



Independent observer  
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## The involvement of civil society organizations and communities in the fight against HIV, tuberculosis and malaria is undermined

### Background

Within the Global Fund's overall ecosystem, the involvement of civil society organizations (CSOs) and communities has long been valued and promoted as an indispensable practice in the fight against HIV, TB and malaria. There is at least official agreement that these diseases cannot be effectively addressed without meaningful community participation in the various stages of Global Fund grant implementation. In reality, however, this is far from the stated intention. The much-vaunted participation seems to be in disarray. It looks more and more like an illusion, a sort of democratic veneer that is slipped into texts and speeches to look good, without being followed up in reality.

It is not uncommon to meet stakeholders in the fight against the three diseases in West and Central Africa who say that they are deeply disillusioned by the long-standing gap between discourse and reality.

The Global Fund's Francophone Africa Regional Platform launched an online questionnaire, as a prelude to the regional forum on community engagement that took place from 25 to 27 January 2023 in Cotonou. The objective was to collect both lessons learned on community and civil society participation in NFM3 and evidence to support proposed recommendations for improved civil society participation in Global Fund Grant Round 7 (GC7). While there are some good examples or practices here and there, the overall conclusion of this study is that community participation in NFM3 was far from optimal. And when CSOs

had the opportunity to participate in various Global Fund processes or activities, their voices were not always heard or valued. Community priorities were not aligned with the priorities in the National Strategic Plans (NSPs) or adequately reflected in the country grants. Most importantly, a large majority of CSOs stressed that they did not participate in the grant application finalization sessions.

In the same critical vein, the Technical Review Panel (TRP) [2020-2022 Observation Report](#) points out the flaws and shortcomings of community involvement:

“Real community input into programme design, implementation, review and evaluation requires strong and effective participation in multi-sectoral partnerships at national and sub-national levels. Such participation can improve the quality and impact of national strategies, policy development and the effectiveness of services. The TRP found too few examples of effective community participation in multi-sectoral partnerships and governance structures where the community contributed to programme planning, oversight and review. Where it did exist, efforts to translate this community participation into quality services were rarely sufficient. The reviewers noted that there has been an increased emphasis on programmes with active community participation and leadership, although still largely in HIV prevention and antiretroviral treatment programmes. There are few examples of effective community leadership being strengthened in the fight against TB and malaria.”

The Global Fund’s [Technical Information Note on Community Systems Strengthening](#) (Allocation Period 2023-2025, dated December 2022) ) reiterates these findings:

“Key and vulnerable populations are not sufficiently engaged in and benefiting fully from HIV, TB and malaria efforts. There is a need to improve coordination and strengthen linkages between community-based, community-led and formal health sector programmes, and to increase social participation.”

More broadly, many community actors regularly admit, anonymously or during various meetings (conferences, webinars, informal exchanges, etc.), that the Global Fund’s highly technical jargon, the omnipresence of English (documentation, high-level Global Fund meetings) and the slow turnover of community representatives in the bodies or forums related to the Global Fund were an obstacle to effective and efficient community participation.

The “fossilization” of community participation

Speaking specifically of the slow turnover in community representatives, the criticism at this level seems to be directed less at the Global Fund as an organization than at local bodies, dynamics and processes.

Some CSO and community actors anonymously denounce what could be termed the “fossilization of community participation”. The bodies and meetings related to the fight against the diseases sometimes resemble a club of friends where the same people have been meeting for several years. According to

these actors, a sort of ‘old boys’ network’ is taking hostage of what is being touted to be ‘community participation’. While the expertise and experience of these ‘old hands’ cannot be questioned, it is doubtful that the fight against the three diseases can be enriched with new perspectives if it remains under the control of these long-standing community representatives.

There can be no satisfactory results in the fight against HIV, TB and malaria without constant community involvement or participation. Better still, there can be no effective response to the diseases without real and meaningful community engagement at all stages of the grant process: development, implementation and evaluation, etc. It is important to oxygenate CSO and community participation by constantly renewing its leadership, actors and torchbearers.

This is not an untimely reminder. Community engagement, and more specifically the participation of CSOs and communities in the work of the Global Fund, is not an unnecessary expense; it is an essential investment that maximizes the impact of Global Fund grants. Participation comes at a price, and it must be paid. Here are some additional arguments in support of this position.

