# A Reminder of What Community Engagement (CE) & CLM is

CE & Monitoring using Citizen Science with the CLM model

- CE is a structured, supported, meaningful and accountable process that ensures that people living with HIV have a SEAT and a VOICE in decision-making, planning, implementation, monitoring and evaluation, in order to achieve access to quality HIV care for all.

- CLM is a science-based accountability innovation through which communities collect data to generate evidence for improvements in services, programs, and policies.

*It is led by directly-impacted communities and owned by them*
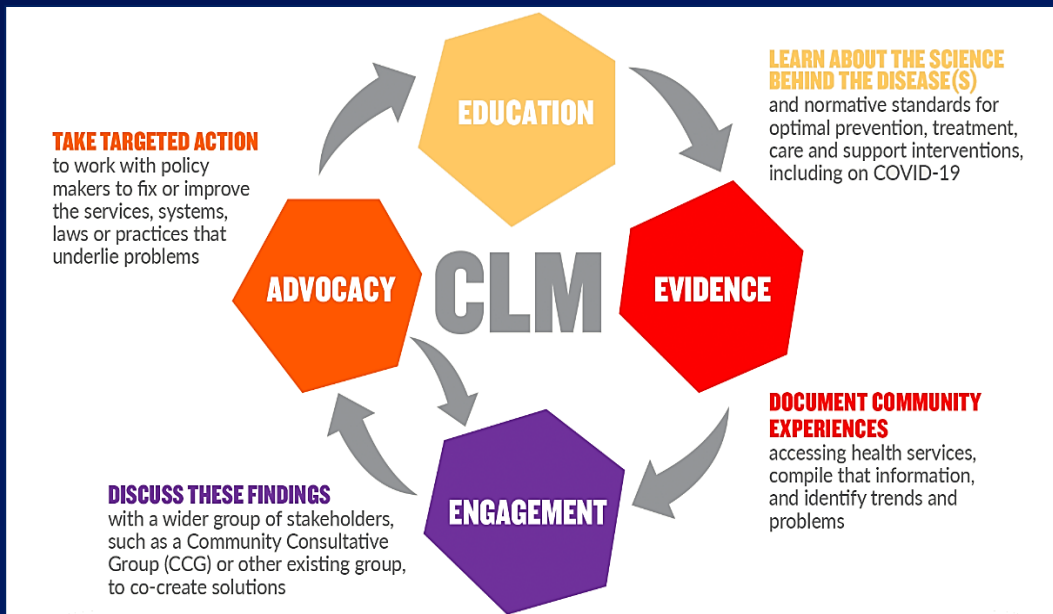
# Integration From the Community Perspective

**1. Holistic, Person-Centred Care**

Health is interconnected; integrating non-HIV services (like mental health, maternal care, and TB) means addressing the full spectrum of health needs, not just HIV.

People living with HIV often have additional health needs. Integrated care offers comprehensive treatment, improving overall health outcomes.

**2. Improved Accessibility**

By integrating services (e.g., HIV care with maternal health), people can access multiple services in one visit, reducing barriers like stigma, travel, and cost.

**3. Community Ownership**

Communities should be actively involved in the design, implementation, and monitoring of integrated services.

Engaged communities ensure services meet local needs, build trust, and improve care uptake, leading to more sustainable health systems.

## 4. Equity and Inclusion

Integrated services must be inclusive, ensuring marginalized groups (e.g., women, refugees, LGBTQ+ people) have access to all necessary care. Integration ensures that everyone, including vulnerable populations, gets the care they need.

## 5. Sustainability and System Strengthening

Integration should be a long-term commitment, with adequate funding, resources, and coordination between different sectors (e.g., HIV, mental health, maternal health).  Sustainable, well-resourced integrated services improve the overall health system, making it more responsive and resilient over time.

# What Role Can Communities Play in the Integration of Non-HIV Services



Lived Experience Navigating Health Systems

Collection of data on barriers and gaps on service integration in the ground

Co-creation of solutions based on community data

**Beyond demand generation:**
Communities should be engaged as **system experts** who **pinpoint problems** and **offer concrete solutions**

Ideally seen and treated as a WHOLE person!

