



ITPC @



AIDS 2024  
22 - 26 July



# DAILY HIGHLIGHTS

2024.07.20

@itpcglobal

Saturday

## IMPLEMENTATION SCIENCE AND THE HIV RESPONSE

# Beyond Academia: How Community Led Science can Deliver at Scale

Solange Baptiste addressing the Securing progress and extending impact: Implementation science and the HIV response Pre-Conference at AIDS2024 in Munich



**Science, in its ideal form, is owned by no one and belongs to everyone.**

That was the key takeaway from ITPC’s Solange Baptiste during the *Securing Progress and Extending Impact: Implementation Science & the HIV Response* Pre-Conference earlier today.

It is a collective endeavour driven by curiosity, inquiry, and the pursuit of knowledge for the benefit of all humanity. However, several groups dominate the practice and dissemination of science: Academic Institutions, Government Agencies, and the Private Sector often leaving the Public missing and under-valued as a mere after-thought.

**KEEP READING ON PAGE 2**



## The leading cause of death for people living with HIV is inaccessible diagnostics

Loon Gangte reminds us that **advanced HIV disease (AHD) is real** and people dying from it have been failed by governments, donors, pharma and the HIV movement. *Continue reading on pages 3-4.*

**IMPLEMENTATION SCIENCE AND THE HIV RESPONSE**

# How can Community-Led Science deliver at Scale



## What is Community-led Science?

It starts with **community-led strategic planning** and decision-making to address local needs and priorities.

Then comes **community-driven policy advocacy**, with community groups gathering evidence to influence public policy, for example, advocacy groups conducting surveys and collecting testimonies to push for better healthcare policies for marginalized groups.

That advocacy is **informed by community-led research initiatives** such as Community-Led Monitoring (CLM), Citizen Science, Participatory Action Research (PAR), and Community-Based Participatory Research (CBPR).

And finally, **community-driven efforts** to put strategies, designs, and policies into practice, managing projects, delivering services, and ensuring effective execution.

**Community-led Monitoring (CLM) is a science-based accountability innovation that puts communities first.**

CLM is a process where communities take the lead to routinely monitor issues that matter to them. Then communities work alongside policymakers to **co-create solutions** to their identified problems. When problems uncovered through CLM aren't resolved, communities escalate with evidence-based advocacy and campaigning until they implement corrective actions by duty bearers.

## Scale Considerations: Collaboration and Integration

Valuable community data isn't being used. Community-led science pinpoints health system problems faster and offers practical solutions from end users. We need to challenge the perception that communities are separate (*and only antagonistic*) from government health systems and elected officials.

**We need greater data transparency and we must do more to publicize examples of effective collaborations between communities and government.**

**Learn more about CLM at tomorrow's pre-conference in Rm 14a**

**LIVING 2024 - PEOPLE LIVING WITH HIV**

## **It's time to get our hands dirty and hold governments accountable**

**There is some good news - since antiretroviral therapy has scaled up and many of us have achieved undetectable viral load levels.** We have become healthy, sexy, better – but if you look at my country India, about 30% of people living with HIV have CD4 counts below 200. These are the people who develop advanced HIV disease. Why is this still happening? **Governments, funders and even networks of people living with HIV have forgotten that advanced HIV disease (AHD) is still killing people.**

**20 years ago, we all had advanced HIV disease. My CD4 cell count was 98 before I started taking ARVs.**

A year ago, my organization - the Network of Positive People began an AHD outreach project because as an HIV advocacy network, we felt we had been neglecting this population. We reached out to more than 1100 people and more than 400 of those people had advanced HIV disease.

This is why it is so important to focus on advanced HIV disease.

As people living with HIV, we have all had to confront the reality that we are going to die eventually, but **people with AHD often develop cryptococcal meningitis. It is the most horrific way to die. You can't see, you can hear. It is a very painful disease.**

So, who are these people with AHD? They are adolescents. They are children under 5 years old. They are adults presenting with CD4 counts below 200.

**In our organization, roughly 30% of people are developing AHD.** They haven't been able to access treatment and don't have the opportunity to achieve U=U. They have TB, sometimes MDR-TB and they develop cryptococcal meningitis.

