

# Can *Communities* Improve Laboratory Systems?

## The Case for Community Data & Monitoring

LabCoP Satellite Meeting: Strengthening Laboratory Systems and Networks:

Better Data for Better Action 11 December 2023

Solange Baptiste | Executive Director, ITPC



# About ITPC

- Is an **issue-based global activist network**
- Our HQ are in Johannesburg, South Africa with a global mandate
- ITPC was started in 2003 when ARV prices were prohibitive
- We work with >3000 network members (individuals & organizations)
- **We have *regional partners* in**
  - Latin America and the Caribbean (ITPC LATCA)
  - Eastern Europe and Central Asia (ITPC EECA)
  - South Asia (ITPC South Asia)
  - Middle East & North Africa (ITPC MENA)
  - West Africa (ITPC WA)



**How can we improve  
laboratory systems?**

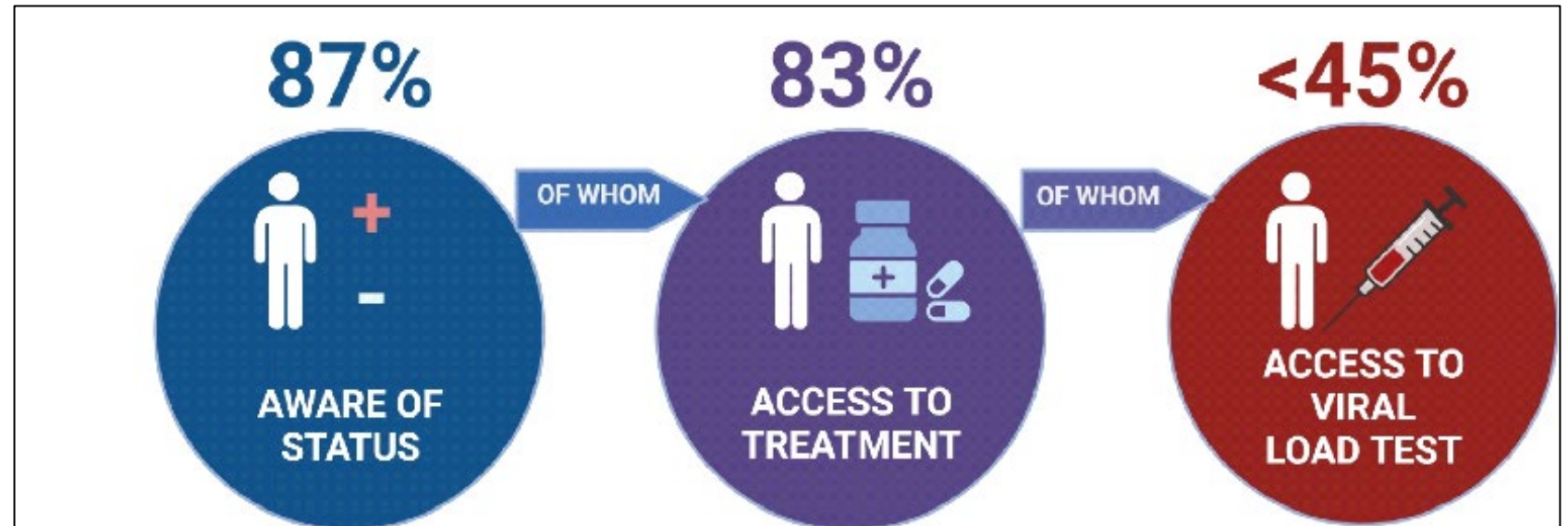




# Traditional Approaches to Evaluate and Improve HIV Laboratory Systems

TOP DOWN

## Cost Analysis



Surveillance of populations at risk, i.e. **percentage access to viral load testing** (no measure of quality of testing or turnaround times to recipients of care)



# What role can Communities Play in Evaluating and Improving Laboratory Systems?

**BOTTOM UP**



Share lived experiences navigating lab systems



Collect data about barriers & gaps on the ground



Co-create solutions based on community data

## Beyond Demand Generation

Communities should be engaged as **system experts** who **pinpoint problems** and **offer concrete solutions**



# What techniques can be harnessed to collect and use community data?

A very brief introduction to  
Community-Led Monitoring (CLM)





# What do we mean by “Community-led”?

CLM Is NOT	CLM IS
X Community-BASED	✓ Community-LED
X Indicators are set by outside entities (governments, donors); data collected corresponds to established M&E systems and frameworks	✓ Indicators are determined by communities and correspond to their own priorities; provide a valuable piece of the <b>whole data story</b>
X One-time evaluation (a “snapshot”)	✓ Routine, <b>recurring data collection</b> over time (usually monthly or quarterly)
X Data is owned by entities outside of the community (governments, healthcare facilities)	✓ Data is <b>owned</b> by communities
X Fault-finding	✓ <b>Fact</b> -finding
X The end goal of the data is to understand the trends and issues	✓ The end goal is to <b>improve a particular issue</b> that has been identified as important by communities



# What is Community-led Monitoring? *Agreed principles*

CLM is a process where communities take the lead to routinely monitor *an issue that matters to them*.

- Led by directly-impacted communities, including people living with HIV, TB and/or malaria and key populations;
- Maintain local leadership and independence
- Be owned by communities in every stage
- Include advocacy activities aimed at generating political will and advancing equity
- Adhere to ethical data collection, consent, confidentiality, and data security.
- Ensure community monitors are representatives of service users, and that they are trained, supported, and adequately funded

Communities then work alongside policymakers to **co-create solutions** to the problems they have identified.

When problems uncovered through CLM aren't resolved, **communities escalate with evidence-based advocacy** and campaigning until they achieve implementation of corrective actions by duty bearers.

## 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:

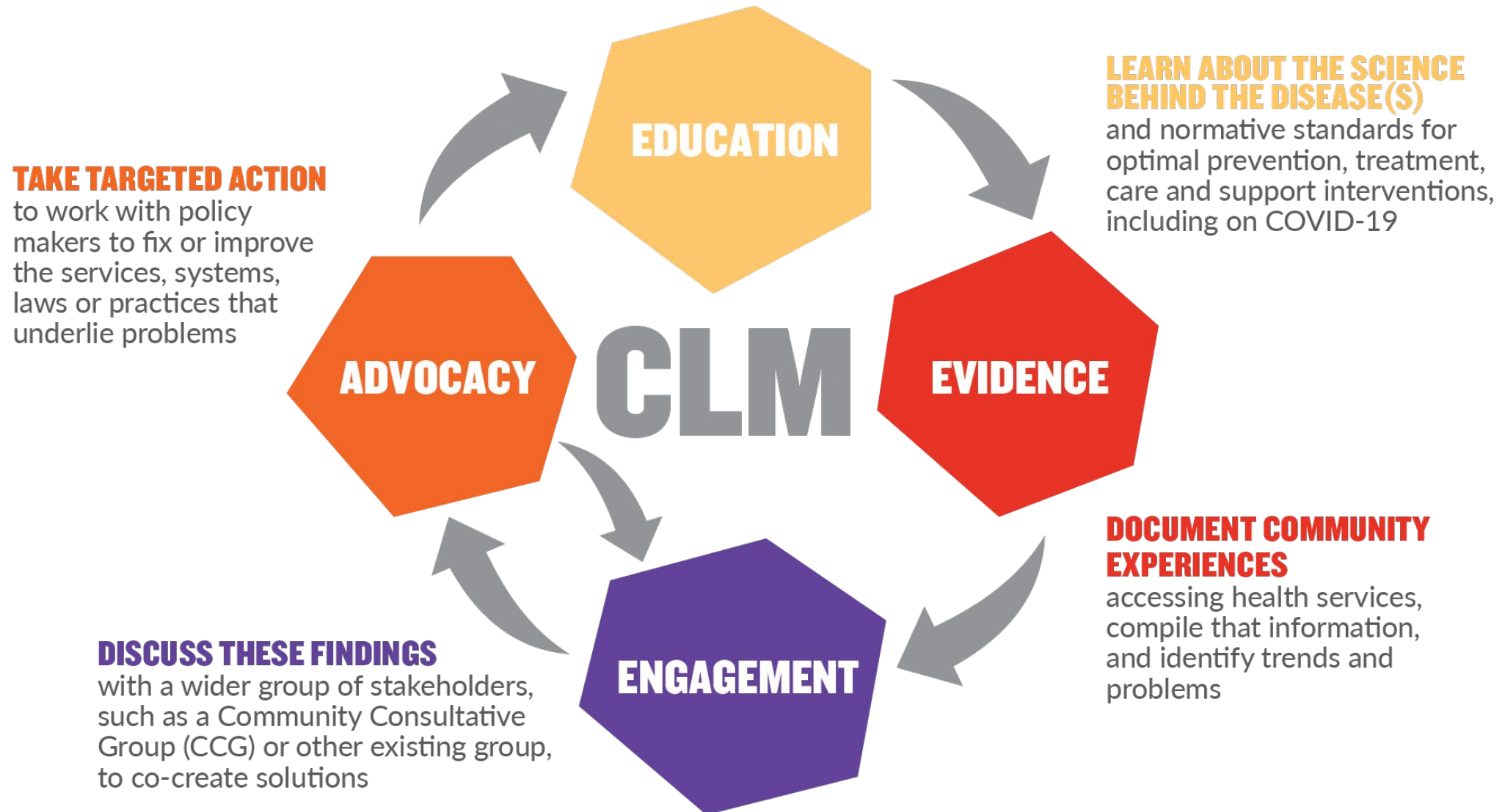
Community Data for Change (CD4C) Consortium led by ITPC Global, with MPact Global Action for Gay Men's Health and Rights, Asia Pacific Coalition for Men's Sexual Health (APCOM), Caribbean Vulnerable Communities (CVC), Eurasian Coalition on Health, Rights, Gender, and Sexual Diversity (ECCOM), Global 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 Communautaire 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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# ITPC Community-Led Monitoring Model

“CLM is a mechanism through which communities and service users collect data to generate evidence *for improvements in services, programs, and policies.*”

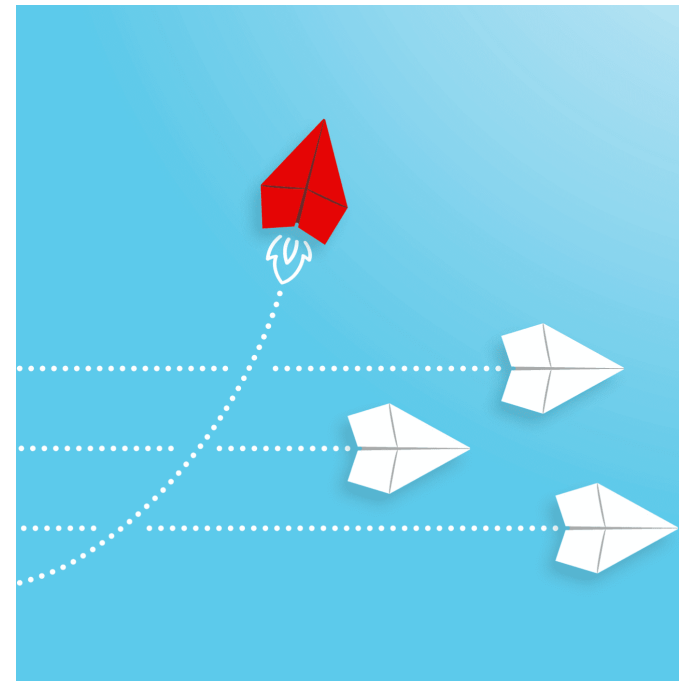


**How can we apply CLM to  
strengthen laboratory  
systems?**





# Can CLM be applied to Diagnostics?



# Community Perspectives on Diagnostics

**“...in the absence of the use of RVLT ... we will continue fighting HIV in the dark!”**

*An Adolescent LHIV from Jinja Uganda*

**“People’s blood samples are taken but people don’t know for what”**

*Sibongile from Western Cape South Africa*

**“...Reagents are out of stock when you go for the test, but when you go with money the reagents appear. It’s magic!”**

*PLHIV youth, Panama City, Panama*

**“...we travel from far to have blood drawn, go through the pain of a needle prick only to have the blood sample discarded because the lab has run out of reagents...”**

*PLHIV mother of 3 from Mafikeng in Lesotho*



# Vital role of communities for *monitoring and improving* diagnostic services

- Routine viral load testing (RVLT) is **essential to effective HIV treatment monitoring** among people living with HIV (PLHIV).
- Scaling up **RVLT is a key contributor to the goal of achieving viral suppression** among people on antiretroviral treatment. However, **uptake of RVLT among PLHIV remains low, hindered by a mix of demand and supply-side barriers.**
- Our experiences illustrate that increasing uptake of RVLT involves **not only creating demand but addressing more systemic issues.**
- Understanding the **nature and extent** of these systemic barriers is critical to **identifying solutions** and improving the viral load cascade.



