

COMMUNITY-LED MONITORING BRIEF

This brief is for individuals, communities and organisations seeking to propose Community-Led Monitoring (CLM) to donors, especially at PEPFAR Country and Regional Operational Planning (COP/ROP) Meetings and during The Global Fund to Fight AIDS, Tuberculosis and Malaria (GF) national processes.

COMMUNITIES ARE AT THE CENTRE OF HEALTH CARE

Communities are those people intended to receive and benefit from health care.

What started as ITPC's Regional Community Treatment Observatory for HIV in 11 West Africa countries in 2017 has now become a model that **YOU** can use to help improve access to uninterrupted quality health care anywhere in the world.

Community-led monitoring can work for prevention, other disease areas, and even outside of the health sector to address a range of issues that people care about, such as corruption, human rights violations and budget tracking.

5 KEYS TO EFFECTIVE COMMUNITY-LED MONITORING

1. Conducted BY communities	<h3>2. ROUTINE</h3> <p>Community-led monitoring is routine and done over time.</p>	<h3>3. RIGOROUS</h3> <p>Data is verifiable, reliable, and collected under human rights principles that ensure informed consent, confidentiality, security and no harm.</p>
	<h3>4. INDEPENDENT</h3> <p>Community-led monitoring is independent of government systems, and data is owned by communities.</p>	<h3>5. ACTIONABLE</h3> <p>Community-led monitoring leads to advocacy wins that improve services from the ground up.</p>

Community-led monitoring creates a structured, supported, meaningful and accountable process so that people who receive and benefit from care have a seat and a voice in the decision-making, planning, implementation, monitoring and evaluation of services that their lives and health depend on.

Community-Led Monitoring is NOT...

It's NOT monitoring OF people.	<h3>✗ BY GOVERNMENTS</h3> <p>It's NOT established government M&E systems that include some community-centred indicators.</p>	<h3>✗ BY FACILITIES</h3> <p>It's NOT periodic check-ins by facilities to ensure that services intended to serve communities are doing so effectively.</p>
	<h3>✗ BUSINESS AS USUAL</h3> <p>It's NOT a community-led quality improvement program.</p>	<h3>✗ A SNAPSHOT</h3> <p>It's NOT just studies and surveys conducted to understand what communities experience.</p>

ELEMENTS OF EFFECTIVE COMMUNITY-LED MONITORING

EDUCATION

Training recipients of care on international standards for care and services, as well as methods for data collection and information gathering.

EVIDENCE

Trained community-level data collectors monitor access to and quality of prevention, treatment and care services, including for key populations, using user-defined indicators, through a wide range of qualitative and quantitative methods.

ADVOCACY

Data is used as evidence to inform targeted action at the local, national, regional and global level. This advocacy is vital to ensuring access to affordable optimal care for all.

ENGAGEMENT

Building partnerships among treatment activists, policymakers, technical partners, multi- and bilateral organizations, donors and other stakeholders, in order to co-create solutions and sustain the desired change.

COMMUNITY-LED MONITORING WORKS!

- In 2017, ITPC established the RCTO West Africa, and trained and supported national networks of people living with HIV to collect and analyze HIV treatment data from 125 health centers.
- From January 2018 to June 2019, the observatory produced 1781 monthly quantitative reports, 1501 interviews, and 143 focus group discussions. Feedback was provided to communities, government and health center staff to help improve performance.
- Results included a range of advocacy wins. For example, in Côte d'Ivoire, where the majority of people living with HIV were economically disadvantaged, the observatory pressured the Ministry of Health to enact legislation removing hidden fees, effectively making on-site treatment free of charge.

FIND OUT MORE
[Understanding gaps in the HIV treatment cascade in 11 West African countries.](#)
[Data For a Difference.](#)
[Community-Led Monitoring of Health Services.](#)
[ITPC's Community Treatment Observatories.](#)
[ITPC Community Monitoring Model Explained.](#)

ACKNOWLEDGEMENTS
 ITPC thanks those who have supported our work in this critical area of community-led monitoring. Together with ITPC West Africa, we recognize the tireless efforts of the 11 national networks of people living with HIV and the members of the Regional Advisory Board in the RCTO-WA. ITPC also acknowledges support from the Global Fund to Fight AIDS, Tuberculosis and Malaria, Open Society Foundations, The Robert Carr Fund, the International AIDS Society and the French 5% Initiative.

ABOUT ITPC
 The International Treatment Preparedness Coalition ITPC is a global network of people living with HIV and activists working for universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars:

- Community monitoring and accountability (#WatchWhatMatters)
- Treatment education and demand creation (#TreatPeopleRight)
- Intellectual property and access to medicines (#MakeMedicinesAffordable)