Agenda item 1.4

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NGO REPORT

From Community Consultation to Co-Leadership: Six Principles to Guide the Global HIV Response

UNAIDS

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Action required at this meeting—the Programme Coordinating Board is invited to:

- *Take note* of the report by the NGO representative, including the six principles described therein, designed to ensure that community leadership, co-creation and co-leadership are safeguarded and strengthened within the governance of the HIV movement;
- *Recall* the Global AIDS Strategy 2026–2031, Results Area 8 (Priority 3: Community Leadership), and the decisions relating to the meaningful engagement of communities and civil society in the HIV response of the 56th and 57th meetings and the 2026 Special Session of the Programme Coordinating Board, especially decision points 4.2 and 4.5 of the 57th PCB, and 3.4 of the 2026 Special Session;
- Recalling decision 3.1 of the Special Session on the approval of the overall strategic direction for the transition of UNAIDS set out in the final report of the PCB Working Group on the further transition and integration of UNAIDS into the UN System and beyond and looking forward to the implementation plan of the Transition Task Team, *request* Member States to:
    a. Continue to ensure that country-level HIV governance, coordination and transition arrangements institutionalize meaningful community and civil society participation and co-leadership in agenda-setting, policy and priority-setting, implementation and accountability;
    b. Ensure and sustain the involvement of communities and civil society in country-level capacity and readiness assessments and in shaping the timing and arrangements for the transfer of functions, in line with national contexts and the principles of community leadership set out in the Global AIDS Strategy 2026–2031;
    c. Ensure that the further transition and integration of UNAIDS into the UN system and beyond maintains meaningful involvement of communities and civil society in decision-making and governance, and ensures continuity of community-facing support and engagement currently delivered by the UNAIDS Hub, building on the lessons of existing mechanisms for civil society participation;
- Further *request* Member States to:
    a. Support civil society organizations in the implementation process of the six principles including the scaling up action to address structural, legal, policy and regulatory barriers that restrict civic space or limit the meaningful participation of community-led organizations in accountability and governance, and ensure that country-level transition arrangements are supported by enabling legal and policy environments that protect human rights and gender equality and support community leadership, in line with the Global AIDS Strategy 2026–2031;
    b. Recall decision 4.4.a of the 57th PCB, ensuring “predictable, sustainable, and direct financing for community led organizations engaged in the HIV response, including through institutionalized social contracting, dedicated domestic budget lines and funding mechanisms, including within UNAIDS”, that further support the implementation of the six principles and community leadership, advocacy, community-led monitoring and accountability;
    c. Based on the UNAIDS guiding principles, support civil society organizations in the implementation of the six principles by developing context-appropriate safety protocols for community participation in governance, community-led monitoring and grievance mechanisms;
- *Request* the Joint Programme, through the work of the Transition Task Team and beyond, and in support the implementation of the six principles, to:
    a. Plan for the additional administrative requirements that accommodate the operational needs of civil society and community-led organizations, taking into account proportionate institutional due diligence, for travel, interpretation, connectivity and technical support, to facilitate their meaningful participation in governance and decision-making, further to the outcome of the work of the Task Team regarding co-creation;
    b. Ensure designated community-led representation and engagement in regional and country-level Joint UN Teams and other relevant coordination arrangements; and provide sustained resources for community-led engagement, monitoring and accountability mechanisms;
    c. Include regular reporting on resources invested in community-led HIV responses in financial, performance and accountability frameworks, building on PCB decision 6.12 from the 56th PCB and the indicator to be included in the 2027 Work Plan and Budget, and provide the Board with updates on the methodology used to track these resources;
    d. Ensure that, in the context of the transition consultation, the NGO delegation and wider Civil Society Organizations are involved in respective consultation modalities at different levels, in partnership with community representatives, people living with, affected by and vulnerable to HIV, key[1] and other priority populations, and ensure that consultation outcomes inform transition decisions;

Cost implications for the implementation of the decisions: none

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Executive Summary

For over four decades, communities have not just participated in the HIV response, they have built it. People living with HIV, key populations, women and young people challenged systems that were never designed to include them and claimed a place in governance structures, creating one of the most rigorous models of community leadership in global health. As the HIV response enters a period of profound change, it is more important than ever to protect and strengthen that model.

This report builds on the long-standing tradition of community led governance that has defined the HIV movement since its earliest days, beginning with the Denver Principles, which asserted that people living with HIV must be central to decisions that affect their lives. Those principles established a standard for self determination and accountability that remains essential today.

Through the Global AIDS Strategy 2026–2031 and the 2026 UN General Assembly Political Declaration on HIV/AIDS, Members States and the Joint United Nations Programme on HIV/AIDS (UNAIDS) have committed to a roadmap to end AIDS with community leadership at its core (see Annexes 1 and 2). The focus now must be on ensuring these commitments are implemented.

On 26 October 2026, the UNAIDS Programme Coordinating Board approved a new strategic direction for the Joint Programme, which will entail a transition from the current UNAIDS structures to a more streamlined “Hub” with clear functions: global leadership and advocacy; coordination of a unified budget and workplan; and data to support accountability. Alongside this, responsibility for functions that depend primarily on technical mandates, thematic expertise, operational presence and proximity to national institutions will be increasingly led by UNAIDS Cosponsors and national actors.

The transition plan, drawn up by a Working Group of the Board, builds community co-creation and leadership into all facets of the restructured UNAIDS Joint Programme. This is an important outcome in a process that could have forced the closure of the only part of the UN system that meaningfully engages communities in its governance. However, "the devil will be in the detail". Given that this is a period of significant change this report asks: what principles for meaningfully embedding community leadership should guide the institutions that will govern the HIV response up to 2030 and beyond?
This report focuses on the centrality of community leadership. It begins by summarizing the planned transformation of the UNAIDS Joint Programme, in particular how communities will be involved in the reformed governance structures.

The report then outlines six core principles that should guide all structures and systems that govern the HIV response—within UNAIDS, the Cosponsors and at national level—in order to protect and strengthen the leadership role of communities. Those principles reflect what communities have learned to be essential over four decades:

1. institutionalized participation,
2. shared power,

3. resourced engagement,
4. self-determined representation,
5. rights-centred governance, and
6. mutual accountability.

The principles are not abstract ideals; they are practical conditions for an effective HIV response and a direct continuation of the values first articulated in the Denver Principles. They are also mutually reinforcing. Participation without power is symbolic, power without resources is unusable, representation without rights and safety is precarious, and none of it can endure without accountability.

Each principle is outlined along with lessons that can be learnt from existing governance structures—within the HIV response and in the wider sphere of health and human rights.

The report goes on to outline some of the emerging threats to community leadership. Cuts to financing, shrinking civic space, the withdrawal of UNAIDS at country level, the planned transition of the Global Fund to Fight AIDS, TB and Malaria (Global Fund) out of an increasing number of countries compared to the previous cycle, and a political climate that is increasingly hostile to the very communities most affected by HIV.

The report is built on the direct testimony of community and civil society leaders and a small number of partners. Their responses reveal that community participation is being weakened at the very moment it is needed most. Respondents described challenges they are already facing as UNAIDS and other partners reduce their presence in countries—including the loss of spaces that UNAIDS had convened to bring even the smallest and most marginalized community organizations into dialogue with governments and donors, creating opportunities to influence national priorities. At this time of flux, many fear that without deliberate protection, community engagement will be reduced to symbolic consultation rather than meaningful influence.

The report ends with recommendations linked to the reports' six governance principles. First, there is a short set of recommendations that are specifically focused on protecting and strengthening community leadership during the UNAIDS transformation to ensure that the transition process itself is held to the same standards as the governance arrangements that emerge from it. Finally, the key recommendations of the report are outlined, each relating to one of the six governance principles, each designed as practical and achievable guidance to translate the promises Member States and UNAIDS have already made into governance architecture fit for the world today.

The conclusions of this report are straightforward. Community leadership is not an optional feature of the HIV response; it is one of its defining strengths. If action is taken now, the next phase of HIV governance can embed community leadership more deeply and more securely than ever before.

Through the Global AIDS Strategy 2026–2031, the 2026 UN General Assembly Political Declaration on HIV/AIDS, and successive Programme Coordinating Board (PCB) decisions

Member States and UNAIDS have already committed to strengthening the role of communities. The PCB does not need to invent a new mandate for community leadership. It needs to act on the one it already has.

Introduction

1. Every year the NGO Delegation to the UNAIDS Programme Coordinating Board (PCB) presents a report on a topic of critical concern to civil society and communities affected by HIV. The report includes recommended decision points for all members of the PCB to consider.

2. The 2025 report examined community-led, integrated HIV services and their essential role in advancing people-centred, equitable, sustainable, and rights-based HIV responses.[i] Following on from this, the 2026 report focuses on how to safeguard the essential roles which communities play in the governance of the HIV response.

3. This report considers the changing governance architecture of the HIV response—the institutions, governance structures and decision-making bodies that shape it—and asks what will be required to protect and strengthen meaningful community leadership across this architecture in the next decade?

The importance of distinguishing between communities and civil society

This report centres on community leadership, making a distinction between communities and wider civil society. The term community is used to refer to people with shared lived experiences. Civil society also includes nongovernmental organizations working at local and international level alongside communities and community-led organizations. While the whole of civil society must be engaged in the HIV response, communities play a unique role which only they can fill.

In the AIDS response, community-led organizations, groups and networks are defined as "whether formally or informally organized, [as] entities for which the majority of governance, leadership, staff, spokespeople, membership and volunteers, reflect and represent the experiences, perspectives and voices of their constituencies and who have transparent mechanisms of accountability to their constituencies". They are "self-determining and autonomous, and not influenced by government, commercial or donor agendas".[ii]

Progress towards ending AIDS

4. There has been significant progress since the early days of the epidemic when an HIV-positive diagnosis amounted to a death sentence. Annual new HIV infections have fallen 42% since 2010 and AIDS-related deaths are down 57% over the same period.[1] HIV treatment now reaches an estimated 78% of the 41 million people living with HIV worldwide.

[1] Unless otherwise indicated, all data cited in this report are available at https://aidsinfo.unaids.org.

5. This was achieved because communities built an evidence base, delivered and monitored services, held governments to account, and claimed their place in governance structures that were not designed to include them. An extensive scoping review of 279 studies of community-led interventions has shown more than 40 beneficial outcomes linked to community-led HIV prevention, treatment, care, support, monitoring and advocacy.[iii]

6. However, progress has also been uneven. The share of new HIV acquisitions among people from key populations and their sexual partners increased globally from 44% in 2010 to 49% in 2024. Women and girls continue to be disproportionately affected by HIV in sub-Saharan Africa, accounting for 6 out of 10 new acquisitions. Globally, there were an estimated 3,800 new HIV infections among adolescent girls and young women every week in 2025.[2] In the same year, only 55% of children living with HIV were on antiretroviral therapy, which left more than 570 000 children living with HIV but untreated.

7. The message from UNAIDS is: "The world is not on track to achieve the 2030 goal of ending AIDS as a public health threat—but the goal remains within reach." [iv]

The HIV response and community leadership at a crossroads

8. The HIV response is facing a convergence of several shocks: dramatic cuts to HIV financing, the transformation of UNAIDS, the planned Global Fund transition out of 33 countries over the next few years,3 and a legal and political climate that is increasingly hostile to the very communities the response depends on. Each of these risks threatens the effectiveness of the HIV response and the leadership of communities within it. Together they are generating significant changes.

Cuts to financing

9. The past few years have seen momentous changes in the way the HIV response is financed, with financial responsibility increasingly shifting to national governments. External HIV financing to low- and middle-income countries fell 18% in 2025 alone, part of a broader 23% collapse in overseas development assistance.[v] [4] At the end of 2025, around 60% of available HIV resources in low- and middle-income countries came from domestic sources.

10. In recognition of this, the theme for the 59th PCB thematic segment in December 2026 is “Addressing the impact of funding cuts on people living with, affected by, and at risk of HIV”, a priority theme chosen by the PCB itself, including the NGO Delegation.

