

# SETTING COMMUNITY PRIORITIES FOR TREATMENT ACCESS IN WEST AFRICA

## A Meeting Report of the Inclusive Regional Dialogue and Meaningful Engagement of Civil Society, Key Populations, People Living with HIV and other Stakeholders for ITPC's Regional Concept Note to the Global Fund

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ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION WEST AFRICA

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## The Regional Dialogue at a Glance:

When: 2 December 2015

Where: Harare, Zimbabwe
(on the margins of the 18th ICASA Conference)

Number of Participants: 34
Number of Countries Represented: 15

### Types of Organizations Present

National and regional PLHIV networks, key populations organizations, women's organizations, technical support providers, Global Fund representatives & multilateral organizations.

### Main Themes of Discussion

90-90-90; new WHO Guidelines on when to start ART; barriers to access; sustainability; government accountability; regional advocacy with ECOWAS and WAHO; synergies with other national and regional initiatives; TRIPS flexibilities; capacity building of national PLHIV networks.

### Consensus on Priorities for the Concept Note

Community Systems Strengthening, with a strong focus on capacity building of networks in order to make the regional community treatment observatory function optimally as well as be more sustainable. Next, Removing Legal Barriers to Access was selected as a secondary priority, with a focus on policy advocacy, empowering community-based organizations and networks of women and key populations to implement a time-bound, measurable advocacy plan around the data collected in the regional community treatment observatory.



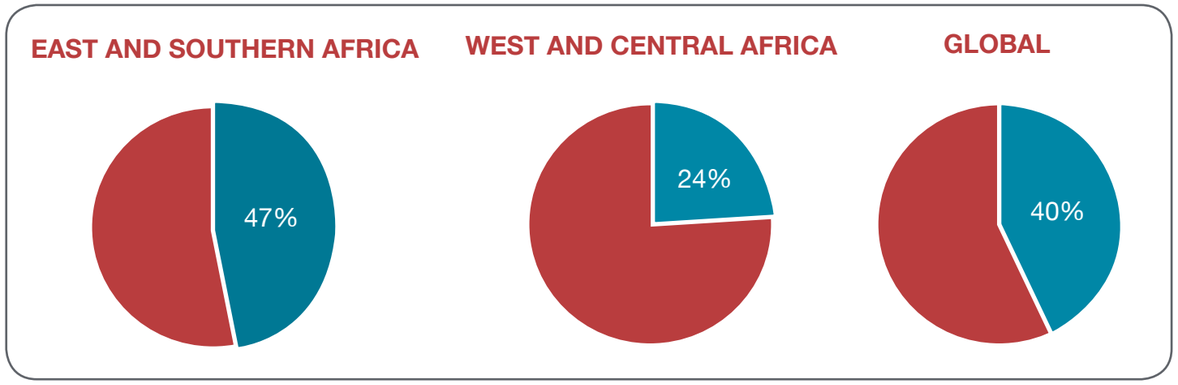
## INTRODUCTION

According to treatment eligibility criteria established in 2013, 72% of all people living with HIV (PLHIV) (globally) were receiving antiretroviral therapy (ART) in 2014, up from 8% in 2000[1]. On the back of this remarkable progress, UNAIDS has set even more ambitious treatment targets for 2020, called the Fast-Track Initiative, commonly referred to as the 90-90-90 targets: 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy; 90% of all people receiving antiretroviral therapy will have viral suppression. Further, the new World Health Organization (WHO) guidelines now recommend that ART should be initiated in everyone living with HIV regardless of CD4 level[2].

While the world celebrates the recently announced achievement of 15.8 million people on antiretroviral therapy (ART), and the fact that the Millennium Development Goals (MDGs) for AIDS have been achieved and exceeded, it is important to also recognize that progress has not been evenly felt in all corners of the globe. Looking at the average ART coverage of all people living with HIV – in line with the new WHO guidelines – is it clear that there is still a long way to go. Figure 1 shows that the gap between the current situation and achieving the Fast Track targets is much larger in some regions than in others.

The average coverage of people receiving ART is 47% in East and Southern Africa, slightly greater than the global average of 40%. However, in West and Central Africa, ART coverage is just 24%[3]. With just a quarter of people accessing the life-saving medicines they need, enormous investment and effort will be needed to turn the tide in West and Central Africa. In order to achieve the goal of 30 million people on treatment by 2020, it is clear that unreached communities in West Africa should be an investment priority.

FIGURE 1: COMPARISONS OF ADULT ART COVERAGE (UNAIDS, 2014)




1. UNAIDS (2015). How AIDS Changed Everything. MDG 6: 15 Lessons of Hope from the AIDS Response. United Nations General Assembly (2011). Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS. New York, United Nations. Page 40.
2. World Health Organization (2015). Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV. Page 12.
3. 2014 Spectrum and GARPR Data collected from AIDSinfo Online Database

## BACKGROUND

In light of these treatment access challenges, ITPC responded to a call from the Global Fund to submit expressions of interest (EOI) for regional HIV grants. ITPC submitted the EOI in April 2015, which detailed a $4.8 million request covering eleven West African countries: Benin, Côte d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Senegal, Sierra Leone and Togo.

TABLE 1: EPIDEMIOLOGY OF HIV AND ACCESS TO TREATMENT IN WEST AFRICA (2014)[4]

| COUNTRY | HIV PREVALENCE (ADULTS 15-49) | NUMBER OF ADULTS (15+) LIVING WITH HIV | NUMBER OF PEOPLE RECEIVING ART | COVERAGE OF PEOPLE RECEIVING ART | DEATHS AVERTED DUE TO ART | 12 MONTH RETENTION ON ART |
|---|---|---|---|---|---|---|
| BENIN | 1.1% | 70,000 | 28,850 | 37% | 2,400 | No Data |
| CÔTE D'IVOIRE | 3.5% | 420,000 | 140,710 | 31% | 11,000 | 70% |
| GAMBIA | 1.8% | 18,000 | 4,586 | 23% | 450 | No Data |
| GHANA | 1.5% | 230,000 | 83,712 | 33% | 11,000 | 92% |
| GUINEA | 1.6% | 110,000 | 32,040 | 27% | 3,500 | 89% |
| GUINEA BISSAU | 3.7% | 37,000 | 8,127 | 19% | 890 | 74% |
| LIBERIA | 1.2% | 29,000 | 6,910 | 21% | 870 | No Data |
| MALI | 1.4% | 120,000 | 31,472 | 24% | 2,900 | 72% |
| SENEGAL | 0.5% | 40,000 | 16,682 | 38% | 940 | 77% |
| SIERRA LEONE | 1.4% | 50,000 | 10,672 | 20% | 1,300 | 71% |
| TOGO | 2.4% | 100,000 | 37,511 | 33% | 3,700 | 86 |

These countries were chosen based on epidemiological indicators such as disease burden and treatment coverage as well as financial indicators such as national income level and the presence of other funding partners. The EOI frames the urgent need to address barriers to access, which make 90-90-90 a distant reality for the region.

