Conflict of interest disclosure

I have no relevant financial relationships with ineligible companies to disclose.
Community Data Matters: A Look Into Community-led Monitoring

Solange Baptiste, International Treatment Preparedness Coalition

Health Innovation
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
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PHARMACIE COMMUNAUTAIRE

Centre Plus

RUBAN ROUGE CI  Tél(225) 23.50
“Come back tomorrow, we are out of stock!”
Community-led monitoring is global health innovation.
WHAT IS CLM?
Understanding Community-led Monitoring in Context
CLM in Context

COMMUNITY Systems

COMMUNITY-LED INTERVENTIONS

Service Delivery
Advocacy
*Citizen Science
Evaluations
Life Mapping
Research

Monitoring
Campaigns

HEALTH SYSTEMS

*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*
- Only data collection
- A snapshot of data (cross-sectional data) to understand recipient of care experiences
- A quality improvement (*QI*) initiative

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 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.
ITPC’s Community-led Monitoring Model

**Take Targeted Action**
- to work with policy makers to fix or improve the services, systems, laws or practices that underlie problems

**Advocacy**

**EDUCATION**
- Learn about the science behind the disease(s) and normative standards for optimal prevention, treatment, care and support interventions, including on COVID-19

**CLM**

**EVIDENCE**
- Document community experiences accessing health services, compile that information, and identify trends and problems

**Engagement**
- Discuss these findings with a wider group of stakeholders, such as a Community Consultative Group (CCG) or other existing group, to co-create solutions
Applying CLM as a Model in *Varying Contexts*

CLM, HIV & HCV

CLM, HIV & COVID 19

CLM & Tuberculosis

CLM, HIV Prevention

CLM, HIV & Human Rights

CLM, HIV & TB Treatment

https://itpcglobal.org/?resourcetopic=community-monitoring
CLM in 6 Steps

1. Need and gap analysis
2. Indicator selection & data collection
3. Data analysis with periodic data quality assessments
4. Insight harvesting
5. Community Consultative Group (CCG) meetings to determine advocacy priorities
6. Targeted action and co-problem solving for CHANGE
DATA IN ACTION
Concrete Examples, Actionable Data Insights and Advocacy Wins
## 2018 Regional Community Treatment Observatory Project in West Africa (RCTO-WA)

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<tr>
<th>CTO</th>
<th>Host Organization</th>
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<td><strong>BENIN</strong></td>
<td>Réseau Béninois des Associations de Personnes vivant avec le VIH (REBAP+)</td>
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<td><strong>CÔTE D'IVOIRE</strong></td>
<td>Réseau Ivoirien des organisations de Personnes vivant avec le VIH/SIDA (RIP+)</td>
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<td><strong>GAMBIA</strong></td>
<td>Gambia Network of AIDS Support Societies (GAMNASS)</td>
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<td><strong>GHANA</strong></td>
<td>National Network of Persons Living with HIV in Ghana (NAP+ Ghana)</td>
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<td><strong>GUINEA</strong></td>
<td>Réseau Guinéen des Associations de Personnes infectées et affectées par le VIH/SIDA (REGAP+)</td>
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<td><strong>GUINEA-BISSAU</strong></td>
<td>Rede Nacional das Associações das Pessoas Viventes com VIH (Network of Associations of PLHIV of Guinea Bissau) (RENAP+GB)</td>
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<tr>
<td><strong>LIBERIA</strong></td>
<td>Liberia Network of People Living with HIV (LIBNEP+)</td>
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<td><strong>MALI</strong></td>
<td>Réseau Molien des Personnes vivant avec le VIH (RMAP+)</td>
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<td><strong>SENEGAL</strong></td>
<td>Réseau National des associations de PVIH du Sénégal (RNP+)</td>
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<td><strong>SIERRA LEONE</strong></td>
<td>Network of HIV Positives in Sierra Leone (NETHIPS)</td>
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<td><strong>TOGO</strong></td>
<td>Réseau des Associations de Personnes Vivant Avec le VIH au Togo (RAS+)</td>
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The Power of **BIG DATA** in the Hands of **Activated Communities**

- **11** Countries
- **2** 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
- **35,577** Key populations reached
- **98,651** Young people reached

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

KEY RESULTS of the ITPC RCTO Project (2018)

Frequency of Recorded ART Stock-outs at RCTO-WA Monitored Facilities

- Period 1 (January-June 2018): 23.6%
- Period 2 (July-December 2018): 16.4%
- Period 3 (January-June 2019): 15.2%