Photo: Young man (age 15 years) at the Badirile Clinic in South Africa, receiving PrEP information for the first time

# Some Examples of Community Led Integration of Non-HIV Services

- Peer-led promotion of **regular screening for Non-HIV services** like TB, Cervical Cancer Hypertension, Diabetes, and Cardiovascular diseases into existing HIV services

- Community-led integration of **Non-HIV services Awareness & Education** into HIV counselling sessions to promote healthy living and prevent or manage especially NCDs

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

# Some Examples of Community Led Integration of Non-HIV Services - 2

- Help **coordinate ART with especially NCD treatments** and provide adherence support for both ART and NCD medication through community-based programs

- Help **strengthen health information systems** through CLM to capture and track both HIV and NCD data

# Some CLM Activities & Progress that Influence Integration



*Photo: Young woman in Malawi, employed as a Citizen Science data collector, conducting a clinic records survey*

- CLM was used to **identify service knowledge gaps** that boost knowledge and demand for services:
  - In South Africa, improved knowledge increased Uptake of **Voluntary Medical Male Circumcision (VMMC)**
  - And **increased PrEP uptake** in Malawi
- During COVID-19, CLM helped **find missing people with TB** in South Africa using GeneXpert for TB Testing by:
  - Improved record keeping
  - Ongoing advocacy (to prioritise testing)
  - Education (increased demand via awareness raising) at specific CLM sites vs non CLM ones
- Post-COVID, turnaround times for **TB test results dramatically improved** in South Africa

# Some CLM Activities & Progress that Influence Integration -2

- CLM was used to **monitor procurement of HCV treatment in EECA** countries helping in price reduction of the same over the years
- CLM collecting data on the number of **people who received intimate partner violence (IPV) screening** before being offered HIV services in Malawi to improve HIV testing
- CLM facilitated the **employment of Female sex workers** to collect data from and educate peers on SRHS etc. in Malawi
- CLM involved data collectors engaged with health workers in South Africa with regards to **access to contraceptives**
  - Pregnancies among adolescent girls and young women have since declined at monitored sites in South Africa post-COVID for all ages and sero-status groups

# TOP-LINE OUTCOMES IN SOUTH AFRICA - 2023

https://itpcglobal.org/resource/insight-influence-impact-clm-report/

Following PrEP-related CLM feedback sessions with facility managers, people who visited our 19 monitored sites were **32% more likely to initiate PrEP** following an HIV test compared to the other 70 West Rand health facilities (1.32 OR 95% CI 1.27-1.38).

The percentage of older **men living with HIV who know their status increased** from 86.8% in 2022 to 88.9% in 2023, following a CLM data-driven campaign to increase community-led HIV testing from 20.4% in 2022 to 33.6% in 2023 (UN target achieved).
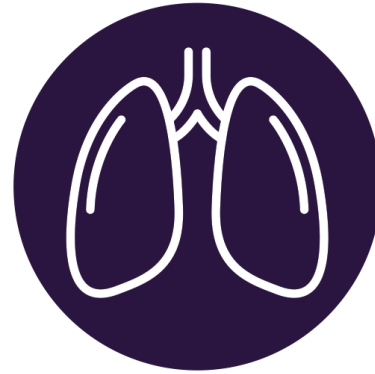
After using CLM data to alleviate **stockouts of TB** medicines, the **treatment success rate at our CLM sites increased** from 88% in 2022 to 91% in 2023, surpassing the End TB target of 90% by 2025 as well as South Africa's national treatment success rate of 79%.

Enhanced patient tracking for **pregnant foreign nationals** was implemented based on CLM insights. In 2023, women at our monitored sites were **twice as likely to deliver in the health facility** as compared to other West Rand facilities (1.99 OR 95% CI 1.51-2.62), reducing risk of vertical transmission.

When CLM data suggested HIV/SRHR service integration would increase HIV testing uptake (r = 0.36, p = < 0.001), we promoted this approach. In 2023, the **cost to diagnose one AGYW living with HIV was cheaper** at our CLM sites, at $2,852, compared with $4,154 at non-CLM sites (in terms of numbers needed to test).

