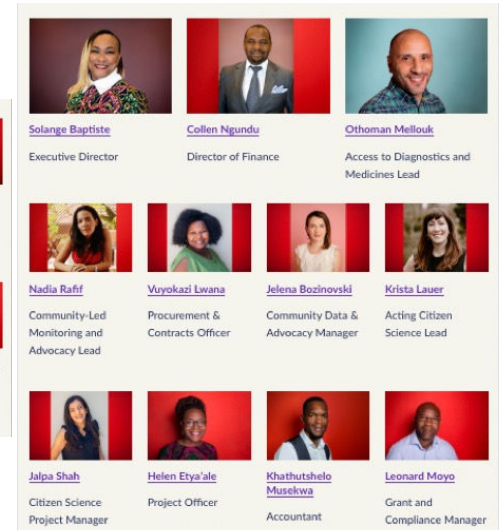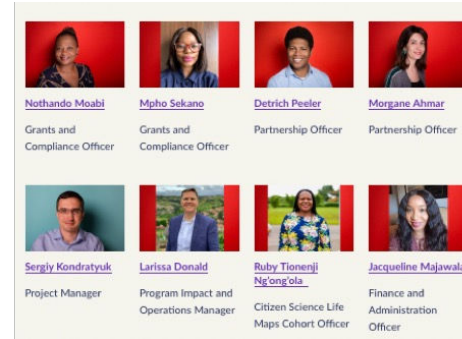# ITPC

- an **issue-based global activist network**

- HQ in Johannesburg, South Africa with a global mandate

- Started in 2003 when ARV prices were prohibitive

- Work with >3000 network members (individuals & organizations)
  - regional offices in Middle East & North Africa (ITPC MENA), West Africa (ITPC WA), Latin America and the Caribbean (ITPC LATCA), Eastern Europe and Central Asia (ITPC EECA) and South Asia (ITPC South Asia)

Over the past decade, ITPC has expanded its work **beyond HIV** by responding to the health priorities of coalition members and advocating for access to medicines and quality healthcare for TB, viral hepatitis, and other life-threatening conditions, including hypertension and diabetes.

OUR MISSION ...is to enable people in need to access optimal HIV treatment.

OUR VISION ...is longer, healthier, and more fulfilling lives for people living with HIV, their families, and their communities.

OUR VALUES
- Communities of people most affected by a particular disease are at the center of the response.
- There should be equity in treatment access.
- We work in solidarity as a global movement.
- We are transparent about our finances and how we work.
- We are accountable to the communities we serve.

Community-Led Monitoring

- What is CLM?

- How is CLM implemented?

- CLM in Action:
  - Citizen Science Project (Malawi and South Africa)
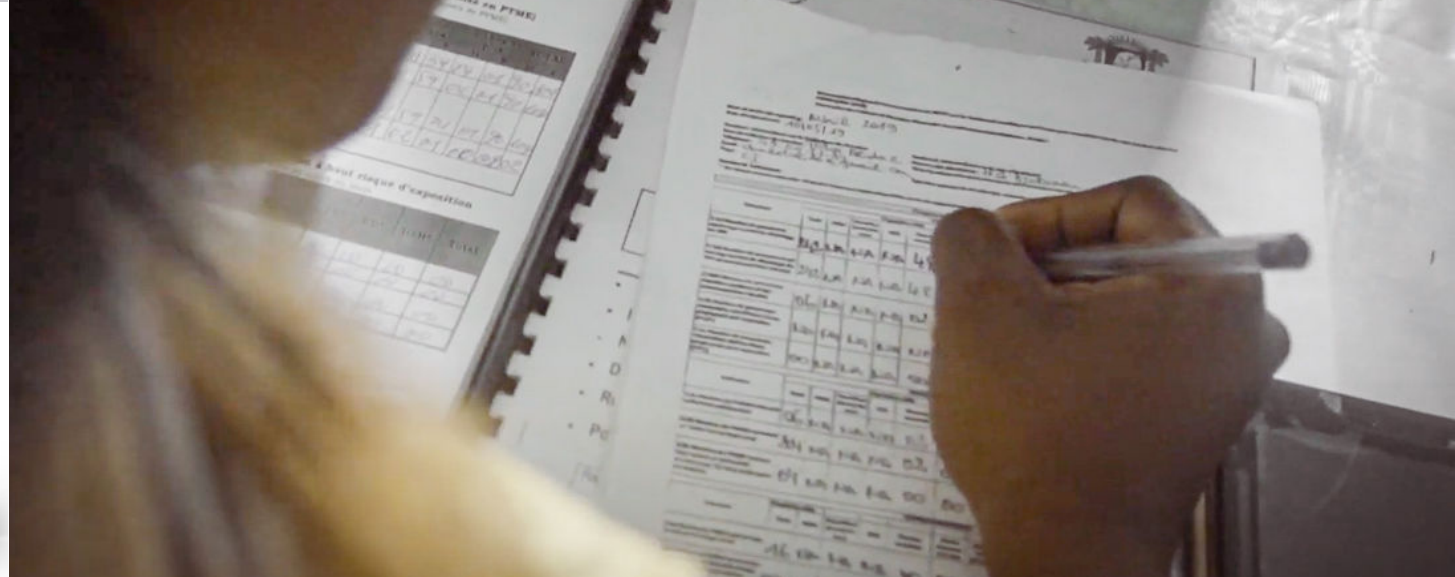 - Differentiated Service Delivery – Community Advocates Network (CAN)

