being handled, with government quarantine and everything, it just made everybody stand up in caution. Those of us who were involved with people with presumptive TB, we found that when we come to a facility with these people, the first thing that comes to everyone's mind is not tuberculosis – but that it is COVID. And when that*

*happens, we were harassed (by nurses), and faced hesitancy and aloofness when trying to get care for people with presumptive TB.*

**(Dorothy Adongo, Community TB Advocate and Focal champion for Western Kenya)**

One patient supporter in **Indonesia** shared how the role of patient supporter was especially salient for those already undergoing TB stigma—not just for the provision of medicines but also for encouragement and support amidst medication side effects:

*There is one patient that is facing a lot of stigma and discrimination and her family didn't want to manage her treatment at all – so every week during COVID, patient supporters, no matter rain or shine we took it to her because we wanted her to be healed. But there were side effects and her family said that this medication was perhaps not important, so she threw the medication away.*

**(Indri Purwandari, DR-TB Patient Supporter Persahabatan Hospital, Jakarta, Indonesia)**

## B. BEST PRACTICES IN TB COMMUNITY SERVICE DELIVERY DURING COVID-19

### CAMBODIA

In Cambodia, focus group discussions and key informant interviews were conducted with TB-affected community members, CHWs, and the National TB Programme. The National TB Programme established the following best practice interventions to minimise disruptions to TB diagnosis, care, and treatment:

- Allowing **multi-months dispensing of TB medications** to people on TB treatment.
- Replacing in-person consultation **with virtual or tele-health follow-up**, through phone calls, and mobile applications such as Telegram and Facebook Messenger to provide counselling and TB information, as well as to closely follow up with patients' medication adherence.
- **Linking (referral) services to private sector clinics**

to detect missing TB cases.

- **Increasing the use of personal protective equipment (PPE)** amongst TB service providers.
- **Providing direct cash support** to those in possession of an equity card (at the national level).



Sor Sothea, a lay counsellor based in Leuk Daek in southeast Cambodia, describes how collaboration with commune councils enabled some community outreach during the COVID-19 pandemic.



Sarin Thy, a leader of a peer support group in Kandal Province, described how recruiting newly diagnosed TB patients to refer their close contacts was effective in detecting missing TB cases.

Both types of community health workers in the Cambodian TB context (i.e., peer support workers and lay counsellors) complemented the work of the National TB Programme by following up with people with TB online or with phone calls. In addition, in-person counselling sessions were replaced with virtual counselling sessions. While in-person community outreach activities drastically reduced during lockdown,

with the collaboration of local authorities (including commune councils and village chiefs) these services were offered in some locations—enabling counselling, referrals, community support, and sputum collection.

*During the COVID-19 pandemic, there was a need to have full engagement of local authorities to support TB active case finding. Engagement with commune councils allowed the community health workers (lay counsellors and peer support groups) to conduct home-based sputum collection of people with presumptive TB and to bring to the health facilities.*

**(Sor Sothea, lay counsellor, USAID-funded COMMIT project in the Operational Health District of Leuk Daek (OD-Leuk Daek), Kandal Province, Cambodia)**

In addition, individuals who were diagnosed with TB were recruited as 'seeds,' (i.e., persons within the community to reach out and refer their close contacts to diagnostics, treatment and care services).

*Recruiting people who had been bacteriologically confirmed with TB as seeds to engage and recruit their close contacts was a good model for community-based action to find missing TB cases during the COVID-19 outbreak.*

**(Sarin Thy, leader of peer support group of people living with and experienced TB in Operational Health District of Sa'Ang (OD-Sa'Ang), Kandal Province, Cambodia)**

Focus group discussions with lay counsellors and peer support group members highlighted how the trust that communities had toward them enabled uptake of TB treatments and TB preventive therapy, with at least fifty new people with TB identified and linked to care during lockdown. This trust was reflected in comments by Phorng Chanthorn, Senior Coordinator, Policy, Partnership and Networking at KHANA:

*During the crisis, it was difficult to (stay) connected with people with TB. So that's why lay*

*counsellors and peer support groups stayed connected – to provide encouragement as well as information, timely counselling, and materials such as COVID preventive and control measures, facemasks, and alcohol (sanitisers). So this provided them with some basic mental health support and to (alleviate) hesitancy, worries, and sadness.*

**(Phorng Chanthorn, Senior Coordinator:  
Policy, Partnership & Networking, KHANA,  
Cambodia)**

As in other countries in this report, communities in Cambodia were financially impacted due to the pandemic. All individuals earning below a certain amount could apply for an 'equity card' to receive direct bank transfers of approximately USD\$70 transmitted through a collaboration between the government and microfinance institutions. According to Chanthorn, while the amount was small, at least TB communities benefited from some government support.

## INDIA

Interviews with organisations in India captured the diverse and nuanced nature of community responses across different geographies. This included the work of TB champions, community-based organisations, and TB advocates in Hyderabad (the capital of the state of Telangana in southern India), Karnataka (a state in southwest India), Mumbai (the capital of the state of Maharashtra in western India), Delhi (in north India), and Chennai (the capital of the state of Tamil Nadu in south India).

With the closure of multiple health centres and the diversion of healthcare staff to COVID-19, TB champions and TB community health workers were central to the TB response. Community-led innovations included:

- **Take-home TB medications** for one month.
- **Home-based delivery of TB medications** and adherence support by community health workers.
- **Upskilling of TB communities and champions**, who were trained to fix and maintain Truenat molecular diagnostics machines (Tamil Nadu).
- **The use of digital tools** to share information and connect with peers and TB communities in different regions and locales.
- **Tele-counselling, followed by home-based collection of sputum** by community health workers.
- **Communication skills training** for over one hundred TB champions to address misconceptions and perceptions about COVID-19 (Chennai).
- **Integrated COVID-19, TB, and non-communicable disease (NCD) care** through partnerships with laboratories and free coupons for diabetes and hypertension screening (Chennai).

In Chennai, where the TB organisation REACH operates, TB Nanbans (TB friends) were available to provide in-person support through Nakshatra Centres,<sup>10</sup> which are free spaces provided by private hospitals that function as a referral hub for people with symptoms of TB and people with TB and provide integrated support for TB and NCD care. This support included facilitating follow-up visits with private practitioners in person or via phone/WhatsApp, even when clinics were closed; ensuring people on treatment had a month's stock of medications; facilitating linkages to *Nikshay Poshan Yojana* (the programme providing cash support through direct bank transfers); and motivating people to get vaccinated for COVID-19.<sup>11</sup> In addition, as a response to COVID-19 and to provide easy access to screening facilities for NCDs, REACH established private-private partnerships with several laboratories in Chennai and provided free coupons for diabetes and hypertension screening to people with TB, people with drug-susceptible TB, and their family contacts.<sup>12</sup>

<sup>10</sup> Chennai has 38 Nakshatra Centres, which are free spaces provided by the private hospital that function as a referral hub for people with symptoms of TB/people with TB. People are referred to the Nakshatra centre either from within the hospital or from private practitioners located in areas around the centre. In 2019, REACH began providing integrated care for TB and NCDs (Diabetes and Hypertension), by offering screening and access to care for NCDs for people with TB, people with symptoms of TB, and contacts of people with TB. This has resulted in a comprehensive, people-centred package of care services for people with TB.

<sup>11</sup> Annual Report 2020–21. REACH. <https://img1.wsimg.com/blobby/go/52cad3d5-1167-465b-8f13-e419aeae141/REACH%20Annual%20Report%202020-21.pdf>.

