BOUNCING BACK
How a Community-Led Monitoring Initiative in Malawi and South Africa is Supporting the Recovery of HIV and TB Services in the wake of COVID-19

February 2023
ABOUT ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through its focus on three strategic pillars:

- **Intellectual property and access to medicines (#MakeMedicinesAffordable)**
- **Community-led monitoring and accountability (#WatchWhatMatters)**
- **Activism and capacity building (#BuildResilientCommunities)**

To learn more about ITPC and our work, visit www.itpcglobal.org.

ABOUT WATCH WHAT MATTERS

Watch What Matters is a community monitoring and research initiative that gathers data on access to and quality of HIV treatment globally. It fulfills one of ITPC’s core strategic objectives: to ensure that those in power remain accountable to the communities they serve.

Watch What Matters aims to streamline and standardize treatment access data collected by communities. It helps ensure that data is no longer collected in a fragmented way and reflects the issues and questions that are most important to people living with and affected by HIV. It relies on a unique model that empowers communities to systematically and routinely collect and analyze qualitative and quantitative data on access barriers, and use this data to guide advocacy efforts and promote accountability.

To learn more about Watch What Matters and our work, visit www.WatchWhatMatters.org.

ABOUT CITIZEN SCIENCE

COVID-19 continues to profoundly impact global health, particularly in low- and middle-income countries, where the struggle for equal access to healthcare has never been more important. As COVID-19 blurs traditional boundaries between journalism, advocacy, research, and policy development, ITPC has launched COVID-19 Citizen Science, a ground-breaking, community-led project documenting real-time perspectives, experiences, and advocacy priorities among people living with HIV in Malawi and South Africa. Citizen Science moves from models of “data extraction” to “data democracy” by combining community-led monitoring, operational research, and an innovative research methodology that we have called Life Mapping, which uses collaborative and participatory visual and textual media tools.

ABOUT THIS PUBLICATION

This publication is the second in a series of reports from ITPC’s Citizen Science project. In the first report, entitled “The Good, the Bad, and the Unfinished Business,” we shared community-led monitoring data from 2020 and 2021 and compared it with data from 2018 and 2019. The purpose was to gain insight into how COVID-19 affected HIV and TB services in Malawi and South Africa, informing strategic advocacy messages. This report, entitled “Bouncing Back,” shares data and advocacy outcomes from 2022. It tells an optimistic story of recovery and resilience, highlighting how community-led initiatives can help restore health services in the aftershock of a crisis like COVID-19.

FOR MORE INFORMATION

Please contact us at admin@itpcglobal.org.
ACKNOWLEDGEMENTS

ITPC thanks and acknowledges those who have supported our work in this critical community-led monitoring project. In particular, we recognize the tireless efforts of our partners. In Malawi, these partners are the Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (MANERELA+) and The Network of Journalists Living with HIV (JONEHA). In South Africa, they are the Networking HIV & AIDS Community of Southern Africa (NACOSA), Access Chapter 2, and Rotanganedza Community Care. We especially recognize the 66 data collectors, who steadfastly visited health facilities and communities, day in and day out, in the midst of a pandemic, watching what matters on the ground. We also commend the efforts of the 40 Life Maps participants, who shared intimate details of their lived experiences in order to improve access to health services in their communities.

We are grateful to our research partners in the School of Public Health and Family Medicine and the Centre for Social Science Research at the University of Cape Town, South Africa.

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Dr. Gemma M. Oberth, independent consultant, is the lead author of this report. ITPC would like to thank reviewers for their feedback and comments on earlier drafts.
<table>
<thead>
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<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immune deficiency syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>CLM</td>
<td>Community-led monitoring</td>
</tr>
<tr>
<td>COVID-19</td>
<td>Coronavirus disease 2019</td>
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<tr>
<td>DSD</td>
<td>Differentiated service delivery</td>
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<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>IPV</td>
<td>Intimate partner violence</td>
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<td>ITPC</td>
<td>International Treatment Preparedness Coalition</td>
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<td>JONEHA</td>
<td>The Network of Journalists Living with HIV</td>
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<td>MANERELA+</td>
<td>Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS</td>
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<td>MTB/RIF</td>
<td>Mycobacterium tuberculosis DNA and resistance to rifampicin</td>
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<td>NACOSA</td>
<td>Networking HIV &amp; AIDS Community of Southern Africa</td>
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<td>PrEP</td>
<td>Pre-exposure prophylaxis</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
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<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<td>VMMC</td>
<td>Voluntary medical male circumcision</td>
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<td>WHO</td>
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SUMMARY
This paper examines the recovery of HIV and TB services in the context of COVID-19 in Malawi and South Africa, using data from a community-led monitoring (CLM) initiative called Citizen Science. It considers service recovery along three dimensions: (1) demand, (2) quality and (3) equity.

Our 2022 data paint a picture of progress. Many HIV and TB services have “bounced back” from COVID-19 setbacks. In several instances, our community-led monitoring is linked to service improvements.

Key Findings on Increased Demand for Services
Post-COVID, demand for voluntary medical male circumcision (VMMC) is recovering faster at our monitored sites in South Africa than in the rest of the country. Similarly, demand for GeneXpert TB testing is recovering seven times faster at our monitored sites. We believe that our unique CLM model contributes to these successes by emphasizing community health education and demand generation for services.

New PrEP initiations have recovered to pre-pandemic levels at our monitored sites in Malawi following significant declines in 2020 and 2021. New antiretroviral therapy (ART) initiations have also bounced back following a COVID-related slump in 2020. Healthcare workers credit our CLM with improvements to treatment navigation.

Key Findings on Improved Quality of Care
After long delays in 2020 and 2021, turnaround times for viral load test results have recovered and are now faster than before the pandemic in Malawi. In 2022, more than half of people being tested received their results within a month. Turnaround times for TB test results at our monitored sites in South Africa have also dramatically improved since 2020. In 2022, it took an average of 1.4 days to receive one’s results.

While TB treatment success rates declined in South Africa during COVID-19, they steadily increased at our monitored sites. We engaged healthcare workers to promote greater support for people with TB.