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# TOP-LINES OUTCOMES IN MALAWI - 2023

https://itpcglobal.org/resource/insight-influence-impact-clm-report/

People accessing ART at sites with a CLM-informed DSD strengthening intervention were six times more likely to be in **a DSD model** (6.79 OR 95% CI 6.04-7.63) and **twice as likely to be virally suppressed** (2.34 OR 95% CI 2.16-2.54) as sites without DSD strengthening.
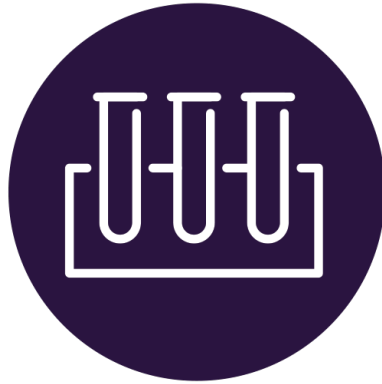
The number of **HIV tests among young sex workers doubled** (from 217 in 2022 to 434 in 2023), as did HIV positivity (from 1.7% to 2.4%), following CLM engagements with district hospitals to designate **key population focal points and KP clinic spaces**.

CLM data was used to engage **District Condom Coordinators** and train condom distributors, which led to a 23.4% **increase in condom distribution** in 2023. This contributed to **fewer new infections** in the two districts, which fell from 868 in 2022 to 632 in 2023.

CLM advocacy secured a commitment from the Global Fund to procure 50 new **GeneXpert machines.** As a result, 39% of TB tests at our CLM sites in 2023 were Xpert tests, up from 18% in 2022. **People diagnosed with TB and enrolled onto treatment nearly tripled**, from 320 in 2022 to 907 in 2023.

Following CLM advocacy to expand static VMMC sites, the proportion of **circumcisions among men aged 15 years and older increased** from 77% in 2022 to 82% in 2023. According to the Naomi model, there were 205 new HIV infections among men in this age group in the two districts in 2023, down from 284 in 2022.

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World Health Organization

GUIDELINES

CONSOLIDATED GUIDELINES ON

HIV TESTING SERVICES

2019

HIV TESTING SERVICES

# Screening for Intimate Partner Violence as Part of HIV Testing Services

In 2022, we began collecting data on the number of people who received intimate partner violence (IPV) screening before being offered HIV services.

This was catalyzed by qualitative reports that *"during COVID, the violence was there"* and that IPV *"is something that is now spreading."*

**Six health facilities in Malawi began informally collecting data on IPV screening as part of HIV testing after this new indicator was added to our community-led monitoring tool.**

**Indeed, community-led monitoring strengthens data collection at health facilities:**

*"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."*

**— Healthcare worker, Malawi**

CITIZEN SCIENCE

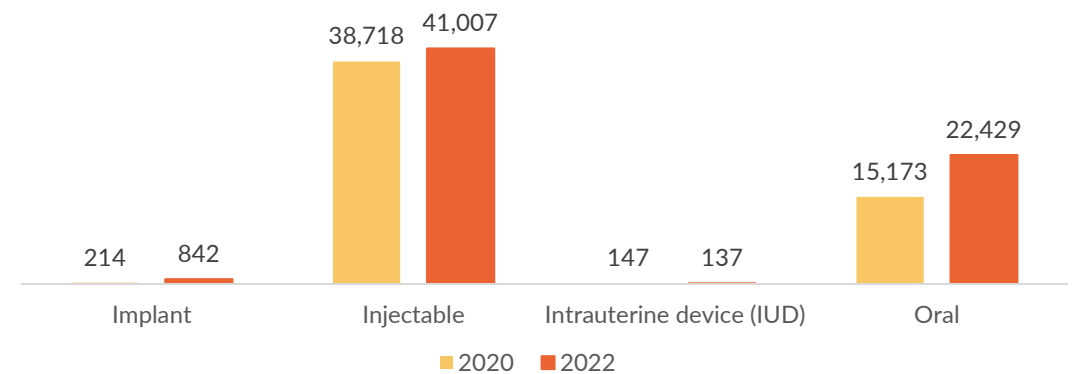# Increased Access to Contraceptives and Reduced Teenage Pregnancies

| Input | Output | Output | Outcome | Impact |
|---|---|---|---|---|
| **Indicator on contraceptive access added to CLM tool in South Africa** | Data collectors ask healthcare workers about contraceptive access during monthly data collection | Data collectors and CLM implementers work to popularize youth service times | CLM data reveal increased uptake of contraceptive services at our monitored sites | CLM data reveal fewer adolescent pregnancies at our monitored sites |