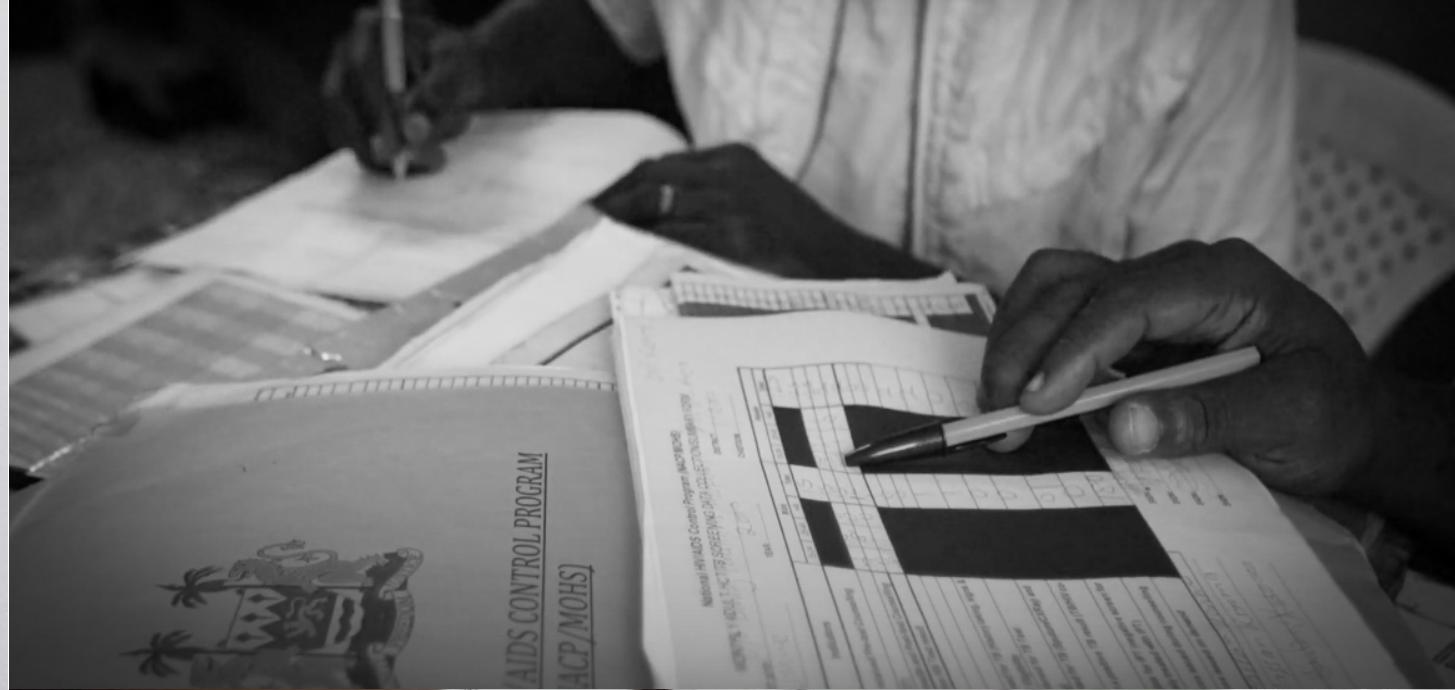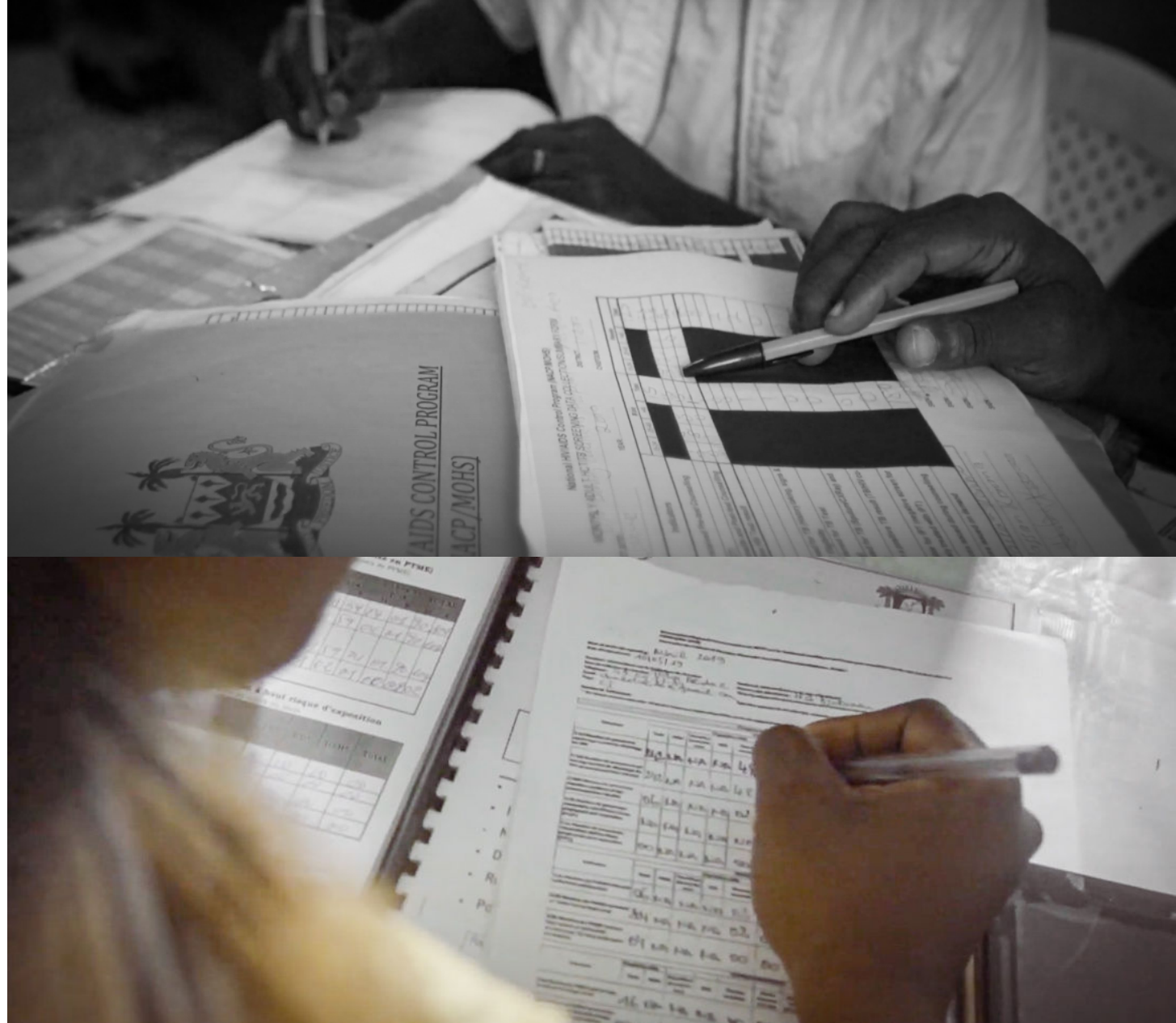"Come back tomorrow, we are *out of stock*!"

