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Applying Community-led Monitoring to HIV Testing

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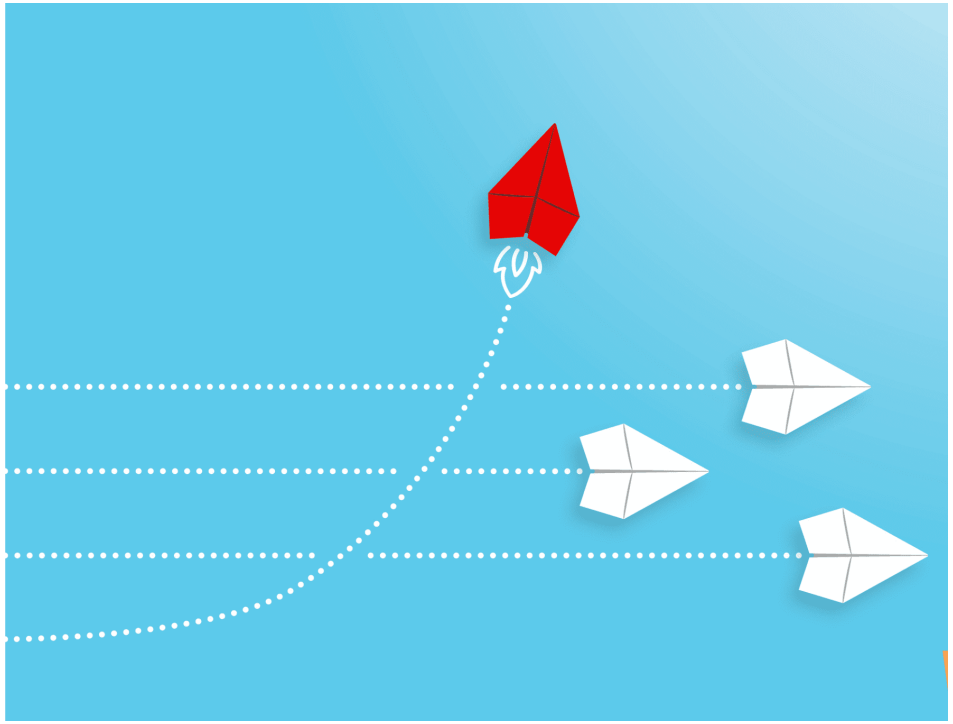
Leveraging DSD Strategies to Optimize HIV Testing and Linkage Services
March 13-16, 2023 | Nairobi, Kenya

Community-led Monitoring…
Can it be applied to HIV Testing?



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Refresher:
Principles and Practice of CLM

White Paper: Best Practices for Strengthening the CLM Model

This paper clarifies the principles behind community-led monitoring of health services, a methodology that uses systematic data collection by communities for evidence-based advocacy to improve accountability, governance and quality of health services.

This paper was developed by CD4C Consortium, CLAW Consortium and EANNASO-APCASO-ATAC Consortium and aims to support CLM implementers and donors into developing effective CLM programs

http://clm.itpcglobal.org/download/cd4c-claw-eannaso-atac-apcaso-community-led-monitoring-best-practices-for-strengthning-the-model.pdf

COMMUNITY-LED MONITORING

Best practices for strengthening the model

White Paper

This paper clarifies the principles behind community-led monitoring of health services, a methodology that uses systematic data collection by communities for evidence-based advocacy to improve accountability, governance and quality of health services.

This document was developed by:

Community Data for Change (CD4C) Consortium led by ITPC Global, with MPact Global Action for Gay Men's Health and Rights, Asia Pacific Coalition for Men's Sexual Health (APCOM), Caribbean Vulnerable Communities (CVC), Eurasian Coalition on Health, Rights, Gender, and Sexual Diversity (ECOM), Global Coalition of TB Advocates (GCTA), ITPC EECA and ITPC WCA

Community-Led Accountability Working Group (CLAW) Consortium formed by Advocacy Core Team (ACT), amfAR, Health GAP, HEPS, International Community of Women Living with HIV Eastern Africa (ICWEA), Observatoire Communitaire sur service de VIH (OCSEVIH), O'Neill Institute, SMUG and Treatment Action Campaign (TAC)