[2] Globally, an estimated 200 000 [130 000–280 000] adolescent girls and young women acquired HIV in 2025. Of the estimated 3,800 new HIV infections among adolescent girls and young women each week in 2025, approximately 3,000 occurred in sub-Saharan Africa.
[3] This figure relates to the number of countries where the HIV component of Global Fund grant will come to an end following the GC8 (2026–2028) allocation period. https://resources.theglobalfund.org/media/hvkncr4j/cr_gc8-transition-timelines_list_en.pdf
[4] Data from the Organisation of Economic Co-operation and Development.

11. Community-led organizations were among the first to feel the impact of funding cuts, in part because they are disproportionately dependent on external funding and struggle to find alternative, predictable financing. In 2024, approximately 25% of external HIV financing was channelled to nongovernmental organizations and civil society organizations, much of which has subsequently been reduced or cut.[vi] Where money is earmarked from domestic budgets for HIV the priority is frequently allocated to treatment, and community-led programmes and initiatives are often left unfunded.

12. A 2026 survey of 79 community-led organizations across 47 countries looked at the impact of funding cuts. It reported a 50% drop in support services for people living with HIV, especially the non-medical care that keeps people living with HIV engaged in treatment.[vii] The hardest-hit services were those providing legal support or addressing gender-based violence.

13. In humanitarian and crisis settings, nearly nine in ten women's organizations say they can no longer meet current levels of need, including on sexual and gender-based violence, psychosocial support and HIV.[viii]

14. While the need for governments to fund the HIV response domestically increases, including support for community leadership, civic space is shrinking in many places. Some governments are openly hostile towards marginalized and criminalized communities and will not fund them. In a survey of organizations led by people who use drugs carried out after United States bilateral funding was cut in 2025, the International Network of People who Use Drugs (INPUD) found that 23% of organizations had lost more than three-quarters of their funding.[ix]

15. Many countries also lack the regulatory mechanisms to finance community-led and civil society organizations. Only 62 out of 106 countries report having laws or policies that allow for domestic funding of community service delivery via social contracting.[x] Some governments that would like to support community- and civil society-led organizations are simply unable to mobilize the resources required to address HIV and other health and development issues and are further hampered by high debt burdens, and competing priorities, including climate and humanitarian crises and conflict.

16. In response to the changing financing context, many countries are moving towards integrating HIV within broader health systems. However, this also risks diminishing community leadership particularly in countries that do not formally recognize community organizations or community-led monitoring as integral to their national HIV responses. It is also unclear what models for integration can preserve the trust, legitimacy, advocacy, and rights-based functions that communities have built over decades.

<u>Structural change</u>

17. There are also significant changes taking place within the Global Fund. Reduced support from donors led to cuts to grants which had already been allocated in 2025. As the eighth replenishment summit failed to reach its funding target, countries have

also been warned that they will receive reduced allocations for the next grant cycle. These cuts put community-led programmes at risk. Until now, the national level Global Fund Country Coordinating Mechanisms have formed one of the strongest models of institutionalized community power in health governance. However, the Global Fund is preparing to transition out of countries that will graduate from eligibility, raising the question of what will happen to Global Fund structures in those countries, and will they be integrated into national systems?

18. At the same time, UNAIDS is undergoing institutional restructuring as part of wider UN reform. In 2025, the UN Secretary-General's proposed "sunsetting" UNAIDS, a move that was strongly opposed by the PCB NGO Delegation at the time.[xi] In December 2025, the PCB agreed to establish a Working Group to develop a plan and timeline for the further transition and integration of UNAIDS into the United Nations (UN) system and beyond.[xii] This laid the "sunsetting" proposal to rest and created an opportunity to shape the transformation of UNAIDS.

19. Nonetheless, it has been a year of huge uncertainty and fear about the future of the HIV response and the leadership of communities in it. Alongside this, wider funding cuts and UNAIDS restructuring have already taken place, leading to closed offices, fewer staff, reduction of grants for community-led monitoring, and fewer opportunities for marginalized communities to join dialogues with government officials and donors.

If we lose UNAIDS, community will lose a place at a very significant table. It was part of our history, where UNAIDS PCB inspired other structures where we are included.
– Community expert, Latin America

Shrinking civic space

20. This all takes place within a challenging political climate of anti-gender and anti-rights rhetoric, shrinking civic space and systemic discrimination against key populations. Restrictive laws are being used in some countries to monitor, control and restrict the activities of certain communities as well as some community-led organizations. For example, "foreign agent" laws are being used against organizations receiving funding from external sources.

21. In 2025, civic space was reported to have narrowed, repressed or closed in 159 of 198 countries,.[xiii] As of mid-2026, 168 countries criminalize various aspects of sex work, 152 criminalize drug possession for personal use, 66 criminalize same-sex sexual acts and 14 criminalize transgender people. Globally, women hold only 64% of the legal rights that men enjoy.[xiv] A growing number of countries have also prohibited the "promotion" of homosexuality, making it increasingly dangerous for community-led organizations providing HIV services for men who have sex with men or transgender people, or advocating for LGBTQ+ rights.

22. Even where key populations are not explicitly criminalized, they face other forms of institutional discrimination and legal, policy and structural conditions that increase their vulnerability and exclusion, such as a lack of gender recognition based on self-determination for transgender people or compulsory treatment programmes for

people who use drugs. Anti-rights movements are also trying to limit the leadership space that communities have, both at country level and within the UN governance and transformation, by undermining existing national and global commitments.

From leadership to solidarity

23. The HIV response has produced a rigorous community engagement governance framework, reflecting decades of political struggle by communities who refused to accept total exclusion or mere advisory status. After ten years of leadership by the World Health Organization, through the Global Programme on AIDS, the Joint United Programme on HIV/AIDS was established in recognition of the need for a broader response to the epidemic that includes addressing human rights, discrimination, the social and economic impact of the epidemic, and the needs and concerns of communities.

24. A purely biomedical approach to HIV would never have been effective, as HIV transmission, treatment and outcomes are profoundly shaped by stigma, discrimination, criminalization, gender inequality, violence, poverty and other expressions of marginalization. It is only by having people affected by HIV at the heart of the response that it has been possible to build an effective HIV response.

25. People living with and affected by HIV have brought knowledge, legitimacy, trust and accountability that only they could contribute. Keeping a focus on their experience is essential if the HIV response is to grow even more effective in meeting the needs of people living with, affected by, and at risk of HIV.

26. The HIV response also needs to share what it has learned with the wider world: there are clear connections to be made with sexual and reproductive health, non-communicable diseases, mental health, disability, gender equality and broader health and rights movements. The governance models, community leadership frameworks, and accountability mechanisms built within the HIV response belong to a wider world.

Building on previous commitments

27. Governments have repeatedly pledged their support for inclusive participation, citizen engagement, community accountability and civil society partnership through multiple commitments, including the Beijing Declaration and Platform for Action, the UN Political declaration on Universal Health Coverage, Sustainable Development Goal 16, and the 2018 Declaration of Astana.[xv]

28. The case for a stronger role for community leadership does not require new promises; many of the stakeholders have already made their commitments. The PCB has affirmed the NGO Delegation as an integral component of its own governance, with many PCB members emphasizing the importance of protecting the role of civil society in decision-making in discussions on the ongoing transition of UNAIDS.[xvi] The 58th PCB meeting, for example, heard repeated calls to strengthen community leadership across programme and policy design, implementation and accountability.

29. The Global AIDS Strategy 2026–2031 names community leadership both as a priority and a strategic results area. It explicitly states: “Embracing and supporting community leadership is not only strategic; it is essential for ending the AIDS epidemic.” The 2026 Political Declaration commits Members to protect civic space and ensure that communities are empowered and fully funded.

The purpose of this report

30. This report does not attempt to propose a new structure for UNAIDS or suggest reforms for the global health architecture, but it is grounded in the current moment. It sees the transformation of UNAIDS as an opportunity to reflect on the success of the HIV response and particularly the unique role that communities have played in governance structures.

31. The report identifies what has worked well and suggests what could be improved. It distils six principles for future governance, drawn from what already works, within and beyond the HIV response. The recommendations that accompany those principles are intended to guide Members and the Joint Programme to enact the commitments on community leadership made through their endorsement of the Global AIDS Strategy and UN General Assembly Political Declaration.

32. The principles and recommendations are designed to ensure that community leadership is safeguarded and strengthened within the governance of the HIV movement. They should serve as the criteria for assessing whether the community commitments outlined in the PCB transition and integration plan are delivered. It is hoped that they will be embedded in UN structures and will also guide national, regional and global organizations within the HIV response and beyond, creating a new global health and human rights architecture that is stronger and better suited to the world today.

33. The report draws on the views and experience of experts who participated in stakeholder consultations, as well as a review of comparable governance models. Those consulted were primarily community and civil society experts, while a smaller number of partners from National AIDS Councils, donors and UNAIDS Cosponsors also shared their views. The research methodology and a list of participants who consented to share their names can be found in Annexes 3 and 4.

The UNAIDS transformation process

34. The strategic direction set out in the “*Final* report *and* plan *of the PCB Working Group on the Further Transition and Integration of UNAIDS into the UN System and Beyond*” was approved at the October 2026 Special Session of the PCB. Although the details have not yet been finalized, it gives a clear outline for a new model for the UNAIDS Joint Programme and the role of communities within it.

35. The plan describes how a more streamlined global Hub of the UNAIDS Joint Programme will retain responsibility for certain functions including: global leadership and advocacy; development of the Global AIDS Strategy; mobilizing high-level

political and financial commitments to deliver on global AIDS targets; ensuring accountability within a unified budget and workplan; gathering and analyzing data; supporting the institutionalization of community co-creation and co-leadership across all aspects of the UNAIDS Joint Programme; and helping to preserve the role of the Board as a key global agenda-setting and policy-making forum for HIV.[xvii]

36. Critically, the plan retains the PCB as the governing body for the UNAIDS Joint Programme and the current UN Economic and Social Council (ECOSOC) mandate on governance, alongside continued resourcing of the NGO Delegation's governance role. These guarantees are essential to protect the role of the NGO Delegation and provide a solid foundation for community leadership.

37. Additionally, the plan proposes creating a limited number of community-held positions within the global Hub with decision rights and access to resources for expert work that community representatives perform.

38. The model envisages responsibility for functions that depend primarily on technical mandate, thematic expertise, operational presence and proximity to national institutions increasingly led by Cosponsors and national actors. The report is explicit that Cosponsors will be expected to support community co-creation and co-leadership. It also proposes that functions that require proximity to communities living with and affected by HIV be led by community and civil society actors.

39. The plan entails the UNAIDS Joint Programme's presence in countries transitioning over time, with functions ultimately being absorbed in national institutions and systems. The report urges care to be taken as functions transition from UNAIDS to national actors, including taking steps to preserve "*community leadership (through institutionalized community engagement within country arrangements, including dedicated financial support for sustainable community engagement mechanisms)*."

40. The plan also calls for the inclusion of community-led representatives in Joint UN Teams at regional and country levels, and incentives to include community partners in catalytic country-level activities that are funded through a pooled funding mechanism, with community representatives involved in decisions around how funds from the mechanism are allocated.

41. Particularly at national level, where certain functions have not previously been delivered by Cosponsors, governments or other national actors, it will be essential to institutionalize community leadership in new structures and ways of working. The plan includes a proposed accountability chain that would apply to all levels of the HIV response with verifiable indicators on co-creation and co-leadership.

42. The Transition Working Group emphasises that the transition must be sequenced according to functional readiness, rather than a uniform organisational timetable. Existing capacity should not be withdrawn until an agreed arrangement has a named owner, an agreed mandate, sufficient resources, an operational service standard and an accountability route. Country-level transitions should be shaped by the needs and preferences of governments, communities and other national stakeholders, with

functions transferred only when the receiving entity has the mandate, capacity, resources and accountability arrangements to carry them forward.

43. The HIV response has a long proud history of engaging communities, the report of the PCB Working Group continues this tradition, explicitly building community co-leadership into its plan. To help realize this vision, this report proposes six principles to practically guide institutions, Members and UN bodies to ensure that their structures and processes allow for genuine co-leadership by communities.

