The Right to Participation in Global Health Governance

Lessons Learned

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What should the role of those most affected by pandemics be in future pandemic governance and coordination mechanisms?

Drawing on human rights standards and principles, and on existing structures in the HIV, TB and malaria sectors, we argue that the human right to participation should extend to permanent seats and votes for civil society and affected communities on governance boards.[1] Our argument is informed by an analysis by STOPAIDS, Aidsfonds, CSSN and Frontline AIDS, by consultations led by STOPAIDS, and by the examples of the Global Fund to Fight AIDS, TB and Malaria ("the Global Fund"), Unitaid, and the Access to Covid Technologies-Accelerator (ACT-A).

The right to participation is now widely accepted in development cooperation. Under international human rights law, this right is grounded in the rights to information, freedom of expression, peaceful assembly and association, and freedom of political and other opinion established in the *International Covenant on Civil and Political Rights*. The right to participation is articulated in other human rights treaties that are binding on states, including the *Convention on the Elimination of Discrimination Against Women*, *Convention on the Rights of Persons with Disabilities*, and the *International Convention on the Rights of All Migrant Workers and Members of their Families*.

The content of this right has been elaborated by human rights treaty bodies and special procedures, as well as in other statements of soft law: the *Declaration on the Right to Development*, the *Declaration on the Rights of Indigenous Peoples*, and the *Guideline for States on the Effective Implementation of the Right to Participate in Public Affairs*. UN member states further committed to upholding participation rights through the Sustainable Development Cooperation Framework. Global community networks successfully pushed UNAIDS to institutionalize the Greater Involvement of People Living with HIV/AIDS (GIPA) principle. Member states endorsed the GIPA principle again in the 2021 UN Political Declaration on HIV and AIDS.

In practice, interpretations of the right to participation vary. Certainly, it includes a right to be consulted throughout decision-making processes. Consultation is widely recognized in development cooperation, with good examples in health. For example, the Global Commission on HIV and the Law held regional dialogues with lawmakers, policymakers and communities to interrogate the relationship between law, human rights and HIV. This resulted in new analyses, tools, and national reforms, work that continues today.

Considering the unprecedented suffering caused by COVID-19, any future pandemic lawmaking should be informed by public consultations that prioritize hearing the experiences of people most affected by the crisis, and that facilitate their identifying the redress and reforms they want. Such a process will be critical to rebuilding trust in public institutions.

However, consultation, whether to inform the drafting of a legal instrument, or in the establishment and governance of any mechanism that instrument may establish, is likely to have a minimal effect unless it is backed up with permanent governance seats and votes for these communities.

The failures of the ACT-A are a case in point. The ACT-A's poorly-designed structure favors the priorities of the Global North, lacks meaningful representation

[1] We use both "communities", to describe those most affected by a disease, and "civil society", which may include organizations led by those not directly affected.

from the Global South, and marginalizes civil society and communities affected by Covid-19. In our experience, it took a fight to get civil society and communities representation into all the pillars of the ACT-A. Once included, they joined ACT-A working groups, but had little opportunity to input meaningfully, with real decision-making happening behind closed doors among powerful agencies. In a context of global vaccine inequity, civil society inclusion in the ACT-A has given legitimacy to decisions, even though their input has either not been sought or been ignored.

The Global Fund has also struggled to fulfill the right to participation. Many implementing states that receive Global Fund financing still fail to include key populations (sex workers, LGBTIQ+ people, people who use drugs) in national governance and programming. One 2016 community-led survey of African key populations shared allegations of tokenistic consultation, and of threats of retaliation by powerful national actors.

However, there is a strong organizational commitment to meaningful participation at both Unitaid and the Global Fund Secretariats; permanent seats and votes were established early on for community and civil society on their governance boards. Similarly, UNAIDS was the first UN programme with formal civil society representation on its governing body. While many challenges still remain, these structures have made community input more difficult to ignore.

This is in part through design. Representatives on these boards benefit from a steady flow of input from national and global networks of key populations, transnational networks of women's groups, trade unions, faith-based organizations, and many others in every region. The structure of voting on the Global Fund board, and the requirement to include civil society and community on powerful standing committees, creates multiple openings for internal debate that leverage underlying input. Important attention has also been paid to governance culture, explicitly recognizing power imbalances and building relationships of trust among diverse board members.

Each civil society and community delegation tries to ensure gender balance, have representation from all geographic regions, as well as to ensure technical expertise on each of the three diseases and cross-cutting topics such as intellectual property, medicine, health systems, epidemiology, programming, etc. Delegations that fail to be inclusive face criticism by their constituencies, or by peers on the board.

This representation and consultation structure (supported by funding from the Secretariats) enables civil society and community delegations on the board to escalate concerns from national and community levels and to push the board and Secretariat for solutions, a "boomerang effect" in which advocates who are blocked locally can directly access global mechanisms. As a result of the work of these delegations in partnership with their constituencies: millions more in funding has gone to address human rights and gender inequality, human rights and gender equality has been institutionalized in the Fund's strategy and technical guidance, and key populations representation is now an eligibility requirement for the over 100 national CCMs that manage millions in HIV, TB and malaria financing.

We argue that the right to participation as institutionalized in the HIV, TB and malaria responses should not be limited to these sectors but apply equally to all. The development of any future treaty, and design and operation of any resulting new global health mechanism, should include such formalized roles.

It is critical that these representatives are selected through a legitimate, open and transparent process that is led by civil society themselves, as is normally done for the Global Fund and Unitaid, and as was also done in the case of the ACT-A Civil Society and Representatives Platform. Once the mechanism is established, financial support from the host institution should enable civil society and community delegations to convene and consult with those they represent; fulfilling the right to participation should not leave rights-holders with a financial deficit.

The increasing reduction in civic space, including sweeping attacks on civil society, coupled with the criminalization of and widespread discrimination against particular groups in many countries, means that many consultation processes fail to capture all

voices, and that rich local experience fails to shape global health decision-making. It is more important than ever to ensure that the most marginalised have a voice and a vote in their own future.

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