Six health facilities in Malawi began informally collecting data on intimate partner violence screening before HIV testing as a result of our CLM. ITPC hopes that this leads to updates of the HIV testing register.

We found evidence of improved privacy and confidentiality in Malawi. Healthcare workers changed the way they did the intake of recipients of care and improved safeguarding data about men who have sex with men.

Key Findings on Enhanced Gender and Population Equity
After disproportionate declines during COVID-19, HIV testing among sex workers has recovered to triple its pre-pandemic levels at our CLM sites in Malawi. Similarly, testing has doubled among young people at our South African sites. ITPC employs data collectors from these groups and they promote service uptake among their peers.

Female condom distribution reached low points at our monitored sites in Malawi in 2020 and South Africa in 2021. Since then, there is evidence of more gender-equitable condom distribution in both countries. In South Africa, one in five condoms distributed is a female condom.

Pregnancies among adolescent girls and young women have declined at our monitored sites in South Africa post-COVID for all age and serostatus groups. This is linked to increased access to contraception.

Recipients of care report reduced stigma and discrimination, emphasizing the de-coupling of COVID- and HIV-related stigma. ITPC’s findings in 2020/2021 showed the two were very interlinked, with people living with HIV and key populations often blamed for elevated COVID-19 rates.

Remaining Gaps
While we commend these improvements, the work of ITPC is not finished. There are ongoing challenges with HIV and TB services in the context of COVID-19 that require persistent advocacy. In particular, we are focused on strengthening access to social protection, information on new forms of PrEP, non-discriminatory services for key populations, treatment monitoring, and COVID-19 vaccine literacy.
**CONTEXT**

The COVID-19 pandemic fueled devastating declines in prevention, diagnosis, and treatment levels for HIV and TB. Now, as the world emerges from the worst of the pandemic, there are encouraging signs of recovery.

Worldwide, the number of HIV tests taken by priority populations fell from 5.8 million in 2019 to 5.4 million in 2020. This leapt to 6.7 million tests in 2021. After plummeting to just 4.5 million people on TB treatment in 2020, the number rebounded to 5.2 million in 2021 and is nearing pre-pandemic levels of 5.5 million.

![Figure 1. HIV and TB Service Disruption and Recovery in the Midst of COVID-19, Select Interventions, Globally (millions)](chart)

The recovery of HIV and TB services is hastened by COVID-era innovations and adaptations. In our 2022 report, “The Good, The Bad, and The Unfinished Business,” we found evidence of increased access to multi-month dispensing, scaled-up HIV self-testing, community condom distribution, and intensified TB screening.

Yet, gaps remain and the world cannot be said to have put COVID-19 and its effects behind us altogether.

Existing gender and population inequalities were exacerbated by COVID-19. Between March 2020 and September 2021, women were significantly more likely than men to report disruptions in healthcare. Key populations were disproportionately affected by human rights violations, experiencing violence, exclusion, and arrest under lockdown orders.

Many aspects of COVID-19 remain with us today, including misinformation, strained health systems, and rising inflation. These challenges must be addressed as ongoing barriers to HIV and TB services.

**A Note on Terminology:**

This paper uses the term, “post-COVID,” to describe the period when the worst of the COVID-19 pandemic and its associated restrictions have passed.

We recognize that COVID-19 is not over and that many people are still affected by the disease through new infections, long COVID, socioeconomic hardship, and the loss of friends and family.
THE CITIZEN SCIENCE APPROACH

This is the second report in a series from the Citizen Science project. The first report, entitled “The Good, the Bad, and the Unfinished Business,” includes a detailed section on our CLM methodology.

This report focuses mainly on the implications of new data, collected between January and October 2022. We have included some older data (from 2019, 2020, and 2021) to allow for trend analysis.

In 2022, we monitored a total of 33 health facilities: 14 in Malawi (eight in Kasungu and six in Dedza) and 19 in South Africa (all on the West Rand) (Table 1). Together, these facilities serve a catchment area of nearly one million people (989,848). For the first time, we have added non-governmental service providers to our monitored sites (two in Malawi and two in South Africa).

On a monthly basis, we conducted clinic records surveys of HIV and TB services using a tool that contains 34 indicators in Malawi and 20 indicators in South Africa. Indicators were defined in collaboration with recipients of care. In 2022, we added eight new quantitative indicators, many of which reflect an intensified focus on TB.

We also interviewed 123 recipients of care (71 in Malawi and 52 in South Africa) and 64 healthcare workers (30 in Malawi and 34 in South Africa) to understand the qualitative dimensions of HIV and TB services in the context of COVID-19.

Adding further depth, we followed 40 Life Maps participants to document the more personal aspects of how HIV, TB, and COVID-19 affect their daily lives, using photography, narrative, and textual tools.

Figure 2. ITPC’s Approach to Community-Led Monitoring

We are monitoring 33 health facilities in Malawi and South Africa, together serving a catchment area of nearly one million people (989,848).

From January to October 2022, we conducted 264 clinic records surveys and interviewed 183 stakeholders.
<table>
<thead>
<tr>
<th>Facility Name</th>
<th>District</th>
<th>Facility Type</th>
<th>Location</th>
<th>Catchment Area</th>
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<td>Primary Healthcare Clinic</td>
<td>Urban</td>
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<td>Primary Healthcare Clinic</td>
<td>Urban</td>
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<td>Rural</td>
<td>19,777 people</td>
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</tbody>
</table>
INCREASED DEMAND FOR HIV AND TB SERVICES

Improving Knowledge and Increasing Uptake of Voluntary Medical Male Circumcision

From 2019 to 2020, when the COVID-19 pandemic hit, the number of voluntary medical male circumcisions (VMMCs) fell by 64% across all facilities in South Africa (from 451,636 to 164,499). Data from our CLM sites show a similar decline over this period (66%). As COVID-19 abated, our CLM data collectors engaged with recipients of care about returning for services, including VMMC.