Six principles to embed community co-leadership in HIV governance

> *Communities constitute the third pillar of the Global AIDS Strategy and are central to its success. They are the heart of the HIV response and perform life-saving work.*
> *– Global AIDS Strategy 2026–2031, Results Area 8 (Priority 3: Community Leadership)*

44. This report sought principles for embedding community leadership in the future governance of HIV and health more broadly. Models that exist across the HIV response, particularly civil society leadership in the UNAIDS PCB and on the Global Fund Board, were achieved through decades of struggle and now set the standard. Participants in the research for this report called for those principles to be preserved and for future structures to go further in order to respond to a context that is now very different from the one in which communities first spurred the world to act on HIV. The principles are outlined below; they build on multiple documents and guidelines including:
    - Principles for the Meaningful Involvement of Civil Society and Communities in Global Health Governance (developed by a civil society task force);
    - Guidelines from the Global Network of Young People Living with HIV (Y+ Global) for the meaningful and ethical engagement of young people living with HIV in the HIV response; and
    - Committee on the Elimination of Discrimination against Women (CEDAW) General recommendation No. 40 (2024) on the equal and inclusive representation of women in decision-making systems.

See Annexes 5–7 for further details.

45. The six core principles provide direction for future governance structures at global, national and local levels, setting new standards for the leadership of communities and civil society in HIV and health governance (Figure 1). The principles should be understood as mutually reinforcing and indivisible: participation cannot be meaningful without power, power cannot be exercized without resources and autonomy, representation cannot be equitable without rights and safety, and none of these can produce structural change without mechanisms for implementation and accountability. While this report is focused on governance, it is important to state that meaningful community leadership must also extend from decision-making to

implementation and accountability.

> *Communities, particularly people living with HIV, young key populations, women, transgender people, sex workers, people who use drugs, and other affected groups, must have protected seats with voting influence in decision-making bodies at national, regional, and global levels.*
>
> *– Community expert, Asia*

Figure 1. A compass for meaningful community co-leadership



Principle 1: Institutionalized participation

46. Community and civil society participation must be permanent, formally institutionalized, and embedded within decision-making structures for HIV and health.

47. Conventions or goodwill, which can be reversed, are not enough. Community participation must be built into every level of decision-making from global bodies to district health systems.

48. The 2026 Political Declaration on HIV/AIDS calls on UN Member States to "commit to engage with people living with, at risk of, or affected by HIV, women, young people and adolescents, and Indigenous peoples in coordination and decision-making mechanisms at all levels of the response, including HIV financing mechanisms."

49. The NGO Delegation is unique among other UN bodies in that it is a permanent member of the PCB. It was the structure which most participants in the survey held up as a model of effective community engagement in governance. No other

institutions within the UN system match UNAIDS' track record for engaging communities as partners.

In my view the UNAIDS PCB model provides a strong governance model by its inclusion of CSO delegation in the Board. In each of the PCB meetings I have attended, the participation of the various members of the NGO delegation has been critical.

– Partner

The UNAIDS Programme Coordinating Board: a UN first

When UNAIDS was established in 1994, it was the first time that an NGO delegation was built into a UN governance structure. ECOSOC decision 1995/2 outlines the arrangements for the participation of NGOs. The PCB is the governing body for all issues concerning policy, strategy, finance and monitoring and evaluation. It is made up of representatives of 22 Members, 11 Cosponsors and NGO representatives (5 members and 5 alternates) from geographic regions: Africa, Asia-Pacific, Europe, Latin America and the Caribbean, and North America.

NGO Delegates can participate in PCB discussions and make interventions, but do not have the right to vote. The PCB Bureau also includes representatives of the NGO Delegation. There is a dedicated mentoring process for incoming delegates and a funded communications and consultation facility that provides them with practical and technical support.[xviii]

A former PCB member describes the background to this breakthrough: "The rationale for civil society's involvement lies in the fact that the HIV/AIDS movement was really based on participation. Since the beginning, people living with HIV and key populations pushed and insisted that politicians, scientists and affected people should come together and figure out how to create solutions together. We built this social movement where it was almost impossible to move forward any discussion without involving us. We were pressing since the beginning to have meaningful participation. Because of this, when the PCB was formed, civil society was considered a very important player that had to participate. This was very innovative at that time and continues to be innovative today." [xix]

50. The new model for UNAIDS protects the ECOSOC commitment and the role of communities within the governance of the Joint Programme. Under the current arrangements, NGO Delegation representatives participate directly in PCB discussions and negotiations, including on proposed decision points, and contribute to the work of the PCB Bureau, although they do not have voting rights.

51. However, as certain technical, thematic and operational roles are increasingly taken over by Cosponsors and national actors, there is a risk that their structures will not formally include a leadership role for communities.

52. UNAIDS has 11 Cosponsors, six of which are designated as lead Cosponsors (UNDP, UNFPA, UNHCR, UNICEF, UNODC and WHO) and five as affiliate Cosponsors (ILO, UNESCO, UN Women, WFP and the World Bank), each with its own structures for engaging or consulting civil society. In a recent report, the Cosponsors emphasized the importance of community partnerships to end AIDS, and shared multiple examples of how each of the agencies works with communities.[xx] Except for the ILO, whose tripartite governance structure formally incorporates workers' and employers' representatives, none of the UNAIDS Cosponsors has formal representation for civil society or affected communities within its principal governing body, or formal decision-making rights for civil society representatives.

53. UNESCO, for example, provides formal opportunities for civil society participation in its programming cycle through its NGO partnership framework. Official NGO partners may submit written recommendations on UNESCO’s strategy and programme, contribute collective views through the International Conference of NGOs, and address General Conference commissions, committees and plenary sessions, subject to applicable rules. However, these arrangements are consultative rather than decision-making: they provide opportunities to influence priorities but do not confer a formal role in adopting decisions. The specific opportunities under this framework are also only available to NGOs with official partnership status, although UNESCO also engages with other civil society organizations on an ad hoc basis.[xxi]

54. In 2023, WHO created a Civil Society Commission to make engagement with communities more systematic and structured. The Commission is supported by a secretariat and includes a steering committee, annual general meetings, and working groups (although participation in these is not open to all members).[xxii]

55. While this is a formalized structure for community engagement, unlike the UNAIDS PCB it is advisory and acts as a consultative body rather than a decision-making one. In addition, although over 400 organizations are listed as taking part in the Commission, they appear to have had limited opportunities to engage, even at an advisory level.

56. Reporting on its 2026 annual general meeting, WHO stated that a survey of more than 120 Commission members had found that members were highly motivated and engaged, but the Commission's potential was constrained by gaps in communication, clarity and engagement design. Members called for clearer participation pathways, more regular communication, practical tools and guidance, and greater focus on country-level impact.[xxiii]

57. Beyond the HIV response, some institutions have successfully embedded community participation as a legal obligation. The Convention on the Rights of Persons with Disabilities is widely seen as the first body to formally embody the principle of "nothing about us without us," which has become the Greater Involvement of People

Living with HIV principle (GIPA) in the HIV response.[5]

Convention on the Rights of Persons with Disabilities: participation as a legal obligation

Article 4(3) requires States to "consult with and involve persons with disabilities in developing and implementing legislation and policies and in decision-making processes concerning people with disabilities". Article 33 also requires that civil society, in particular persons with disabilities and their representative organizations, be involved and participate fully in all aspects of monitoring.

Legal analysts consider this more expansive than any other core human rights convention.[xxiv] The Convention sets an important precedent within UN structures for community participation as a human rights obligation.

For participation to be truly meaningful, communities and civil society should not only have a top-line level of representation but instead have a guaranteed place on all technical committees and working groups. The Convention does not quite extend to this. While there are structured opportunities to participate at various levels in the work of the UN Committee on the Rights of Persons with Disabilities, there is no universal rule requiring disabled people's organizations to be represented on every Committee working group or technical body.

58. The institutional embedding of community participation is equally important at national level. In Ghana, for example, the law creating the Ghana AIDS Commission requires HIV-focused civil society organizations and representatives of people living with HIV to serve on the governing structure of Commission at national, regional and district levels.[xxv]

59. Similarly, in the Philippines, sustained advocacy led by ACHIEVE and CARAM Asia, organizations working on promotion of migrant worker's health rights, changed the National AIDS Council from a body of civil servants and medical professionals into one that formally includes civil society groups and key populations. This guaranteed communities a voice in national HIV policy and decision-making and established a replicable model for participatory governance.

[5] For further information see: https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities

Three tiers, one table: lessons from South Africa

South Africa's 2003 National Health Act requires each local health facility to have a health committee that includes community members, giving local populations a voice in health-care delivery.[xxvi] The South African National AIDS Council also structurally embodies the principle of community engagement, organized into three tiers with government and civil society represented at each level.

The plenary is the top-tier decision-making body, the programme implementation committee reports directly into it, and below this are sector coordinating committees that are organized around specific constituencies. The Council's Civil Society Forum represents 18 sectors, including people living with HIV and key populations. Each sector is self-organized and sends its own representatives into the sector coordinating committees which feed up through the programme implementation committee to the plenary, giving affected communities a direct institutional channel into national policy.[xxvii]

This model allows civil society to advocate directly for policy and programmes and makes collaboration between civil society and government a requirement. Although these structures are mirrored at regional and local levels, research has shown them to be less effective there, with less trust between stakeholders.[xxviii]

Beyond consultation: Brazil's thematic group

Brazil's Expanded UN Thematic Group on HIV/AIDS is an interesting example of how community participation can be institutionalized at country level through.[xxix] Established in 1997, the mechanism brings together UN agencies, Government representatives, civil society, networks of people living with HIV and key populations, alongside other partners such as diplomatic missions and international cooperation actors. The Group provides a regular space for communities to engage directly with government and UN actors, raise emerging priorities and contribute to discussions on the national HIV response. Importantly, the Group's role has gone beyond consultation and information-sharing—at times, it provided a platform for joint advocacy and engagement for example on policy and human rights issues.[xxx]

60. Whether at the global, regional, national or local levels, permanent, guaranteed representation is essential to allow representatives to observe and influence decisions over time, rather than only informing discussions or decision-making in an ad hoc manner or when an institution or government chooses to consult them.

Principle 2: Shared power

61. Communities and civil society should have formal decision-making power within HIV and health decision-making structures, with voting rights as the desired standard, alongside agenda-setting authority and meaningful opportunities for co-creation.

62. Critically, it cannot be assumed that all communities will be equally represented within decision-making structures. Deliberate efforts must be made to ensure that young people, women, key populations and people living with HIV have seats at the table. Despite years of advocacy, it was only in 2023 that Global Action for Trans Equality was granted ECOSOC status allowing it to more meaningfully engage in UN systems.[xxxi]

> *Community leadership is key in this context; we need to protect it. The whole HIV movement is built on voices and demands from communities.*
> – Partner

63. If the HIV response is to be gender-responsive, a gender perspective must be integrated into governance. The CEDAW recommendations, outlined above, call for "fifty-fifty parity between women and men in all their diversity in terms of equal access to and equal power within decision-making systems."

64. The Global AIDS Strategy calls on stakeholders to: *"*Formally recognize and institutionalize the important roles of communities in co-developing policy guidance, targets and accountability frameworks at all levels in HIV responses." It is not enough to grant them observer or advisory status; they need to be shaping priorities from the outset, not be consulted afterwards.

65. Stakeholders consulted for this report called for all future HIV and health governance structures to go beyond the good practice of the current PCB NGO Delegation and extend voting power to communities and civil society. While the plan for the reformed UNAIDS Joint Programme advises delaying further governance changes until the new model "*has had a chance to work*", there remains the possibility of extending voting rights to communities in the future. The report states: "*Community engagement will move towards a model of co-leadership, where communities are involved from the earliest stages in shaping, driving and monitoring the UNAIDS Joint Programme's strategy and activities, as equal partners."*

66. The principle of shared power must also be applied to the role that UNAIDS currently plays in convening dialogues around HIV, health, gender equality, and rights and coordinating between UNAIDS, WHO, the Global Fund, the United States President's Emergency Plan for AIDS Relief (PEPFAR), and various UN agencies and donors.