Community-led monitoring **is** global health **innovation**.

COMMUNITY-LED MONITORING DEFINED

A Science-based Accountability Innovation that puts Communities First

Community-Led Monitoring is <u>NOT</u>…

❌ 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

❌ *Only* data collection

❌ *A snapshot* of data (cross-sectional data) to understand recipient of care experiences

❌ A quality improvement (*QI*) initiative

❌ Community-based Monitoring

WHERE

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Community-Led Monitoring IS...

✓ 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

WHO

Community-Led Monitoring *Defined*

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

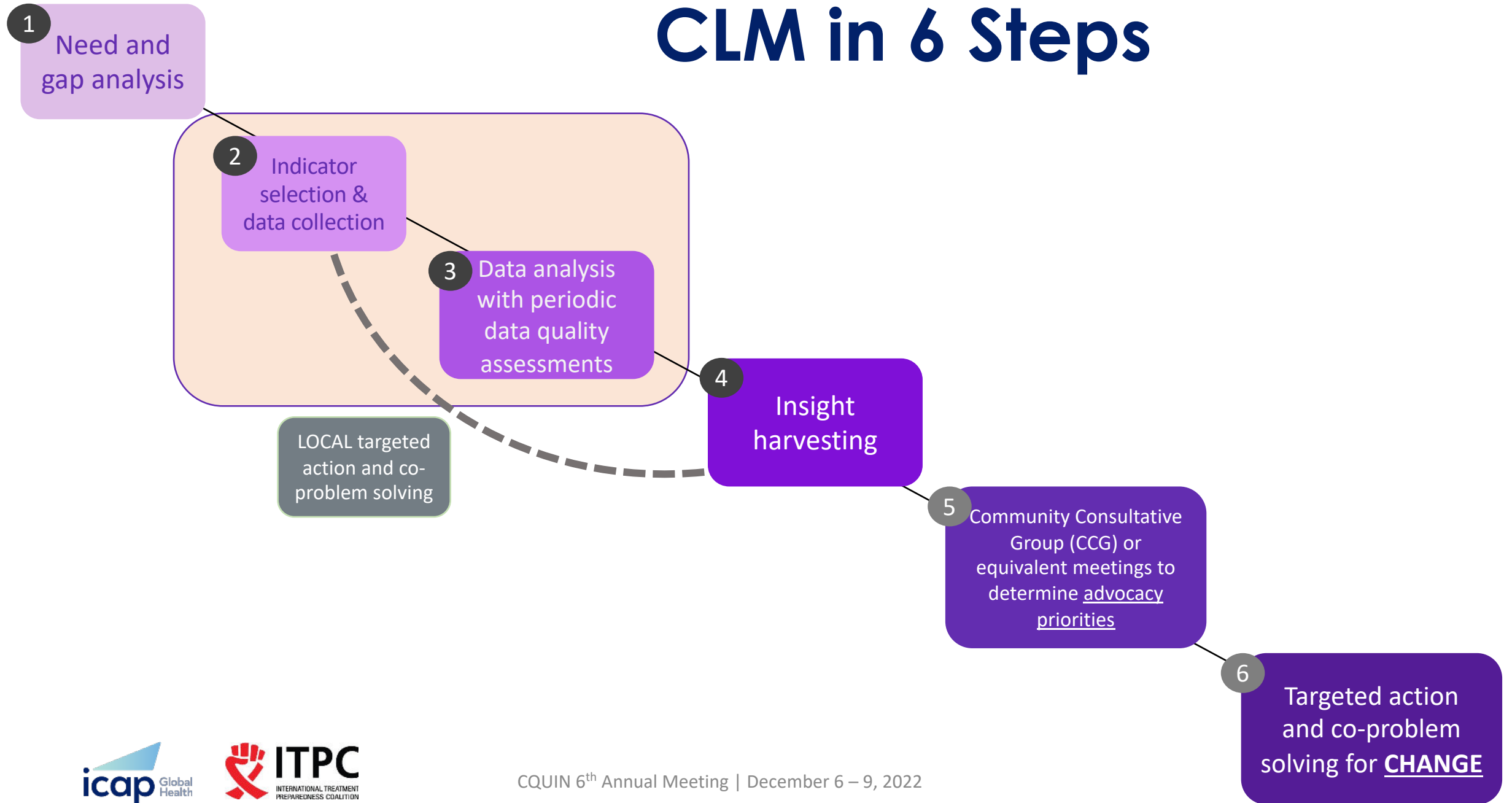- Communities then work alongside policymakers to co-create solutions to the problems they have identified.

