

Conflict of interest disclosure

I have no relevant financial relationships with ineligible companies to disclose.





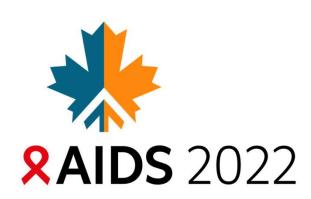




Health Innovation

#AIDS2022

Community Data Matters: A Look Into Community-led Monitoring







Sincere Thank You

- Access Chapter 2
- Centre Plus
- NACOSA
- NETHIPS
- MANERELA+
- Ritshidze
- Rotanganedza
- Wame Jallow
- Jane Harries
- Rebecca Hodes
- Gemma Oberth
- Susan Perez
- Emmanuel Simon
- ITPC West Africa Regional Community Treatment Observatory Team and 11 PLHIV Network Partners
- Global Public Investment Expert Working Group
- Global Fund Advocacy Network
- The Bill and Melinda Gates Foundation
- The CQUIN Project for Differentiated Service Delivery and the Community Advocacy Network (CAN)
- The Global Fund for HIV, TB and Malaria
- UNAIDS
- ITPC Regions
- ITPC Global Staff



Photo Credits

BBC slide 48

https://www.bbc.com/news/world-africa-40653944

Cepheid slide 8

https://www.cepheid.com/en/systems/GeneXpert-Family-of-Systems/GeneXpert-System

The Guardian slide 48

https://www.theguardian.com/global-development/2016/jul/31/aids-could-spiral-out-control-

africa-again-experts-warn

HIV Justice slide 48

https://www.hivjustice.net/news/brazil_law_withdrawn/

NETHIPS slide 37

Ritshidze slides 34 and 35

UNAIDS (HPTN 05 Study) slide 8 Shutterstock slide 13 Nkosikhona Mpungose slide 33

Thobani Ncapai slides 29 and 54









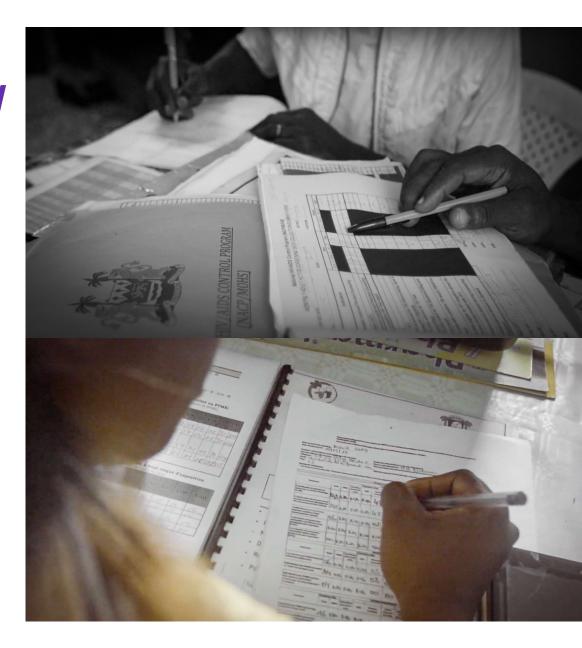


Community-led monitoring



global health innovation.



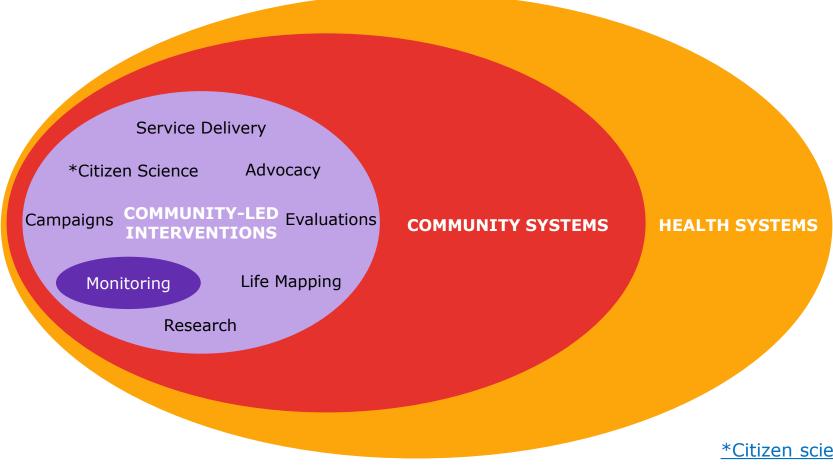


WHAT IS CLM?

Understanding Community-led Monitoring in Context



CLM in Context





*Citizen science

CLM is NOT...

Community-based Monitoring



- Monitoring people by governments or any other group
- Providers carrying out monitoring projects with the support of recipients of care
- A parallel M&E system to the routine government monitoring and evaluation
- Communities covering data collection gaps for donor M&E
- X Only data collection
- X A snapshot of data (cross-sectional data) to understand recipient of care experiences
- \mathbf{X} A quality improvement (QI) initiative



Community-led Monitoring IS...