> *Communities, key populations and people living with HIV should sit on the future governing body as decision-makers with agenda-setting power, not as observers giving two-minute interventions.*
>
> – Civil society expert, North America

67. Genuine influence over decision-making is a core pillar of the GIPA principle: the right for people living with HIV to self-determination and participation in decision-making processes that affect their lives.

68. Equal voting rights help representatives from different groups work together better, allowing civil society and community members talk to, and partner with, government and other officials as equals.

> *Communities, particularly people living with HIV, young key populations, women, transgender people, sex workers, people who use drugs, and other affected groups, must have protected seats with voting influence in decision-making bodies at national, regional, and global levels.*
> – Community expert, Asia

Enhanced community power in Global Fund governance

The Global Fund followed the precedent set by the PCB and embedded community participation in its governance structures. At one level, the Global Fund has gone even further by giving communities and civil society voting rights. A Board oversees strategy development, governance and the commitment of financial resources for the Fund; it has 20 voting members, three of which represent civil society and communities. They have real voting power and are only one vote short of being able to block proposals they disagree with.[xxxii] Significantly, in June 2026, Javier Hourcade Bellocq, a community leader from Latin America, was elected vice chair to the Board, the first time this senior role has been held by a community representative.[6] [xxxiii]
At country level, CCMs bring together government, the private sector, NGOs and people living with HIV, tuberculosis and malaria into the design and oversight of Global Fund grants.[xxxiv] CCMs are tasked with putting together their countries' funding requests, which entails shaping the priorities for the HIV response within their countries. To encourage meaningful engagement, most grant applications must be submitted with an accompanying annex outlining the top 20 priorities of communities and civil society. This allows those deciding on the grant to measure how far community priorities have shaped the country's application, and to request amendments if they have not.[xxxv]

69. Following the Grant Cycle 8 funding round, the Global Fund will begin transitioning out of many low- and middle-income countries, and there is a risk that CCMs will be disbanded in these countries. Conscious efforts need to be made on the part of governments, particularly through their National AIDS Councils, to ensure that they retain a mechanism to ensure formal community and civil society involvement in decision-making within their national structures.

70. Communities have succeeded in exercising real influence over outcomes even in spaces where they do not have formal voting rights. The NGO Delegation to the UNAIDS PCB is one such example. The NGO Delegation has direct access to

[6] Javier Hourcade Bellocq has a long history of leadership within the HIV movement. He was previously Board Member for the Communities Delegation of the Global Fund and a member of the Strategy Committee. He has also held leadership and advisory roles with key global health organizations including UNAIDS, WHO, UNITAID, and the Pan American Health Organization, as well as national governments in Latin America and was Chair of the Global Network of People Living with HIV (GNP+).

drafting rooms and can propose decisions or amendments to them. Critically, this has enabled delegates to bring lived and community experience directly into negotiations, including by identifying and challenging language that may be harmful or exclusionary. In addition, one of the PCB NGO representatives is a formal member of the PCB Bureau, with responsibility for collaborating with the Executive Director to set the agenda for PCB meetings.

71. It is difficult to attribute PCB decisions to the actions of a single constituency, as decisions are reached over time, through negotiations that lead to consensus decision- making, a process which often takes into account discussions in previous meetings. However, the NGO Delegation has championed causes where significant gains have been made. For example, the Delegation has repeatedly highlighted the needs and concerns of key and vulnerable populations. When UNAIDS developed its first guidance note on HIV and sex work, in 2006–2007, the NGO Delegation worked with the Global Network of Sex Work Projects to change the original abolitionist stance to a rights-based approach to sex work and HIV.[xxxvi]

72. The Delegation also drove progress in agreeing on definitions of community-led HIV responses. The NGO report to the 39th PCB began the discussion with its focus on recognizing and funding community-led responses.[xxxvii] Two years later, the 43rd PCB adopted a decision to develop a standardized definition, leading to an extensive expert consultation on defining HIV community-led responses which took place in 2019.[xxxviii] [xxxix]

73. In 2012, when the United Nations Office on Drugs and Crime (UNODC) proposed downgrading its Global HIV Programme, the NGO Delegation, supported by PCB observers such as the International Network of People who Use Drugs, advocated for the programme's continuation. This contributed to its survival and, in February 2013, to the establishment of the UNODC Civil Society Group on Drug Use and HIV.[xl]

74. Most recently, the NGO Delegation’s advocacy helped halt the hasty “sunsetting of UNAIDS and move the conversation towards its transformation instead. The Delegation issued a statement opposing the proposal on 19 September 2025 which garnered endorsements from more than 1,000 organizations.[xli]

75. Communities and civil society also seize other opportunities to shape the agenda, such as joining discussions in International AIDS Society conferences, and participating in multi-stakeholder structures like the Global HIV Prevention Coalition and the Global Partnership for action to eliminate all forms of HIV-related stigma and discrimination. Communities also influence the agenda nationally through National Strategic Plans, and regionally and globally through commitments such as the Lusaka Agenda, the 2026 Political Declaration on HIV/AIDS and High-Level Meetings on HIV.

76. Communities and civil society have had to repeatedly fight for their meaningful involvement. At the 79th World Health Assembly in May 2026, a consortium of civil society organizations denounced a WHO-hosted joint process to reform the global health architecture, which had been approved by Member States. The arrangement

included a 25-member task force which lacked even a single seat for civil society or people with lived experience of health conditions and inequities.[xlii]

77. For communities to exercise decision-making power, whether through formal voting rights, or meaningful opportunities to set the agenda and influence discussions, they need to be well informed and have the capacity to act, as outlined in the principles below.

Principle 3: Resourced engagement

78. Community and civil society engagement requires dedicated, predictable financing for participation itself, distinct from programme funding and disbursed ahead of major decisions.

79. Involving civil society and community-led organizations structurally without providing support is tokenistic.

80. Community and civil society participation must be ring-fenced and secure, otherwise engagement is threatened when funds disappear. For example, in South Africa sustainable financing for community participation in National AIDS Council structures was partly supported by external donors and is now at-risk following funding cuts.xliii

81. A dedicated annual budget for each constituency should not only cover expenses but also research, planning and consultation meetings, as well as some funding to allow delegates to engage, consult and gather information at country level.

82. Delegates who represent communities in governance structures have a difficult job. They are usually unpaid, carrying out their tasks alongside full-time jobs, and engage in highly technical conversations that require significant preparation, often provided at short notice. They are expected to travel frequently or to join online meetings that are rarely organized to align with their time zones and engage in highly technical conversations. They are also expected to be well-connected to their communities (which may be large and geographically widespread), but there are rarely resources to support this connectivity.

> *Our participation has to be resourced and sustained: Funding that covers our real costs (transport, data, etc) without assuming a salaried professional's flexibility.*
> – Community expert, East Africa

83. The PCB addresses some of these issues through its Communications and Consultation Facility which is tasked with (among other things) facilitating outreach and communication between the NGO Delegation and wider civil society constituencies, consolidating feedback and bringing forward unified messages to the Board and providing administrative and recruitment support.

84. The plan for the transformed UNAIDS Joint Programme explicitly calls for “a focus on key and priority populations, supported by resourced engagement of communities and civil society in co-decision-making and shared delivery, alongside their existing

role in governance."

85. The transition plan also proposes a pooled funding mechanism within the Joint Programme's annual budget to support catalytic country-level work that "will afford a new means to support partnerships and consortia that include community-led activities". Decisions on awarding and disbursing funds would be made collaboratively by the Hub, Cosponsors, and community and civil society representatives, with the PCB retaining ultimate authority over allocations.

86. The plan states that "the pooled fund should explicitly allow for direct financing of community-led organizations and initiatives, alongside activities led by Cosponsors, national governments or others." Important design questions remain open, such as where the fund will be hosted and how it will be governed. These decisions will determine whether the commitments to resourced engagement described in this report indeed reach community-led organizations in practice.

87. Governance structures also need to recognize the different needs of community and civil society representatives from low- or middle-income countries. They may not have the same levels of financial and institutional support as representatives from the Global North and may be unable to commit the same amount of time to unpaid work. Differences in cost of living between their countries and cities like Geneva or New York, where multilateral decision-making is often concentrated, mean that they are also disproportionately affected by out-of-pocket expenses incurred on work travel and by long delays in reimbursement.

88. Depending on their nationality, community and civil society representatives can struggle to get the necessary visas to be able to attend meetings in person when those take place outside their home country. Members States could provide them with laissez passer documentation to enable them to travel freely when on official duties.

89. Representatives from certain communities may need more support than others. For example, young people may benefit from mentoring and additional training.

90. Both the Global AIDS Strategy and the UN General Assembly Political Declaration on HIV/AIDS explicitly support youth leadership: "Support youth leadership in the HIV response by increasing predictable and flexible youth-responsive funding, ensuring meaningful youth engagement in decision-making, and supporting intergenerational and peer collaboration and mentorship models that intentionally build successive generations of leaders."[xliv]

91. The International Community of Women living with HIV's manifesto specifically calls for the UN system to resource leadership pathways for young, rural, Indigenous, and transgender women.[xlv]

92. Representatives also need well-funded constituencies behind them, so they are not operating alone. Governments and donors must shift from short-term, project-based grants toward long-term, flexible, core funding paid directly to community-led

organizations.

93. Both the 2026 UN General Assembly Political Declaration and the Global AIDS Strategy call for "effective social contracting mechanisms that enable predictable, long-term and flexible financing of community-led responses" with the Global AIDS Strategy adding the need to "ensure those mechanisms are accessible to community-led entities such as youth-led organizations, women's networks and key population organizations."

94. Support must not be limited to financing: thorough orientation, ongoing training and technical support are also required to ensure that community and civil society representatives can engage meaningfully in discussions. In addition, consideration needs to be given to providing information in a timely manner allowing time for meaningful reflection and ensuring there is sufficient handover time between representatives.

The Stop TB Partnership: practically supporting participation

The Stop TB Partnership, an UN-hosted initiative bringing together country, regional and global partners, includes dedicated support for participation.[xlvi] Its Board includes representatives of communities affected by TB, key and vulnerable populations, and NGOs, with significant investment in TB community networks.

In recognition of the workload involved, applicants for community delegate roles must provide documentation from their employer acknowledging that the role will occupy approximately 10–15% of their time. New delegates receive an orientation programme and ongoing mentoring, expenses are covered for both Board meetings and pre-Board meetings, and a dedicated Constituency Focal Point organizes meetings, circulates papers and coordinates communication.[xlvii]

95. The Global Fund arrangement also recognizes that community participation cannot be meaningful unless it is resourced: delegations representing developed- or developing-country NGOs and communities receive annual budgets to support meeting preparation, communications, information dissemination and technical and advisory support. However, the financial support is not always adequate or provided in advance.

Commit to predictable, multi-year, flexible funding that is directly accessible to community-led organizations, ensuring long-term sustainability, stronger community leadership, and uninterrupted HIV services.

– Community expert, Middle East and North Africa

96. The model of consultation used by the Convention on the Rights of Persons with Disabilities with disabled people's organizations similarly recognizes the breadth of support required for genuine inclusion. The support provided includes ensuring that information is accessible (through translations, braille, accessible formats, etc.), making meetings accessible (with sign-language interpretation, captioning,

accessibility arrangements, etc.) and permitting multiple routes for participation (such as written submissions, oral briefings, private meetings and remote participation).xlviii

97. The model for supporting civil society participation in The Committee on the Elimination of Discrimination against Women is different. A trusted NGO—International Women's Rights Action Watch Asia Pacific—has been contracted to provide support through a mechanism developed by civil society.xlix Officially recognized by the Office of the High Commissioner for Human Rights and the Committee, it coordinates NGO participation in the Committee' sessions. It supports grassroots, national, and regional feminist advocates to navigate and influence the Committee review process, providing training, mentoring and support to develop shared demands, spanning the period before, during and after Committee state reviews. The model is fully independent from the UN but is not institutionalized in the Committee's own structures.

