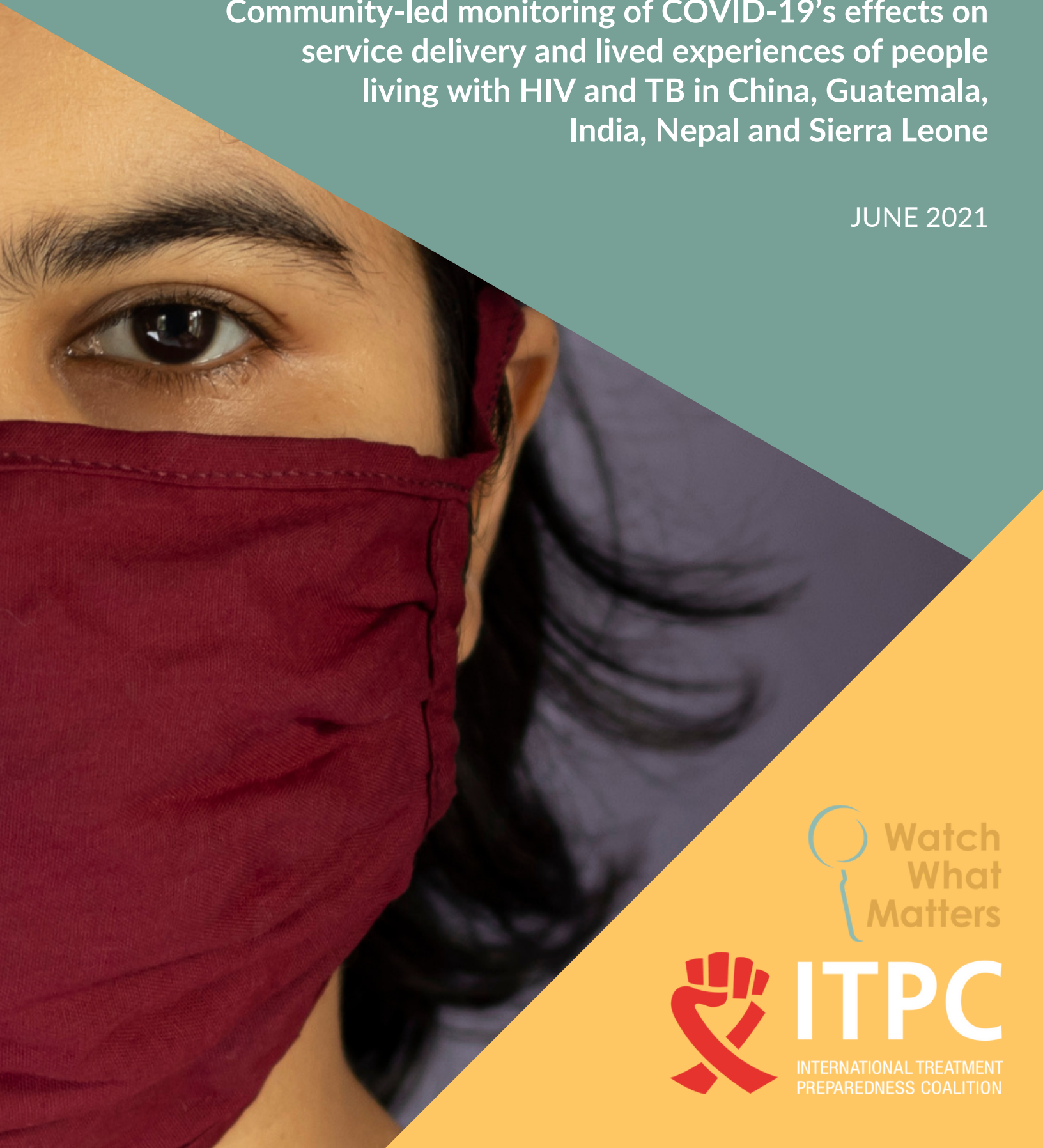


# COMMUNITY PANDEMIC PREPAREDNESS

Community-led monitoring of COVID-19's effects on service delivery and lived experiences of people living with HIV and TB in China, Guatemala, India, Nepal and Sierra Leone

JUNE 2021



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## Acronyms & Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ASW	Adherence Support Worker
CAG	Community Adherence Groups
CCG	Community Consultative Group
CHA	Community Health Agent
CLM	Community-Led Monitoring
CLM&A	Community-Led Monitoring & Advocacy
COVID-19	Coronavirus Disease – 2019
CTO	Community Treatment Observatory
GAN	Global Activist Network
GBV	Gender-based Violence
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
ITPC	International Treatment Preparedness Coalition
KP	Key Population
LTFU	Lost to Follow-up
MMD	Multi-month Dispensing
SARS-COV2	Severe Acute Respiratory Syndrome Coronavirus 2
SW	Sex Worker
TB	Tuberculosis
UNAIDS	United Nations Joint Program on HIV/AIDS
WHO	World Health Organization

## 1. Executive Summary

With funding from UNAIDS, the International Treatment Preparedness Coalition (ITPC) adapted its Community Treatment Observatory (CTO) model to rapidly implement short-term Community-Led Monitoring and Advocacy (CLM &A) during the COVID-19 pandemic. CLM&A was conducted to assess the impact on access to, and quality of HIV and/or TB treatment, and other essential health and human rights provisions. The project had two main objectives:

1. To meet the acute need for adherence support among people living with HIV in the main cities and local surrounding area of five focus countries
2. To create a scaled-down, time-and scope- curtailed community observatory with the purposes of monitoring access to care and treatment, and health and human rights experiences during the ongoing COVID-19 pandemic. Our work covered high-volume, urban facilities in China, Guatemala, India (which monitored TB indicators only), Nepal and Sierra Leone.

This report focuses on the methods and results achieved for the second objective. To achieve objective 2, ITPC worked closely with its existing partners: AIDS Care China (ACC), ITPC- Latin America and the Caribbean (ITPC LATCA), the Global Coalition of TB Activists (GCTA), DRISTI ('Vision' – Nepal) and the Network of HIV Positives (NETHIPS) in Sierra Leone, all of whom have strong relationships with networks of people living with HIV and/or TB and other stakeholders - and staff already on the ground. The CTO model was expanded from its original focus on HIV-related indicators to include TB, human rights such as food security and violence, and COVID-responsive indicators selected in consultation with ITPC's partners. Each partner customised their indicators, according to their areas of direct focus, and the final indicator for each tool was an assessment of governments' performance and its management of the COVID-19 pandemic. Data collection was shortened, bookended by four months. Partners collected quantitative data on 31 indicators at 17 health facilities, which served over 20,000 persons on ART.

### *Key Findings*

Monitoring revealed the impact of successive waves of COVID-19 on HIV services. The number of people newly initiated on ART declined at six health facilities in Guatemala, from 114 in October 2020 to 59 in December 2020, an overall reduction of 48%. In Sierra Leone, the number of ART initiations for the monitoring period averaged 106 across five health facilities, increasing from 97 in September 2020, reaching 119 in November 2020 and 105 in December 2020.

Across all facilities in this study, people faced additional obstructions to HIV testing and treatment facilities, particularly as 'lockdown' regulations limited freedom of movement, and instituted new regulations which obstructed access to public healthcare as COVID-19 superseded other healthcare concerns. Quantitative data demonstrates that, out of 15 facilities in four countries, 42% of those initiated on antiretroviral therapy (ART) were diagnosed with HIV on the same day. The rate was highest in China (82%), followed by Guatemala (65%), Sierra Leone (27%) and Nepal (17%). In Guatemala, 71% of all ART initiations in October 2020 were "same-day", dropping to 58% in November 2020, and to 53% in December 2020.

ARV stock-outs were a persistent problem; documented during 16 out of 39 (41%) monthly observations across clinics in China, Guatemala and Sierra Leone. This calls for more robust buffer stock, to avoid future disruptions to ART access.

Although COVID-19 has had severe consequences, the CLM uncovered an opening for enhancing key services, as highlighted below:

- **Digital Tools:** CLM has provided an opportunity to maximize – and hopefully optimize – the use of digital tools, such as eHealth and telemedicine.
- **Differentiated Services:** Although those lost to follow-up in Guatemala and Sierra Leone did not exceed seven percent of the reported number of persons on ART each month, disaggregation by age revealed that young people accounted for at least one-third of those lost – posing potential for using SMS and social media to re-engage young people with digital devices and ‘airtime’.
- **Scale up in MMD:** More healthcare facilities implemented multi-month antiretroviral (ARV) dispensing, which people living with HIV and their advocates had long been fighting for. This also ensures the need to strengthen supply chain management, where several facilities reported stock-outs of essential medicines and commodities.
- **Community- ART Delivery:** People living with HIV described the critical importance of home-deliveries of ART, particularly while restrictions on public movement were in place.
- **Disclosure & Confidentiality Concerns:** Stigma and concerns about confidentiality flourished during the pandemic. Restrictions and policies, such as being forced to disclose HIV status to the police before accessing healthcare or having to get a COVID-19 test before accessing TB testing, impeded people’s ability to seek healthcare, TB testing and treatment and HIV testing, care and treatment services. This rendered even more difficult their retention in care.
- **Decline in Clinical Monitoring:** Access to viral load testing decreased, and turnaround time for the results increased – two concerning trends. This has provided partners with data to advocate for continuity of services, even as demands for COVID-19 and other services are being met.
- **Data-Driven Advocacy:** The project yielded valuable data on TB and HIV services from the perspectives of recipients of care and healthcare workers in India. It inspired real-time advocacy and rapid responses to identified needs, including providing ART to refugees from Myanmar who were stranded on the border with China, together with mental health care, adherence support and linkage to HIV services, and advocacy to roll-out video-observed TB treatment.

## *Advocacy Implications*

The advocacy agenda from this rapid community-led monitoring project with just a few months of data collection is unfolding in real time. Some preliminary data-driven actions and early advocacy wins are presented below.

### **Advocacy Priority #1: Don't Get Side-Tracked**

ITPC's data show a declining trend in GeneXpert TB testing in Guatemala and Sierra Leone from September to November 2020. These findings validate community concerns that GeneXpert machines were being overwhelmed and monopolized by COVID-19 testing, and that TB had been deprioritized by healthcare workers and laboratories as a result.<sup>1</sup> Furthermore, findings in India suggest that people were denied access to TB testing if they were not able to be tested for COVID-19 first. ITPC and its partners are using this data to reinforce advocacy messaging from a recent Stop TB Partnership community report, calling on governments to leverage testing platforms (like GeneXpert) to increase COVID-19 testing capacity - while ensuring that TB testing is not stopped.<sup>2</sup>

The qualitative data suggest a culture of fear around COVID-19, which led to healthcare avoidance among people living with HIV and TB. It is vital that these communities have sustained access to treatment and adherence support. Protection against COVID-19 should not mean avoiding life-saving HIV and TB services. ITPC and its partners are advocating for improved healthcare practices identified through this project, including innovative service delivery models.

### **Advocacy Priority #2: Go Virtual**

The data collected by communities throughout this project show a disproportionate likelihood that adolescents and young people are being lost to follow-up in the context of COVID-19. ITPC and its partners are using this data to advocate for the use of virtual (e.g. SMS, social media) tracking and tracing to recover these clients into care.

In December 2020, the Global Fund recommended the expansion of video-observed TB treatment to support adherence and limit the spread of COVID-19.<sup>3</sup> ITPC included the number of people receiving video-observed therapy as an indicator in its TB community-led monitoring in India, but such data were not available. Advocacy for the rollout of video-observed TB treatment is being conducted by ITPC's partners in India, GCTA.

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<sup>1</sup> Wits University (2020). GeneXpert testing platform for TB repurposed to accelerate testing for Covid-19. Online at <https://www.wits.ac.za/covid19/covid19-news/latest/genexpert-testing-platform-for-tb-repurposed-to-accelerate-testing-for-covid-19-.html>

<sup>2</sup> Stop TB Partnership (2020). The impact of COVID-19 on the TB epidemic: A community perspective. Page 10. Online at <http://www.stoptb.org/assets/documents/resources/publications/acsm/Civil%20Society%20Report%20on%20TB%20and%20COVID.pdf>

<sup>3</sup> Global Fund (2020). COVID-19 Situation Report #34 Reporting period 25 November - 8 December 2020. Page 9. Online at [https://www.theglobalfund.org/media/10428/covid19\\_2020-12-09-situation\\_report\\_en.pdf](https://www.theglobalfund.org/media/10428/covid19_2020-12-09-situation_report_en.pdf)

Based on results from interviews, ACC in China formed a virtual community of people living with HIV. After a month, 170 people enrolled in the online community. ACC hopes to help people living with HIV obtain better health outcomes and provide opportunities for support through this channel, and to use this platform for comprehensive adherence support. ACC is now advocating for other community groups and health facilities to establish virtual support groups for people living with HIV.

### **Advocacy Priority #3: Strengthening Systems to Differentiate, Differentiate, Differentiate**

The data show promising increases in the percentage of people living with HIV who are receiving multi-month ART dispensing (of at least a three-month supply) of ART in Guatemala and Sierra Leone. Qualitative data point to decentralization and delivery of medicines in China and Nepal. ITPC and its partners have long advocated for the scale-up of differentiated service delivery for HIV. This new data, in the context of COVID-19, is being used to intensify this advocacy and urge rapid action. An important component of offering services tailored to the needs of recipients of care, will be maintaining a reliable supply chain that ensures availability of commodities and medicines. The data have shown that several countries faced stockouts of essential medicines for periods exceeding 30 days. The report highlights the urgent need to leverage investments to strengthen systems (community and facility) to ensure they are resilient and are able to maintain quality services, within the context of multiple pandemics.

### **Advocacy Priority #4: A Little Support Goes a Long Way**

Qualitative findings underscore the need for intensified psychosocial support, mental health care, and activities to reduce stigma and discrimination during COVID-19. HIV-related stigma was compounded with stigma related to COVID-19 and TB. Facility visits also uncovered the need for transport refunds for people with TB, especially in instances in which they were meant to be provided based on government policy. By contrast, most recipients of care did not report receiving transport stipends during interviews, thus bearing the cost of transport to clinic and medicines access themselves.

ITPC and its partners are advocating with governments, funding partners and other civil society groups to scale-up social protection. It is essential that countries continue to provide economic and psychosocial services for all in need. Addressing the social determinants of health that lead to inequality will remain an essential tenet of reaching the 2030 goals. This project leads by example, integrating adherence support (helping recipients of care adhere to their treatment regimens) into community-led monitoring.



### **ADVOCACY WIN: Turning “No Data” into a New National Indicator in Sierra Leone**

In Sierra Leone, NETHIPS aimed to collect quantitative data on the number of people living with HIV who experienced ART treatment failure during COVID-19. In September 2020, after the first month of monitoring, NETHIPS discovered that the current service registers do not capture this indicator. NETHIPS then initiated a conversation with the National AIDS Control Program (NACP), where they learned that a facility-level committee examines individual clients' need to change regimens, and stores this information on the appointment cards. The NACP said committees store treatment failure information in another book in some facilities, separate from the master register. From this conversation, NETHIPS secured a commitment from the NACP to develop a new tool – a new set of service registers – that captures this indicator.

**“That is the beauty of projects like this. They identify how people fall through the cracks. We will be bringing this issue to the community consultative group, and advocating for NACP to accelerate the production of new treatment registers that include treatment failure in them”**

*– Martin Ellie, NETHIPS Sierra Leone*

### *Conclusion*

ITPC's community-led monitoring and advocacy approaches, executed through community treatment observatories (CTOs), were initially designed to put people living with HIV, their communities, networks and/or organizations at the center of decision-making. This project provided a platform to adapt the model for other priority diseases, thus highlighting the value of CLM&A.