<sup>12</sup> Annual Report 2020–21. REACH. <https://img1.wsimg.com/blobby/go/52cad3d5-1167-465b-8f13-e419aeae141/REACH%20Annual%20Report%202020-21.pdf>.





In Tamil Nadu, a state in southern India, when lab technicians were redirected to the COVID-19 response, TB communities took initiative and received training to fix Truenat molecular diagnosis machines. Ramya Ananthakrishnan, the Director of Resource Group for Education and Advocacy for Community Health (REACH) explained:

*There were many innovations in (multiple) different projects within our work with TB in different settings and in different states. In Tamil Nadu, for example, when the lab technicians were diverted for COVID-related activities, our communities, women, TB leaders, got trained to fix Truenat machines and do the direct problem solving. I think one innovation is how the communities came together to find local solutions to the local problems.*

**(Ramya Ananthakrishnan, Director REACH, Chennai, India)**

In addition, some individuals receiving TB treatment were recruited into service delivery as TB champions during the COVID-19 pandemic. TB champions spoke about delivering medications to the homes of affected communities and providing counselling and information to communities about available TB and COVID-19 services. One respondent shared how the persistence and resilience of TB champions was critical, especially when communities did not want contact with them due to fears of COVID-19 infection:

*I started dispensing medicines under the mentorship of Saba (another TB champion). We both took the responsibility of providing medicines to all the patients from our DOT centre. I also did counselling with patients. Many patients were not supportive and didn't want to test for COVID – we all were at risk but we still wanted to provide the services.*

**(Gulshana, TB champion, Touched by TB, New Delhi, India)**

A lack of understanding about COVID-19 risks and misconceptions about COVID-19 tools emerged as a key barrier during the pandemic. Given the position of trust that many TB champions have within the communities they serve, it was strategic for them to be trained and deployed to engage and mobilise communities on both COVID-19 and TB messaging. As Anupama Srinivasan from REACH explained:

*We engaged ninety to a hundred TB champions to build their capacity to become more skilled, effective communicators with their local communities. And the reason we felt this was important was that then they could take TB and COVID messages to their communities, reinforce the key messages and address all the misinformation and myths and misconceptions that were floating around.*

**(Anupama Srinivasan, Assistant Director, REACH, Chennai, India)**

As described earlier, lockdowns also meant that TB activities could no longer take place in person. TB Alert India took the initiative to introduce a call centre model to enable tele-counselling for TB communities, albeit with two counsellors manning the lines due to resource constraints. According to Vikas Panibatla, the CEO of TB Alert India, these tele-counselling lines were incredibly useful to link individuals into TB screening and further care:

*(People were) able to give a missed call to that number and get a call back from the call centre (counsellors), who would then ask, 'what is your problem', and if they have (queries or health problems), and if they are ready for the next step in the screening process, it could be a probability that they are presented for TB care. (After that), the counsellors would refer them onwards to the local outreach worker to give them a call and confirming on the call (their symptoms and concerns). And if he or she gets confirmation, only then will a house visit occur to take a sputum sample to the NTEP<sup>13</sup> site.*

**(Vikas Panibatla, CEO, TB Alert India, Hyderabad, India)**

In addition to tele-counselling lines, TB champions and communities conducted zoom meetings and met virtually to share best practices and strategize for TB detection. Anupama Srinivasan, Assistant Director with TB REACH stated that communities became much more adept with digital tools during this time and that utilizing them became a source of empowerment and connection with peers in different states. Virtual platforms also provided individuals who had previously not come to TB facilities every month (due to stigma, privacy concerns, busy schedules, etc.) an opportunity to engage more closely. According to Tejaswini Hiremath, Project Lead at Karnataka Health Promotion Trust, once they offered the option for people to log in virtually from their smartphones or

through a conference call for continuity of support, a few teachers in government facilities that had never come in-person found the virtual meetings very useful.

## INDONESIA

In Indonesia, focus group discussions, community health center visits, and home visits revealed several key community-led innovations that were initiated during COVID-19. These include:

- **Home-based sputum collection.**
- **Online outreach to TB communities**, including through WhatsApp, video calls, etc.
- **Take-home TB medications**, including weekly supplies of MDR-TB drugs.
- **Coordination between different health facilities** to enable continuation of TB treatment for individuals who were formerly receiving treatment from main hospitals that had been designated COVID-19 referral centres, and who were no longer able to provide treatment during the pandemic.
- **Coordination with patient supporters in other districts** to secure hospital beds for DR-TB patients requiring hospitalisation.

In addition, at the national level, a **Presidential Decree on Tuberculosis 67/2021**, empowered district leadership on TB;<sup>14</sup> established a multi-Ministerial facilitation team for TB elimination;<sup>15</sup> and authorised public communication channels for the widespread dissemination of factual information on tuberculosis.<sup>16</sup>

Community cadres and patient supporters played an essential role in filling the gap left by clinics and health staff who had been diverted to the COVID-19 response. According to the National TB Programme:

*From the community level, I think they really helped us a lot with reaching more (individuals) because at that time what was being provided by the Puskesmas (community health centre) was very limited. So, community had and is really having a vital and important*

<sup>13</sup> National TB Elimination Programme.

<sup>14</sup> Presidential Decree on Tuberculosis Countermeasures 67/2021. Government of Indonesia, November 2021. <https://peraturan.bpk.go.id/Home/Details/174557/perpres-no-67-tahun-2021>.

<sup>15</sup> Idem.

<sup>16</sup> Idem.

role in helping us find new cases during the active case finding, giving TB education to the society, doing the mass screening, and reporting back to health facilities. And they are also good at giving, counselling – i.e., TB survivors that provide pendampingan (peer support). The thing is we cannot make it far without community help. They are essential in keeping people affected by TB on treatment and (ensuring) that they are not lost to follow up and provide emotional support.

**(Siva Anggita, Policy Advisor, National TB Programme, Ministry of Health, Indonesia)**

Budi Hermawan, the Executive Director for POP TB Indonesia, spoke about how communities used multiple innovations to continue providing TB support services, including shifting to online activities:

*All of the energies (sumber daya) shifted to COVID, and when restrictions came there were issues with mobility of families of patients. So, us as programme implementers had to shift activities from offline to online activities.*

**(Budi Hermawan, Executive Director, POP TB, Indonesia)**

Hermawan further noted that community health workers, whether attached to Puskesmas (community health centres) or the District Health Office, were mobilised for the COVID-19 response and thus carried a dual burden of tracking and tracing both COVID-19 and TB cases. In addition to tracking and tracing activities, patient supporters attached to TB facilities that were designated as COVID-19 reference hospitals played an essential role in ensuring patients receiving treatment there were able to continue treatment elsewhere. In the words of Washadi, a PETA patient supporter who was attached to Persahabatan Hospital:

*During COVID-19, patients were given weekly dose DR-TB treatment. We (patient supporters) call our patients daily, not only to know how they are taking their medicine but their personal stories as a peer supporter. As part of a network of TB communities and TB*

*survivor network, I was able to coordinate with other patient supporters to ensure that DR-TB patients who initiated treatment in Persahabatan Hospital (national referral hospital) could go back to their hometown in different provinces and continue their treatment. When the pandemic happened, we also coordinated closely to help identify available hospital beds for newly admitted DR-TB patients who needed special care.*

**(Washadi, Patient Supporter, Persahabatan Hospital, Jakarta, Indonesia)**

In the Community Health Centre in Banten province, TB staff spoke about how community health workers in their district continued delivering sputum samples to their laboratory for analysis, as well as delivered medications to homes:

*Our health facility did not close when the pandemic spread to our district. We still provide TB services and schedule our meetings with patients. The community cadres also helped us because they were able to collect sputum in pots, shared by our facility, and keep it (i.e., in their cooler box, funded by the GF C19RM) to deliver it to our laboratory. They also support us to deliver medications to patients' homes when they cannot visit the Puskesmas.*

**(Haniifah, TB Programmer, Puskesmas Rau, Banten Province, Indonesia)**

However, it was evident during interviews that community activities on sputum collection, referrals, and tracing meant that nutrition and counselling and TB awareness had been deprioritised. Given that nutrition and peer support are essential for successful TB outcomes, it is necessary that future programming ensure sufficient focus in these areas. According to the National TB Programme, intensification towards TB elimination has begun, facilitated by the Presidential Decree on TB, with increased collaboration and cadres activated on active case finding, case managers standing by in MDR-TB hospitals, and peer supporters for MDR-TB counselling, education, and adherence support for MDR-TB patients. Siva Anggita, Policy



Visiting the home of a young woman with MDR-TB along with the cadre.

Advisor from the NTP elaborated further on why the presidential decree and related multi-Ministry collaboration was catalyzing genuine change:

*Achieving TB elimination under the Ministry of Health alone will be not possible. We cannot push the district leadership to do what we want, but the Ministry of Home Affairs can push those districts; so the release of the presidential decree really helped us. (With this decree) we can collaborate with other ministries like the Ministry of Home Affairs to encourage TB notifications and asking that TB be accounted for by district leaders. We are also collaborating with other Ministries like Public Works, Infrastructure, Housing, and the Ministry of Village, Development of Disadvantaged Regions, so we will reach more people. We cannot reach them by ourselves.*

**(Siva Anggita, Policy Advisor, National TB Programme, Ministry of Health, Indonesia)**

While community-led innovations helped fill gaps where possible, COVID-19 restrictions meant that persons with presumptive TB reached health centres extremely late. This may have resulted in a reversal of gains. Discussions with TB communities revealed key needs moving forward, including the provision of nutritious food to ensure people with TB do not default on treatment, a more consistent approach for mass media campaigns aimed at community sensi-

tisation, better collaborative relationships between District Health Offices and CSOs, and professionalisation/upgrading of community health volunteers to community health workers.

#### **KENYA**

Data collection in Kenya through focus group discussions and in-depth interviews with TB champions elaborated several key community service delivery innovations:

- **Home drug delivery** by community health workers.
- **Longer take-home supplies and deployment of community health workers** for adherence support.
- **No-contact sputum collection from homes**, including sputum vials being left on windowsills and doorsteps for collection.
- **Night visits** to protect privacy and address stigma concerns from neighbours who were concerned about COVID-19 infection.
- **Removal of TB-branded bibs and uniforms** to prevent community panic while delivering services.
- **Empowerment of community health workers** to deliver services and detect missing TB infections by the Ministry of Health.

As in other countries described above, drug delivery at homes was essential. According to Stephen Shikoli, the National Coordinator of TB champions, healthcare workers based at clinics would instruct TB champions as to which members of the community required medication delivery and TB champions

would then take supplies to households. In addition, TB champions continued to work to pick up sputum, although they faced significant challenges in the beginning due to lack of PPE provision.

As described above, TB champions and community health workers also faced significant stigma. Communities perceived the workers to be at high risk of bringing COVID-19 into their communities as their jobs took them from house to house. Consequently, in the initial stages, CHWs working on TB were unwelcome, shouted at, and asked to leave. TB champions were determined, however, to keep working to prevent defaulting of TB treatments. A decision was made to continue community outreach, but without branded uniforms. One respondent shared:

*If you're seeing going to house X, the communities think there must be somebody who's HIV positive or TB positive, and that results in stigma. To address that, TB champions stopped wearing anything branded - any bibs and uniforms. They went with normal clothes, so they do not stand out or be recognised in the community. Because if they go in the branded (outfit), then neighbours can make a conclusion that somebody in that household has TB or COVID.*

**(Evaline Kibuchi, Chief National Coordinator, Stop TB Partnership Kenya)**

Other respondents noted that drug and/or sputum collection through night visits or meetings at covert locations or locations away from households were necessary innovations to prevent further stigmatisation. Additionally, TB champions noted that due to multi-layered issues, including loss of incomes and lockdowns, they had to work longer hours to deliver drugs to communities during the pandemic. Related to this, Gladys Wanga, TB champion from Siaya County in southwest Kenya described that it was sometimes necessary to make multiple visits to the same location in a short amount of time to ensure adherence. She stated:

*Coming back four times or more, back and forth in a short space of time because some people live very far and especially in the initial stages there were a lot of problems with drug delivery and with access to food. And if you don't follow up closely and repeatedly, sometimes people would default.*

**(Gladys Wanga, TB champion, Siaya County, Kenya)**

In Kenya, the work of TB champions within communities was facilitated by the Ministry of Health with coordination by county authorities. Jacqueline N Kisia from the National TB Programme described how coordination with counties helped empower communities and enable longer take-home doses:



Kangemi Health Center, where TB champions within that subcounty are based, collect drugs, and deliver sputum.



TB champions from Nairobi County in front of the Kangemi Health Centre.

*The Ministry of Health does not directly deal with the communities, so coordination had to come from the county authority, and then the county links to the community level. So, through communications with 47 counties, there were meetings, sensitisation, then eventually a plan on how patients should receive their medication. Number one, for example, if you're in the intensive phase (of treatment), you can pick your medication up for a prolonged time, and the community health worker will monitor whether the patient is adhering to medications and keeping up with tests which are supposed to be done during TB monitoring and progress of the patient.*

**(Jacqueline N Kisia, National TB Programme Manager, Division of National Tuberculosis and Lung Disease, Ministry of Health, Kenya)**



TB champion Clarity Okibo in her branded TB champion bib, describing supplying food to TB communities so they could continue treatment.

TB champions went over and above their normal duties to ensure that families who had lost income had enough food to take their medications, and to ensure there was sufficient nutrition and energy to travel for health appointments. Clarity Okibo, TB champion from Bungoma County, shared, "Sometimes you have to buy something small, maybe some milk, so they have the strength to sit at the waiting room bench." These examples not only illustrate the ingenuity of community workers, but they also demonstrate their motivation and passion to ensure that TB communities receive the services they need.

