

COMMUNITY-LED MONITORING AND ADVOCACY FOR HEALTH

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What Community-Led Monitoring & Advocacy is **NOT**

- ✗ **Not...community-based service delivery**
- ✗ **Not...the monitoring of community-based service delivery**
- ✗ **Not...the monitoring of communities by** service providers or governments
- ✗ **Not...M&E** that includes some community-centered indicators
- ✗ **Not...periodic community-check ins** by facilities/HCPs to ensure that services intended to serve communities are doing so effectively

Community-Led Monitoring & Advocacy



- ✓ Monitoring of services **BY communities**, where they are the end-user.
- ✓ Monitoring can be **routine or at a point in time**.
- ✓ Monitoring is of **indicators that are relevant** to that community in order to improve services (quality, type of service etc.).
- ✓ Monitoring provides an evidence-informed platform for the all-too-often **missing voice** in the response to advocate for change.

What is Community-Led Monitoring & Advocacy

Community-based Monitoring – “A process by which service users or local communities **gather and use information** on service provision or information on local conditions impacting on effective service provision, **in order to improve the responsiveness, equity and quality of services and hold service providers to account.** “**Top-down**” approaches to monitoring focus on macro level targets and financial accountability and **are inadequate to highlight local realities in communities and remain slow in responding to needs of individuals within those communities.** *CBM extracts essential information which quantitative monitoring cannot.* It determines the **quality and suitability** of services delivered with the consideration of local realities and highlights barriers to accessing services.”



“Observatories play two roles: mechanisms to monitor and evaluate health systems that complement top-down approaches to monitoring; and citizen movements that give a voice to patients.

- They are centered on **local, community and citizen involvement**
- They aim to **sound the alarm on problem areas** and to collect valid information on the *state of access and quality* of health services, which they disseminate on a regular basis at various different levels
- They create **dialogue** between stakeholders and strengthen advocacy at all levels of the health pyramid
- They contribute to improving health systems by highlighting the **accountability of all actors**
- They are located **within the health system** and provide a *complementary alternative* to institutional information systems.”



Who is THE community?

UNAIDS Meeting June 2019:

*“Community-led organizations, groups, and networks, irrespective of their legal status, are entities for which the majority of governance, leadership, staff, spokespeople, membership and volunteers**, reflect and represent the experiences, perspectives, and voices of their constituencies and who have transparent mechanisms of accountability to their constituencies. Community-led organizations, groups, and networks are self-determining and autonomous, and not influenced by government, commercial, or donor agendas. Not all community-based organizations are community led.”*

“Community-led responses are actions and strategies that seek to improve the health and human rights of their constituencies, that are specifically informed and implemented by and for communities themselves and the organizations, groups, and networks that represent them. Community-led responses are determined by and respond to the needs and aspirations of their constituents. Community-led responses include advocacy, campaigning and holding decision-makers to account; monitoring of policies, practices, and service delivery; participatory research; education and information sharing; service delivery; capacity building, and funding of community-led organizations, groups, and networks. Community-led responses can take place at global, regional, national, subnational, and grassroots levels, and can be implemented virtually or in person. Not all responses that take place in communities are community led. “

ITPC's Community-Led Monitoring Model

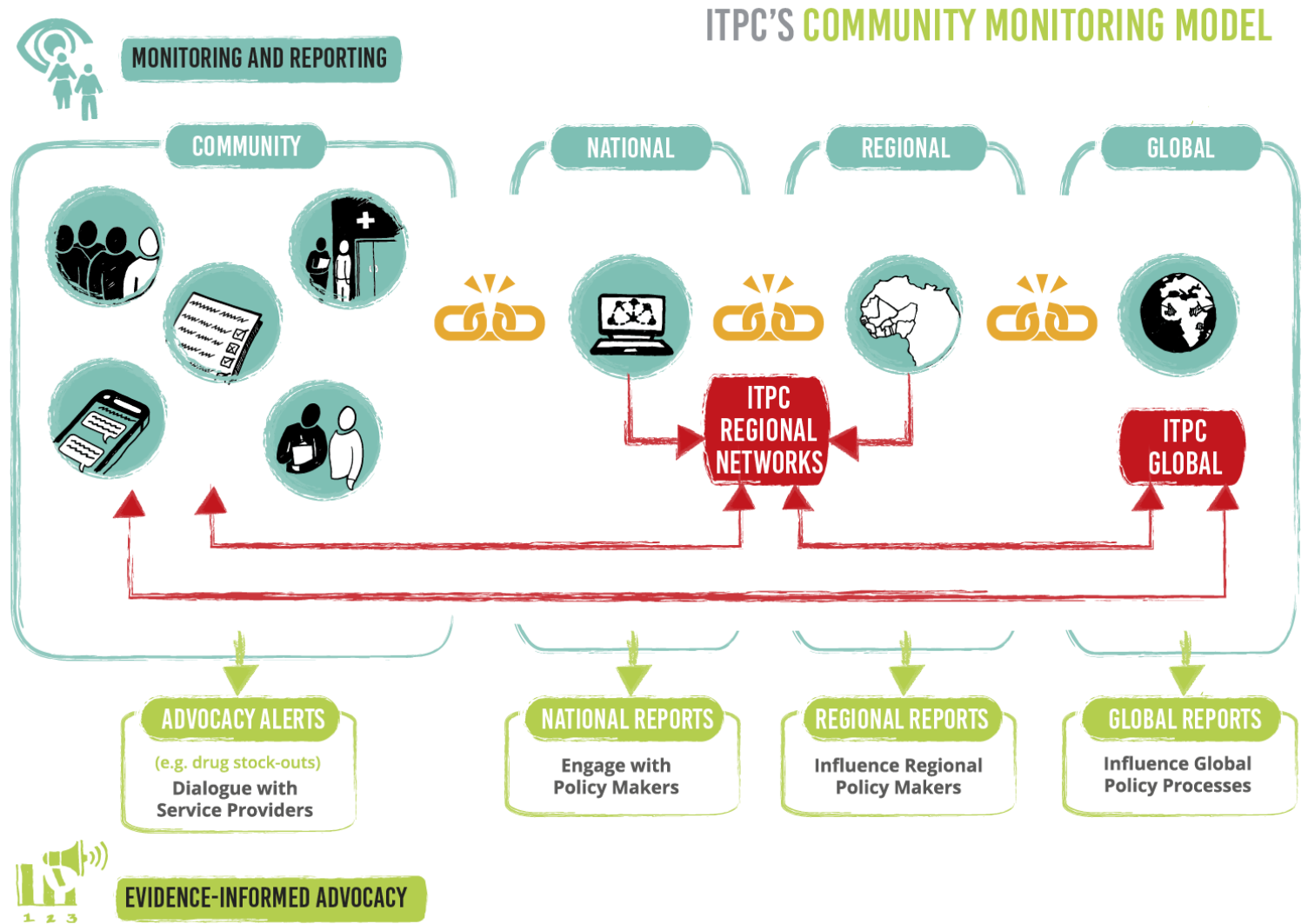
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What is a CTO?