The goal of the proposed program is:

- To increase access to antiretroviral treatment for PLHIV in the 11 focus countries. The Program will be implemented by ITPC Global as Principal Recipient (PR), with ITPC WA as Sub-Recipient (SR) and with 12 Sub-Sub-Recipients (SSRs), primarily: PLHIV national organizations in the 11 focus countries and the regional network of PLHIV (NAP+ WA).

To achieve this goal, the program has two main objectives:

- The first objective is to involve PLHIV communities in these countries in effectively measuring and accelerating progress towards UNAIDS' Fast Track Targets and universal access to ART through the implementation of a regional community treatment observatory.
- The second objective is to achieve more effective regional and national level advocacy on treatment access. This will be accomplished through building capacity in development of guidance and support on advocacy on ART issues that occur in all countries in the region. Regional advocacy will be catalyzed in order to lower prices and increase access to medications by challenging trade, intellectual property, and other policies and frameworks that currently make medications unaffordable.

In August 2015, ITPC received confirmation from the Global Fund that its EOI was successful and that the organization was invited to submit a full concept note for a maximum funding amount of $5 million over a three year period. The concept note will be submitted on 1 February 2016.

It is very important that this concept note be informed by an inclusive and participatory process where stakeholders from a



4. 2014 Spectrum and GARPR Data collected from AIDSinfo Online Database

variety of constituencies come together to discuss priorities, interventions and activities for the proposed program. The program must be reflective of the collective priorities and inputs from civil society, PLHIV, key populations, members of country coordinating mechanism (CCMs) and other vital stakeholders.

This meeting report reflects the results of the main consultation for ITPC's regional concept note to the Global Fund. The discussions from this regional dialogue incorporate and build on the results of an online regional consultation administered in November 2015, which generated responses from 157 individuals.

## PARTICIPANTS

While the online dialogue had a broad range of participants from key populations (21%), women's organizations (15%), religious and faith-based organizations (3%), UN agencies (4%), health professionals (7%), government (13%) and other HIV organizations (19%), among others, the in-person dialogue was geared more towards empowering the national and regional networks of PLHIV to own the concept note development process. Indeed, 46% of respondents to the online dialogue were from PLHIV organizations, though the intent of the in-person consultation was to carry the results of the online survey through to practical priority setting. For instance, improving the availability of data was a key result from the online regional dialogue, as was regional watchdogging; both of these also came out strongly in the in-person dialogue.

Another important aim of the regional in-person dialogue was to ensure that the networks of PLHIV – as the main architects of the program – would be empowered to be at the fore of its conceptualization. Many of the PLHIV networks present also expressed that they are women's networks or that they work specifically with key populations.

The results of the online dialogue were discussed in the morning session, revealing that approximately half of delegates present had also taken the online survey. Some suggested that doing an online dialogue is sometimes a challenge, both from an internet standpoint as well as a capacity standpoint (people are not familiar with this style of survey). However, the high rate of response helped to demonstrate that these kinds of consultation tools can be employed successfully in a diverse range of settings. In any case, the in-person dialogue was also a way for delegates to engage with their online results, but also for those who did not access the online survey to participate in the discussion about priorities.

Further, while not all countries that completed the survey are in the concept note, this was an opportunity for others in the region to still have a say in the program, as the outcome of the program affects all countries in the region since advocacy will be done on a regional level. Participants from Guinea Bissau apologized for not filling in the online survey, due to the timing of a Global Fund mission to the country. But they also expressed gladness for being in attendance at the in-person dialogue so that they may have their voices heard.

The results of this report, which directly feed into ITPC-WA's concept note, are reflective of participants' voices from the following countries: Benin, Botswana, Burkina Faso, Canada, Côte d'Ivoire, Gambia, Ghana, Guinea, Guinea Bissau, Liberia, Mali, Nigeria, Senegal, Sierra Leone and Uganda. See the Appendix for a full list of organizations represented in the regional discussion, as well as the meeting agenda.

## BEFORE WE BEGIN – "WHO'S WHO?" AND MAPPING SYNERGIES

As delegates introduced themselves and their respective organizations, the dialogue moved into a discussion about how those represented would endeavour to participate in such a way as to ensure that synergies are identified, and duplications are avoided, with other national and regional initiatives. Several delegates present were not from the countries prioritized for ITPC's concept note, though they were invited for their strategic value as critical links with overlapping and existing national and regional programs. This was not an accident; in response to the TRP comments on the EOI, ITPC and supporting partners made sure that the in-person dialogue had the right partners in the room to ensure discussions on program synergies. Collaboration and coordination is deemed one of the key value-adds of regional programs, so the dialogue intentionally set aside time to map these out before beginning. The section below highlights the strategic synergies fostered among participants during the in-person dialogue.



First, the representative from Canada was from Handicap International (HI), an organisation which is also submitting a regional Global Fund concept note in Window 09 on 1 February 2015. Their proposed program would cover Mali, Senegal, Burkina Faso, Niger, Guinea Bissau and Cape Verde. As there is some country overlap, her presence was important to ensure the discussion is guided and informed by their proposed initiative. It was discussed that ITPC's treatment observatory could collect treatment access for people with disabilities in the overlapping countries, sharing this with HI.

Second, the representatives from Uganda were members of the Key Populations Experts Group, which is working with UNDP to support the work of the ARASA/Enda Santé regional concept note which has already been approved and has proceeded to grant-making. As the ARASA/Enda Santé program has a heavy focus on removing legal barriers to access, and overlapping countries – Côte d'Ivoire and Senegal – it was important to ensure that ITPC's dialogue was able to link up with the work which has just begun on that grant (indeed, information sharing around the Legal Environment Assessments being conducted for that project arose during the activity setting session).