The data reported by partners gave real-time insight into the impact of COVID-19 on continuity of services. Furthermore, it provided an opportunity to identify emerging solutions to ensure maintenance of quality services for people living with HIV and /or TB. As the findings continue to be used for advocacy, the value of CLM for raising site- and community-specific issues is underscored. Through CLM, partners were able to gather evidence within the evolving context of the COVID-19 pandemic. The routine analysis of, and multi-stakeholder discussions about data were a mechanism for developing shared solutions to drive community-led action. By highlighting the lived experiences and community-led solutions devised by people living with HIV and/or TB, the project highlighted the importance of community pandemic preparedness and reinforced how empowered communities can play a pivotal role in supporting the continuity of services through established and new networks. It also identifies opportunities for strengthening community systems, to ensure their resilience in the face of the concurrent pandemics of HIV, TB and COVID-19.



## 2. Introduction

In 2016, the global health community committed to the United Nations General Assembly's *Political Declaration on Ending AIDS*, which included the 90-90-90 targets (that 90% of all people living with HIV would be aware of their HIV status; 90% of people diagnosed with HIV would receive continuous antiretroviral therapy [ART]; and 90% of people receiving ART would achieve viral suppression).

Countries worked to reduce barriers to HIV treatment and services, strengthen service delivery, improve quality of care, and optimize treatment and monitoring. Despite significant progress – by the end of 2019, 81% of all people living with HIV knew their status and global treatment coverage increased to 67% (or 25.4 million people) and 59% percent of people on ART were virally suppressed<sup>4</sup> - the 2020 targets were not met. Community monitoring of access to, and quality of HIV services remains essential for the health, well-being and quality of life among people living with HIV, and to identify – and surmount – barriers to achieving the 2025 AIDS targets. For example, HIV-related stigma is still a pervasive and deadly barrier for two-thirds of people living with HIV, who reported that it negatively affected their access to HIV services over the past year.

The world is lagging behind on meeting targets for lowering tuberculosis (TB) incidence and mortality – and for increasing access to diagnosis and treatment. Areas for improvement include addressing human rights violations, and filling gaps in diagnosis and treatment, particularly for drug-resistant forms of TB. In 2019, only 61% of people with TB had access to initial testing for drug-resistant (DR) forms of the disease and only 69% were tested for HIV.<sup>5</sup> Newer oral drugs – which are now recommended by WHO - offer great promise for successfully treating drug-resistant forms of TB, yet only 38% of people received them in 2019.<sup>6</sup>

In 2020, COVID-19 emerged as an unprecedented global challenge, threatening to undo years of progress against HIV and TB. The world's first known case of COVID-19 (the illness caused by SARS-CoV-2) was reported in late November 2019, and the first inklings of a pandemic emerged in January 2020 when transmission was confirmed outside of China.<sup>7</sup>

Despite an enormous global effort to mitigate the COVID-19 pandemic, numerous challenges with testing, prevention, care, and treatment remain. COVID-19 continues to have a negative impact across all realms of society, including on the health and well-being of people living with HIV and TB.

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<sup>4</sup> UNAIDS (2020). Update: Topic : 90-90-90 Treatment for All. 21 September 2020. Online at [https://www.unaids.org/en/resources/presscentre/featurestories/2020/september/20200921\\_90-90-90](https://www.unaids.org/en/resources/presscentre/featurestories/2020/september/20200921_90-90-90) Accessed 12 April, 2020

<sup>5</sup> WHO (2019) Global Tuberculosis Report. Online at: <https://apps.who.int/iris/bitstream/handle/10665/329368/9789241565714-eng.pdf?ua=1>. Accessed 2 April 2020.

<sup>6</sup> WHO. Global Tuberculosis Report 2020. Online at <https://apps.who.int/iris/bitstream/handle/10665/336069/9789240013131-eng.pdf>. Accessed April 12, 2020

<sup>7</sup> Brahma D, Chakraborty S, Menokey A. (2020) The early days of a global pandemic: A timeline of COVID-19 spread and government interventions. Online at <https://www.brookings.edu/author/dweepobotee-brahma/>. Accessed April 3, 2020.

Information about the impact of COVID-19 on community-level HIV and TB service delivery – including access to ART and TB treatment – is required to improve these services. On-the-ground data is essential for generating local and community-based solutions for barriers to, and gaps in, essential health services for people living with HIV, TB and COVID-19 - and for identifying how communities have adapted policies and services during the pandemic.

### *Background*

Public health measures taken to control COVID-19, such as curfews, lockdowns and the closure or sole focus of healthcare facilities to COVID, are likely to have widened gaps in access to treatment and services for people living with HIV and TB. It is important to learn as much as possible about such disruptions, their potential impact, and what has been done - and can be done - to address them.

This report summarizes the technical approach and key findings from implementation of the modified CTO model (the second of two objectives from this project).

This five-country project aimed to use community-led monitoring and advocacy (CLM&A) to identify and respond to immediate needs among people living with HIV and TB in the midst of the COVID-19 pandemic. It was funded by UNAIDS, and built on the successes of community treatment observatories (CTOs), which monitored quality of and access to HIV services across the cascade of care, using data to inform advocacy strategies for improving them.

This project used HIV services as the entry point; and was achieved through work with ITPC's trusted partner organizations. Modified CTOs, adapted to COVID-19 safety protocols, were implemented in China, Guatemala, India, Nepal, and Sierra Leone.

### 3. Adapting Community Treatment Observatories to Support CLM&A in the context of COVID-19

#### *An Overview of ITPC's CLM&A approach, implemented through the CTO Model*

ITPC's community-led monitoring and advocacy approaches, executed through community treatment observatories (CTOs), are designed to put people living with HIV, their communities, networks and/or organizations at the center of decision-making.

Since 2015, ITPC has monitored scale-up and quality of HIV treatment in different countries, from a community perspective. ITPC's Community-led Monitoring and Advocacy (CLM&A) is a system that increases accountability for national HIV programs. Community-led monitoring involves the people who have the most at stake - recipients of care and others affected by HIV - in monitoring access to, and quality of HIV treatment and services, and working to co-create solutions that improve them. CLM&A is based on routine, systematic oversight of local and national health systems, consultations with community members to identify service gaps and areas for improvement and collaborate on advocacy campaigns and strategies. Service quality can be measured by numbers (quantitative) and by people's descriptions of their experiences (qualitative).

CLM&A uses quantitative and qualitative indicators to provide a fuller picture of the issues, to inform advocacy, monitor progress and, critically, to work together with local healthcare workers and facilities to improve the quality of care. For example, CLM&A may be used to track the number of people who get a viral load test, as well as whether stigma has made it difficult for them to access HIV services. The evidence that is generated by CLM&A is fed back to programme managers and policy makers, enabling them to increase the "five As" (availability, accessibility, acceptability, affordability and appropriateness) as well as the efficiency and effectiveness of their services.

## The Components of CLM&A

CLM&A covers four key areas: **education, evidence, engagement and advocacy**. The work begins with **education** - sharing WHO-recommended standards for prevention of, and testing, care and treatment for multiple diseases, such as TB, COVID-19, and HIV, the scientific information that these are based on, and why these things are essential to the health, quality of life and survival of people living with HIV. Communities use this information and their local and national contexts to develop their own indicators; including access to and uptake of HIV prevention and testing services, the number of people who are receiving continuous antiretroviral therapy (ART) and viral load monitoring, and the quality of these services. After they are trained on what to look for, and why it matters to do so, data collectors gather information on the indicators (whether there are drug stock-outs, the turn-around for viral load test results, etc.), **which is the evidence**. This evidence is presented to a multi-stakeholder group, including representatives of national PLHIV networks, recipients of care, healthcare providers and policy makers, who work together to analyze the data and identify priority issues – **this is engagement**. These stakeholders work together to **advocate** for improvements.

### *Adaptation of the CTO Model*

Although the ITPC CTOs were HIV-specific, the model can be applied to monitor trends in other disease-areas (TB, malaria etc.) and for social and structural health interventions, such as human rights advocacy, promotion and protections. This project provided ITPC and its partners with an opportunity to expand the model to include monitoring key TB indicators and identify and monitor COVID-19 responsive indicators for TB and HIV.

ITPC adapted the CTO model to rapidly implement CLM &A in five countries (China, Guatemala, India, Nepal and Sierra Leone). The CTO model was adapted for:

1. Rapid Implementation
2. Maximizing the Use of Digital Tools
3. Expanding the System (to Include Priority Infections)

### *Rapid Implementation of CLM &A – from Design to Implementation in 90 days*

ITPC adapted the CTO model to the context of COVID-19, including ensuring that data collection methods were aligned with COVID-19 protocols – and for a swift start, since the project had a six-month timeline. To support rapid implementation, ITPC collaborated with partners from its Global Activist Network (GAN) who have long-standing, strong relationships with local communities of people living with HIV. These partner organizations have trained staff working on the ground, which facilitated the rapid scale-up and implementation of CLM&A.

Key indicators for data collection were based on priorities identified by partner organizations, who monitored the impact of COVID-19 on access to HIV and TB prevention, testing, care and treatment services from September 2020 to December 2020 (Table 1). Data were collected

retrospectively and where possible, on a monthly basis. When possible, Community Consultative Groups (CCGs) reviewed the data each month (instead of quarterly).

The project addressed two major objectives:

**Objective 1:** To meet the acute need for adherence support for people living with HIV in the main cities and local surrounding area of five focus countries (China, Guatemala, India, Nepal and Sierra Leone)

In support of the first objective, sub-grants covered the cost of adherence support worker (ASW) time and incentive packs (data, petrol, subsistence, maintenance of vehicles, bikes etc.) for transportation necessary to deliver antiretrovirals (ARVs) to their beneficiaries. ASWs were workers from established partner networks who already had government-issued permits during respective country lockdowns. ASWs also provided distance support when not actively transporting ARVs. They supported the coordinator of community adherence groups (CAGs) by location and shared information about COVID-19/HIV/TB.

**Objective 2:** To create a scaled-down, time-and scope-limited community observatory. Covering high-density, urban facilities in the five focus countries.

As part of the grant implementation, ITPC Global agreed with UNAIDS to focus in high-density, urban facilities in five focus cities in Asia, Latin America, and West Africa, by working with key partners in ITPC’s Global Activist Network, who have a long-standing, trusted relationship with communities of people living with HIV in their respective locations.

ITPC Global partnered with the following organizations to execute this work: **Dristi based in Kathmandu, Nepal; International Treatment Preparedness Coalition Latin America and the Caribbean (ITPC-LATCA), based in Guatemala City, Guatemala; ITPC South Asia (using the Delhi Network of Positive People as their fiscal sponsor), based in New Delhi, India, the Global Coalition of TB Activists (GCTA) in New Delhi, India, NETHIPS in Freetown, Sierra Leone and AIDS Care China, in Kunming, China.** By leveraging ongoing partnerships and engaging new partners, ITPC’s implementing partners (Table 1), were able to rapidly establish adapted CTOs to collect data on key HIV and TB indicators.

Grantees were required to select high-burden, low retention facilities in their local area as project sites and identify Community Health Agents (CHAs) from their staff who were already in the field due to the COVID-19 pandemic. The identification of health facilities was an important step in the process, given the intervention’s purpose. Implementing partners felt that it was critical to include urban and rural areas in the focus cities.

**Table 1:** Implementing Partners and Scope of Community- Led Monitoring Activities

Countries	Organizations	Cities	Health Facilities Sites	Scope	Data Period
China	AIDS Care China (ACC)	Kunming Gejiu city	Yunnan Infectious Disease Hospital Kunming Third People’s Hospital Gejiu Infectious Disease Hospital	HIV	Nov 2020

<b>Guatemala</b>	ITPC- LATCA	Guatemala City Escuintla	San Juan de Dios Hospital Roosevelt Hospital Comprehensive Clinic Coatepeque Comprehensive Clinic San Benito Petén Guatemalan Institute of Social Security Escuintla Hospital	HIV	Oct – Dec 2020
<b>India</b>	Global Coalition of TB Activists - GCTA	New Delhi	TB Alert India Designated Microscopy Center (DMC), Burar TB Alert India DMC, Mukundpur	TB	Oct – Dec 2020
<b>Nepal</b>	DRISTI	Kathmandu	Bir Hospital T.U Teaching Hospital (TUTH) Sukraraj Tropical and Infectious Disease Hospital	HIV	Oct – Dec 2020
<b>Sierra Leone</b>	Network of HIV Positives in Sierra Leone (NETHIPS)	Freetown	Ola Daring PCMH Connaught Hospital Waterloo Health Center Tombo Community Health Center	HIV	Sept -Dec 2020

### Monitoring in the Context in COVID-19 – Maximizing the Use of Digital Tools

COVID-19 has had a significant impact on health systems across the globe. Although it has had severe consequences, the pandemic has provided an opportunity to maximize - and hopefully optimize - the use of e-Health and telemedicine tools to deliver services based on the needs of recipients of care.

As the project was being implemented, ITPC and its partners carefully considered the safety of country teams and ensured that data collection procedures were in alignment with COVID-19 mitigation measures. During the project’s implementation, ITPC convened virtual sessions with the five implementing partners. These forums were an opportunity to share progress updates and lessons learnt across countries.

In each country, teams optimized the use of virtual platforms across all components of CLM&A, from education to advocacy (*Table 2*). Data collection was done virtually – using telephone and/or internet based, SMS-queries and social media (for initial collection of information). Data were collected from existing community and facility structures and networks, such as community adherence groups (CAGs), community health agents, community and peer outreach workers and health facility staff. In-person data collection activities were conducted with appropriate personal protective equipment and physical distancing procedures.

To support country-level engagement and advocacy based on the CLM findings, ITPC advised the community consultative groups (CCGs) to meet on a monthly basis – but this was flexible. There were formal CCG meetings in China and Sierra Leone. In the other countries, dissemination meetings were used to discuss the CTO findings (as with GCTA in India).

**Table 2: Key Adaptations of ITPC’s CLM&A Model to Support Implementation Within the Context of COVID-19**

Component	Key Adaptations
<b>Education</b>	ITPC conducted virtual learning sessions with partner institutions  All webinars included a dedicated session with up-to date information about COVID-19
<b>Evidence</b>	As part of the induction session ITPC agreed on COVID-19 responsive indicators Data were collected on a weekly basis and reported monthly
<b>Engagement</b>	CCGs were convened where possible, meeting monthly (instead of quarterly)
<b>Advocacy</b>	Virtual platforms were leveraged for advocacy activities

### Expanding the System: Applying the CTO model to implement CLM&A for TB and COVID-19

COVID-19 responsive indicators were selected in consultation with in-country partners to monitor the impact of COVID-19 on access to prevention, diagnostic and treatment services for HIV and TB. Data were collected on 31 indicators (14 HIV, 15 TB and 2 HIV/TB) (Appendix A & Appendix B).

#### **About TB**

TB, one of the world’s deadliest infectious diseases, thrives on inequality. It is most prevalent among people living in poverty- especially in urban slums, refugee camps, detention centers, shelters and in other crowded conditions. It flourishes among vulnerable and key populations, ethnic minorities, women, children, homeless people, migrants, refugees and internally displaced persons. People with TB are faced with catastrophic expenses, job loss, stigma, discrimination, lack of necessary social services and poor quality, uncoordinated health care – as well as a potentially fatal illness that is curable when properly diagnosed and treated.