- A mechanism that **systematically and routinely collects** and analyses **qualitative and quantitative data**, for targeted **action**.
- The data is used for **monitoring trends** along the HIV care cascade, and to **inform targeted action** that will improve the quality of HIV services. This includes alerts for **immediate feedback loops**.
- In a CTO, an organized group of **community members collect data** on various aspects of HIV prevention, testing, care and treatment services.
- A CTO can **operate** at district, provincial, national, regional or global level.
- Takes a process from start to finish, **not only reactionary** (alert vs comprehensive response).

Broken links
in the
pathway
often means
that the voice
of the
community is
missing!



What do Communities Care About the Most?

ITPC COMMUNITY MONITORING

Along the HIV Continuum of Prevention, Care and Treatment



What do CTOs monitor?

CTOs collect and analyse data on **availability**, **accessibility**, **acceptability**, **affordability** and **appropriateness** of HIV care and services – *model can be applied in various contexts/disease focus areas.*

“The Five As” — A Person-Centered Conceptual Framework for Access



Methodology – Quantitative Tool

- # of HIV tests performed
- # of HIV tests performed where people know their results
- # of positive test results from HIV tests performed
- # of eligible people receiving PrEP
- # of eligible people receiving PEP
- # of people initiating ART
- # of people receiving ART
- # of PLHIV known to be on ART 12 months after initiating
- # of PLHIV that have received a viral load test
- # of PLHIV that received their viral load test result within 2 weeks of taking the test
- # of PLHIV that received their viral load test result between 15 days and 3 months of taking the test
- # of PLHIV on ART who have achieved viral suppression (1000 copies/ml)

(All the above indicators are disaggregated by MSM, SW, PWID, pregnant women, young men age 15-24, and young women age 15-24)

- Stock-outs of ARVs in the past month (Yes/No)
- Stock-outs of HIV test lab supplies in the past month (Yes/No)
- Stock-outs of HIV test lab equipment in the past month (Yes/No)
- Stock-outs of viral load test lab supplies in the last month (Yes/No)
- Stock-outs of viral load test lab equipment in the past month (Yes/No)

(All the above indicators are disaggregated type of stock-out and # of days)

- Delays in viral load tests returning from the lab in the last month? (i.e. beyond 6 weeks) (Yes/No)
- Delays in other tests (besides HIV e.g. FBC, DNA PCR, Us and Es) returning from the lab in the last month? (Yes/No)

(All the above indicators are disaggregated by # of days)

In the recent ITPC GF Regional
Community Treatment
Observatory project there
were 103 Indicators



The CTO Model *only*
works if we start
with
health/treatment
education!