Why is CSO and community participation so important?

The following argument does not claim any originality, but it enables us to remember the foundations and relevance of community participation that time, petrification or bad organizational habits have made us forget.

CSO and community participation in the three disease responses refers to a form of self-governance of diseases by the body concerned. It is the idea of stakeholder participation in decisions that affect them. An approach in which the inclusion of communities is more valued strengthens the robustness of the decisions taken. It brings the fight against disease to a much more inclusive and engaging local level. It calls for the empowerment of CSOs and local communities in the different stages of the grant process. It contains the time-tested conviction that the sustainability and success of the response to disease is inexorably dependent on community involvement. And the Global Fund is no exception. Indeed, the [Global Fund Strategy](#) for the period 2023-2028 states that

“The leadership of communities living with or affected by the three diseases has been key to the success of the Global Fund’s unique model since its inception. Communities are often in the best position to guide and implement health programmes that effectively address their diverse needs and to remove structural barriers to progress in the fight against HIV, TB and malaria. Strong community engagement ensures that investments are equitable, sustainable, evidence-based, grounded in human rights, and gender- and age-sensitive”.

The participation of CSOs and communities is also a solution to the shortcomings of (traditional) decision-making models based on standardized solutions. Through the requirement of inclusion and deliberation, the idea of participation here appears to be the right vehicle for differentiated programme development

and effective implementation. When it is effective, inclusive and regularly reviewed or given a new lease of life, it allows the development of prevention and health care adapted to each context and not imposed or presupposed. In other words, it allows us to move away from the usual problems caused by solutions considered in isolation and applied wholesale, developed in the wrong kind of context.

Finally, it is worth noting that broad participation in the process of deliberation and program development increases the motivation and degree of mobilization of those who are primarily responsible for implementing the decisions, namely, the communities. In this way, communities will inevitably see themselves as builders, co-responsible for and co-implementers of the decisions taken.

In short, subordinating disease control processes, activities and programs to the requirement of intersubjective validity is a guarantee of democratic legitimacy, community buy-in, optimization of Global Fund investments and many other global health initiatives. We should emphasize that only co-participation in decision-making creates and reinforces co-obligation in the execution of that decision.

### How to enhance the right kind of community participation

However, to be fully effective and efficient, community participation requires a set of prerequisites or conditions. The following is a non-exhaustive list of actions that could enhance the quality of participation.

It should be noted that the suggestions are addressed to the different levels of the Global Fund ecosystem (CSOs, communities, governments, the Global Fund, UNAIDS and other technical and financial partners in the fight against HIV, TB and malaria). It is up to everyone to play their part in the following:

- Train CSOs and communities on issues and techniques of participation and discussion.
- Train and build the capacity of civil society members and communities on Global Fund policies, processes, mechanisms, approaches, philosophy, etc.
- Coalesce, pool, synergize and coordinate the actions of CSOs and communities in order to influence the orientation and decisions taken within the various decision-making bodies, such as Country Coordination Mechanisms (CCMs).
- Accompany CSOs and communities in the different stages of a funding cycle (country level dialogues, National Strategic Plan/concept note/application process, grant implementation, community monitoring, evaluation, etc.).
- Translate Global Fund texts and increase the number of spaces for exchange and discussion in French to remove the language barrier which is a challenge for many people in West and Central Africa. This is an opportunity to salute the multi-sectoral support of L'Initiative and Expertise France in making Global Fund information accessible in French.

More broadly, the new funding round (Grant Cycle 7) is a window of opportunity to better address the concerns of CSOs and communities. A percentage of the budget that will be allocated to the country should be dedicated to community activities. Thus, GC7 can help re-vitalize CSO and community participation in the fight against the diseases.

The [TRP](#) provides the following guidance for applicants preparing new funding applications:

- Include integrated, holistic services for most affected communities and KVPs, in particular programs with active and meaningful engagement of communities, especially leadership of people with lived experiences of HIV, TB and malaria.
- Strengthen government leadership, working in partnership with relevant stakeholders, in the design and operationalization of policies and practices that will place people at the center of quality services.
- Include public contracting mechanisms and co-financing for sustainable delivery of services through civil society, communities and key and vulnerable populations in all contexts, but especially in countries planning for transition.
- Plan sustainability solutions, including public funding for civil society and community-led advocacy, monitoring and other functions critical for government accountability, political commitment and quality of services, especially in countries planning for transition (p.27).