We found evidence of recipients of care using internet search engines to do research and find information in response to our interview questions. This shows how the act of CLM can boost knowledge and demand for services. For example, one Life Maps participant in South Africa had clearly researched his response to our question about VMMC access. He told us, via Telegram:

"Voluntary medical male circumcision services are available at community health centres and district hospitals in the community and you can get medically circumcised at any time throughout the year, summer or winter. It helps to reduce your risk of contracting sexually transmitted infections, such as chancroid, syphilis, genital warts and herpes."

Further, a professional nurse we interviewed in South Africa spoke about “starting afresh, giving health education” after our CLM intervention. This likely included invigorated information-sharing on HIV prevention options.

When compared with national data, the number of circumcisions is rebounding much faster at our CLM sites than within the country as a whole. Circumcisions increased by 156% (from 474 to 1,209) from 2020 to 2021 at our CLM sites compared with 126% nationally (164,499 to 372,588) (Figure 3).

Our partners are mobilizing communities back into care, post-COVID.

VMMC services are recovering faster at our CLM sites compared with national data.

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1 A note on terminology: ITPC believes that the term, “data collectors”, is sorely lacking as a description of the full breadth and depth of the work these individuals carry out. Their role goes far beyond collecting information. They also interpret the data and provide real-time feedback to the health facilities and recipients of care. Their role has also evolved into that of a liaison between communities and healthcare workers, acting as frontline health science educators, generating demand for health services, and actively participating in their improvement. We are working on a consensus for a more suitable job title.
Targeted Education Sessions Boost New PrEP Initiations

PrEP services were negatively affected by COVID-19. In April 2020, the Malawi Ministry of Health’s COVID-19 Guidance for HIV Services said that new initiation of PrEP should be suspended until further notice. ITPC CLM data show how this affected demand and provision of this critical prevention option.

In 2019, our monitored sites in Malawi were doing about 23 new PrEP initiations each month. This fell to 14 per month in 2020 and down to as low as two per month in 2021. Fortunately, our most recent data from 2022 show that our monitored sites have increased PrEP initiations back to pre-pandemic levels, with about 25 initiations per month. (Figure 4).

In South Africa, national data show that the number of new PrEP initiations climbed steadily in 2020 and 2021 despite COVID-19 restrictions. ITPC data confirm this trend, with new PrEP initiations increasing from three per month in 2019, to 21 per month in 2020, 109 per month in 2021 and 302 per month in 2022 (Figure 3).

South Africa implemented COVID-19 adaptations for PrEP, which helps explain the resilience of this intervention. Our monitored facilities scaled up multi-month dispensing of PrEP during COVID-19, increasing three- and six-month dispensing of PrEP from 1.5% of recipients of care in December 2020 to more than half (53.7%) by August 2021. Further, healthcare workers at our monitored sites spoke about improvements in PrEP knowledge and acceptability, noting in 2022 that “most of the people know what PrEP is. Most of the people, when given information, are now interested to get PrEP.”

Our qualitative data help explain the lower PrEP initiations we see in Malawi. Of the people we interviewed, 82% there said they had never heard of PrEP. Those who had heard of it held misconceptions that the medicine reduces one’s sex drive and that it can cause HIV drug resistance. There is a need to restart basic health literacy on HIV and TB prevention, treatment, and care as a fundamental component of “bouncing back.” The role of trusted community partners therein is vital.

COVID-19 policies restricted PrEP access in Malawi, while South Africa harnessed COVID adaptations that made PrEP services resilient.

In both countries, education activities are incorporated into our CLM. This is contributing to more PrEP initiations each month.
Our partners have done targeted advocacy and education around PrEP, helping increase demand for this prevention intervention in both countries. For example, we noticed that Bua Health Centre in Malawi had not initiated any recipients of care on PrEP despite being a site that offered PrEP. We held a mobilization and education session on PrEP targeting Bua communities. In the month that followed, this site enrolled three recipients of care. Similarly, in February 2022, IPTC held a community awareness session with young people (aged 13-15 years) on PrEP at the Badirile Clinic in South Africa. The majority had not heard of PrEP before.

Through our interactions with healthcare workers, we are encouraging them to share information and create demand for PrEP. There is evidence of this taking place. As one Life Maps participant said: “Yes, [PrEP is available]. The health workers, they even go to schools to teach pupils about it.” We also harness the data collection process as an education opportunity. During interviews, when recipients of care appeared to have limited or no knowledge about PrEP, some of the data collectors gave information about its availability and uses.

“The recipient of care elaborated more on his knowledge and whatever he finds difficult to answer, he will ask for clarification because he’s eager to learn. I was able to explain some of the questions and I am very happy that my explanation helped him to answer questions that he did not understand.”

- CLM data collector, South Africa, reflective notes

Greater Differentiation in HIV Treatment Services Boosts ART Initiations and Adherence

Nationally, new ART initiations grew by just 6% in Malawi from 2020 to 2021 (from 31,595 to 33,377). At our monitored sites, new ART initiations grew by 56% over the same period, bouncing back after a significant COVID-related slump in 2020 (Figure 5).

**Figure 5.** Average Number of New ART Initiations Per Month at Our 14 CLM Sites in Malawi, 2019-2021

<table>
<thead>
<tr>
<th>Year</th>
<th>CLM Sites</th>
<th>National</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019</td>
<td>318</td>
<td>31,595</td>
</tr>
<tr>
<td>2020</td>
<td>189</td>
<td>33,377</td>
</tr>
<tr>
<td>2021</td>
<td>293</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 6.** % Change in New ART Initiations from 2020 to 2021, CLM Sites vs. National

- CLM Sites: 56%
- National: 6%
Evidence suggests that our CLM approach contributed to the recovery of new ART enrollments at our monitored sites in Malawi. Healthcare workers explained how the collection and presentation of CLM data prompted them to improve navigation services in the clinics, guiding people from testing to treatment. For example:

“MANERELA+ did an analysis that compared the total of people becoming newly HIV-positive against the number of people newly initiated on HIV treatment. This showed a gap, which caused us to ask why so few had initiated HIV treatment. This led to discussions and finding solutions, one of which was to start escorting new HIV-positive clients to HIV treatment counselling and potential initiation as part of our test-and-treat policy.”