The Ugandan representatives were also able to share experiences of regional concept note development in the first window, as they are members of an East African harm reduction network and participated in the KANCO application. This was valuable advice for ITPC-WA and the other participants ahead of their concept note submission. They chiefly highlighted the need for robust regional data collection as part of their regional program, pointing out how the problem they are seeking so solve is largely similar to the one ITPC proposes to address in terms of the need for harmonized regional data. They said that the lack of systematic and comprehensive regional data was hampering their activism around law and policy reform. There are a lot of similarities between this proposal and the KANCO one, including the need for community data collection and empowering those most affected to be leading the data collection in their region. This in turn is then used to do more effective national and regional advocacy. Similarly to East Africa, there are also opportunities to leverage the successes of some countries in order to promote others to pick up the pace and follow suit, using a regional level advocacy.

Third, the participant from Burkina Faso was an important link to several other collaborative initiatives. First,

it was advantageous to have the presence of the Global Fund's Regional Platform for Communication and Coordination for Francophone Africa, hosted by RAME (Réseau Accès aux Médicaments Essentiels). This platform will be a critical support system for ITPC's proposed program in terms of information sharing with communities as well as providing a vital link to technical assistance.

This is particularly important for the PLHIV networks as sub-sub-recipients, and a formal agreement will be pursued through the Regional Platform with the French 5% Initiative. Second, this participant was also able to share information on the community treatment observatory that RAME is running in Burkina Faso, Guinea and Niger, called the Community Observatory on Access to Health Services (OCASS). One of the key objectives for ITPC's proposed regional observatory will be to standardize and harmonize data collected that is already being collected through initiatives like OCASS.

Fourth, yet another strategic link was made by ensuring that representatives from the International HIV/AIDS Alliance in West Africa were present. As the Alliance has linking organizations in Côte d'Ivoire and Senegal, and is also submitting a concept note on the 1st of February, through their new Key Populations Centre of Practice in Dakar (within ANCS), there were important discussions to be had about potential linkages and synergies. The Alliance program focuses on harm reduction in the region, so it was discussed how there may be an opportunity for the regional observatory to also collect disaggregated data on treatment access among key populations, especially drug users, to share with ANCS.

Fifth, the representative from the UNAIDS regional office provided an important connection to the existing initiative led by the JURTA PSM group, comprising UNAIDS, WHO, UNICEF, OCEAC, ECOWAS/WAHO. The group is doing work around antiretroviral stock security in ECOWAS member states, mainly focused on better technical solutions as well as supporting buffer stock initiatives. It was discussed that the ITPC regional observatory could provide valuable information for the JURTA PSM group, and that joint advocacy would be an enhanced approach.

Lastly, many of the participants were also members of their respective Country Coordinating Mechanisms (CCMs), helping to ensure that this regional process is linked with national Global Fund programs. These delegates provided important information on what was already ongoing at national level, guiding the discussion to make sure regional efforts have a value-add to national Global Fund investments.

As this is ITPC's first Global Fund concept note, all delegates in the room welcomed the opportunity for the regional dialogue to be a learning experience. With the support of those present, information sharing on other national and regional initiatives, especially around experiences and best practice around Global Fund processes, was a rich element of the discussions.

## DIVING IN - OUR SHARED CHALLENGES

Following introductions and a vibrant discussion about synergies from various participants, the dialogue moved to begin talking about shared challenges in the region, looking at the results of the online survey and how delegates in the room agreed or disagreed with the findings.

The idea was to digest the results of the online regional survey through the lens of the participants who had gathered in Harare, making sure that one dialogue fed into the other.

Christine Stegling, the Executive Director of ITPC global began by acknowledging that "Most of you in this room are from a region where treatment access is a huge challenge. A large part of this challenge is that West Africa is not a region where a lot of resources are going." This framed the need in the region as well as the rationale for requesting investment from the Global Fund. Stegling continued to express that out of all the regions where ITPC works, West Africa was the clear priority for a treatment access program. The results of the online dialogue also show the interest in the region around these issues – 157 responses is an unprecedented show of community support for this initiative.

It also shows that preconceived notions about internet access or capacity to use tools like Survey Money in West Africa are unfounded. West Africans can and will participate in dialogue in innovative ways in order to have their voices heard and their issues addressed.

Shared challenged were highlighted around PLHIV networks not accessing funding. Or, when they are, they are only receiving very little. There were also shared issues of capacity which were raised. The topic of regional concept notes was discussed as both a way to respond to common challenges as well as an opportunity.

Importantly, there was consensus that the regional level is a way to leverage progress at national level.

Building on this discussion about the value-add of the regional approach, Sylvere Bukiki, Director of ITPC-WA, noted that

*"HARMONIZING TREATMENT OBSERVATORIES AT THE REGIONAL LEVEL IS IMPORTANT. AT THE MOMENT, COMMUNITY MONITORING AROUND TREATMENT ACCESS IS VERY FRAGMENTED AND THIS IS HAMPERING ADVOCACY EFFORTS IN THE REGION."*

As one participant noted, it is really important not to neglect lower burden countries, because there are people living with HIV there too and they must not be left behind or forgotten. Bukiki continued with an important emphasis – that the value of ITPC's proposed program is not only regional, but national, too.

*"OUR REGIONAL PROGRAM WILL HAVE GLOBAL VALUE. WE WANT TO ESTABLISH A DATABASE THAT ORGANIZATIONS LIKE THE WORLD HEALTH ORGANIZATION CAN USE. IF WE HAVE A FUNCTIONAL DATABASE, THIS CAN BE COMPILED AND GLOBAL PARTNERS CAN ALSO HAVE ACCESS TO IMPROVED DATA IN THE REGION."*

So, the use of this data through the observatory is not just for the use of the networks and their national and regional advocacy, but it also has important uses for international partners to use the data to ensure international funding and policy responds accurately to the needs on the ground in West Africa.