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

EDUCATION

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

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

ADVOCACY

CLM

EVIDENCE

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

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

ENGAGEMENT

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CLM in 6 Steps

1 Need and gap analysis

2 Indicator selection & data collection

3 Data analysis with periodic data quality assessments

LOCAL targeted action and co-problem solving

4 Insight harvesting

5 Community Consultative Group (CCG) or equivalent meetings to determine advocacy priorities

6 Targeted action and co-problem solving for CHANGE

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What can CLM monitor in the context of DSD?

What
What clinical, laboratory, and psychosocial services are needed?

Appropriateness – are services tailored to the needs of specific populations? Availability – do the required medicines exist & in adequate supply?

When
How often are services provided?

Accessibility – how long are wait times? Are hours of operation convenient? Are referral processes along the care cascade smooth?

SERVICE INTENSITY

SERVICE FREQUENCY

PEOPLE LIVING WITH HIV

SERVICE LOCATION

HEALTH WORKER CADRE

Where
Where are services being provided?

Affordability - Do services require out-of-pocket spending on behalf of the ROC?

Who
Who is providing HIV services?

Acceptability - Are services provided free of stigma and discrimination?

https://cquin.icap.columbia.edu/about-cquin/dsd/

2 countries
Malawi and South Africa

3 districts
Dedza (Malawi), Kasungu (Malawi), and West Rand (South Africa)

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

58 data collectors
16 men (including 5 men who have sex with men and 7 men living with HIV)
41 women (including 4 young women, 5 sex workers, 2 lesbians, 1 trans woman, and 9 women living with HIV)
1 gender non-conforming person

884,000 beneficiaries
Total catchment area of the monitored health facilities

1 year of continuous monitoring (October 2020 – September 2021)
Plus, retroactive data collection for a pre-COVID comparison (October 2018 – September 2019)

637 surveys of quantitative clinic records
330 in Malawi and 307 in South Africa, with a total of 32 indicators monitored

318 qualitative interviews
138 with health care workers and 180 with recipients of care

20 Life Maps
Citizen journalist approach to documenting how COVID-19 affects daily life for people living with HIV

19 health care workers observed in operational research
Gaining better understanding of the "know-do gap" – why knowledge and practice do not always align.

The Citizen Science Project Dataset
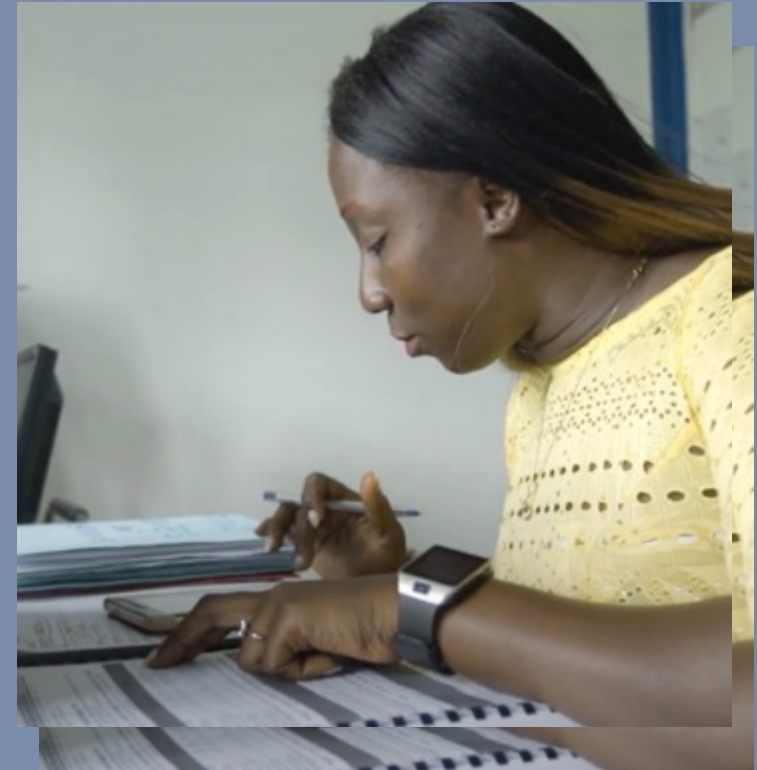
ITPC data collector, conducting a survey of clinic records as part of community-led monitoring.

