In-depth Thematic Studies

During the month of October 2016, a Community Action and Leadership Collaborative (CLAC)-affiliated researcher[1] conducted 19 extensive independent interviews with key and vulnerable populations and community respondents. CLAC members themselves identified the interviewees to ensure representation of all disease cohorts and geographies relevant to the Global Fund, and their involvement in the thematic areas of exploration. Interviews averaged 90 minutes in length and were, by necessity, flexible to ensure capture of the dynamics specific to respondent experiences. A vetted list of qualitative open-ended questions guided the discussions. The views presented here are not necessarily CLAC's, but represent those of the respondents, further endorsed by in-country community consultations.

To maintain confidentiality, as requested by interviewees, quotes are anonymous, and editorial liberties taken to further mask identity and ensure narrative flow.

The CLAC is a unique collaboration between AIDS and Rights Alliance for Southern Africa (ARASA), the Global Network of People Living with HIV (GNP+), Global Action for Trans* Equality (GATE), the Global Forum on MSM & HIV (MSMGF), the Global Network for Sex Work Projects (NSWP), the International Network of People Who Use Drugs (INPUD), and the International Treatment Preparedness Coalition (ITPC). The collaboration between these regional networks supports a deep understanding and connection with key populations to strengthen expertise in the areas of HIV and tuberculosis, treatment access, human rights and community engaged. www.clac.cab.

Thematic Study 1: Engagement in Governance and Decision-making Structures

Summary

Involvement in grant processes, pre-, during, and post-grant making, is sometimes hampered by insufficient engagement of key and vulnerable populations in governance and decision-making structures. Communities do have, however, positive examples of how some country coordinating mechanisms (CCM) are fostering engagement, and can identify desired strategic actions to further improve processes and overcome barriers at the country level.

This thematic study highlights both challenging and enabling factors as experienced in actual practice by respondents. Using quotes from interviews, it proposes grassroots-envisaged adjustments based on their collective experience to further improve their meaningful engagement throughout the grant process.

As a result of the New Funding Model (NFM) and mandates for community participation, all respondents reported having at least one selected community CCM representative, but representation effectiveness varied. Lingering **challenges** include:

1. *Lack of government support* for community engagement and sufficient community representation to be meaningful
2. The tendency to *categorize together 'as one'* all discrete communities, their issues and needs
3. *Short two-year terms* for community CCM representatives, which create gaps and inconsistencies in representation across the grant cycle
4. *Loopholes in existing CCM governance guidelines*, such as where gaps in guidance exist or there is lack of clarity, which are being used to diminish community engagement (e.g., lack of or incomplete definitions, lack of a communications framework)

Areas for **replication** found to better engage communities and facilitate their greater influence in grant processes through CCMs include:

1. *Better support and manage the selection process and criteria* for community CCM

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representatives to guarantee that discrete populations are represented:

 1.1 In larger numbers (more populations represented by more representatives)

 1.2 Specifically, and not collectively

 1.3 Themselves, and not by proxy

2. ***Collectively develop enforceable terms of reference*** for all CCM representatives—both government and community, with the latter owned by community themselves and not imposed:

 2.1 To allow for longer (community representatives) and maximum (community and government representatives) term limits (4 years suggested for both)

 2.2 As a mechanism of accountability to improve the quality of their representation

3. ***Develop reviewable governance structure guidelines*** through a rigorous, transparent, and facilitated process that

 3.1 Defines conflicts of interest

 3.2 Supports consultation processes to feed into grant and implementation processes, and inform communities of progress

 3.3 Ensures there is adequate time for communities to respond

 3.4 Provides guidelines for communication up, down, and across the process

 3.5 Engages community representatives on working groups and other decision-making committees

4. ***Recognize and build governance structures upon existing and legitimate mechanisms for civil society action*** (e.g., using existing governance structures, adopting existing rotation systems, embracing community advocates, utilizing successful communications strategies) as some countries in Latin America have done, ensuring:

 4.1 Valued and encouraged community engagement

 4.2 Sustainability and resiliency

Overall, there is a **strong need for sufficient resources and technical support to inform and mentor community representatives to improve the quality of their representation and feedback to their constituencies.**

1. Better Support and Manage the Selection Process for Community CCM Representatives

Since launch of the NFM, respondents report positive changes in the level of engagement experienced by key and vulnerable population communities. "Under the NFM, with engagement mandates for civil society involvement, things improved. In the past, our level of ownership was very poor. Our participation was a rubber stamp and at best we provided advice to the government or concept note consultants… Under the NFM and the country dialogue process, things are better." Further, "**NFM requirements are very helpful in pushing for and getting community engagement.** By facilitating the engagement process, politicians and government representatives are interacting sometimes for the first time with key populations, and their awareness and compassion and understanding increases exponentially sitting around the same table talking about the same issues from different perspectives. This is a huge success."

While the mandate for community engagement forces their participation in Global Fund processes, including on the CCM, many governments do not embrace this participation. They may visibly uphold it, but in practice, it remains tokenistic. "**The CCM is a high-level and highly politicized body with little or no natural community representation.** It is composed of senior officials from a wide range of ministries and agencies, with a bilateral seat or two. Essentially, it is politically inaccessible." "The Global Fund is pushing for community engagement under the NFM, but that doesn't mean the government pays attention to us." "Governments often feel that engaging with communities will undermine their positions." Failure to effectively manage the mandated selection process, or enforce CCM representative criteria, may also be the result of a lack of skills, knowledge, or resources.

Some note that **community presence at meetings and on working groups and task forces is often**

to satisfy attendance criteria set by the Global Fund, with little space or support provided for their true input—and perceived dire consequences if they object. "There is no governmental or political will to include us on the CCM. It is minimal representation to satisfy the Global Fund requirements only. And there is no recourse, for communities have nowhere to go to complain without risk of exposing the gap, and losing critical funding altogether." "It is well known that if governments fail to include key populations on the CCM, the Global Fund will not sign the grant, and this only affects key populations the most. It is as if we are being punished for the failures of our government." "I think the process should be stopped entirely until the country can prove itself capable of embracing active, free, and strong participation from the inside out, not imposed from the outside in."

1.1 Mandate a larger number of community representatives from a broader range of key and vulnerable populations

Examples abound of how the community engagement mandate is being handled by CCMs. Participation goes much deeper than guaranteed seats on the CCM, however, to the quantity of those seats, and the quality of representation.

In some places, those living with disease (HIV usually, less those with TB or malaria) are prioritized as representatives above other key and vulnerable populations. Despite the need to distinguish individual needs, it becomes a tougher conversation when 'criminalized' populations are involved, and the "CCM and government are more willing to accept broader packages with more expansive definitions of key [and vulnerable] populations than those narrowed down to controversial people who use drugs, sex workers, men who have sex with men, and transgender people." **People living with HIV (PLHIV) as CCM representatives tend to make discussions easier because they are more socially accepted**, and their priority concern (treatment) is more straightforward and less politicized than prevention and behavior change, with illusions to sexuality, the need for counseling and testing, and protections against stigma, discrimination, and human rights violations. "It is harder to *argue* against PLHIV needs." **This 'easy way out' must be discouraged.**

Where more diverse populations are represented on the CCM, respondents identify efforts to ensure that only 'safe' representatives within those populations, defined as those who "don't raise difficult questions or make it uncomfortable by discussing the white elephant" are involved—and early—making it harder for the more outspoken to engage. **A transparent and democratic selection process must be ensured: "Nothing for us without us."** Further, there are long-term repercussions, for "those involved early are the ones most likely to be chosen as SRs (sub-recipients), and given opportunities to play greater implementation roles."

In other cases, generic civil society representatives are filling community seats. This should be disallowed. "Key populations represented by civil society do not allow our diverse voices to be heard. **We must ensure that countries do not claim community representation when we are not sitting, ourselves, at the table."** In one extreme example, the CCM's token civil society representative is a retired government official who created a non-governmental organization (NGO) in order to secure his seat.