– Healthcare worker, Malawi

ITPC’s CLM approach is also contributing to improved ART initiation rates and improved treatment adherence rates through monitoring, educating, and advocating for differentiated service delivery (DSD) models (see “CLM in Action” box).

Following a COVID-related slump in 2020, new ART initiations are recovering 10 times faster at our monitored sites than in the rest of Malawi.

Healthcare workers credit our CLM approach with improvements to treatment navigation in the facilities. Our advocacy for differentiated service delivery is expanding treatment access.

In South Africa, Life Maps participants spoke about the continued expansion of DSD, which continues to improve access to HIV treatment in the post-COVID environment. One spoke of a “new system of people collecting their treatment at Dis-Chem [private pharmacy],” Another said: “We have mobile pharmacies that park in the community daily to dispense medication.” A third participant noted: “Ward-based outreach teams (WBOTs) go from house to house following up and dispensing meds to individuals with special needs, the elderly, or those who have knee problems to walk to the clinic.”

In feedback meetings with the West Rand District Department of Health, ITPC has used its CLM data to advocate for the rollout of such differentiated models of care.

We found evidence of greater differentiation in HIV treatment services in both countries.

In South Africa, people accessed medicines at private and mobile pharmacies, and through home delivery. In Malawi, 241 people accessed treatment through after-hours models and 2,950—including 15 young men who have sex with men—used teen clubs.
CLM IN ACTION: Data Training in Kasungu Empowers Recipients of Care and Engages Government on Differentiated Service Delivery

In January 2022, MANERELA+ added new CLM indicators to its tools, collecting data on access to differentiated HIV treatment models. From January to October 2022, 78 men, 140 women, 22 young people, and one transgender person used after-hours models at our 14 monitored sites. A further 2,950 people used teen club models, including 15 young men who have sex with men.

Yet, in 35 different clinic records surveys, data collectors recorded that there was little demand for these DSD models since community members were not aware of them.

In response to this finding, MANERELA+ held a data training on DSD in Kasungu district on 21 September 2022. The aim was to present the CLM data and improve community awareness of the different models. Government and other decision-makers were also invited to the training as part of the project’s strategic advocacy. Our partner, JONEHA, documented the training and its outcomes.

One of the men who have sex with men who participated commended the DSD models, noting that it is extremely helpful for young key populations, who feel shy to mix with the elders in accessing HIV services: "DSD models save us from discrimination. Hence, having our own space to access healthcare services makes us feel comfortable and not ashamed of anything."

A representative from the Ministry of Health said that the CLM is improving government’s understanding about the multiple issues that define the character of people in accessing HIV care in various service delivery points, and that it is beneficial to use DSD models by segregating people according to their needs.

Our data show that to date, community ART groups (CAGs) are not operational in any of the 14 monitored sites. This is a key advocacy point going forward.

Finding More Missing People with TB Through GeneXpert TB Testing

During COVID-19, TB testing declined. One of the reasons, a professional nurse told us, was because the symptoms are very similar to COVID-19: "Most of the time, we would focus on testing for COVID rather than for TB and then only after if it's excluded for COVID, we go and test for TB."

Our most recent data show a significant recovery in the number of people who accessed GeneXpert testing for TB at our monitored sites in South Africa, increasing from 3,818 in 2020 to 9,839 in 2022 (a 158% increase). In fact, this rate of recovery is faster than at the national level, where GeneXpert tests increased from 2,046,832 in 2020 to 2,494,985 in 2022 (a 22% increase). Post-COVID demand for GeneXpert TB testing is recovering seven times faster at our CLM sites than in the rest of the country.

The large increase is also partially explained by improved record keeping at facilities, possibly linked to our CLM. Our data collectors’ notes reveal that in some facilities, GeneXpert data is captured manually, and the book of records for 2020 was not available. In other facilities, there was a clear lack of interest or attention to data on GeneXpert testing. As one data collector noted: "I collected this data from the District Health Information System. They could not help me [at] the facility." We are doing ongoing advocacy work with facilities about the importance of GeneXpert testing for people with TB symptoms.

Post-COVID, GeneXpert TB testing is recovering seven times faster at our CLM sites than in the rest of South Africa.
**IMPROVED QUALITY OF CARE AND PERSON-CENTEREDNESS**

### Speedier Turnaround Times for Lab Test Results

The quality of treatment monitoring is affected by the turnaround time for viral load test results. When recipients of care do not receive their results in a timely manner, their treatment monitoring suffers. Guidelines suggest that healthcare workers must ensure that the results of any viral load tests are checked within one week.\(^\text{11}\)

In our last data report, we demonstrated how COVID-19 is associated with greater delays in receiving viral load test results. During COVID-19, 39% of results took more than three months to come back at our monitored sites in Malawi compared with 23% before the pandemic.\(^\text{12}\) In 2022, the situation dramatically improved. Our most recent data show that turnaround times for viral load tests in Malawi have bounced back post-COVID, now with 18% of test results taking more than three months to be returned and the majority (54%) coming back within the month (Figure 10).

![Figure 10. Turnaround Times for Viral Load Test Results at Our Monitored Sites in Malawi](image)

**After long delays in 2020 and 2021, turnaround times for viral load test results have recovered and are now faster than before the pandemic in Malawi.**

**In 2022, more than half of people received their results within a month.**

In South Africa, our partners began monitoring the turnaround times for TB test results in 2022. Prompt Xpert testing for mycobacterium tuberculosis (MTB) DNA and resistance to rifampicin (RIF) and result reporting allows timely treatment initiation. South Africa’s guidelines indicate that treatment should be initiated within five days of a person presenting with TB.\(^\text{13}\) Past studies have shown the median time to treatment at 11 days.\(^\text{14}\)
Our data are encouraging. Compared with 2020 when laboratories were completely overwhelmed with COVID-19 testing demand, turnaround times for TB tests have improved. In 2020, 60% of TB tests done at our 19 monitored facilities were returned within a week. In 2022, 92% of tests came back in that time. More specifically, in 2022, 41% of tests were returned within 24 hours, 34% within 48 hours, and 3% within 72 hours. On average, in 2022, TB test results were returned within 1.4 days.

