

No More Broken Promises: Challenges and Opportunities for Key Populations in Demanding More Transparency, Accountability, and Participation in the Global Response Against the HIV and AIDS Epidemic

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Abstract

The global fight against HIV/AIDS continues to pose challenges: infection rates are on the rise in many settings, stigma and discrimination remain rampant, and the global response is under increasing financial pressure. There is a high risk of losing what has been achieved so far in the fight against HIV and AIDS, but also the momentum to meet the so-called Fast Track targets for 2030. In light of these trends, it is fundamental to focus on the human rights of key populations (KPs)—especially to health, non-discrimination, access to information, and to equal and meaningful participation in political and public affairs—by placing them at the center of the global HIV response. Such rights, and the demand for more transparency, accountability, and participation (TAP), have been recognized as both a necessary social justice imperative, and as a way to build more responsive, inclusive, and sustainable health systems. This article will argue that embracing TAP as key guiding principles of the global HIV response (especially in low- and middle-income countries) could have the potential to create the conditions for KPs to have their human rights fulfilled, and to expand their participation in the decision-making processes that guide the efforts against the epidemic. It will then propose a number of avenues for further engagement between different communities of practice in terms of research, agendas, and policy and practices that could be beneficial in maximizing the impact of the global efforts to end HIV/AIDS.

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Introduction

During the last United Nations (UN) General Assembly High Level Meeting on Ending AIDS in 2016, then-UN Secretary General Ban Ki-moon presented a report requesting that the international community strengthen its support for human rights-based interventions as fundamental components of the fight against the HIV/AIDS epidemic.¹ He highlighted the importance of promoting gender equality and empowering the people most affected by the disease, that is, key populations (KPs).² In this article, the term ‘key populations’ refers to individuals and groups (organized or not as a civil society organizations) of: men having sex with men (MSM), transgender persons (TG), people who use drugs (PWUD), and sex workers and their clients.

According to the World Health Organization (WHO), KPs are extremely socially vulnerable individuals and communities, which often experience an increased impact from HIV/AIDS due to their limited access to public health services and their lack of voice in public affairs.³ Additionally, because of social barriers, stigmatizing policies, and punitive laws that keep KPs away from services—different forms of violence, discrimination, criminalization, and marginalization—they are most likely to be exposed to HIV and to remain excluded from participating in, and benefiting from, the policies that should address their needs.⁴ Along these lines, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), underscore that beyond overcoming stigma and discrimination against KPs, their engagement and participation is critical to a successful HIV response everywhere, since they are both key to the epidemic and key players in the response.⁵

For decades, the international community—pursuant to international declarations and resolutions, such as the Declaration of Alma-Ata, the Paris AIDS Summit Declaration of 1994, various UN resolutions on human rights, the Declaration of Commitment on HIV/AIDS of 2001, and the Political Declarations on HIV and AIDS of 2006, 2011, and 2016—has reaffirmed the need to include the people that are themselves affected in the processes

that lead to the design and implementation of the policies and strategies aimed to improve health outcomes and address HIV.⁶ Such recognition is commonly known as the GIPA Principle, which is an acronym for ‘Greater Involvement of People Living with HIV/AIDS.’ Moreover, the recently approved Sustainable Development Goals (SDGs) include the achievement of “responsive, inclusive, participatory and representative decision-making at all levels” as a means to promote good governance and achieving sustainable development in a transparent, accountable, and inclusive manner.⁷

International organizations and donors, such as the UN, GFATM, and WHO, among others, are working to fulfill such commitments by creating and promoting spaces for KPs to participate both at the international and national levels. In many contexts, civil society organizations and key populations have been critical actors in calling for health programs, access to treatment, investments, political leadership, and human rights protection for addressing the HIV epidemic. These contributions have allowed the global fight against HIV to achieve major victories in the last decade: the global coverage of antiretroviral (ARV) therapy expanding, and the number of people who die from AIDS steadily decreasing.⁸

However, global efforts against HIV have now reached a historical juncture: HIV infection rates are on the rise in many parts of the world, while mounting challenges could further compromise the fight against the epidemic.⁹ If these remain unaddressed, there is a risk of losing what has been achieved in the last decade and failing to meet the so-called Fast Track targets to end AIDS by 2030.

On the one hand, the effectiveness and legitimacy of the HIV response is weakening as KPs have no real ownership and their human rights continue to be violated, posing a long-term sustainability threat to the response.¹⁰ Even when KPs now have more spaces for participation, for example via the Global Fund’s processes, this has not translated into any substantial change or more prioritization of KP’s needs in the HIV response.¹¹ On the other hand, the long-term sustainability of the HIV response is at stake. First, because available financial resources needed to cope with the HIV epidemic

are either dwindling or not being allocated efficiently to reach KPs.¹² And second, because a big part of the resources are getting lost to corruption, mismanagement, and/or poor service delivery.¹³ This means that by failing to respond and support those who need it the most, the international community will not see the end of the epidemic.