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

- Period 1 (January-June 2018): 17.2%
- Period 2 (July-December 2018): 7.3%
- Period 3 (January-June 2019): 6.5%

Average Length (days) of ART Stock-outs at RCTO-WA Monitoring Facilities in Côte d’Ivoire

- Period 1 (January-June 2018): 53 days
- Period 2 (July-December 2018): 33 days
- Period 3 (January-June 2019): 23 days

Average Quality of Care Rating (out of 5) at RCTO-WA Monitored Health Facilities

- Period 1 (January-June 2018): 3.8
- Period 2 (July-December 2018): 4.0
- Period 3 (January-June 2019): 4.2

Viral Load Tests Performed at RCTO-WA Monitored Health Facilities

- Period 1 (January-June 2018): 16,532 tests
- Period 2 (July-December 2018): 31,472 tests
- Period 3 (January-June 2019): 33,376 tests

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

- Period 1 (January-June 2018): 48.4%
- Period 2 (July-December 2018): 67.9%
- Period 3 (January-June 2019): 77.4%

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

- **58 Data Collectors**
  - 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.
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](http://www.ritshidze.org.za)

### 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

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.
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.

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.

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

“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

“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

“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

Issues of confidentiality

Life Maps submissions showing lack of privacy in South Africa from COVID-19 policy of queuing outside
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

Increased turnaround times for viral load test results at our 15 monitored sites in Malawi.
## Limited Access to HIV Testing Services, especially for Key Populations

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<td>Number of HIV tests</td>
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<tr>
<td>among the general population</td>
<td>80,215</td>
<td>59,864</td>
<td>Testing fell by 25.4%</td>
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<tr>
<td>among men who have sex with men</td>
<td>248</td>
<td>117</td>
<td>Testing fell by 52.8%</td>
</tr>
<tr>
<td>among female sex workers</td>
<td>132</td>
<td>27</td>
<td>Testing fell by 79.5%</td>
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"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.

"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 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.
Monitoring Community Engagement: Amplifying the Voice of Communities

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 green.

Learn more here: https://cquin.icap.columbia.edu/country-to-country-learning/communities-of-practice/
From August-December 2020, ITPC & NETHIPS implemented a community-led monitoring project at five health facilities in Freetown, Sierra Leone.

Field researchers aimed to collect 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)
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.

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

“The majority of people living with HIV were coming from disadvantaged communities and couldn’t afford to pay the fees for on-site treatment. The Observatory pressured the Ministry of Health to sign a by-law stating that from now on, on-site treatment wouldn’t be charged. This was a major aspect of our intervention.”

— Valentin Keipo, RCTO CLM Focal Point CÔTE D’IVOIRE
ITPC CLM Hub Launch: Global Village Treatment Networking Zone @ 6pm today (1 Aug)

Refreshments will be served

To learn about the ITPC CLM Hub scan this QR code

www.clmhub.org
Resources on CLM

[Image: Multiple booklets and resources related to CLM]

OTHER KEY RESOURCES
rittshidze.org.za
healthgap.org
amfar.org
unaids.org
theglobalfund.org
initiative5pour100.fr

itpcglobal.org/resources/
CLOSING THOUGHTS

CLM Challenges, Community Data and Key Considerations
Isolating the Effect of Community-led Monitoring

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

Martin Luther King Jr.

“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**

- **Percentage of people living with HIV who know their HIV status**
- **Percentage of people living with HIV who know their status and are on treatment**
- **Percentage of people living with HIV on treatment who have suppressed viral loads**

**Source:**
UNAIDS epidemiological estimates, 2022 (https://aidsinfo.unaids.org/)
Saving Lives & Reaching our Targets: Traditional Methods Only Will Not Get Us There!

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

**Ambitious Targets and Commitments for 2025**

**2025 HIV targets**

10% < REDUCING INEQUALITIES = 95%

- Less than 10% of people living with HIV and key populations experience stigma and discrimination
- Less than 10% of people living with HIV, women and girls and key populations experience gender-based inequalities and gender-based violence
- Less than 10% of countries have punitive laws and policies

93% of people at risk of HIV use combination prevention
99% of women access sexual and reproductive health services
95% coverage of services for eliminating vertical transmission
40% of people living with HIV receive preventive treatment for TB
93% of people living with HIV and people at risk are linked to other integrated health services

**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

Community data is a valuable piece of the whole data story of the global HIV response.
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.
"Until the lions have their own historians, the history of the hunt will always glorify the hunter."

Chinua Achebe