It was clear that in all four countries the Ministries of Health relied on community health workers as the backbone for community outreach—including identifying symptoms in communities and bringing patients to facilities for diagnosis. Notably, discussions highlighted how community health workers (including TB champions, peer support groups, patient supporters, etc) built trust within their communities that many times surpassed that of clinicians and nurses. In the words of Anupama Srinivasan in India:

*What emerged strongly for us during the COVID period, was that the trust and the relationships that the TB champions had built with their own communities became even more evident. because I think one of the things that emerged is when COVID first started, obviously for all of us in the cities, news was coming to us directly - but I think it took a lot of time for information to reach people across the country. And as a result, there were a lot of anxieties, a lot of misinformation... And when all of this emerged, what we saw was that people began to approach TB champions to say, "Okay, what do we do about this?" Because they were seen as trusted voices in the community as people who understood the health system to a certain extent, could navigate that health system and know help people understand what's going on better.*

**(Anupama Srinivasan, Assistant Director, REACH, Chennai, India)**

This was also observed in Siaya County in southwestern Kenya, with one TB champion using the rapport she had built with communities to find reasons to continue treatment despite side effects:

*(The patient) has the right to refuse to take the drugs. But of course, if he doesn't, he or she is a health risk to others. You've got to find a way to create a rapport with them. Let them understand why they have to take the drugs for one, and secondly, you try to make it easy on them. If they cannot come to you, then I offer my services to come and bring*

*you those drugs. It is not easy. If they're still adamant (about defaulting from treatment), you have to make numerous until they do because your work is to help them find a reason to take the drugs.*

**(Gladys Wanga, TB champion, Siaya County, Kenya)**

*medicines for those who had gone back to their villages. We followed up with our clients over the phone and provided counselling. We coordinated with service providers from other states.*

**(Aarti Chauhan, TB champion, Touched by TB, New Delhi, India)**

Community health workers were especially skilled at addressing root issues within communities, including when people with TB were reluctant or embarrassed to say that they didn't have enough money for food and therefore had to default with treatment. For example, in Bungoma County, Kenya, Dorothy Adongo elaborated how the role of the TB champion was not just to gather resources to provide some food to families, but also to provide encouragement, support, and hope:

*When you deliver the drugs, you must assess what condition the household is in. Maybe it is the wife or even a child who will tell you "Auntie, you know, Dad has not told you we have not eaten for two days." Because you see sometimes the index recipient of TB care is feeling too proud to tell you that they're having (financial) problems, but you're wondering why they're not improving. So as a TB champion you've got to gather intel about the overall wellness of the household – it's not about drug delivery alone. Sometimes you stay there longer just to offer some hope.*

**(Dorothy Adongo, Community TB Advocate and Focal champion for Western Kenya)**

In India, community mobilisation for food supplies led to TB champions engaging politicians to provide food for TB communities. Aarti Chauhan shared:

*We got together and advocated with our local MLA (Member of Legislative Assembly) to provide food for them. We also coordinated with the state and district TB officers to arrange*

These narratives illustrate how community health workers—out of necessity and within the context of a challenging environment—adapted to an unprecedented health crisis and developed multi-layered and multipronged strategies to ensure people with TB were supported to achieve optimal TB outcomes. They also illustrate how critical community-led initiatives are to TB treatment and care. In many of the cases described above, TB treatment outcomes would have been worse off, if not unsuccessful, without the community-led adaptations that were implemented.

## C. HUMAN RIGHTS AND GENDER BARRIERS FACED BY TB COMMUNITIES

People with TB face human rights and gender violations regularly.<sup>17</sup> This includes lack of access to effective TB care; discrimination in employment, healthcare centres, and other settings; and isolation against their will. These barriers are exacerbated by the economic costs to accessing TB services, which remains another barrier. Compounded by the human rights violations brought by the COVID-19 pandemic—including prison sentences for those violating COVID-19 rules and the worsening of care in prisons, among many other examples—people with TB found themselves in environments and conditions where TB services were further out of reach than before. Given the inextricable linkages between health and human rights,<sup>18</sup> these bear important implications for TB care as societies transition out of the acute COVID-19 pandemic phase and start planning for the next pandemic.

<sup>17</sup> Dingake OBK. Human Rights, TB, Legislation, and Jurisprudence. *Health Hum Rights*. 2017 Jun;19(1):305–309. PMID: 28630563; PMCID: PMC5473060. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5473060/>.

<sup>18</sup> Sekalala S, Forman L, Habibi R, Meier BM. Health and human rights are inextricably linked in the COVID-19 response. *BMJ Glob Health*. 2020 Sep;5(9):e003359. doi: 10.1136/bmjgh-2020-003359. PMID: 32938607; PMCID: PMC7496572. <https://gh.bmj.com/content/5/9/e003359>.

## GENDER-BASED VIOLENCE

It is well-documented that the COVID-19 pandemic and associated lockdowns resulted in intensified gender-based violence (GBV).<sup>19</sup> Before the pandemic, 1 in 3 women globally experienced some form of gender-based violence and during the pandemic, some countries saw calls to helplines increase five-fold. One study in eight Asian countries showed that internet searches related to violence against women (including how to cover up bruises) rose significantly during COVID-19 lockdowns.<sup>20</sup>



Laxmi, TB champion from TB Alert India, New Delhi.

Our interviews indicated that women affected by TB found it difficult to negotiate self-isolation with husbands who demanded sex, and that lockdowns increased their risk of marital rape. One TB champion from TB Alert India shared:

*During lockdown the wife of one of my patients called me up late at night for help. Her husband is TB positive and had just started treatment one week back. She didn't want to talk to anyone and didn't know to whom to share her problems. She said, 'my husband is not listening to me' (about sex). She didn't want me to talk to her husband and was scared that her husband would get angry. I told her to convince her husband to not have sex as he was infectious. After that I don't know what happened. She didn't call me up. After two days I asked the doctor in our*

*centre to call her husband for a counselling session.... This is the problem with our women. Husbands torture their wives.*

**(Laxmi, TB champion, TB Alert India, New Delhi, India)**

Other community health workers and TB champions shared similar stories, like Aarti Chauhan, TB champion from Touched by TB, who was able to help the young couple negotiate some time apart so the wife could recuperate from TB:

*One of my patients is a newly married young lady who was diagnosed with TB. She was very weak and had just started on medicines. Her husband wanted to have sex with her regularly. She couldn't refuse and say 'No'. She shared the problem with me. I counselled both the husband and wife and finally the husband agreed to send his wife to her parent's place for 2 months.*

**(Aarti Chauhan, TB champion, Touched by TB, New Delhi, India)**

These examples highlight several areas that should be considered by funders, and local and national governments, in preparedness efforts for the future. Notably, specific considerations for the protection of women must be addressed, especially women from vulnerable/marginalised populations during periods of lockdown and community health workers, whose roles in some cases expanded from delivering medications to managing numerous social and environmental factors that could affect TB outcomes, including the risk of violence.

## GENDERED IMPLICATIONS OF COVID-19-RELATED LOCKDOWNS

Many of the TB communities we spoke to in all four countries work in the informal economy and had no income protection or disposable income to rely on during lockdowns. Some testimonials revolved around traditional gendered male-female roles in households and how these affected marital relationships. One

<sup>19</sup> The impact of COVID-19 on violence against women and girls. UN Women, February 2022. <https://www.unwomen.org/en/what-we-do/ending-violence-against-women/facts-and-figures>.

<sup>20</sup> Idem.



community health worker in Bungoma County, Kenya described her role in managing familial conflicts from loss of income:

*Another thing that happened when they were arresting people for (not having) masks - so many people were losing their jobs. Most people who suffer from TB disease, they come from the low class, they come from this land, and depend on the land; they depend on these jobs that you have to get out every day to go into work and you add something to the family when you come back with food. We found that during this period, guys were missing out on their income, and missing food. And as a result, the food is missing and so many households were breaking up, because the wife would be like you're not manly enough to bring this (food) home, you see. In the setup (environment) that we have, it has always been the men who has been going out to fend for their families. So what happens is that this man becomes mentally disturbed to the extent that conjugal rights issues crop up. Stress from the loss of jobs meant that men weren't up for snuggling and sex, fights ensued, and temporary separations happened. People struggled keeping up with their anti-TB drugs and they would ask me to talk to their wives to help them understand.*

**(Dorothy Adongo, Community TB Advocate and Focal champion for Western Kenya)**

Timothy Wafula, Program Manager for HIV and TB at the Kenya Legal and Ethical Issues Network (KELIN), stated that while gender barriers to accessing TB services had existed before COVID-19, there has been a lack of acknowledgment as to the extent that COVID-19 has exacerbated these barriers. In Wafula's own words:

*Gender barriers were an issue even before COVID. What is documented through our gender assessment tools, we could see that more women were not accessing services and (we had) documented issues were due to the power relations in the family, where the*

*person with more economic (power) makes decisions about the woman's health. I think we have probably failed to understand the extent to which this was exacerbated during COVID times.*

**(Timothy Wafula, Program Manager HIV and TB, KELIN, Kenya)**

In **India**, Ganesh Acharya, a TB advocate based in Mumbai shared how lockdowns made it more difficult for women to access services as police forces enforcing restrictions would prefer speaking to male guardians when seeking clarifications as to why a woman was outdoors. In addition, lockdowns made it significantly more difficult for women to keep their diagnoses secret. As Acharya described:

*One of the women here is a migrant from Chennai to Mumbai, and only her husband knew her MDR-TB status. Her in-laws suddenly (during lockdown) they realised she had (TB) and (there was) a big problem and they just separated within the house and said without our permission you can't go out. So, I know and saw domination within a household like this.*

**(Ganesh Acharya, TB Advocate, Mumbai, India)**

Acharya also described how trans people were disproportionately affected by lockdowns, with those who had previously survived through street begging losing income and needing to seek welfare support for food in addition to facing transphobia:

*Societal acceptance is not there... here in Dharavi, the biggest slum in Mumbai, the trans people didn't have food and so went to the local political office to get their daily food, and other people from the general population didn't want the trans person to stand in the queue with them. So because of that (stigma) some left the city without their HIV treatment and without their TB treatment.*

**(Ganesh Acharya, TB Advocate, Mumbai, India)**

These discussions brought to the fore multiple issues, including the need for free and accessible mental health support services, income loss support for individuals and families in the informal economy, overreliance of health systems on unpaid community health workers, and the role of adequate compensation for community health workers who spend significant time providing psychosocial support to communities living with TB. An additional issue revealed in discussions was that some people with TB are employed as sex workers, and TB champions felt that there was insufficient planning and support to address the specific needs of the sex worker population,<sup>21</sup> including income support and support against stigma. There is also a further need to consider the role of governments in ensuring trans people and individuals with co-occurring vulnerabilities are accounted for in future pandemic response restrictions.

#### **ARBITRARY ARRESTS, EXTORTION, AND COVID-19-RELATED POLICE VIOLENCE**

The involvement of police in enforcement of COVID-19 rules disproportionately affected TB communities and compounded stigma that already existed. As coughing is a symptom of both COVID-19 and TB, people affected by TB who coughed were at risk for being reported for COVID-19. Further, if they were arrested by the police, they were then required to remain in enforced isolation at a government facility at their own cost. Evaline Kibuchi, Chief National Coordinator, Stop TB Partnership **Kenya** explained how it had almost become criminal to cough:

*It was almost criminal to cough, because if you coughed anybody around you would call the police. The police would call an ambulance and the ambulance would come with the police together. And whenever neighbours saw the police car coming to your household, they definitely knew somebody with COVID lived there and they avoided that home. And there was a lot of COVID death, so they thought you're never coming back, so there was a lot of stigma. And when they started the COVID protective measures, for example, the use of masks, social distancing, curfews, they used a lot of force to enforce those laws*

*to the extent of beating people if you were found without a mask. If you're found outside curfew hours, you get beaten. It was terrible. How that manifested for TB patients was that if you need to cough, you had better suppress that cough. Because if people think you've got COVID police will come for you, and you'd be put in isolation for fourteen days at your own cost, which is pretty expensive.*

**(Evaline Kibuchi, Chief National Coordinator, Stop TB Partnership Kenya)**

This was corroborated by Timothy Wafula, Program Manager HIV and TB, KELIN Kenya, who said:

*We have heard from the communities that the coughing has created some new level of stigma – stigma that was associated with COVID.*

**(Timothy Wafula, Program Manager HIV and TB, KELIN, Kenya)**

Mask mandates were enforced strictly by police and CHWs working on TB were not initially provided PPE, despite the door-to-door nature of their work. As a result, they were particularly vulnerable to arrests and to extortion associated with release from lockup facilities. Gladys Wanga, TB champion from Siaya County, described this in more detail:

*If you were to walk without a mask, they (police) didn't care whether you can afford it or not. You will be locked up and because we live in a country where you have to pay your way out if you don't want to be taken to the cells, then you must give (the police) something small. They used to come with a very big police lorry, and you're all put inside there. At that time, they forgot that might make somebody contract COVID because of the way everyone's put in the lorry with no masks, but they didn't care about that. If you pay to get out, you can get out but then they don't care where they drop you off. And usually this happened around midnight – they drop a group of us off when all the buses have stopped running. So you'll have to walk home, and sometimes before you make*

<sup>21</sup> Interview with Gitanjali, TB champion. TB Alert India, July 2022.

*it to your house there is another two or three policemen walking around doing their rounds and you could get caught again. So, it's up to you how you're going to get your house safely, it is not nice. It was very bad.*

**(Gladys Wanga, TB champion, Siaya County, Kenya)**

In addition to the financial impact of having to pay police to secure release from lockup, some community workers were released far from their homes, requiring further cash for public transport to make their way. With release occurring in the middle of the night, it also resulted in safety concerns for TB champions, the majority of whom are women. Rather incoherently, individuals were also bundled in large groups in police lorries without consideration of the inherent COVID-19 risk and thus their right to health.

In **India**, curfews also manifested in extortion risks, and community health workers were also particularly vulnerable because of the door-to-door nature of their work. Prabha Mahesh from Touched by TB in Mumbai elaborated further:

*During lockdown and curfews, there was a small bracket in which people could go for essentials and medicines that they needed. What happened was the police used to stop them and ask them for money and say that it is a curfew time you should not go out, and when they were stopped by police, I always ask the patient to call me. So, they would call me. Eventually I had to sensitise and have a dialogue with the police station and the top police officer there. Basically, we did advocacy with the state police force, telling them that these are TB patients that need their medications.*

**(Prabha Mahesh, Founder & Board Member Touched by TB, Mumbai, India)**

Mahesh further described that once sensitised, police too became an important source of referrals, with police members referring their own for TB care and treatment.

This also illustrates the dynamism and innovative problem-solving approaches that are employed by CHWs in ensuring continuation of TB services despite strict security protocols. Future pandemic response efforts, including the design of quarantine programs, should employ coherent, rights-based approaches that consider the financial impact and health risks.

In March 2020, Kenya Legal and Ethical Issues Network (KELIN), together with more than 30 NGOs, issued an advisory note to several government and UN officials, including Mutahi Kagwe, the Cabinet Secretary for Health, and Hilary Nzioki Mutyambai, the Inspector General of the National Police Service, stating, inter alia, that government organisations should respect the rule of law and that they recognise that 'punitive measures or criminal sanctions are not effective in epidemic control. Criminal sanctions are counterproductive because they drive people underground and expose more people to the virus.'<sup>22</sup>

In emphasising the government obligations on rights-based approaches, Allan Maleche, Executive Director of the Kenya Legal and Ethical Issues Network (KELIN), suggested that development partners and donors play a stronger role in insisting on human rights prerequisites during pandemics. He explained:

*In terms of human rights, whatever stage a pandemic is in, governments must not move away from a rights-based approach. Development partners must not shy away to remind the government because during COVID times, we (KELIN) did raise to UN partners and World Bank and say, "You guys are dropping the ball. You're not giving government the correct advice." One thing I'd emphasise is whatever pandemic, whatever the outbreak, rights don't disappear out of the window. And let's not forget about the community-led response, i.e., we shouldn't medicalise everything that happened. And that for me remains the biggest lesson from COVID.*

**(Allan Maleche, Executive Director, KELIN, Kenya)**

<sup>22</sup> Advisory Note on Ensuring a Rights-Based Response to Curb the Spread of COVID-19. KELIN, 28 March 2020. <https://www.kelinkenya.org/wp-content/uploads/2020/03/letter2.pdf>.