# The Value-Add of Community Monitoring

Assessments come **from a recipient of care perspective** rather than from a healthcare provider or health systems management perspective

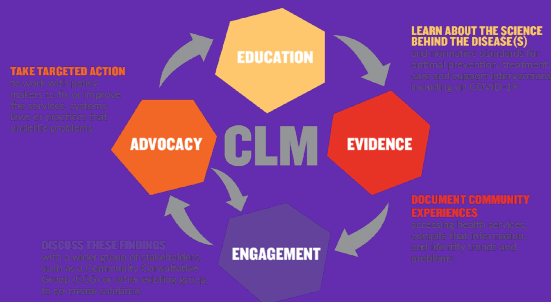
## Why does this matter?

- More **relevant** community-defined indicators have extremely high added value
- They capture **missing**, highly relevant community data that provides **granular insight** into how laboratory systems can and do fail recipients of care
- This specificity, combined with **co-creation of solutions**, can result in **measurable change**
- Our experience is that **increasing uptake of RVLT involves not only demand creation but addressing more systemic issues**. **Understanding the nature and extent** of systemic barriers is critical to **identifying solutions** and improving the viral load cascade.

Solely tracking guidelines and rates of virologic suppression leaves out crucial information about service **availability** and **quality**.



# 1. Education



MANERELA+

23 November 2021 · 🌐



**Modern women care for their wellbeing as they know they are pillars to their family**

**#GET TESTED, KNOW YOUR VIRAL LOAD**

# Barriers to Access: Lack of knowledge

People's blood samples are taken but people **don't know for what**.

*Sibongile from Western Cape South Africa*

In my experience, those knowledgeable on HIV treatment are able to confidently interact with the health care workers and ask for things like VLT. What about **those living in rural areas who aren't knowledgeable**? Due to their lack of knowledge, they are **not able to ask** for these services.

*Nellie a community health worker from Blantyre in Malawi*

...we travel from far to have blood drawn, go through the pain of a needle prick only to have the blood **sample discarded because the lab ran out of reagents**...

*PLHIV mother of 3 from Mafikeng in Lesotho*





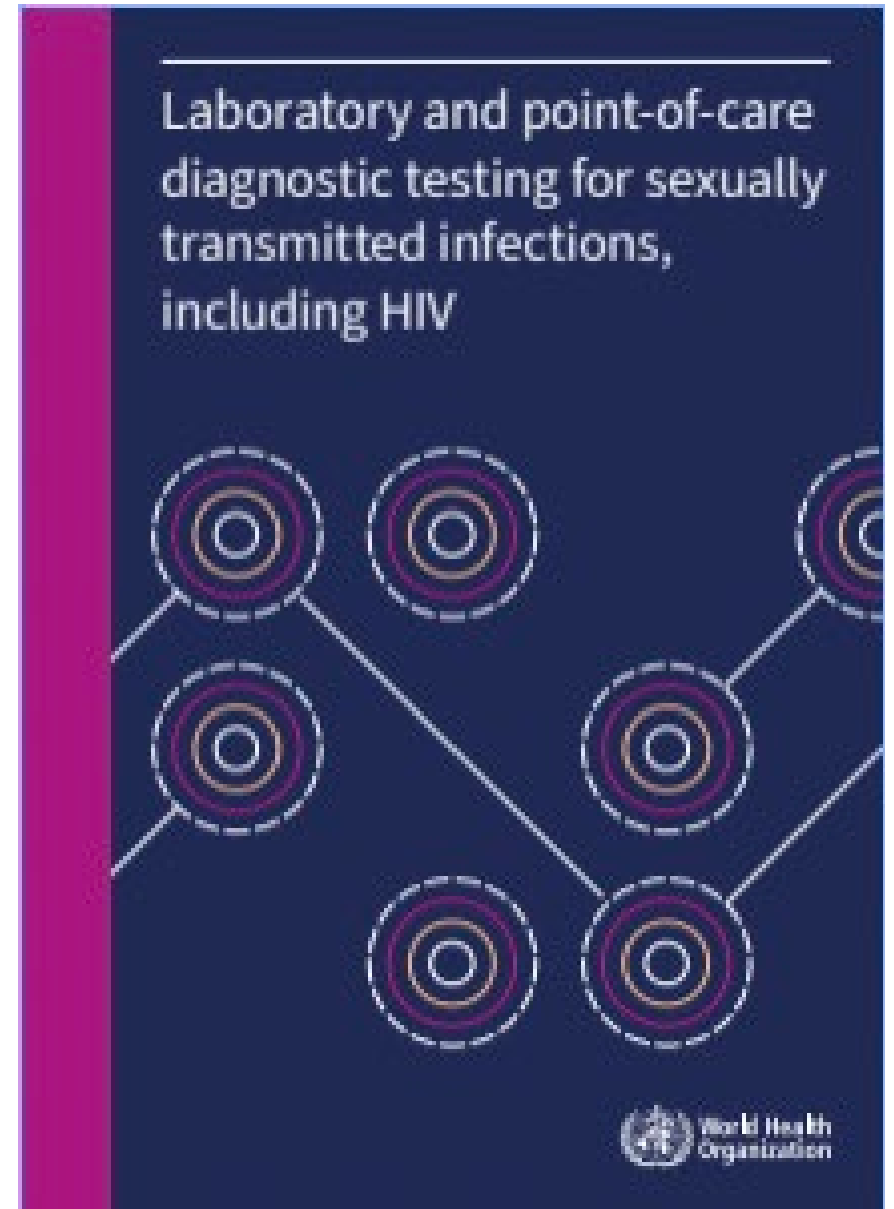
# 1. Education

We start by building community knowledge about:

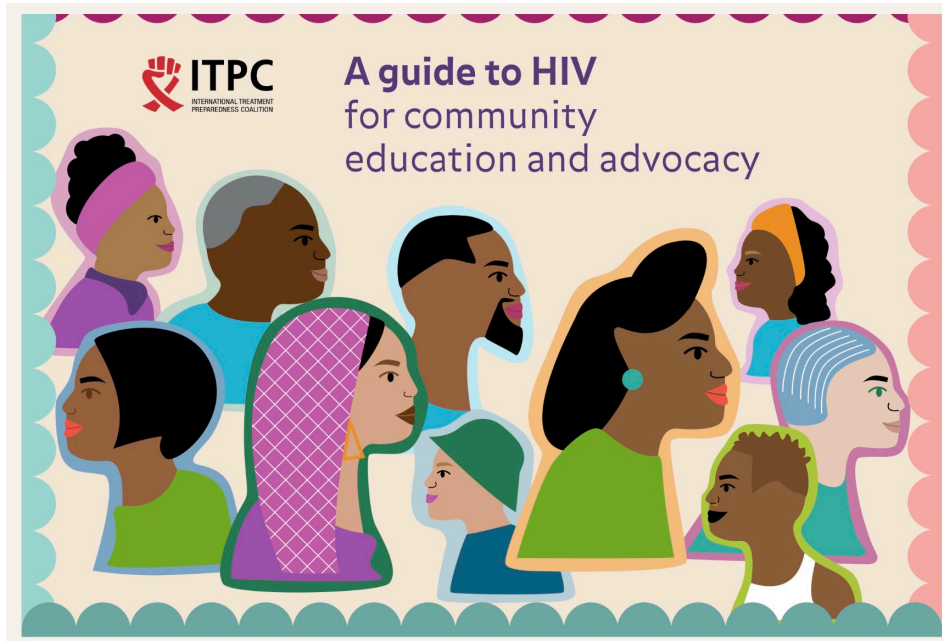
- The **science** of transmissible diseases (HIV, TB, COVID-19, malaria...)
- The **standards** of prevention, testing and care set by WHO and National Guidelines

Why is this step important?

- **Equips communities to demand the quality** of services they deserve
- Makes for **more effective monitoring** (i.e. if you know HIV treatment interruptions can cause drug resistance and treatment failures, you are more empowered to fight drug stock-outs)



# 1. Education



ITPC's 2022 *A guide to HIV for community education and advocacy*  
<https://itpcglobal.org/resource/a-guide-to-hiv-community-education-and-advocacy/>

## Community-friendly scientific information

- Clear, simple, and direct
- Does not assume prior knowledge
- Tailored to the specific audience
- Learning can take many forms

The image is a screenshot of a quiz titled "What is your COVID IQ?". The title is in white and orange text on a purple background. Below the title are icons of COVID-19 particles and flags for English (EN), French (FR), Portuguese (PT), Spanish (ES), and Russian (RU). The main text asks "How much do you really know about COVID-19? It's time to find out your COVID IQ." and provides a brief introduction to the quiz. On the right, there are three orange buttons for quiz topics: "1. COVID-19 ORIGIN, TRANSMISSION & PREVENTION", "2. COVID-19 TESTING, SYMPTOMS and ILLNESS", and "3. COVID-19 VACCINES AND TREATMENT".

What is your  
COVID IQ?

EN FR PT ES RU

EN How much do you really know about COVID-19? It's time to find out your COVID IQ.

It's been more than two years since the start of the COVID-19 pandemic. After all the headlines, studies, and videos, is there anything else you still don't know about COVID-19? Is your COVID-19 knowledge helping you save lives? Or are you a public danger and at risk of spreading wrong information?

Take our quiz and find out your COVID-19 IQ!

1. COVID-19 ORIGIN, TRANSMISSION & PREVENTION

2. COVID-19 TESTING, SYMPTOMS and ILLNESS

3. COVID-19 VACCINES AND TREATMENT

The image is the cover of the ASLM Lab Culture journal, June 2022, Issue 27. The cover is dark blue with white and yellow text. The ASLM logo is in the top left. The main title "LAB CULTURE" is in large white letters. Below it, the subtitle "ADVANCING THE LABORATORY PROFESSION AND NETWORKS IN AFRICA" is in smaller white letters. The main headline is "Bringing diagnostic testing closer to communities". Below this are several colored bars with text and icons of hands, each followed by a group of circular portraits of people: "Malaria rapid test" (pink bar), "Outbreak detection" (yellow bar), "Fever panels" (green bar), "HIV early infant diagnosis/viral load" (orange bar), "Tuberculosis testing" (blue bar), and "Essential diagnostics" (purple bar). At the bottom, the text "In this issue" is followed by two paragraphs of text.

June 2022 | Issue 27

ASLM  
AFRICAN SOCIETY FOR LABORATORY MEDICINE

LAB CULTURE  
ADVANCING THE LABORATORY PROFESSION AND NETWORKS IN AFRICA

Bringing diagnostic testing closer to communities

Malaria rapid test

Outbreak detection

Fever panels

HIV early infant diagnosis/viral load

Tuberculosis testing

Essential diagnostics

In this issue

Improving access to diagnostics at the community level:  
How can national Essential Diagnostics Lists help?