EANNASO-APCASO-ATAC Consortium formed by Eastern Africa National Networks of AIDS and Health Service Organizations (EANNASO), Asia Pacific AIDS Service Organizations (APCASO) and Alliance Technical Assistance Centre (ATAC) in Ukraine

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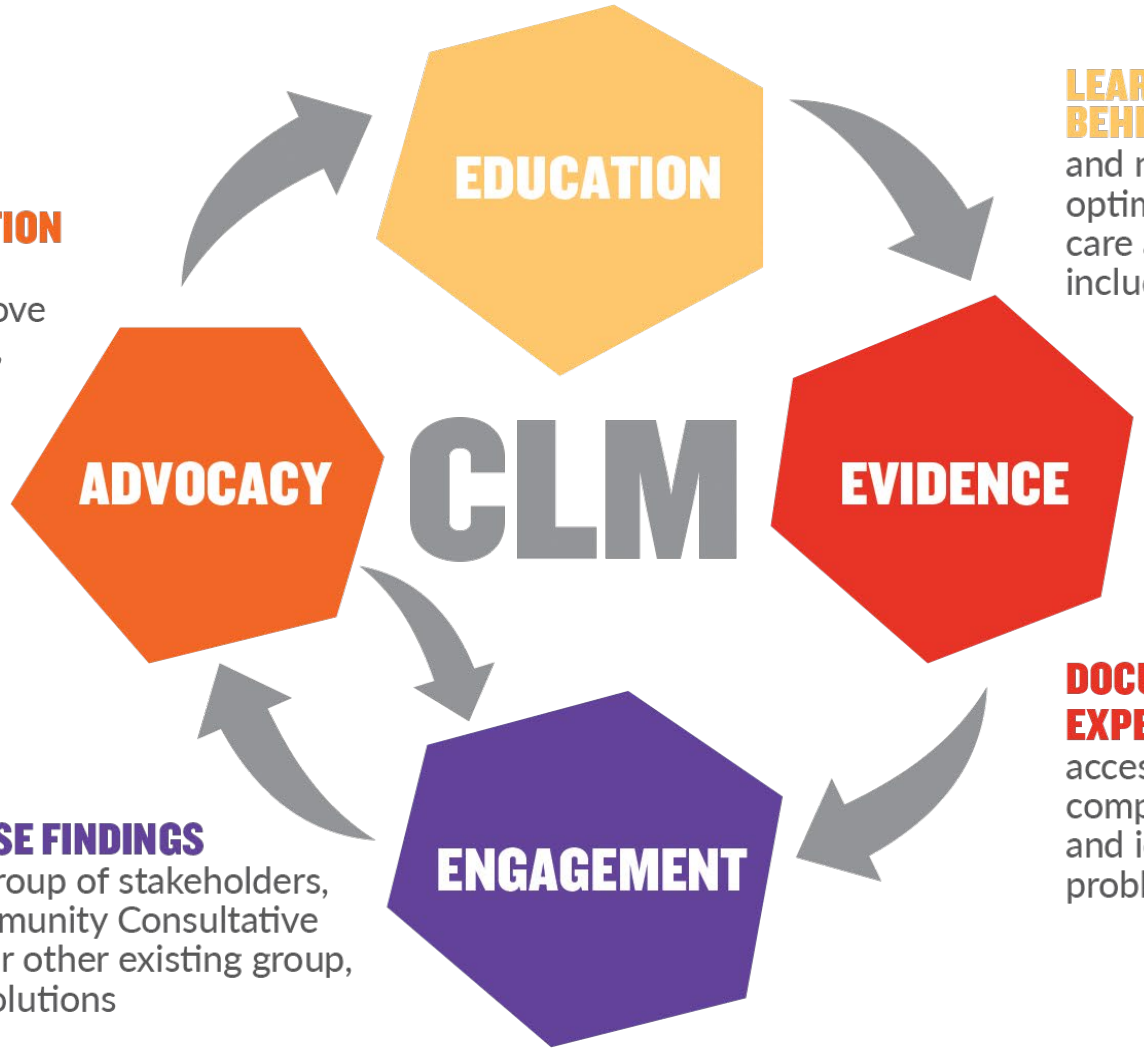
CLM: Core Principles (1/2)