## STIGMA, DISCRIMINATION, AND OSTRACIZATION

Stigma and ostracization of TB communities is well-documented, with some studies documenting ostracization beyond treatment periods<sup>23</sup> and numerous publications recommending programs and initiatives to educate communities to reduce social stigma.<sup>24</sup> Interviews in all four countries suggest stigma towards TB communities was compounded by fears of COVID-19 infection.

In **Cambodia**, TB peer support group workers in Kandel Province described incidents where TB communities who were migrant workers were asked to leave their hometowns due to perceptions from neighbours that they would bring COVID-19 to the community, perhaps due to the perception that TB communities had increased vulnerability to COVID-19.

Multiple interviewees in **Kenya** noted that increased hostility by healthcare workers at TB facilities during the COVID-19 pandemic had a direct impact not only on patient health-seeking behaviour and willingness to receive care, but also on TB champion motivation and self-worth. Dorothy Adongo described her experience accompanying a patient to the TB facility, and how the patient's coughs created panic among the nurses:

*The patient was coughing non-stop in the line (queue). Then (the patient with presumptive TB) was harassed and left to stand in the dirt, and other times shouted at and told go sit at the end of the line, without respect, and even if you've already waited in the line for some time.*

**(Dorothy Adongo, Community TB Advocate and Focal champion for Western Kenya)**

Clarity Okibo, a TB champion in Bungoma County, Kenya, explained how these attitudes discouraged health-seeking behaviour, increased mental stresses faced by the individual seeking TB care, and created complexity and increased work burdens for the accompanying TB champion. Okibo described a

specific incident involving a patient suffering with TB symptoms who had been spoken to poorly by a nurse:

*Let me just go and die. I'm suffering, I'm in a lot of pain and these people don't want to help me. Some of them haven't had any food and you know what it's like when people are hungry, they also become angry. Sometimes they have also come from very far, walking distance, and even if you tell them that TB is curable, when they come and get harassed and mistreated by doctors and nurses, as a TB champion you really feel so bad... Because when the nurse comes she will shout at them. Some will start crying. And as a TB champion sometimes you have to make excuses, maybe the nurse has worked a lot today, maybe she is tired. And you have to convince that person to accept treatment or diagnosis or to give the sputum.*

**(Clarity Okibo, TB champion, Kanduyi Sub-County, Bungoma County, Kenya)**

On the issue of poor treatment by health professionals, Allan Maleche, the Executive Director of the Kenyan Legal and Ethical Issues Network (KELIN) explained:

*Generally, you want a health care worker to know how to be patient centric, how to be rights based in their response to how we deal TB. For me it goes back to the question the funding that we get from the Global Fund on strengthening health systems, or when they are reprogramming money, can some of these go towards structured trainings for healthcare workers in different facilities to ensure that they are respectful of the rights of the people who access their clients or services from them? Because it is a legal requirement, it is our constitutional requirement.*

**(Allan Maleche, Executive Director, KELIN, Kenya)**

<sup>23</sup> Mbuthia GW, Nyamogoba HDN, Chiang SS, McGarvey ST. Burden of stigma among tuberculosis patients in a pastoralist community in Kenya: A mixed methods study. PLoS One. 2020 Oct 15;15(10):e0240457. doi: 10.1371/journal.pone.0240457. PMID: 33057420; PMCID: PMC7561176. <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0240457>.

<sup>24</sup> Daftary A, Frick M, Venkatesan N, Pai M. Fighting TB stigma: we need to apply lessons learnt from HIV activism. BMJ Glob Health. 2017 Oct 31;2(4):e000515. doi: 10.1136/bmjgh-2017-000515. PMID: 29225954; PMCID: PMC5717927. <https://gh.bmj.com/content/2/4/e000515>; Strategy to End Stigma and Discrimination Associated with Tuberculosis. National TB Programme India, March 2021. <https://tbcindia.gov.in/WriteReadData/1892s/2581521802Strategy%20to%20End%20Stigma%20and%20Discrimination%20Associated%20with%20TB%2018032021%20New.pdf>.

In contrast, similar hostilities were not observed in India and Indonesia, with respondents from both countries reporting collaborative and cordial relationships during COVID-19 and efforts to work together to find and detect TB and ensure completion of TB regimens. The above reflections from Kenya require urgent examination and consideration within TB programmes and by donors to TB programmes for the inclusion of healthcare worker communication skills and civility towards patients. These may occur via training courses and emotional intelligence interventions that explain the value of civility and respect towards patient outcomes. In addition, consultative meetings must be held between healthcare workers and TB champions to ensure respectful working relationships that recognise the complementarity of both roles in ending TB. Given that discrimination is defined as 'any distinction, exclusion, or restriction made on the basis of various grounds that have the impact of... nullifying the recognition, enjoyment, or exercise of human rights',<sup>25</sup> and these actions prevent TB communities from quality care, these events should also be viewed from a right to health perspective.

### DELAYED AND/OR CONDITIONAL TB CARE DURING THE PANDEMIC

All countries saw delayed TB care as a result of TB facilities being converted to COVID-19 facilities and due to an overall shift in priorities and resources towards COVID-19.

In **Cambodia**, Huot Chanyuda from the National Center for Tuberculosis and Leprosy Control (CENAT), Cambodia, stated that some health facilities were delayed in providing TB services to communities based on their needs. Also in Cambodia, people with TB were required to undergo COVID-19 testing before receiving TB tests, even if this was against their wishes. While bidirectional screening for TB and COVID-19 is recommended by the WHO,<sup>26</sup> in no circumstance should TB diagnosis, treatment, and care be withheld upon certain conditions.

### FRAUDULENT PROCUREMENT PRACTICES AFFECTING SUPPLY OF COVID-19 AND TB MEDICAL SUPPLIES

In **Kenya**, COVID-19 saw a disruption of medical supplies due to alleged corruption, flouting of procurement regulations, and mismanagement of tenders<sup>27</sup> within the Kenyan Medical Supplies Authority (KEMSA), affecting both COVID-19 tools and reagents. As a result, donors preferred to bring in medical supplies through a different route, with the government refusing to let medicines and other medical supplies across the borders.<sup>28</sup> This situation has affected access to GeneXpert TB cartridges and stockouts have been reported nationwide.

Stephen Shikoli, TB champion based at the health centre in the Kangemi slums in Nairobi shared:

*We have not had GeneXpert cartridges for 6 months now, so all diagnosis is done with smear microscopy.*

**(Stephen Shikoli, National Coordinator, Network of TB champions, Kenya)**



Stephen Shikoli, National Coordinator, Network of TB champions, Kenya.

<sup>25</sup> The Right to Health: Fact Sheet No. 31. OHCHR, 2008. <https://www.ohchr.org/sites/default/files/Documents/Publications/Factsheet31.pdf>.

<sup>26</sup> Information Note: Tuberculosis and COVID-19. WHO, 12 May 2020. <https://www.who.int/docs/default-source/documents/tuberculosis/infonote-tb-covid-19.pdf>.