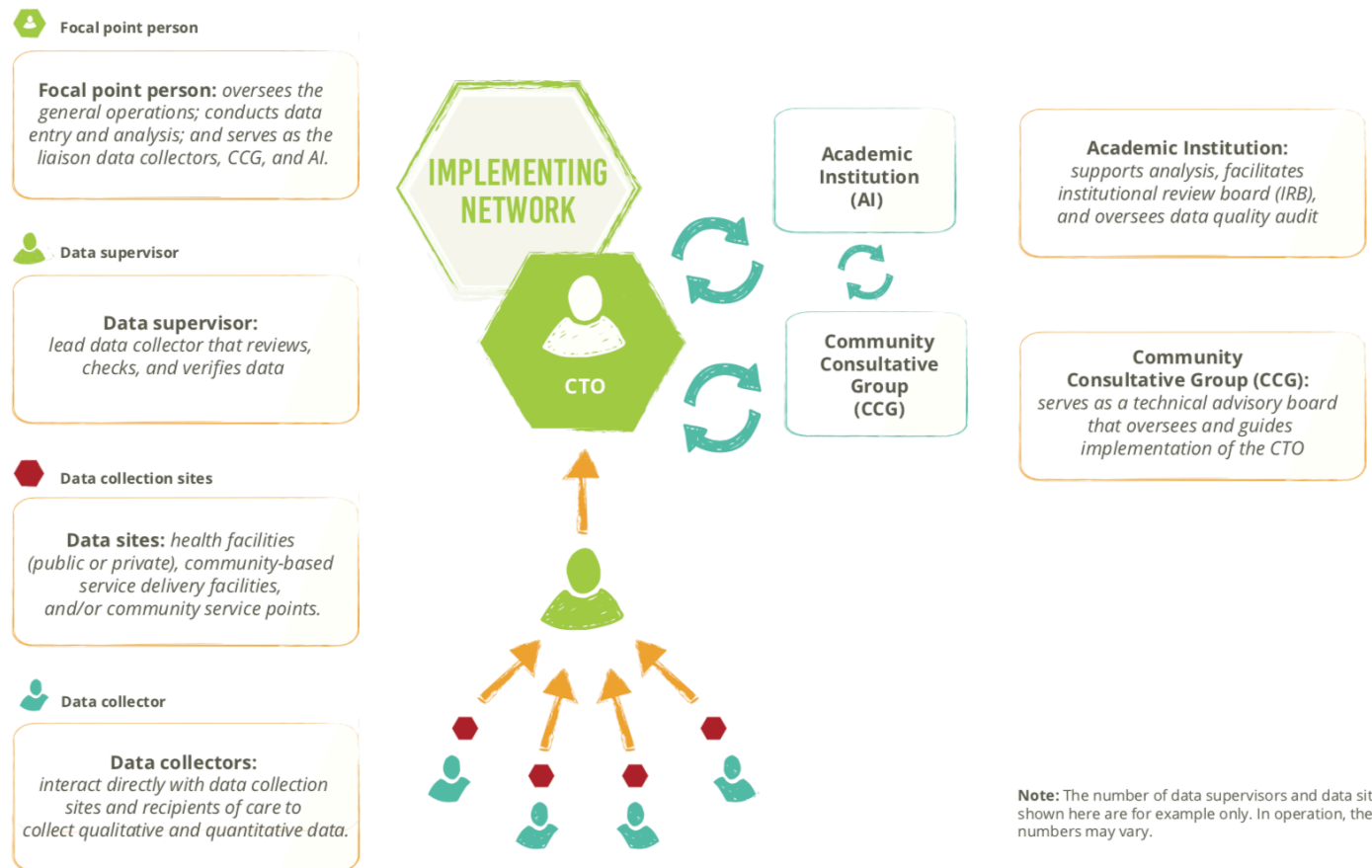
Who is in a CTO?

The Basic Structure

FIGURE 3

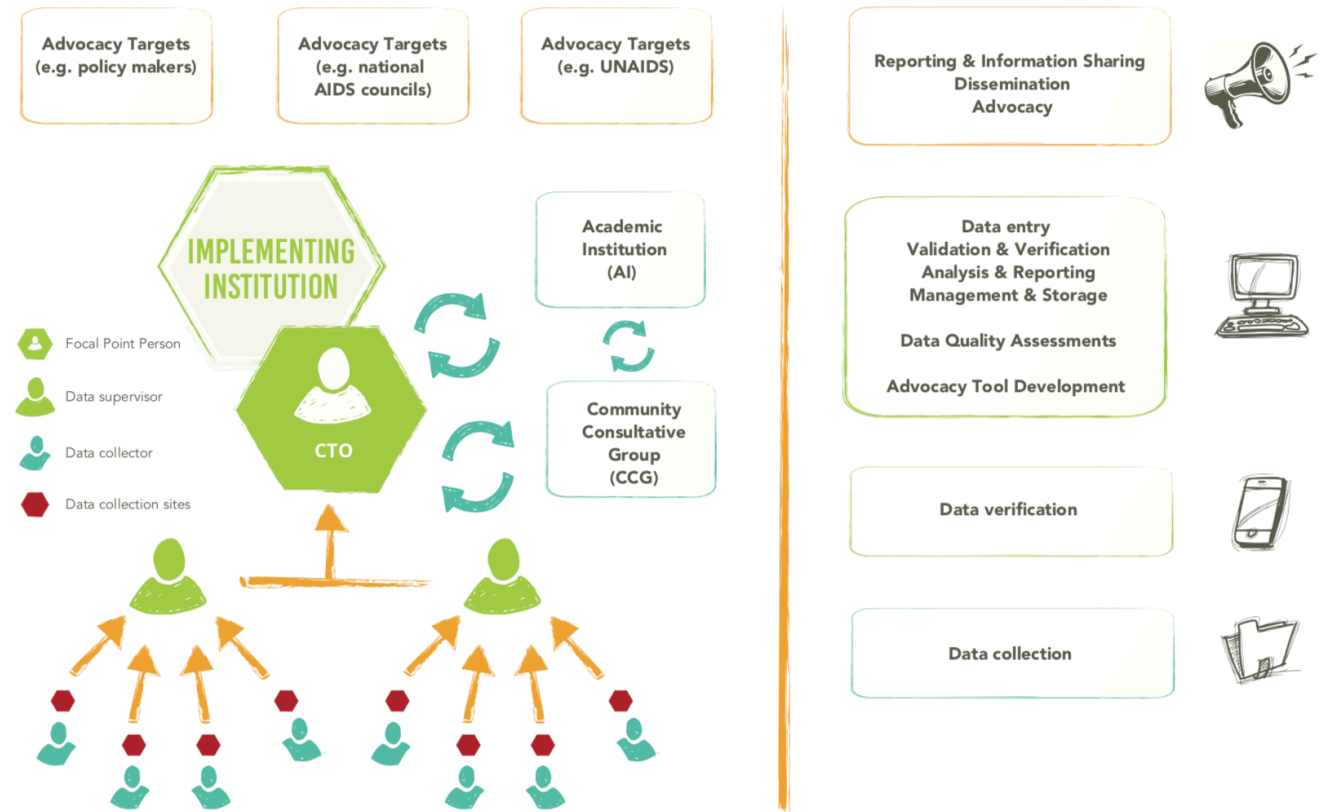
ITPC's CTO Structure.