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.

Before COVID-19
Nov 2018 - Sept 2019

1%
6%
48%
10%
34%

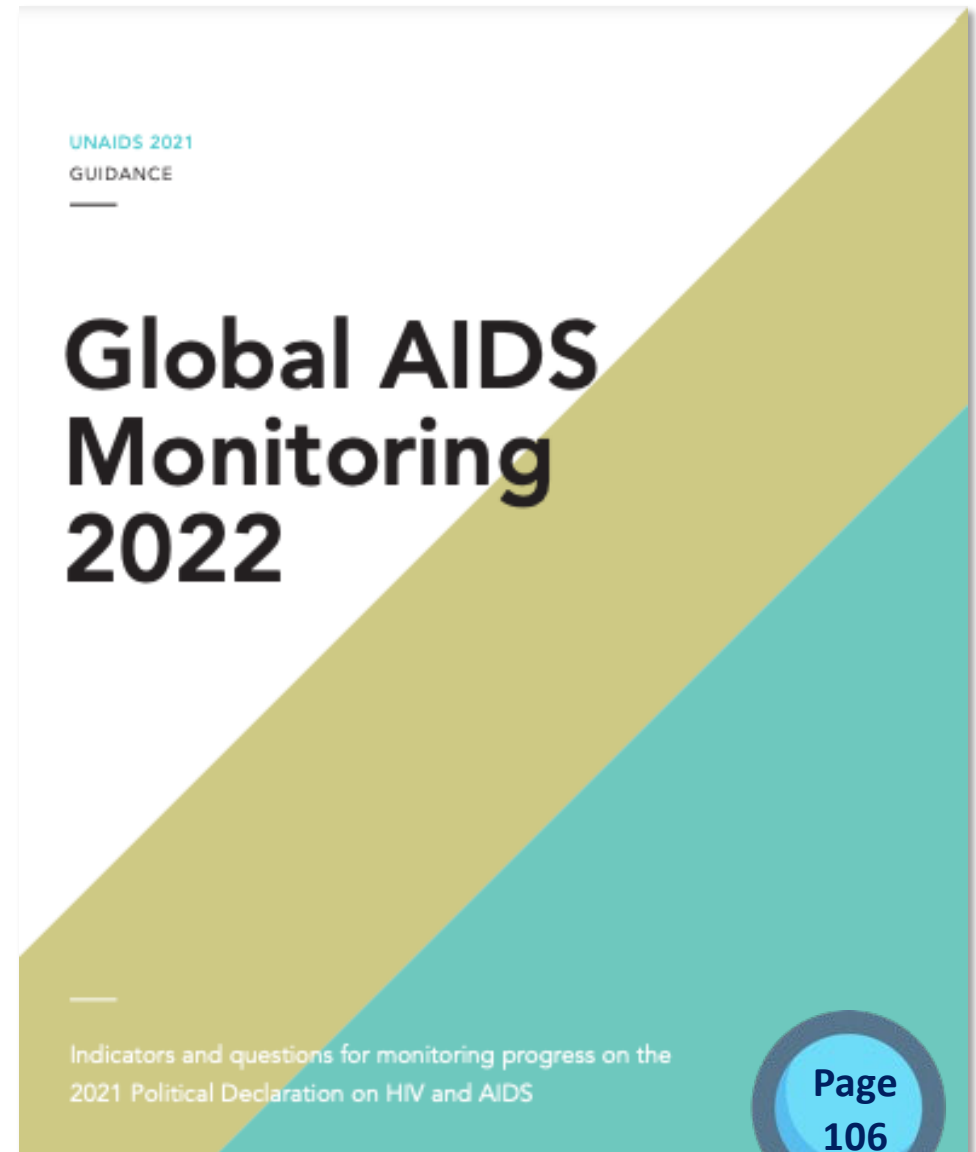**During COVID-19**
Nov 2020 - Sept 2021

1%
31%
48%
7%
13%

■ 1 month   ■ 2 months   ■ 3 months

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

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When Community-Led Monitoring Drives 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
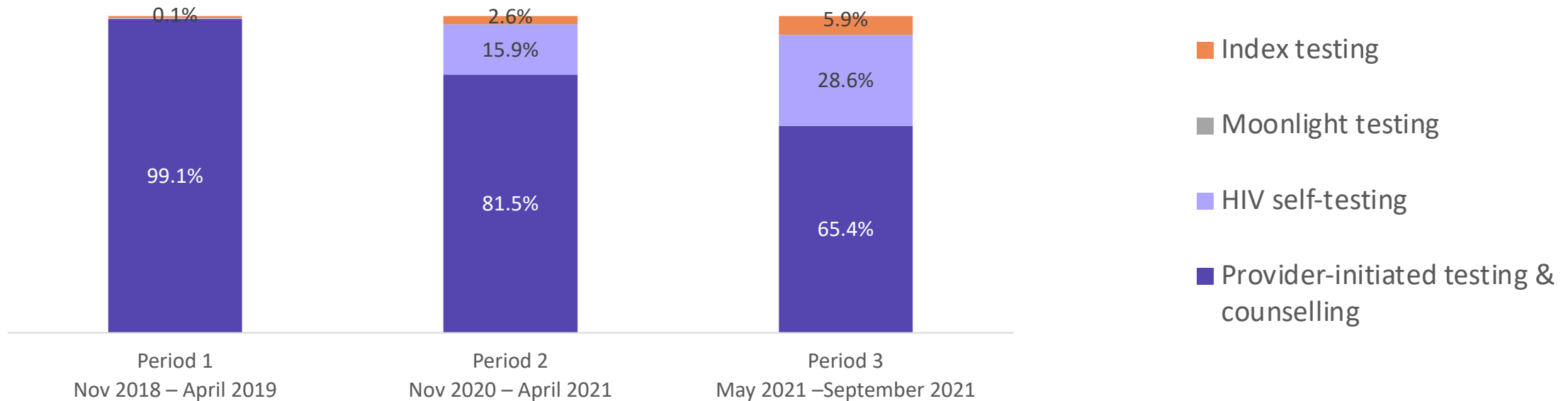
UNAIDS 2021
GUIDANCE