<sup>27</sup> Corruption is undermining Kenya's COVID-19 response. ONE, 29 September 2021. <https://www.one.org/africa/blog/corruption-undermining-kenya-covid19-response/>.

<sup>28</sup> Interview with Allan Maleche, Executive Director. KELIN, 15 July 2022.

## THE DIGITAL DIVIDE AND THE RIGHT TO INFORMATION

COVID-19 has exacerbated social isolation and loneliness, with particular consequence for elderly populations. A WHO report<sup>29</sup> suggested that a multisector approach must be involved in tackling social isolation in elderly populations. During global and national COVID-19 response, difficulties emerged with reaching elderly people with TB—both in ensuring their continued engagement with TB-related information and ensuring they were supported to continue and complete treatment regimens.



Indri Purwandari, a patient supporter working with 20 patients in the Greater Jakarta region.

In **Indonesia**, Indri Purwandari, a patient supporter who is supporting 20 patients in the greater Jakarta region, shared:

*Some of the older patients only have normal phones so can't do video calls, and even then sometimes they answer (the phone) really late, and there are some families who can't afford mobile phones... if it wasn't a pandemic I would have just gone to their houses but I couldn't do that during the pandemic.*

**(Indri Purwandari, DR-TB Patient Supporter  
Persahabatan Hospital, Indonesia)**

Total lockdowns thus meant that elderly people without access to mobile technology were disproportionately affected by the inability to access the right to timely support and health information, consistent with scholarly literature on social isolation among elderly people during COVID-19.<sup>30</sup> As such, it will be necessary for governments, and TB programmes, in particular, to ensure that home visits continue during pandemics where phone conversations aren't possible. As described earlier, they should also ensure that community health workers are provided adequate personal protective equipment to carry out these essential TB sensitisation and health support activities.

## POOR REMUNERATION OF TB COMMUNITY HEALTH WORKERS

Article 23 of the Universal Declaration on Human Rights states that everyone has a right to 'just and favourable conditions of work' and 'the right to equal pay for equal work'.<sup>31</sup> In addition, Recommendation 7A of the WHO Guideline on Health Policy and System Support to Optimize Community Health Worker Programmes states that practising CHWs should be remunerated with a 'financial package commensurate with the job demands, complexity, number of hours, training, and roles that they undertake'.<sup>32</sup>

By and large, TB community health workers by whatever name or designation—including patient supporters and TB champions—received poor or no remuneration for the extent of services that they provided to people with TB and people affected by TB. This was found to be true across the board, whether the services provided included referral to TB testing and treatment, treatment adherence support, provision of food, or emotional support and encouragement.

In **Indonesia**, community cadre members receive a stipend with a budget cap of 25,000 rupiah

<sup>29</sup> Social isolation and loneliness among older people: advocacy brief. WHO, 29 July 2021. <https://www.who.int/publications/i/item/9789240030749>

<sup>30</sup> Abbaspur-Behbahani S, Monaghesh E, Hajizadeh A, Fehrest S. Application of mobile health to support the elderly during the COVID-19 outbreak: A systematic review. *Health Policy Technol.* 2022 Mar;11(1):100595. doi: 10.1016/j.hlpt.2022.100595. Epub 2022 Jan 7. PMID: 35018280; PMCID: PMC8739352. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8739352/pdf/main.pdf>

<sup>31</sup> Universal Declaration of Human Rights. UN, 1948. [https://www.un.org/en/udhrbook/pdf/udhr\\_booklet\\_en\\_web.pdf](https://www.un.org/en/udhrbook/pdf/udhr_booklet_en_web.pdf)

<sup>32</sup> WHO guideline on health policy and system support to optimize community health worker programmes. WHO, 2018. <https://www.who.int/publications/i/item/9789241550369>

(approximately USD\$1.67) per day. According to Budi Hermawan, however, this amount was insufficient for the work community cadres were undertaking in their communities:

*The budget cap of 25,000 rupiah (US\$1.67 per day) for cadre stipends was and is really irrelevant and unsuited to the situation we're facing now, as sometimes community cadres spend up to more than seven hours working from home to home in the community.*

**(Budi Hermawan, Executive Director, POP TB, Indonesia)**

Given that national minimum wage is USD\$297 per month,<sup>33</sup> pro-rated to approximately USD\$12 per day for 24 days of full-time equivalent work, this shows that CHWs working on TB earning only USD\$1.67 per day are being grossly underpaid vis-à-vis national law.

Yoana Anandita from the WHO office in Jakarta explained how financial incentives are important to 'activate' community-led responses:

*They (TB patient supporters) don't have any incentive from any donors, (except) sometimes from Puskesmas (community health centres). They are only given 20,000 rupiah (US\$1.35) every three months. But they have big hearts and motivation on how to bring about a healthy community for their neighbourhoods. If we push the issue, I think this is a good opportunity for Indonesia on how the Puskesmas can activate the community more in their areas where they work.*

**(Yoana Anandita, COVID-19 RCCE Focal Point, World Health Organization, Jakarta)**

In **Kenya**, community health workers from Nairobi County, Bungoma County, and Siaya County all reported being unpaid and having to dig into their own pockets whenever people with TB had insuffi-

cient food to take their medicines. According to Vivian Faith, a TB champion from Mathare sub-county, Nairobi County, TB champions must rely on side-income or 'hustles' to support their work as health workers:

*At times as a TB champion because I'm not on a salary, I am forced to take the little hustle I got and get my own cash, dip down into my pocket and buy something (food) for them, at least to push them for a week to avoid the child defaulting from any type of medication.*

**(Vivian Faith, TB champion, Mathare subcounty, Nairobi, Kenya)**

Others spoke of being paid stipends only under specific programs. In Bungoma county, community health worker Dorothy Adongo discussed the stipends of 2000 Kenyan shillings (approximately US\$16.70) that were provided under a specific TB and human rights project:

*Right now, we have been doing TB and human rights work, so we are getting a stipend from Stop TB – if you do health talks at the facility you get 2000 shillings and if you do an outreach outside them (the facilities) it becomes 4000 shillings (approximately US\$33.45).*

**(Dorothy Adongo, Community TB Advocate and Focal champion for Western Kenya)**

These unfair pay conditions create uncertainty and instability for community health workers and have been referred to by one expert as 'modern day slavery'.<sup>34</sup> Human rights organisations such as KELIN described how structured proposals are necessary to professionalise community health workers and ensure they receive fair financial remuneration (salaries) for their work. This includes passing legislation and developing guidelines for donors to ensure that they adhere to government guidelines on salaries for CHWs:

<sup>33</sup> Minimum Wage Update in Indonesia from 01 January 2022 – 31 December 2021. Wage Indicator. <https://wageindicator.org/salary/minimum-wage/minimum-wages-news/2021/minimum-wage-update-in-indonesia-from-01-january-2022-december-31-2021>.

