

Community Driven Actions to address the needs of children & adolescents

Handaa Enkh-Amgalan and Gloriah Moses



DEFINING CLM

*“A science-based accountability innovation
that puts communities first”*



What Is Community-Led Monitoring?

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 whole data story
X One-time evaluation (a “snapshot”)	✓ Routine, recurring data collection over time (usually monthly or quarterly)
X Data is owned by entities outside of the community (governments, healthcare facilities)	✓ Data is owned by communities
X Fault-finding	✓ Fact-finding
X The end goal of the data is to understand the trends and issues	✓ The end goal is to improve a particular issue that has been identified as important by communities

Community-Led Monitoring Defined

- CLM is a process where communities take the lead to routinely monitor **issues that matter to them**.
- 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.



CLM Principles

Despite slightly different CLM definitions by UNAIDS, Global Fund and PEPFAR and FRENCH 5 %, the key three principles of:

- a) Community-LED (community ownership)
- b) Community organization for effective monitoring, and
- c) Community focus on enacting change and ensuring accountability

...are consistently present in all definitions.



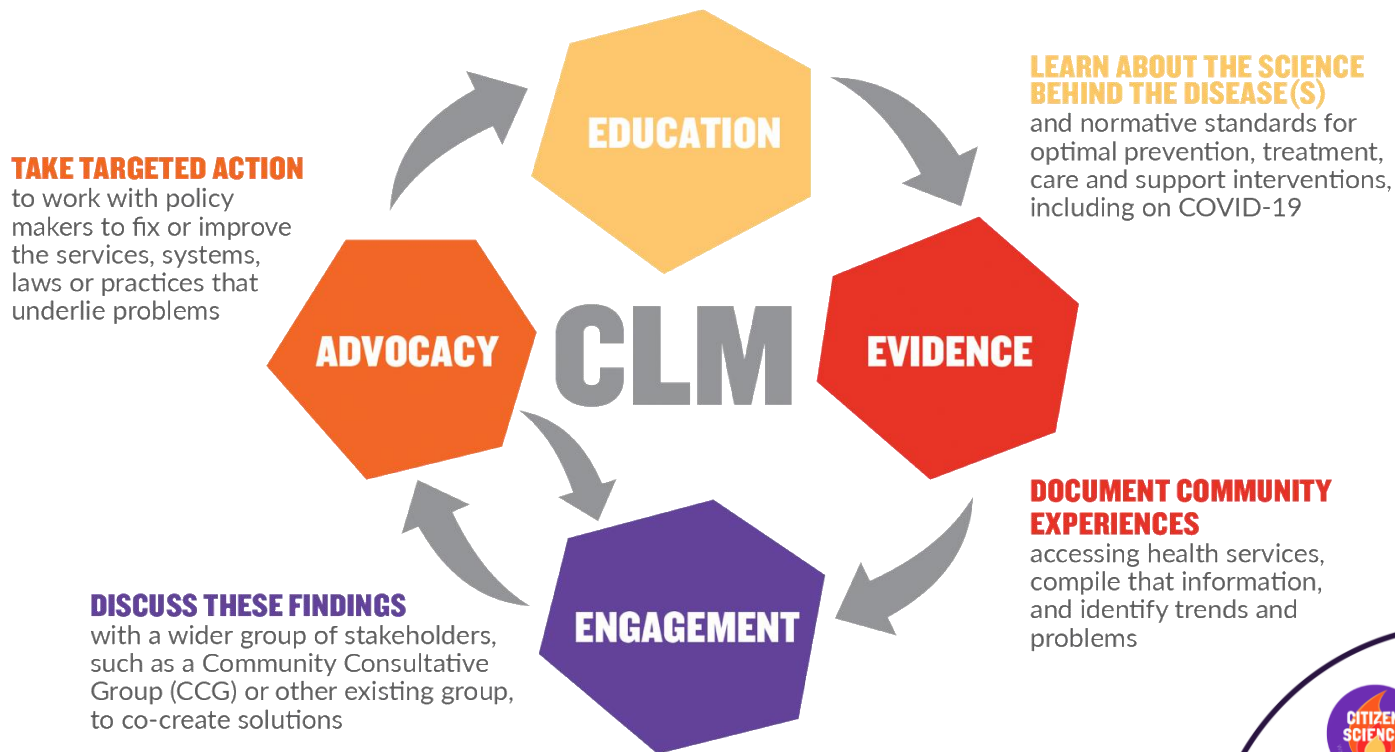
CLM in Action

*The CLM Model: Citizen Science Project
Implementation*



The Citizen Science Approach

ITPC'S COMMUNITY-LED MONITORING MODEL



The Triple I Report - 2023 CLM Data Report!