The basic structure of a community treatment observatory includes five basic components



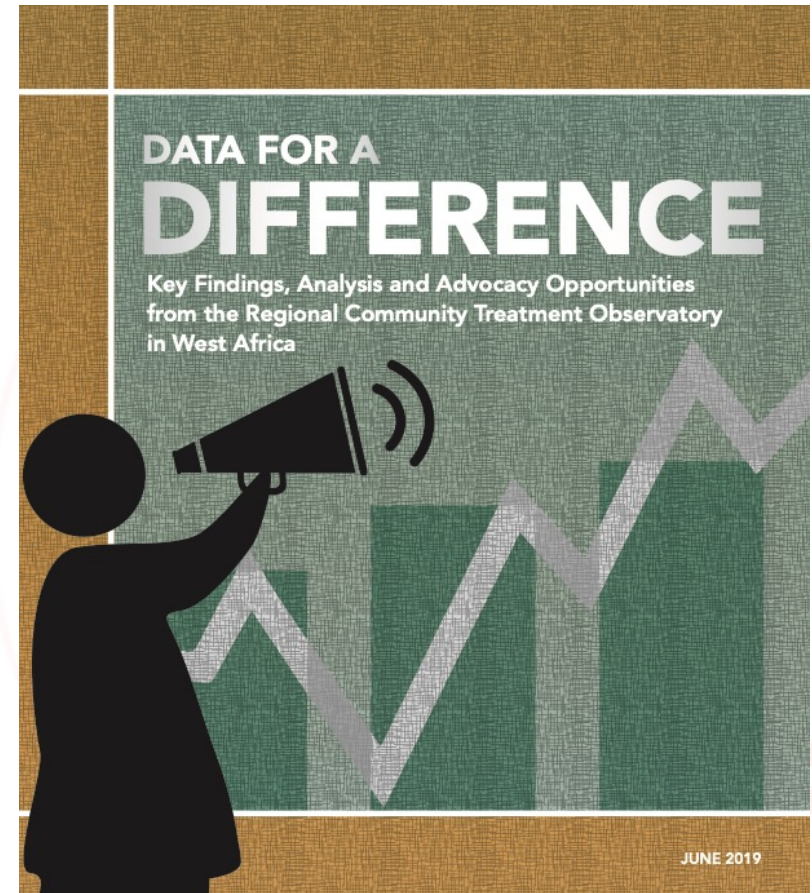
How the Data Flows

FIGURE 4
ITPC's CTO Operational Data Flow



Select Highlights of ITPC's CLM Publications Include:

- A [short video](#) on “What is a Community Treatment Observatory”
- The ITPC [CTO Model explained](#) (and [short version](#)) “[Data for a Difference](#)”, report from our Regional Community Treatment Observatory (RCTO) in West Africa
- A [regional fact sheet](#) on the gaps found from the RCTO
- [Abstract-driven session](#) at the IAS 2019 conference in Mexico City
- Report's findings in [English](#) and in [French](#) in the Global Fund Observer
- NAM aidsmap: <http://www.aidsmap.com/news/aug-2019/leakages-art-treatment-cascades-west-africa-and-zambia>
- Center for Social Science Research – “[Understanding Gaps in the HIV Treatment Cascade in 11 West African Countries Findings from a Regional Community Treatment Observatory](#)”



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



11
Countries



631,863
HIV tests performed



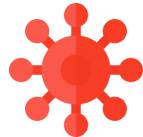
2
Years of monitoring



105,435
People on ART



84
Data collectors



81,380
VL tests performed



125
Health facilities



1501
Interviews



98,651
Young people reached



1781
Quantitative reports



143
Focus groups



35,577
Key populations reached

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

KEY RESULTS of ITPC's Ongoing Community-led Monitoring

Fig 1. Frequency of Recorded ART Stock-outs at RCTO-WA Monitored Facilities

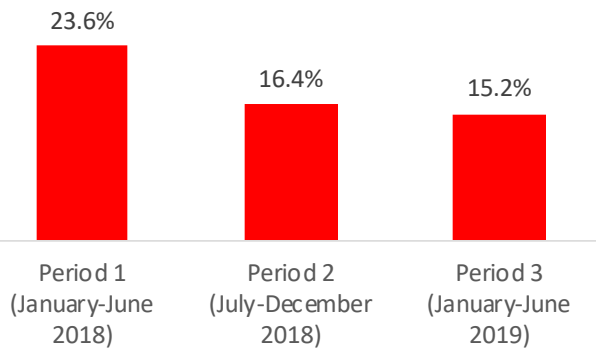


Fig 2. Frequency of Recorded VL Lab Supply Stock-outs at RCTO-WA Monitored Facilities