Most of us have forgotten what AIDS looks like. Many countries hardly do CD4 tests anymore and manufacturers have stopped making the tests because they say they are profitable. Without CD4 tests how do we manage AHD?

**Most experts will tell you the leading cause of death for people with AHD is TB. They are wrong—the leading cause of death for people living with HIV is inaccessible diagnostics.** We have developed very cheap, effective TB diagnostics called TB LAM that only cost about \$3, but in many countries including my own, we can't access it.

We must ask ourselves who we are advocating for.

*Continue reading on page 4.*

**LIVING 2024 - PEOPLE LIVING WITH HIV**

**The leading cause of death for people living with HIV is inaccessible diagnostics**

Do our organizations only represent healthy people living with HIV or are we working where we are needed most, for people with AHD? We must ensure that everyone benefits from the scientific advances we have access to, but the reality is that we've forgotten these people.

We will talk about AHD at this conference, but when we go home we need to remember that AHD is real, and it is killing our friends. We need to advocate for the diagnostics required for AHD, cryptococcal meningitis and MDR-TB.

We need to get back to our roots and save our friends because that is the reason my organization exists and if we don't advocate for the rights of people with advanced HIV disease funders and governments certainly won't. **It's time to roll up our sleeves and hold our government accountable.**



**Visit our Artivism Booth**

**Global Village A002**

Blood Type Attitude Philosophy Access

# Activist

**100% Human**

**WARNING**

Contents may be volatile due to lack of sleep, donor imposed deadlines, extensive travel, and /or in response to human rights violations.

**Handle with respect**

**INSTRUCTIONS**

1. Understand the problem
2. Get angry
3. Do your research
4. Make a plan
5. Connect with others
6. Execute
7. Keep up the fight!

**medicines** make affordable  
END UNFAIR MONOPOLIES

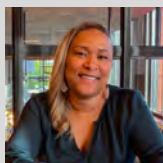
# VISA DENIED

## Difficulties in obtaining visas for the #AIDS2024 conference?

Coalition Plus is collecting testimonies. Share your experience [here](#). We remind you that you can contact the IAS for help with your visa application at [visa@aid2024.org](mailto:visa@aid2024.org)

**CATCH THESE SESSIONS TOMORROW**

**CLM Pre-Conference**



**08h00-09h00 | Room 14a/Channel 9**  
Session 1: Celebrating CLM to Date - Impact, outcomes and role in the HIV/TB/ Malaria response: Celebrating CLM: Stories of impact, outcomes and change  
**Presenter: Solange Baptiste**



**15h00-16h30 | Room 14a/Channel 9**  
Session 5: Community-led monitoring in a changing world - Safeguarding Social Accountability: Toward a consensus statement on CLM in changing world: Loon's must haves and challenging questions  
**Presenter: Loon Gangte**

**UNDP Pre-Conference**



**08h00-09h00 | Room 5/Channel 8**  
Session 1: **From dreams to reality - Achieving the global 10-10-10 HIV targets with and for key populations: Countdown to Change: Can We Achieve the 10-10-10 HIV Targets by 2025?**  
**ITPC Presenter: Nadia Rafif**

**GFAN Civil Society Meetings**



**09h00-12h00 Appel à la Solidarité francophone**  
**Pre-register at <https://bit.ly/46IRfr3>**  
**14h00-17h00 Civil Society pre-conference meeting**  
**Pre-register at <https://bit.ly/4cVzp0x>**

**Global Village**

**16h30-17h30 | Main Stage**  
Session Title: **Challenges in the NGO sector**  
**Presenter: Veriano Tertó, ABIA Brazil**

**Time TBC | Youth Pavilion**  
Session Title: **Community-Led and Person-Centered approaches to retention and re-engagement in HIV**  
**Presenter: NEPHAK**

## PLANNING SESSION

**COMMUNITY SCIENTISTS AT AIDS2024**

**JOIN US TO PLAN A "WHITE COAT" ACTION**

**SUNDAY, JULY 21**  
**16h30-17h00**  
Room 14a, International Congress Center Messe München

COMMUNITY SCIENTIST