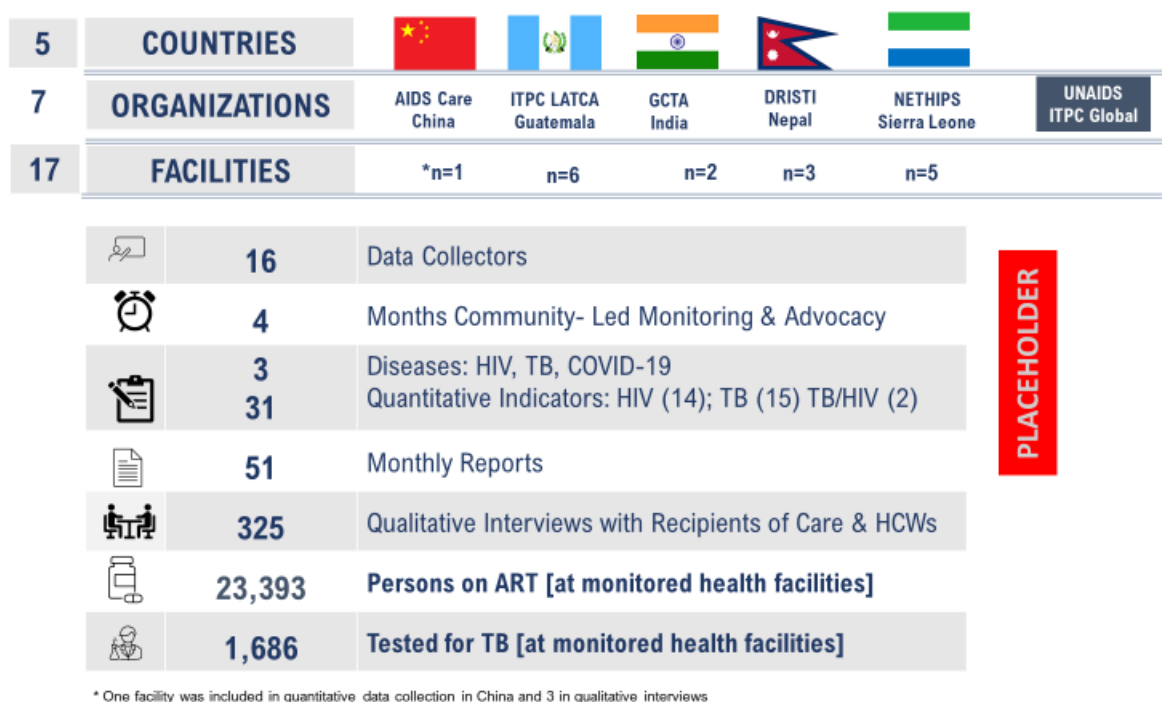
TB is rampant in India; in 2019, it accounted for 26% of the world’s TB burden, and it is home to the world’s highest rate - 27% - of drug-resistant forms of TB.<sup>3</sup> Failure to properly diagnose and treat TB, especially drug-resistant forms, can be deadly, also allowing TB to continue spreading. Community-led monitoring of TB services, especially in the context of COVID-19, is essential to ensure that people living with TB have access to high-quality services and care – and the best possible treatment outcomes.

Building on successful HIV monitoring, CLM, was expanded to include priority indicators for TB. With ITPC, the Global Coalition of TB Activists (GCTA), expanded the model to include TB treatment and services in the context of COVID-19, identifying indicators based on key programmatic and policy issues relevant to TB service delivery in India.



## 4. Methods – CLM&A Data Collection & Analysis

During the project, ITPC’s partners monitored HIV and TB services in the context of COVID-19, working at a total of 19 health facilities in China, Guatemala, India, Nepal and Sierra Leone, from September to December 2020. The majority of facilities monitored were high-volume hospitals located in urban centers; together, they served more than 20,000 people living with HIV who were receiving ART (Figure 1).



*Figure 1: The Project by Numbers (Placeholder for a full- page infographic in the final design)*

Sixteen data collectors were trained to capture information on quantitative indicators and to conduct qualitative interviews and focus group discussions. India’s community-led monitoring had a specific focus on TB, while the other countries focused on HIV within local key populations. The quantitative data collected from healthcare facility records was captured on paper tools and entered into an online digital portal for centralized quality assurance and comparative analysis (Appendix A- B).

Partners gathered qualitative information from recipients of care and health care workers (HCWs) through face-to-face and virtual interviews. A total of 325 qualitative interviews (one-on-one and focus group discussions) were completed across the supported sites. In China, three sites were included in qualitative interviews (compared on one facility for quantitative data collection). These two additional sites brought the total number of participating sites to nineteen.

Partners analysed and used the data they collected to interpret findings in relation to quantitative results – with both convergences and divergences – and to identify gaps in access to and quality of services. Partners used quantitative and qualitative findings as evidence to inform their advocacy with decision-makers at local and national levels.

To complement country level analysis, ITPC analysed data from all partners at the end of the project. Quantitative analysis focused on country-specific monthly trends for the selected indicators, highlighting age, sex and other key disaggregates when available. The qualitative information was analysed using a thematic analysis approach, in which main themes and categories were identified and explored within each location and summarized for all countries.

Initial categories for analysing data were established from the questions that structured interview schedules (Appendix C, D, E and F) – which were developed iteratively by ITPC and its partners. Illustrative quotes from the worksheets and country reports were selected to validate and triangulate quantitative findings, and to highlight and capture experiences and key issues among healthcare workers and recipients of care. The findings and themes that have emerged in the quantitative data demonstrate similarity and diversity in participants' views and experiences about the impacts of COVID-19 on aspects of their healthcare, socio-economic status and food security, general safety, and human rights.

This summary data highlights key themes from community-led monitoring.

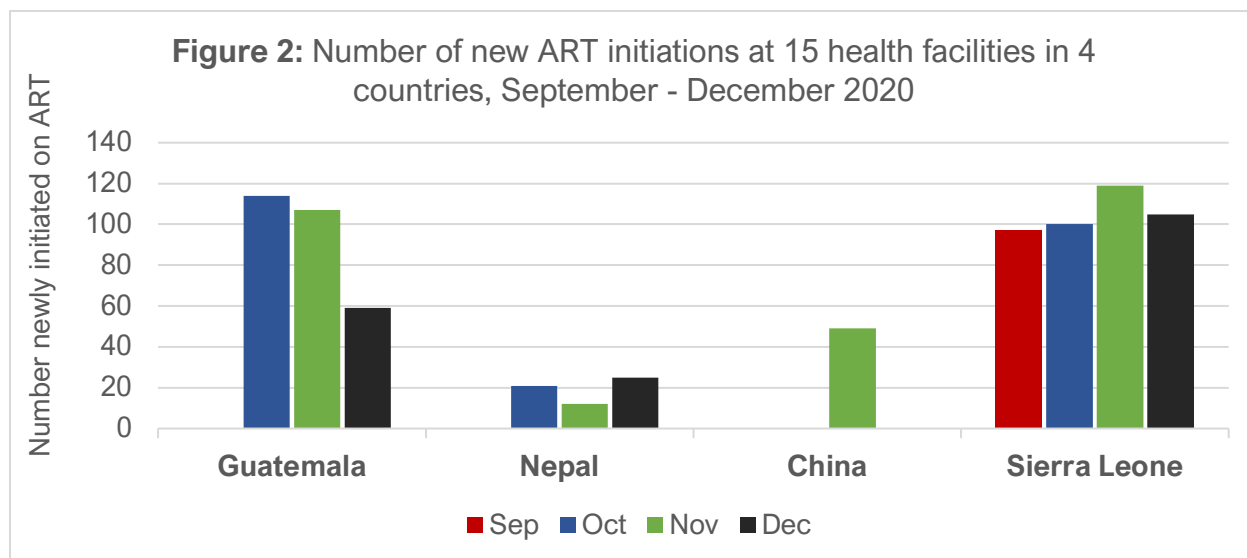
## 5. Findings – Community Data for Action

### Theme I- Accessibility and Uptake of Services

#### New ART Initiations

COVID-19 had a negative impact on access to HIV testing and initiation into ART after receiving an HIV diagnosis. One modelling study estimated that COVID-19 may cut the rate of new ART initiations by 50%.<sup>8</sup>

During the project, partners monitored the number of new ART initiations at 15 facilities in 4 countries. Over the course of the project, the number of new ART initiations declined at six health facilities in Guatemala, from 114 in October 2020 to 107 in November 2020, and dipped to 59 in December 2020 (Figure 2): an overall reduction of 48%. In Sierra Leone, the number of ART initiations at the five facilities averaged 106 during the monitoring period; increasing from 97 in September 2020 to 104 in October 2020, reaching 119 in November 2020 (Figure 2). and 105 in December 2020.



#### Same-day ART Initiations

In accordance with WHO recommendations, and to reduce traffic at health facilities, many countries adjusted their protocols to implement rapid ART initiation during the COVID-19

<sup>8</sup> Hogan, A. B., Jewell, B. L., Sherrard-Smith, E., Vesga, J. F., Watson, O. J., Whittaker, C., ... & Hallett, T. B. (2020). Potential impact of the COVID-19 pandemic on HIV, tuberculosis, and malaria in low-income and middle-income countries: a modelling study. *The Lancet Global Health*, 8(9), e1132-e1141. Online at <https://www.thelancet.com/action/showPdf?pii=S2214-109X%2820%2930288-6>

pandemic and urged same-day ARV initiation when not medically contraindicated.<sup>9,10</sup> To track implementation of these adjustments, ITPC and its partners disaggregated ART initiation data, where possible, to determine the proportion of people diagnosed with HIV who initiated ART on the same day.

Across the 15 facilities in four countries, 42% of those initiated ART were diagnosed on the same day. The rate was highest in China (82%), followed by Guatemala (62%), Sierra Leone (27%) and Nepal (17%) (Table 3).

- In Sierra Leone, same-day ART initiations were far more common among pregnant women than others, occurring in 80% of pregnant women aged 18-24 years and 88% of pregnant women aged 25 years and over.
- In Guatemala, same-day ART initiations were most common among pregnant women ages 18-24 years (100%), followed by men aged 18-24 years (81%) and men aged 25 years and over (62%).
- In China, same day ART initiation rates were 100% for pregnant and non-pregnant women aged 25 years and older and young men aged 0-17 years. In contrast, same-day ART initiation was 79% among young men aged 18-24 years and 75% among men aged 25 years and older.

A declining trend in same-day ART initiations was observed in Guatemala, with 71% of ART initiations in October 2020 being same-day, dropping to 58% in November 2020, and 53% in December 2020.

**Table 3.** Rate of same-day ART initiation in the context of COVID-19 in four countries

Country	Period of community-led monitoring	Number and type of health facilities monitored	Total number of ART initiations	Number of same-day ART initiations	Rate of same-day ART initiation in the context of COVID-19
China	November 2020	1 hospital	49	40	82%
Guatemala	October-December 2020	4 clinics 2 hospitals	282	175	62%
Nepal	October-December 2020	3 hospitals	58	10	17%
Sierra Leone	September-December 2020	4 hospitals 1 community health center	425	116	27%

<sup>9</sup> Mendelsohn, A. S., & Ritchwood, T. (2020). COVID-19 and Antiretroviral Therapies: South Africa's Charge Towards 90-90-90 in the Midst of a Second Pandemic. *AIDS and Behavior*, 24 (10), 2754-2756.

<sup>10</sup> Radix, A. et al. (2020). Guidance: Rapid Antiretroviral Therapy (ART) Initiation During COVID-19. New York State Department of Health AIDS Institute Clinical Guidelines Program. Online at <https://www.hivguidelines.org/antiretroviral-therapy/rapid-art-covid-19/>

### *The Decentralisation of ART in the era of COVID-19*

In some contexts, COVID-19 galvanised and strengthened home ARV delivery mechanisms – a powerful lesson about a positive impact from the pandemic, and its effect on the realisation of recommendations to improve treatment access and outcomes for people living with HIV.

People living with HIV described the critical importance of home-deliveries of ART, particularly while restrictions on public movement were in place. In Guatemala, HIV treatment-experienced recipients of care reported that ART was delivered to their homes during the COVID-19 ‘lockdown’. ITPC-LATCA attributed successes in decentralization and delivery of medicines to years of HIV advocacy with civil society and government partners.

In China, healthcare workers described innovative ways to deal with the impact of COVID-19 on healthcare provision, especially around ART access and delivery. They explored different ways to provide recipients of care with medications including express mail delivery and more persistent contact tracing and follow-up with patients. A doctor explained:

*‘Considering that some patients cannot go to the hospital for regular follow-up visits due to regional restrictions, the hospital will consider sending them medicines. In a special period, we have adopted a special method to allow patients to go to the nearest medical institution to complete routine medical tests, and after photographing relevant indicators to our staff, we will express delivery them to them. In the event that the express delivery cannot be accessed, we suggest that he go to the local treatment point to pick up the medicine.’ [ Doctor, China]*

A woman living with HIV in Nepal saw herself as helping recipients of care - ‘deliver ART to their homes’ in the future, a clear indication of the desire for decentralized distribution, and of the ambition among people living with HIV to help ensure ART accessibility and to support adherence among other people living with HIV. [Recipient of Care, Nepal] Her sentiments were echoed by a number of recipients of care in Nepal, who hoped to be a part of future HIV treatment programmes, in which they delivered medicines directly to the homes of those on treatment [Recipient of Care, Nepal]. For instance, one participant described how she would like to ‘raise [her] voice... [to] treat PLHIV equally’ [Recipient of Care, Nepal].

In China, a new innovation supported harm reduction: as the pandemic led to border-closings, HIV activists used a pole to send methadone to individuals who were stranded at the border between China and Myanmar. (Photo 1) Through this innovation, people who inject drugs who were unable to receive their methadone maintenance treatment in China were granted access.



*Photo 1: The China/ Myanmar Border: a pole is used to deliver methadone maintenance treatment to people who inject drugs*

Successes at some health facilities during COVID-19 was prompt treatment of recipients of care, who were provided with three months' supply of ART medications, thereby avoiding long waiting times and the necessity of frequent return visits (with the added challenge of increased transport costs). A provider in Sierra Leone explained '*We have de-congested the health facility and the management of the flow of clients to the facility - we now give them 3 months supplies to avoid overcrowding and maintain social distancing*'. [Healthcare Worker, Sierra Leone]

Providers noted that the pandemic led to important improvements in hygiene measures. A healthcare worker in Sierra Leone explained: '*There is improvement on hygiene at facilities and observance of IPC (washing of hands, the use of face mask etc) In the future, the washing of hands and the use of hand sanitizer before and not touching the patient will continue*'. [Healthcare Worker, Sierra Leone]

#### *Barriers to Accessing Services (Stigma, Discrimination and Confidentiality Concerns)*

Although COVID-19 created an opportunity to identify and scale-up innovations that improved access to services, for some people living with HIV, the pandemic was a repeated reminder of the negative impacts of their experience with, or uptake of HIV services. During qualitative interviews, recipients of care recounted concerns about their confidentiality and fears of discrimination that resurfaced during COVID-19.

#### **Stigma and discrimination**

In Nepal, many people living with HIV described experiences of violence and stigma that predated COVID-19, raising concerns about certain measures that could increase stigma around HIV. During the COVID-19 pandemic, while living in Kathmandu, a recipient of care described that she feared that healthcare workers and doctors would disclose her HIV status to others and found social distancing to be alienating and frightening. She worried that, because of living with HIV, she would get poorer quality of treatment (or care) from healthcare workers, who themselves were anxious and fearful about COVID-19, and who perhaps feared that people with HIV posed a more

serious risk of COVID transmission due to replete information about the dangers of ‘co-morbidities’. [Recipient of Care, Nepal]

Many recipients of care feared discrimination and loss of confidentiality about their HIV status during the pandemic [Recipient of Care, Nepal], due to new bureaucratic requirements, such as disclosure of HIV status to policemen and other state officials before accessing healthcare facilities. A woman in Kathmandu who lost her job because of her HIV status and endured ongoing discrimination in her employment search described how she and her family had faced stigma and ‘abandonment’ among their families and their employees, because of their HIV status [**Recipient of Care Nepal**].

Similarly, in the AIDS Care China report, most recipients of care reported discrimination and stigma: *“Thirteen people said that there is real discrimination, the most serious is discrimination in employment and medical treatment. We are worried that in the face of emergencies like COVID-19, many people will actively choose to give up treatment because they are afraid of revealing their situation. At present, Yunnan Province has issued a local law that requires HIV testing for both employment and school”*. [AIDS Care China Virtual Learning exchange session].

In China, most of the recipients of care who were surveyed said they feared discrimination related to disclosure of their HIV status. They worried that living with HIV might jeopardise both employment opportunities and access to comprehensive healthcare, and sought to protect themselves by keeping their HIV status a secret, including from their families.