1. Be **led by directly-impacted communities**, including people living with HIV, TB and/or malaria and key populations;
2. Maintain local leadership and **independence**, protecting against programmatic interference from other actors including donors, national government, and other monitoring and evaluation systems;
3. **Be owned by communities** in every stage, including identifying priority issues in the community, defining indicators, establishing preferred channels of communications with partners, and deciding how data are housed and used;
4. **Include advocacy activities** aimed at generating political will and advancing equity, given CLM's fundamental function as a social accountability tool;

CLM: Core Principles (2/2)

5. Adhere to **ethical data collection**, consent, confidentiality, and data security. Data collection must be verifiable, reliable, conducted in a routine/continuous cycle and collected under 'do not harm' principle;
6. Ensure that **data are owned by communities**, with programs empowered to share CLM data publicly and at their discretion. CLM programs should not be made to re-gather, replace, or duplicate M&E data from existing systems;
7. Ensure community monitors are representatives of **service users**, and that they are trained, supported, and adequately paid for their labor, while maintaining the community independence from the donor;
8. Be coordinated by a central, **community-owned structure** capable of managing the programmatic, financial, and human resource components of the program.

The Citizen Science Model - ITPC



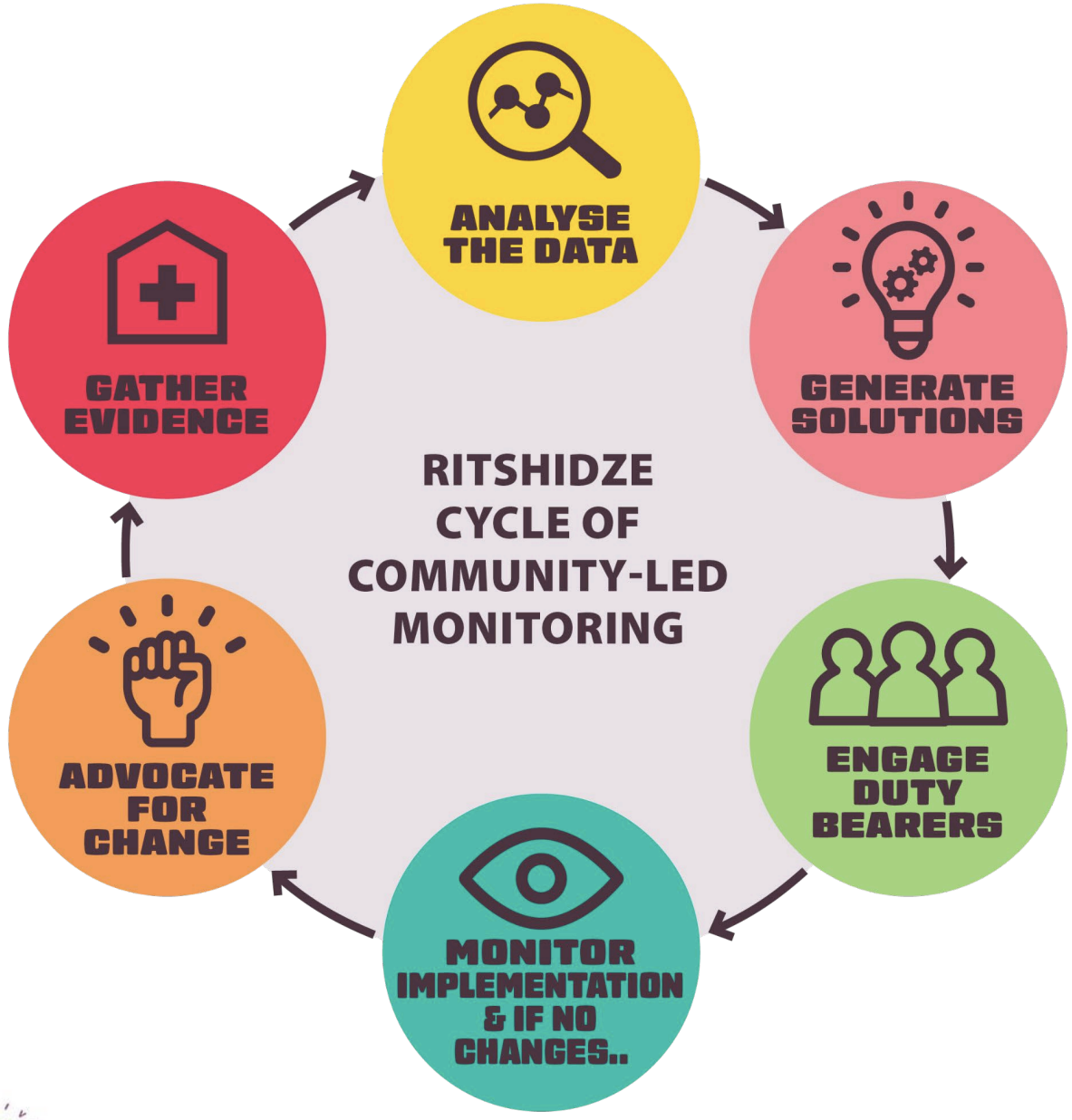
LEARN ABOUT THE SCIENCE BEHIND THE DISEASE(S)
and normative standards for optimal prevention, treatment, care and support interventions, including on COVID-19