98. Financial support for International Women's Rights Action Watch Asia Pacific is also not guaranteed within the Committee's guidelines and therefore depends on the NGO's financial status, causing fragility which ring-fenced funding can avoid. As with all the different models for providing practical and technical support for community and civil society participation, the funding stream is key.

Principle 4: Self-determined representation

99. Communities and civil society must be able to act autonomously, including making decisions free from external influence and choosing their own representatives.

100. No single organization can speak for all constituencies; diverse voices need to be represented to reflect geographical diversity as well as different constituencies. Attention should be paid to gender balance, proactively including young people and ensuring no community is forgotten, whether representatives from low- or middle-income countries, specific geographical regions or people who are most marginalized within already-marginalized communities.

> *There is need to shift power dynamics and avoid dominance by same people or structures. In many cases marginalized groups need support to understand complex discussions so that they are not reduced to by-standers or rubber stampers of government, UN or donor representatives.*
>
> – Civil society expert, Southern Africa

101. The Principles for the Meaningful Involvement of Civil Society and Communities in Global Health Governance include detailed guidance on how to identify appropriate organizations to run selection processes and support interim Board Members in newly established institutions.

102. It is essential that there are community representatives, not just from wider civil society, in governance structures, because their lived experiences position them to understand the reality of living with HIV or belonging to a particular key population.

103. Within the reformed UNAIDS Joint Programme multiple roles are planned for communities, including remunerated positions within the Hub, Task Team seats, pooled fund governance, and a potential community lead for Result Area 8 of the Global AIDS Strategy (which focuses on community leadership). Deliberate efforts will be required to ensure that these positions are held by a diversity of representatives and with strongest representation from community-led organizations rather than other NGOs.

104. Meaningful community engagement also requires that representatives have clear communication channels with their constituencies, so they can articulate their experiences and opinions, as well as transparent, rotating appointment processes, so that representation remains legitimate over time.

> *Communities need to be registered and recognized on a local level, trained and empowered to well represent the needs and challenges faced by the community and to be able to advocate on local, regional and international level.*
> – Community expert, Middle East and North Africa

105. Autonomy is one of the PCB NGO Delegation's core strengths. NGOs select their delegation members themselves, guided by ECOSOC resolution 1995/2, and the PCB formally approves the nominees. NGOs try to ensure that delegation members are not only regionally diverse but also represent a wide range of communities and voices.

106. The Global Fund's Communities, Developing Country NGO and Developed Country NGO Delegations are another strong example of this approach. They select Board members based on their expertise, authority and capacity to solicit and represent the views of the stakeholders they represent. This happens through consultations, nomination processes, and advisory bodies. The Communities Delegation comprises up to 40 people living with HIV and affected by TB and malaria, drawn from community networks and organizations around the world, thereby tying membership to lived experiences and community representation rather than government or donor appointment.

107. The Delegations also run their own internal governance rather than being administered by the Global Fund. Their work is coordinated by leadership consisting of a Board member and alternate Board member, who formally represents the Delegations to the Global Fund Board, guided by its own policy and procedures handbook. This self-authored document outlines how the Delegations organize themselves, set priorities, and hold their leadership to account.[li]

108. However, there are challenges with representation within Global Fund structures. Despite CCMs being required to show “evidence of membership of affected communities in the Coordinating Mechanism”, women living with and affected by HIV have documented their under-representation on CCMs.[lii]

Self-organized and autonomous: the Civil Society and Indigenous Peoples Mechanism of the Committee on World Food Security

The Civil Society and Indigenous Peoples Mechanism is frequently cited as one of the strongest models for community participation in an intergovernmental body.[lii] It is a self-organized, autonomous part of the Committee on World Food Security, drawing participants from 11 constituencies and 17 sub-regions to ensure balance across sectors, regions and genders, with no governmental involvement in who is selected.

The Mechanism develops independent policy positions, submits evidence, participates in negotiations, engages directly with governments to support the use and application of Committee guidelines, and scrutinizes implementation.

Evaluations have highlighted some of the strengths of this model.[liii] Its role is institutionalized, so members are formal participants, not just observers, and their participation does not depend on goodwill. It receives technical and financial support from a well-regarded secretariat and trusted international NGOs.

Civil society participation has been consistent and substantive leading to the mechanism being seen as a key stakeholder within Committee governance. Members go beyond simply representing their constituents' views to acting as "facilitators", enabling communities to participate in the discussions and work of the Committee.[liv]

Most significantly, it has real influence: participation goes beyond consultation to include agenda-setting and policy development, and it is widely credited with shaping the Committee's voluntary guidelines on the responsible governance of tenure, discussions on land rights, and, most recently, giving testimony on the famine in Gaza.[lv]

Importantly, the Mechanism allows representatives to be selected autonomously through their own constituency structures. While evaluations do flag some concerns, including that some constituencies are more organized and influential than others, the system is regarded as very effective, particularly in the way that representatives act as facilitators, working with their communities to enable them to input into decision-making processes.

109. At national level, the South African National AIDS Council's Civil Society Forum, described above, follows the same logic: each of its 18 sectors is self-organized and sends its own representatives forward, rather than having them appointed.

110. The Brazilian system of Health Councils (Conselhos de Saúde) is another example of a deliberate selection model. These legally mandated bodies exist at municipal, state and federal levels, bringing together civil society, government and health professionals to inspect public health accounts, demand accountability for services, and influence how public health resources are spent.

111. Half of the seats on every council are reserved for service users, filled by delegates chosen through existing civil society associations with their own internal elections—in other words, a selection process, not an appointment. The system is not without its flaws. Research has found representatives risk becoming too "professional" and

removed from their communities, face difficulty representing diverse constituencies and experience government interference.[lvi] Nonetheless, it remains a useful model for community and civil society participation in decision-making at national and local levels with genuine self-selection of participants.

Principle 5: Rights-centred governance

112. The future architecture of the HIV response must explicitly protect and promote the rights of the most marginalized, including those in criminalized and hostile legal environments, and support the creation of an enabling environment.

113. Promotion of rights and gender equality are critical, given the current context of growing anti-rights and anti-gender movements, shrinking civic space, and the danger of key populations being pushed from the centre of the response. The Association for Women's Rights in Development surveyed over 1,174 feminist, women's rights, LBTQI+, and allied organizations in 2023 and found that the total funding they received was half of that given to just three global anti-rights actors.[lvii]

> *Representatives also require protection from stigma and reprisal, given that criminalization and social stigma still shape daily realities for people living with HIV and key populations across parts of the region*.
> – Community expert, Caribbean

114. The Global AIDS Strategy calls for action to: "Reform laws, policies and regulations that limit the ability of community-led organizations to participate in all aspects of HIV responses, particularly advocacy, engagement in decision-making, and service delivery [...] That includes support to safeguard civic spaces and to track the status of civic space and community participation in HIV planning and decision-making at national, regional and global levels."

115. The transition working group report explicitly recognizes "the critical importance of human rights and gender equality to an effective HIV response" and states that "the UNAIDS Joint Programme's capacity in these areas will need to be ensured at all levels". The report also flags the importance of human rights and gender equality as factors in decisions about the pace at which country-level functions are integrated into national institutions.

116. Communities have always been at the forefront of efforts to advance human rights, challenge stigma and discrimination, and hold decision-makers to account. One channel for this work is the Universal Periodic Review, a Human Rights Council mechanism that requires every UN Member State to undergo a peer review of its human rights record every 4.5 years.

117. The Review covers all aspects of human rights and is an important tool for holding countries accountable for their pledges to end AIDS and respect the rights of people living with HIV and key populations. Alongside it, civil society groups and networks create shadow reports highlighting human rights gaps, legal barriers and

discrimination. For example, as part of Uganda's 4th Cycle Universal Periodic Review, Global Action for Trans Equality supported Prism Uganda to develop and submit a shadow report documenting the lived realities of transgender people in Uganda.[lviii] Similarly, during the 4th cycle of the Review in Indonesia, the Indonesia National Coalition of the Marginalised Group Against Discrimination produced a shadow report on the human rights situation in their country.[7] [lix] These reports are a formally recognized part of the evidence and agenda setting process, they feed into a stakeholder summary report and inform recommending States.

118. A parallel mechanism also exists at the Committee on the Elimination of Discrimination against Women, where 23 independent experts monitor implementation and member countries submit progress reports every four years, with civil society often filing shadow reports to highlight gaps. For example in Ukraine, Positive Women, in coalition with organizations representing sex workers, women who use drugs and LBTQI women, developed Committee on the Elimination of Discrimination against Women shadow reports in 2017 and 2020, holding the government to account for its lack of support for women's rights, including in the context of harm reduction and violence against women.[lx]

Legal challenges as a tool for communities

Community organizations have increasingly used litigation to challenge discriminatory laws, denial of treatment, criminalization and discrimination. Although outside formal governance structures, these cases often drive policy change.

A successful legal challenge in Kenya, supported by the International Community of Women Living with HIV, brought an end to the practice of sterilizing women living with HIV without their informed consent in Kenyan health facilities.[lxi]

In March 2026, Botswana formally removed the colonial-era provisions criminalizing same-sex relations from its penal code, the culmination of over a decade of advocacy led by community groups like LEGABIBO.[lxii]

119. It is also important to protect the safety, security and rights of individuals operating within governance structures. Representatives of communities and civil society must be safe to speak and act independently, without fear of harassment, risk of retaliation, or risk of being exposed as a member of a criminalized population.

120. Their safety and security should not be the responsibility of the individual participants or their organizations. Measures should be built into the governance structure to assess and manage risk, protect confidentiality and promote safety.

121. A study into community engagement in Global Fund CCMs highlighted some of the challenges. It included numerous first-hand testimonies from community

[7] The Coalition represents 36 Indonesian NGOs or civil society organizations working to advocate and campaign for rights of vulnerable groups in Indonesia, which include groups of people with disabilities, people with HIV and key populations, women, indigenous peoples, religious minorities and LGBTIQ people.

representatives who had been discriminated against, harassed or intimidated when participating in their CCM. This included several participants from key populations reporting acts of homophobia and discrimination by their counterparts, leading to some community members declining to serve on the CCM to protect their safety.[lxiii]

122. The report concluded that there was a need for the Global Fund to reinforce and promote its policies around non-discrimination and the protection of human rights, and to ensure that these standards are being disseminated through regular trainings, outreach, and direct intervention from the Secretariat.

123. The Y+ Global "We Matter, Value Us" principles include detailed guidelines on safety from safeguarding policies to travel advice and the importance of consent when using people's words and images.

> *Given the criminalized status of sex work in East Africa, we need legal safety guarantees, including confidentiality and protection from arrest or exposure tied to being named in official decision-making spaces.*
>
> – Community expert, East Africa

124. The San Jose Guidelines are a formal policy designed to protect individuals and groups from intimidation or reprisals when cooperating with UN human rights treaty bodies.[lxiv] They are designed to safeguard people who share information, testify, or engage with UN human rights mechanisms.

125. A fully rights-centred approach cannot only focus on the structural elements required for an enabling environment; it must also prioritize the safety and security of individuals.

Principle 6: Mutual accountability

126. Accountability must apply in all directions: institutions are accountable to communities, and representatives are accountable to their constituencies, through transparent decision-making, published timelines and documented responses, with agreed consequences when indicators are not met.

127. Without mutual accountability, co-leadership becomes performative and rights commitments aspirational.

> *As countries, we have reported to donors like the Global Fund and, but they didn't report to us. When they disappeared, the data disappeared.*
> – Partner

128. The Global AIDS Strategy (2026–2031) calls for government- and community-led monitoring to be formalized for mutual accountability, and multiple PCB decisions have called for dedicated support for community-led monitoring mechanisms and, critically, for the resulting data to truly inform decision-making.