At this stage, the representative from the Regional Platform for Francophone Africa stepped in to play an important coordination role. He reiterated that ITPC's proposed program must not duplicate efforts:

"As the Regional Platform I am dedicated to ensuring that there is coordination, to make sure that treatment observatories are harmonized. If there is a functional regional observatory, the data collected through the various models can all be input into one database."

Following the point about WHO usage of the regional data, delegates reminded one another that information needs to trickle to communities. The information collected through the observatory is also not just for the networks to use, but also for that information to reach communities and for communities to be empowered. This, too, was discussed as a job for the Regional Platform to make sure that the information is translated into a format that communities can access and use.

## CAN WE ACHIEVE 90-90-90 WITHOUT COMMUNITIES?

Next, the dialogue shifted gears to discuss how the shared challenges in the region relate to new global Fast Track targets and 90-90-90. A large barrier cited was level of investment. One delegate passionately reminded the room: "We need to increase domestic funding, but how can we do this? We need to advocate with data and information. Having strong community monitoring is critical for advocating for more resources. Resources for coordination should be part of this grant. We need to also have support to advocate with the data we collect." Building on this comment, another said that this is an opportunity for networks to discuss fundamental issues. Indeed, these fundamental issues for communities directly affect the ability of countries (and the world) to achieve the Fast Track targets. One participant aptly insisted:

*"90-90-90 – IF WE DON'T HAVE A STRONG COMMUNITY VOICE, IT CANNOT BE ACHIEVED."*

At this stage, the representative from UNAIDS began to discuss the OCAL concept note, though there were regrettably no strategic representatives from that program in the room. UNAIDS highlighted how this existing regional program – approved in the first round of regional concept notes - works with migrants along the corridor in West Africa. Participants were urged to consider how this program might coordinate and collaborate with that one, as treatment access issues are a well-documented challenge for migrant and mobile populations. He continued to note that it is not easy to lobby CCM at national level, but we should not also view that as an obstacle. He continued: "We need to use Global Fund and UNAIDS support, both of which acknowledge that community treatment observatories are very important.

"We also have the blessing of ECOWAS, as what we are proposing is in line with regional strategies."

Sylvere Bukiki jumped in again to link the challenges being faced with civil society's current momentum, noting that "A recurring issue is how to revive activism. People don't have information about what is happening. This is a barrier to activism." This is identified as the main blockade for effective activism around



treatment access in the region, pointing to the data from the regional community treatment observatory as a vehicle for informing and empowering networks to kick-start evidence-informed activism. A participant from Senegal agreed, noting that there are missing objectives in the EOI - the need to revive activism at the national and regional level (see prioritization section below, to see how participants made sure this point came through in their community design of the modular template).

The EOI was presented by Solange Baptiste as an opportunity to further engage participants around the specifics of the proposed program. The participants were invited to unpack the EOI to see what they agree with and what they have questions around, inviting them to shape the concept note based on their perspectives and experiences. Importantly, this is not the first time many of the participants had meaningfully participated in the discussion about the EOI. ITPC West Africa facilitated an online and telephonic dialogue to inform the EOI. This is also partly how the countries were chosen: based on disease burden, income level, presence of other donors as well as eagerness to be involved. Countries in the region were invited to be part of the regional proposal and the ones selected all expressed interest (through the respective national networks). The buy-in from the networks was deemed important, from the pre-EOI stage:

*"IT'S REALLY ABOUT WAKING UP THE NATIONAL NETWORKS, INVESTING IN COMMUNITIES, AND INCREASING THE ADVOCACY AROUND TREATMENT ACCESS IN THE REGION,"*
said Solange Baptiste of ITPC Global.

Participants emphasized that the community part of the regional community treatment observatory is very important. It's not the UNAIDS model. It will collect quantitative and qualitative data, so this will include monitoring the prices and availability of drugs, but also documenting experiences and stories. These will be monitored with equal value, as participants felt that personal experiences and stories would be vital to deepen and augment any quantitative data and analysis. Affirming the value of stories, and commending the room for taking a lead in suggesting what kind of data should be collected, Solange Baptiste said "It's community driven. You don't need a PhD in epidemiology to do this. It's led by communities and PLHIV. It's what communities think should be measured."

Building on what should be measured, one participant said "We will always have the word 'quality' in front of ART." She referred to the issue of D4T access in the MENA region, as well as various community responses to the new WHO guidelines, where quality is a big concern.

Participants agreed that the qualitative data collection for the regional community treatment observatory would be vitally important, as there is a need to also measure the quality of treatment access. Indeed, the second most common barrier to access cited by the 157 participants in the online regional dialogue was that "the type of ARVs that I need are not available in the clinic or in my country."

## THE NEW WORLD HEALTH ORGANIZATION GUIDELINES – CAN "TEST ALL, TREAT ALL" POLICIES WORK FOR US?

Building on the 90-90-90 discussion and reflecting on the online dialogue, participants began interrogating what the new WHO guidelines (on when to begin ART) will mean for West Africa. Many participants expressed scepticism about their practicality, given the region's current state of affairs: "People are saying we have seen less ambitious initiatives that were not even implemented. This new initiative, will they be implemented? People are saying no. We do not have faith in the political will to achieve this."

*"BUT IF WE DON'T HAVE FAITH IN OUR LEADERS, CAN WE AS COMMUNITIES DO SOMETHING TO ACHIEVE THIS*

### *RECOMMENDATION? WHAT CAN WE DO TO SUPPORT IMMEDIATE TREATMENT FOR ALL, REGARDLESS OF CD4 COUNT?"*

This was a powerful charge, coming from the Regional Platform for Francophone Africa.

So how can ITPC West Africa's proposed program help support policy dialogue around the new WHO guidelines? How can the regional community treatment observatory help achieve their implementation?

A participant from Sierra Leone noted that it is possible to create policy space around these guidelines, despite seeming like an insurmountable challenge. He related to the room that his country's new National Strategic Plan (NSP) contains a "test all start all" policy, to be implemented as of 2017. He was then asked to expand on how the country got there, achieving this policy transformation. The participant expanded how a meeting funded by the Global Fund in Dakar was a turning point for achieving this policy progress.