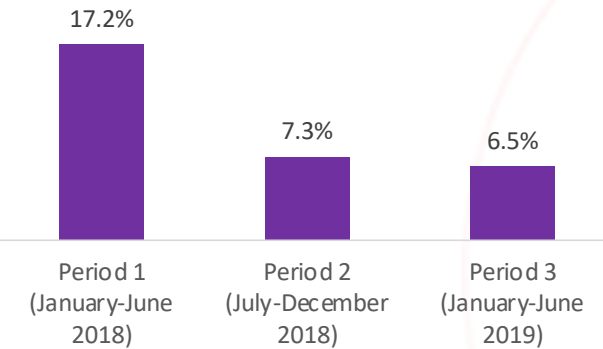


Fig 3. Average Length (days) of ART Stock-outs at RCTO-WA Monitoring Facilities in Côte d'Ivoire

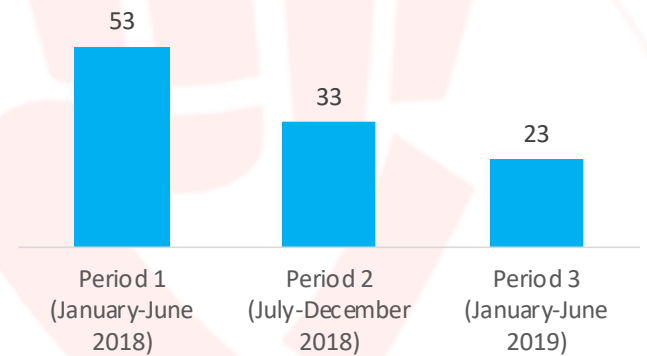


Fig 4. Average Quality of Care Rating (out of 5) at RCTO-WA Monitored Health Facilities

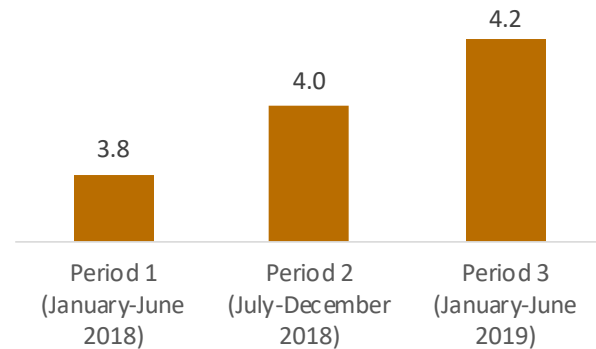


Fig 5. Viral Load Tests Performed at RCTO-WA Monitored Health Facilities

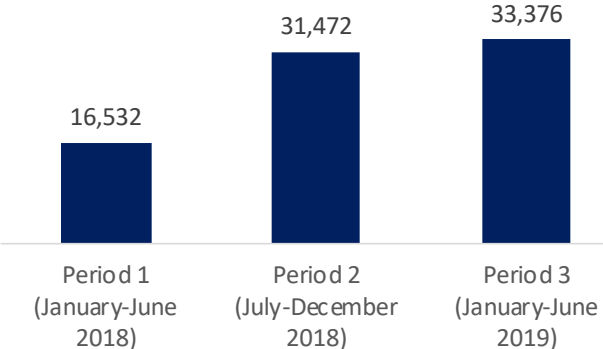
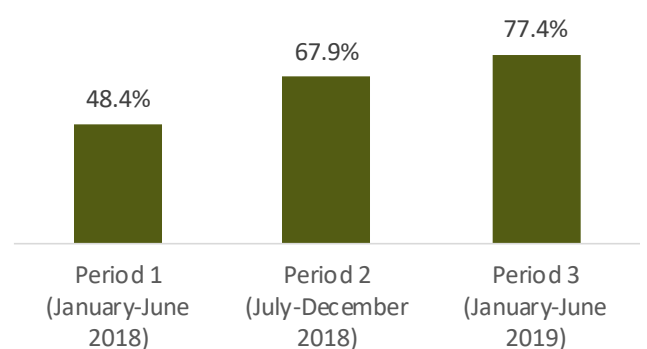