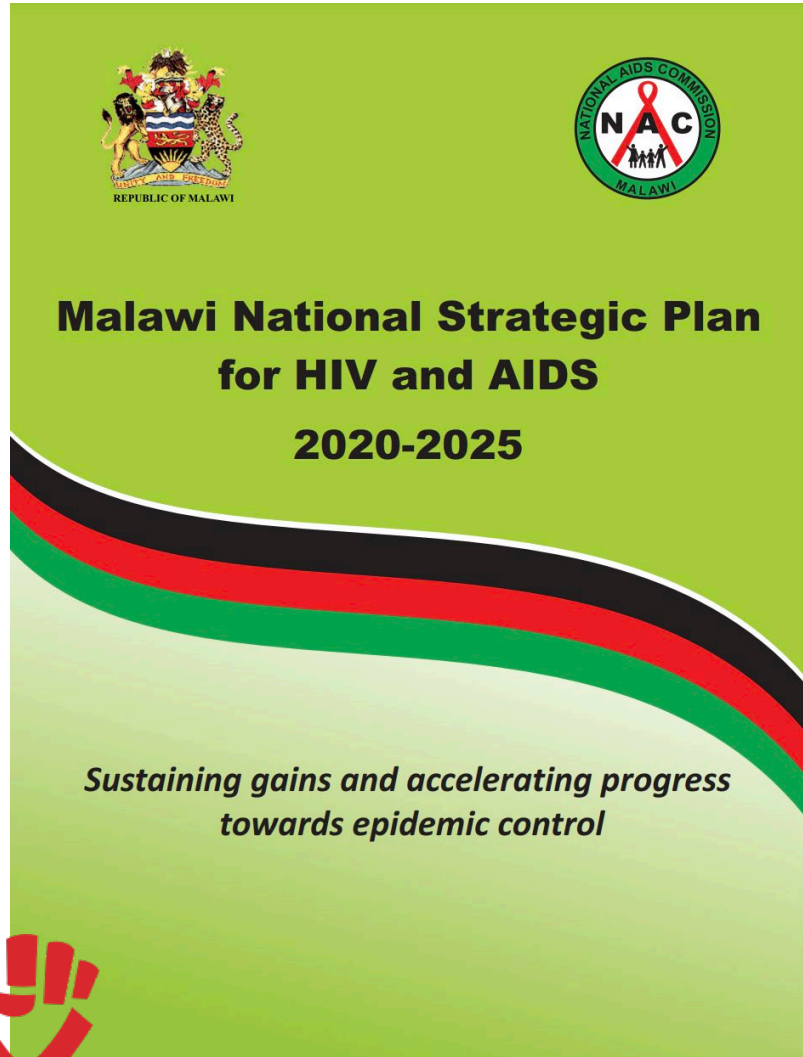
Disease testing in the community: the under-utilized opportunity.

Accelerating detection and early action for outbreaks:  
Role of decentralized testing capacities.



# 1. Education

Which policy commitments and targets apply in your setting?



Importance of continuous learning as new products come into the market



**WHO recommends long-acting cabotegravir for HIV prevention**

New WHO guidelines advise countries to deliver long-acting cabotegravir as part of comprehensive approach to HIV prevention

Reading time: 3 min (830 words)

**FDA Approves First Extended-Release, Injectable Drug Regimen for Adults Living with HIV**

[Share](#) [Post](#) [LinkedIn](#) [Email](#) [Print](#)

For Immediate Release: January 21, 2021

**Background on Cabotegravir–Rilpivirine**

FDA NEWS RELEASE

The FDA has approved 48 medications for people diagnosed with HIV.

to integrate into... likely to draw stigma and/or... reduced worry because injectable medication... pills for long periods of travel time and/or other similar situations (Mantsios et al., 2020).

with oral regimens, is more... the private nature of injectable medication... VH taking oral medications. They also discuss... the barrier of having to pack significant quantities of... situations (Mantsios et al., 2020).



# 1. Education

## Education Campaigns



Let us know our viral load for the health of our families.

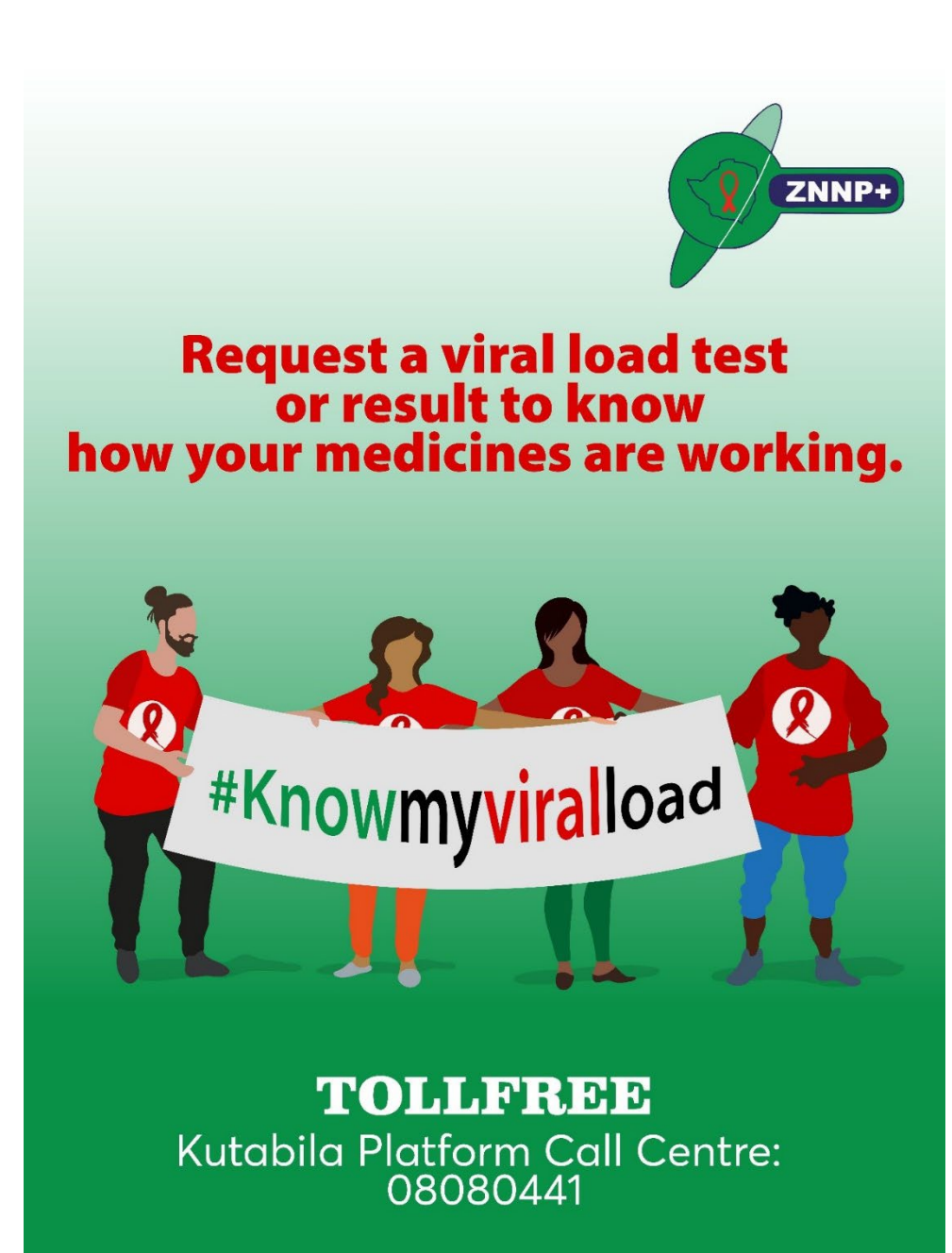
Our families matter let us be productive.


#ViralLoadTestIsLife

**Contact Us:** ZNNP+ 28 Divine Road Milton Park, Harare. **Kutabila Platform Call Centre: 08080441**  
**Website:** [www.znnp.org](http://www.znnp.org) **Tel:** +263 774 151 276 **Email:** [info@znnp.org](mailto:info@znnp.org)  [@znnpinfo](https://twitter.com/znnpinfo)  [@znnpinfo](https://facebook.com/znnpinfo)

Example: RVLT communication campaign run in Zimbabwe by adult and youth PLHIV networks across Facebook, Twitter and WhatsApp (2020 – 2021)





**Request a viral load test  
or result to know  
how your medicines are working.**

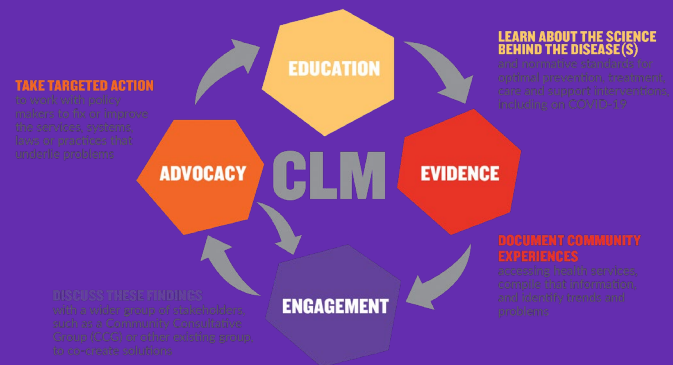
**#Knowmyviralload**

**TOLLFREE**  
Kutabila Platform Call Centre:  
08080441

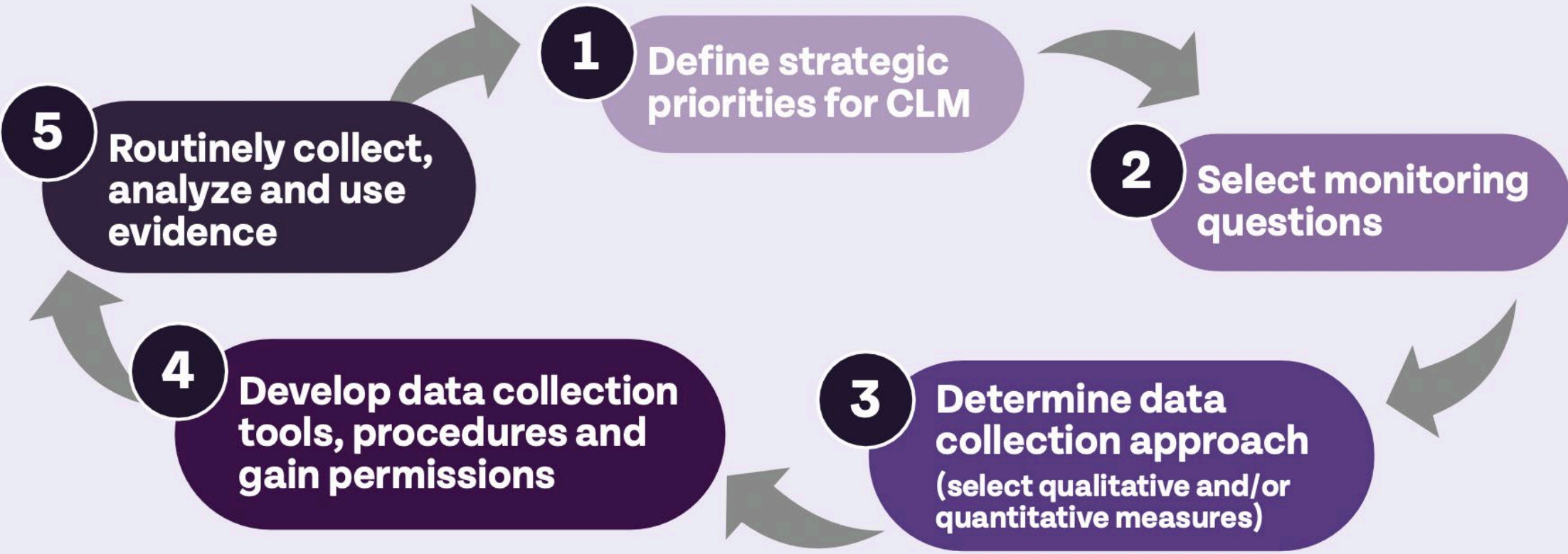
**Contact Us:** ZNNP+ 28 Divine Road Milton Park, Harare. **Kutabila Platform Call Centre: 08080441**  
**Website:** [www.znnp.org](http://www.znnp.org) **Tel:** +263 774 151 276 **Email:** [info@znnp.org](mailto:info@znnp.org)  [@znnpinfo](https://twitter.com/znnpinfo)  [@znnpinfo](https://facebook.com/znnpinfo)