DOCUMENT COMMUNITY EXPERIENCES
accessing health services, compile that information, and identify trends and problems

DISCUSS THESE FINDINGS
with a wider group of stakeholders, such as a Community Consultative Group (CCG) or other existing group, to co-create solutions

TAKE TARGETED ACTION
to work with policy makers to fix or improve the services, systems, laws or practices that underlie problems

RITSHIDZE
SAVING OUR LIVES



POSITIVE ACTION CAMPAIGN

TAC TREATMENT ACTION CAMPAIGN

POSITIVE WOMEN'S NETWORK for women living with HIV/AIDS

NAPWA SOUTH AFRICA

HEALTH GAP GLOBAL ACCESS PROJECT

amfAR MAKING AIDS HISTORY

O'NEILL INSTITUTE FOR NATIONAL & GLOBAL HEALTH LAW GEORGETOWN LAW

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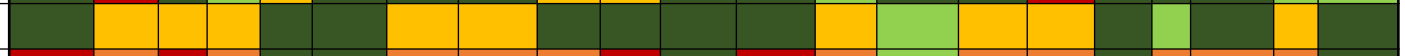
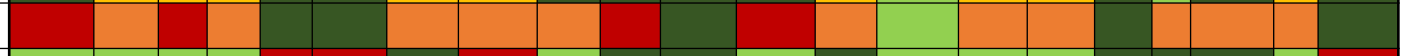
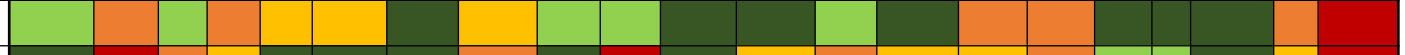
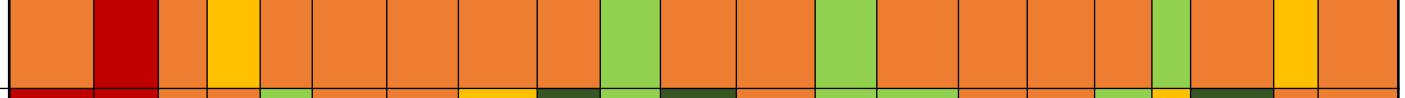
Case Studies: HIV and Testing