![Turnaround Times for TB Tests at Our 19 Sites in South Africa, 2020 vs. 2022](image)

Turnaround times for TB test results have dramatically improved in South Africa since 2020 (when laboratories were overwhelmed with the burden of COVID-19 PCR tests).

In 2022, results were returned within 1.4 days (on average), which is within the national guidelines of five days to treatment initiation.

Part of this improvement in TB test turnaround times is linked to our national advocacy to put TB back at the top of the agenda. There was a sense that it was deprioritized during COVID-19, especially in terms of laboratory services like GeneXpert testing. Indeed, many machines that were originally meant for TB were repurposed for COVID-19 testing (photo).

Starting in March 2021, our CLM partners in South Africa participated in a community-led campaign to "Declare TB a National Health Emergency." Our CLM data, alongside CLM data from the PEPFAR-funded Ritshidze project, was used to strengthen the campaign. We believe advocacy efforts like these helped improve laboratory focus on TB testing in the months that followed, improving test turnaround times and quickening treatment initiation for people with TB.
In 2022, ITPC partners in Malawi began collecting data on the number of people who received intimate partner violence (IPV) screening before being offered HIV services. This is based on global normative guidance on HIV testing that says healthcare providers should ask about exposure to IPV and offer first-line support when women disclose. It was also catalyzed by qualitative reports that “during COVID, the violence was there” and that IPV “is something that is now spreading.”

By adding this indicator to their tool, data collectors discovered that IPV screening is done in only six out of the 14 monitored facilities (Kasungu District Hospital, Dedza FPAM, Mayani, Bua, K2 Taso, and Kaluluma) and is done very inconsistently. From July to October 2022, only 113 people were screened for IPV at these six facilities although 15,746 HIV tests were conducted. Staff at health facilities explained that service providers do not have adequate training to do IPV assessments and there are no registers to document this. In fact, where facilities are collecting data on IPV screening, it is because of this project. Healthcare workers are improvising by keeping informal records of IPV screening and service provision. Importantly, the health facility keeps this information confidential. This may be the first step in a process to include an IPV screening indicator in the HIV testing register, which would improve quality of care in line with the global guidance.

The new IPV data confirms our previous operational research finding that our community-led monitoring strengthens data collection at health facilities. One healthcare worker in Malawi told us: “The internal data tracking at our clinic has improved as a result of this project. Because MANERELA+ comes to get reports on a monthly and quarterly basis, the clinic staff prepare reports ahead of time to be prepared before MANERELA+ comes.”

Ask and you shall receive. Six health facilities in Malawi began informally collecting data on IPV screening after this new indicator was added to our CLM tool.
Enhancing Privacy and Confidentiality in Facility Settings

Our community-led monitoring in 2021 found that privacy and confidentiality were negatively affected by COVID-19 through measures like outdoor queuing and public triaging. In 2022, we are seeing signs of improvement.

After engaging with our CLM data, healthcare workers in Malawi report making changes to their intake procedures to enhance privacy and confidentiality. For example:

“Our clinic improved its protocols for patient confidentiality due to CLM data and discussions. Previously, people were asked at the entrance of the facility, in the presence of everyone else, where they were going, and then initial patient ... assessments and documentation were also done in the open waiting area in front of others. Now, our facility is more discreet as people come in and we have a dedicated private space for patient intake and consultations. These improvements, along with sensitization of health staff, has led to increased numbers of people from key populations coming in for services.”

– Healthcare worker, Malawi

Further, at two health facilities in Malawi (Kasalika Health Center and Kasungu District Hospital) our data collectors were told that data on HIV testing uptake among men who have sex with men could not be shared with our CLM data collectors because data are not public information. They were told that one healthcare worker is responsible for collecting and safeguarding this information. While this creates limitations for our CLM efforts, it is encouraging to see such privacy and confidentiality being enforced, especially for criminalized populations.

We also discovered a potential risk in that TB infection control measures at our monitored sites may compromise privacy and confidentiality. Life Maps participants in South Africa shared photos of consultation rooms with signs on them to keep the doors open to increase airflow and reduce the risk of TB (and COVID-19) (photo). We are working with facilities to ensure that privacy and confidentiality can be maintained during consultations that take place behind closed doors.

Improving TB Treatment Success Rates by Encouraging Physician and Nurse Support

Better quality of care, including physician and nurse support, leads to improved TB treatment outcomes. During COVID-19, TB treatment success rates declined in South Africa as a whole, from 79% in 2019 to 78% in 2020. Conversely, TB treatment success rates have steadily improved at our monitored sites, climbing from 78% in 2019 to 86% in 2022 (Figure 12).
By engaging with healthcare workers through our CLM initiative, we regularly promote good practices in TB care and support. We found evidence of healthcare workers at our monitored facilities providing improved TB treatment support. One recipient of care told us: “Yes, they support us to be linked back to care. The follow up is done by healthcare workers.” In 12 separate interviews, recipients of care mentioned that healthcare workers pay home visits to monitor treatment adherence and promote completion.

One recipient of care in South Africa related how healthcare workers at the Mogale Clinic helped them take their TB treatment correctly:

“What I’ve noticed, which is important, is that when I used to take TB treatment as well as HIV treatment, I never used to take them on time. The TB ones, I’d take them in the morning at 8 and then the HIV ones, at night at 9. When they tested me, they saw I’ve been taking medication incorrectly, so they asked me to take it at the same time.

So, healthcare workers really want us to continue and live.”

- Recipient of care, Mogale Clinic, South Africa
ENHANCED GENDER AND POPULATION EQUITY

Tailored HIV Testing Services for Priority Populations

In our last report, “The Good, the Bad, and the Unfinished Business,” we found that COVID-19 had a disproportionately negative effect on key populations’ access to HIV testing services. At our 15 monitored health facilities in Malawi, HIV testing fell by 25.4% among the general population compared with 52.8% among men who have sex with men and 79.5% among sex workers.

