

## MULTI-LAYERED ACTIVIST STRATEGY FOR A LONG-TERM CAMPAIGN: COMPASS, THE MALAWI CIVIL SOCIETY ADVOCACY FORUM AND THE FIGHT FOR “U=U” IN MALAWI

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### SUMMARY

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The public health intervention that is known as “U=U” or “Undetectable=Untransmittable” involves multiple components including access to medication, viral load testing, communications, demand creation and policy change. Many HIV strategies that need to be scaled up are similarly multi-faceted and require action, commitment and funding from an array of different stakeholders. An activist campaign to “win” U=U in Malawi is one example of successful, multi-layered activism for a complex HIV intervention. This multi-layered activism involved working at both country and headquarters level, within and outside of established channels for decision-making, and with a sophisticated analysis of the sequencing of interim milestones that needed to be met in pursuit of the ultimate goal. This case study of the COMPASS coalition contribution to the ongoing fight for “U=U” in Malawi shows the way that a North-South coalition structure leveraged skills and strategic assets across geographies to move Malawi towards becoming the first sub-Saharan African country to launch a U=U campaign.

The foundation for this approach was a North-South coalition that:

- Deployed power analysis to identify allies and barriers
- Created sufficient support and trust among coalition members that high-risk tactics could be undertaken when the power analysis and dynamics warranted working outside of formal channels of communication
- Employed civil-society scientific and budgetary savvy to make a compelling case for innovation in the Malawian ART program

This approach has implications for advocacy and activist funding including the need to:

- Provide long-term support for complex activist campaigns that is consistent, flexible and reliable even when campaigns hit barriers that slow progress for months at a time
- Integrate technical and strategic expertise into initial planning, so that the problem and solutions are well defined.
- Fund and reward risk-taking, including and especially work that allows civil society to define its roles and modes of action, rather than being assigned to do demand creation, for example, or required to make all requests through specific bureaucratic channels

In 2019-2020, PEPFAR, Global Fund and other funders of the AIDS response began to place increasing emphasis on and investment in civil society-led monitoring of health facilities and sites. This investment has the potential to infuse activism with new resources and information; it can also create complex power dynamics as civil society is asked to monitor the source of funding and to provide recommendations specific to that funder, versus to multiple stakeholders who might be accountable or required for lasting change. The new community-led monitoring resources also come with explicit

or assumed expectations about the appropriate channels for providing recommendations and sharing findings. Against this backdrop, it is crucial to understand the components and structure of risk-taking activism that takes on multiple targets in the service of a single campaign goal, and which sets its own rules for action.

Civil society advocates can use the lessons in this case study to replicate similar U=U campaigns in their contexts and to think through planning, implementation and iteration of other complex campaigns. Funders and implementers can consider the ways that civil society power is supported and amplified by this model, and adopt core aspects into other investments.

## BACKGROUND

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In 2017, COMPASS Africa, a North-South coalition focused on supporting data-driven activism and advocacy for impact, began working in Malawi, Tanzania and Zimbabwe. In Malawi, the work built upon the efforts of a pre-existing loosely coordinated civil society platform which, until then, had no clearly defined governance structure. COMPASS resources helped to develop this civil society platform into a high-functioning, ambitious structure which is now recognized within Malawi as being the “go-to” source for advocacy input on a range of issues.

As in other COMPASS countries, in Malawi civil society groups and partners from the global North work together to gather, analyze, and use evidence and data to drive strategic advocacy campaigns and change policy. Using the data analytical skills developed through COMPASS, members of the Malawi Civil Society Advocacy Forum (CSAF) are now able to pull data in different formats, analyze it and use it to advocate for changes in HIV prevention and treatment policies and programs. With support and intel from global and regional COMPASS partners, CSAF members are using business unusual tactics to escalate their advocacy agendas at global level in a way that had not previously been possible.

## CAMPAIGN LAUNCH: PLANNING AHEAD, SECURING BUY-IN FROM MULTIPLE STAKEHOLDERS, LEVERAGING THE PEPFAR PROCESS

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The Malawian “U=U” campaign was officially “launched” at the 2018 PEPFAR Regional Planning Meeting (RPM), where it was proposed by activists who were part of the civil society delegation participating in this annual planning session. The ability to advance this bold proposal, which entailed purchasing sufficient viral load (VL) platforms and reagents to provide one VL test for every Malawian PLHIV per year, accelerating transition to dolutegravir-based regimens, and investing in treatment literacy and demand creation for viral load as part of a U=U campaign, derived from prior collaboration and a foundation of trust between Malawian activists, which had formed the Civil Society Advocacy Forum (CSAF), and international allies, including amfAR, AVAC and Health GAP. In the run up to the RPM, the group had begun to talk about what Malawian civil society wanted to “win” in the PEPFAR Country Operation Plan (COP) planning cycle. This annual exercise involves reviewing PEPFAR and community-generated data, prioritizing issues, formulating “asks” and building consensus on the key issues to raise during the in-person meeting.