Community-led





- ✓ Monitoring of services BY communities (end-users) or recipients of care
- ✓ Same data measured over time
- ✓ Monitoring of indicators that are relevant to communities in order to improve services
- ✓ Monitoring that provides an evidence base for advocacy





Community-Led Monitoring *Defined*

CLM is a process where communities take the lead to <u>routinely</u> monitor **issues that matter to them.**

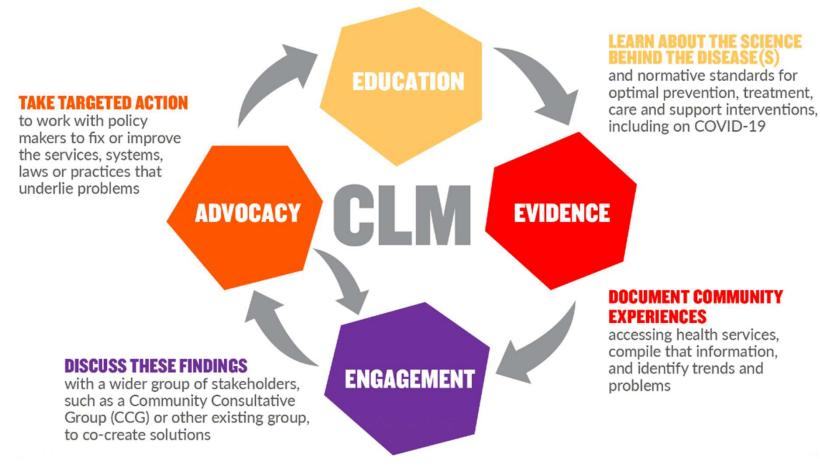
Communities then work alongside policymakers to co-create solutions to the problems they have identified.

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.



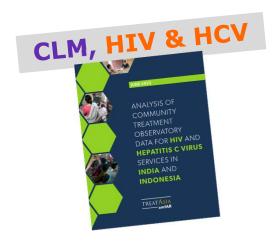


ITPC's Community-led Monitoring Model





Applying CLM as a Model in Varying Contexts

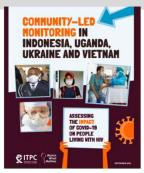
















https://itpcglobal.org/?resourcetopic=community-monitoring



CLM, HIV & TB Treatment



Need and gap analysis

2 Indicator selection & data collection

3 Data analysis with periodic data quality assessments

LOCAL targeted action and co-

Community
Consultative Group
(CCG) meetings to
determine
advocacy priorities

6 Targeted action and co-problem solving for **CHANGE**



problem solving

DATA IN ACTION

Concrete Examples, Actionable Data Insights and Advocacy Wins





2018 Regional Community Treatment Observatory Project in West Africa (RCTO-WA)





сто	HOST ORGANIZATION
BENIN	Réseau Béninois des Associations de Personnes vivant avec le VIH (REBAP+)
CÔTE D'IVOIRE	Réseau Ivoirien des organisations de Personnes vivant avec le VIH/SIDA (RIP+)
GAMBIA	Gambia Network of AIDS Support Societies (GAMNASS)
GHANA	National Network of Persons Living with HIV in Ghana (NAP+ Ghana)
GUINEA	Réseau Guinéen des Associations de Personnes infectées et affectées par le VIH/SIDA (REGAP+)
GUINEA-BISSAU	Rede Nacional das Associações das Pessoas Viventes com VIH (Network of Associations of PLHIV of Guinea Bissau) (RENAP+GB)
LIBERIA	Liberia Network of People Living with HIV (LIBNEP+)
MALI	Réseau Malien des Personnes vivant avec le VIH (RMAP+)
SENEGAL	Réseau National des associations de PVVIH du Sénégal (RNP+)
SIERRA LEONE	Network of HIV Positives in Sierra Leone (NETHIPS)
TOGO	Réseau des Associations de Personnes Vivant Avec le VIH au Togo (RAS+)



The Power of **BIG DATA** in the Hands of **Activated Communities**





11 Countries



Years of monitoring



84
Data collectors



125 Health facilities



1781 Quantitative reports



631,863 HIV tests performed



105,435 People on ART



81,380 VL tests performed



1501 Interviews



143 Focus groups

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



98,651
Young people reached



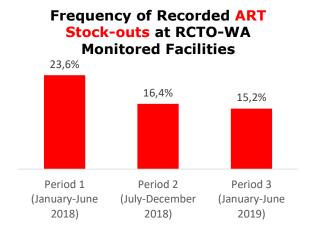
35,577Key populations reached

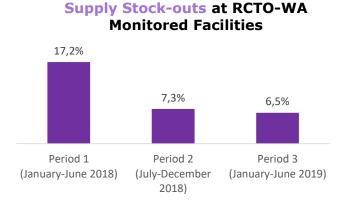


http://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf

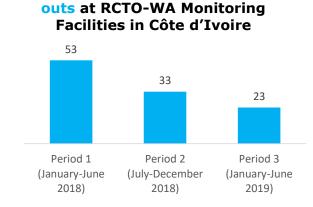


KEY RESULTS of the ITPC RCTO Project (2018)