Commit to strengthen investments in integrated country-owned surveillance, information and data collection systems, including community-led monitoring and research by communities, linked to high-quality resource-tracking systems and engaged with multiple sectors and communities, to collect and disseminate data disaggregated and tailored to local contexts and needs.
– UN General Assembly Political Declaration on HIV/AIDS 2026

129. Community-led monitoring draws on the perspectives of people living with, at risk of, and affected by HIV to monitor their own experiences and the services they use, generating data that can be used to improve HIV service delivery and document and address human rights violations.

Community-led monitoring findings and recommendations have to be treated with the same importance and respect as evidence from a clinical trial.
– Community expert, Global

130. Community-led monitoring is often framed as a service delivery tool but it should also be seen as a governance mechanism and a means for measuring whether governments deliver on their promises. When communities generate independent evidence which institutions are required to respond to, participation moves from consultation to accountability.

131. Data and evidence gathered by researchers, governments and donors can often miss essential information. For example, recent research has shown that across Europe and central Asia, countries are largely failing to collect and report data on transgender people's access to HIV prevention and other services.[lxv] Community-led monitoring is well placed to capture this type of data.

132. Other mechanisms are also used by communities to gather data including the People Living with HIV Stigma Index, which is designed and implemented by networks of people living with HIV to hold governments accountable for commitments on stigma and discrimination.

133. Grievance mechanisms provide accessible and confidential channels through which communities can report service failures, human rights violations or other concerns, and seek appropriate responses without fear of retaliation.

134. In many countries (including Jamaica and Zimbabwe) civil society organizations have developed scorecards to assess different elements of the HIV response including implementation of National Strategic Plans, access to treatment, stigma and discrimination, and financing.lxvi lxvii

Using data to change policy: a case study from Malawi

In Malawi, communities track, report and respond in real time to stockouts, discrimination and gaps in the health system. The International Treatment Preparedness Coalition has worked with communities to develop a four-stage approach to community-led monitoring: education, evidence, engagement and advocacy.

Communities are first educated about HIV and standard levels of care. They then gather data to identify trends, problems and what is working well. The engagement phase involves discussing challenges with other stakeholders and developing solutions. In the final stage, they identify relevant decision-makers and work with them to bring about improvements.[lxviii]

The Malawian Government was among the pioneers to commit to embedding community data in its national health system. This has helped the Government ensure that funds are invested where they can have the most impact as well as put communities affected by HIV at the heart of the decision-making process. In one case, data highlighting the challenges experienced by rural people living with HIV prompted a policy change, enabling a six-month antiretroviral supply plan.[lxix]

135. Accountability also requires clear, transparent linkages between community representatives and the constituencies they serve. The Global Fund's Delegations require Board members to communicate regularly with their constituencies, seek their input and report back to them, organizing frequent calls to prepare for and debrief after Board meetings. Brazil's Health Councils take a similar approach at national level. Once selected by their civil society association, a council representative answers back to that same association, ensuring the link between selection and accountability.

136. Unitaid offers an interesting example, where both NGOs and communities living with and affected by HIV, TB and malaria have formal representation on the Executive Board. Unitaid’s governance arrangements explicitly hold community and NGO representatives accountable to the constituencies they represent, requiring them to seek constituency input before taking significant positions or decisions on their behalf. Dedicated funding and constituency focal points support ongoing communication, consultation and reporting between representatives and their constituencies, helping ensure that representatives remain responsive to those they are mandated to represent.[lxx]

137. Accountability also depends on clear feedback loops so that communities and civil society can track whether their input has influenced decisions. A WHO Civil Society Commission study evaluating civil society involvement in drafting key World Health Assembly resolutions cites a commitment to reporting back as essential to building trust and to the success of civil society engagement.[lxxi]

138. There are a few examples of good practice in this area. The Global Fund’s grant-making process does now suggest that communities and key populations should be told which interventions were funded and the rationale for selection or exclusion.

Criminalized and marginalized communities, like sex workers, cannot count on national governments to ensure that they are meaningfully included and adequately resourced in HIV programmes. There needs to be some way to hold governments accountable to respecting key populations' health and human rights in the realm of HIV. It is unclear how this will happen in the future.
– Community expert, Global

139. The report on the UNAIDS transition process warns that "*individual and collective accountability will be essential to how this new model operates*". The plan proposes that Board members, including those representing communities and civil society, should have the authority to escalate concerns where commitments have not been delivered.

140. Although accountability is essential within governance, there are currently very few frameworks to monitor whether communities are effectively participating in governance and decision-making (see the box, below). One exception is the guidelines from Y+ Global for involving young people in the HIV response. They comprise a range of tools, including a checklist for organizations to measure how effectively they are engaging young people in their work.

141. The Global AIDS Monitoring framework includes National Commitments and Policy Instrument indicators that are specifically designed to encourage best practices, in particular community leadership in the HIV response. However, these indicators currently only measure participation, not influence.[lxxii]

Need for a new monitoring framework: measuring who holds power

A framework is needed to assess whether community co-leadership is meaningfully embedded in HIV governance and decision-making. It should monitor progress against the six principles outlined in this report.

- **Institutionalized participation.** Is community participation formally embedded in governance and decision-making structures?
- **Shared power.** Do communities have meaningful influence over priorities, decisions and resource allocation?
- **Resourced engagement.** Are community representatives and organizations provided with adequate, predictable resources and support to participate?
- **Self-determined representation.** Can Communities select their own representatives through transparent, constituency-led processes?
- **Rights-centred governance.** Are the rights, safety and autonomy of communities protected in governance and decision-making?
- **Mutual accountability.** Are institutions accountable for acting on community input, and are representatives accountable to their constituencies?

Threats to community participation in the HIV response

142. As shown in this report, the HIV response has been a strong model for community leadership. However, there are already signs that some of the systems and processes for enabling community representatives to participate in the governance of the HIV response are being eroded. This section of the report provides a warning: if community engagement is not proactively safeguarded there is a risk that it will diminish.

143. A survey conducted by the NGO Delegation in June and July 2026 was sent to community and civil society organizations, as well as some donors and National AIDS Commission representatives. It asked whether participants had already seen signs of civil society and community organizations being affected by the restructuring of UNAIDS".

> *The greatest risk is that the HIV response becomes disconnected from the people it is meant to serve [...] This could lead to reduced funding for community-led initiatives, weaker protection of human rights, increased stigma and discrimination, and less attention to key populations and adolescent girls and young women who continue to face the greatest barriers to accessing services.*
> – Community expert, East Africa

Protect community engagement

144. Community and civil society stakeholders predominantly ranked "community engagement" as the most important UNAIDS core function, describing it as a matter of "survival" and "meaningful influence," and fearing it might be reduced to "tokenistic consultation" if the function sits within a different institution, outside UNAIDS.

> *Communities are not a core function but an enabler. UNAIDS can perform its core functions best when communities lead, shape data or influence policy development or uptake of policy*.
> – Partner

Preserve access to decision making spaces

145. The most consistent concern across participants was the potential to lose the bridging role which UNAIDS plays, providing a space where communities and governments can sit alongside each other.

> *The greatest risk is the loss of a mandated role for communities in the governance of the HIV response. No other UN body requires this, and it is unclear how this function can be meaningfully transitioned to another entity.*
> – Civil society expert, Global

146. For decades, that convening function has allowed even the least resourced and least heard community voices in the room to talk to ministries, donors and other UN

agencies on an equal footing. Respondents describe watching this architecture erode with cancelled meetings and, in some cases, UNAIDS office closures.

147. For communities, already marginalized within health systems, extra distance to the nearest UNAIDS office can be the difference between being heard and being forgotten.

The regional office of UNAIDS from EECA which was strategically located in Bonn has been moved to Bangkok where the communities from EECA cannot reach it, and where they are completely incapable of doing advocacy for the EECA region in matters of policy.
– Community expert, Western Europe

148. If the UNAIDS presence is removed from a country, alternative and ideally even stronger convening mechanisms must be put in place to ensure that communities can continue to shape national policies and programmes.

We have observed reduced capacity and uncertainty around community engagement, technical support, and coordination functions traditionally supported by UNAIDS... In response, community and civil society organizations have sought to strengthen peer networks, increase collaboration, and diversify funding sources. However, these efforts cannot fully replace the unique role of UNAIDS as a neutral convener, technical partner, and advocate for meaningful community participation.
– Community expert, Asia

Advocate for human rights

149. Several respondents outlined their concerns about the potential loss of UNAIDS' human rights expertise on issues such as HIV criminalization, stigma, discrimination, gender and legal and policy barriers. This expertise, and the technical support UNAIDS provides, is particularly important with the rise of anti-rights and anti-gender movements and hostile political environments.

I worry about losing an essential interlocutor that can support, guide, promote and relay the needs of the community and defend the human rights of key populations. I worry community will be left alone with often dismissive or hostile governments.
– Civil society expert, North America

150. Without UNAIDS monitoring human rights abuses and encouraging countries to take a rights-based approach to the HIV response, there is a risk that organizations representing people living with HIV and key populations in particular will be excluded from decision-making and their capacity to protect the rights of their communities will be reduced.

Retain capacity to support communities

151. Staffing and structural cuts inside UNAIDS have already reduced support for community engagement. Respondents reported delayed technical assistance and offices that are no longer reachable.

152. Furthermore, an evaluation of UNAIDS found that "*the closure of the UNAIDS Regional Support Team in the MENA region in 2023 was considered by stakeholders to have had significant strategic, operational, and public health consequences, creating a leadership vacuum in a region already struggling with rising HIV infections and weak surveillance systems*"[lxxiii]

> *Resources that previously flowed through or were linked to UNAIDS-coordinated mechanisms have become less predictable, and there is reduced presence in key meetings and spaces where young sex worker voices were previously represented, even informally.*
>
> – Community expert, East Africa

153. If UNAIDS withdraws its presence from a country, alternative mechanisms are needed to ensure that critical assistance can continue to be provided to communities at national level.

Continue to fund community-led accountability

154. In the past year, many governments prioritized funding for essential services like HIV treatment in the face of dramatic cuts to international aid. However, survey participants from community-led organizations noted that funding to monitor services or advocate for the rights of key populations and people living with HIV was no longer available. Much of this had previously been channelled through funding and programmes that ran through or alongside UNAIDS-coordinated mechanisms.

155. Community-led monitoring is a powerful accountability tool as communities are best placed to know when a policy does not match the reality on the ground. With greater integration of HIV into health systems, communities will have to work harder to monitor the quality of services just as the funding for community-led monitoring becomes harder to secure. National programmes are in danger of losing a critical feedback loop.

> *Colombia has closed the UNAIDS office […] this has resulted in the fragmentation of the HIV movement and a lack of support for civil society organizations working on the HIV response.*
>
> – Community expert, Latin America

Communities forced to adapt

156. Civil society and community respondents who described disruption also described adapting to it. They gave examples of organizations diversifying away from UNAIDS-linked funding, deepening peer and regional networks for solidarity and joint advocacy, strengthening their own community-led monitoring, and building alternative coordination mechanisms directly with governments and other UN agencies.

> *Changes in UNAIDS' structure and resourcing have affected coordination spaces, strategic dialogue, and opportunities for engagement between civil society and key global and regional stakeholders. This has had implications for how community voices are represented and integrated into policy discussions. In response, community and civil society organizations have adapted by strengthening alternative coordination mechanisms, deepening partnerships, and seeking other avenues to maintain engagement in global and regional advocacy spaces. However, these adaptations require additional effort and resources and may not fully compensate for the convening and bridging role that UNAIDS has traditionally played.*
>
> – Community expert, South America

157. Communities have demonstrated this resilience consistently, but they have only limited capacity. Whatever governance architecture succeeds the current model, it must purposefully include a multilateral convening function that ensures that communities can continue to access decision making spaces.

> *Following the restructuring of UNAIDS and the resulting uncertainties, we were compelled to enter an emergency management phase to anticipate the impact on the continuity of the HIV response. In this context, our organization worked alongside national authorities and other partners to develop a contingency plan aimed at safeguarding essential interventions despite growing resource constraints.*
>
> – Community expert, western and central Africa

When the safety net goes: the Caribbean

The Caribbean region provides an illustration of what UNAIDS cutbacks mean at a community level. [8]

In 2025, following funding cuts, UNAIDS reduced its regional presence to a single community engagement officer. The office that had historically convened governments and community-led organizations, provided technical and financial support, and sounded the alarm when things were going wrong, effectively ceased to function.