# 2. Evidence

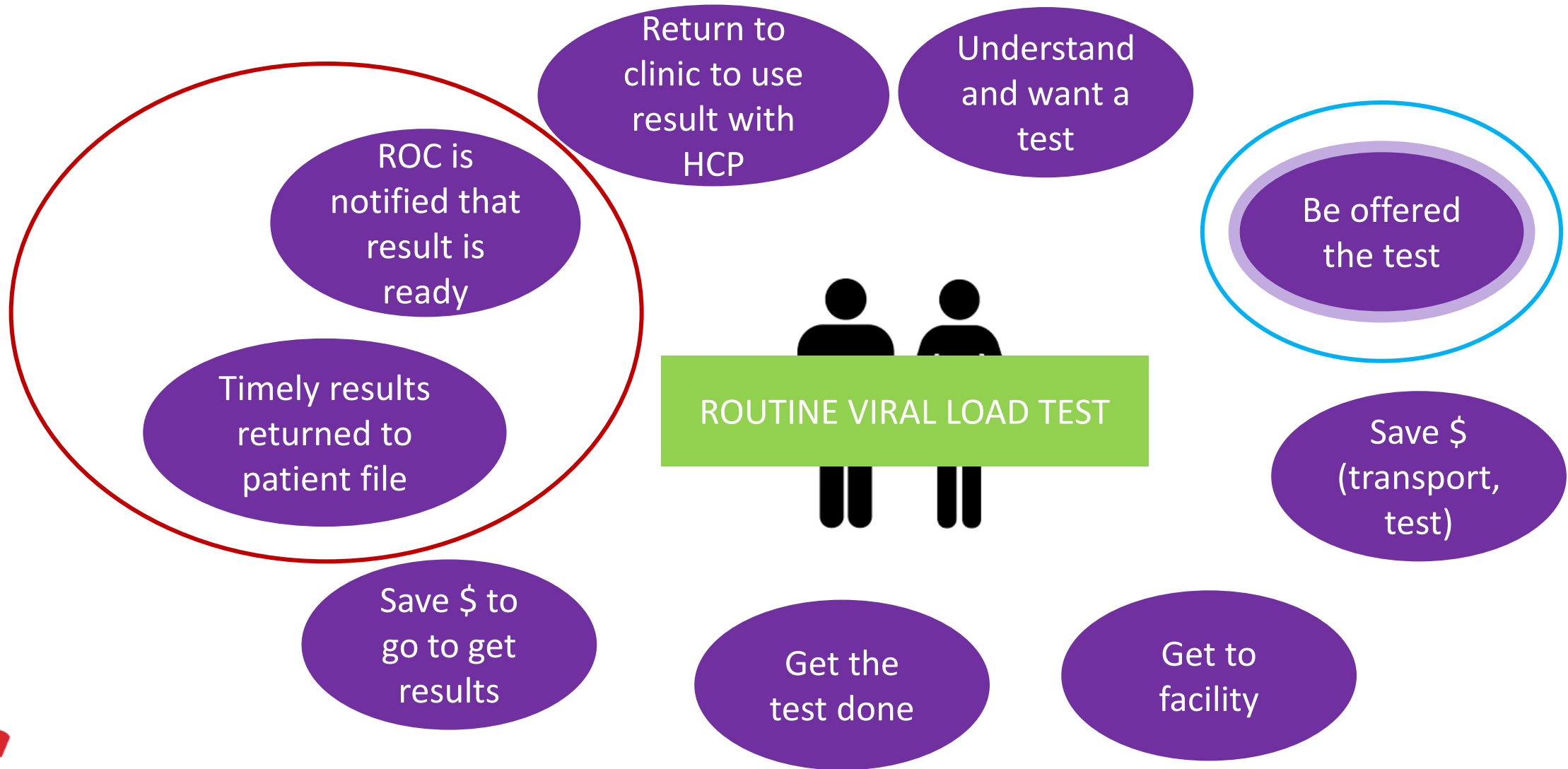



# Roadmap for CLM

**FIGURE 1 Roadmap for Generating and Using Evidence for Community-led Monitoring**



# What routine VL Testing should look like for Recipients of Care





Ideally seen and treated as a  
**WHOLE** person!

## Recipients of Care want:

- Option to do the **right test**
- **Least amount of runaround**
- At the **right time**
- Get an **accurate result quickly**

So that...





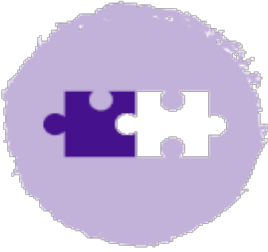
- They can get the **appropriate treatment and care** to be able to move on with their lives.





# Applying CLM to Viral Load Testing & CD4 Counts

## What do we monitor?

Availability	Accessibility	Acceptability	Affordability	Appropriateness
				
<ul style="list-style-type: none"><li>• Do the required testing services, commodities and supplies exist?</li><li>• If so, do they exist when they are needed and in adequate supply?</li></ul>	<ul style="list-style-type: none"><li>• Are there long travel distances or wait times? (<b>Capped # tests per day?</b>)</li><li>• Are hours of operation convenient? (<b>Moonlight testing?</b>)</li><li>• Are testing referral processes smooth?</li></ul>	<ul style="list-style-type: none"><li>• Is there a high quality of care? (<b>Wait time to receive results?</b>)</li><li>• Are services provided free of stigma and discrimination?</li><li>• Are the human rights of patients promoted and protected?</li></ul>	<ul style="list-style-type: none"><li>• Do services require out-of-pocket spending on behalf of the client?</li><li>• Is the service delivery model(s) efficient?</li><li>• What is the sustainability of the response?</li></ul>	<ul style="list-style-type: none"><li>• Are services tailored to the specific needs of key and vulnerable populations?</li><li>• Are age and gender considered in service packages?</li><li>• <b>Are VLT and CD4 counts administered appropriately? Are treatment regimens adjusted based on results?</b></li></ul>





# Lab Tests that Count for HIV Infection

- Reliable **HIV Testing** Kits
  - Linking positive self test with confirmation testing & initiation of ART
- **CD4 Testing** – PLHIV with AHD
  - Inconsistent implementation of country guidelines
  - Using the results in the management of PLHIV with AHD
- **Viral Load Testing** – ALL
  - Many PLHIV on ART still not accessing at least 1 annual viral load test
  - Turnaround time for results and use results is poor
- **Resistance Testing** – For at least those who VL alone is not as helpful
  - Unclear/lack of country guidelines
  - More treatment experienced PLHIV are not switched to the right regimens in time

## AND DON'T FORGET

- Full blood count
- Liver function
- Kidney function
- Cholesterol levels
- Blood sugar



# Use of both QUALITATIVE & QUANTITATIVE data unlocks the full potential of CLM

Quantitative	Qualitative [Respondent = PLHIV]
<p># of PLHIV that have received a VL test</p> <p># of PLHIV that received their VL test result within two weeks of taking the test</p> <p># of PLHIV that had a blood sample taken for VL test but results never made available</p> <p># of PLHIV who received an explanation of their VL test results</p> <p># of PLHIV who changed ART after receiving a viral load result</p>	<ul style="list-style-type: none"> <li>• Have you taken a VLT?</li> <li>• What motivated you to get a VLT? Why didn't you get a VLT? (distance, cost, etc.?)</li> <li>• Did someone explain why your blood was taken?</li> <li>• Did you receive your test result? Were you contacted to come for your result? Were the results explained to you?</li> <li>• Did your ARV regimen change after your test result?</li> <li>• Do you think it's beneficial for PLHIV to get a VLT?</li> </ul>



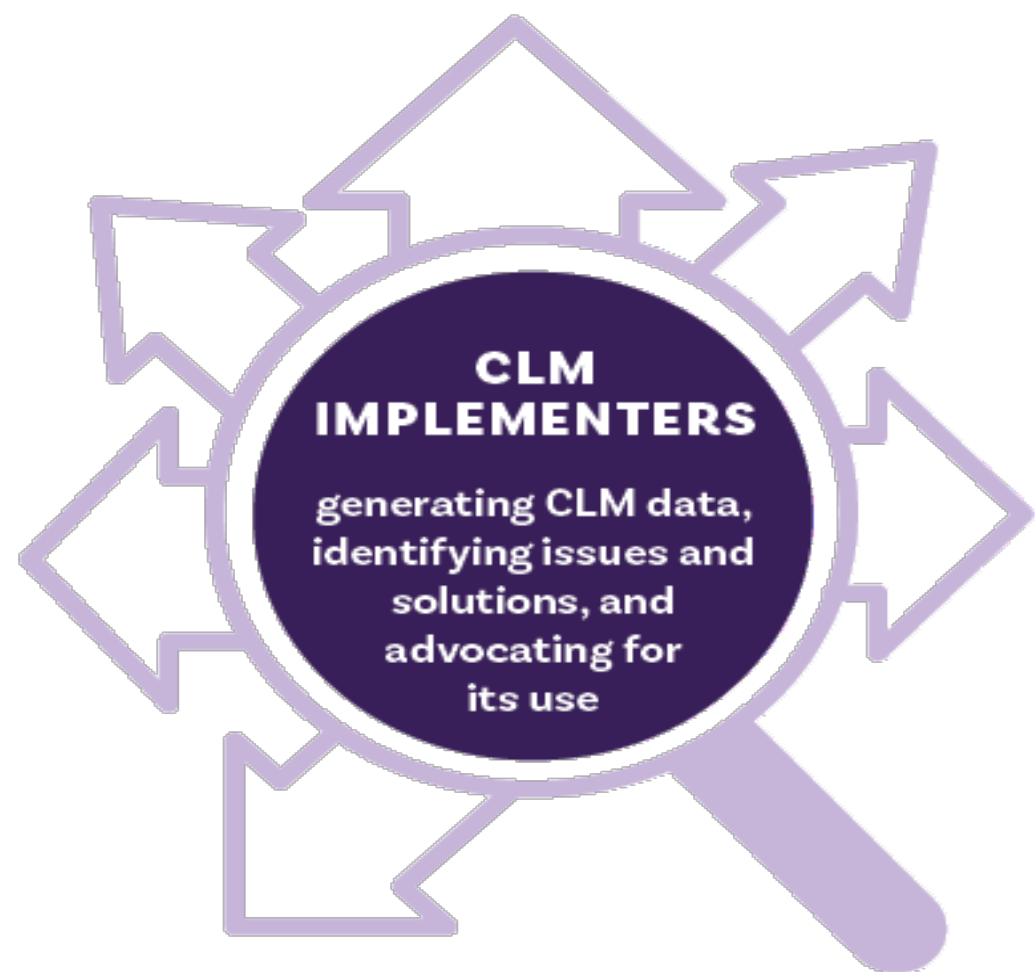
Photo: NETHIPS

Community monitors conduct data collection at Princess Christian Maternity Hospital in Freetown, Sierra Leone