Where CCMs include a larger number of community representatives, things run smoother. Country's felt to have exemplary CCM's include Morocco, with nine community representatives, and Costa Rica, with six. **A minimum number of community seats should be stipulated based on the country context, and including seats for all key and vulnerable populations.** A greater number of community seats helps reduce competition, as more populations are able to participate (those living with HIV, TB, and malaria; women and youth), including those highly stigmatized or criminalized often left out or overlooked (transgender people, men who have sex with men, sex workers, people who use drugs, etc.). It also means communities cannot be easily ignored—both due to specific representation (see below), and by sheer number (see also Thematic Study 2). Numbers lead to stronger, and in some cases majority voting power, and "the greater possibility that our voices will be heard and acted on." Otherwise, "we are often

silenced by decision-making models that call for votes and majority-based decisions" which we fail to reach.

1.2 Ensure specific, not collective, CCM representatives from all communities

It is a simplistic presupposition that one or two representatives are, in fact, capable of representing all key and vulnerable populations. Respondents agree, particularly those from TB and malaria sectors, that **communities must be represented specifically, not collectively, as it is unrealistic to expect a handful of representatives to speak to all populations, disease areas, and issues.** "Why do we assume all key population issues are the same, and that the cohort is holistic? If you unpack the community," you will realize that all populations have distinct as well as interlinked needs. "It is not enough to say that key populations will be involved in grant processes. You must ask: which key populations?"

In several cases, CCM guidelines specify that community representatives must come from within the communities they are representing. **"Specific communities know their specific needs and situations, and their engagement gives meaning to the activities and priorities."** The caveat is that representatives from criminalized or discriminated groups place themselves at risk of further stigmatization and violence. Some believe "it requires a strong representative who is willing and able to speak without fear." Others disagree, arguing that it is too dangerous, and that **representative identities must be safeguarded** through generic carte blanche 'community' or 'civil society' representative titles. "To protect our identity and keep us from discrimination and even violence, we are anonymous. Nobody outside of the CCM knows which population we are representing, just that we are representing key and vulnerable populations."

Further, several note the reality that the more actively involved communities are usually those better organized, more established, and less controversial. **When a representative is speaking on behalf of a population outside of their own, they do not always know the issues, posing challenges and creating tensions within and between discrete communities.** "If we stand up and communicate on behalf of our constituents, and we fail, then we are labeled and ridiculed. The result is that we often attend meetings and remain silent." Some feel it was too much pressure on individual representatives, and sets them up to 'fail' in the eyes of communities, particularly where discrete communities are not united under 'taskforces' (see Thematic Study 2). This must be anticipated and protected against.

1.3 Avoid proxy community representation

Respondents did not support the idea of proxy representation by civil society. Only in rare cases is proxy, or supplemental representation, condoned, and that is where deemed necessary by communities themselves who feel unprepared to self-represent. In these cases, they welcome more technical and skilled advocacy on their behalf, as long as the representative works closely with them to ensure their priority needs guide the representation. In one case, "we identified the need to have someone document our process and needs, and negotiate on our behalf. This was supported through an external consultancy. The idea was ours, based on a recognition that we lacked certain capacities necessary for success."

A majority of respondents, however, feel that "if it is to be for key populations, then it must be by key populations, for when it is done without key populations, then it is often against key populations—even when that is not the intention." In order to ensure this, the ability to communicate and lead is felt a prequalification to sitting on the CCM. "He or she must be articulate with a proven ability to communicate with stakeholders from the top, to their constituents at the grassroots levels." This was felt especially true where there were issues of criminalization involved. While key and vulnerable communities do not lack courage, **without sufficient training, mentoring, ongoing support, and especially protections, it can be dangerous in some countries for them to speak out against their governments, even within the framework of the CCM.** Regardless, they "must be able to express themselves and lead the process" on behalf of their constituents. "It is too easy, otherwise, for governments to go back to business as

usual." **Community representatives must have voice within the CCM, including the** "**skills to engage at that level of discussion, or they will only be heard but not listened to.** They must have the capacity to make the process meaningful. They must be strong leaders. It is not enough to participate in meetings and workshops and be on working groups. This is only visibility. They need to actually be able to speak and present and represent in order to get proper programming and funding support that will make a difference."