Both in South Africa and Malawi, Life Maps participants reported that during the peak of the COVID-19 pandemic, HIV testing was impacted. Now, with the easing of restrictions, they say that HIV testing services have slowly recovered.

We are also seeing signs of improved equity in testing access for key populations. For example, after falling from 12 tests per month before COVID-19 to three per month during COVID-19, the average number of HIV tests among sex workers rose to 40 per month in 2022 in Malawi (Figure 13). That’s triple the pre-pandemic levels. In Dedza district, in particular, there has been marked progress in testing equity for sex workers. From January to June 2022, 0.6% of all HIV tests were among sex workers. In July-October 2022, this figure rose to 1.3%.

Our partners in Malawi employ five female sex workers as part of their data collection team, collecting data in the health facilities. This visibility of key populations in the facility is helping remove stigma and encourage their peers to come for HIV services. This underscores the importance, as part of CLM, of engaging data collectors who are themselves from communities of people most affected by HIV and TB.

More sex workers accessed HIV testing services in 2022, with demand bouncing back to triple its pre-pandemic levels.

We employ five female sex workers as data collectors, helping make the health facilities a more open and welcoming environment for this key population.

Figure 13. Average # of HIV Tests Performed per Month Among Sex Workers at Our Monitored Sites in Malawi
Similarly, in South Africa, there is evidence that COVID-19 disproportionately affected young people’s access to HIV testing services. Studies show that COVID-19 was associated with a 60% decline in HIV testing among 15-24 year olds compared with a 47.6% decline across all age groups. Recipients of care in South Africa think that this is because “health workers were paying more attention to people who have COVID-19, more than people who come to the clinic for HIV testing.”

In 2022, our partners in South Africa began monitoring the uptake of HIV testing services, disaggregated by age and sex. Our data are promising. The number of HIV tests performed among young people has more than doubled since 2020 (Figure 14). The 10 young people we employ as data collectors helped encourage their peers into HIV services (see photos). Further, young people report increased ease of access to services: “Nowadays we have the stations to be tested at. You go to school, you can get tested. You go to town, taxi rank, you can go and test.”

![Figure 14. Total # of HIV Tests Performed Among Young People at Our Monitored Sites in South Africa](image)

Young women, employed as data collectors in the Citizen Science project, conducting a clinic records survey (left) and a focus group discussion with their peers (right) in Malawi.
Improvements in HIV testing uptake for vulnerable populations are partially explained by increased access to preferred testing modalities, including self-testing. In 2019, HIV self-tests made up 7.6% of all tests in South Africa (1,375,376 out of 18,070,050) and 0.1% of all tests in Malawi (4,396 out of 4,059,342). In 2022, self-tests make up 22.7% of tests at our monitored sites in South Africa and 13.9% of tests at our monitored sites in Malawi.

Life Maps participants confirm this increased access to self-testing post-COVID: “On the issue of self-testing kits, these were difficult to find during COVID but at least now, in health centres, they are found.” Another said: “HIV self-testing kits are available in three places: at a tent behind [the] under-five clinic, VCT clinic next to MCH, and ART clinic.” Two Life Maps participants shared photo evidence of the increased visibility of OraQuick tests at their local health facilities (see photo).

Another explanation for the improved access to HIV testing services, especially for key populations, is our CLM advocacy for key population focal points in health facilities (see “CLM in Action” box).

CLM IN ACTION: A Key Population Focal Point in Every Health Facility (Malawi)

In our last report, we found that COVID-19 had a disproportionately negative effect on key populations’ access to HIV testing services (see “The Good, the Bad, and the Unfinished Business”).

In response to this finding, engagements were held at the at ministerial level, which have trickled down to the district level. At district level, there is a special coordinator for key population services.

Using our CLM data, MANERELA+ made the case for a key population focal point at the facility level, too. Now, each of our 14 monitored sites has a key population focal point.

MANERELA+ also held a data training to increase demand for services among key populations and find ways of making services more welcoming. A total of 210 people from key populations from our monitored sites participated, including men who have sex with men, sex workers, adolescent girls and young women, and adolescent boys and young men. Healthcare workers were also invited for sensitization purposes.

We believe these advocacy actions contributed to the improvements we see in the uptake of HIV testing services among key and vulnerable populations.
Enhanced Gender Equity in Condom Distribution

Access to female condoms is a key consideration for gender equity in HIV prevention programs. Our CLM data suggest that gender equity in condom distribution suffered as a result of COVID-19, with female condom distribution reaching low points in Malawi in 2020 and South Africa in 2021 (Figure 14). This aligns with other evidence that between March 2020 and September 2021, women in sub-Saharan Africa reported sexual and reproductive healthcare disruptions at significantly higher levels than men.22 Post-COVID, there are signs of improved equity in condom distribution in both countries. Female condom distribution (as a proportion of all condoms distributed) is higher now than before the pandemic. In 2022, female condoms made up 0.5% of all condoms distributed at our monitored sites in Malawi and 20.1% in South Africa (Figure 15). Some facilities in Malawi have continued to increase the distribution of female condoms throughout the year. In Dedza district, 1,052 female condoms were distributed at our monitored sites from July to October 2022 compared with just 40 from January to June 2022. Life Maps participants in both Malawi and South Africa shared photographic evidence of the increased availability and/or visibility of female condoms in the clinics (see photos). This suggests that not only are clinics moving more female condoms out of their storerooms, but recipients of care are also noticing and taking the condoms.

The project has helped deconstruct myths and misconceptions around female condoms, as well as lubricant use, through education sessions. Our partners have also conducted advocacy meetings with District Health officials about the availability of HIV prevention commodities and supplies.

While this progress is encouraging, the proportion of female condoms distributed in Malawi remains far too low, limiting female-controlled prevention options. Healthcare workers reported that they have stopped ordering female condoms from the central medical stores due to low demand. Recipients of care reported a preference for male condoms due to ease of use and also gender and cultural norms, which make it taboo for women to be seen taking condoms and initiating condom use during sex.