The consequences of funding cuts and UNAIDS' restructuring have been far- reaching. CRN+, the region's sole network of people living with HIV, lost its funding, weakening the capacity for regional advocacy. Smaller grassroots organizations are disappearing, women-led organizations are struggling to survive, and community-led monitoring activities have ceased in many countries.

At the same time, many small island states in the region have been reclassified as middle- or high-income countries, a label which, as a community leader put it, "does not reflect the real economic and health system constraints these countries face." Reclassification makes those countries ineligible for Global Fund grants.
While community peer navigators may still be funded to deliver services, funding for advocacy on human rights has been cut. Civil society in the region faces political pressure not to highlight inaccuracies in national data or service gaps in the HIV response.

"The situation is very precarious," says a community expert from the region. "It has silenced the community even more and it is hard for community-led organizations to have an impact or even get information."

What the Caribbean's experience shows is that when UNAIDS retreats, communities can lose their place and voice in the governance of their national HIV response.

158. The challenges outlined in this chapter are a warning. If community leadership in the HIV response is to be safeguarded, any changes to the architecture that governs the response must protect the six principles identified in this report. The next section outlines how the principles can be applied to the UNAIDS transition process to ensure that the decisions that communities are meaningfully influencing the decisions that will be made over the coming months.

[8] All the information for this case study was taken from key informant interviews and survey responses from community experts in the Caribbean.

Applying the principles to the UNAIDS transition process

159. Drawing on feedback from stakeholders, the recommendations below set out practical actions for applying the six principles to protect meaningful community engagement throughout the UNAIDS transition process. They are intended to guide implementation of the PCB-approved transition plan, including the design of the new Hub and the work of the Cosponsors, Joint UN Teams and country-level arrangements. They also respond to the Transition Working Group's emphasis on readiness-based sequencing, community co-creation and co-leadership, direct financing of community-led organizations, and mutual accountability. Each recommendation is mapped to one of the report's six principles so that the transition itself is held to the same standard as the structures that follow it.

> *A transition should strengthen the HIV response — not create more barriers for the people it is meant to serve.*
>
> – Community expert, East Africa

Principle 1: Institutionalized participation

160. **Publish a roadmap.** Create a public transition roadmap, listing milestones, decision points, the sequencing of organizational and country-level transitions, and specific opportunities for community input, and regularly update it.

161. **Keep local structures in place.** Maintain community-facing structures without further interruptions, so communities are not left without a UNAIDS point of contact at any point in the transition process.

Principle 2: Shared power

162. **Retain the NGO Delegation**: The PCB NGO Delegation must retain all current powers, seats and functions for the duration of the transition (as articulated in ECOSOC 1995/2), with no lapse in status, until the Board has formally agreed how the function will be preserved or replicated in a successor structure.

163. **Involve communities in the transition design**. Protect formal, self-determined and adequately resourced community representation, including diverse constituencies and gender balance, on transition planning bodies, including the Transition Task Team, and maintain these arrangements until the new structure is operational. Ensure community representatives are involved from the outset in shaping the designated community-held roles within the Hub, including their decision rights and access to resources for expert work. Ensure community-led representatives also have designated roles in Joint UN Teams and relevant regional and country coordination arrangements.

Principle 3: Resourced engagement

164. **Dedicate funds.** Establish a ring-fenced and predictable budget for community participation throughout the transition, covering interpretation, travel, connectivity and staff time, as well as proportionate administrative, due-diligence and technical support arrangements suited to community-led organizations. Funds should be made available in advance of consultations and decision-making processes.

165. **Protect data collection.** Secure dedicated, flexible, and sustained funding for Community-led Monitoring, community-led monitoring generated evidence and accountability throughout the transition, and ensure that this evidence informs country planning, transition decisions and the Joint Programme's accountability processes.

Principle 4: Self-determined representation

166. **Ensure autonomy**. Allow communities to select their own representatives to join transition working groups and design bodies.

167. **Consult communities**. Create an inclusive and accessible transition consultation process, facilitated by current NGO Delegation members in partnership with community representatives, with adequate notice for each consultation window and intentional outreach to historically marginalized groups, including young key populations and disabled people. Consultations should inform relevant transition and country-planning decisions, with documented responses explaining how community input has been considered.

Principle 5: Rights-centred governance

168. **Prioritize human rights advocacy**. Ensure political and financial support for advocacy to push back on criminalization, stigma and discrimination, and gender inequalities during the transition.

169. **Protect community representatives**. Establish safety protocols for community participation in governance, community-led monitoring and grievance mechanisms, including secure communication channels and options for representatives from criminalized and marginalized populations to engage without public disclosure.

Principle 6: Mutual accountability

170. **Ensure communication**. Establish a resourced, multidirectional communication channel between UNAIDS, the Hub, Cosponsors and communities for the duration of the transition, with a committed response time for queries.

171. **Monitor the transition**. Establish a resourced accountability mechanism, agreed before the transition is finalized, with defined review points and agreed indicators to assess whether commitments on community participation, co-creation, co-leadership and resourcing are being met, including agreed corrective action where they are not met. This should include regular reporting to the PCB, through the Joint Programme's performance and financial reporting, on resources allocated to community-led organisations and initiatives, including through the pooled funding mechanism, and on progress against community-engagement indicators.

Recommendations

Institutionalized participation

172. **Ensure structural representation**. Community and civil society co-leadership must be formally institutionalized and written into the founding legal documents of health and HIV structures, not secured through policy commitment or convention alone.

173. **Embed participation at all levels.** Governance mechanisms must guarantee community and civil society participation in agenda-setting, decisions-making, implementation and accountability at all levels from local to global health governance structures.

174. **Formalize engagement with all stakeholders.** Establish formal mechanisms for community and civil society engagement with all stakeholders involved in any HIV governance structures and include designated focal points, scheduled consultations and opportunities to contribute to policy processes.

2. Shared power

175. **Close the leadership gap.** All HIV and health governance structures at global and national levels must be based on a model of co-leadership including formal, resourced community and civil society seats with influence over agenda-setting and decision-making processes.

176. **Extend culture of co-leadership across the UN system.** Cosponsors, Joint UN Teams and anybody that coordinates HIV action across UN agencies and Member States must institutionalize and resource community and civil society leadership, extending the Joint Programme's culture of community leadership into those spaces.

3. Resourced engagement

177. **Fund and support participation**. Dedicated funds must be allocated for communities and civil society to participate in governance structures, covering travel, interpretation, preparation time and institutional and technical capacity, and disbursed ahead of major governance decisions, supported by administrative arrangements that fit the realities of community-led organizations.

178. **Adapt funding mechanisms**. Long-term, flexible core funding should be provided directly to community-led and civil society organizations, covering staff development and leadership infrastructure, including advocacy, governance participation and community-led monitoring, and allocated by community determined needs and priorities rather than income classification or donor priorities.

4. Self-determined representation

179. **Safeguard community-led selection.** All governance structures should adopt a self-selection model in which community-led and civil society organizations can nominate and replace their own delegates, and the wider governance body formally confirms, rather than selects, nominees.

180. **Guarantee inclusivity**. Governance structures must go beyond a single generic community seat and include dedicated, resourced seats for diverse groups that are often excluded even from community delegations, with accessibility built in at every stage.

5. Rights-centred governance

181. **Preserve the human rights mandate.** HIV and health governance structures at global and national levels must have an explicit, funded mandate for promoting rights and gender equality.

182. **Put safety first.** Governance structures must have built-in safeguards to ensure that community representatives are protected from all forms of violence and sexual harassment. They must also guarantee safe participation for representatives from criminalized and marginalized populations, including protection from stigma, reprisal or exposure, through protocols that are agreed and in place before the structure is operational, not introduced after an incident.

6. Mutual accountability

183. **Build an accountability mechanism with teeth**. Establish a resourced accountability mechanism for community and civil society engagement that tracks representation (including by gender, key population and age), resourcing, influence over decisions, responsiveness and constituency accountability, with pre-agreed indicators and named consequences if they are not met.

184. **Prioritize strategic information and data systems**. Protect and expand systems, including community-led systems, that collect and validate HIV data, particularly data that are disaggregated by gender, key population and age, as these are essential for accountability (with safeguards and consent over data on key populations).

185. **Make community-led monitoring a standing input**. Community-led monitoring must remain independent, be sustainably financed, formally institutionalized, and embedded in national planning and reporting cycles, with governments expected to respond to findings publicly and act on recommendations.

Conclusion

186. Over the last four decades, communities have built the HIV response—not as beneficiaries, but as architects of its most significant gains. Their leadership is the reason HIV acquisitions have decreased, treatment has expanded, and rights have advanced.

187. Yet the current convergence of funding cuts, shrinking civic space, the rise of anti-rights and anti-gender actors, and the restructuring of UNAIDS is weakening the mechanisms that previously enabled their leadership.

188. We are at a crossroads.

189. Countries and the Joint Programme can allow community leadership to be quietly lost in the redesign of global health architecture, function by function and office by office. Or they can use this moment to reinforce, rather than erode, the unique role of communities within the leadership of the HIV response—a defining feature of the HIV movement and a key source of its success.

190. They could create a more durable arrangement that embeds community leadership at every level: governance that is built on the institutionalized participation, shared power, resourced engagement, self-determined representation, rights-centred governance and mutual accountability.

191. The Board has an opportunity and a responsibility to ensure that, as the architecture of the HIV response changes, the communities who built it are in the room shaping the decisions that will affect their future.

192. This report with its recommendations and the decision points below outlines the concrete actions that are required.

Proposed decision points

The Programme Coordinating Board is invited to:

193. *Take note* of the report by the NGO Representative, including the six principles described therein, designed to ensure that community leadership, co-creation and co-leadership are safeguarded and strengthened within the governance of the HIV movement;

194. *Recall* the Global AIDS Strategy 2026–2031, Results Area 8 (Priority 3: Community Leadership), and the decisions relating to the meaningful engagement of communities and civil society in the response of the 56th and 57th meetings and the 2026 Special Session of the Programme Coordinating Board, especially decision points 4.2 and 4.5 of the 57th PCB, and 3.4 of the 2026 Special Session;

195. Recalling decision 3.1 at Special Session on the approval of the overall strategic direction for the transition of UNAIDS set out in the final report of the PCB Working Group on the further transition and integration of UNAIDS into the UN System and beyond and looking forward to the implementation plan of the Transition Task Team, *request* Member States to:

    a. continue to ensure that country-level HIV governance, coordination and transition arrangements institutionalize meaningful community and civil society participation and co-leadership in agenda-setting, policy and priority-setting, implementation and accountability;

    b. ensure and sustain the involvement of communities and civil society in country-level capacity and readiness assessments and in shaping the timing and arrangements for the transfer of functions, in line with national contexts and the principles of community leadership set out in the Global AIDS Strategy 2026–2031;

    c. ensure that the further transition and integration of UNAIDS into the UN system and beyond maintains meaningful involvement of communities and civil society in decision-making and governance, and ensures continuity of community-facing support and engagement currently delivered by the UNAIDS Hub, building on the lessons of existing mechanisms for civil society participation;

196. *Further request* Member States to:

    a. support civil society organizations in the implementation process of the six principles including the scaling up action to address structural, legal, policy and regulatory barriers that restrict civic space or limit the meaningful participation of community-led organizations in accountability and governance, and ensure that country-level transition arrangements are supported by enabling legal and policy environments that protect human rights and gender equality and support community leadership, in line with the Global AIDS Strategy 2026–2031;

b. recall decision 4.4(a) of the 57th PCB, ensuring “predictable, sustainable, and direct financing for community led organizations engaged in the HIV response, including through institutionalized social contracting, dedicated domestic budget lines and funding mechanisms, including within UNAIDS”, that further support the implementation of the six principles and community leadership, advocacy, community-led monitoring and accountability;

c. based on the UNAIDS guiding principles, support civil society organizations in the implementation of the six principles by developing context-appropriate safety protocols for community participation in governance, community-led monitoring and grievance mechanisms;

197. *Request* the Joint Programme, through the work of the Transition Task Team and beyond, and in support the implementation of the six principles, to:

a. plan for the additional administrative requirements that accommodate the operational needs of civil society and community-led organisations, taking into account proportionate institutional due diligence, for travel, interpretation, connectivity and technical support, to facilitate their meaningful participation in governance and decision-making, further to the outcome of the work of the Task Team regarding co-creation;

b. ensure designated community-led representation and engagement in regional and country-level Joint UN Teams and other relevant coordination arrangements; and provide sustained resources for community-led engagement, monitoring and accountability mechanisms;

c. include regular reporting on resources invested in community-led HIV responses in financial, performance and accountability frameworks, building on PCB decision 6.12 from the 56th PCB and the indicator to be included in the 2027 Work Plan and Budget, and provide the Board with updates on the methodology used to track these resources;

d. ensure that, in the context of the transition consultation, the NGO delegation and wider Civil Society Organizations are involved in respective consultation modalities at different levels, in partnership with community representatives, people living with, affected by and vulnerable to HIV, key populations and other priority populations [9], and ensure that consultation outcomes inform transition decisions;

[Annexes follow]

[9] As defined in the GAS 2026-2031.