*"IN DAKAR, THANKS TO THE GLOBAL FUND, THEY AGREED ON THE 'TREAT ALL, TEST ALL AND RETAIN ALL' – TATARA – APPROACH."*

Reiterating issues of quality, as well as sustainability, a young woman from Liberia once again challenged the room:

"If they treat all, how are we going to be treated?" What do we do once Global Fund pulls out too? The policy is good, but the question is whether or not our government is willing to support the implementation."

Indeed, implementing the new WHO guidelines will have large sustainability implications for a region which is already spending the least amount of its total HIV budget on care and treatment – even less than North Africa where treatment coverage is lower.

In agreement, a Senegalese delegate said

"It's over ambitious vis-a-vis the funds that are available. In Senegal, we began prioritizing the southern zone where prevalence was higher. We started implementing treat all policies in that particular zone of the country only."

Another delegate suggested that test-and-treat for all cannot work in many of the current legal environments in Africa.

*"HOW IS TEST ALL TREAT ALL GOING TO WORK?"*

said one Ugandan delegate. He cited criminalization of certain populations and harmful laws. "How is 'test all treat' all going to work when there are criminalizing environments?" He also noted that PrEP is being seen as a way of promoting homosexuality, which is also a challenge.

In response, a delegate from Sierra Leone spoke of the modes of transmission study, which he said showed that new infections were coming from key populations, mostly MSM. "These are populations which are criminalized in the country." He said that the study was shared with the NAC, and

*"WE HELPED EVERYONE TO UNDERSTAND THAT HIV IS ABOUT EVIDENCE. AND NOW IF WE HAVE THE EVIDENCE WE NEED TO RESPOND ACCORDING TO THE EVIDENCE."*

Delegates agree, reminded of the importance of collecting good quality data through the regional community treatment observatory. The participant from Sierra Leone continued to note that "Commercial sex work is illegal in Sierra Leone, but we are




looking at the evidence. Based on this, we were given space to do community observatory work with ITPC, we were able to establish a key populations coalition." This includes IDUs, MSM etc.

> "Now we are actually responding to their needs, we are really responding to HIV as a human rights issue. We are using a human rights angle. Existing observatories are organized to do key populations' treatment observatories in particular places where evidence shows these are the populations which need focus."

In closing this themed discussion, one participant assured the room that the WHO recommendation is the first step. He closed with "We need to have this in place to advocate with our policy makers. What are the key tools that exist to help us? Do we know about them?"

## ENSURING SUSTAINABILITY FROM THE VERY BEGINNING – LET'S NOT START WHAT WE CAN'T FINISH

From the very start of the dialogue, participants had sustainability on the tips of their tongues. "How are you going to transition to other sources of funding?" one young woman from Liberia asked. "This is a key thing we need to emphasize. Domestic funding is important," she continued. Others responded that this is a clear aim of the advocacy around the data collected through the regional community treatment observatory.

*"WE WILL USE THE DATA TO ADVOCATE FOR IMPROVED DOMESTIC FUNDING"*

one participant replied. Another reminded the room that this also goes back to the point about how the observatory will be an open database, so that other partners such as the WHO can access the information.

*"WE BELIEVE THAT THIS WILL INSPIRE GREATER GLOBAL INVESTMENT TOWARDS TREATMENT ACCESS, AS WELL AS GREATER DOMESTIC INVESTMENT"*

a third participant said.

A Senegalese participant reminded the room that they should have confidence in the long-term viability of the project for good reason:

> "Many partners have started to implement observatories. Some started with other partners, others just did their own initiatives. I think this shows that the sustainability is there, because this is an existing initiative. The need is just to centralize this information collection."

Other agreed that once the centralized system is in place – through ITPC's Regional Community Treatment Observatory - the existing activities are likely to continue (as they have been) but will feed data collected into the regional observatory going forward.

Agreeing with the Senegalese delegate, the UNAIDS regional representative said that networks of PLHIV have already created their own approach, and they are already to set up to do advocacy at the ECOWAS level. "Even if there are not in all 15 counties, the advocacy benefits all 15," he said. Successful advocacy at the ECOWAS level will lead to change in each country. He continued to impress upon the fact that the proposed regional community treatment observatory fits into an existing mechanism, which is important to highlight. ECOWAS ART Stock Security is one mechanism, so there is already a regional approach to respond to these challenges.

Circling back on the opening discussion about synergies, coordinating with other initiatives was raised three times during the morning session. The Regional Platform for Francophone Africa was again charged to ensure that ITPC's proposed program will coordinate effectively with all the other community led efforts in the region.

## TRIPS – HOW DO COMMUNITIES ENGAGE WITH INTELLECTUAL PROPERTY LAWS?

Also responding and reflecting on the results of the online dialogue, delegates noted that TRIPS flexibilities were neglected in the online survey. Based on this observation, the group elected to discuss strategies around this topic in the in-person dialogue. When posed as a question to the room, only two participants – one from ITPC West Africa and one from the Regional Platform for Francophone Africa - put their hands up as people who know about TRIPS and how they can use it in their work. It was clear then that this level of technical advocacy can and should happen at the regional level, and delegates were glad to have regional leaders in place on these issues.

With the leadership of those in the room who had an understanding of TRIPS, it was highlighted that implementing TRIPS flexibilities can reduce the price of drugs by up to 50%. However, only one or two countries in Africa have managed to implement this agreement. "Second and third line treatments are two, three and four times more expensive than the first line drugs that your countries are already struggling to keep in stock," one delegate said. Another challenged the room:

> "If ARVs are not always available at our local clinic, what questions do we need to ask? Is it a central procurement issue? Did the truck break down when delivering them? Is this related to prices?"

One participant lamented that "If PLHIV do not understand how the prices are determined for the medicines that they are taking every day, how can we succeed?" She said literacy is an important part of how this program will succeed. However, in disagreement, players at the regional level said that

A debate began as a delegate from Côte d'Ivoire said it was the job of networks to translate complicated information in to a language that communities could understand;

> "it is not necessary for all of us to understand the A-Z of what to do [about TRIPS], but it is one of the building blocks. Do we need to have experts in each country? No. We can have two or three at the regional level to help support all countries in the region. This is a good example of regional value add."

she said they do in fact need to be experts. She said they have an initiative that brings together all organizations, including the coalition of women living with HIV, around access to viral load testing advocacy and the national level.