<sup>34</sup> Vuyiseka Dubula, Postdoctoral Fellow, Stellenbosch University. 2022 International AIDS Conference, 1 August 2022. [https://twitter.com/VandeveldeWim/status/1554094679775404033?s=20&t=DoRUtgvCRZ\\_BWJl9kICcSA](https://twitter.com/VandeveldeWim/status/1554094679775404033?s=20&t=DoRUtgvCRZ_BWJl9kICcSA)

*We've had a bill pending in Parliament around community health care workers, and I think that law needs to be passed so that it creates a structure and performance to engage with them. I recently was involved in an assessment of the national TB strategy. And it's unfortunate how much reliance is placed on community health volunteers to do the tracing to check their adherence. And some CHWs in the process, end up getting TB, and then they become clients to the same places where they are finding support. We as a country have failed in this group of people yet the connection between the people who are unwell and the health facility is so significant that if you pull them out, you will have the increased number of persons lost to follow-up not only for TB, but for every condition that requires some form of follow-up. So that's what I think if the bill is passed, they are clear structures, then every donor will have to adhere to what the government is saying.*

**(Allan Maleche, Executive Director, KELIN, Kenya)**



## LESSONS LEARNED

Several key lessons emerged from these four countries on how to ensure continuous quality TB care and support during pandemics and other health emergencies. It remains clear that the TB response should be documented and systematized during pandemics. In peak COVID-19 and lockdown periods, TB community health workers innovated to ensure continuity of services, including sputum collection and treatment adherence support. This included removing branded uniforms to blend in and prevent stigma towards patients and themselves and working together with local authorities to allow for health service delivery and contactless sputum collection in communities. Pandemic response protocols or checklists for TB communities may help in future pandemics to ensure seamless service delivery. In addition, based on the interviews and testimonials of TB communities and CHWs working on TB, the following recommendations are made:

- 1. CHWs should be compensated for optimal TB response.** Community health workers, including TB champions, must be professionalised and fairly compensated, in-line with international labour and human rights laws. They carry out promotive, logistical, and clinical work and non-compensation/poor compensation compromises their essential TB work. It is also counter to WHO recommendations on fair remuneration of CHWs, as well as most national labour laws.
- 2. CHWs are using their own resources to provide nutrition support.** Given that TB medications must be taken with food, nutrition support is an essential adherence tool. Insufficient nutrition support disproportionately impacts families and communities in poverty, and countries still do not budget sufficiently to ensure CHWs do not have to reach into their own pockets (potentially impoverishing or further impoverishing themselves while doing so).
- 3. Health systems for TB should be strengthened.** TB health systems must be strengthened in preparation for the next pandemic to ensure community-led responses aren't disrupted or compromised. This includes ensuring protection of CHWs with PPE; providing them with infection, prevention, and control training and mental health support; providing them with problem-solving support on the supply of molecular diagnostics cartridges; and incorporating safeguards to ensure nutrition support for TB communities isn't disrupted. In addition, decision-makers need to ensure that there is adequate investment across all health systems components (leadership/
- governance, health human resources including remuneration, training and supervision, supply chains, data and information systems, referral systems, etc.) needed for CHWs to be effective.
- 4. Integrated care is essential for optimal TB outcomes.** The CHW model works because CHWs are sources for multiple home-based care services, including diagnostics, treatment, and psychosocial support. Further work needs to be done to ensure vetted domestic violence support, and to emulate best practices in joint NCD support for TB communities.
- 5. Government authorities, including security forces, should be engaged on TB and human rights.** Pandemic-related human rights violations further disrupted access to TB care and services. Local government authorities must be sensitised on the scale of TB in their local areas, as well as the necessity of human rights-based interventions and the value of such interventions to the credibility of their institutions. In addition, government authorities must provide explicit authorisation for CHWs to continue work in communities despite lockdowns.
- 6. The digital divide during pandemics must be addressed and planned for.** Elderly people and those without smartphones were left out of online TB support interventions. Not only did this digital divide result in further social isolation, but it also compromised care. Notably, CHW teams must be well-funded to deploy telephone-based services, and they must be supported with adequate PPE stocks to minimise risk for in-person meetings.

- 7. Better planning is needed to ensure continuity of care.** Pandemic preparedness and planning must ensure that, inter alia, TB clinic services can continue, that psychosocial support is provided to clinic workers, and that protocols exist for surge capacity. TB communities must work with TB programmes to ensure pandemic protocols consider the TB communities' multifaceted needs.
- 8. Corruption during pandemics compromises TB outcomes.** In Kenya, ongoing allegations of fraud have compromised access to molecular diagnostics. Governments must strive to eliminate fraudulent practices that compromise access to medical technologies and exacerbate inequalities.

## CONCLUSION AND RECOMMENDATIONS

Findings from all four countries underscore how community-led innovations were fundamental to sustaining the engagement of TB communities with care services during the COVID-19 pandemic. Indeed, without these community-led interventions—including the support of TB champions, peer supporters and other community health workers—TB detection may have stopped altogether as health systems prioritised the COVID-19 response. As countries transition out of the acute phase of the pandemic, community-led innovations remain critically important to reverse lost gains and to expedite progress on TB elimination. They also require increased collaboration with and recognition by government agencies, donors, service providers, and others.

The following reflects recommendations from the TB community towards this aim:

1. **Provide structured remuneration packages for community health workers in the form of salaries and benefits**, as recognition of the value that they bring not only to TB case detection and medicine adherence, but also to support for pandemics, NCDs, and other disease areas. This could occur through legislation or other policies to professionalise CHWs, but also through guidelines that require donors to provide fair pay for work.
  - a. **NTP:** Initiate high-level discussions with donors and politicians on fair remuneration of CHWs.
  - b. **GF:** Stipulate fair remuneration in GF country grants and fund community advocacy on remuneration.
  - c. **CHWs:** Increase advocacy on fair pay for work, including to increase national, regional, and global visibility on their work.
2. **Ensure considerations for those with co-occurring vulnerabilities in pandemic preparedness planning and restrictions**, including those participating in the informal economy, LGBTI communities, people with TB and PLHIV, and elderly people. This should include robust plans for direct cash support for those who must self-isolate or stop work. It should also ensure that community health systems can deliver health support during times of facility overload and those facing a digital divide can still receive in-person visits through CHW engagement.
  - a. **NTP:** Work with key health security and pandemic response departments, as well as Ministries of Finance, to identify contingency plans for vulnerable populations.
  - b. **GF:** Finance multi-agency discussions with community participation towards these goals.
- c. **CHWs:** Gather intel on key vulnerable populations for feedback into these meetings.
3. **Diversify TB molecular diagnosis platforms.** Overreliance on certain platforms, combined with alleged COVID-19 misconduct by procurement agencies, resulted in stockouts that have lasted beyond COVID-19. These can be addressed through diversification of platforms.
  - a. **NTP:** Begin consultations to diversify molecular diagnosis platforms in health facilities and to have digitised inventories of functioning platforms.
  - b. **GF:** Finance/facilitate opportunities for molecular platform diversification and local manufacturing of cartridges where feasible.
  - c. **CHWs:** Establish community advisory boards towards these goals.
4. **Provide specific funding support to communities to include nutritious food as a core TB treatment adherence tool.**
5. **Increase collaboration between government agencies and community-led organisations.** In Kenya, the lack of collaboration was expressed particularly in the form of poor civility between overworked clinical staff and TB champions. Consultative meetings are necessary to heal divides and to optimise working relationships. In Indonesia, communities urged that District Health Offices work more collaboratively with CSOs as part and parcel of TB elimination plans.

*(The role of CHWs) is so significant that if you pull them out, you will have the increased number of persons lost to follow-up not only for TB, but for every condition that requires some form of follow-up.*

**Allan Maleche, Executive Director, KELIN, Kenya**

*The most important thing that emerged during the pandemic was the critical roles of peer support group leaders and lay counsellors who stayed connected with TB affected communities during the COVID outbreak – and provided treatment adherence support when they had side effects.*

**Chanthorn Phornng, Senior Coordinator: Policy, Partnership & Networking (PPN), KHANA**