To counter these problems, civil society organizations, advocates, activists, and KPs' organizations have been advocating worldwide for more transparency, accountability, and participation (TAP) not only in the health and HIV sectors, but more generally in political decision-making processes, as those impact KPs' daily lives. Advocating for human rights to access health care, to be informed, and to participate meaningfully in public decision-making, has proven to be both a necessary social justice imperative and a way to build more responsive health systems.¹⁴ Empowering KPs to have a say in how public resources are allocated and to monitor service delivery will help ensure the long-term effectiveness and sustainability of the response to the epidemic.

This paper will first describe the most important challenges that are affecting the effectiveness and sustainability of the global response against HIV/AIDS. Second, it will explain why we need to advance human rights-based TAP programming, and why they need to strengthen social movements of KPs, based on the lessons learned from communities' participation in health policymaking and implementation. Lastly, it will introduce how cross-cutting TAP-based alternatives may lead to a more resilient, inclusive, and effective response against the HIV epidemic.

The global HIV response at risk: issues around sustainability and effectiveness

In the past three decades, the global HIV response has achieved major milestones, such as the reduction in the number of people who die yearly from AIDS and the expansion of the global coverage of ARV therapy.¹⁵ Many of these successes have been made possible thanks to the engagement and mobilization of KPs and communities affected by HIV.

Despite these successes, there has been no decline in new HIV infections among adults since 2010, and over 2.1 million people were newly infected with HIV worldwide in 2015.¹⁶ Social and structural factors—including poverty, gender inequality, violence, stigma, and discrimination—are key drivers of the HIV epidemic that continue to undermine the effectiveness of proven HIV interventions.¹⁷ This has led to a renewed call to intensify global HIV efforts within the UNAIDS “Fast-Track Strategy” that aims to end the epidemic by 2030 and ensure gains are sustained. It is therefore necessary to increase investments aimed at sustaining HIV prevention and treatment activities to stop the spread of the epidemic, as well as to establish responsive and inclusive monitoring mechanisms for accountability at all levels.

Financial constraints

In recent years, international funding for the HIV response has experienced significant constraints as development agendas change in response to changing donor priorities. As countries shift from lower- to middle-income countries, these donor recipient countries are being urged to increase their domestic investments to finance broader health services, including HIV.¹⁸ However, available data both at the international and national levels show evidence that resources are not only becoming scarce, but they are often allocated inadequately by not addressing KPs' needs and grievances.¹⁹ Furthermore, even if domestic investments made by national governments increase, such resources are difficult to track and monitor due to inefficient, opaque, and non-accountable governance structures and processes that are highly susceptible to corruption.²⁰ The impact of such losses is so big that it is impossible to determine with precision the overall costs of corruption in the health sector worldwide, but some estimates point out that around 10–25% of the annual global health expenditure (about US\$7.2 trillion in 2010) is lost due to corruption and mismanagement.²¹

On the other hand, there has been an increase in the proportion of global HIV/AIDS investment coming from within affected countries. Domestic

spending by low- and middle-income countries now comprises the majority of all HIV expenditure.²² For example, African countries have increased their domestic resources to respond to HIV by 150% in the last four years.²³

This transition from international to local financing to sustain the HIV response is also likely to shift power from international donors to local actors and authorities. As such, with less foreign assistance, national governments will become less accountable to international donors, redirecting demands for accountability towards beneficiaries in their home countries. Conversely, there is mounting fear on the future of HIV programs for KPs in the near future. If international resources from bilateral and multilateral donors, crucial to supporting the HIV response worldwide, are already becoming scarce, those allocated for KPs and human rights interventions—for which available resources are already limited—will be most affected as a result of more countries transition to domestic financing.²⁴

Failing to reach KPs and the limited protection of their human rights. Globally, there is clear evidence of the violation of KPs' human rights.²⁵ The lack of protection directly increases their vulnerability to HIV, fueling stigma, discrimination, and violence.²⁶ Harmful beliefs, gender norms, and practices are rooted in a lack of understanding and correct information about the disease and how it is transmitted. Also, HIV is incorrectly associated with behaviors that are perceived as immoral and even criminal (such as sex work, homosexuality, and drug use).²⁷

For some people, an HIV-positive diagnosis could mean a progressive loss of civic, political, social, economic, and cultural rights. In extreme cases, this results in social exclusion and marginalization of KPs and people living with HIV that could lead to mental health illnesses, loss of self-esteem, and diminished chances of employment, housing, and education. Moreover, HIV-related taboos, stigma, and discrimination from politicians, public servants, and health professionals discourage or directly obstruct individuals living with HIV from accessing

and making use of health and social services.²⁸

In addition, further legal restrictions directly affect KPs' human rights. For example, laws limiting persons living with HIV from their rights to freedom of association and access to information (due to sexual orientation or gender identity, for example) mean that KPs may be barred from getting proper health information or even from discussing issues related to HIV in public. Thus, without such rights, participating in HIV/AIDS-related policy-making and in politics becomes very difficult, and forming support or advocacy groups can lead to penalties or prosecution.

The combined results: Uncertainty, unsustainability and ineffectiveness of current HIV strategies.