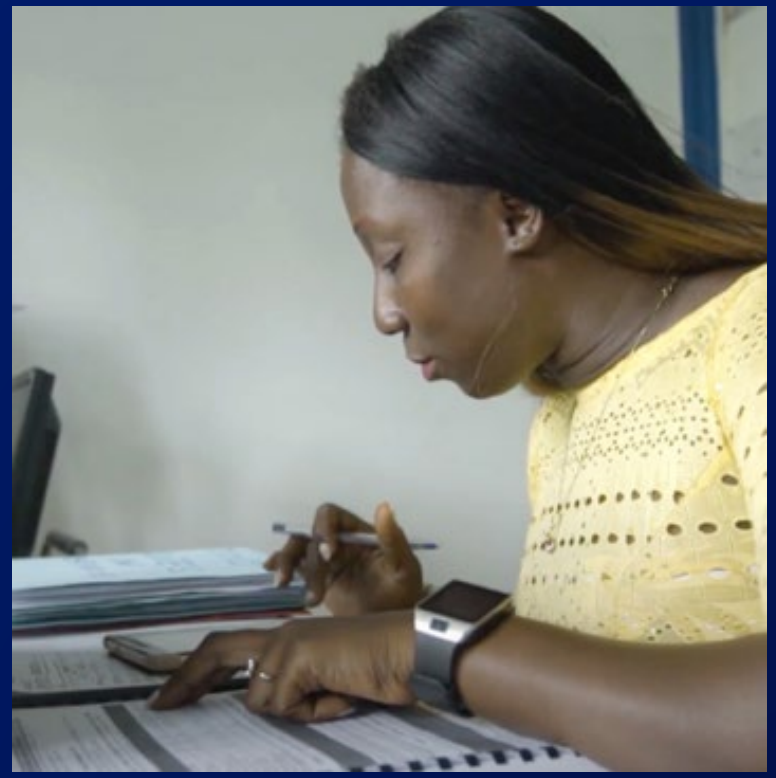
Country staging results for the dHTS CMM 2023

	Domain	CQUIN member countries
Policies/ Guidelines	1. Strategic model mix and decentralization	
	2. Optimizing HIV Testing	
	3: Linkage	
	Financing and resource allocation	
	SOPs	
	Implementation and scale up plan	
	Meaningful community engagement	
	Private sector engagement/oversight	
	Coordination	
	dHTS Training	
	M&E	
	Procurement & supply chain management	
	Population coverage	
Linkage to tx	1: Timely Linkage	
	2: Confirmatory/ Verification testing	
	Linkage to prevention and other services	
Quality of testing services	1: EQA/IQC	
	2: Proficiency Testing	
	3: Clinical services	
Impact	1: Knowledge of HIV status	
	2: Linkage to treatment	
	3: Linkage to prevention	

The Citizen Science project

- 2 countries: Malawi and South Africa
- 33 health facilities:
  - 14 in Malawi (eight in Kasungu and six in Dedza)
  - 19 in South Africa (all on the West Rand)
  - INCLUDING: **4 non-governmental service providers** (two in Malawi and two in South Africa)
- 58 data collectors
- 989,848 beneficiaries in this catchment area
- 2 years of continuous monitoring (October 2020-October 2022)
- Monitoring: 34 indicators in Malawi and 20 indicators in South Africa.
- Qualitative Interviews:
  - 123 recipients of care (71 in Malawi and 52 in South Africa)
  - 64 healthcare workers (30 in Malawi and 34 in South Africa)
- 40 Life Maps participants: citizen journalists documenting the more personal aspects of how HIV, TB, and COVID-19 affect their daily lives, using photography, narrative, and textual tools.

Purpose: monitor impact of COVID-19 on HIV and TB Services, particular attention to prevention



ITPC data collector, conducting a survey of clinic records as part of community-led monitoring.

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Community Partners

SOUTH AFRICA

Access Chapter 2 and Rotanganedza Community Centre are the community partners leading this work, in partnership with NACOSA.

Implementing CLM focused on prevention among youth, integrating with efforts of the National Department of Health and West Rand District Health Services.

MALAWI

MANERELA+ is an interfaith and voluntary membership network of religious leaders living with or personally affected by HIV and AIDS in Malawi.

Implementing CLM, integrating with efforts of the Malawi Ministry of Health, and in collaboration with JONEHA (the Network of Journalists Living with HIV).

40 of our 58 data collectors are from key or vulnerable population groups. This helps empower communities, sensitize health care workers, and reduce stigma.