All respondents request that CCM representatives receive long-term leadership support, tailored and targeted mentorship, and training on the Global Fund procedures and processes throughout their tenures to ensure successful representation. In countries where training and mentorship are provided, community members feel better prepared to take on their CCM role. Given the level of technical complexity involved in the Global Fund grant processes, support packaged as one-off orientations or issue-specific trainings is exasperatingly insufficient to prepare community representatives for the herculean and largely voluntary task before them – unless representative have pre-exposure to operating at that level, and the requisite skill set, common language, and technical savvy required to do so effectively. **"There needs to be more training aimed at enhancing community knowledge and building confidence in the Global Fund processes so that we can use our voices more."**

2. Collectively Develop Enforceable Terms of Reference (TOR) for all CCM Representatives

"The CCM community representative process is failing communities. Yes, we are there, elected and sitting, but we have no idea what is going on, we cannot keep on top of the huge volume of paperwork and communications and deadlines, we don't speak the language [English] to be able to do our homework and find entry points or fully understand the by-laws to insist in those places where we can raise our voice, and so on." Respondents feel strongly that **attending meetings, ensuring that CCM representatives are communicating information and input to-and-from their constituents, and terms of service long enough to be effective, are minimum CCM representative TOR criteria.**

"Because the CCM is linked to the government, everyone on the CCM is pushed to work in the interest of the government. The CCM is an independent body and has a mandate to be mindful of politics. It should not become tribalistic or political, but the Global Fund must also realize that the CCM is run by people and won't always go according to plan." Several respondents point to Thailand's highly politicized CCM as an example of what can happen in the absence of TORs. "The CCM coordinator should be someone affected by one of the three diseases or who has worked on key populations issues, and should not be a political appointee, so that he or she knows the importance and relevance of the work being implemented, and the necessity of involving beneficiary communities."

It is important, however, that **communities be supported—not directed—to have a cross-constituency/community working group meeting to develop the TOR for community representatives, and feed this into participatory meetings within the CCM to develop an overarching TOR for all CCM representatives, so that there is uniformity in term limits and accountability mechanisms. In this way, TORs will be owned by community, and not imposed.**

2.1 Allow for longer representative term limits

For most, two-year terms prove insufficient to fully understand and appreciate the Global Fund processes and be effective CCM representatives. "It is such an overwhelming process for non-technical community representatives, and it takes nearly two years [and often longer] to fully understand what is going on." Further, **two-year rotations are almost guaranteed to end mid-grant process, usually during implementation, leaving communities under-represented and lacking continuity at critical junctures** while new representatives attempt to catch up. "Terms ended during the middle of the submission process, and newly elected members brought on board had no idea what was happening. Subsequently, they were not involved in things like the oversight committee, and are playing no role in anything related to implementation." Instead, representatives comment that they sit in meetings and

"don't say anything and feel overwhelmed and panicky. This is not engagement. We need longer terms to be effective!"

Unlike the largely elected community representatives on short voluntary rotations, government representatives are often assigned to CCMs, paid to participate (representation falls under their job), and remain in place for years – even indefinitely. Longevity means they often see grants through from start to finish. There is a need to ensure that term limits, for both community and governmental representatives, are long enough to be effective and cover a full grant cycle, but not indefinite. Four years is suggested as both a minimum (for community representatives) and maximum (for all representatives) term.

2.2 Mainstream an accountability mechanism

"It is so difficult to find good people from the government to be on the CCM, and then it is so hard to replace them when they are not." Government representatives were said to lack motivation and did not take their roles seriously, for there is no accountability mechanism or any personal consequences. Subsequently, they often miss meetings, or send substitutes with little knowledge or understanding of the CCM.