Fig 6. Rate of Viral Load Suppression at RCTO-WA Monitored Health Facilities

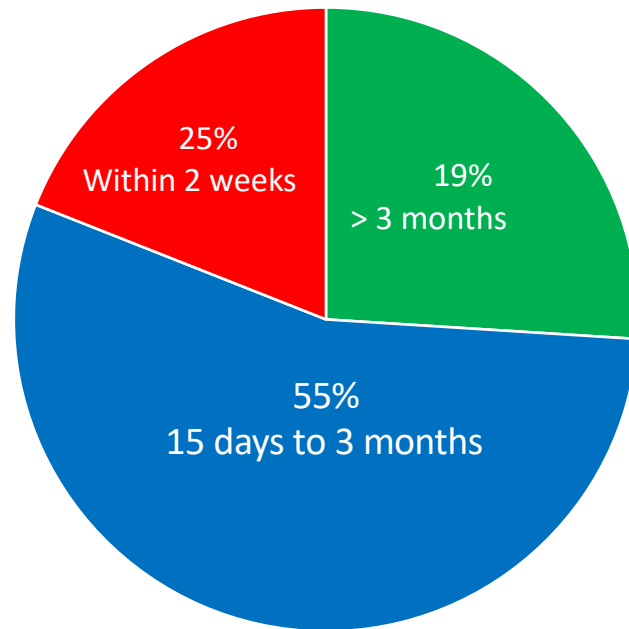


RCTO Data on VL Test Return Time

ITPC Regional Community Treatment Observatory – 11 West African Countries

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

VL Test Result Return Time Across
all 11 RCTO Countries



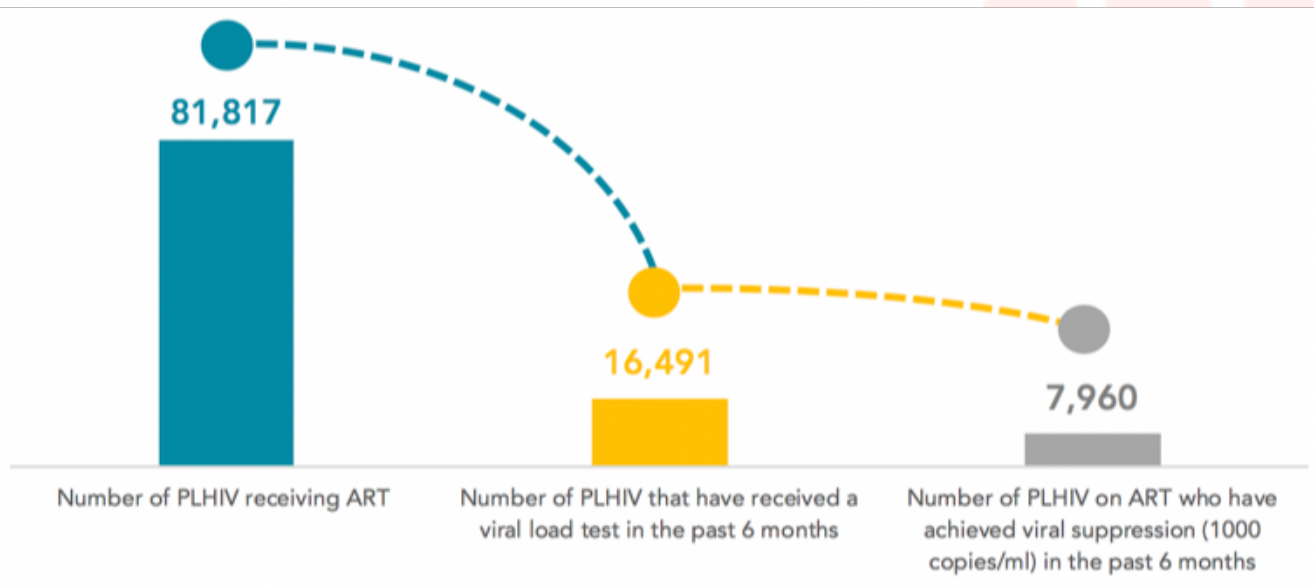
■ Within 2 weeks ■ 15 Days to 3 Months ■ More than 3 Months

**Sadly, only
1 in 4 viral load
test results are
returned within
two weeks!**

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Access to Viral Load Testing Services and Viral Load Suppression Data at RCTO-WA monitored Health Facilities (as of June 2018)

ITPC Regional Community Treatment Observatory – 11 West African Countries

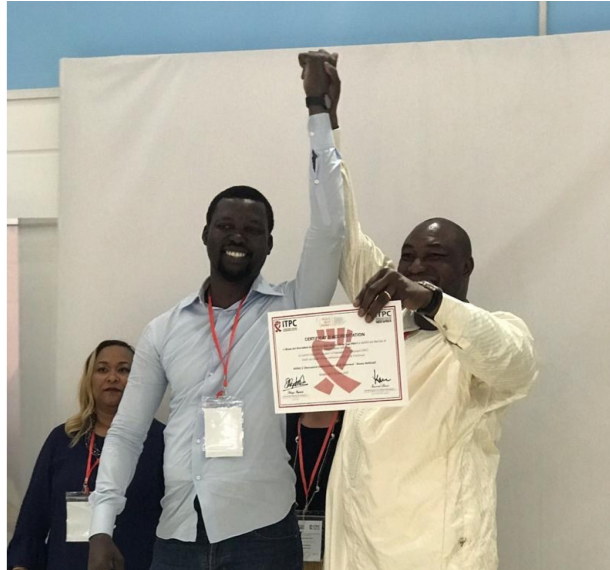


Of those who received a viral load test, less than half (48%) were virally suppressed - far lower than the UNAIDS estimate of 73%.

To what extent can community data challenge academic data?

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

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Funding
Monitoring
is **NOT** enough!

Change is the
Goal!