# 3. Engagement



# 3. Engagement

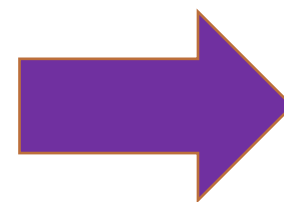


**DECISION-MAKING AUTHORITIES**  
with mandate and power to act on the data, for program improvement, such as:

- ✓ **HEALTH SERVICE PROVIDERS** (incl. clinicians, front line workers, community workers)
- ✓ **SOCIAL SERVICE PROVIDERS** (incl. legal aid)
- ✓ **MANAGERS AT FACILITY LEVEL** (incl. health facility managers, members of health facility oversight and advisory groups)
- ✓ **MANAGERS AT PROGRAM & POLICY LEVEL** (incl. from ministry of health, ministry of justice and other related ministries, at central and decentralized levels)
- ✓ **TECHNICAL PARTNERS & FUNDING PARTNERS** (incl. multilateral and bilateral partners)

**RECIPIENTS OF CARE**  
(including individuals and communities)

Key users of CLM Data to consider



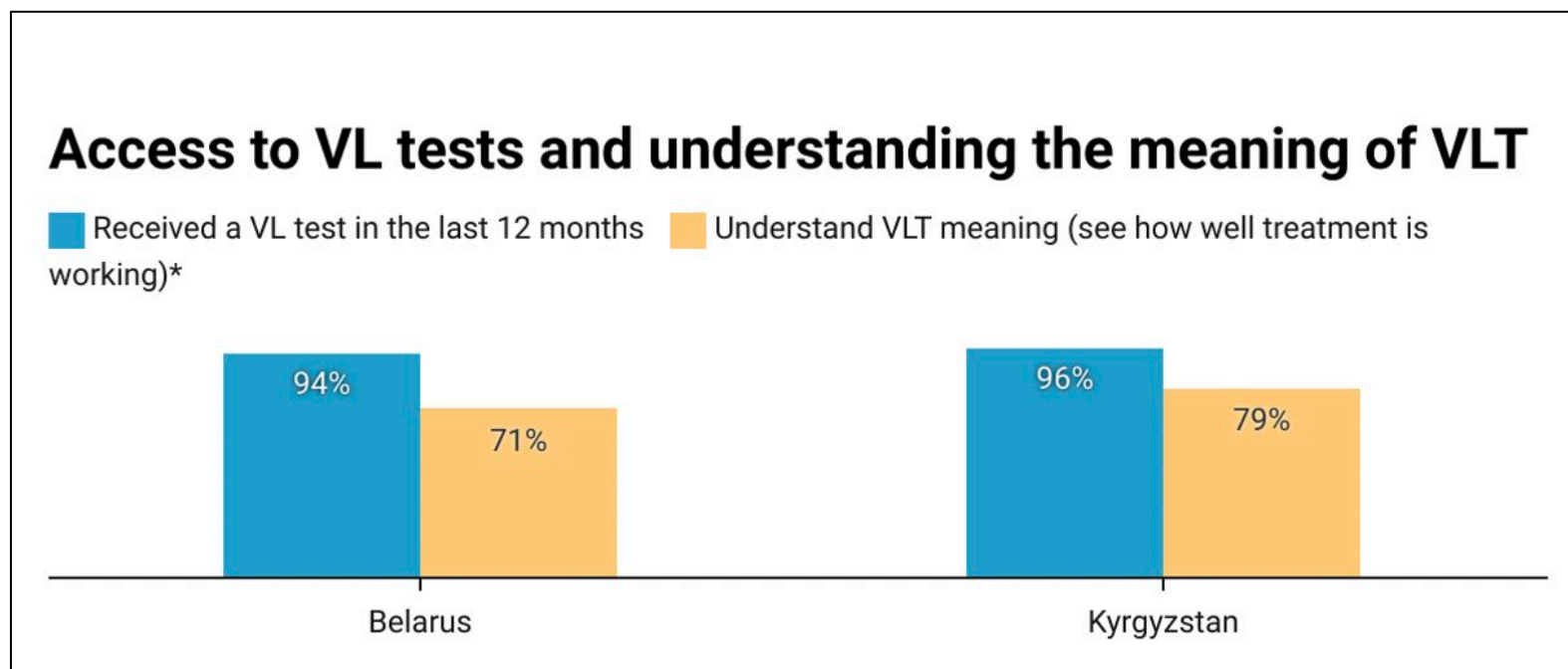
# 3. Engagement

## Data analysis, visualization, and communication

- Communities analyze their own CLM data and present the findings to a larger group of stakeholders
- Data analysis of trends over time helps to pinpoint the most urgent issues for action

## Partnerships and Mentorship is key

- Academics and/or expert consultants are often asked to assist with this step
- Have other key actors reviewing data and trends



*Community-led monitoring to assess treatment regimen among people living with HIV experiencing treatment failure Eastern Europe and Central Asia (2023) – ITPC Report to be published, preliminary results*

# 3. Engagement

## To whom do we present the data?

- Communities analyze CLM data and present the findings to a larger group of stakeholders – including key Lab staff
- Data analysis of trends over time helps to pinpoint the most urgent issues for action

## The end goal is change

- Reporting alone is insufficient
- Action to improve the conditions identified is vital

## What is a Community Consultative Group? (CCG)

- Multistakeholder technical advisory board
- Meets on a monthly or quarterly basis to review CLM data that have been cleaned, validated and analyzed and to prioritize advocacy issues

### Members of the CCG

The CCG typically has 10-15 members, including a chair, a vice-chair, and representatives from:

- **Normative agencies** (UNAIDS, PEPFAR, WHO, Global Fund)
- **Government organizations** (National AIDS and/or TB, Malaria programs; Ministry of Health) – Laboratories systems
- **Civil society organizations and partners** (**Networks** of key populations and people living with HIV networks.
- **Research institute or independent expert.** People with relevant expertise can be invited to join the CCG



## 4. Advocacy





# 4. Advocacy

## When problems aren't addressed, communities escalate to advocacy

- CLM data is compelling, but often the data alone is not enough to ensure changes are implemented
- CLM implementers have to plan advocacy efforts – starting with identifying who has the power to affect change, then crafting evidence-based arguments

## Advocacy tactics vary

- Advocacy is **not only protests and placards in the streets** – it can take many forms, including cups of tea with stakeholders; dialogues around a boardroom table; citizen journalism, and presentations to elected officials or funders

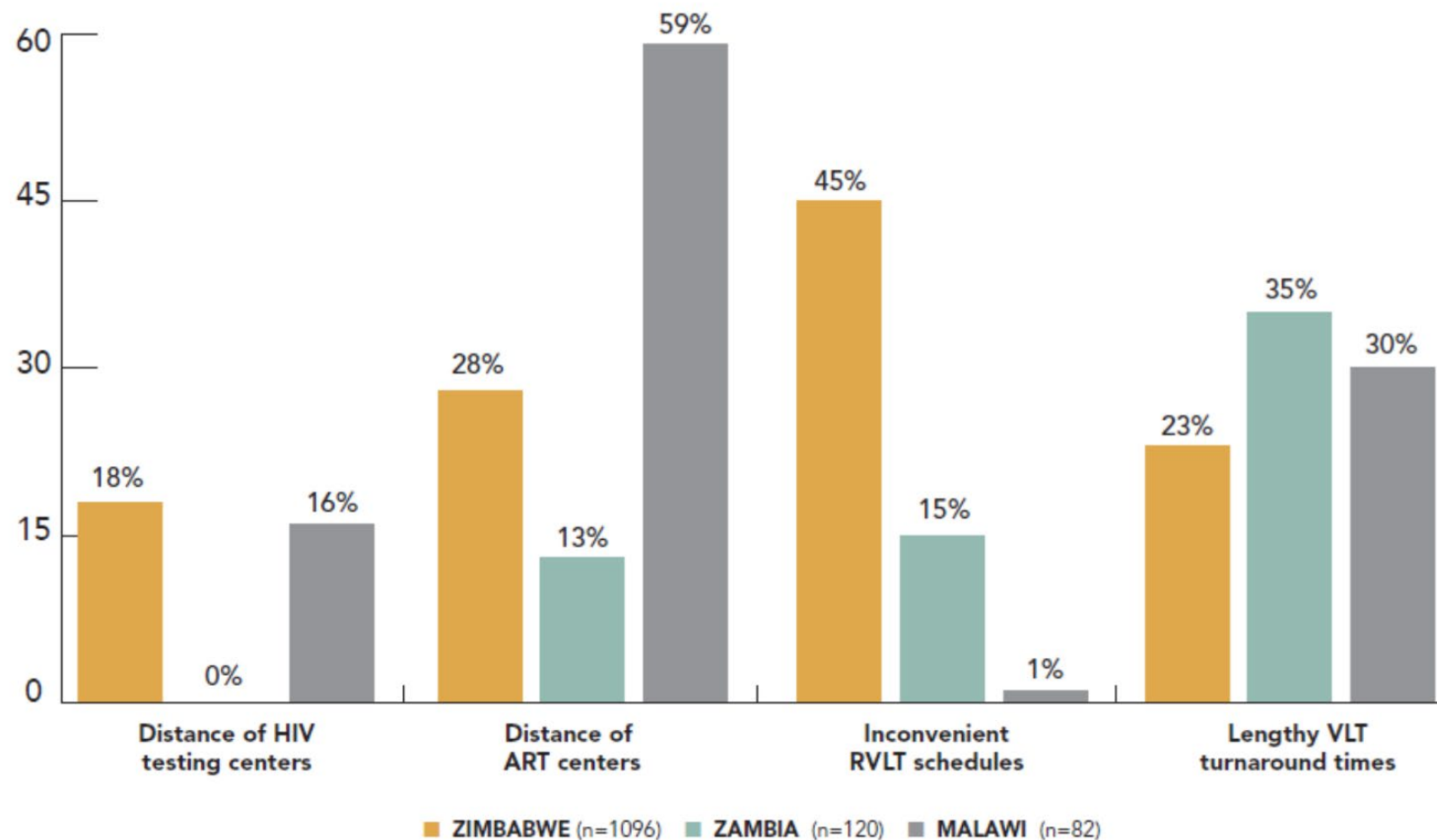


Citizen Science data collector Makhatazle Engie Tiba (left) with local government HIV secretariat member Lulu Kotobe Sosibo (right) at the Badirile Clinic in West Rand, South Africa (February 2022)

**ITPC's operational research indicates that Data Collectors are powerful advocates – leveraging their relationships in their own communities and with health facility staff to (a) inform others about problems or gaps and (b) to help push forward facility-specific changes**

# Change in National Guideline for VL testing: *Malawi Case Study*

**FIGURE 3.** Accessibility barriers along the HIV care cascade



2020 CTO data was also key in advocating for changes in the national guidelines for viral load testing.

After tireless advocacy from civil society, the Ministry of Health aligned with WHO recommendations, from 24 months to 12 months. This will improve HIV treatment monitoring.



Source: Doing things differently: Key findings from community treatment observatories in Malawi, Zambia and Zimbabwe

[https://itpcglobal.org/wp-content/uploads/2020/10/saCTO-Analysis\\_9-21\\_rev2-2.pdf](https://itpcglobal.org/wp-content/uploads/2020/10/saCTO-Analysis_9-21_rev2-2.pdf)

# Changes brought about by CLM

Improvements to Laboratory Systems, Diagnostics, and Outcomes



# The Citizen Science project

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

- 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.