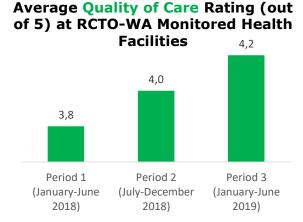


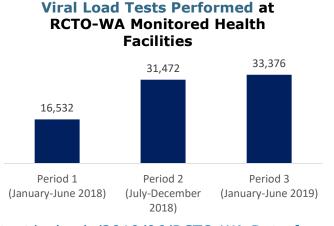


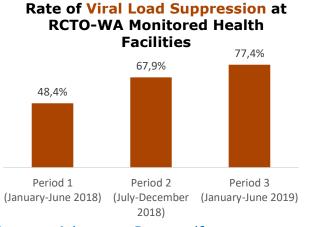
Frequency of Recorded VL Lab



Average Length (days) of ART Stock-







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

2020 *Citizen Science Project* DATASET AT A GLANCE



2 Countries HIV and COVID Monitoring

Malawi and South Africa



3 Districts

Dedza (MW), Kasungu (MW), and West Rand (ZA



29 Health Facilities

- 3 hospitals, 3 community health centers, and 24 clinics
- 5 in Dedza, 10 in Kasungu, 14 in West Rand





- 16 men (including 5 men who have sex with men, and 7 MLHIV)
- 41 women (including 5 sex workers, 2 lesbians, 1 transwoman, and 9
 WLHIV)
- 1 gender non-conforming person



884,000 people

Total catchment area of the monitored health facilities



1 year of continuous monitoring (Nov 2020 – Oct 2021)

• & retroactive data collection for a pre-COVID comparison (Nov '18 – Oct '19)



637 clinic records surveys

330 in Malawi & 307 in South Africa, with a total of 32 indicators monitored



318 Interviews

138 with healthcare workers and 180 with recipients of care



20 Life maps

Close anthropologies of how COVID-19 affects daily life for PLHIV





Young man (age 15 years) at the Badirile Clinic in South Africa, receiving PrEP information for the first time. ITPC's model always includes health education as part of community-led monitoring.

Community Data Collectors as Change Agents

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



Who asks the questions matters

The Citizen Science principle of going from data extraction to data democracy means that data collectors are not just gathering information—they are also change agents, providing health education and improved accountability. The data collectors regularly interact with the health facility staff about their findings and analysis and co-create solutions.



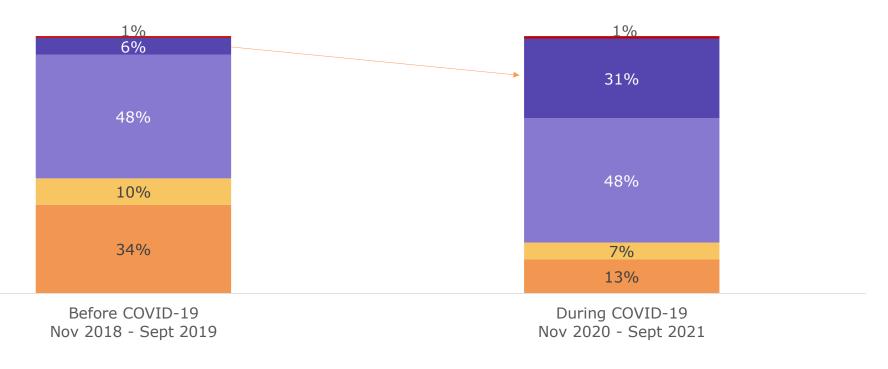


"THE GOOD"

Findings on the Scale-up of COVID-19 Adaptations

Expansion of Multi-Month Dispensing of ART

At our 15 monitored sites in Malawi, six-month ART dispensing grew from 6% in the before COVID-19 period to 31% during COVID-19.





■1 month ■2 months ■3 months ■6 months ■Other

Proportion of people living with HIV receiving multi-month dispensing of ART at our 15 monitored health facilities in Malawi

RITSHIDZE: CLM IN SOUTH AFRICA



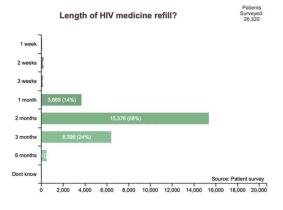
SUMMARY OF KEY RESULTS

October 2021 to June 2022

Facilities Assessed: 417
Observations completed: 1,189
Patient interviews: 44,361
PLHIV interviews: 29,999
Young people interviews: 9,482
Facility Manager interviews: 772
Medicines surveys: 804

We collect data through observations, as well as through interviews with healthcare users (public healthcare users, people living with HIV, key populations) and healthcare providers.