Community representatives also face accountability challenges, missing meetings and failing to promote constituent priorities for reasons including (but not limited to) feeling overwhelmed by, disrespected within, or indifferent to the process, or lacking needed financial backing. "Some key population representatives won't attend CCM meetings because the environment has not been conducive to their presence, or willing to listen to their voice." **Where Terms of Reference for CCM members are in place (Ecuador, for example), expectations and responsibilities are clearer and accountability enforceable, with consequences for both government and community representatives.** "TORs are a mechanism to call to account and monitor representative actions, and provide an 'out' to call for reelection if the terms are not met. If there is no TOR, then this can't be done."

3. Develop Reviewable and Transparent Governance Structure Guidelines

Respondents are quick to point out that while having selection criteria and TORs will help monitor and enforce performance and engagement, there is still need for a rigorous, transparent, and facilitated process of establishing CCM governance structure guidelines, with regular review and revision. A lingering concern is the exploitation of loopholes in existing CCM governance guidelines, or lack thereof, to diminish community engagement.

Areas of concern respondents hope governance structure guidelines will correct for include:

3.1 Defining 'conflict of interest'

Respondents said that **CCM chairs often use 'conflict of interest' as a tool to silence community representatives during critical decision-making.** "We need to be clearer on what a conflict of interest is. It seems to be made an issue at the last minute when something is on the table and the opinion or vote of a certain community member is not desired." Several examples note sudden and strategically timely exclusion for being affiliated with organizations benefitting from—or standing to benefit from— Global Fund resources. One example occurred following a CCM representatives' participation in a community protest after the CCM failed to listen to concerns about unqualified SR selection. "Activism is a conflict of interest, they told me." (Ironically, this country failed their pre-award SR assessment, forcing the selection of new, qualified SRs.)

Selection of community representatives is, in fact, directly tied to their community engagement, advocacy, and organizational affiliations, which are not likely to discontinue during tenures on the CCM. "Most of us on the CCM are on the board of an organization, or involved with an organization, receiving direct or indirect Global Fund funding. There just are not that many good organizations, and we earn our living by working with them. This is how we came to the attention of the CCM. How can this be avoided?" "If someone involved in a grant activity cannot be on the CCM, then only very weak people not

tied into what is happening on the ground and with constituents will be eligible to sit on the CCM."

Respondents point out that government CCM representatives often come from departments benefiting from Global Fund resources, and must also therefore be guilty of conflict of interest. "It is hard to have a transparent and unbiased process when there are so few players. Both government and community representatives often have multiple ties, direct and indirect, to proposed principle recipients (PR), SRs, and sub-sub-recipients (SSR), and activity implementation." Overall, "there is a lack of people with the technical capacity to participate on the CCM." There is a need to define, clearly and transparently, the parameters of acceptable versus breached power.

3.2 Supporting representatives to pursue community consultation processes

Often voluntary positions, CCM obligations for community representatives take them away from paid employment. "The work I do on the CCM is not connected to my professional job." "It is an intense process and at times a full time job to attend all the meetings and work groups and discussions." **Critical to representative success is the need to create advisory groups and layers of community consultations so that individual representatives are informed and making decisions on behalf of their constituents, and constituents are informed and aware of decisions made.** There is a need for financial and logistical compensation to pursue these consultations. "We on the CCM are challenged to reach our communities even though that is why we are on the CCM. Many of our community members do not know about the Global Fund, and platforms to raise awareness and exchange information require time and resources. Quarterly forums, for example, allow us to give updates and gather information from the ground, ensuring that decision-making stays true to prioritized issues."

In a few cases, external organizations underwrote expenses, or the CCM was known to provide minimal provisions. "There is a small budget under the CCM for us to hold meetings with constituents to gather information… it is very small." In most cases, though, respondents noted that "my organization has been generous and we have an agreement that I may connect my work on the CCM with my job, because my voice on the CCM is so important."

3.3 Ensuring adequate timelines for communities to participate and respond

Community respondents unanimously complain about unrealistic deadlines and time pressure. "A barrier to engagement is that turnover times for input or response is often only 24, sometimes 48, hours. It is inappropriate to send something out to a community member and expect such a rapid turnaround." **"Without time to participate and bring real perspective and voice into the process, issues will be missed.** In the end, the missing issues will cause problems during implementation." "Often we are told that there is no time to discuss it now, or we are asked to deal with things 'later' and to sign or vote without full [participation]."