A participant who had been living with HIV for 10 years explained: *‘I did not feel the discrimination from my surroundings because I did not tell anyone about my illness. Especially HIV, only one knows. My heart is still under great pressure, and I am also very inferior.’* [**Recipient of Care Kunming Third People’s Hospital 10 years living with HIV**].

Another recipient of care said: *‘Because I protect my privacy better, I am not discriminated against or stigmatized. But I have heard that because I am infected with HIV, I need to go to a designated specialist hospital for treatment. When I go to a general hospital, the doctor may use other excuses not to perform surgery on the patient. This kind of discrimination also exists in terms of employment, because for professions like civil servant teachers, the medical examination standard needs to be screened for HIV. Many people have passed the exam, but because of this reason, they lose their jobs.’* [Recipient of Care, China].

A 26-year-old transgender person in China highlighted the impact of HIV stigma and the means they would resort to, to hide their HIV status, especially in seeking medical care.

*The moral label of this disease is very serious. I don’t dare to tell anyone about my situation. I will be under a lot of pressure, even my family... Another point is to seek medical treatment. I am afraid that I will not be treated by the hospital when I am sick, and I am also afraid that they will look at me with strange eyes. Once I went to a plastic surgery hospital for a hair transplant...I was very worried about being tested. I used photoshop to falsify the HIV test results before I could have surgery.* [Recipient of Care, China]

In Sierra Leone – unlike China and Nepal – most people living with HIV did not report being stigmatized. However, a few recipients of care recounted instances of name calling and social isolation. In a double interview, two participants explained: *‘People point fingers at us because of*



*our HIV status, and some people when they know you're HIV positive they will think that you got it through sex and they will not like to come close to you'.*

In India, TB-related stigma was compounded by the similar symptoms of COVID-19. A recipient of care with active TB who felt ostracised explained '*no one wanted to sit near or talk to her for fear of contracting TB*'. Another recipient of care explained: '*Since COVID-19 and TB have the same symptoms, people get confused between the two. When coughing, people think one might have contracted COVID and ask one to go get tested*'. [Recipient of Care, India]

## Theme II – Supporting Adherence and Viral Suppression (MMD & Viral Load Testing)

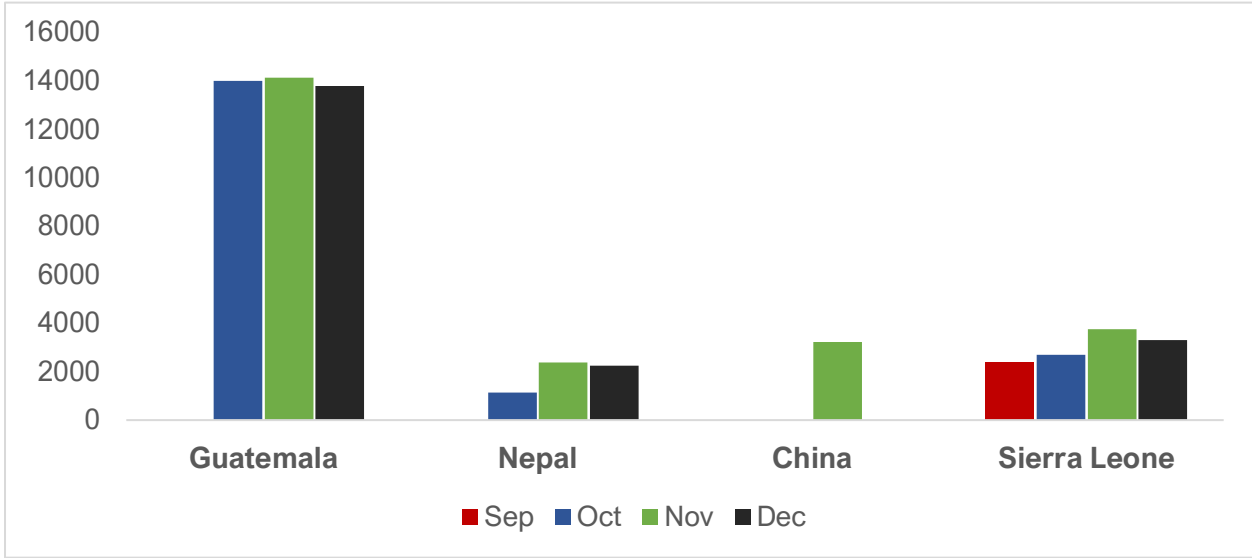
### ART Uptake at Monitored Facilities

There were over 20,000<sup>11</sup> recipients of care receiving ART at the 15 monitored facilities in Guatemala, Nepal, China and Sierra Leone. Where data were available, partners reported an increase in the number of persons on ART between October and November (Figure 3).

The total number of persons on ART in Nepal increased substantially, doubling between October and November 2020. Data collectors recorded a large surge in people on ART at one facility in November 2020 (1735 people on ART, up from 386 the month prior). The number of people on ART at the other two facilities was relatively constant during the project.

All partners reported declines in the number of people on ART between November and December 2020. The total number on ART declined by 2.3% in Guatemala, 5.5% in Nepal and 12% in Sierra Leone.

**Figure 3.** People enrolled on ART at 15 facilities in Guatemala, Nepal, China & Sierra Leone



### Multi-month Dispensing

Although three- and six-month ART refills have been WHO-recommended policy for stable patients since 2016, COVID-19 rapidly sped up implementation of multi-month dispensing

<sup>11</sup> Data for the total number of persons on ART (Appendix A: Indicator 5) was incomplete; the autosum of persons receiving ART by dispensing amount was used to calculate the number of persons on ART; if dispensing data were incomplete this would have underestimated the total number of person on ART

(MMD).<sup>12,13</sup> As of December 2020, WHO reported that 12% of countries are dispensing a one-month supply; 6% provide two months of ARVs; 63% have adopted three-month dispensing and 8% implemented a six-month supply, while 10% have yet to adopt the policy and 1% did not specify.<sup>14</sup> However, an August 2020 UNAIDS report found that MMD policy and practice during COVID-19 were not always aligned.<sup>15</sup>

Partners collected data on the number of people receiving MMD of ART during the pandemic. The data paints an encouraging picture of expansion: across the 11 facilities in two countries with multi-month dispensation of ARVs, on average, the percentage of recipients of care who were receiving MMD increased from 68% in October to 73% in December 2020 (in Sierra Leone and Guatemala).

- In Sierra Leone, the number of people receiving a three-month ART prescription in five health facilities grew steadily, increasing by 54% over the four-month monitoring period. (Figure 4). The number receiving three or more months of ARVs supply accounted for 55% of persons on ART across the monitored facilities; an increase of six percentage points from the September 2020 figures, where 49% of recipients received a three-month ARV supply. Six-month dispensing is not yet occurring in Sierra Leone.
- In Guatemala, the vast majority of people on ART (90% in December 2020) in six health facilities were receiving a three-month ARV supply; there was little change during the three-month monitoring period.
- One hospital in China provided a month of ART to everyone (data were available for November 2020 only, trend analysis was not possible). In general practice, patients get 3 months supply when they get stable with the regimen. The Nov2020 patient getting one month supply is due to the stock constrain caused by the COVID epidemic
- In Nepal, none of the patients received MMD. In October, 39% of people on ART received a 2-month supply with 73% of patients in December 2020. Though a decline in the proportion receiving a 2-month supply was noted in November, this coincided with a doubling of the number of people on ART.
- In India MMD of TB treatment was very limited; only five people received one month of TB treatment in November 2020.

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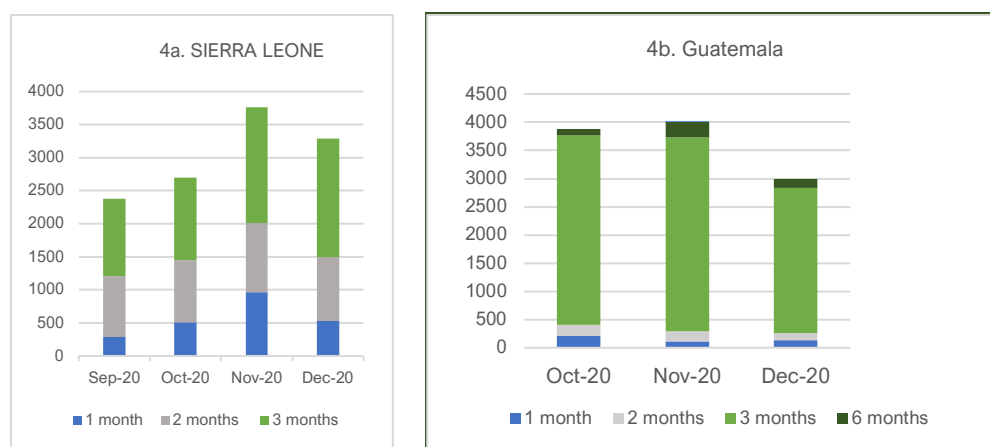
<sup>12</sup> Peabody, R. (2020). COVID-19 pandemic has speeded up the implementation of multi-month dispensing. Aidsmap. Online at <https://www.aidsmap.com/news/jul-2020/covid-19-pandemic-has-speeded-implementation-multi-month-dispensing>

<sup>13</sup> UNAIDS (2021). COVID-19 spurs on multi-month dispensing of HIV treatment in Cambodia. UNAIDS. Online at <https://www.aidsmap.com/news/jul-2020/covid-19-pandemic-has-speeded-implementation-multi-month-dispensing>

<sup>14</sup> GAM UNAIDS/WHO/UNICEF and WHO HIV/HEP/STI COVID-19 Questionnaire, as cited in “Impact of COVID on HIV programs” presented by WHO at the Global Fund Joint Working Group (JWG) in December 2020. Slide 4.

<sup>15</sup> UNAIDS (2020). Rights in a Pandemic: Lockdowns, rights and lessons from HIV in the early response to COVID-19. Page 31. Online at [https://www.unaids.org/sites/default/files/media\\_asset/rights-in-a-pandemic\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/rights-in-a-pandemic_en.pdf)

**Figure 4.** People enrolled in MMD of ART at 13 facilities in Guatemala and Sierra Leone



Reports from recipients of care supported the positive trend in MMD provision observed in Guatemala and Sierra Leone. In Sierra Leone, most people reported access to a three-month ART supply and praised the healthcare services they received, explaining that *‘the healthcare workers are hospitable any time I come to the facility... The healthcare workers followed-up on adherence.’* Another participant relayed her positive experience: *‘Healthcare workers are helping us greatly. They follow up on clients that do not meet their appointment and encourage those that are afraid to come to the facility.’*

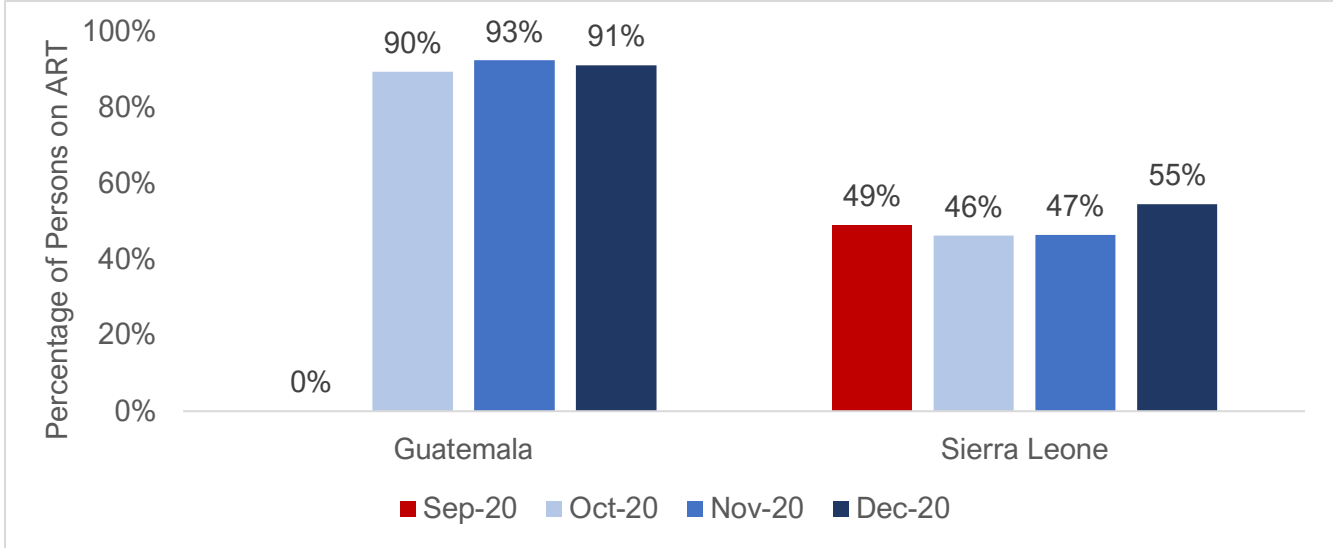
Similarly, recipients of care in China reported only limited barriers to ART access, with ITPC’s partners working to provide healthcare to refugees from Myanmar. During qualitative interviews, most recipients of care in China also reported receiving a three-month supply of ART, which reduced their visits to healthcare centres. Some received ART via express mail or courier delivery. Importantly, the recipients of care interviewed were from three different facilities, whereas quantitative data was collected from one facility in November 2020. This may partly explain the differences in these findings.

Decentralization of ART was also reported in Guatemala (described further below); it is an example of how one long-standing demand by HIV treatment advocates was ultimately realised – perhaps only temporarily – during the COVID-19 pandemic. While some recipients of care reported receiving multiple months of ART (usually three), others, including in China and Guatemala, experienced a reduction in the amount of ART dispensed at healthcare facilities, which they attributed to fears about stockouts among public health officials leading to rationing.

In China, participants generally recounted no challenges with ART adherence, and stated that they took their medicines regularly. One recipient of care stated: *‘I always take my medicines on time and according to the amount, and I have never missed my medicine’*. Similarly, most participants did not report any challenges to ART adherence, with the exception of greater food scarcity - which reduced ART adherence due to the widespread belief that ART cannot be taken on an empty stomach.

In Nepal, some recipients of care reported receiving a longer supply of ART. Before the pandemic, they had received a one-month supply of treatment; this increased by perhaps another month during the pandemic. Although none of the recipients of care was reported to be receiving 3 months or more of medication during the monitoring period, this finding was consistent with the trend of an increasing proportion of recipients of care in Nepal (from 39% to 73%), receiving two months of ART between October and December 2020. While some Nepalese participants were glad to receive multiple months of ART, others reported changes in their ART regimens, which they believed to have resulted from stockouts, necessitating ‘line changes’ of ART. These participants recounted that border closures, particularly with India (an important trade partner with Nepal) had limited ART stocks, and that their ART regimen had been switched due to the unforeseen need for larger ART stocks to ensure ongoing access during a public health emergency such as the COVID-19 pandemic.

**Figure 5:** Percentage of Persons Receiving Three or More Months of ART (MMD)



Across countries, healthcare workers underscored the importance of clinical monitoring for people living with HIV, including through conducting CD4 and viral load tests, as a matter of grave concern during the COVID-19 pandemic. A healthcare worker in China recounted:

*‘For medicines, the biggest impact is the amount of delivery. Compared with the past, we follow up once every third month, and we can give patients three months of medicine at a time. But this year, we can only issue one month’s worth at a time, and it lasted until December. For PLHIV testing, I think the impact should be the detection of CD4 cells. When COVID-19 was the most serious this year, because our hospital did not have CD4 testing technology, we needed to send blood samples to Kunming. It took about 7 days.’ [Doctor, China]*

Healthcare workers and recipients of care reported that provision of, and adherence to ART among people living with HIV, were by no means universal before COVID-19. A recipient of care who had been living with HIV for eleven years recounted the discrepancy between government

promises that ART would be publicly accessible, and real-world accessibility in all facilities. He explained that facilities without foreign donor funding faced interruptions in their drug supply, and were unable to fulfil commitments to MMD in the era of COVID-19.