*"WE EXPLAIN WHAT VIRAL LOAD IS TO THE COMMUNITY, TO ALLOW FOR IMPROVED TREATMENT ADHERENCE. THIS IS AN INITIATIVE THAT CAN SERVE AS AN EXAMPLE, AND CAN BE REPLICATED AT THE REGIONAL AND SUB-REGIONAL LEVEL."*

## OUR SOLUTIONS – WHAT ARE WE DOING NOW, AND WHAT COULD WE BE DOING IN FUTURE?

As the afternoon session approached, and participants geared up to set practical priorities and solutions to the shared issues highlighted above, delegates began thinking strategically about how they could improve the treatment access situation in the region. One woman said: "Three months ago we had a stock out of ARVs. PLHIV went to NRP+, the national network, to voice their concerns. An observatory was set up to monitor the distribution and access. We found that there were ARVs in the country, but it was just a distribution issue!"

Another delegate spoke of a sub-regional solution that was already emerging where he lives:

> "This is unacceptable! They were telling us that the dollar rates had gone up and so they could not make the financial transaction to place the order. They started renegotiating. During that time people living with HIV who were supposed to receive these drugs were receiving nothing. That is unacceptable!"

"We need to tell government that they must sort out their financial issues, but they must not tell us to wait because you want to negotiate a better contract. We asked the neighbouring countries to help, to send ARVs, to send an order to resolve this issue." This delegate continued to impress upon the room that a regional solutions was already underway to address these issues, and that participants from other countries could learn from the Senegalese example:

> "When we had this problem in Senegal, what did we do? We linked with the regional stock which is based in Abidjan. We also wanted to be closer to the other countries in the region, so we may also lean on them to have back-up stocks."

A participant from the Gambia said there were no stock outs in his country currently. He said that in the past, they had the drugs in the central medical store, but were not being distributed to their respective clinics. In 2012, 2013 and 2014, this was happening. Then, they set up the Gambia treatment observatory - "GTOC". At the time, he was a member of the CCM. We engaged the director to tell him that these drugs were not available. When he came back there was a fair distribution of the drugs at the facilities. "On a few occasions, we experiences stock outs and drugs were borrowed from neighbouring Senegal to stop the stock out. Now, with the advocacy and based on our efforts, there are no stock outs of drugs."

Another positive experience was shared by a participant from Côte d'Ivoire. This delegate said that they are working on community quantification of new infections, so that this data will help us come up with better planning for the distributions of ARVs. This delegate then suggested to the room that

***"WE CAN DO QUANTIFICATION AT THE REGIONAL LEVEL!"***

Another participant chimed in: "I suggest that we adopt a systematic approach to resolve these issues. If in a clinic, there is no drug, the question is what you, as community, can do. Don't say what other people can do - what can you do? I propose two main things. Advocacy and information sharing. When advocacy doesn't work at the national level, write a report and bring that report to a higher level.

> If at national level you cannot capture their attention, go to the regional and international level! Go to the UN level! This is a value-add when nothing has been found as a solution at the national level.

The second thing is information sharing. Automatically and quickly you can alert other networks in the region. Sometimes it's not a national stock out, it's a sub-regional issue." Another participant agreed that "Information sharing is critical for having credible advocacy. Monitor and document what is missing. Where, why and how often? Frequency is key."

Indeed, others agreed that there was a need to ask "What are the regional bodies we can access and target in terms of legal and policy advocacy?" This will be vital for determine how the regional community treatment observatory can have maximum strategic impact.

One participant suggested that the networks consider how to work with the media at the national and regional level. "When there is stigmatizing information coming from the media, say, on a radio station, that can easily be passed to other countries." This, too, is part of why a regional approach is needed. "There are also opportunities. There is a regional network of journalists living with HIV which we can engage as part of our solution to these issues."



Another delegate responded, indicating that there is an HIV/AIDS Reporters Association in Sierra Leone, too. "These are people who are trained on HIV reporting. We collaborate with them on a regular basis. We also have a forum where we train law enforcement bodies." This was agreed as another important advocacy example that other countries in the region could learn from.

Based on these successes, other participants agreed that actors from other countries are ready to follow suit. However, some expressed that advocacy around legal and policy change is sometimes too long-term for such an emergency situation:

> "This is an opportunity for us to find a solution. Laws that exist today can help us do much, but we cannot always be revising them. We can exploit the existing flexibility. We need to move faster than that. People out there need treatment. We need to do something and changing laws takes too long."

In closing this discussion theme, a participant urged the room to think carefully about "What can we learn from each other? What are the things that could be done by you, putting your forces together? It should never duplicate what you are doing at the national level." He suggested that when we go to drafting concrete examples (in the afternoon session), it will be easier. This delegate shared the experience of the Handicap International[5] concept note (being submitted on 1 February 2016, as well). He said they chose activities that for some reason or other, were activities that were not integrated at the national level. The regional concept note is an opportunity to fill gaps in Global Fund grants at national level. Indeed, a recent report published by AMSHeR shows that this is a key opportunity for regional programs for PLHIV in Africa. In AMSHeR's report, 57% of PLHIV respondents indicated that national Global Fund concept notes did not meet any needs - or met very few needs - of their constituency. The remaining 43% said that country concept notes met some of their needs. Not one PLHIV respondent felt that the national concept note met quite a lot, or all of their needs. ITPC's regional program will fill some of these critical gaps for PLHIV at country level. The survey includes data from Togo, Ghana, Cote d'Ivoire, Liberia and 9 other African countries.

Another solution provided was that "We need to get ARVs to be considered emergency medicines. This is an example of how we can improve supply with TRIPS flexibilities," said one participant.

***"ECOWAS PARLIAMENT AND THE WAHO ARE KEY PARTS OF HOW THIS RESPONSE CAN BE IMPROVED."***

The room agreed with one technical partner who said that "At the country level, you need to tell us about the issues of capacity building. What should be in the concept note? This discussion should allow you to affirm that."

Another participant continued to emphasize that the value-add of the regional approach is to catalyze existing regional efforts. Monitoring committees on ARVs have been established, which bring together Ministries of Health, National AIDS Councils (CNLS), and technical partners. These are forums where actors can see the supply chain plans and this can help. This is another good example of something that can be done in other countries. ECOWAS is taking interest in issues of states, who are putting pressure on countries to make this kind of advocacy. It's not easy for one organization alone to do this, it's better to have common advocacy from civil society in the region to come together and advocate with ECOWAS, and the African Union.