- 9 are women living with HIV
- 7 are men living with HIV
- 6 are young people living with HIV
- 5 are men who have sex with men
- 5 are female sex workers
- 4 are young women aged 18-24 years
- 2 are lesbian women
- 1 is a trans woman
- 1 is a gender non-conforming person

Citizen Science data collector Makhatazle Engie Tiba (left) with local government HIV secretariat member Lulu Kotobe Sosibo (right) at the Badirile Clinic in West Rand, South Africa (February 2022)

Who asks the questions matters

- **Data Collectors** routinely gather data and information, AND…
- Regularly interact with the health facility staff about their findings and analysis, co-creating solutions to problems they see
- Share their data with the wider community and provide treatment education, engaging communities in the advocacy agenda

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Case Study #1: HIV Program Improvements that triple HIV Testing Among Sex Workers in Malawi

Limited Access to HIV Testing Services, especially for Key Populations, in 2021

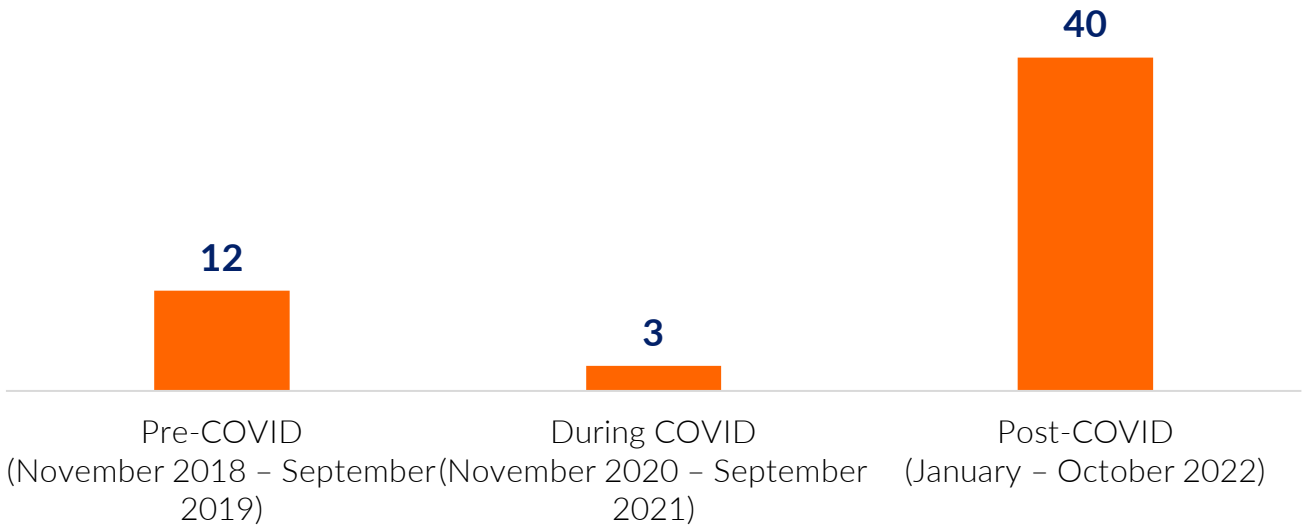
Number of HIV tests performed at our 15 monitored health facilities in Malawi, by population	Before COVID-19 (November 2018 – September 2019)	During COVID-19 (November 2020 – September 2021)	% CHANGE
Number of HIV tests among the general population	80,215	59,864	Testing fell by 25.4%
Number of HIV tests among men who have sex with men	248	117	Testing fell by 52.8%
Number of HIV tests among female sex workers	132	27	Testing fell by 79.5%

"COVID has been one of the things that they prioritize, and when it comes to HIV testing, you don't get those mobile clinics or those tents anymore. Most of them, they focus on COVID testing. You might find that once in a week, there are tents that do HIV testing, but other than that, it's been COVID and COVID and nothing else but COVID."