All Ritshidze's data collection tools, our data dashboard, and all raw data are available through our website: www.ritshidze.org.za



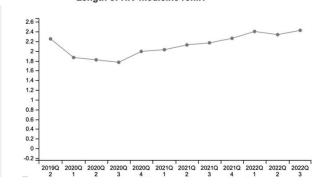


Length of HIV medicine refill?

Dont know

October 2020 to September 2021





Several key indicators of healthcare quality have improved in South Africa since the start of Ritshidze implementation. For example: ARV refill length has improved with 11% increase in people living with HIV collecting 3MMD in the last year.

October 2021 to June 2022

4.000 6.000 8.000 10.000 12.000 14.000 16.000

Community-Led Monitoring *driving the Global Conversation on Data*

ITPC and its partners started collecting data on multi-month dispensing of ART in September 2020 because it was particularly relevant to people living with HIV in the context of COVID-19.

A year and a half later, in February 2022, UNAIDS added multi-month dispensing of ART as a brand-new indicator in Global AIDS Monitoring GUIDANCE

Global AIDS Monitoring 2022

Indicators and questions for monitoring progress on the 2021 Political Declaration on HIV and AIDS

Page 106



7.14 People living with HIV receiving multimonth dispensing of antiretroviral medicine

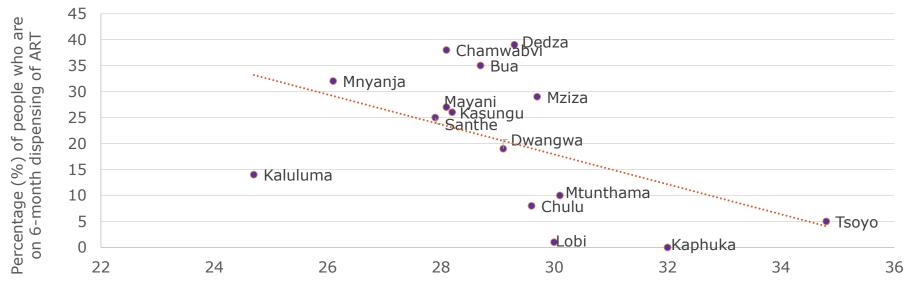
Proportion of people living with HIV and currently on antiretroviral therapy who are receiving multimonth dispensing of antiretroviral medicine

Quickly Resolve Stock-outs to Promote Further Scale-up of Multi-Month Dispensing





Our data show that the main factor delaying further scale-up of six-month dispensing is not whether stock-outs occur, but rather, how quickly they are resolved.





Average number of days that ARVs remain out of stock

Relationship between the duration of ART stock-outs and 6-month dispensing at our 15 monitored health facilities in Malawi



"THE BAD"

Findings on COVID-Related Service Disruptions and Quality of Care Challenges

Heightened Stigma and Discrimination

"We are serving a few people at a particular time and most people wait outside. The challenge is most people have not come out in the open, they think a relative might pass by and see them on the line. As a result, they are complaining that there is no privacy in the facility, hence we do not know how to help them. In the past, we used to allow all people to get inside the room and assist them all together and counsel them together, but now with COVID-19, that is not the case."

Health Surveillance Assistant in Malawi

CITIZEN SCIENCE Issues of confidentiality

As experienced by recipients of care...

"What makes it worse is the stigma and discrimination that as people living with HIV we are experiencing now with the pandemic. People have misinterpreted the messages of being at an increased risk to thinking that people living with HIV have the coronavirus and are infecting others."

Recipient of care, Malawi



As experienced by key populations...

"Us, as sex workers, people were talking bad rumors that we are spreading the disease COVID-19 because we meet with different people by the time we're doing our work."

Life maps participant

As experienced by health care workers...

"When I try to deliver my service in a community, people sometimes discriminate against

me, saying that it is service providers who are spreading COVID-

19 because they are mostly close to COVID-19 patients."

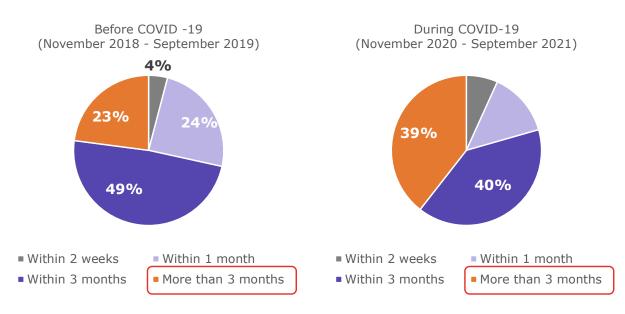
Health care worker

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







Limited Access to HIV Testing Services, especially for Key Populations

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."