Using Data to Improve Quality of Care

The Critical Role of Advocacy

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

CTO SUCCESS STORY

MALI

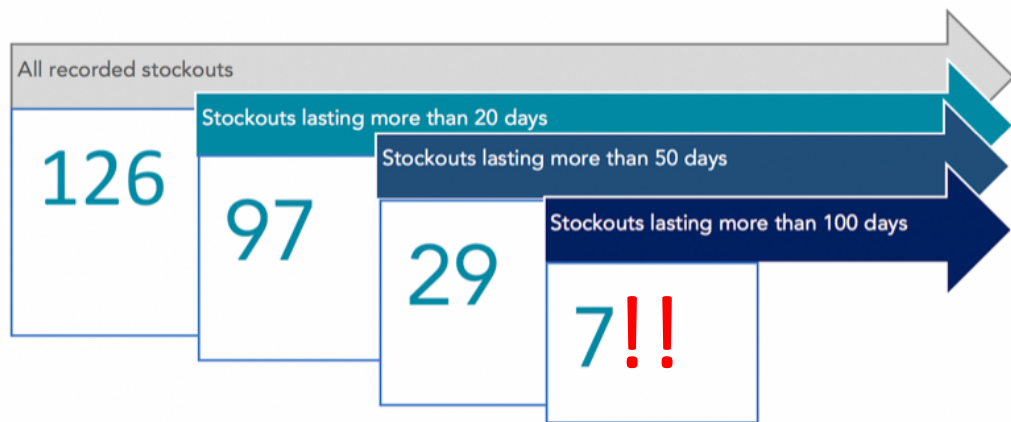
The host of the national CTO in Mali, RMAP+, has used CTO data to improve quality of care in health facilities by improving data quality and individual patient monitoring. During a recent CTO monitoring visit to the Gabriel Touré University Teaching Hospital in Bamako, RMAP+ drew the attention of health facility managers to data entry issues. Viral load test results were being transferred from patient registers to the central viral load databases in groups, clustered by date. Using their CTO data analysis, RMAP+ pointed out that it is better to record this data individually, by patient.



Stock Outs...Shortages!

What I need is not there!!

ITPC Regional Community Treatment Observatory – 11 West African Countries



Length of ARV Stockouts at RCTO-WA Facilities, January-June 2018

Country	Average Number of Days that ARVs Remain Out of Stock
Benin	No reported stockouts
!!! Côte d'Ivoire	53 Days
Gambia	26 Days
Ghana	32 Days
Guinea	34 Days
Liberia	39 Days
Guinea-Bissau	31 Days
Mali	37 Days
Senegal	37 Days
!!! Sierra Leone	25 Days
Togo	67 Days

Length of Reported Stockouts at RCTO-WA Facilities, January-June 2018

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

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Using Data to Alleviate Stockouts

The Critical Role of Advocacy

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

CTO SUCCESS STORY

BENIN

At the Bethesda Hospital in Cotonou, Benin, CTO host REBAP+ noticed that the site had not been supplied with lab reagents for more than 10 months. This meant that patients were not receiving critical treatment monitoring services, including viral load and CD4 count test. The CTO data on reagent stock outs was recorded in REBAP+'s report, for presentation to the CTO's Community Consultative Group (CCG). During this meeting of the CCG, the Deputy Coordinator of The National AIDS Control Program (Programme santé de lutte contre le Sida-PSLS) was confronted with REBAP+'s CTO data on reagent stock-outs. The CCG's function as a feedback mechanism for the CTO worked, and a solution was found. After the meeting, PSLS stocked Bethesda Hospital with reagents.



Advocacy Opportunities



- *By 2020, 90% of people living with HIV will know their status*
 - Expand the **availability of non-facility-based HTS**, including **community-led and community-based HTS**.
 - Intensify HIV communication and **awareness campaigns** to increase demand for HTS.
 - Include **costed activities to promote and protect human rights of PLHIV and key populations** in national plans.
- *By 2020, 90% of people living with HIV will know their status*
 - Improve **communication along the supply chain to prevent antiretroviral stockouts**.
 - **Enhance linkage to—and retention in—care and treatment**, especially for key and vulnerable populations.
 - Strengthen community systems and responses to support the **roll out of differentiated service delivery (DSD)**.
- *By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression*
 - Increase **funding to ensure the availability of adequate viral load testing machines** and laboratory supplies.
 - Enhance knowledge among **PLHIV and healthcare workers to increase demand for viral load testing services**.
 - Ensure **effective treatment monitoring through acceptable turn-around times for viral load test results**.

LESSONS LEARNED, Challenges and Success Factors

- ✓ **Strong leadership is critical.** The more successful observatories had strong leadership within the national network, and high-level political buy-in. In Benin, the **Community Consultative Group (CCG)** was chaired by the Office of the Presidency. Initiatives must invest in the strength of the host organization as well as feedback mechanism (like the CCG) for the community treatment observatory to be successful.
- ✓ **The model must be embedded in the national response.** Working closely with governments and other key national stakeholders was vital. Rather than finger-pointing, the treatment observatories created a **culture of collective problem solving among health care workers, decision-makers, and recipients of care**. Governments came to see PLHIV networks as an asset and an ally in the response.
- ✓ **Moving from ad hoc alerts to systematic monitoring is key.** This enabled the observatories to be **proactive instead of reactive**. By monitoring services along the entire cascade, other issues were unearthed, such as stigma and discrimination as a barrier to access, and gender-related health inequities.
- ✓ **Different observatories function at different levels.** The differences in geographic coverage and the varying capacities of the national networks presented challenges. ITPC developed an **accreditation** tool, classifying the observatories into tiers. This improved the efficiency of the support provided.
- ✓ **Data-driven advocacy works.** Results and analysis from the Côte d'Ivoire observatory caught the eye of Ambassador Deborah Birx, the United States Global AIDS Coordinator. This observatory is now being **funded by PEPFAR in COP19** and has successfully advocated for the **removal of user fees** in the country.