> "We can come up with a way to do coordinated advocacy. This role is well defined by African Union Roadmap, but we are not taking this opportunity yet. This is a value add of the regional approach."

The strongest solution that the room agreed would contribute immense value to the issue of treatment access was simple documentation of systematic data.

5. The Handicap International concept note is being submitted on 1 February 2016, addressing issues in Mali, Senegal, Burkina Faso, Niger, Guinea Bissau and Cape Verde. A critical link was made during the regional dialogue, and information sharing has been ongoing to ensure the two regional concept notes are as synergistic as possible.

*Regional dialogue participants standing proudly around their prioritized Community Systems Strengthening module*

*"IF WE HAVE SYSTEMATIC DATA ON THE STATE OF HEALTH AND COMMUNITY SYSTEMS, WE COULD PRODUCE REALLY STRONG REGIONAL REPORTS."*

Agreeing, Christine Stegling, Executive Director of ITPC Global reminded the room that "This is not just for your countries, for your governments. It's also for the international community. How do we document a regional state of affairs that informs the global conversation about access to treatment?" –

*THIS IS SOMETHING THAT MAKES THIS REGIONAL PROGRAM RATHER UNIQUE.*

It has regional objectives, but also a global purpose. "The disconnect is so visible," continued Christine. "We see all of these challenges yet we are discussing 90-90-90 and test and treat. This will never work [as things are now]." Agreeing with ITPC leadership, many delegates put forward the idea to do annual reports with the observatory data as a core proposed activity.

It was also discussed how the advocacy is not just for HIV, but for all access to health services. This is a way to leverage HIV structures, as is suggested for optimal sustainability.

In preparation for prioritization of interventions and engaging with the Modular Template, Solange Baptiste reminded the room about the three key barriers which emerged from the online dialogue: (1) stock outs, (2) health systems (not enough clinics, too far) and (3) legal and policy environment. She also suggested delegates think through how those barriers filter through today's discussion so far.

Another thing that was posed to the room to continuously think about was: What is the value add of the regional approach? A representative from the International HIV/AIDS Alliance, again providing a strong and critical link to the ANCS concept note, said it is fundamental to realize that this is not a new thing. We need to identify the thematic that you will conduct at the regional level and to which body will you advocate with.

> The theme of a regional watchdog for national implementation was agreed for the program.

Delegates wondered: Can we add pressure to national governments based on the progress of their neighbours?

In agreement, the observer from the Global Fund, who attended the meeting for the full day to provide assistance and guidance, reminded the room of this critical part of regional proposals – the value-add. "We need to make sure that the regional grant has added value to what we are already funding in the countries," she said. "You have to identify what is your value addition. What is unique? There are other regional proposals in West Africa, but none is focusing on treatment access. At the national level, what is the Global Fund paying for? Be realistic about what can happen in three years. Ask how this will be sustainable.

## PRIORITIZING ACTION - A MODULAR TEMPLATE DESIGNED BY COMMUNITIES

In the afternoon session of the regional dialogue, delegates set out to translate the content from the morning's discussions into a prioritized program using the Global Fund's Modular Template. Based on the results of the online dialogue, it was clear that the two modules for ITPC's proposed program would be (1) Community Systems Strengthening and (2) Removing Legal Barriers to Access. Using these two modules, the room split into two groups to prioritize interventions and proposed activities within them. The following represents the results of that prioritization exercise, which is intended to guide and inform the design of ITPC concept note, placing community priorities as an important element of the proposed response.

## Priority Module #1: Community Systems Strengthening

### Priority Intervention #1: Institutional capacity building, planning and leadership development

It was suggested that the regional community treatment observatory can only operate with a foundation of strong and capacitated networks, which will be doing the data collection, analysis and advocacy. This must necessarily be the first priority, as no other interventions can follow without it as a foundational activity. This will include capacity building of community sector groups, organizations and networks in a range of areas necessary for them to fulfil their roles in service provision, social mobilization, monitoring and advocacy. Specifically, communities identified the need for support to regional networks to strengthen the networking and coordination of national networks, including ambassadors of hope activities, training, and provide core budget for the functioning of networks.

### Priority Intervention #2: Social mobilization, building community linkages, collaboration and coordination

After capacity building, mobilization was deemed a secondary priority to ensure that the right linkages are in place to prepare for effective implementation of the regional community treatment observatory. This includes strong informal and formal relationships between communities, community actors and other stakeholders. Specifically, this will include the establishment of community observatories in each country (where they don't already exist), reviving those that had already been established but might need additional support, and ensuring that all actors are trained, coordinated and prepared to begin feeding information into the regional database. This was a logical second priority, with the third priority focusing on the actual implementation of the treatment observatory. In this sense, intervention 1 and 2 are necessary foundational components.

### Priority Intervention #3: Community-based monitoring for accountability

Once capacity building and community mobilization interventions have been implemented, delegates prioritized the roll-out of the regional community treatment observatory. As mentioned in the introduction to this report (and in the EOI), the proposed program would support the implementation of a regional community treatment observatory, empowering networks of people living with HIV to systematically collect and analyze qualitative and quantitative data on barriers to access. This may include documenting prices and stock outs of medicines, access to viral load testing, as well as experiences at health facilities. This will be a mechanism for ongoing monitoring of health policies and performance and quality of all services related to treatment access, including challenges in the environment such as discrimination and gender-based inequalities. An open source regional website will be created, so that the data can be of use to national actors, regional actors and even international actors.

### Priority Intervention #4: Advocacy for social accountability

With the data collected under priority intervention #3, communities and affected populations will then analyze and publish the information, promoting dialogue and advocacy regional levels to hold leaders and decision-makers accountable based on the results. This will focus on basic issues such as prices of availability of medicines and stock outs, but also on broader issues such as discrimination, gender inequality and sustainable domestic and international financing. Delegates suggested it will be the mission of "Ambassadors of Hope" to support the advocacy efforts using data from the regional observatory, helping remove barriers of treatment.