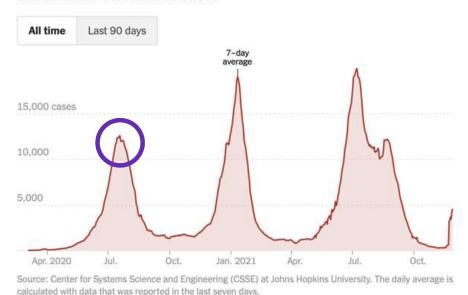


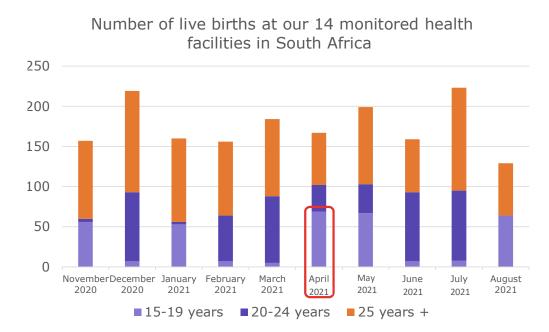
- Life Maps participant, South Africa

Spikes in Teenage Pregnancies

The highest number of live births to teenage mothers was in April 2021 (n=69), which follows exactly nine months after the peak of South Africa's first wave in July 2020.

South Africa Coronavirus Cases >







"During this period, we have witnessed as a nation of over 20,000 teenage pregnancies through coercion or by default falling prey to prevailing circumstances at the time. This 'pregnancy boom' was a result of induced school break for six months." – Life maps participant, Malawi

RITSHIDZE: KEY POPULATIONS

Ritshidze collects qualitative and quantitative data to document the challenges key populations face in accessing quality HIV, TB + other health services

Between August and October 2021 Ritshidze collected 5,979 surveys in 18 districts, across 7 provinces in South Africa

1476 quantitative interviews with gay, bisexual and other men who have sex with men

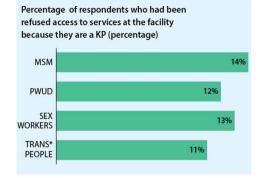
2397 quantitative interviews with people who use drugs

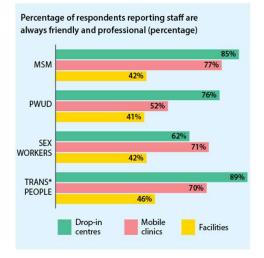
1344 quantitative interviews with sex workers

762 quantitative interviews with trans* people

398 additional qualitative interviews with key populations

"The staff here in this clinic do not treat us people who use drugs as human beings. They are so judgemental towards us. They are calling us names that make us feel offended." "Clinic staff have a negative attitude. They did not assist me when I asked for lubricants. They refused to give me and said they are used for and by women only. In reality, they must also give us, as we need them as well."







KEY FINDINGS

- + 20% of KPs were no longer accessing healthcare anywhere, often due to ill treatment & openly hostile clinic staff
- + Of those who were accessing services, most used a public health facility instead of a drop-in centre (range 75%-86%)
- + Poor staff attitudes, lack of safety/privacy were the main complaints & many had been denied services
- + There is limited availability and/or accessibility of KP specific services including lubricants, harm reduction services, gender affirming care, PrEP/PEP etc.
- + While drop-in centres had better overall service satisfaction and acceptability they are few and far between and not a panacea to KP health needs.



Influencing National Resource Mobilization Processes

 In South Africa's most recent Global Fund application, submitted in August 2021, community CLM data and methodology is explicitly referenced. This helped rationalize a five-fold increase in funding for community-led monitoring (from \$318,221 in the 2019-2022 grant to \$1,578,691 in the 2022-2025 grant).

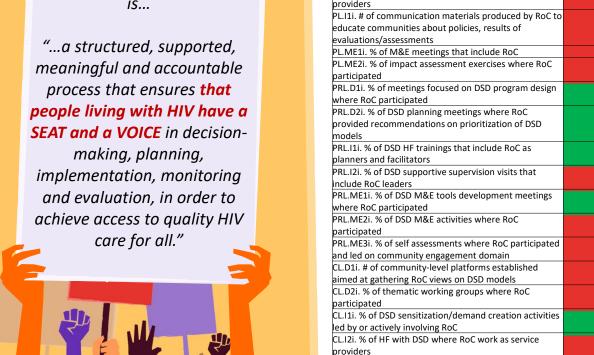


 In Malawi's 2022 Country Operational Planning (COP) process for PEPFAR programs, community CLM data was used to advocate for increased funding for viral load testing, including for additional sites and to speed up turnaround time to no more than 14 days. They also pushed for an increase in funding for community-led monitoring, from \$694,898 in COP21 to \$1.08 million in COP22.





Community engagement is...