Annex 1

Global AIDS Strategy for 2026–2031 Results Area 8 (Priority 3: Community Leadership)

Actions required for community leadership in the HIV response include:

- Institutionalize and formally designate community representation (including of people living with HIV, key populations, women and young people) in coordination and decision-making mechanisms at all levels of the response, including HIV financing mechanisms.
- Formally recognize and institutionalize the important roles of communities in co-developing policy guidance, targets and accountability frameworks at all levels in HIV responses.
- Reform laws, policies and regulations that limit the ability of community-led organizations to participate in all aspects of HIV responses, particularly advocacy, engagement in decision-making, and service delivery, including testing, treatment and prevention services. That includes support to safeguard civic space and track the status of civic space and community participation in HIV planning and decision-making at national, regional and global levels.
- Adequately resource all components of community responses, from advocacy to engagement in decision-making and accountability, service delivery and community-led monitoring and research.
- Enact effective social contracting mechanisms that enable predictable, long-term and flexible financing of community-led responses through domestic resources and that ensure those mechanisms are accessible to community-led entities such as youth-led organizations, women’s networks and key population organizations.
- Sustain and scale up existing community-led service delivery systems, including innovations such as digital services and campaigns, key population- or youth-friendly drop-in centres, by establishing minimum domestic allocation thresholds to ensure consistent and equitable funding for these approaches.
- Enable and resource community-led monitoring and research and provide for their systematic inclusion in planning and decision-making processes, using data for programming and accountability. Community-led research should assess both the effectiveness and cost-efficiency of HIV interventions to strengthen programme sustainability.
- Support youth leadership in the HIV response by increasing predictable and flexible youth-responsive funding, ensuring meaningful youth engagement in decision-making, and supporting intergenerational and peer collaboration and mentorship models that intentionally build successive generations of leaders.
- Support the capacity strengthening, resilience and preparedness of community-led organizations, particularly those which represent and serve underrepresented and under-served populations. That includes addressing human rights-, age- and gender-related barriers, and providing for legal literacy, resource mobilization and political engagement.

- Support community engagement in the sustainability planning processes, and support the integration of community services and advocacy as part of national systems, including the establishment or expansion of social contracting.

Annex 2

Political Declaration on HIV/AIDS: United to End AIDS by 2030 – 19 June 2026

Excerpt on community leadership

91. In line with the Greater Involvement of People Living with HIV/AIDS principle and recognizing their essential contributions to the progress and sustainability of the HIV response, commit to ensure that communities of people living with, at risk of or affected by HIV, together with the contributions of civil society organizations, are empowered and fully funded to continue to lead the HIV response by shaping policies, delivering services, providing quality assurance and driving accountability for commitments;

92. Commit to engage with people living with, at risk of or affected by HIV, women, young people and adolescents, and Indigenous peoples in coordination and decision-making mechanisms at all levels of the response, including HIV financing mechanisms;

93. Commit to create an enabling environment by reviewing and reforming, as needed, laws, policies and regulations that limit the ability of civil society organizations, including community-led organizations, to participate in all aspects of HIV responses, particularly advocacy, engagement in decision-making, and service delivery, including testing, treatment and prevention services, and support community participation in HIV planning and decision-making at the national, regional and global levels;

94. Commit to strengthen community leadership and renew efforts to reach the 30–80–60 targets by 2030, so that:

(a) 30 per cent of HIV testing and supportive services related to care and treatment is delivered by organizations led by people living with, at risk of or affected by HIV;

(b) 80 per cent of people-centred HIV prevention programmes for key populations is delivered by organizations led by people living with, at risk of or affected by HIV;

(c) 60 per cent of programmes that support achievement of the societal enablers are delivered by organizations led by people living with, at risk of or affected by HIV;

95. Commit to enact effective social contracting mechanisms that enable predictable, long-term and flexible financing of community-led responses;

96. Reaffirm support for youth leadership in the HIV response by increasing predictable and flexible youth-responsive funding for advocacy and youth-led initiatives and programmes, ensuring meaningful youth engagement in decision - making, and supporting intergenerational and peer collaboration and mentorship models that intentionally build successive generations of leaders.

Annex 3

Stakeholders who contributed to this report through surveys and interviews, and who were willing to share their names and organizations.

Name	Surname	Organization
Jeff	Acaba	APCASO
Aniedi	Akpan	Drug Free and Preventive Healthcare Organization
Dulce	Almonte	Redovih
Aivan	Alvarez	Wagayway Equality
Bella	Aubree	Inti Muda Indonesia
Anurita	Bains	UNICEF
Solange	Baptiste	ITPC
Gould	Baratedi	Goulden Foundation
Emily	Bass	HEAR CSO
Danne	Belmont	Fundacion GAAT
Fabian	Betancourt	Parche Dulcero
Amanita	Calderón-Cifuentes	TGEU
Soubhagya	Chakrabarty	India HIV/AIDS Alliance
Gastón	Devisich	Fundación Huésped
John	Eliasu Mahama	Ghana AIDS Commission
Tan	Fok Jun	Youth LEAD
Nekesa	Gloria	Mbale Network of Young people living with HIV/AIDS-MNYPA
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Julia	Martin	The Global Fund
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Sue	Purchase	Harm Reduction Sisters
Valeriia	Rachynska	100% LIFE
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Annex 4

Methodology

This report draws on a variety of sources to explore the themes relevant to safeguarding community leadership during the transition of the global HIV response and beyond.

- Desk research. A literature review was conducted of documents, including reports, journal articles, thematic websites, press releases, statements and other resources prepared by UN, academic and civil society bodies.
- Community and civil society survey. An online survey gathered input from community-led and civil society organizations from across the world. This included current and past members of the PCB NGO delegation. The survey was conducted in English, French, Spanish and Russian. There were 46 respondents.
- Community and civil society interviews. Key informant interviews were held with six people to gather more detailed information on certain topics.
- Partner consultation. Key partners such as representatives of National AIDS Councils, UN Cosponsors and bilateral and multilateral donors were offered an option to provide feedback either through an online survey or key informant interview, both designed specifically for partners. Seven partner organizations responded.

  Peer review process. A workshop was held with members of the NGO Delegation to share evidence gathered from the surveys and get feedback on the principles and key themes proposed for the draft report. Drafts of the report were reviewed by members of the NGO Delegation and governance and technical experts from the UNAIDS Secretariat. A second workshop took place with the Working Group and the members of the UNAIDS governance team to finesse the draft recommendations and proposed decision points.

Limitations

- The report was not intended to produce quantitative data or statistical analysis. While written documents in the bibliography provide both quantitative and qualitative information, the research methods used in preparing the report were largely qualitative. As such, the report is limited to drawing on the literature and on community and other experts to seek understanding and recommendations for ensuring community leadership within governance of HIV response during and beyond the transition.
- A challenge for this report was that the data collection phase (June to July 2026) coincided with an extremely busy period for all stakeholders in the global HIV response, particularly community and civil society advocates. There were very important advocacy opportunities they had to prepare for, participate in and follow up on. This included the High-Level Meeting on AIDS, UNAIDS PCB meeting, Global Fund Board meeting and the International AIDS Conference.

Annex 5

Principles of meaningful involvement of communities and civil society in global health governance

For Global Health Institutions and their key stakeholders

Principle 1

Communities and civil society are represented in decision-making structures with a permanent role and equal voting.

1.1 Permanent representation (and recognition of the diversity) of both civil society organizations and affected communities;

1.2 Permanent seats in decision-making processes and structures;

1.3 Voting powers;

1.4 Representation within all decision-making committees (e.g. audit, finance, risk and strategy) and working groups.

Principle 2

Governance support is provided for governance roles and to facilitate broader civil society and community engagement.

2.1 Establish a governance support mechanism based within the governing body;

2.2 Establish civil society and community engagement mechanism(s) / constituency(ies) around the civil society and community Board Members.

Principle 3

Funding is provided for governance roles and to facilitate broader civil society and community engagement.

3.1 Recognizing and addressing the resource gap for communities and civil society in low- and middle-income countries;

3.2 Ensure an annual budget for each constituency.

Principle 4

Civil society and communities design and lead their own open selection processes for Board members and constituency that reflects the diversity, knowledge and experience of their constituencies and the work of the institution.

4.1 The selection process should reflect the diversity, knowledge and experience of their constituencies and the work of the institution;

4.2 Identify appropriate organizations to run selection processes and support interim Board Members in newly established institutions.

Principle for community and civil society constituencies

Principle 1

Civil society and community representatives are transparent and accountable, seeking to understand and represent the perspectives and priorities of their constituencies.

See: https://governance-principles.org/

Annex 6

Excerpts from Y+ Global, “We Matter, Value Us” — A guideline for organizations on the meaningful and ethical engagement of young people living with HIV in the HIV response. The foundations of meaningful and ethical engagement:

1. Keeping young people safe,
2. Valuing the contribution of young people,
3. Ensuring diverse representation of young people,
4. Providing support,
5. Building positive youth partnerships,
6. Investing in young people and the sustainability of youth-led organizations,
7. Promoting greater accountability to young people.

Principles for engagement. Participation is a right and must be:

- Transparent and informative: young people are informed about the process and its purpose.
- Voluntary: young people understand that it is their choice to participate, and they are free to stop or withdraw at any point. Voluntary does not mean unpaid.
- Respectful: young people are listened to and their contributions are valued.
- Relevant: the content is important to the lives of young people.
- Inclusive: the process respects diversity and seeks different ways to engage and gather views from a wide range of young people.
- Supported by training: organizations are trained to work with young people, and young people are offered support and training as part of the process.
- Accountable: the views of young people are taken seriously and can impact on decisions. Young people receive feedback of outcomes, decisions, and next steps.
- Safe and sensitive to risk: the process takes account of any risk to young people by assessing processes and ensuring spaces are safe, confidential and offer support to young people.

https://www.yplusglobal.org/resources/14.02.2022.A4-Guide-English-web-ready.pdf

Annex 7

Committee on the Elimination of Discrimination against Women

General recommendation No. 40 (2024) on the equal and inclusive representation of women in decision-making systems

Seven pillars of equal and inclusive representation of women in decision-making systems:

A. Fifty-fifty parity between women and men in decision-making systems as a starting point and universal norm;

B. Effective youth leadership conditioned by parity;

C. Intersectionality and the inclusion of women in all their diversity in decision-making systems;

D. A comprehensive approach to decision-making systems across spheres;

E. Equal power and influence exercized by women in decision-making systems;

F. Structural transformation for the equal and inclusive representation of women in decision-making systems;

G. Civil society representation in decision-making systems.

https://docs.un.org/en/CEDAW/C/GC/40

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