## Priority Module #2: Removing Legal Barriers

### Priority Intervention #1: Policy advocacy on legal rights

As a secondary priority module to CSS, this module primarily focuses on the advocacy that will be done with the data and analysis produced by the regional community treatment observatory. The top priority intervention was identified as empowering community-based organizations and networks of women and key populations in particular to implement an advocacy plan for law and policy reform, but also better implementation of existing laws and policies through TRIPS flexibilities. Specifically, participants prioritized raising awareness among PLHIV on existing HIV-related laws for better buy-in; this was deemed essential as PLHIV are the leaders of this program. The group suggested this could be done through community-centered approaches such as through focus groups, radio shows and community dialogues. Delegates also emphasized that they would make use of existing legal environment assessments (LEAs) being conducted through the ARASA/Enda Santé grant for this intervention. Delegates present committed to sharing this information.

### Priority Intervention #2: Legal aid services and legal literacy

Along with advocacy about legal rights for PLHIV, participants prioritized further legal advocacy around training for people living with HIV to do advocacy around harmonizing laws on HIV at the national and regional level, citing CD4 staging policies as one example; Mali is the only country in this proposed program to initiate treatment at CD4 500. Further, Senegal and Liberia are still initiating at CD4 200. The rest are at CD4 350. Indeed, evidence shows that fewer than one in ten people living in a country that is implementing the current WHO guidelines. In light of the lengthy discussion on 90-90-90 and "test all, treat all" as a priority, this was deemed a strong focus of this intervention.

### Priority Intervention #3: Training on rights for officials, health workers and police

Participants prioritized offering legal assistance to people living with HIV, who have been victims of rights violations. Delegates also prioritized sustaining dialogue between key populations and law enforcement which has been supported by USAID and UNAIDS to date.

### Priority Intervention #4: Community-based monitoring of legal rights

Building on the discussions of the day, where TRIPS expertise was a key component to be centralized at the regional level, participants prioritized setting up and training a pool of community experts on intellectual property (IP) and other laws that put barriers to treatment access in place. This should be done at the regional level to save resources, not having an IP expert in each country.

### Priority Intervention #5: Legal and policy environment assessment and law reform

Lastly, using information sharing from the ARASA/Enda Santé grant LEAs (highlighted above), this intervention will aim to use that shared information to do capacity building (and strengthening) of health workers, health officials and police on rights and duties of the community vis-a-vis HIV. This could be a collaborative activity in the three countries where the ITPC regional program and the ARASA/Enda Santé program overlap: Côte d'Ivoire, Ghana and Senegal.

## WAY FORWARD

With a prioritized approach in place, informed by an intensive online and in-person regional consultation, delegates closed the day feeling optimistic and energized about the opportunities for improved treatment access in their region. As ITPC gears up to begin concept note writing, coordinating partners committed to keeping communities informed of the process, throughout writing, submission, revision and results.

## CONTACT


**SOLANGE L. BAPTISTE**
Director of Global Programs and Advocacy
ITPC - Global Team

494 8th Avenue, Suite 505
New York, NY 10001, U.S.A.

Phone: +1 (617) 470 1573
Email: sbaptiste@itpcglobal.com

**SYLVERE B. BUKIKI**
Regional Director, ITPC West Africa

16 B.P 1945 Abidjan 16
Côte d'Ivoire

Skype: biziyaremye.bukiki.sylvere
Phone: +225 225 244 63 / + 225 08 956 621
Email: biziyaremyes@yahoo.fr


## APPENDIX 1 - LIST OF PARTICIPATING ORGANIZATIONS

Aboya (Senegal)

AFeP + ESPOIR (Benin)

AIDS Strategy, Advocacy and Policy (ASAP)

APMGlobal Health

COF+ Cote d'Ivoire

GAMNASS (Gambia)

Global Fund to Fight AIDS, Tuberculosis and Malaria

Handicap International

ICW (Mali)

International HIV/AIDS Alliance

ITPC Global

ITPC West Africa

LIWEN (Liberia)

MARPI Uganda

Mutapola Voices (Gambia)

NAP+ Ghana

NETHIPS (Sierre Leone)

RAME International

REBAP+ (Benin)

REGAP+ (Guinee)

RENAP+ (Guinea-Bissau)

RIP+ (Cote d'Ivoire)

RMAP+ (Mali)

RNP+ Senegal

SABO NHIMA (Guinea-Bissau)

SFS

TIERS

UAF+

Uganda Harm Reduction Network

UNAIDS

# APPENDIX 1 - MEETING AGENDA

## Regional Dialogue Agenda

**(2 December 2015 • 8:00am – 17:45pm • Holiday Inn • Harare, Zimbabwe)**

| SESSION | TIME | ACTIVITY |
|---|---|---|
| **SESSION 1**<br><br>What is the Global Fund and what is ITPC's concept note all about? | 8:00-8:30 | Registration |
| | 8:30-9:00 | Welcome and Introductions |
| | 9:00-9:30 | Introduction to the Global Fund and Regional Concept Notes |
| | 9:30-10:00 | Access to Treatment in West Africa: Availability of Drugs, Intellectual Property Rights & ART Services (an overview) |
| | 10:00-10:30 | ITPC's Successful Expression of Interest (EOI) |
| | 10:30-11:00 | Tea |
| **SESSION 2**<br><br>Identifying Gaps and Challenges around treatment access and uptake at National & Regional Levels | 11:00-11:30 | Results of the Online Regional Dialogue: What have communities said so far? |
| | 11:30-1:00 | Regional Brainstorming: Is there a regional solution to our national challenges? What is the value added of a regional approach? |
| | 1:00-2:00 | Lunch |
| **SESSION 3**<br><br>Our Challenges, Our Solutions: How the regional concept note can improve treatment access in West Africa | 2:00-3:30 | Responding to our Challenges: Engaging with the Modules and Prioritizing Interventions and Activities (Group Work with Module Packs) |
| | 3:30-4:00 | Tea |
| **SESSION 4**<br><br>Steps for Continued Engagement: Leaving no one behind and achieving 90-90-90 | 16:00-16:30 | Report back to the room from group work session |
| | 16:30-15:30 | Feedback and discussion about group work – Agree on a consensus of priorities |
| | 17:30-17:45 | Summary of Conclusions and Next Steps (Meeting Closing) |

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