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

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Greater Differentiation in HIV Testing Services

o At our 15 monitored sites in Malawi, as a proportion of all HIV tests performed, self-testing rose from 0.1% in 2018/2019 to 15.9% in 2020/2021 and 28.6% in 2021.

Legend:
- ■ Index testing
- ■ Moonlight testing
- ■ HIV self-testing
- ■ Provider-initiated testing & counselling

Period 1: Nov 2018 – April 2019 — 0.1%, 99.1%
Period 2: Nov 2020 – April 2021 — 2.6%, 15.9%, 81.5%
Period 3: May 2021 – September 2021 — 5.9%, 28.6%, 65.4%

Proportion of people receiving differentiated HIV testing at our 15 monitored health facilities in Malawi

> "A lot of people were taking tests at home. They were HIV testing at home. They would buy those tests, those home test kits, so they don't have to go to the clinic because of the queue, and because they were scared they would be infected by COVID".
>
> – Life Maps participant in South Africa

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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

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Community Engagement Tracking Tool
Extended rollout throughout *Community Advocacy Network*

- Collecting data for the indicators and identifying data sources to assess community engagement
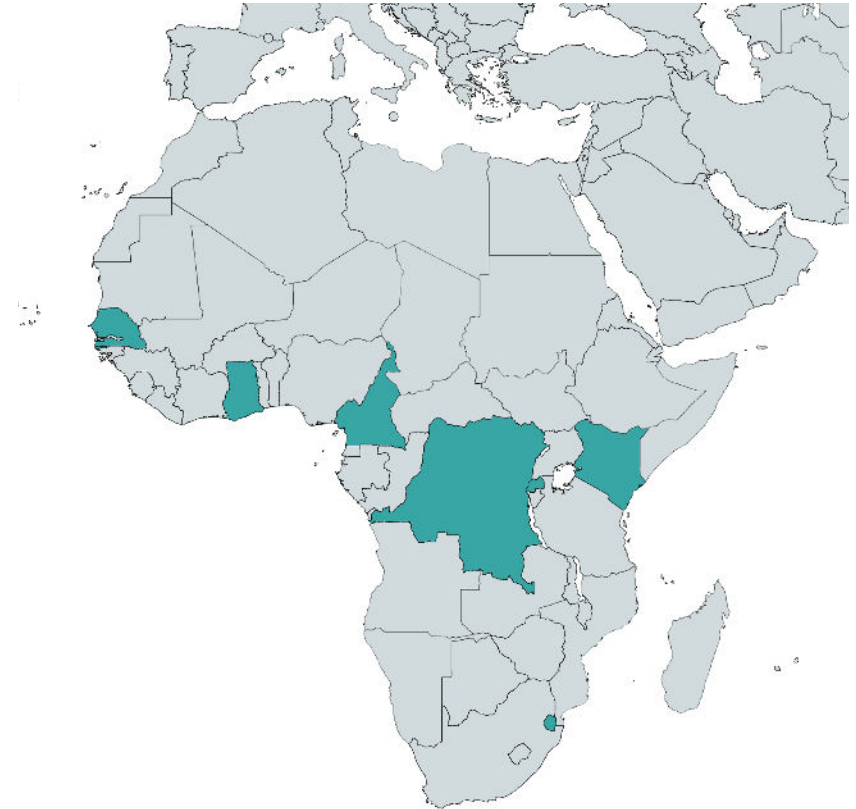
- Trained 5-person country teams of community representatives in the objective and use of the tool

- Rollout in 19 countries, focus on 7 countries (Cameroon, Democratic Republic of Congo, Eswatini, Ghana, Kenya, Rwanda, Senegal)

- Data collection between July-November 2022; information collected for the period of 1 June 2021 – 31 May 2022