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



# Community Partners



**NACOSA**  
COLLECTIVELY TURNING THE TIDE  
ON HIV, AIDS AND TB



**MANERELA+**

Malawi Network of Religious Leaders Living with or Personally Affected by HIV & AIDS

## 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).



# Case Study #1: Improved Viral Load Test Turnaround Times in Malawi and South Africa

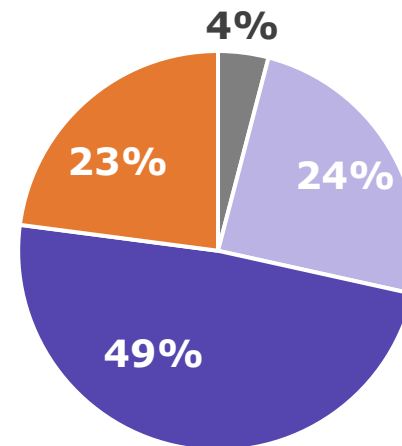
## COVID Era: Poor Quality Viral Load Monitoring

Before the pandemic, 23% of viral load test results at our 15 monitored health facilities in Malawi took **more than three months to be returned to the recipient of care**. During COVID-19, this figure rose to 39%.

*“This month was **my blood [viral load] month**. It was very different from the way they did things before COVID, because firstly, when I had to go take bloods at the clinic I used to go, weigh, and then see a Sister and then the Sister will see how am I doing. [This time] when I went back to her **all she did was give me my new appointment card for June**. It was very strange for me because I even asked ‘why are they doing it this way’ and they were saying ‘**they are trying to eliminate time spent at the clinic**.’”*

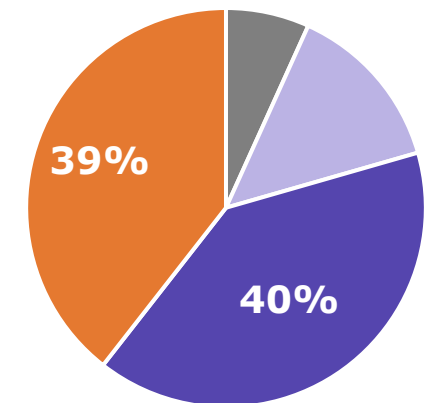
– Life Maps participant, South Africa

Before COVID -19  
(November 2018 - September 2019)



■ Within 2 weeks  
■ Within 1 month  
■ Within 3 months  
■ More than 3 months

During COVID-19  
(November 2020 - September 2021)



■ Within 2 weeks  
■ Within 1 month  
■ Within 3 months  
■ More than 3 months

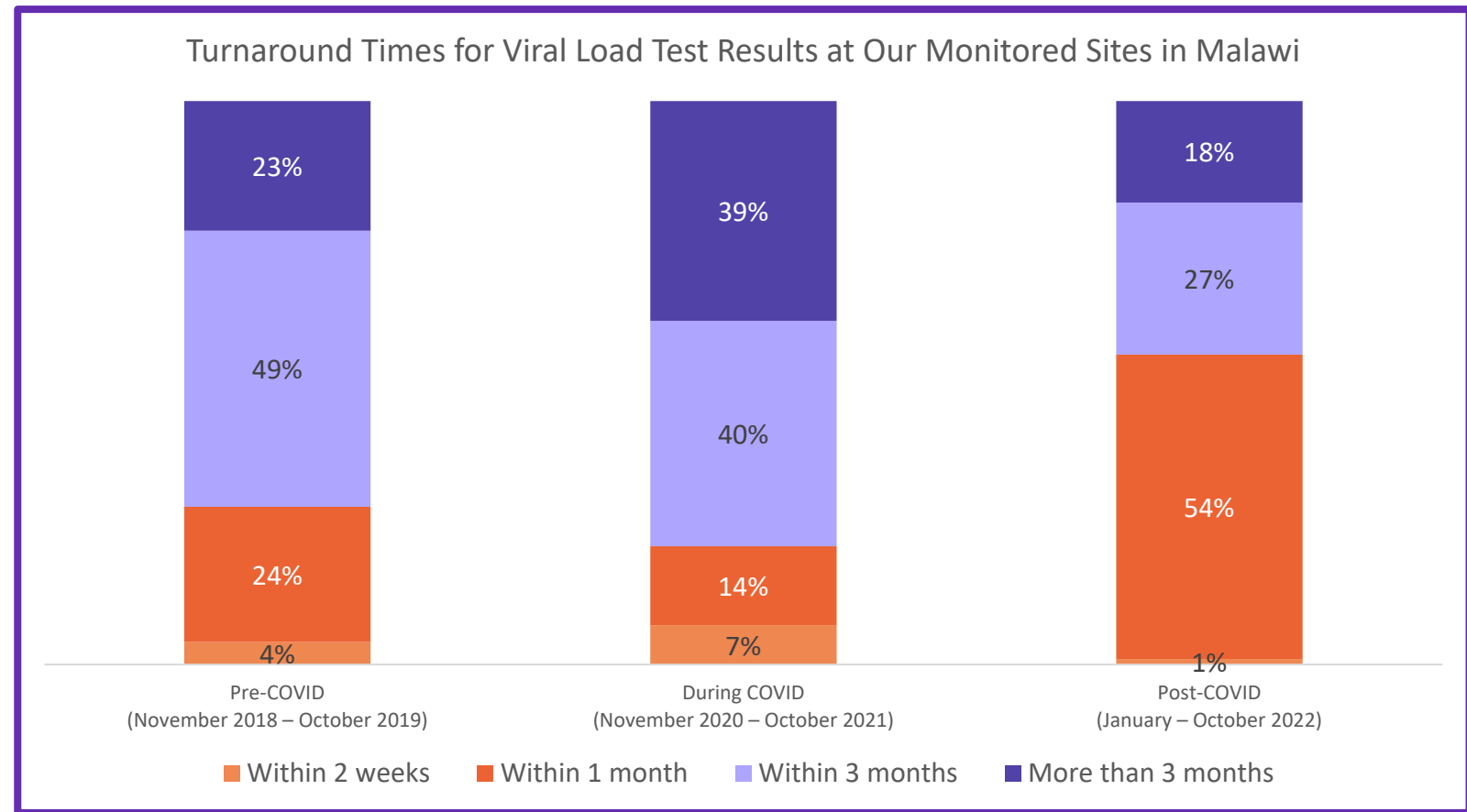
Increased turnaround times for viral load test results at our 15 monitored sites in Malawi



# Faster 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.



# 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.

*"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

*"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





# Case Study #2: 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	<b>Before</b> COVID-19 (November 2018 – September 2019)	<b>During</b> COVID-19 (November 2020 – September 2021)	% CHANGE
Number of HIV tests among the <b>general population</b>	80,215	59,864	Testing fell by 25.4%
Number of HIV tests among <b>men who have sex with men</b>	248	117	Testing fell by 52.8%
Number of HIV tests among <b>female sex workers</b>	132	27	Testing fell by 79.5%

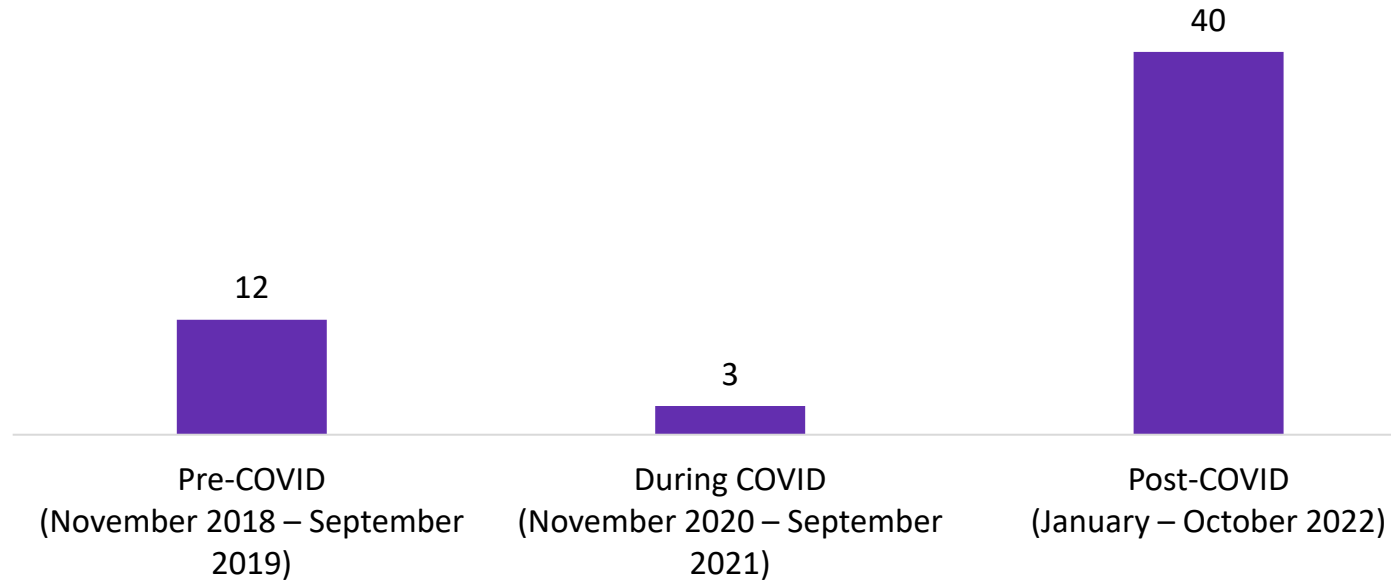
*“COVID has been one of the things that they prioritize, and when it comes to HIV testing, you don't get those mobile clinics or those tents anymore. Most of them, **they focus on COVID testing.** You might find that once in a week, there are tents that do HIV testing, but other than that, it's been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

– Life Maps participant, South Africa



# 2022: Access to HIV Testing Services for Priority Populations

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



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.

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



# 2022: Access to HIV Testing Services for Priority Populations

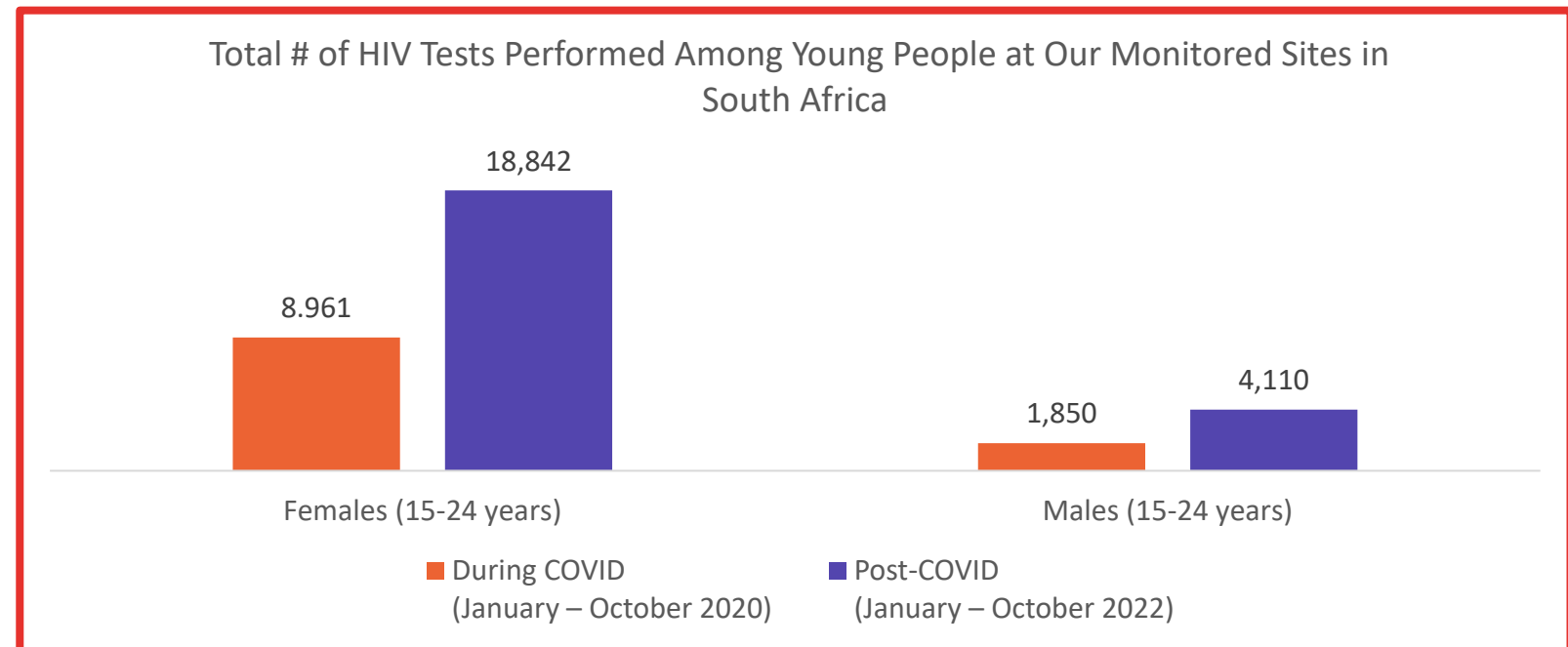
The number of HIV tests performed among young people at our monitored sites in South Africa has more than doubled since 2020. We employ 10 young people as data collectors who help encourage their peers to test.