Dennis Mseu, of Manerela, was one of the Malawian civil society representatives for the COP 2018 regional planning meeting. He says, “There were a number of things that I did. The most important thing was to find the allies. One of the important allies was Matt [Kavanagh] from Health GAP [a COMPASS partner]. We had a discussion before we went there, and then we strategized on how best we can handle it.”

Maziko Matemba (MANASO) and Dennis Mseu (Manerela), pressed for once-off viral load testing (VLT) for all ART clients before Malawi transitioned to TLD in January 2019, with investments in viral load platforms included in PEPFAR's Country Operational Plan for 2018. Dennis Mseu says they pressed the government, "Okay, the TLD transition is good news to us, but we would love if we can have a once off viral load" for all the 756,000 people on ART before switching to the new drug.

In response, PEPFAR partners pointed out that there was a challenge related to a Malawi government policy position on viral load testing which called for one VLT six months after initiation and every two years thereafter. Activists took advantage of the presence of multiple stakeholders to leverage a government commitment. Mseu says,

*That is when I took that advantage to say, these guys, of course, there was Principal Secretary and also the Director for the Department of HIV and AIDS in Malawi, and other representatives from the Ministry of Health. So, I said, it's unfortunate that our country, we are retrogressive when it comes to policies. We are not progressive. We need to be ambitious.*

Activists at the RPM were strategic in advancing demands that met the specific interests of different stakeholders in the room. CSOs felt at that time that Government of Malawi had, as a top priority, procurement of commodities and equipment including reagents, VL platforms, etc. whereas civil society was also concerned with non-biomedical and community interventions in order to have a holistic approach in addressing the epidemic. The U=U campaign was a strategic approach to meeting these multiple goals with a cohesive, multi-component "ask."

Dr. Rose Nyirenda of the Malawi Department of HIV/AIDS (DHA) attended the PEPFAR RPM and noted that the U=U campaign helped crystallize the steps needed to make it a reality,

*We needed to mobilize resources for it to be implemented, because we realized that within the in-country resources, it was not going to materialize. But also we needed to move into another area of change of policy. So, these were two very important strategic areas, resource mobilization, and creating an enabling policy environment for that initiative to be operationalized.*

For the proposal to be adopted, the Government of Malawi (GoM) had to agree to the policy shifts in guidance on timing of and use of viral load tests, and funders had to agree to invest in specific elements of the proposed plan. Securing simultaneous commitments from multiple stakeholders is challenging; the fact that all of the key players were on site at the RPM and at a subsequent PEPFAR meeting in Crystal City in April 2018 enabled negotiation and agreement that allowed the campaign to be included in the official "outbrief" slides from the RPM.

## TRANSLATING COMMITMENTS INTO ACTION: COALITION-DRIVEN FOLLOW-UP TO CREATE CORE RESOURCES

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While all stakeholders were on board at the PEPFAR RPM, on return to Malawi, momentum slowed down. This isn't uncommon: the PEPFAR RPM space is intense, charged and can secure verbal and slide-based commitments that require review and follow up in the country context, especially when there are commitments, funding needs and queries that fall outside the scope of a single funder or partner. In this instance, Malawi CSAF sought to maintain momentum by creating a set of resources that gave structure and substance to the PEPFAR RPM commitments. Specifically, the CSAF:

**1) Created a summary document that was above and beyond the PEPFAR Country Operational Plan, and which contained all of the commitments and costs.**

Eric Mcheka, COMPASS Malawi coalition coordinator says,

*We quickly developed a proposal concept note. CSAF received support from Health Gap, AVAC and PEPFAR in the development of the joint proposal, whose initial format was a public private partnership (PPP). The understanding was that the budget was around \$14 million and the Government of Malawi had the obligation to commit some resources. The idea was that if we could get some savings from the Global Fund, that would also be considered as Government of Malawi committing resources. Although, in principle it would have come from the Global Fund.*

This plan was used to catalyze discussion with PEPFAR, Bill and Melinda Gates Foundation (BMFG), and the Government of Malawi, which had indicated willingness to put Global Fund resources into procuring viral load platforms and reagents. Expanding viral load capacity to be able to provide annual VL to all Malawian PLHIV was a pre-requisite for all subsequent steps including PEPFAR investments in dolutegravir (DTG) transition, demand creation, social marketing and treatment literacy, and BMGF investment in an SMS-based results-sharing system. GoM could not, itself, fund VL expansion.