LIST OF INDICATORS

	POLICY LEVEL (6)	PROGRAM LEVEL (7)	COMMUNITY LEVEL (6)
DESIGN	1. % of TWG on DSD where RoC participated 2. % of policy validation exercises where RoC participated 3. % of online DSD platforms that include RoC, policy makers, program implementers and health providers	1. % of meetings focused on DSD program design where RoC participated 2. % of DSD planning meetings where RoC provided recommendations on prioritization of DSD models	1. # of community-level platforms established aimed at gathering RoC views on DSD models 2. % of thematic working groups where RoC participated
IMPLEMENTATION	1. # of communication materials produced by RoC to educate communities about policies, results of evaluations/assessments	1. % of DSD HF trainings that include RoC as planners and facilitators 2. % of DSD supportive supervision visits that include RoC leaders	1. % of DSD sensitization/demand creation activities led by or actively involving RoC 2. % of HF with DSD where RoC work as service providers 3. # of trainings organized for peer educators and RoC
MONITORING & EVALUATION	1. % of M&E meetings that include RoC 2. % of impact assessment exercises where RoC participated	1. % of DSD M&E tools development meetings where RoC participated 2. % of DSD M&E activities where RoC participated 3. % of self assessments where RoC participated and led on community engagement domain	% of DSD facilities where community score cards and/or client satisfaction surveys are implemented

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Key Findings of the Community Engagement Tracking Tool

AVERAGE SCORES PER LEVEL OF ENGAGEMENT

LEVEL	AVERAGE SCORES
COMMUNITY	59%
POLICY	55%
PROGRAM	51%

AVERAGE SCORES PER STAGE OF DSD ROLL-OUT

STAGE	AVERAGE SCORES
DESIGN	65%
IMPLEMENTATION	51%
M&E	45%

Scoring Levels & Definitions (DSD Dashboard 3.0)				
0-20%	21-40%	41-60%	61-80%	81-100%
Representatives from the community of people living with HIV (PLHIV) and civil society organizations (CSO) are not involved in any activities related to DSD and there are currently no plans to engage these groups or the activity is not developed / planned or data source not available	PLHIV and CSO are not currently engaged in DSD activities, but engagement is planned or meetings and discussions are ongoing	PLHIV and CSO are meaningfully engaged in DSD implementation	PLHIV and CSO are meaningfully engaged in implementation and evaluation of DSDM	PLHIV and CSO are meaningfully engaged in implementation and evaluation of DSD, as well as oversight of DSD policy (e.g., through inclusion in DSD task force or other group)

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Comparing Country Self-reports *to* Community Scoring of <u>Community Engagement</u>

COMMUNITY SCORING

AREA	INDICATORS - *Numerical indicators will be scored and analysed in the interim report, after further feedback from countries	Country 1	Country 2	Country 3	Country 4	Country 5	Country 6
POLICY LEVEL	% of TWG on DSD where RoC participated						
	% of policy validation exercises where RoC participated						
	% of online DSD platforms that include RoC, policy makers, program implementers and health providers						
	% of monitoring and evaluation (M&E) meetings that include RoC						
	% of impact assessment exercises where RoC participated						
PROGRAM LEVEL	% of meetings focused on DSD program design where RoC participated						
	% of DSD planning meetings where RoC provided recommendations on prioritization of DSD models						
	% of DSD health facility trainings that include RoC as planners and facilitators						
	% of DSD supportive supervision visits that include RoC leaders						
	% of DSD M&E tools development meetings where RoC participated						
	% of DSD M&E activities where RoC participated						
	% of self assessments where RoC participated and led on community engagement domain						
COMMUNITY LEVEL	% of thematic working groups where RoC participated						
	% of DSD sensitization/demand creation activities led by or actively involving RoC						
	% of health facilities with DSD where RoC work as service providers						
	% of DSD facilities where community score cards and/or client satisfaction surveys are implemented						

COUNTRIES

VS

CQUIN NATIONAL SELF-SCORES on meaningful community engagement

Countries: DR Congo, Eswatini, Ghana, Kenya, Rwanda, Senegal

Scoring Levels & Definitions (DSD Dashboard 3.0)

0-20%	21-40%	41-60%	61-80%	81-100%
Representatives from the community of people living with HIV (PLHIV) and civil society organizations (CSO) are not involved in any activities related to DSD and there are currently no plans to engage these groups or the activity is not developed / planned or data source not available	PLHIV and CSO are not currently engaged in DSD activities, but engagement is planned or meetings and discussions are ongoing	PLHIV and CSO are meaningfully engaged in DSD implementation	PLHIV and CSO are meaningfully engaged in implementation and evaluation of DSDM	PLHIV and CSO are meaningfully engaged in implementation and evaluation of DSD, as well as oversight of DSD policy (e.g., through inclusion in DSD task force or other group)

LEGEND

| Meaningful Community Engagement | Recipients of care are not involved in planning, implementation, or evaluation of differentiated ART (DART) programs as defined in the footnotes below [5,6,7] OR There are insufficient data to determine the level of ROC engagement in DART | Recipients of care are meaningfully engaged in one of the following domains: 1. Planning/policy 2. Implementation 3. Evaluation | Recipients of care are meaningfully engaged in two of the following domains: 1. Planning/policy 2. Implementation 3. Evaluation | Recipients of care are involved in all three of the following domains: 1. Planning/policy 2. Implementation 3. Evaluation | The country team has assessed CE using the *Community Engagement Toolkit* developed by the CQUIN Community Advocacy Network and scored dark green in ≥ 4 of the policy domains, ≥ 6 of the programmatic domains, and ≥ 5 of the community domains |