**January 2022-----------------------------------------------------------------------------**
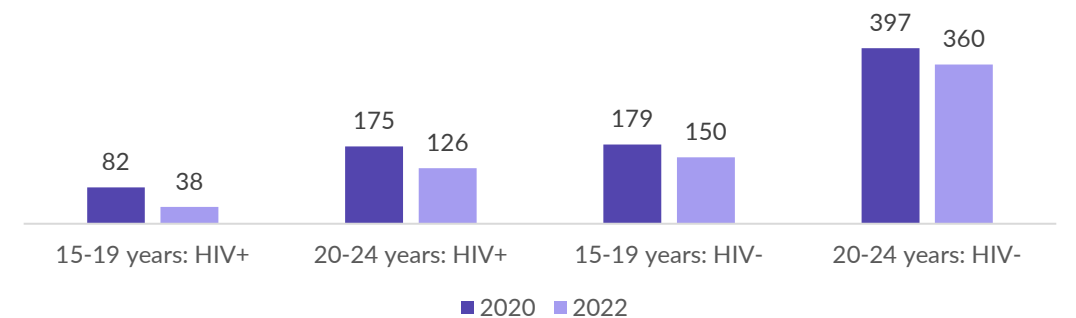**October 2022**

**Pregnancies among adolescent girls and young women have declined at our monitored sites in South Africa post-COVID for all age and sero-status groups.**

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



**Figure 15.** Number of People Accessing Contraceptives at Our Monitored Sites in South Africa, by Option, 2020 vs. 2022

Implant: 214, 842
Injectable: 38,718, 41,007
Intrauterine device (IUD): 147, 137
Oral: 15,173, 22,429

■ 2020 ■ 2022



**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

15-19 years: HIV+: 82, 38
20-24 years: HIV+: 175, 126
15-19 years: HIV-: 179, 150
20-24 years: HIV-: 397, 360

■ 2020 ■ 2022

# Challenges

**1. Limited Resources and Capacity**

Expanding CLM to monitor non-HIV services often requires more resources (e.g., funding, training, tools) that communities may not have. This can hinder the sustainability of monitoring efforts.

**2. Fragmented Health Systems and Coordination**

Different health services (HIV, TB, maternal health, mental health, etc.) are often managed by separate organizations or government sectors, leading to fragmentation. This lack of coordination makes it difficult to integrate services and data effectively.

**3. Stigma and Social Barriers**

Health issues like mental health, substance use, or sexual and reproductive health are often stigmatized. This can prevent communities from engaging fully in monitoring non-HIV services and hinder the inclusivity of the monitoring process.

# Challenges

**4. Resistance from Service Providers**

Health service providers may resist integrating non-HIV services into community-led monitoring, either due to concerns about losing their authority, lack of resources available to answer to additional needs, or fear of negative feedback, which can limit collaboration and the effectiveness of the monitoring system.

**5. Data Integration and Standardization**

Different health services may use distinct data collection tools, formats, and indicators, complicating the process of aggregating and analysing data across services. Without standardized systems, it becomes difficult to get a comprehensive and actionable picture of community health.

# Opportunities



- Community driven data should not be ignored; never ignore what comes out of the *'Horse's Mouth'*.
  - Community volunteers at local level could be used successfully **to collect indicator data at health facility level as well as to interview ROC and CHWs** to assess availability and accessibility of services and quality of care.
  - CLM projects upskilled previous volunteers to become **field researchers**

- **Better messaging of interventions** using CLM processes to achieve better outcomes
- **Better collaboration with Policy makers, Health workers and Academia** in improving integration of services
- Better **Acceptance of DSD services** by various communities