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.”***



Availability and visibility of HIV self-test kits. *Photo by Life Maps participant in Malawi, 28 June 2022*



# 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 **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.**



# Case Study #3: ITPC's Regional Community Treatment Observatory (RCTO)

The power of **BIG DATA** in the hands of **Activated Communities**



**11**  
Countries



**631,863**  
HIV tests performed



**2**  
Years of monitoring



**105,435**  
People on ART



**84**  
Data collectors



**81,380**  
VL tests performed



**125**  
Health facilities



**1501**  
Interviews



**1781**  
Quantitative reports



**143**  
Focus groups



**98,651**  
Young people reached



**35,577**  
Key populations reached

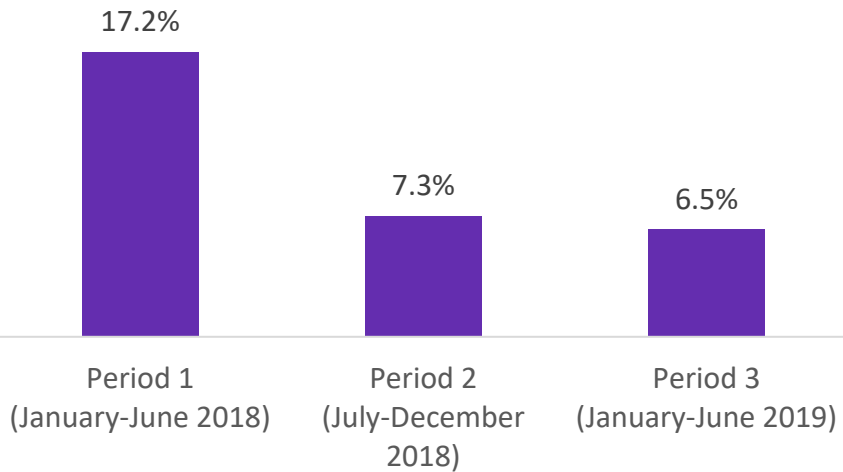
A representative sample size for the entire West and Central African region (95% confidence interval).



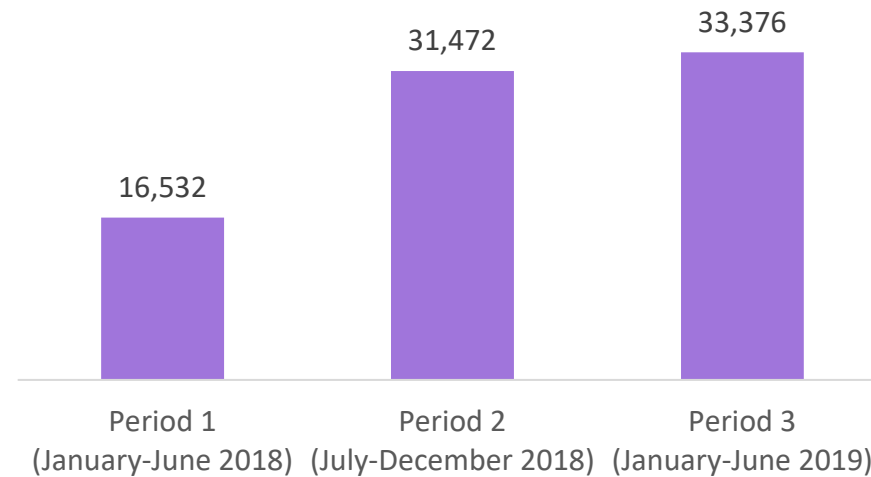
# CLM Leads to Demonstrable Improvements on Viral Load Supplies, Tests & Suppression

ITPC Regional Community Treatment Observatory – 11 West African Countries

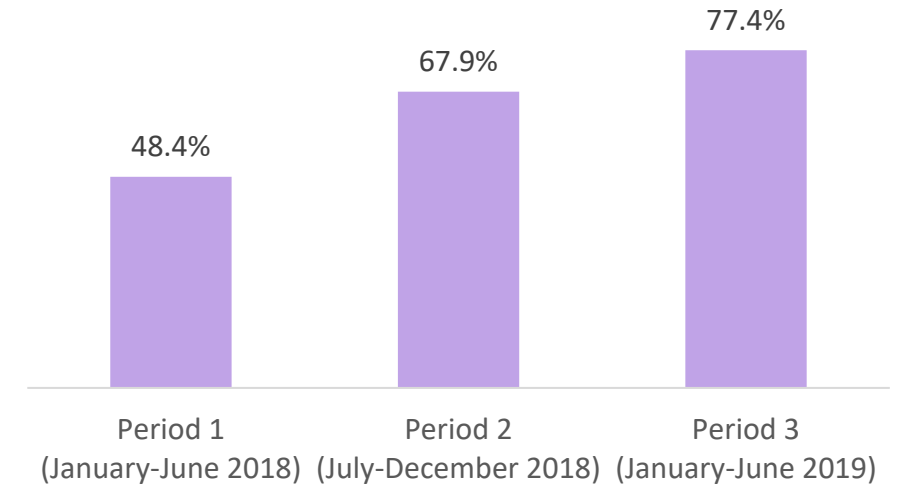
Frequency of Recorded VL Lab Supply Stock-outs at RCTO-WA Monitored Facilities



Viral Load Tests Performed at RCTO-WA Monitored Health Facilities



Rate of Viral Load Suppression at RCTO-WA Monitored Health Facilities



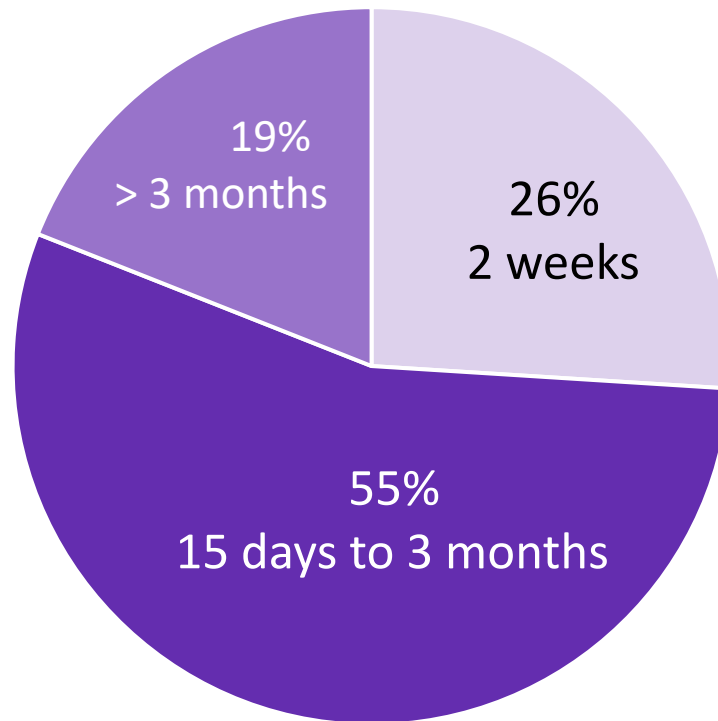
Source: <http://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>



# Viral Load Test Turnaround Time

IIPC Regional Community Treatment Observatory – 11 West African Countries

VL Test Result Return Time Across  
all 11 RCTO Countries in Monitored Sites



■ Within 2 weeks   ■ 15 Days to 3 Months   ■ More than 3 Months

Sadly, only 1 in 4 viral load test results are returned to the RoC within two weeks!

Source: <http://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>





## BENIN

### CTO SUCCESS STORY

## BENIN

At the Bethesda Hospital in Cotonou, Benin, CTO host REBAP+ noticed that the site had not been supplied with lab reagents for more than 10 months. This meant that patients were not receiving critical treatment monitoring services, including viral load and CD4 count test. The CTO data on reagent stock outs was recorded in REBAP+'s report, for presentation to the CTO's Community Consultative Group (CCG). During this meeting of the CCG, the Deputy Coordinator of The National AIDS Control Program (Programme santé de lutte contre le Sida-PSLS) was confronted with REBAP+'s CTO data on reagent stock-outs. The CCG's function as a feedback mechanism for the CTO worked, and a solution was found. After the meeting, PSLS stocked Bethesda Hospital with reagents.



## MALI

### CTO SUCCESS STORY

## MALI

The host of the national CTO in Mali, RMAP+, has used CTO data to improve quality of care in health facilities by improving data quality and individual patient monitoring. During a recent CTO monitoring visit to the Gabriel Touré University Teaching Hospital in Bamako, RMAP+ drew the attention of health facility managers to data entry issues. Viral load test results were being transferred from patient registers to the central viral load databases in groups, clustered by date. Using their CTO data analysis, RMAP+ pointed out that it is better to record this data individually, by patient.