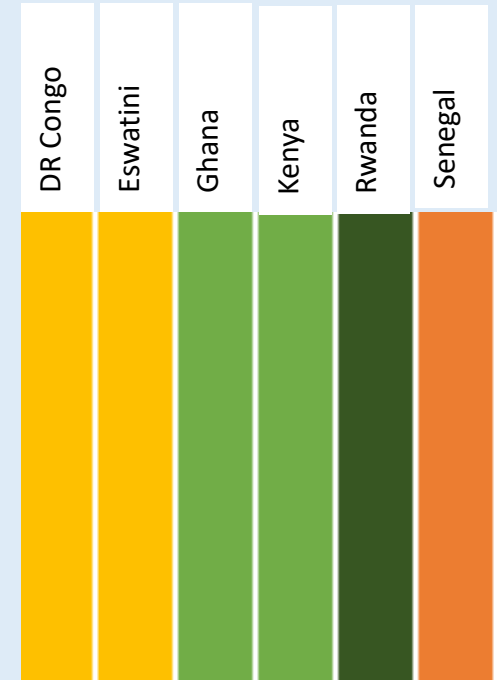# Comparing Country Self-reports *to* Community Scoring of Community Engagement

COMMUNITY SCORING

TRIANGULATION IS KEY

AREA	INDICATORS - *Numerical indicators will be scored and analysed in the interim report, after further feedback from countries*	Country 1	Country 2	Country 3			Country
POLICY LEVEL	% of TWG on DSD where RoC participated						
	% of policy validation exercises where RoC participated						
	% of online DSD platforms that include RoC, policy makers, program implementers and health providers						
	% of monitoring and evaluation (M&E) meetings that include RoC						
	% of impact assessment exercises where RoC participated						
PROGRAM LEVEL	% of meetings focused on DSD program design where RoC participated						
	% of DSD planning meetings where RoC provided recommendations on prioritization of DSD models						
	% of DSD health facility trainings that include RoC as planners and facilitators						
	% of DSD supportive supervision visits that include RoC leaders						
	% of DSD M&E tools development meetings where RoC participated						
	% of DSD M&E activities where RoC participated						
	% of self assessments where RoC participated and led on community engagement domain						
COMMUNITY LEVEL	% of thematic working groups where RoC participated						
	% of DSD sensitization/demand creation activities led by or actively involving RoC						
	% of health facilities with DSD where RoC work as service providers						
	% of DSD facilities where community score cards and/or client satisfaction surveys are implemented						

+

CQUIN NATIONAL SELF-SCORES on meaningful community engagement

DR Congo	Eswatini	Ghana	Kenya	Rwanda	Senegal

Scoring Levels & Definitions (DSD Dashboard 3.0)

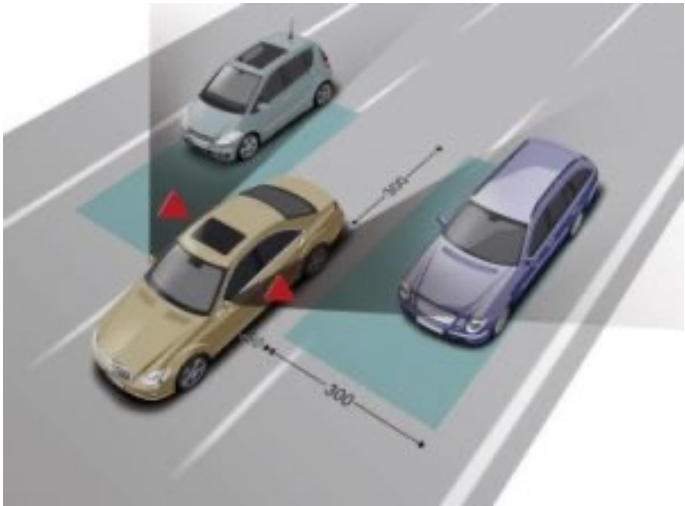| 0-20%	21-40%	41-60%	61-80%	81-100%
Representatives from the community of people living with HIV (PLHIV) and civil society organizations (CSO) are not involved in any activities related to DSD and there are currently no plans to engage these groups or the activity is not developed / planned or data source not available	PLHIV and CSO are not currently engaged in DSD activities, but engagement is planned or meetings and discussions are ongoing	PLHIV and CSO are meaningfully engaged in DSD implementation	PLHIV and CSO are meaningfully engaged in implementation and evaluation of DSDM	PLHIV and CSO are meaningfully engaged in implementation and evaluation of DSD, as well as oversight of DSD policy (e.g., through inclusion in DSD task force or other group)

LEGEND

Meaningful Community Engagement	Recipients of care are not involved in planning, implementation, or evaluation of differentiated ART (DART) programs as defined in the footnotes below 5 6 7 **OR** There are insufficient data to determine the level of ROC engagement in DART	Recipients of care are meaningfully engaged in one of the following domains: 1. Planning/policy 2. Implementation 3. Evaluation	Recipients of care are meaningfully engaged in two of the following domains: 1. Planning/policy 2. Implementation 3. Evaluation	Recipients of care are involved in all three of the following domains: 1. Planning/policy 2. Implementation 3. Evaluation	The country team has assessed CE using the *Community Engagement Toolkit* developed by the CQUIN Community Advocacy Network and scored dark green in ≥ 4 of the policy domains, ≥ 6 of the programmatic domains, and ≥ 5 of the community domains

Differentiated service delivery is a recipient of care (ROC)-centered approach, one that simplifies and adapts HIV services across the cascade, in ways that **_both_**

serve the needs of PLHIV better and

reduce unnecessary burdens on the health system.

CLM and its Role in DSD