– Life Maps participant, South Africa

2022: Access to HIV Testing Services for Priority Populations

Figure 1. Average # of HIV Tests Performed per Month Among Sex Workers at Our Monitored Sites in Malawi



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 in Malawi. They help generate demand for services during focus group discussions and make the health facilities a more welcoming environment for their peers.

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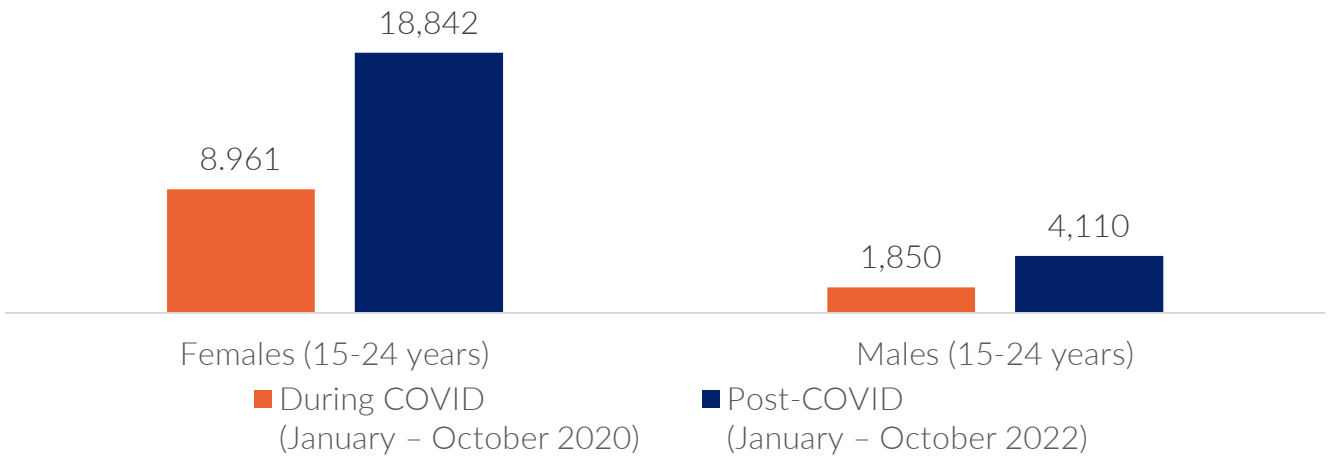
2022: Access to HIV Testing Services for Priority Populations

Figure 2. Total # of HIV Tests Performed Among Young People at Our Monitored Sites in South Africa



The number of HIV tests performed among young people at our monitored sites in South Africa has more than doubled since 2020. We employ 10 young people as data collectors who help encourage their peers to test.

Young people report increased ease of access to HIV testing services, post-COVID:

"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."

"On the issue of self-testing kits, these were difficult to find during COVID but at least now, in health centres, they are found."

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

Our 2021 data indicated that COVID-19 had a disproportionately negative effect on key populations' access to HIV testing services.

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 community-led monitoring data, our partners in Malawi **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.**

Our partners 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.

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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.

"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."

– Man who has sex with men, Recipient of care, Malawi

BARRIERS IDENTIFIED:

- **Stock-outs of test kits**
- **Stigma and discrimination**
- **Lack of funding for differentiated services (primarily external funding from PEPFAR)**

Eight health facilities, all in Kasungu District, cited a lack of resources as the reason they are not doing moonlight testing for key populations.

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Advocacy Messages

HIV testing services for men who have sex with men

- 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.