# Opportunities
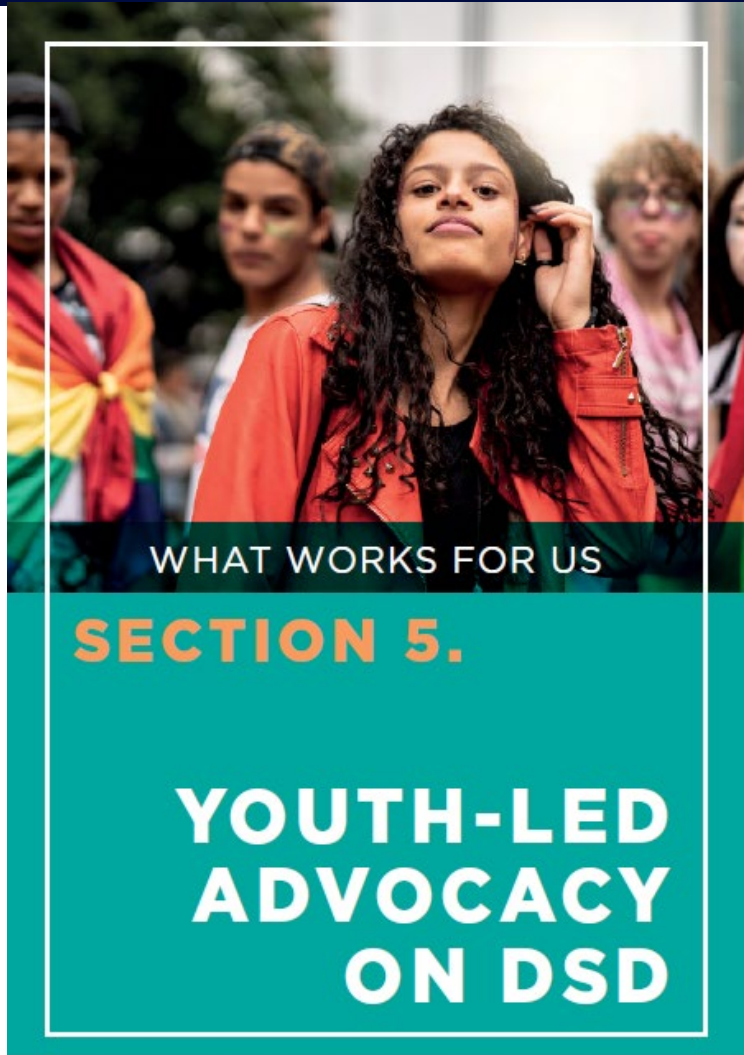
- Improved **Community empowerment** and Ownership

- **Increased Access to Integrated**/Comprehensive services

- Strengthening **Health Systems Accountability**

- **Tailored Interventions for Vulnerable Populations** (women/refugees/adolescents/ppl with disabilities)

- **Early detection and response** (problems with service delivery can be identified and addressed quickly.)

- **Health System Resilience**: CLM strengthens health systems, helping them adapt and maintain services in the face of challenges, including new pandemic (Mpox)