This is also echoed in the [Applicant's Handbook](#) for the Global Fund allocation period 2023-2025 (p.16):

### Build Capacity for Community Based & Led Organizations

Evidence shows that strong community systems ensure stronger responses to the three diseases and lead to better results and outcomes for people infected and affected by HIV, TB and malaria. The Global Fund encourages applicants to invest in community systems strengthening (CSS). CSS investments can include the establishment, strengthening and building of sustainability of community-led and community-based organizations, particularly those led by key populations, women, youth and people living with or affected by the three diseases. Building their capacity will ensure better access to services.

The Global Fund's [Modular Framework](#) is even more explicit than the two documents mentioned above. It suggests a set of interventions and activities related to CSO and community participation.

Module	Intervention	Scope and Description of Intervention Package - Illustrative List of Activities
RSSH: Community Systems Strengthening	Community engagement, linkages and coordination	<p>Activities to mobilize communities, particularly of marginalized, under-served and key and vulnerable populations, in responses to the three diseases, barriers to accessing health and other social services, social determinants of health and progress towards Universal Health Coverage (UHC) and the realization of the Sustainable Development Goals (SDGs). For example:</p> <ul style="list-style-type: none"> <li>• Building community capacity on the use of appropriate new information communication and coordination tools and technologies, including digital tools.</li> <li>• Community-led development/revision of strategies, plans, tools, resources and messages for social mobilization.</li> <li>• Mapping of community-led and community-based organizations and networks and their service packages.</li> <li>• Creation and/or strengthening of platforms that improve coordination, joint planning and effective linkages between communities and formal health systems, other health actors and broader movements such as human rights and women's movements.</li> <li>• Establishing or strengthening formal agreements between community-led service providers and health facilities or private health service providers, linkages with community health worker associations, joint outreach activities and bi-directional referral mechanisms between health and community-led service delivery points.</li> <li>• Representation, participation and engagement of community actors in high-level health advisory or governing bodies, oversight committees (including clinic health committees), disease councils and other decision-making fora.</li> </ul> <p>→ Disease-specific community mobilization activities should be included under the relevant disease module.</p> <p>→ Support for country coordinating mechanisms (CCMs) or community representation/engagement on CCMs should not be included in country grants.</p>
Module	Intervention	Scope and Description of Intervention Package - Illustrative List of Activities
RSSH: Community Systems Strengthening	Capacity building and leadership development	<p>Activities related to the establishment, strengthening and sustainability of civil society organizations, especially those that are community-led (informal and formal), key population-led, women-led, led by people living with or affected by the three diseases, community networks and associations. For example:</p> <ul style="list-style-type: none"> <li>• Capacity building and mentorship of community organizations.</li> <li>• Capacity strengthening (technically and programmatically) to deliver high quality integrated community-led and community-based health services.</li> <li>• Small grants to community-led organizations to increase their capacity in health service delivery, social mobilization, community-led monitoring, community-led research and advocacy, understanding labor rights and social dialogue, etc.</li> <li>• Development of strategy, governance and policy documents for community organizations, such as human resource policies, resource mobilization strategies and social dialogue strategies, etc.</li> <li>• National- or regional-level peer-learning initiatives.</li> <li>• Legal registration of community organizations, especially those led by and/or working with marginalized populations, including preparation and/or revision of necessary documents.</li> <li>• Development and/or revision of tools and other forms of support for community organizations and networks to assess capacity and develop appropriate capacity building plans.</li> <li>• Infrastructure (furniture and equipment) and core costs of community organizations and networks to support/strengthen service provision, social mobilization, community monitoring and advocacy, organizing and social dialogue.</li> </ul>

Source: Global Fund Modular Framework Handbook, December 2022, pp.15-16.

## Conclusion

However, it is essential to continually think about the terms of disease management within a truly participatory approach (diversity, inclusion, etc.) without ever presuming the content of solutions in advance. Advocating for and leveraging the funding that matters, translating commitment into budgets and ending the diseases as public health problems requires the real and broad participation of CSOs and communities. Global Fund investments will be maximized because they have been subject to the judgement and involvement of civil society and communities. Let's move away from junk participation.

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