Case Study #2: Speedier Turnaround Times for Lab Test Results

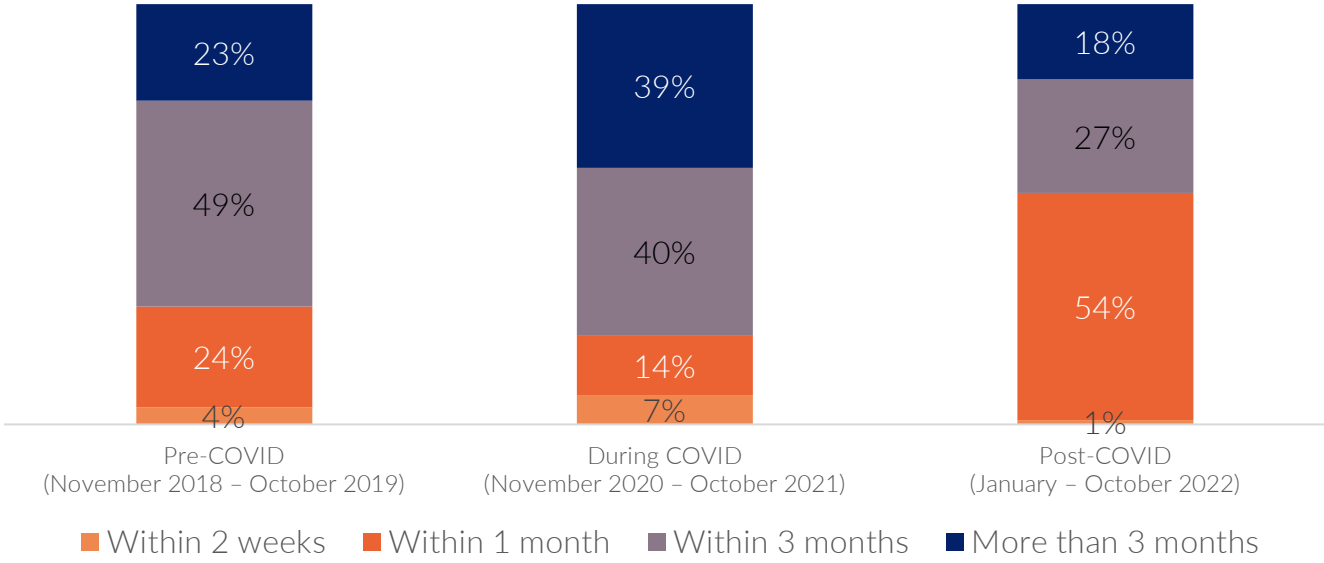
After long delays in 2020 and 2021, turnaround times for viral load test results have recovered and are now faster than before the pandemic in Malawi.

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

The quality of treatment monitoring is affected by the turnaround time for viral load test results.

Guidelines suggest that healthcare workers must ensure that the results of any viral load tests are checked within one week.

Figure 3. Turnaround Times for Viral Load Test Results at Our Monitored Sites in Malawi



Return of Viral Load Test Results

- 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.

"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."

– Recipient of care, Malawi

"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."

– Recipient of care, Malawi

Advocacy Messages

Access to—and return of—viral load test results

- Governments should conduct a root cause analysis to determine why so many people report never receiving their viral load test results.
- Healthcare workers must not limit access to multi-month dispensing of ART while people await viral load test results.
- Communities have a right to transparency about their own health information, including when they can expect to receive test results, and if results are not received, information about what happened.

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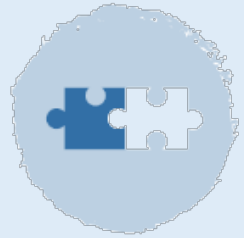
Additional Strategic Application of CLM in the Context of Testing

Applying CLM to Viral Load Testing and CD4 Counts

*Communities collect and analyze data on **availability**, **accessibility**, **acceptability**, **affordability** and **appropriateness** of HIV testing*

Availability	Accessibility	Acceptability	Affordability	Appropriateness
				
• Do the required testing services, commodities and supplies exist? • If so, do they exist when they are needed and in adequate supply?	• Are there long travel distances or wait times? (**Capped # tests per day**?) • Are hours of operation convenient? (**Moonlight testing?)** • Are testing referral processes smooth?	• Is there a high quality of care? (**Wait time to receive results?)** • Are services provided free of stigma and discrimination? • Are the human rights of patients promoted and protected?	• Do services require out-of-pocket spending on behalf of the client? • Is the service delivery model(s) efficient? • What is the sustainability of the response?	• Are services tailored to the specific needs of key and vulnerable populations? • Are age and gender considered in service packages? • **Are VLT and CD4 counts administered appropriately? Are treatment regimens adjusted based on results?**

Learn More: CLMHub.org

Thank you!