During focus group discussions, some recipients of care reported challenges within their communities and in their homes which could have an impact on ART retention. In Nepal, women living with HIV were forced to deal with new bureaucracy that restricted their movements and access to healthcare (including ART). These restrictions were exacerbated by additional, privately imposed measures taken by landlords and neighbours, who sought to prevent the movement of tenants and neighbours as a means of COVID-19 infection control. In response to the question, *'How has the COVID-19 pandemic specifically affected women (including those living with HIV)?'*, one recipient of care stated bluntly: *'Owner of house giving torture due to inability to pay rent. No job. No foods...'*

As lockdown restrictions limited mobility in Nepal, many people who rented accommodation in cities had to circumnavigate public restrictions on their movements, as well as limitations imposed by their landlords, families, and neighbours. People who left their homes were – at times – regarded with suspicion, particularly if they were absent for longer than a short visit to buy groceries. The increased surveillance and panic about people's mobility as a conduit for COVID infection affected people living with HIV, as they feared inadvertent disclosure through having to travel to healthcare facilities while strict limitations on movements and access to healthcare provisions were in place.

These reflections underscore the complexities of barriers to clinic visits and ART adherence that some recipients of care faced during the pandemic. Coupled with fear of COVID-19 (explored under Theme V), they provide further context for an exploration of issues that impact retention and may contribute to loss to follow-up.

### *Loss to Follow-Up*

There is much amount of uncertainty about the impact of COVID-19 on retention in HIV care. While it may still be too early to judge, the emerging consensus is that COVID-19's impact on HIV treatment has been less severe than initially feared. A July 2020 study projected that 25-50% of people on ART might have their treatment interrupted during the pandemic.<sup>16</sup> Yet global data from 15 high-burden countries shows that after an initial dip in early 2020, the number of people on ART was largely recovered by Q3 2020.<sup>17</sup> However, this raises concerns about acquired drug resistance, especially among people who are on efavirenz-based treatment, particularly in the context of less access to viral load monitoring.

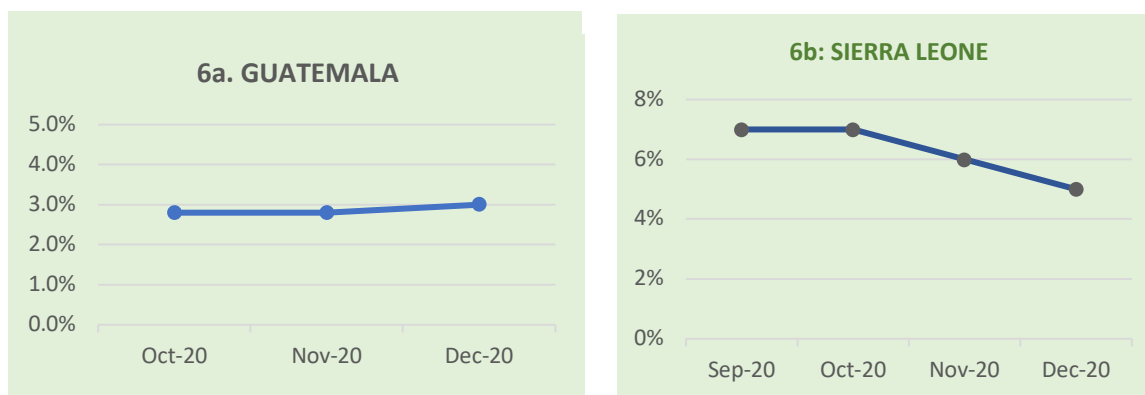
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<sup>16</sup> Hogan, A. B., Jewell, B. L., Sherrard-Smith, E., Vesga, J. F., Watson, O. J., Whittaker, C., ... & Hallett, T. B. (2020). Potential impact of the COVID-19 pandemic on HIV, tuberculosis, and malaria in low-income and middle-income countries: a modelling study. *The Lancet Global Health*, 8(9), e1132-e1141. Online at <https://www.thelancet.com/action/showPdf?pii=S2214-109X%2820%2930288-6>

<sup>17</sup> Mitigation of the impact of COVID-19 on Global Fund supported HIV programs. Long-term adaptation of HIV service delivery. Global Fund PHME Session, 20 January 2021. Slide 11.

CLM reports showed a gradual reduction<sup>18</sup> in the percentage of persons lost to follow-up (LTFU) over the monitoring period (Figures 6a & 6b), despite increasing monthly reports of attrition (Figure 7a). In Guatemala, monthly LTFU rates were 2.8% in October 2020 and November and 3.0% in December of 2020 (Figure 6). In Sierra Leone, the monthly attrition decreased from 7% in September 2020 to 5% in December 2020.

**Figure 6.** Number of persons LTFU as % of all People on ART at 10 Facilities in Guatemala and Sierra Leone

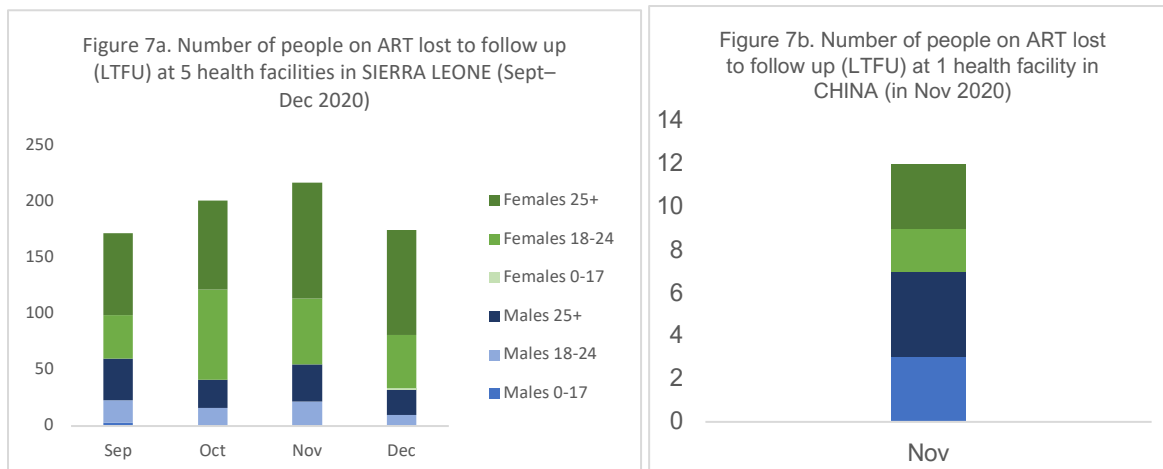


The age- and sex-disaggregated data on LTFU collected by partners provides important nuances to these trends. **Young people (aged 15-24 years) on ART seemed disproportionately likely to be lost to follow-up in the context of COVID-19.** In Sierra Leone, young people aged 15-24 years make up 18% of people living with HIV<sup>19</sup>, yet they accounted for 37% of LTFU at monitored sites. In China, 42% of those LTFU at monitored sites were young people (no data is available on HIV burden) (Figure 7a and Figure 7b). During October 2020, young women (aged 15-24 years) made up 40% of all LTFU at five health facilities in Sierra Leone (Figure 6a). Advocacy for virtual (SMS, social media) tracking and tracing may be needed to recover people who are LTFU into care.

<sup>18</sup> The number of persons lost to follow up was expressed as a percentage of the total number of recipients of ART for the reporting month. Reduction in the percentage of persons LTFU is in part driven by the total number of persons on ART in each country (Figure 3). Partners did not collect data on persons returning to treatment or cumulative data on all persons LTFU, therefore comparison with global projections was limited.

<sup>19</sup> The comparison noted is based on the total burden of HIV amongst the subgroup- data on the total number on ART by age group was not available for the monitored sites.





### Box 2: A Holistic Model – Layering Adherence Support into Community-Led Monitoring and Advocacy

Woven into ITPC’s community-led monitoring model is the provision of adherence support to people living with HIV and affected by TB at the monitored health facilities. In Sierra Leone, COVID-19 has meant that the established support groups could not function as they used to. Instead, they are divided into smaller groups called community ART groups. In Sierra Leone, NETHIPS worked with these groups directly to identify issues and see how to address them, including stigma, discrimination, and challenges with service update. In Guatemala, ITPC-LACTA provided adherence support information to the Health Units and to the recipients of care. In China, ACC established a virtual adherence support group with 170 people enrolled in the online community. **ITPC and its partners are encouraged by the finding that there was improved retention in care during the project. The support provided may have helped.**

#### Viral Load Testing

According to a report from WHO, HIV viral load monitoring was the second most common HIV service to be disrupted by COVID-19 (after HIV testing services).<sup>20</sup> As of December 2020, 23 out of 61 countries (38%) reported disruptions in viral load monitoring.

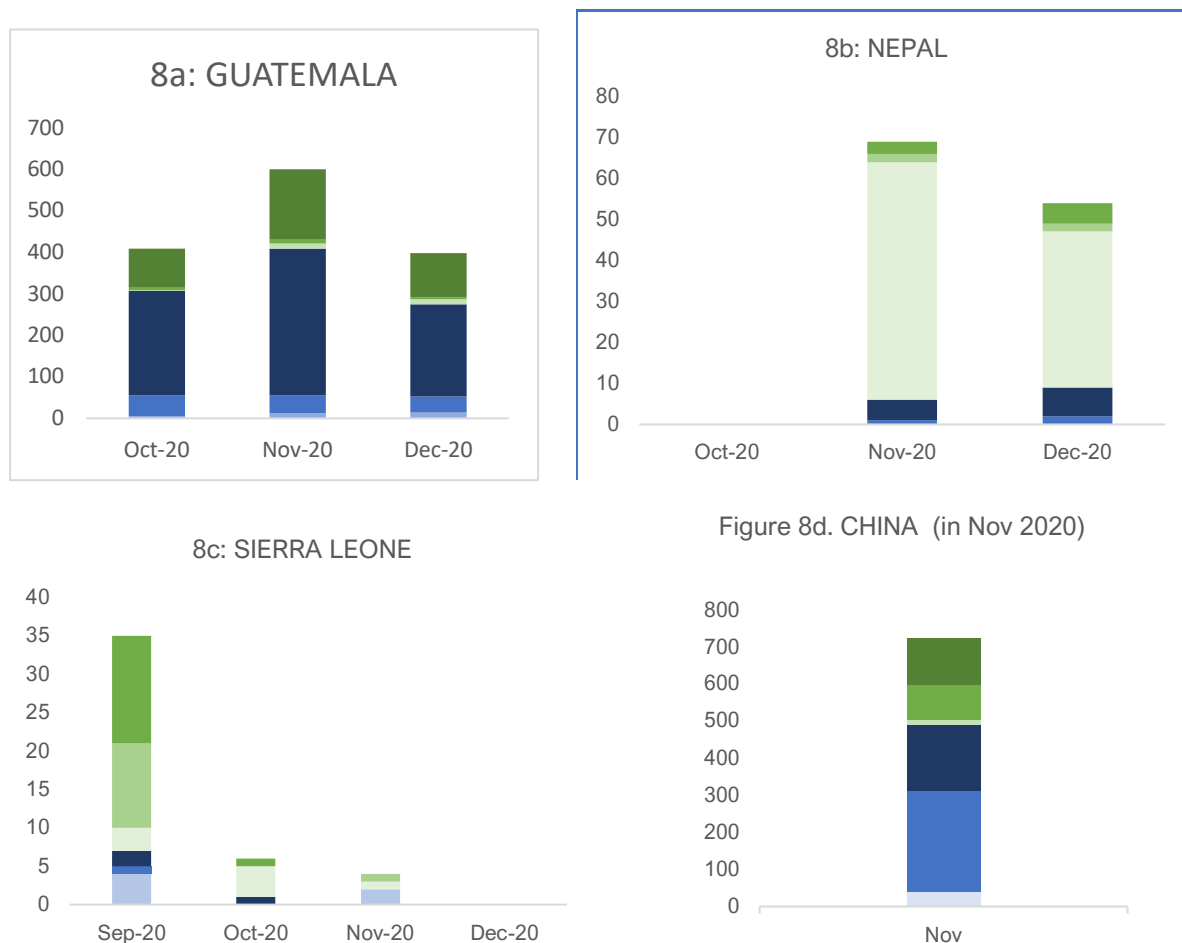
Viral load monitoring is essential for detecting HIV treatment failure; global disruptions during the pandemic occurred because it is not possible to provide virtual or remote viral load monitoring. Furthermore, since machines were being dedicated to COVID-19 testing over viral load monitoring, ITPC and its partners selected viral load testing as a COVID-19 responsive indicator.

In Guatemala, Nepal and Sierra Leone, there were significant decreases in the number of viral load tests done, which coincided with the second wave of COVID-19. Comparing November and December 2020 figures, the number of viral load tests fell by 50% in Guatemala, by 36% in Nepal, and by 100% in Sierra Leone (no tests done in that month) (Figure 8).

<sup>20</sup> Impact of COVID on HIV programs. Presented by WHO at the Global Fund Joint Working Group (JWG) in December 2020. Slide 11.

COVID-19's second wave also seemed to impact turnaround time for viral load tests in Guatemala. The majority of results were returned within a month (80% in October, 81% in November and 77% in December); however only a small percentage of results were returned within 2 weeks: 11%; 14%; and 7% for October, November and December respectively. Each month, at least 19% of results had a turnaround time of 3 months or more. In the six healthcare facilities being monitored, the average turnaround time was 8.1 weeks in October 2020 and 7.2 weeks in November 2020 – it increased to 9.4 weeks in December 2020. However, in China, data were available for November only with all viral load test results were returned within 2 weeks. No turnaround data was available for Sierra Leone.

**Figure 8.** <sup>21</sup>Viral load tests performed at 14 health facilities in Guatemala, Nepal and Sierra Leone



<sup>21</sup> Partners monitored the number of viral load tests performed at the supported sites; complementary data on the total number of virally suppressed patients though planned for collection, was not available for analysis.

■ Males 0-17      ■ Males 18-24      ■ Males 25+  
■ Females 0-17      ■ Females 18-24      ■ Females 25+

The impact of COVID-19 on continuous access and adherence to ART emerged as a concern for both healthcare workers and recipients of care in China. A doctor explained:

*As far as PLHIV in our hospital are concerned, I think the biggest impact should be the inconvenience of taking medicines. At the time when COVID-19 was the most serious, the hospital could not send it out by express delivery and patients could not return to the hospital for follow-up consultation. As a last resort, some patients will not take ART drugs for more than 10 days... For PLHIV, the economy itself is a relatively big problem, and COVID-19 has virtually increased their pressure. For medicines, the country issued a document that patients can borrow medicines for one month at any ART treatment point. [Doctor, China]*

In Guatemala, a doctor explained that stockouts of ART were already a challenge at some healthcare facilities before the pandemic, although he noted that improvements in viral load monitoring led to ARV regimen switches among people who needed them. [Recipient of Care, Guatemala]. She described how Guatemala’s simplification of ART regimens, and in particular a reduction in pill burden, had encouraged greater retention in care and ART adherence among people living with HIV, including during COVID-19. Guatemalan healthcare workers noted the importance of reprioritising HIV in the era of COVID-19, in particular because of vast gains from public provision of ART.