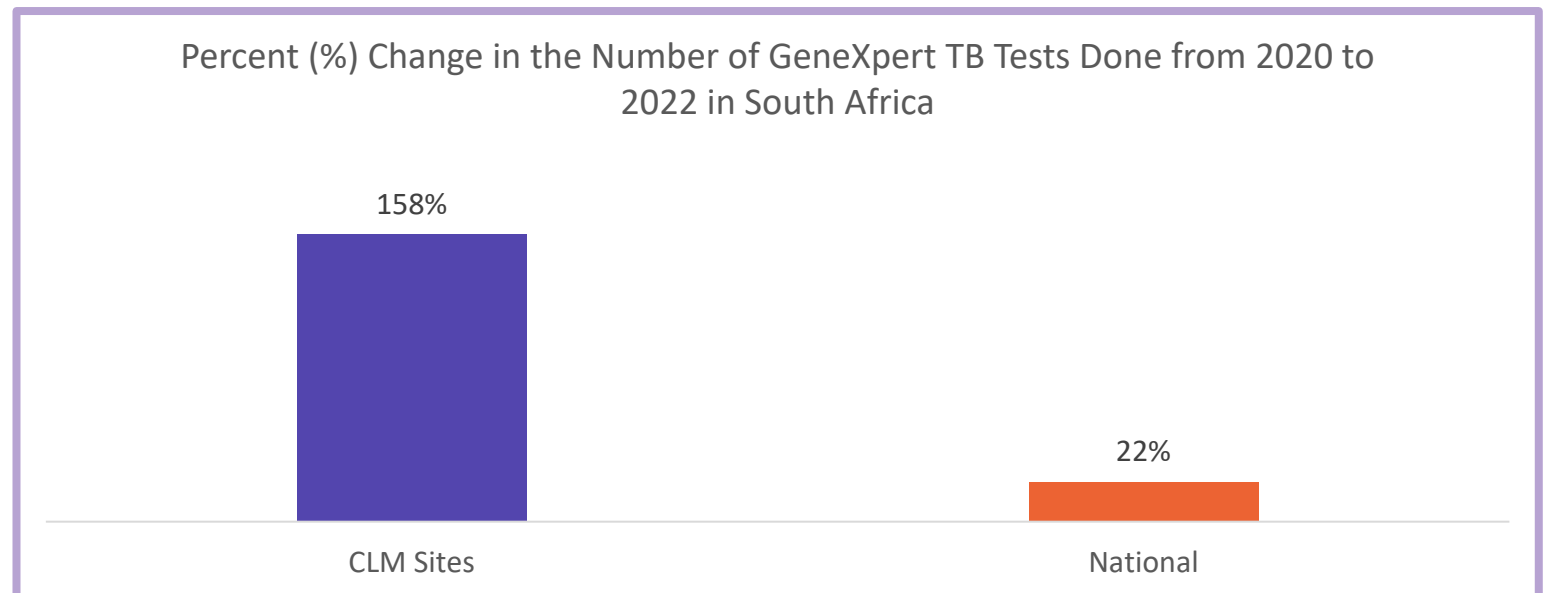
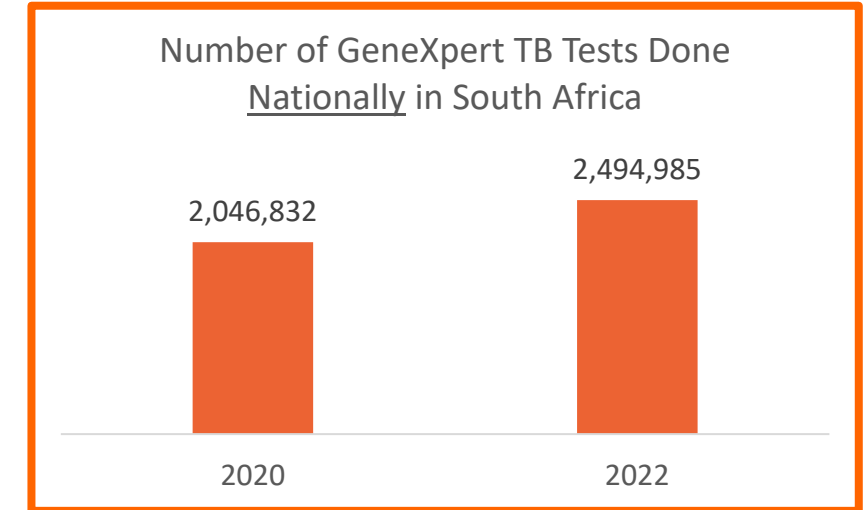
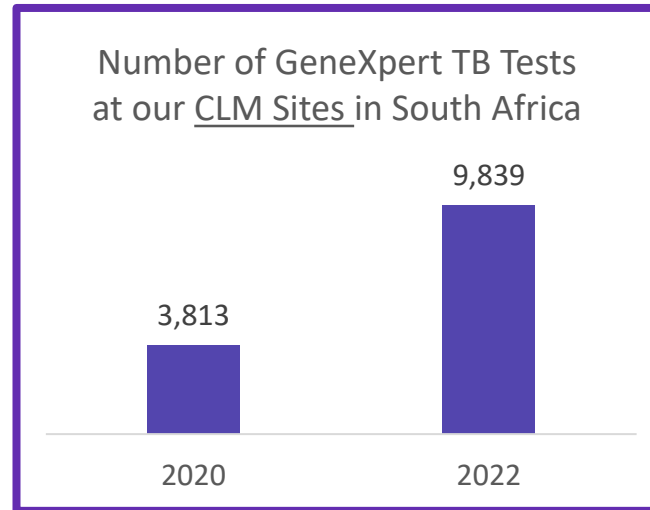


# Case Study #4: Finding Missing People with TB Through GeneXpert TB Testing

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 it's excluded for COVID, we go and test for TB.”*

Post-COVID, we are using our community-led monitoring data to do 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 monitored sites than in the rest of South Africa.**



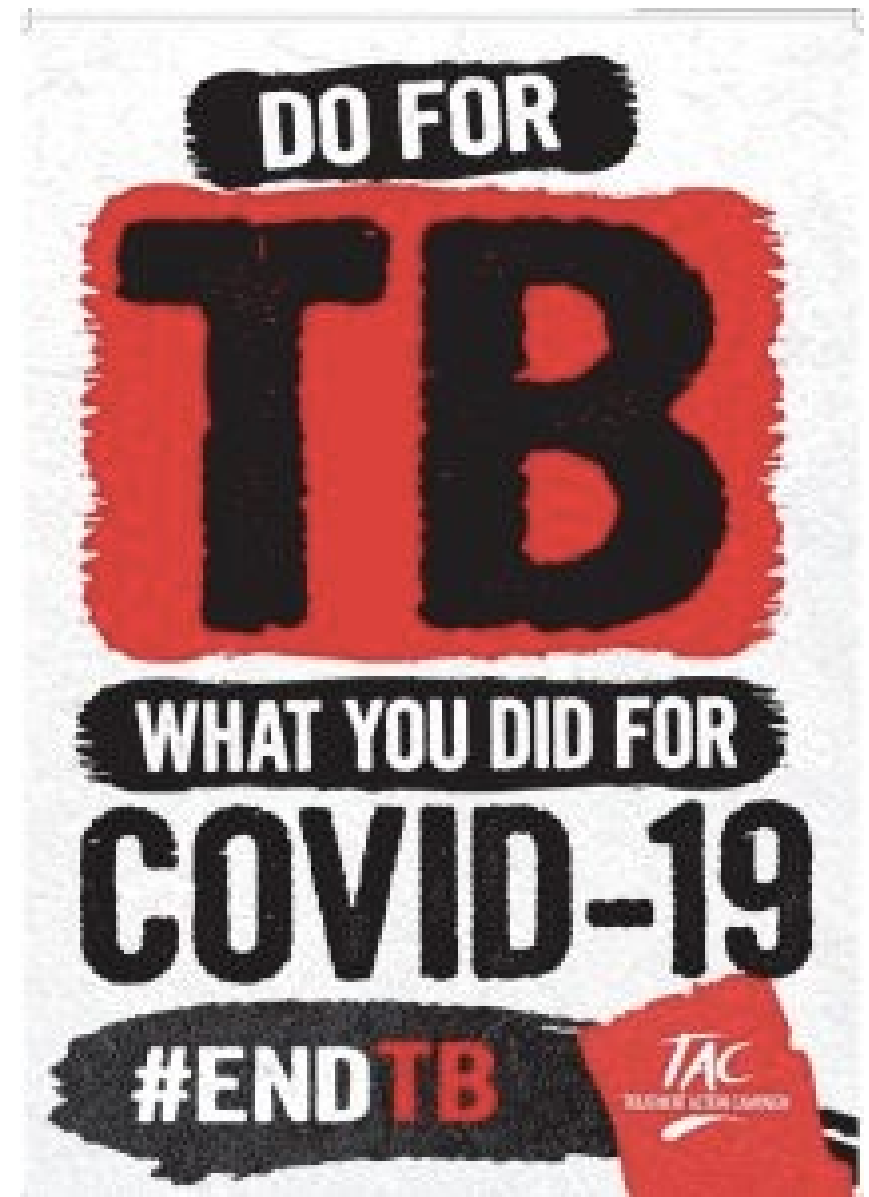
# Speedier Turnaround Times for Lab Test Results for TB

Turnaround Times for TB Tests at Our 19 Sites in South Africa, 2020 vs. 2022



Post-COVID, turnaround times for TB test results have dramatically improved in South Africa.

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



We used our CLM data to strengthen a national advocacy campaign on TB.

# Key Take Home Points for the Future of Strengthening Laboratory Systems

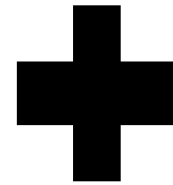
- Community data is credible and brings unique insights **not currently being captured through other evaluations**
- Recipient of care perspectives are **faster and better at pinpointing barriers** to services and poor quality of care than top-down approaches
- CLM has shown **demonstrable improvements** in viral load test turn-around times; addressing stockouts of reagents, and even improved viral load suppression
- Leaving communities out of efforts to strengthen laboratory systems is leaving expertise on the table – and at a time when health budgets are shrinking and we must all “do more with less,” we cannot afford to make this mistake



Addressing **network optimization challenges** and **diagnostic integration** requires engagement with affected communities that goes beyond business as usual.

Demand creation

Providing information to communities increases demand for diagnostics

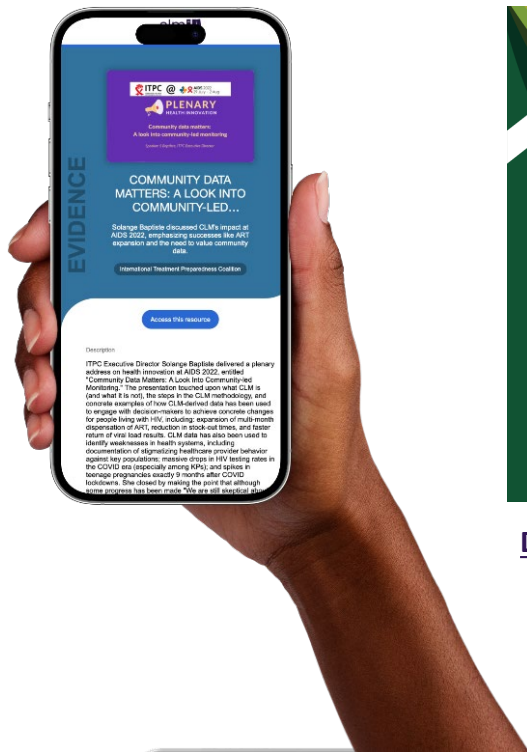


Community-led monitoring

Demand creation alone is insufficient to tackle systemic issues, need evidence-informed advocacy



# CLM Resources: [www.clmhub.org](http://www.clmhub.org)



Community-Led Monitoring of HIV, TB and Malaria Services in the Context of COVID-19

## Data Management Tools

Considerations for choosing tools for data collection, analysis, and presentation for Community-Led Monitoring

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Community-Led Monitoring of HIV, TB and Malaria Services in the Context of COVID-19

## A Community Guide for Introducing Decision-Makers to Using CLM Data

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Community-Led Monitoring of HIV, TB and Malaria Services in the Context of COVID-19

## Data Analysis Methods in Community-Led Monitoring

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Community-Led Monitoring of HIV, TB and Malaria Services in the Context of COVID-19

## From Insights to Evidence

A guide for translating program and policy priorities into qualitative and quantitative measures for Community-Led Monitoring

[Download PDF](#)

clm library

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

LEARN ABOUT THE SERVICE  
and normative standards for optimal prevention, treatment, care and support interventions, including on COVID-19.

DOCUMENT COMMUNITY EXPERIENCES  
accurately, clearly, concisely, that informatics and identify trends and problems.

## CLM Knowledge for All

Open access to the best resources on community-led monitoring (CLM)

EDUCATION EVIDENCE  
ENGAGEMENT ADVOCACY

EDUCATION

COMMUNITY-LED ACTION IS THE CRUCIAL COUNTERMEASURE

ITPC @ AIDS 2022 29 July - 2 Aug

PLENARY HEALTH INNOVATION

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ITPC 20th Anniversary

## Community-Led Monitoring for Increased Community Engagement in DSD Decision-Making and Programming

Results from a field rollout of the Community Engagement Tracking Tool in 20 African countries - July-Nov 2022

AUGUST 2023

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ITPC 20th Anniversary

## COMMUNITY-LED ACTION IS THE CRUCIAL COUNTERMEASURE

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## RESULTS MATTER

Community-Led Monitoring of Routine Viral Load and CD4 Cell Count Testing in Sierra Leone and Kenya

DECEMBER 2022

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