Beyond background reading and consultations, community representatives need the time and space to develop realistic roadmaps, plan and prioritize programmatic areas for inclusion in concept notes and implementation work plans, present and advocate for these priorities. "The CCM is only concerned about meeting their own criteria, not ours. This is obvious when they give us no time to plan our participation." They also need time to review activities in their oversight capacity. "We barely have time to see what the implementation problems are, but have no time or resources to address them." Even attending meetings is problematic when "invitations to meetings come on such short notice," and sometimes without agendas or necessary background documents.

3.4 Providing communication guidelines

Communication with community constituents is not working in many places, nor is it working within the CCM itself. "Community representatives are not copied on everything, and only when a recipient copies us into an email chain do we find out what is happening or has been under discussion." Meeting minutes are often not shared, and activity updates difficult to access. **"We need a communication guideline for**

work within and outside of the CCM that is related to the larger country dialogue process." This is especially necessary in countries where transparent communication is resisted on the grounds that CCM activities are "government business and therefore confidential."

Community representatives must be informed so they may engage appropriately and effectively. This includes even knowing when and what they can and cannot share. "There is conflicting information even from the Global Fund Secretariat how much we can and should consult and share with our constituents."

3.5 Ensuring community representatives participate on working groups and committees

Respondents were quick to exclaim, "We are now active members of the CCM. This was our objective and we yearned for it – to be included and participate. We have it now. We can only move forward from here. Even if we do not get everything, we cannot lose sight of what a big step this is for us. Now, let's show what we can do, so that we may be able to do even more." They also recognized that, **"Having community representatives on the CCM is a huge step forward, but actual decision-making is handled by the task forces and working groups, often [still] lacking their involvement."**

Of note, **levels of engagement varied between populations, with sex workers, transgender people, and those from TB communities reporting less involvement than more established communities like men who have sex with men.**

Dependent upon their ability and skill, respondents feel that **writing, budgetary, and oversight committees should have community member quotas.** These bodies control grant content, funding allocation, and rollout. In some cases, "we decided that at least one (CCM representative) had to be on each working group to ensure our representation everywhere. It made a difference because when someone said anything about our needs, we were right there to emphasize what were the most important needs, what could wait, and what ones were not important. Often this was different from the way the government wanted to prioritize things, for their convenience."

This was brought home in situations with active community consultative processes. "We had many stakeholder meetings, prioritization of issues and needs, and more. In the end, because we were not invited into the grant writing process, our activities were cut." In some cases, cuts were only realized during implementation. "The process is participatory. The end product is not." Further, there is a trend towards less engagement as the country dialogue process proceeds. "The CCM's work isn't done when the grant is signed." **"Originally the process was participatory and appeared to be owned collectively by stakeholders, but as the process moved forward, key population groups were less consulted, less involved."** Respondents perceive they are "removed as soon as possible by the so-called experts or consultants negotiating on behalf of the country's key populations," particularly from applicant responses following the Global Fund review, resubmission, PR capacity assessments, budgeting decisions, and development of performance frameworks.

4. Recognize and Build Governance Structures upon Existing and Legitimate Mechanisms for Community Action

The Peruvian CCM is cited as a role model for having a comprehensive governance structure and rotation system even before the Global Fund developed guidelines requiring this. This reflects their strong civil society activist foundation and legitimate multi-stakeholder coalitions. "Where CCMs are created from scratch, multiple strategies are necessary to keep them going, and they are not sustainable." **Where there is a strong baseline, with civil society advocates already involved in policymaking and response, the CCM process is more organic, rollout is smoother, and community engagement valued and encouraged.** Peru and several other countries in Latin America are able to achieve desirable engagement and positive community outcomes in "half the time" it takes areas lacking or disregarding existing homegrown mechanisms, or which attempt to build parallel governing structures.