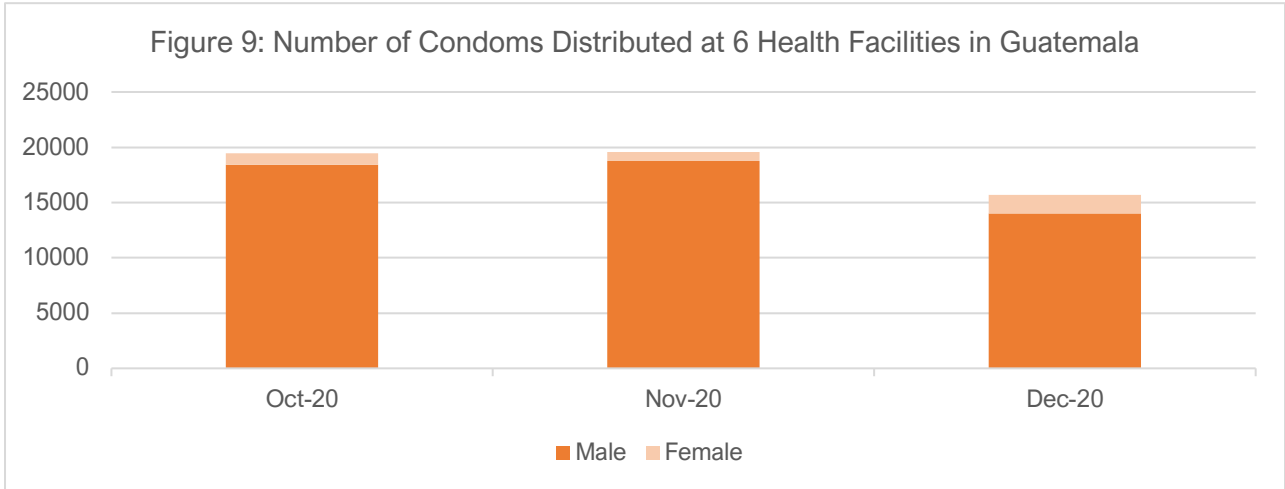
The individual-, facility- and community-level challenges that pose barriers to ART adherence may be compounded by limited supplies of medication and other commodities at health facilities. Partners underscored the importance of CLM for monitoring availability of and access to key prevention commodities, as well as for clinical monitoring. The findings from these key healthcare facility level indicators are summarized under Theme III.

## Theme III – Maintaining the Supply Chain (Stock outs/ EW)

### Condom Distribution

A WHO survey found that 20% of countries reported disruptions in condom distribution during COVID-19, making it the fifth most common HIV service to confront COVID-related interruptions.<sup>22</sup>

ITPC’s community-led monitoring corroborates this in Guatemala – the only country in this project with such data. As the second wave of COVID-19 hit, there was a noticeable drop in distribution of male condoms in Guatemala, which fell by 24% from November to December 2020 at six health facilities (Figure 9). However, community condom distribution programs in Guatemala picked up some of the slack.



### Stock-outs of Medicines and Commodities

Global sustainability of the ART supply was an immediate and pressing concern from the beginning of the pandemic. In mid-2020, 29% of countries had enough ARV stocks of first-line drugs for three months or less, and 54% of countries were at medium/high risk of stock-outs.<sup>23</sup> At a global level, stock-out concerns were largely resolved by the fourth quarter of 2020, with 34 countries reporting ARV disruptions due to COVID-19 in June 2020 compared to 9 countries in November 2020.<sup>24</sup>

ITPC’s community-led monitoring data on stock-outs suggests they have been persistent during COVID-19. Stock-outs were documented during 16 out of 39 (41%) monthly observations across clinics in China, Guatemala and Sierra Leone (Table 4). Stock-outs were most prevalent in Sierra Leone, documented in 12 of 20 (60%) monthly observations – a rate nearly three times higher

<sup>22</sup> Impact of COVID on HIV programs. Presented by WHO at the Global Fund Joint Working Group (JWG) in December 2020. Slide 11.

<sup>23</sup> Impact of COVID on HIV programs. Presented at the Global Fund Joint Working Group (JWG) in December 2020. Slide 4-5.

<sup>24</sup> Impact of COVID on HIV programs. Presented by WHO at the Global Fund Joint Working Group (JWG) in December 2020. Slide 10.

than ARV stock-outs (23%) documented during ITPC’s pre-COVID community-led monitoring in Sierra Leone (Jan-June 2018). Stock-outs were resolved faster in China (13 days), followed by Sierra Leone (24 days) and then Guatemala (120 days). No stock-outs were documented in India or Nepal during the project (Table 4). [It is notable here, and described further in the section below on this project limitations, that data captured through facility registers may be subject to reporting biases.]

**Table 4.** Stock-outs of medicines and commodities in three countries during COVID-19

CHINA			
Type of facility	Medicine or commodity	Date of stock-out	# of days out of stock
Urban hospital 1	Lamivudine	November 2020	13 days
	Zidovudine		12 days
GUATEMALA			
Type of facility	Medicine or commodity	Date of stock-out	# of days out of stock
Urban clinic 1	CD4 Machine	October 2020	240 days
Urban clinic 2	Elvitegravir/Cobicistat Emtricitabine/Tenofovir Alafenamide	December 2020	90 days
	CD4 Machine		
SIERRA LEONE			
Type of facility	Medicine or commodity	Date of stock-out	# of days out of stock
Urban hospital 1	Tenofovir/Lamivudine Efavirenz	September 2020	30 days
Urban hospital 3	Lopinavir/Ritonavir 100/25mg	September 2020	14 days
	Lopinavir/Ritonavir 100/50mg	September 2020	14 days
Rural community health center 1	Tenofovir/Lamivudine	September 2020	30 days
Urban hospital 1	Tenofovir /Lamivudine Efavirenz	October 2020	30 days
Urban hospital 2	Zidovudine 300mg/Lamivudine 150mg	October 2020	21 days
Urban hospital 3	Efavirenz 600mg	October 2020	14 days

Rural community health center 1	Tenofovir/Lamivudine	October 2020	30 days
Urban hospital 1	Tenofovir /Lamivudine /Efavirenz	November 2020	13 days
Rural community health center 1	Tenofovir/Lamivudine	November 2020	30 days
	ABC/3TC Adult	November 2020	30 days
	ABC/3TC Baby	November 2020	30 days

## Theme IV- Tuberculosis Diagnosis & Treatment

### *TB Diagnosis*

In May 2020, the Stop TB Partnership estimated that COVID-19 lockdowns would drop the probability of receiving a TB diagnosis (per visit to a provider) by 70% in India.<sup>25</sup> In a survey conducted by the STOP TB Partnership, including over 1,000 people from 89 countries, 19.4% strongly agreed and 22.2% agreed that capacity to provide TB diagnostic services has decreased significantly during COVID-19.<sup>26</sup> Global Fund surveys in 13 high-burden countries reveal that 29% fewer people were tested for TB in 2020 than in 2019.<sup>27</sup>

ITPC's community-led monitoring in India collected data along the entire TB care cascade to track access to and uptake of screening, testing, treatment, and support.

India was the only country in this project to collect data on TB screening – an important pre-cursor to referral for TB testing. At the two CLM sites in India, TB screening remained relatively stable over the three months, with 59 people screened in October 2020, 64 in November and 62 in December. Of the 185 people screened, 92 were men and 93 were women.

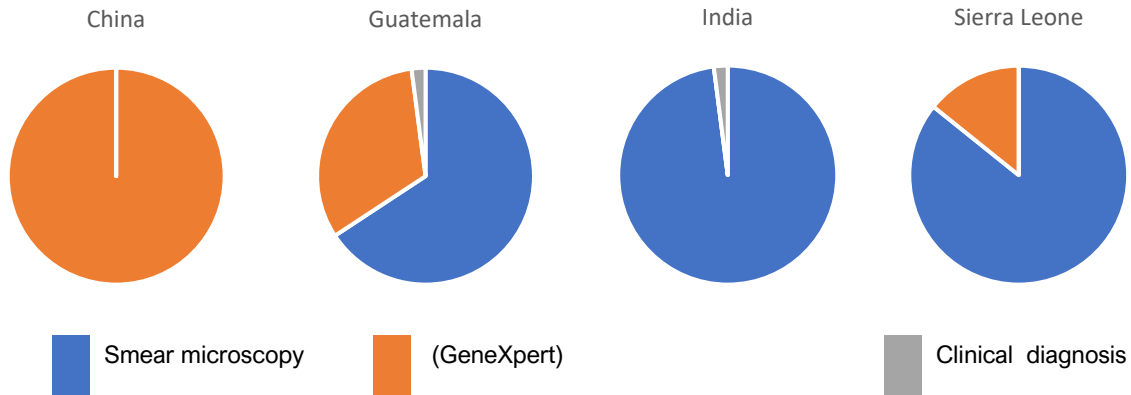
Partners monitored the number of TB tests performed during the pandemic, disaggregated by the type of test (Figure 10). In total, 1,686 people were tested for TB at 11 sites in China, Guatemala, India and Sierra Leone during the four-month project (no data was available for TB testing in Nepal). In these four countries, the majority of TB tests were done using smear microscopy (78%), followed by GeneXpert (21%) and clinical diagnosis (1%).

**Figure 10.** TB Tests done, by Type in 15 Health Facilities in Four Countries, September-December 2020

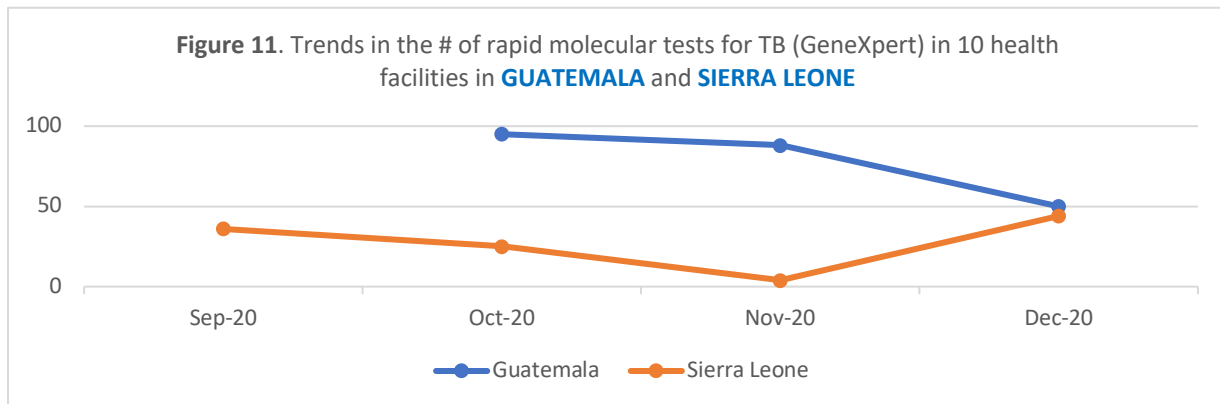
<sup>25</sup> Stop TB Partnership, Imperial College, Avenir Health, Johns Hopkins University and USAID (2020). The Potential Impact Of The COVID-19 Response On Tuberculosis In High-Burden Countries: A Modelling Analysis. Page 7. Online at [http://www.stoptb.org/assets/documents/news/Modeling%20Report\\_1%20May%202020\\_FINAL.pdf](http://www.stoptb.org/assets/documents/news/Modeling%20Report_1%20May%202020_FINAL.pdf)

<sup>26</sup> Stop TB Partnership (2020). The impact of COVID-19 on the TB epidemic: A community perspective. Page 22. Online at <http://www.stoptb.org/assets/documents/resources/publications/acsm/Civil%20Society%20Report%20on%20TB%20and%20COVID.pdf>

<sup>27</sup> Global Fund (2021). News Release: TB testing in 2020 dropped drastically due to COVID-19.



The CLM data showed a **declining trend in use of GeneXpert TB tests in Guatemala and Sierra Leone** from September to November 2020, with an uptick in Sierra Leone in December 2020 (Figure 11).



In one of the monitored health centres in India, communities reported a pre-COVID average of 70-80 TB tests per month. The pandemic changed this: only 25-35 tests had been conducted each month. People are required to present a negative COVID-19 test result before undergoing TB testing. Referrals from self-help group members, volunteers, and TB champions have also gone down.

Focus group discussions and interviews highlighted the impact of COVID-19 restrictions on India's cascade of TB diagnosis, treatment and care. Access to TB testing was delayed and complicated by the requirement for a COVID-19 test first (at a different facility), while lengthy queues raised the fear of exposure to COVID-19 and discouraged people from waiting to receive their TB medicines.

A HCW explained: *“Since the COVID test became mandatory, many patients went back without testing for TB though they were having cough for more than two weeks. The patients also notice long queues, which has discouraged them to go for TB tests.”*[India]



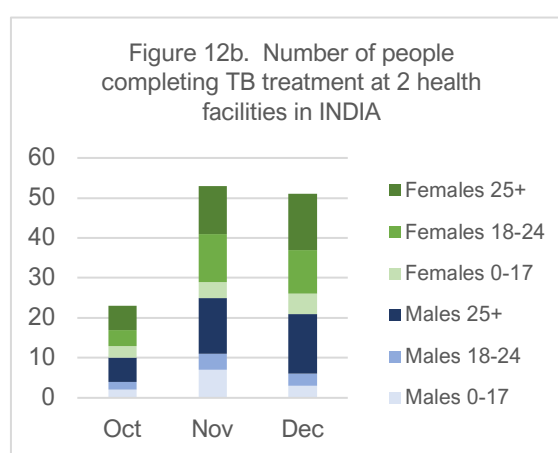
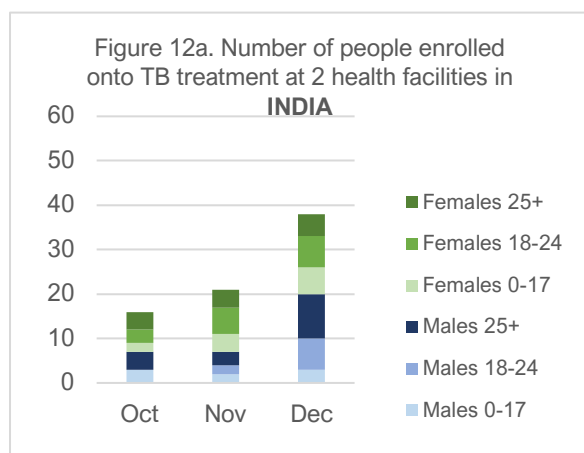
This finding was supported by reflections from interviews in India; a healthcare worker described how: “The uptake of TB testing is low as a result of COVID. Before COVID-19, clients come to the facility on voluntarily bases for testing and treatment, but since the outbreak of COVID we now have less turnout in fear of COVID.” Among recipients of TB treatment in India, further concerns were however raised about not receiving the government’s nutritional allowance, which is an essential component of TB treatment.

Data collectors in India gathered information on the turnaround time for TB tests, with concerns about a delay in results from the laboratory (as with HIV viral load testing). Recipients of care at the two monitored facilities received the results of their TB test within a week.

### TB Treatment

In December 2020, WHO reported that 42% of countries were experiencing a partial disruption in TB case detection and treatment due to COVID-19.<sup>28</sup> WHO estimated that 1.4 million fewer people (corresponding to a 21% reduction) received care for TB in 2020 than in 2019.<sup>29</sup>

Data collected from two health facilities run by non-governmental organizations in India show that the number of people enrolled onto TB treatment more than doubled over the course of the project, rising from 16 in October 2020, to 21 in November, to 38 in December (Figure 12a). Notably, the facilities enrolled more women (n=41) than men (n=34) onto TB treatment, as well as a high number of people with extra-pulmonary TB (n=31). Age- and sex-disaggregated data show particularly positive trends for girls aged 0-17 years, among whom the number newly enrolled on TB treatment tripled in three months. The number of people who completed TB treatment also rose, again, particularly among women. At the two facilities, 13 women completed TB treatment in October 2020, 28 in November, and 30 in December (Figure 12b).



<sup>28</sup> Impact of COVID on HIV programs. Presented by WHO at the Global Fund Joint Working Group (JWG) in December 2020. Slide 13.

<sup>29</sup> WHO (2021). Impact of the COVID-19 pandemic on TB detection and mortality in 2020. Page 1. Online at <https://www.who.int/publications/m/item/impact-of-the-covid-19-pandemic-on-tb-detection-and-mortality-in-2020>

Amid encouraging data on TB treatment enrolment and completion, the data collectors also recorded **10 people on TB treatment who were LTFU, including three young people aged 18-24 years, and two people with drug-resistant TB.**

Partners in India aimed to collect data on screening, testing and treatment for drug-resistant TB, but this information was limited. For three months, no data was available on screening or testing for drug-resistant TB. Two people were enrolled onto DR-TB treatment during the project, one child aged 0-17 years in October 2020 and one adult aged 25 years or older in December 2020.