*Insight, Influence & Impact: 10 Big Change
Stories from the Citizen Science Community-
Led Monitoring Project in 2023*



Top-line CLM Outcomes in 2023 – SOUTH AFRICA



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).



Top-line CLM Outcomes in 2023 – MALAWI



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.

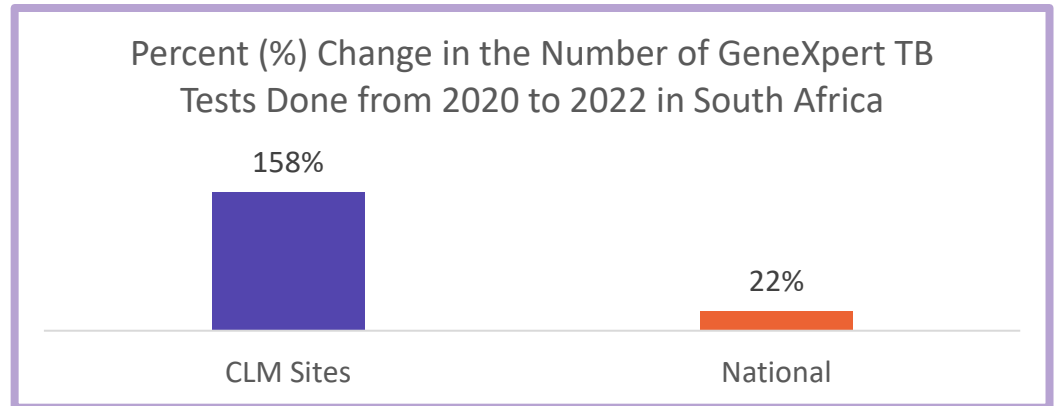
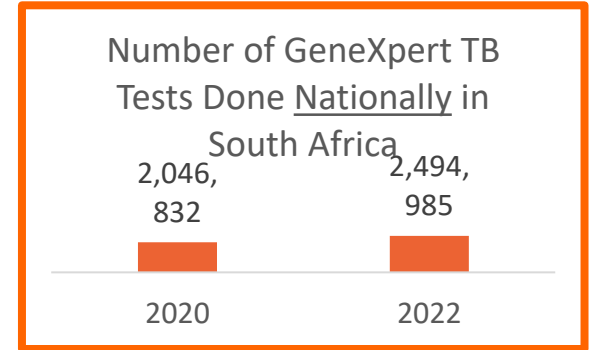
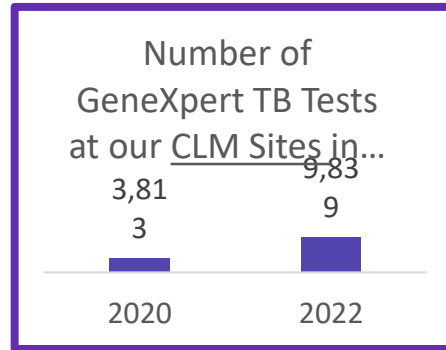


Case Study #4: Finding Missing People with TB Through GeneXpert TB Testing

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 if 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.