Monitoring Community Engagement: Amplifying the Voice of Communities

INDICATOR	COUNTRY A
PL.D1i. % of TWG on DSD where RoC participated	
PL.D2i. % of policy validation exercises where RoC	
participated	
PL.D3i. % of online DSD platforms that include RoC,	
policy makers, program implementers and health	
providers	
PL.I1i. # of communication materials produced by RoC to	
educate communities about policies, results of	
evaluations/assessments	
PL.ME1i. % of M&E meetings that include RoC	
PL.ME2i. % of impact assessment exercises where RoC	
participated	
PRL.D1i. % of meetings focused on DSD program design	
where RoC participated	
PRL.D2i. % of DSD planning meetings where RoC	
provided recommendations on prioritization of DSD	
models	
PRL.I1i. % of DSD HF trainings that include RoC as	
planners and facilitators	
PRL.I2i. % of DSD supportive supervision visits that	
include RoC leaders	
PRL.ME1i. % of DSD M&E tools development meetings	
where RoC participated	
PRL.ME2i. % of DSD M&E activities where RoC	
participated	
PRL.ME3i. % of self assessments where RoC participated	
and led on community engagement domain	
CL.D1i. # of community-level platforms established	
aimed at gathering RoC views on DSD models	
CL.D2i. % of thematic working groups where RoC	
participated	
CL.I1i. % of DSD sensitization/demand creation activities	
led by or actively involving RoC	
CL.I2i. % of HF with DSD where RoC work as service	
providers	
CL.I3i. # of trainings organized for peer educators and	
RoC	
CL.ME1i. % of DSD facilities where community score	
cards and/or client satisfaction surveys are implemented	

Objective: promote community engagement across various levels (policy, programmatic, community) and areas (design, implementation, M&E)

- A community engagement tracking tool was developed for communities, by communities. It covered multi-level assessment areas of policy, programs and community
- Application of CLM model: indicator development >data collection > data analysis > advocacy and engagement for redress
- Move from communities not being involved and no plans for involvement (red) to meaningful engagement in implementation, evaluation and oversight (green)

Table: Detailed view of community monitoring of community engagement for DSD in Country A where Country A's government scored themselves an aggregate

Learn more here:

https://cquin.icap.columbia.edu/country-tocountry-learning/communities-of-practice/





SIERRA LEONE: From "No Data" to a New National Indicator

- From August-December 2020, ITPC &, NETHIPS implemented a community-led monitoring project at five health facilities in Freetown, **Sierra Leone**.
- Field researchers aimed to collected data on the number of people living with HIV who experienced **ART treatment failure** during COVID-19.
- However, after the first month of community-led monitoring, NETHIPS discovered that the current service registers do not capture this indicator.
- Dialogue with National AIDS Control Program (NACP) revealed that facility-level committees examine individual clients' need to change regimens and store this information on the appointment cards. This data is not centralized or analyzed.

 From this conversation, NETHIPS secured a commitment from the NACP to develop a new set of service registers that captures treatment failure as a key indicator. "That is the beauty of projects like this. They identify how people fall through the cracks. We will be bringing this issue to the community consultative group, and advocate for NACP to accelerate the production of new treatment registers that include treatment failure in them."

Martin Ellie, Network of HIV
 Positives in Sierra Leone (NETHIPS)

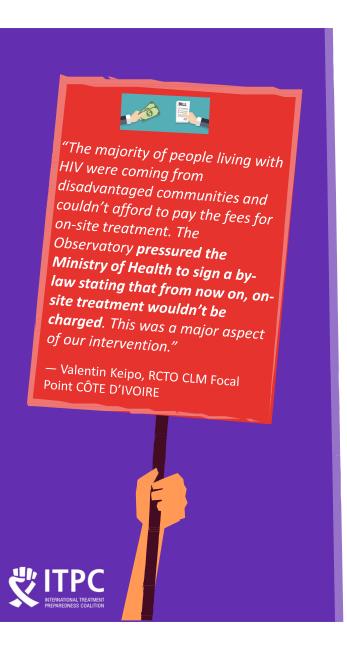


NETHIPS dialogue with decision-makers in Sierra Leone, 17 December 2020



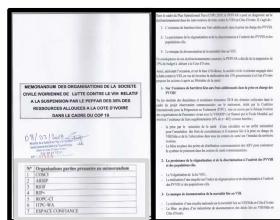
Old ART register in Sierra Leone, before the update that NETHIPS advocated for





CÔTE D'IVOIRE : Eliminating user fees as a cost barrier to services

- From January 2018 June 2019, ITPC &, RIP+ implemented a community-led monitoring project at 27 health facilities across Cote d'Ivoire.
- Over this period, field researchers conducted a total of 600 interviews and 34 focus group discussions with recipients of care to assess barriers to HIV services along the cascade.
- Of these, 17% of the recipients of care identified payment or considerable out-of-pocket expenditure as a reason for not accessing ART. Even at facilities where ART was free, fees for diagnostic tests, consultations with healthcare providers, and medicines for opportunistic infections represented additional cost barriers.
- These findings on barriers to access were presented by CIV CTO team at the Johannesburg PEPFAR COP19 meeting, where the CIV MOH and Amb. Deborah Birx and PEPFAR team were present. The advocacy messages were successful.
- In April 2019, a circular was issued by the Ministry of Health which signaled its commitment to stop people being charged for accessing HIV testing and treatment services, declaring that it will strictly apply previously announced decisions to prevent people living with HIV being asked to pay user fees.