Female condom distribution reached low points in Malawi in 2020 and in South Africa in 2021. Post-COVID, there is evidence of more gender-equitable condom distribution in both countries.
Figure 15. Female Condom Distribution as a Proportion of all Condoms Distributed at Our Monitored Sites in Malawi and South Africa, 2019-2022

Increased Access to Contraceptives and Reduced Teenage Pregnancies

In our last Citizen Science report, we documented disparities in teenage pregnancies among young women living with HIV in South Africa. We found a 10% increase in births to adolescent girls living with HIV during COVID-19, while births declined for their HIV-negative counterparts. Qualitative data suggest there is unique stigma and discrimination faced by young women living with HIV trying to access contraceptive services in health facilities.

Our 2022 data show that live births to adolescent girls and young women have declined post-COVID, across age and status (Figure 16). In 2022, our CLM efforts intensified around access to contraceptives, including new disaggregated indicators on the methods available to young women (for example, implants, IUDs, oral pills, and injectables). We believe that this increased attention to contraception access might have prompted greater demand among young people and greater provider-initiated services. Indeed, our data show increased contraceptive uptake in 2022 than in 2020 (Figure 17). The increased gender equity in condom distribution discussed in the previous section may also have played a role in reducing teenage pregnancies.

We are also working to popularize the youth service hours that are available at the clinics we monitor (see photo). When we engage with young people during data collection, we share this information. This may also contribute to the increased uptake of contraceptive services in recent years.

![Figure 16. Live Births to Adolescent Girls and Young Women (15-24 years) at Our Monitored Sites in South Africa, by Age and Serostatus, 2020 vs. 2022](image)

![Figure 17. Number of People Accessing Contraceptives at Our Monitored Sites in South Africa, by Option, 2020 vs. 2022](image)
Pregnancies among adolescent girls and young women have declined at our monitored sites in South Africa post-COVID for all age and serostatus groups.

New CLM indicators on contraceptive access may have prompted greater uptake. We are also working with health facilities to popularize youth service times.

Table 2: How CLM Contributes to Improved Health Outcomes at Our Monitored Sites

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<thead>
<tr>
<th>Input</th>
<th>Output</th>
<th>Outcome</th>
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<tbody>
<tr>
<td>Indicator on contraceptive access added to CLM tool in South Africa</td>
<td>Data collectors ask healthcare workers about contraceptive access during monthly data collection</td>
<td>Data collectors and CLM implementers work to popularize youth service times</td>
<td>CLM data reveal increased uptake of contraceptive services at our monitored sites</td>
</tr>
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<td>CLM data reveal fewer adolescent pregnancies at our monitored sites</td>
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<td>CLM data reveal few adolescent pregnancies at our monitored sites</td>
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| January 2022                               |                                                                                                                                          |                                                                                                                                                          |                                                                                                            | October 2022---------------------------------------------------------------
Disentangling HIV and COVID-19 Intersectional Stigma

In our last report, our qualitative CLM data revealed how COVID-19 exacerbated stigma and discrimination against people living with HIV and TB, healthcare workers, and key populations—all of whom the general public perceived as being “COVID-19 carriers.”

In the years since, it appears that things have improved. Among recipients of care who were interviewed in Malawi in 2022, 69% said they did not experience any HIV/TB-related stigma. People emphasized the de-coupling of COVID-19 and HIV-related stigma. Previously, the two were very interlinked in Malawi. One recipient of care at the Dedza District Hospital said: “In terms of stigma for people with HIV, there is none because most chiefs have accepted it. The problem is now with COVID-19. They say that if you have COVID-19 and you sneeze at someone, then they will contract COVID-19.” Another from the Kaluluma health facility agreed: “I cannot say that stigma is still there, although in the past, this used to happen for us on ARV treatment, but maybe if you cough, people are just afraid that you might give them COVID.”

We observed a similar trend in South Africa, where people told us that improved knowledge of COVID-19, coupled with the introduction of the vaccine, lessened stigma and discrimination towards those seen to be at risk of acquiring COVID-19, including people living with HIV and TB. “Stigma is still there, but it’s decreasing,” one recipient of care told us.

Life Maps participants also noted that COVID-19 seems to have helped alleviate stigma experienced by people living with HIV. One participant in Malawi said: “During this COVID-19 period, there is not a lot of stigma on people living with HIV because people are more concerned with COVID.” Another Life Maps participant in Malawi agreed, saying: “I don’t think that stigma and discrimination has increased because of COVID-19 because people were more focused on the pandemic.”
REMAINING GAPS AND ADVOCACY MESSAGES

Despite all this promising progress, some aspects of the HIV and TB response have not bounced back post-COVID. As we celebrate our CLM “wins,” we continue to press decision-makers for change in key areas.

Inflation and the Need for Social Protection

The economies of many countries have yet to recover from COVID-19. In Malawi and South Africa, inflation has risen sharply since 2020 (Figure 18).

Figure 18. Inflation Rates in South Africa (left) and Malawi (right) Over the Past Five Years

Recipients of care told us how the increased cost of living has affected their health.

Higher transportation prices mean that going to the clinic is more difficult. One person in Malawi told us that their local transport to the health facility has tripled, from K500 (about 50 US cents) to K1,500 (about US$1.50). Another in South Africa said: “Everything is going up now, so even if you want to go to town and collect your meds or here at the clinic, it’s a hassle, and that is why most of the people skip taking their meds.”

In both countries, recipients of care spoke about how increased food prices mean that they are skipping meals and skipping medication. In Malawi, a Life Maps participant told us that food prices have doubled: “In the past, I used to buy 2 trays [of eggs] and a tray was K2,600 and one egg was K100. Now, a tray is K4,600 and an egg is K200 and now I cannot afford to buy eggs, beef and milk.”