**WHAT WORKS FOR US**

**SECTION 5.**

**YOUTH-LED ADVOCACY ON DSD**
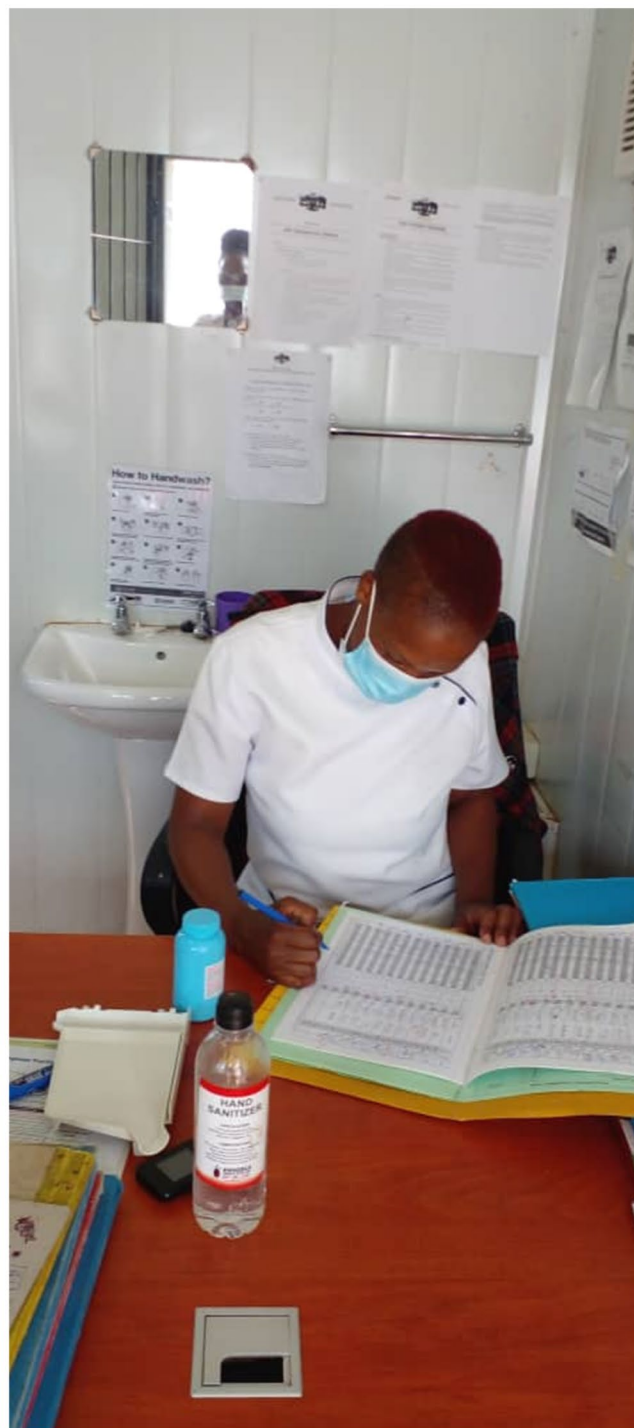
# Key Considerations for Integration:

1) **Community Capacity Building**: Ensure that communities are equipped with the necessary <u>skills and tools</u> to monitor and report on non-HIV services.

2) **Collaboration with Service Providers**: Foster relationships between <u>CLM groups and service providers to</u> ensure collaboration and constructive feedback.

3) **Inclusive Monitoring**: Ensure that monitoring efforts are <u>inclusive,</u> paying special attention to marginalized and hard-to-reach groups (e.g., people with disabilities, rural populations, migrants, etc.).

4) **Feedback Loops**: Develop clear <u>mechanisms for feedback</u>, where findings from monitoring are shared with authorities, and communities can follow up on changes or improvements.

By integrating these non-HIV services into community-led monitoring frameworks, communities can play a **pivotal role in ensuring that comprehensive health services meet the needs of everyone,** particularly the <u>most vulnerable populations.</u>

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# Take Away Messages



- You can't monitor and demand for services you don't know

  - CLM influences communities to <u>learn and gain knowledge of services</u> and what's needed and required

- CLM is used as an intervention to <u>mobilize and engage informed networks with authorities</u> to highlight their own priority problems and to <u>propose solutions</u>

- CLM helps <u>adjust policies, programs, and services</u> that address identified integration gaps, disparities, and population needs

- CLM helps improve <u>collaboration with service providers</u> to help solve integrated health challenges

- CLM can <u>influence In-country funding proposals and plans that allocate resources</u> to achieve greater equity, quality and effectiveness of existing integrated and future services and programs

- CLM helps expose and <u>stop human rights violations</u> that inhibit integration and uptake of programs