Resources on CLM













EMPOWERING COMMUNITIES
TO END TB

















itpcglobal.org/resources/

CLOSING THOUGHTS

CLM Challenges, Community Data and Key Considerations



Isolating the Effect of Community-led Monitoring

Group	Location	# of facilities	CLM in place	Data source	Time periods examined	Change in HIV testing uptake
Intervention	Dedza & Kasungu Districts, Malawi	15	Yes	Citizen Science project	Before COVID-19: November 2018 – September 2019	25.5% fewer tests due to COVID-19
					During COVID-19: November 2020 – September 2021	
Control	Lilongwe District, Malawi	8	No	Thekkur, et al. (2021)	Before COVID-19: March 2019 – February 2020	39.0% fewer tests due to COVID-19
					During COVID-19: March 2020 – February 2021	

Our CLM intervention likely had a positive effect on mitigating the negative impact of COVID-19 on HIV testing services, translating to 10,845 more HIV tests at our monitored sites compared with the control group scenario.



Challenges

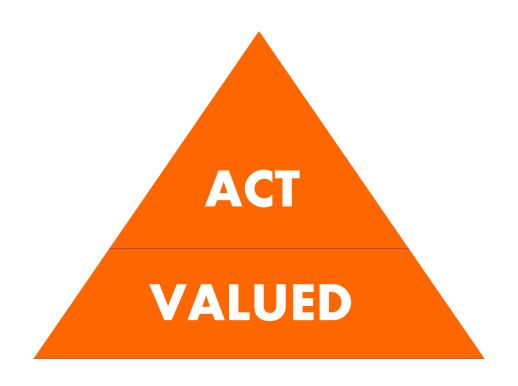
- Varying nature of what is being scaled in CLM:
 - Conflate other critical community-led initiatives with CLM
 - · Need for tighter national and global CLM coordination and harmonization
 - Aspects of CLM not resolved (data ownership, ethics considerations etc.)
- The need to accommodate donor indicators while maintaining relevant community-defined ones when the don't overlap
- Sustainability concerns:
 - Heavy reliance on external funding
 - Not yet refined value proposition for governments to take up paying for CLM
 - Weaker (or no real) community ownership where governments are more authoritarian.
- Low levels of investment and a thin research on aspect of CLM required to make it a core disciple:
 - How much monitoring is enough?
 - What does effective monitoring cost?
 - Who is best placed to implement and/or host CLM?



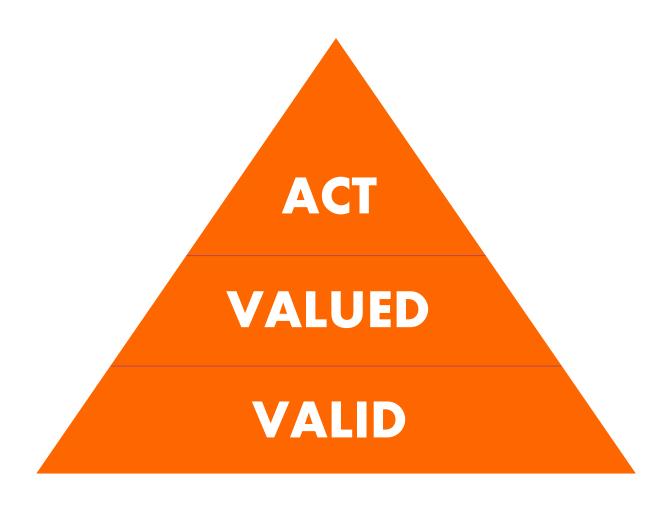
Improved but still sceptical view of community role beyond advocacy and demand creation leading to undervaluing of community data and by extension CLM.