Several recipients of care we interviewed in Malawi said that they skip taking their ART on days when they do not have food. Healthcare workers in Malawi spoke about the ongoing economic impacts of COVID-19. They said that they lack resources to meet the nutritional needs of the recipients of care whom they serve, which has resulted in many adherence challenges. In South Africa, one person said: “It has become a very big challenge to most people who are living with HIV. You cannot adhere to ART due to the increase in food prices due to lockdown.”
While the progress on viral load test turnaround times is commended, there are still unacceptably long waits for viral load test results. Further, more than three-quarters (77%) of the viral load tests taken at our monitored sites in Malawi were not returned at all from April to October 2022. Recipients of care report having to do repeat tests (presumably if samples are lost), which costs them additional transportation time and money. They also report being switched back to monthly refills of ART (instead of three or six monthly) while they await their viral load test results, which again negatively impacts their lives.

This was confirmed during qualitative data collection, where 90% of the people in focus group discussions said they were not able to access routine viral load testing services at their facilities. One recipient of care told us: “Since the start of this year, I have not been able to access viral load testing at the facility. I don’t know why but each time I go to the facility the healthcare workers just say that they are not collecting samples now. I get worried because I cannot tell if the medication I am taking is working or not.” A Life Maps participant shared a similar experience: “I have stayed two years without a viral load test, only to be told that laboratories are busy with COVID-19. A sample was taken in March 2022, but the result is not yet out.”

Advocacy Messages:

- Governments and donors should prioritize funding for social protection interventions, such as nutritional support for people living with HIV and TB, and transport reimbursements for clinic visits.

- Civil society organizations should map existing social protection schemes and increase community knowledge about such opportunities.

- Adherence to medication—essential for treatment success (TB) and viral suppression (HIV)—cannot be considered in isolation. Food security, transportation costs, and other contextual factors must always be integrated into treatment policies and programs.

Return of Viral Load Test Results

“This is my fridge where I keep a lot of things like beef, eggs, chicken, vegetables, Fanta, juice and oranges. But, with the coming in of COVID-19, things have changed. I cannot afford these and hence am just storing water.”

- Life Maps participant, Malawi

“Advocacy Messages:”

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HIV Testing Among Men Who Have Sex with Men

While access to HIV testing for sex workers in Malawi has improved post-COVID, the same is not (yet) true for men who have sex with men. The average number of tests per month among this group has fallen from 23 per month in 2018/2019 to 11 per month in 2020/2021 and seven per month in 2022.

Our qualitative data suggest that stigma and discrimination is a major deterrent, especially for men who have sex with men seeking HIV testing services. One man who has sex with men in Malawi related to us: “When I went to get tested for HIV, the provider insulted me by saying that I already know that I engage in risky and unacceptable sexual behavior ... why do I waste their time to test for HIV as if I can be negative. I was hurt and do not feel comfortable with the experience till now.”

Other barriers that were highlighted include stock-outs of HIV test kits and user fees for testing. Eight different health facilities, all in Kasungu District, cited a lack of resources as the reason they are not doing moonlight testing. Systematic reviews have found that moonlight service delivery has the potential to increase the program reach and uptake of HIV services among men who have sex with men in sub-Saharan Africa. Advocacy for increased access to moonlight service provision for men who have sex with men is needed.

Advocacy Messages:

- Training for healthcare workers must continue to emphasize non-stigmatizing and non-discriminatory approaches to providing HIV services to key populations.

- Governments and donors should prioritize funding for moonlight services, including moonlight testing, to reach marginalized populations, such as men who have sex with men and other key populations.

- CLM implementers should deliberately recruit and train data collectors from affected communities. Increasing the number of data collectors who are men who have sex with men may improve visibility and reduce stigma in the clinic setting, as we saw with the data collectors who are sex workers.

The Link Between COVID-19 Vaccines and Access to HIV and TB Services

Misinformation about COVID-19 and a resultant fear of the vaccine is causing people to avoid healthcare services altogether, including HIV and TB services.
Similarly, in South Africa, a Life Maps participant spoke about being denied health services as a result of vaccine hesitancy: “During COVID, we were told by healthcare workers from our area that [children of] those that did not get the COVID vaccine will not be allowed [to enter] the under-5 clinic. We were thinking that they were lying but we ended up not being assisted.”

Another participant displayed vaccine hesitancy and an internalization of misinformation related to HIV and the COVID-19 vaccine: “People living with HIV/AIDS might have side-effects after [vaccination] and which may cause depression and [them to] fear for their life.” We provided all Life Maps participants with accurate and up-to-date information on the COVID-19 vaccine as part of this project, helping dispel myths and misconceptions like this one. A back-to-basics approach to community health education—going beyond HIV literacy—is essential to sustaining a bounce-back in the post-COVID era.

COVID-19 misinformation and vaccine hesitancy is creating barriers to HIV and TB services.

Information and education must also focus on COVID-19 to promote uptake of HIV and TB services.

One Life Maps participant in South Africa documented how large signs at the clinic’s entrance promote the availability of the COVID-19 vaccine in the clinic (see photo). For people who are vaccine-hesitant or vaccine-avoidant, such signs may be a deterrent to entering the clinic for HIV or TB services.
PrEP Awareness

To promote uptake, communities need more information on PrEP. In Malawi, misinformation on PrEP must be addressed. In both countries, Life Maps participants told us that they were not aware of injectable PrEP and the dapivirine vaginal ring, and they wanted to know more.

Advocacy Messages:

- Civil society organizations and governments should share information on new forms of PrEP, including injectable PrEP and the dapivirine ring.
- PrEP education sessions should address myths and misconceptions about the prevention method.
CONCLUSION

We see compelling evidence that HIV and TB services are bouncing back at our monitored sites, proving to be resilient in the wake of COVID-19. In many cases, services are recovering faster at our CLM sites than in the rest of the country. The act of community-led monitoring is likely playing an important role in hastening this progress. Our data collectors are educating recipients of care and generating demand for services post-lockdown. Our community feedback sessions create spaces for healthcare workers and recipients of care to engage with one another, promoting improved service delivery. Our national- and district-level advocacy spurs policy changes.

As the project proceeds, we will be rolling out an operational research component to better understand how CLM brings about key changes at the facility level. We will interrogate how CLM data is shared, what makes it more or less influential, and what key processes translate advocacy into real change.
REFERENCES

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Citizen Science is a community-led monitoring initiative that examines the recovery of HIV and TB services in the context of COVID-19 in Malawi and South Africa.