ITPC hoped to collect data on the number of people with TB who were receiving allowances for transport and nutrition to support their adherence to TB treatment. Community-led monitoring brought to light that **the government of India is meant to be providing 500 rupees per month to every person on TB treatment - but that this social support provision is not available.**

The lack of public transport during lockdown limited access to healthcare facilities and deliveries of medicines and commodities to facilities - and to recipients of care at home. A lab technician in India explained how, during lockdown, she had to walk from her home to the facility in the hot summer sun. Healthcare workers emphasized the need for buffer stocks of medications to avoid shortages, and in preparation for further lockdowns or health emergencies. Some recipients of care were provided with a month's supply of TB medicine during lockdowns.

## Theme V - COVID-19, Knowledge, Perspectives and Impact

### *Understanding of COVID-19*

Understanding of COVID-19 varied widely across all five countries. In some instances, COVID-19 was considered more serious than HIV due to its ease of transmission. This exacerbated fears about COVID-19 - which seemed uncontrollable - and which, unlike HIV, was perceived to lack current, effective and accessible treatment. A recipient of care explained: *'I think COVID-19 is more serious than HIV. There are only a few ways for HIV to spread, but COVID-19 can be transmitted through the air, which makes me very scared.'* [Recipient of Care, China]

- In Sierra Leone, recipients of care focused on the pandemic's effects on their livelihood - from lockdowns and other restrictions - and social distancing. [Sierra Leone]

One woman explained how the pandemic was affecting her: *"I thank God because I don't go out. My only problem is with the lockdown imposed by government. COVID-19 is a virus more dangerous than HIV and COVID-19 has affected my business as a result of the frequent lockdowns"*. [Recipient of Care, Sierra Leone]

Another woman stated: *"COVID 19 has restricted my movement and pushed us to the use of a face mask and hand washing"*. [Recipient of Care, Sierra Leone]

Lockdowns and curfews had a negative impact on people's livelihoods. *'I need food. My only stress is food and our movement has been seized.'* Restricted movements reduced

income and access to food, with consequential negative effects on ART adherence. A woman in Sierra Leone explained: *We have no way to go fishing in the sea. They (men) cannot fish in the sea and we have no food with COVID. The condition is not favourable with me and I can't take ART without food.* [Recipient of Care, Sierra Leone]

- In China, recipients of care generally had a comprehensive understanding of transmission and prevention of COVID-19, with younger people (aged 20-40 years) having better access to information than those who were middle-aged or older.

A Chinese recipient of care commented: *'I learned from news reports and written materials that COVID-19 is a respiratory disease that spreads through the air. After being infected, the lungs may fail'* [Recipient of Care, China]

- In India, recipients of care were aware of the symptoms (cough and fever) as well as preventive measures such as hand washing, social distancing and wearing masks when going out.

A partner's work in India underscored the similarity of symptoms between TB and COVID-19, and associated prospective stigmatisation. A healthcare worker explained: *'The [COVID-19] pandemic has badly affected TB patients as cough is a common symptom for both diseases'*. [HCW India]

It will be interesting to observe the impact of COVID-19 on previously accepted or normative public behaviours, such as coughing and sneezing in crowded places. Measures collectively termed 'respiratory hygiene' (mask-wearing, coughing and sneezing outside and away from other people, maintaining better air circulation through opening windows etc) may increase. Furthermore, fear and panic about disease transmission through ordinary and essential human interactions may also advance, with prospective negative effects on sociality, affection and intimacy.

Across countries and sites, many people described the fear that COVID-19 would be more severe, resulting in greater illness and death, for people living with HIV.

- In Guatemala, a recipient of care who had been taking ART for four years, and who had become infected with COVID-19, explained the '*panic*' she felt, together with her anxiety that her HIV would exacerbate her vulnerability to severe illness and death from COVID-19. She stated: *'My situation was very vulnerable, and I was really sick after COVID-19 infection. I felt like I was going to die and panicked every time as I am already immune compromised'*. [Recipient of Care, Guatemala].
- An HIV specialist and a psychologist in Guatemala described the initial impact of COVID-19 on people living with HIV, when fears about 'contagion' within facilities had frightened patients away. Among the clearest messages about the dangers of COVID-19 was its severity among people with co-morbidities, including HIV. People living with HIV were anxious about being at greater risk for severe COVID-19 infection and transmission [Recipient of Care, Guatemala]. In response, partners sought to promote evidence-based information about COVID-19. In Guatemala, for instance, IPTC-LATCA led a treatment literacy campaign to provide evidence-based information on COVID-19 transmission and prevention to healthcare workers and recipients of care.

Most healthcare workers reported that people living with HIV were afraid to access healthcare during the COVID-19 pandemic due to perceptions that their compromised immune status put them at greater likelihood of infection with and severe illness and death from COVID-19.

- In Sierra Leone, a healthcare worker explained: *Our clients are afraid to come because their immunity is already compromised. They fear getting COVID-19... [T]here is an increase in the number of defaulting or not meeting their appointment date because of the COVID-19 outbreak”.*
- In China, health care workers alluded to increased workload and other pressures, including a greater number of follow-up visits, time-consuming infection control measures, and shortages of staff. Overall, healthcare workers in China described the COVID-19 pandemic and associated health impacts as ‘under control’ and anticipated that, once the COVID-19 pandemic was contained, healthcare provision would return to relative normality. A doctor in an ART clinic explained: *‘I think that, with the arrival of COVID-19, my workload has almost doubled. A large amount of information needs to be asked of patients, and a large number of forms have to be filled and submitted every day, such as patients’ travel history and epidemic history. Due to insufficient medication, the frequency of follow-up visits in our hospital has changed. It used to be a three-month follow-up visit and now it has become a follow-up visit every month, which greatly increased my work pressure. [HCW, China]’*
- Infection control measures and screening patients added to the workload, but healthcare workers were hopeful that these added tasks would decrease once the epidemic was ‘under control’. *‘What we mainly do is to measure the patient’s body temperature when entering the hospital, scan the health QR code, and check his body temperature again before entering the clinic. If the body temperature is abnormal, we will conduct a more in-depth and detailed examination... (Chest radiograph, nucleic acid check). As the national epidemic is under control, we will stop testing when entering the clinic, and we can enter the hospital with only one test at the hospital gate.’ [Case manager, China]. (Photo 2)*



Photo 2: Entrance to a Health Facility in China, where infection control measures are implemented to reduce COVID-19 transmission risk

On a more personal level, healthcare workers recounted how travel restrictions, fear of contracting COVID-19, and added work commitments impacted on their personal lives and general well-being.

*'The impact is definitely there, and it is quite large. In terms of life, the pressure of doing this job is great. On weekdays, I can gather with friends and chat to release my work pressure. But now it can only be through online chat. I think this is essentially different from face-to-face communication. Work pressure has not been released and new jobs must be ushered in... I originally planned to travel abroad this year, but due to the outbreak of COVID-19, all the vacations of medical staff have been cancelled. It is a great regret for me that I cannot accompany my family.'*  
[Case Manager, China]

### **'Hard to survive': Socio-economic impacts of COVID-19**

When asked about the impact of COVID-19 on people living with HIV, the majority of participants spoke about job losses, food insecurity, school closures and movement restrictions before describing its effects on healthcare. For instance, in response to a question about the burdens and stressors of living with HIV during the COVID-19 pandemic, a recipient of care living in Kathmandu stated: *'No job. Difficult to pay rent and eat.'* [Recipient of Care, Nepal] Another stated: *"Hard to survive. Run out from food and basic needs.'* [Recipient of Care, Nepal] This belief, that survival itself was threatened by the COVID-19 pandemic – through its socio-economic effects – was echoed across interviews conducted with women living with HIV in Nepal. A third recipient of care stated: *'Loss of job. Ran out of food... No mobility. Difficulty to fulfil basic needs.'*

In Nepal, people living with HIV understood that COVID-19 was having a severely negative impact on access to healthcare. For instance, a woman living with HIV, locked-down in Kathmandu, described the negative effects of the COVID-19 pandemic on healthcare services for people living with HIV and TB. She stated: *'[There is] chaos in the hospital due to Corona'* [Recipient of Care, Nepal]

## Healthcare workers perspectives on the impacts of COVID-19

A doctor with five years of experience working on HIV described the ‘physical and psychological’ impact of COVID-19 on her provision of care. When the pandemic first emerged, she was recalled from maternity leave to work as part of the COVID-19 emergency response. Restrictions on public transport and personal movements made it necessary for her to separate from her baby [Doctor, Guatemala]. She described the fear, stress and anger among healthcare workers in the early months of the COVID-19 pandemic, as they feared occupational exposure to the virus, and as facilities ran out of personal protective equipment.<sup>30</sup> She described how: ‘*we did not have material protective equipment because everything ran out*’. (*[N]o teníamos materiales equipo de protección porque todo se agotó*).

Echoing the extreme effects of the COVID-19 pandemic on frontline healthcare workers, a psychologist working with COVID-19 patients and their families described the ‘*emotional shock*’ of the pandemic [Psychologist, Guatemala]. Having witnessed first-hand the pain and suffering of COVID-19, she described the seeming unpredictability of the virus, at times severe in young and healthy people, and at other times mild among the elderly. She also recounted how separating people with COVID-19 from their families exacerbated the fear and sadness surrounding the disease, even as their isolation was understood as an attempt to stop the spread of the virus. This psychologist described early attempts at maintaining infection control at her facility, through setting up a COVID tent, and recounted the perception among healthcare workers that their own wellbeing was fundamentally compromised in the early months of the pandemic.

When asked about the impacts of COVID-19 on people living with HIV in Guatemala, recipients of care and healthcare workers generally began by recounting the socio-economic and emotional impacts of the pandemic, including loss of income, restrictions on movement, school suspensions, and fear and anxiety about being infected with the virus. It is notable that participants focused on the socio-structural and psychological toll of the COVID-19 pandemic generally, before delving in greater depth on the effects of the pandemic on healthcare. Participants shared how the economic impacts of the pandemic, particularly increases in transport costs, had obstructed their access to healthcare and limited household budgets substantially. Recipients of care highlighted the difficulties of traveling to healthcare facilities, particularly during the period of ‘lockdown’, when there was no public transport.

### *Impacts of COVID-19 on HIV and TB healthcare Provision*

Reports from countries and regions provided vastly different insights into the healthcare responses of governments, healthcare workers and recipients of care to the pandemic. In some instances, the responses corroborated the quantitative findings (Table 4). In Sierra Leone and China, for example, some healthcare workers and recipients of care reported well-organized responses with no medicine stockouts. Similarly, in India, healthcare workers reported no stockouts of TB diagnostics or medicines. However, shortages and stockouts of medicines and

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‘[Y] al principio obviamente al personal nos afectaba un montón porque no teníamos materiales equipo de protección porque todo se agotó...’

diagnostics were reported by other healthcare workers and participants - at times within the same sites.

### *Successes*

Healthcare workers in Yunnan Province, China provided positive reports of how COVID-19 had been contained in their facilities with international and national recognition - and praise for their work - with no COVID fatalities amongst health care workers and recipients of care.

*'In terms of achievement, our hospital will definitely have a lot. In Yunnan Province, our hospital admits the most patients. The leaders of our institute have also received national commendations. At the same time, the hospital has also been affirmed by the outside world because of the effectiveness of the treatment... None of the patients treated in our hospital died, and none of the medical staff were infected. The clinical diagnosis and treatment techniques and methods have been recognized by the outside world.'* [ART case manager, China]

Recipients of care described exercising greater caution, including through restricting their movements beyond 'lockdown' periods, due to fears of being at greater risk for severe COVID-infection. Some highlighted the laxity of infection control measures, such as violation of capacity limits on public buses or at nightclubs. The impacts of COVID-19 on risk perceptions among people living with HIV and the potential limiting effects on how they live, work, school, care and seek pleasure, require urgent attention.



## 6. Data Driven Change: The Advocacy Agenda

The advocacy agenda from this rapid community-led monitoring project is unfolding in real time after just a few months of data collection. Some preliminary data-driven actions and early advocacy wins are presented below.

### **Advocacy Priority #1: Don't Get Side-Tracked**

ITPC's data show a declining trend in GeneXpert TB testing in Guatemala and Sierra Leone from September to November 2020. These findings validate community concerns that GeneXpert machines were being overwhelmed and monopolized by COVID-19 testing, and that it had been deprioritized by healthcare workers and laboratories as a result.<sup>31</sup> Furthermore, findings in India suggest that people were denied access to TB testing if they were not able to be tested for COVID-19 first. ITPC and its partners are using this data to reinforce advocacy messaging from a recent Stop TB Partnership community report, calling on governments to leverage testing platforms (like GeneXpert) to increase COVID-19 testing capacity - while ensuring that TB testing is not stopped.<sup>32</sup>

The qualitative data suggest a culture of fear around COVID-19 which led to healthcare avoidance among people living with HIV and TB. It is vital that these communities have sustained access to treatment and adherence support. Protection against COVID-19 should not mean avoiding life-saving HIV and TB services. ITPC and its partners are advocating for the scale up of good practices identified through this project, including innovative service delivery models.

### **Advocacy Priority #2: Go Virtual**

The data communities collected throughout this project show a disproportionate likelihood that adolescents and young people are being lost to follow-up in the context of COVID-19. ITPC and its partners are using this data to advocate for the use of virtual (e.g. SMS, social media) tracking and tracing to recover these clients into care.

In December 2020, the Global Fund recommended the expansion of video-observed TB treatment, to support adherence and limit the spread of COVID-19.<sup>33</sup> ITPC included the number

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<sup>31</sup> Wits University (2020). GeneXpert testing platform for TB repurposed to accelerate testing for Covid-19. Online at <https://www.wits.ac.za/covid19/covid19-news/latest/genexpert-testing-platform-for-tb-repurposed-to-accelerate-testing-for-covid-19-.html>

<sup>32</sup> Stop TB Partnership (2020). The impact of COVID-19 on the TB epidemic: A community perspective. Page 10. Online at <http://www.stoptb.org/assets/documents/resources/publications/acsm/Civil%20Society%20Report%20on%20TB%20and%20COVID.pdf>

<sup>33</sup> Global Fund (2020). COVID-19 Situation Report #34 Reporting period 25 November - 8 December 2020. Page 9. Online at [https://www.theglobalfund.org/media/10428/covid19\\_2020-12-09-situation\\_report\\_en.pdf](https://www.theglobalfund.org/media/10428/covid19_2020-12-09-situation_report_en.pdf)



of people receiving video-observed therapy as an indicator in its TB community-led monitoring in India, but such data were not available. Advocacy for the rollout of video-observed TB treatment being done by ITPC's partners in India, GCTA.

Based on the results of the interviews, ACC in China formed a virtual community of people living with HIV. After a month, 170 people enrolled in the online community. ACC hopes to help people living with HIV obtain better health outcomes and support opportunities through this channel, and to use this platform to provide comprehensive adherence support. ACC is now advocating for other community groups as well as health facilities to establish virtual support groups for people living with HIV.

### **Advocacy Priority #3: Strengthening Systems to Differentiate, Differentiate, Differentiate**

The data show promising increases in the percentage of people living with HIV who are receiving multi-month ART dispensing (of at least a three-month supply) of ART in Guatemala and Sierra Leone. Qualitative data point to decentralization and delivery of medicines in China and Nepal. ITPC and its partners have long advocated for the scale-up of differentiated service delivery for HIV. This new data, in the context of COVID-19, is being used to intensify this advocacy and urge rapid action. An important component of offering services tailored to the needs of recipients of care, will be maintaining a reliable supply chain that ensures availability of commodities and medicines. The data have shown that several countries faced stockouts of essential medicines for periods exceeding 30 days. The report highlights the urgent need to leverage investments to strengthen systems (community and facility) to ensure they are resilient and are able to maintain quality services, within the context of multiple pandemics.