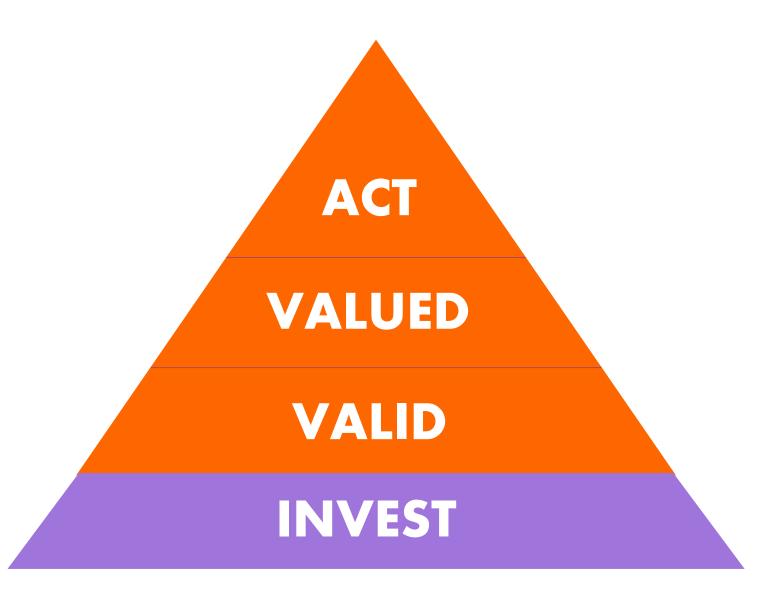




















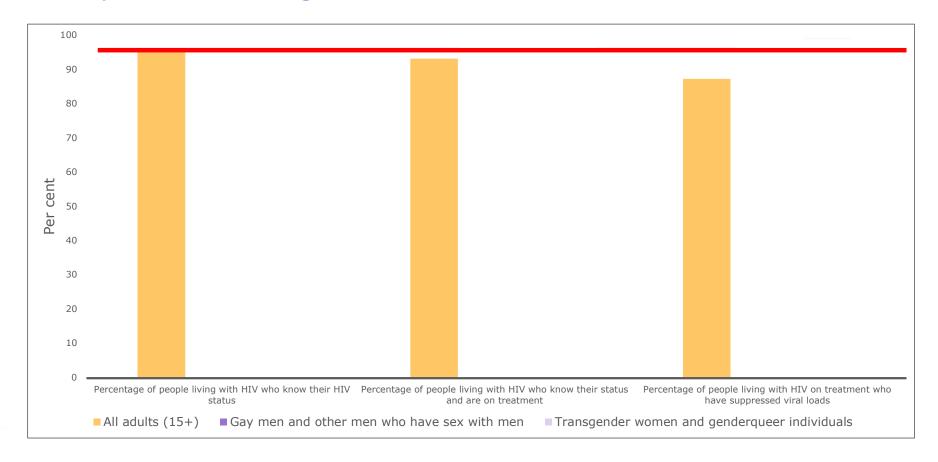
There's really no such thing as the 'voiceless.' There are only the deliberately silenced, or the preferably

unheard."

Arundhati Roy, writer



Inequalities in Progress towards 95–95–95 in Zimbabwe





Source: UNAIDS epidemiological estimates, 2022 (https://aidsinfo.unaids.org/)

Harris TG, Wu Y et al. HIV care cascade and associated factors among men who have sex with men, transgender women, and genderqueer individuals in Zimbabwe: findings from a biobehavioural survey using respondent-driven sampling. The Lancet HIV. Published online: 9 February 2022, s2352-3018.

Saving Lives & Reaching our Targets: Traditional Methods *Only* Will **Not Get Us There!**

AMBITIOUS TARGETS AND COMMITMENTS FOR 2025 2025 targets LESS THAN 10% 95% OF PEOPLE AT RISK OF HIV USE LESS THAN 10% OF PEOPLE LIVING COMBINATION PREVENTION WITH HIV AND KEY POPULATIONS People living EXPERIENCE STIGMA AND 95-95-95% HIV TREATMENT with HIV DISCRIMINATION 95% OF WOMEN ACCESS SEXUAL AND at risk at **LESS THAN 10%** REPRODUCTIVE HEALTH SERVICES OF PEOPLE LIVING WITH HIV, 95% COVERAGE OF SERVICES FOR WOMEN AND GIRLS AND KEY POPULATIONS EXPERIENCE GENDER **ELIMINATING VERTICAL TRANSMISSION BASED INEQUALITIES AND GENDER** 90% OF PEOPLE LIVING WITH HIV RECEIVE BASED VIOLENCE PREVENTIVE TREATMENT FOR TB LESS THAN 10% OF COUNTRIES HAVE PUNITIVE 90% OF PEOPLE LIVING WITH HIV AND LAWS AND POLICIES PEOPLE AT RISK ARE LINKED TO OTHER INTEGRATED HEALTH SERVICES

DEPENDENT ON

- Science, Innovation
- Partnership, Political will
- Resources (\$, people)
- Evidence informed decision-making
- Reliable and whole data picture
 - By sub-population, by KPs

Fast-Track Targets

by 2020

90-90-90

Treatment

500 000

New infections among adults

ZERO Discrimination

by 2030

95-95-95

Treatment

200 000

New infections among adults

ZERO

Discrimination



The Demand Side: A Critical Part of the Whole Data Story























How will we know what we need to change or

where/how to intervene before 2030?

Impossible to know without both supply side (provider data) and demand side (user/recipient of care) data.

Traditional M&E systems **do not adequately integrate community data** as part of the data story to effectively design and target interventions.

Community-led Monitoring is a **critical health innovation tool** in our arsenal.