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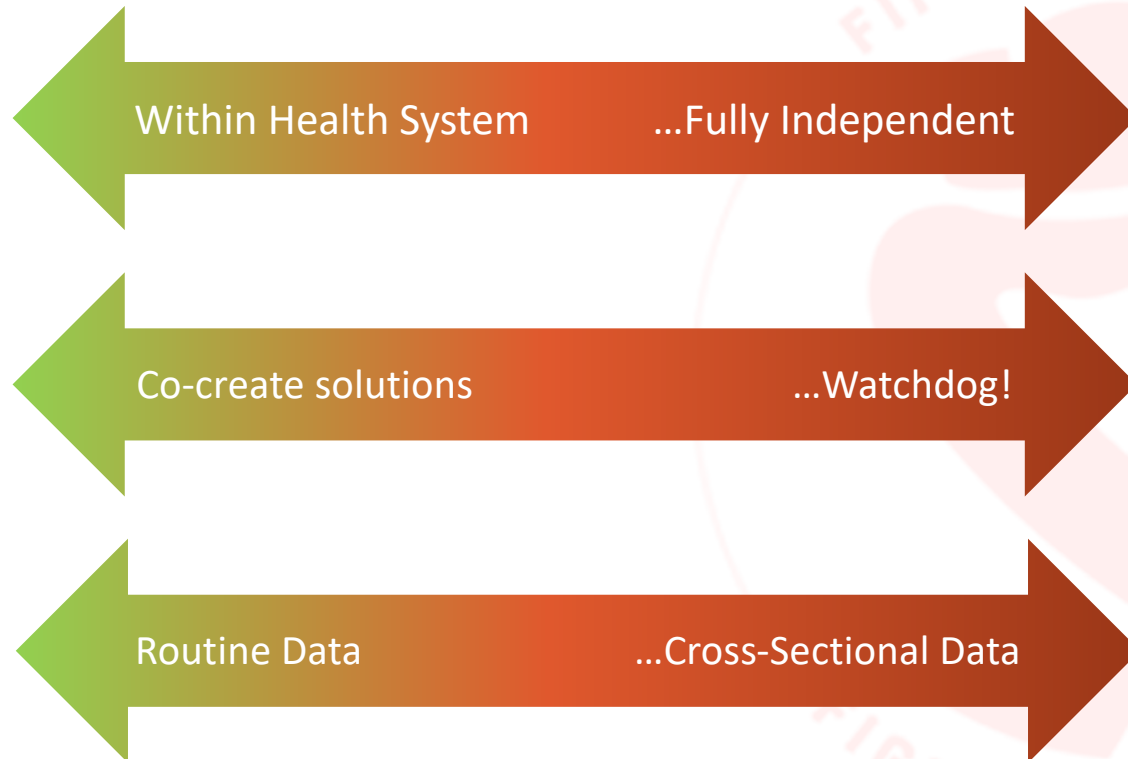


Value of Effective Community-Led Monitoring

- **Forces investments in health/treatment education** – you can't effectively monitor if you don't know the standard.
- The core principle of CLM is that, this is data collected **by** the users of the service to improve the quality of service they ultimately receive. Data that informs national health plans and frameworks is often **void of information from the recipients of care**.
- In addition to the standard indicators collected by health information management systems, CTOs collect **qualitative data** (not collected by the government) that gives **nuance and insight into the data** and tell the story on the **implications of bad quality service for recipients of care**.
- In some instances, communities have **access to data that is not** collected nor analyzed as part of the national HMIS (i.e. KP data).
- CLM has led to communities **finding issues** in the site-level data! CLM is a win for everyone and the whole system.
- The UNAIDS GAM (Global AIDS Monitoring reports) show that community data is **rarely** collected and analyzed at country level – this is due to **lack of capacity and incentive** at national level (based on discussions with UNAIDS). CLM demonstrates an **opportunity to build a system that can contribute to national data systems – with community participation in those processes**.

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Continuum, Continuum, Continuum!



What constitutes a minimum package for effective CLM?

What constitutes a minimum package for effective CLM?

To get to the quality of data that was presented to Ambassador Birx at the Cote d'Ivoire out-brief at the 2019 Country Operational Planning Meeting in Johannesburg, there needs to be a ***reliable, comprehensive community monitoring system*** that:

- Is built upon robust evidence
- Has strong and broad stakeholder buy-in;
- And is housed by a healthy host organization.

What constitutes a minimum package for effective CLM?

Key elements and critical learnings from our Global Fund Regional Grant in West Africa include:

- The ITPC CBM model includes an alert system that forms part of the broader framework where routine data collection allows for a more **comprehensive** database that can detect systemic patterns vs only outing fires.
- The model allows countries to get to the **granularity** (age bands, key populations groups and specific locations etc.) needed to implement change.
- **Healthy Host** = Healthy CTO; issues of governance and financial stability can severely compromise the good program work of a CTO. ITPC purposefully chose to work with PLHIV organizations as hosts in order to ensure that the communities most affected were able to conduct the advocacy. This kind of structure enables much added value including community systems strengthening and community mobilization.
- **Buy-In: Community Consultative Groups** are critical for the “so what” factor that links to targeted action. CCGs are able to help navigate politics and ensure good advocacy.
- **Reliable Evidence:** A strong academic partner is needed (either an institution or consultant) to help with data analysis and ensure a strong evidence-base that informs action.
- **Fidelity and Scale:** We must **pay for what the full model** costs; cutting costs compromises the integrity of the data and the consequent effectiveness of recommended solutions and advocacy. (Global Fund is supporting a costing/value for money analysis). **Annual CTO Budget is \$USD 350,000 - 1 National CTO, 15 sites, CLUSTERED urban focus.**