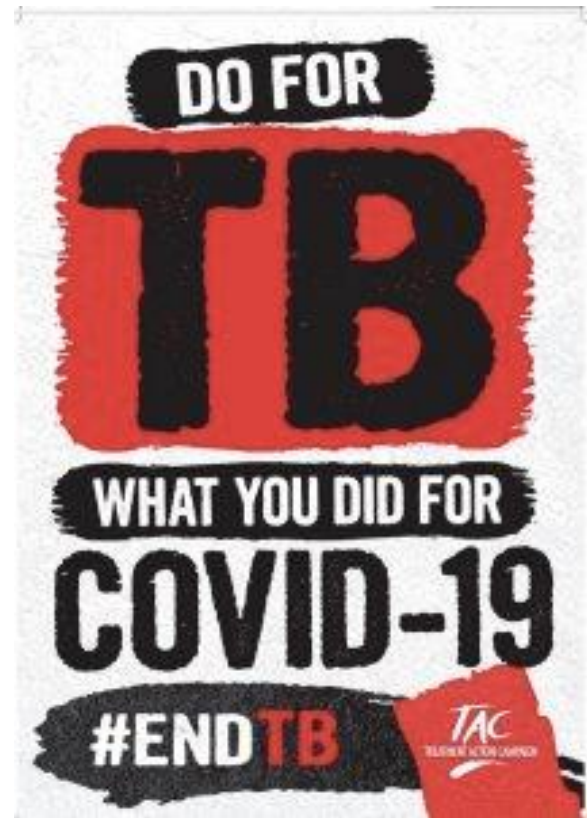
Speedier Turnaround Times for Lab Test Results for TB

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.

CLM for Pediatric TB

A pilot CLM framework to improve TB care for children and adolescents.



About the pilot

- **Context:** Significant paediatric TB burden, especially in low-resource areas.
- **Purpose:** A pilot project to develop and pilot a CLM framework aimed at improving TB care and response for children and adolescents.
- **Locations:** Implemented in South Africa and India

Methodology

- *Qualitative Approach:* Focus group discussions (FGDs) and interviews with healthcare workers, caregivers, and community members.
- *Assessment Framework:* Indicators on Availability, Accessibility, Acceptability, and Quality (AAAQ).



Pilot Key findings



1. Diagnosis and TPT Awareness Gaps:

Low awareness of TB Preventive Treatment (TPT) among caregivers.

2. Medication Shortages:

Inconsistent supply of pediatric TB drugs, leading to treatment interruptions.

3. Accessibility Challenges:

Costs and distance are major barriers, especially for families with limited resources.

4. Support Needs: Insufficient infrastructure for children with disabilities, limited gender-sensitive services, and lack of mental health support.

Next Steps

Recommendations

- Awareness Campaigns: Increase TPT awareness using community media.
- Infrastructure Improvements: Establish local X-ray services, enhance facilities for disabilities.
- Support Mechanisms: Transportation reimbursement, steady medication supply.
- Feedback Systems: Formal channels for caregivers to voice needs and feedback.

Conclusion

- Rollout of the CLM Framework in different contexts.
- Empowering Communities: CLM framework encourages caregiver and community participation.



When Communities Lead

- **Ownership of the Process** – communities have a vested interest in the outcomes; data collected does not “vanish” as it often does with other traditional researchers. Community systems are also strengthened in the process – staff develop skills in data management, M&E and advocacy, orgs. build program track record etc. (CSS).
- **Appropriate & Responsive Interventions** – solutions are closer to the issues; community-led interventions can generate more valuable (honest) insights to address their pressing needs.
- **Action- & Accountability-focused Results** – data collection & analysis is for a purpose; it is directly linked to advocacy or other targeted action to improve quality and service delivery and hold duty-bearers to account. **Success is measured here.**



Communities are Experts!

Learn more about the White Coat
Activism:

<https://itpcglobal.org/our-work/white-coat-activism/>



Connect Interact Learn!!

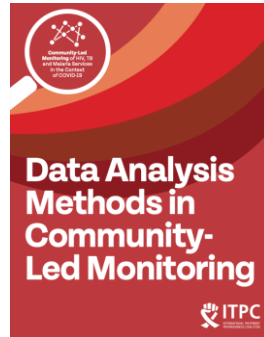
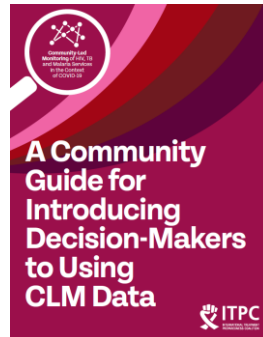


ITPC Website: itpcglobal.org

CLM HUB: CLMHub.org

CLM Library: library.clmhub.org

Contact: gmoses@itpcglobal.org



Thank You!