### **Advocacy Priority #4: A Little Support Goes a Long Way**

Qualitative findings underscore the need for intensified psychosocial support, mental health care, and interventions to reduce stigma and discrimination during COVID-19. HIV-related stigma was compounded with stigma related to COVID-19 and to TB. Facility visits also highlighted the need for transport refunds for people with TB, especially in instances in which these provisions had been promised in government policy, but remained inaccessible for most recipients of care in this project. ITPC and its partners are advocating with governments, funding partners and other civil society groups to scale-up social protection. It is essential that countries continue to provide economic and psychosocial services for all in need. Addressing the social determinants of health that lead to inequality will remain an essential tenet of reaching the 2030 goals. This project leads by example, integrating adherence support (helping recipients of care adhere to their treatment regimens) into community-led monitoring.

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### **ADVOCACY WIN: Turning “No Data” into a New National Indicator in Sierra Leone**

In Sierra Leone, NETHIPS aimed to collect quantitative data on the number of people living with HIV who experienced ART treatment failure during COVID-19. In September 2020, after the first month of monitoring, NETHIPS discovered that the current service registers do not capture this indicator. NETHIPS then initiated a conversation with the National AIDS Control Program (NACP), where they learned that a committee at facility level examines individual clients' need to change regimens, and stores this information on the appointment cards. The NACP said that in some facilities, these committees store treatment failure information in another book, separate from the master register. From this conversation, NETHIPS secured a commitment from the NACP to develop a new tool – a new set of service registers – that captures this indicator.

**“That is the beauty of projects like this. They identify how people fall through the cracks. We will be bringing this issue to the community consultative group, and advocating for NACP to accelerate the production of new treatment registers that include treatment failure in them”**

*– Martin Ellie, NETHIPS Sierra Leone*

### **FROM DATA TO ACTION: How Communities Responded Rapidly to Needs Identified Through CLM&A**

In **CHINA**, ACC distributed ART to 40 refugees from Myanmar who were stranded in China, supported 130 people with relevant knowledge and training on how to quickly and effectively obtain ART in the face of emergencies, and gave nearly 100 people psychological counselling.

In **SIERRA LEONE**, NETHIPS engaged 48 community ART groups (15 rural, 28 urban) in the Western Area, it provided 312 group members with adherence support, and linked 50 people (15 children, 35 adults) with needed HIV services.

In **INDIA**, GCTA saw the need to rapidly scale up community-led monitoring capacity in the face of COVID-19's impact on access to TB services. After data collection finished in December 2020, GCTA trained a team at TB Alert (another civil society organization in India) on the importance of community-led monitoring and how to do the data collection. The model is now being cascaded to other health facilities through this expanded capacity.

## 7. Limitations

The community-led monitoring activities were designed to collect data on key indicators (up to 31) in the selected sites. There were a number of limitations due to implementation constraints and availability of data that limit the conclusions drawn from the analysis, specifically:

1. **Only limited pre-COVID data** were available for fully comparing trends. Since this model was newly implemented in several sites, historical data were not available to fully assess the impact of COVID-19 on service uptake.
2. **The short-time frame** of the community-led monitoring in this project (three- months of data collection for most sites) meant that only limited trend analysis was possible. As such, the fluctuations observed from one month to the next may be anomalies rather than chronic issues. The short-time frame also constrained the project's ability to convene stakeholders to set advocacy agendas, and to implement advocacy plans. Instead, ITPC and its partners employed rapid data-driven responses, engaging directly with decision-makers and providing emergency adherence support to recipients of care.
3. **The small sample size** (17health facilities for quantitative data) and **diverse country contexts** meant that comparative analysis across the countries and across the project necessitated caution.
4. **No face-to-face learning** due to COVID-19. With the entire project implemented virtually among the five implementing partners, there may have been missed opportunities for deeper learning and information-sharing from the project. Trainings are often more effective when they are hands-on.
5. **Data was not available** for some of the indicators, and as such only a subset of the intended metrics were available. This was because some information was unavailable at the site, or due to data collection errors (e.g. ITPC hoped to collect data on the number of people living with HIV who received a baseline CD4 count before initiating ART. However, during data collection, some data collectors recorded the total number of CD4 tests done instead). CD4 testing is still used for routine treatment monitoring in some low-resource settings where viral load testing is not widely available. This inconsistency compromised the dataset on this indicator). Some data disaggregates were not available to allow for comparison of key metrics; for example – total number on ART not available by age/sex to support robust analysis of the numbers of LTFU vs the numbers on ART; viral suppression data for all patients on ART was not reported with fidelity by partners.
6. There was some **variation in data collection** for quantitative and qualitative data (for example, in China quantitative data was available for one month only for one site; however qualitative interviews were possible from three facilities); differences in quantitative and qualitative results may be due to this.
7. As with all forms of monitoring, there is a possibility that respondents and participants fear negative consequences from declaring divergences between what is promised in the health

sector of by the state, and what is provided in reality and in local facilities. Participants may seek to protect themselves from the sanction of authorities by recording data that is clearly false or by inflating results. In this project, for instance, contradictions within qualitative interviews revealed that participants were worried about being honest about their experiences, initially reporting that 'all was well' with government provisions, while – in the same interview and once rapport had deepened – describing serious challenges and problems in the same indicators.

ITPC will continue to review the lessons learned from implementation of the CLM&A activities and use these to guide improvements in the model. Specifically, ITPC will enhance toolkits and guidance documents for partners, as well as to implement robust virtual models for data validation and qualitative assurance to reduce challenges experienced related to data quality.

## 8. Integration and Sustainability

ITPC's community-led monitoring and advocacy approaches, executed through community treatment observatories (CTOs), were initially designed to put people living with HIV, their communities, networks and/or organizations at the center of decision-making. This project provided a platform to adapt the model for other priority diseases, thus highlighting the value of CLM&A.

Through CLM, partners were able to gather evidence within the evolving context of the COVID-19 pandemic. The data reported by partners gave real-time insight into the impact of COVID-19 on continuity of services. Furthermore, it provided an opportunity to identify emerging solutions to ensure maintenance of quality services for people living with HIV and people living with TB. The routine analysis and discussion of the data with stakeholders provided a mechanism for developing shared solutions to drive community-led action. The findings continue to be used for advocacy efforts, underscoring the value of CLM for raising site- and community-specific issues.

By highlighting the lived experiences of and community led- solutions from people living with HIV and TB, the project highlighted the importance of community pandemic preparedness, reinforcing how empowered communities can play a pivotal role in supporting continuity of services through existing and newly established networks. It also identifies opportunities for strengthening of community systems, to ensure resilience in the face of the world's concurrent pandemics of HIV, TB and COVID-19.

A collaborative approach was used to embed the project within existing systems and enhance government and multi-partner investments, in an effort to sustain outcomes beyond the life of the project. The implementation approach involved collaboration between HIV and TB community members and activists, people engaged in HIV and TB services, technical partners, and healthcare workers. All partners used their extensive civil society networks and engaged with government officials to conduct their CLM. For example, in Guatemala, ITPC-LATCA was given access to healthcare facilities to speak to recipients of care and healthcare workers. They were able to observe healthcare provision for people living with HIV across six healthcare and social security facilities, and in four different cities. Alma de Leon, LATCA's director, described this as

facilities ‘opening their doors’ to ITPC-LATCA, for the purposes of community-led monitoring, across four different regions of Guatemala [Figure 14<sup>34</sup>]



**Figure 14:** The four cities in which ITPC- LATCA conducted CLM data collection

A key finding is the importance of well-established networks between advocacy partners, bilateral agencies and governments for the success of CLM, in particular for short-term projects. Within a matter of weeks, partners secured permissions and completed data collection, leveraging existing relationships established over decades of cumulative work to ask challenging questions - in supportive and collaborative ways – about effects of COVID-19 on the health and human rights of people living with HIV.

An important aspect of sustaining CLM&A will be to support networks of affected communities (e.g. people living with HIV, TB, COVID-19), to lead implementation by working through their existing partnerships to support CLM&A implementation across its four components.

<sup>34</sup> ITPC LATCA (2021) CTO Implementation in the LATCA Region

## 9. Appendices

### Appendix A: Health Facility Quantitative Indicators (HIV)

Indicator	Disaggregates
1. Number of PLHIV newly initiated/enrolled onto ART - SAME DAY	male/female, pregnant women and age group (0-17, 18-24, 25+)
2. Number of PLHIV newly initiated/enrolled onto ART - NOT SAME DAY	
3. Number of PLHIV who received a baseline CD4 count before initiating ART	
4. Number of PLHIV who received a viral load test	
5. Number of PLHIV on ART at the health facility (ITPC_LATCA only)	
6. Number of PLHIV on ART who are virally suppressed	
7. Number of PLHIV who have treatment failure	
8. Number of PLHIV who are lost to follow-up (LTFU)	
9. Number of people initiated/enrolled onto TB treatment	
10. Number of PLHIV who tested positive for COVID-19	
11. Percentage of key populations reached with HIV prevention programs (ITPC-LATCA only)	Gay men and other men who have sex with men, people who inject drugs, sex workers and by age group (0-17, 18-24, 25+)
12. Number of condoms distributed (ITPC-LATCA only)	male, female
13. Number of PLHIV enrolled in multi-month dispensing of ART	1, 2, 3, 6 months, other
14. Number of PLHIV who received their viral load test results within a given turnaround time	2 weeks, 1 month, 3 months, >3 months
15. Name of medicines that are out-of-stock at the health facility	Name of medication, stock- out duration

16. Names of commodities and equipment that are out-of-stock or out of operation	Name of commodity, stock out duration
17. Type of TB tests conducted	Smear microscopy; rapid molecular test (GeneXpert); clinical diagnosis

## Appendix B: Healthcare Facility Quantitative Indicators (TB)

Indicator	Disaggregates
1. Number of people screened for TB	male/female, pregnant women; drug-resistant; drug susceptible; extrapulmonary TB and age group (0-17, 18-24, 25+)
2. Number of people coinfecting with HIV	
3. Number of people initiated/enrolled onto TB treatment	
4. Number of people initiated/enrolled onto TB preventive therapy	
5. Number of people defaulting TB treatment	
6. Number of people with TB who tested positive for COVID-19	
7. Number of TB patients on Video Observed Therapy (VOT)	
8. Number of TB patients receiving transport allowance	
9. Number of Patients receiving nutritional allowance	
10. Number of people who completed TB treatment during this period	
11. Number of TB deaths reported during this period	
12. Number of people who received their TB test results within a given turnaround time	2 weeks, 1 month, 3 months, >3 months
13. Number of people enrolled in multi-month dispensing for TB treatment	1, 2, 3, 6 months, other
14. Number of people enrolled in multi-month dispensing for TB preventive therapy	
15. Name of medicines that are out-of-stock at the health facility	Name of medication, duration
16. Names of commodities and equipment that are out-of-stock or out of operation	Name of commodity, stock out duration
17. Type of TB tests conducted	Smear microscopy; Rapid molecular test (GeneXpert); clinical diagnosis

## Appendix C: Healthcare Worker Qualitative Questions (HIV)

<b>Question</b>
1. Tell me a bit about yourself...?
What is your role at this healthcare facility?
How long have you been doing this work?
2. How has COVID-19 affected you personally?
3. How has COVID-19 affected your health facility?
4. How has COVID-19 affected healthcare for PLHIV?
5. How has COVID-19 affected your facility's HIV and TB testing and treatment programmes?
6. What are the impacts of COVID-19 on the use of medicines and medical equipment in your facility?
7. What are the impacts of COVID-19 on the use of medicines, commodities, & equipment in other facilities that you have heard about (you can keep this anonymous)?
8. What are some of the successes of your facility during COVID-19?
9. How is COVID-19 going to affect healthcare provision in the future?
10. Going forward, how do you see your role in this project to monitor treatment access during the COVID-19 pandemic?



## Appendix D: Recipient of Care Qualitative Questions (HIV)

Question
1. Tell me a bit about yourself...?
2. What is COVID-19?
3. How is COVID-19 affecting you?
4. What barriers do PLHIV face in accessing ART now?
5. How many months of ART did you receive during your last visit? 1,2,3 6, months or other
6. How many months of ART are you used to receiving? ( <i>Circle one</i> ) 1,2,3, 6 months or other
7. If the answers to question 5 and 6 are different, What do you believe/feel explains this change?
8. What challenges do PLHIV face in adhering to ART now?
9. How do healthcare workers or community organisations help retain PLHIV and PLTB treatment & care during COVID-19?
10. What examples of stigma and discrimination do PLHIV face now?
11. What are the burdens/stressors of living with HIV or TB during the COVID-19 pandemic?
12. If you (PLHIV) miss your medical appointment, how do the HCW and others follow-up with you?
13. How are PLHIV and TB getting information about COVID-19? What are they learning?
14. How has the COVID-19 pandemic specifically affected women (and women living with HIV in particular)?
15. How has the COVID-19 pandemic specifically affected men (and men living with HIV in particular)?
16. How has the COVID-19 pandemic affected other people (and other people living with HIV in particular)?
17. How is the government fulfilling its promises stated in the national HIV, TB, & COVID-19 plans?
18. Have you faced changes in fees to get your medicines?
19. Going forward, how do you see your role in this project to monitor treatment access during the COVID-19 pandemic?

## Appendix E: Recipient of Care Qualitative Questions (TB)

<b>Question</b>
1. Tell me a bit about yourself...?
2. What is COVID-19?
3. How is COVID-19 affecting you?
4. What barriers do people with TB face in accessing TB treatment now?
5. How many months of TB treatment did you receive during your last visit?
6. How many months of TB treatment are you used to receiving?
7. If the answers to question 5 and 6 are different, What do you believe/feel explains this change?
8. What challenges do people with TB face in adhering to TB treatment now?
9. How do healthcare workers or community organisations help retain people with TB in treatment and care during COVID-19?
10. What examples of stigma and discrimination do people with TB face now?
11. What are the barriers and enablers of living with TB during the COVID-19 pandemic?
12. If you (people with TB) miss your medical appointment, how do the HCW and others follow-up with you?
13. How are people with TB getting information about COVID-19? What are they learning?
14. How has the COVID-19 pandemic specifically affected women (and women with TB in particular)?
15. How has the COVID-19 pandemic specifically affected men (and men with TB in particular)?
16. How has the COVID-19 pandemic affected other people (and other people with TB in particular)?
17. How is the government fulfilling its promises stated in the national TB, and COVID-19 plans?
18. Have you faced changes in fees to get your medicines?
19. Will you be interested in participating in community monitoring?
20. Going forward, how do you see your role in this project to monitor treatment access during the COVID-19 pandemic?

## Appendix F: Healthcare Worker Qualitative Questions (TB)

<b>Question</b>
1. Tell me a bit about yourself...?
What is your role at this healthcare facility?
How long have you been doing this work?
2. How has COVID-19 affected you personally?
3. How has COVID-19 affected your health facility?
4. How has COVID-19 affected healthcare for people with TB and/or TB survivors?
5. How has COVID-19 affected your facility's TB testing and treatment programmes?
6. What are the impacts of COVID-19 on the use of medicines and medical equipment in your facility?
7. What are the impacts of COVID-19 on the use of medicines, commodities, and equipment in other facilities that you have heard about? (you can keep this anonymous)?
8. What are some of the successes of your facility during COVID-19?
9. How is COVID-19 going to affect healthcare provision in the future?
10. Going forward, how do you see your role in this project to monitor treatment access during the COVID-19 pandemic?
11. During lockdown period what challenges did you face and what changes were made to provide care?
12. After the lockdown period approximately what % increase in clients did you notice?
13. What other changes did you notice in people's health needs after lockdown?
14. In the future during any emergency like this, what preparations are needed so that it will not affect normal TB diagnosis and treatment?
15. Did any of your colleagues get infected by COVID-19? If yes, what were their experiences?
16. What equipment was provided in your PPE kits? Was it comprehensive?
17. Do you believe you have enough resources to provide care? (financial/human/other)