# CE Resources: https://itpcglobal.org/our-work/build-resilient-communities/community-engagement
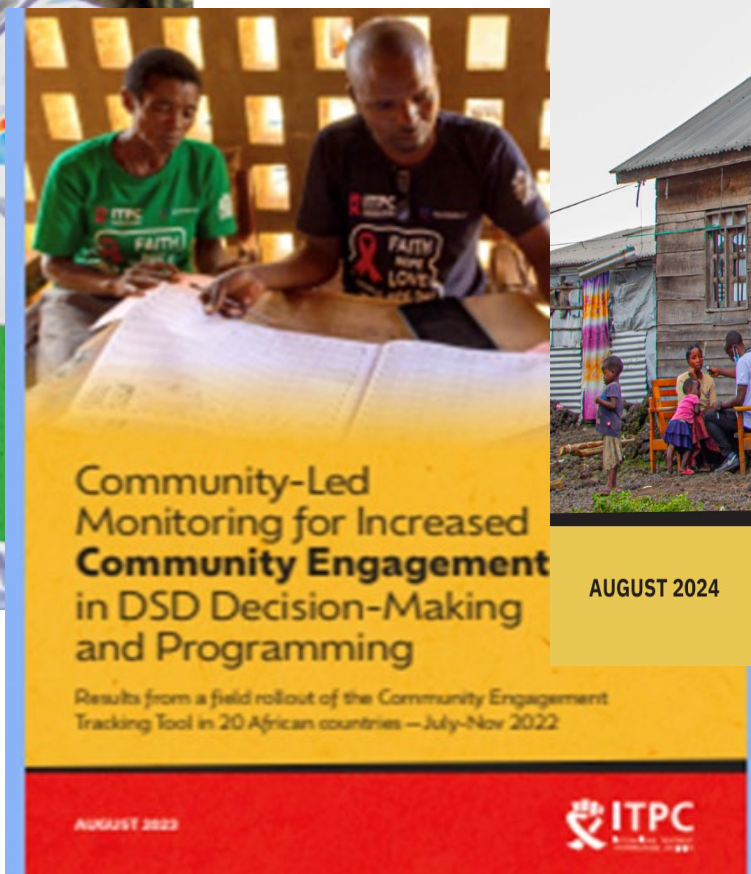
# CLM Resources: www.clmhub.org
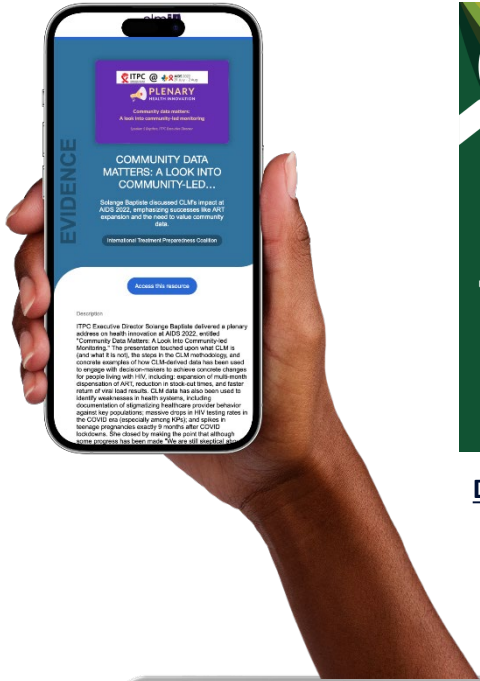


## Data Management Tools

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

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

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## Data Analysis Methods in Community-Led Monitoring

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## From Insights to Evidence

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

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## CLM Knowledge for All

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

EDUCATION   EVIDENCE
ENGAGEMENT   ADVOCACY

**Visit the Hub**
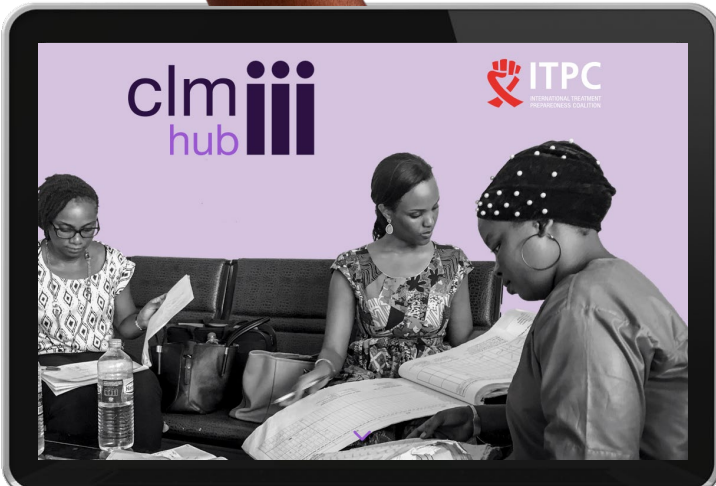
## Community-Led Monitoring for Increased **Community Engagement** in DSD Decision-Making and Programming

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

AUGUST 2023

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## COMMUNITY-LED ACTION IS THE CRUCIAL COUNTERMEASURE

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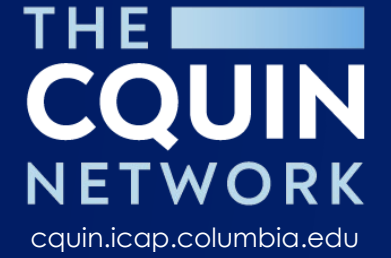
Community-Led Monitoring of Routine Viral Load and CD4 Cell Count Testing in Sierra Leone and Kenya

DECEMBER 2022

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# Thank You!