**2) Developed the cost analysis and proposal for sourcing funds from GFATM portfolio optimization to fill the funding gap for VL platform and reagents.**

**3) Addressed scientific questions.**

DHA officials expressed their fears that the U=U concept had the potential of misleading people as some might choose to forgo condom use after taking a dried blood spot (DBS) viral load test and receiving results that show that the virus is undetectable based on the threshold of detection of these assays, which is not the same as the threshold for whole-blood based viral load. AVAC worked to develop a quick primer on evidence from Viet Nam and other sources that DBS could be used to underpin a U=U campaign. The CSO forum also decided to change the campaign name to T (Tizirombo tochepa/ few HIV viruses in the body) =T (Thanzi/Health), a Malawian phrase that also removed some of the potential for misinterpretation that had been a concern of the Government of Malawi.

## DISRUPTING BUREAUCRACY TO UNLOCK CHANGE: HIGH-LEVEL GLOBAL FUND ADVOCACY

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With these resources in place, there was clarity on the proposal, budgets and science. But funds were still lacking. Two months after the RPM, the Director of HIV AIDS informed CSOs that the T=T campaign in Malawi was a nonstarter. This was because the envisaged savings from the Global Fund grant had already been earmarked to unfunded priorities in the prioritized above allocation request (PAAR) that is submitted with every Global Fund concept note. Standard operating procedures for allocating Global Fund savings do not readily enable shifts in investments to take advantage of new opportunities, such as the ability to unlock additional funding for other elements of a U=U campaign. Sensing that they had reached a deadlock, Malawian CSOs, in consultation with international allies, decided to bring the request for the funds released by portfolio optimization to be allocated for viral load platform expansion directly to leadership of the Global Fund. They did so with the support of the DHA, which could not itself reallocate the funds but indicated support for and appreciation of activist engagement on this request.

Dr. Rose Nyirenda says,

*But I think what was key was the role of civil society. Civil society played a great role. They were very organized. Initially, civil society in Malawi before COMPASS, they were all over the place. We could challenge them for some of the decisions that we make to be incorporated as policy, because they were bringing ideas that were not evidence-based. So, every time they were being challenged. Until when COMPASS came in and they started pulling all the data format for in-country data. And they would show us both the quantitative and qualitative aspect when they are trying to push any policy agenda. That made a mark on all stakeholders. And they also organized themselves in a way whereby they were not just meeting anybody. They met with the top leadership that could make a decision there and then.*

At the 2018 International AIDS Conference in Amsterdam, members of CSAF and COMPASS, in the company of Dr. Nyirenda, Director of the Malawi HIV and AIDS Department and her Deputy, held a meeting with Global Fund Executive Director Peter Sands. Dr. Nyirenda presented the Malawian government's request for support, and Sands committed Global Fund to supporting the T=T Campaign but indicated that Global Fund would do so using resources from the savings in the current grant. He emphasized that Government of Malawi should make a formal request to Global Fund for such support, however such request should come through the Community Coordinating Mechanism (CCM).

Eric Mcheka recalls,

*So, he said, okay, CSOs, what I can advise you is that you go back, engage the Department of HIV and AIDS because they're a principal recipient, they focus on biomedical, engage with them, engage with ActionAid. ActionAid is a principal recipient representing the community. They are implementing community systems strengthening aspect.*

Dr. Nyirenda says,

*A key highlight was when we met the Executive Director of Global Fund just to sell this idea at the international AIDS conference, and he gave it a nod. So that was the best highlight because we knew that even when we come back in country and we send our proposal, it would be agreed upon or we will get the funding.*

The intervention in Amsterdam was not without consequences. Back in Malawi, after the CSAF wrote to the CCM to advise on the developments and request action, the CCM responded with concern that CSAF had gone outside of established channels for communication. The coalition was referred back to the principal recipients for further engagement, a recommendation that led to further delays in action. There's a clear need for Global Fund and all AIDS funding mechanisms to be flexible and responsive, while also preserving structure; funding activism that holds these mechanisms accountable for prioritizing progress over process is essential.



MALAWI GOVERNMENT AND CSO DELEGATION MEETING WITH THE GLOBAL FUND EXECUTIVE DIRECTOR DURING THE 2018 AIDS CONFERENCE IN AMSTERDAM. FROM LEFT TO RIGHT: DR. THOKO KALUA, DEPUTY DIRECTOR OF MALAWI DEPARTMENT OF HIV/AIDS; DR. ROSE NYIRENDA, DIRECTOR OF MALAWI DEPARTMENT OF HIV/AIDS; PETER SANDS, EXECUTIVE DIRECTOR, GLOBAL FUND; CYNTHIA MWASE, HEAD OF THE AFRICA AND MIDDLE EAST DEPARTMENT, GLOBAL FUND; LAWRENCE KHONYONGWA, MANET EXECUTIVE DIRECTOR; MAUREEN LUBA, AVAC AFRICAN REGIONAL ADVOCACY ADVISOR; DENNIS MSEU, MANARELLA EXECUTIVE DIRECTOR

## PROGRESS AGAINST CORE MILESTONES, PURSUIT OF A THE LONG-TERM GOAL

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About eight months after the initial endorsement of the U=U/T=T campaign, concrete steps toward implementation began to materialize. At the end of 2018, the Ministry of Health and Population developed the Integrated National VL and EID Scale up and Implementation Plan 2019-2020, with the aim to provide universal access to VLT services. The plan also recognized the need for increased awareness and demand creation through the T=T campaign. In 2019, it procured additional viral load platforms to fill the capacity gap, using Global Fund grant savings for the purchase. In 2019, GoM updated the viral load guidance to indicate that all PLHIV should receive one test annually to be tied with DTG transition. Other partners have reiterated their pledges to pay for key components of the plan: BMGF has pledged to support the SMS platform in order to address the challenge of people not getting their results on time. PEPFAR has committed to supporting human resources for VL scale up; its prior plan to invest in a firm with experience in human-centered design to develop T=T communications was, in 2019, replaced with a plan to use an existing partner that does not have core HCD competency. Civil society has been following up on this commitment and on the need to invest in treatment literacy by and for PLHIV groups.

A robust community-led monitoring effort that generates national civil society priorities and recommendations is already in place and will be used to monitor and follow up on these additional commitments. A fully-fledged T=T campaign has not yet been launched in Malawi but many of the core components are in place, with a strong civil society activist network tracking and reacting to delays, opportunities and implementation work. This kind of long-term, nimble, committed coalition-based work is essential for the future of the AIDS response.

## KEY LEARNINGS:

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The core components of this multi-layered, long term activist engagement were:

- **A coalition with robust technical expertise and strong contacts at national and headquarters level:**

*You see, as local CSO, sometimes when you're meeting government technocrats they tend to look down on you. The mere fact that when we went to DHA and said, if you can only say, yes, then we can have executive director of Global Fund on that table, raised the profile of CSOs. It enhanced our voice and engagement. We were able to show them that we're serious people and we know what we are fighting for. —Eric Mcheka, CSAF*

*They know we (civil society) are normally serious because when they give us a report, we analyze it, look at it, but we also relate with our international partners, Health GAP, amfAR, AVAC, and with that effective input, when we raise issues, they know we are serious and normally is written feedback. So, stakeholders like PEPFAR have taken us very seriously and our profile has increased. —David Kamkwamba, CSAF*

- **Deep technical expertise related to the science of HIV treatment, the costs of viral load, best practice approaches to demand creation and to Global Fund and PEPFAR processes:** DHA was adamant that there were no savings to be had from Global Fund. They only opened up for continued discussion with the CSO forum when the issue of portfolio optimization was presented to them.

*We know that the civil society is an activist institution, we respect their activism, but we believe that where there is activism, there should also be a sense of responsibility for your country. But also their activism is based on justified reasoning based on science. I think the emergence of the team to reach that level where we can have a conversation that is meaningful, that is a key highlight. —Dr. Rose Nyirenda*

- **Nimble tactical shifts supported by flexible funding:** Strategic collaboration with Northern COMPASS partners can help to unlock some doors and open some new avenues for engagement. CSAF earned some respect from the government because they were able to bring the Global Fund Executive Director to the table for discussion.
- **A multi-target advocacy campaign:** Successful advocacy depends on concerted efforts and targeted interventions. Although the process is opaque, tricky and takes a lot of energy, it is necessary to raise the profile of advocacy issues towards campaign goals. Sometimes bureaucracies must be bent in order to reach the right target and obtain the envisioned response. CSAF started with local engagement with DHA, before switching their approach based on strategic direction yielded through the North-South partnerships. The COMPASS international partners were able to schedule a meeting with the Global Fund Executive Director in Amsterdam, while the task of CSOs in Malawi was to convince DHA to buy into the idea of tapping in to the portfolio optimization funds for T=T campaign implementation. Even then, in the face of resistance, CSOs had to jump hierarchy to get attention, even without a guarantee of getting the resources. After each tactic, CSAF had to assess progress and effectiveness of their action before escalating to another. For instance, after several engagements with DHA without achieving the desired result, CSOs decided to raise the issue to Global Fund secretariat level. These moments of reflection enabled forum members to re-strategize as a team.