Evidence demonstrates that the harm caused by stigma and discrimination—themselves paramount to social justice and human rights issues—worsens the advance of the epidemic and the financial sustainability of the response.²⁹ Such forms of structural violence make it difficult for lifesaving care to reach those KPs most at risk with prevention and treatment. And because the epidemic is highly concentrated among these vulnerable groups, not supporting them puts the whole HIV response at risk.³⁰

Data collected and published by UNAIDS shows that of the total population believed to be living with HIV (around 37 million individuals worldwide), 54% still do not know their status.³¹ These undiagnosed cases not only jeopardize the lives of those individuals because they are not receiving proper care and support for HIV (and other opportunistic diseases like tuberculosis or salmonella), but also increase the chances of passing on the disease to others.

Moreover, the increasing financial constraints that affect the response, limits the funding needed to sustain HIV prevention and treatment programs, resulting in a negative impact over the whole response to HIV and AIDS.³² This would have a greater impact over community responses and programming for and led by KPs.³³ UNAIDS predicts that failing to secure such funding would mean at least new 17.6 million HIV infections and 10.8 million AIDS-relat-

ed deaths globally until 2030.³⁴

According to the International Council of Human Rights (2009) and the Office of the United Nations High Commissioner for Human Rights (2013), corruption disproportionately impacts people that belong to groups that are exposed to social marginalization by reinforcing the exclusion and the discrimination to which they are already exposed.³⁵ Corruption, broadly defined as the “the misuse of entrusted power for private gain,” is not only one of the biggest barriers for sustainable development, but can also reinforce marginalization and discrimination.³⁶ A few examples: if corrupted public officials deviate resources meant for the construction of a public hospital, all potential beneficiaries are affected, but this is most harmful for those groups that already have restricted access to existing hospitals; if HIV policies are formulated by corrupted lawmakers in the interests of a particular group (such as religious lobby groups), these can be framed ignoring the needs of certain communities (such as LGBT persons or sex workers).

Thus, it is critical that those most profoundly affected by the epidemic are given a voice and access to the necessary public information to participate, but also to demand from government the creation of an enabling environment (that is, legal, political, and socioeconomic conditions) that allows and facilitates community monitoring.³⁷

Transparency, accountability, and participation principles as drivers of change in the health sector

After analyzing the increasing problems and contextual factors that are affecting the governance of the global response against the HIV epidemic, it is clear that addressing the several barriers that impede KPs from seeing their human rights realized is of high importance. However, without addressing the lack of transparency, accountability, and participation (TAP) in the health sector, and the harm caused by corruption, the international community will not succeed in achieving the structural changes required to ensure the long-term sustainability and respon-

siveness of the HIV interventions.³⁸ This section will first frame a working definition of TAP, followed by an analysis of the way in which initiatives based on such principles have been applied in practice, and what has influenced their success or not.

TAP in theory: What these principles mean in relation to the human right to health

TAP refers to the combination of transparency, accountability, and participation, three concepts that are different, yet interconnected and interdependent. Transparency usually refers to the level or extent in which the key elements of decision-making by governments and other entities (such as objectives of policy, decisions taken and their rationale, data and information, among others) are provided to the public in a comprehensible, accessible, and timely manner.³⁹ Accountability can be broadly defined as the obligation governments have to demonstrate and take responsibility in front of their constituents, for their performance in light of assigned responsibilities, commitments, and expected outcomes. Hence, accountability includes achieving objectives in relation to their mandates, and the fair and accurate reporting on the administration and management of public budgets in line with laws, rules, and standards.⁴⁰ And finally, participation is defined in relation to three civic rights: the right of every citizen to take part in the conduct of public affairs, the right to vote and to be elected, and the right to have access to public services.⁴¹

Although there are no single definitions of these terms, there is an emerging development consensus acknowledging that transparency, accountability, and participation are principles that have intrinsic ethical and instrumental value: based on human rights principles and norms, and as means to improve state responsiveness and ‘good governance’ more broadly.⁴² The international community, thanks to the efforts of actors such as the United Nations Development Programme (UNDP), the World Bank, and civil society organizations like Transparency International, has recognized that access to information and citizens’ engagement in public decision-making are crucial

components to achieve sustainable development.⁴³ States are believed to be more capable of meeting the needs of their citizens when their processes are guided by principles of TAP, being able to find more efficient and legitimate solutions to failures in service delivery and fight corruption.⁴⁴

Along these lines, TAP can therefore be defined as principles based on human rights: the right to publicly available information about the actions of those in government (transparency, or the right to information); the right to demand compliance and answerability from state actors, and to hold them responsible for their decisions and actions (accountability as a human right principle); and the right to raise one's voice and see one's interests reflected in political decision-making and public policies. TAP also includes rights around service delivery: the right to participation in public affairs, voting rights, and the right of equal access to public service.⁴⁵ In 2015, world leaders adopted the 2030 Agenda, endorsing the new Sustainable Development Goals (SDGs). Notably, Goal 16 refers to governance and the commitment to "build effective, accountable and inclusive institutions at all levels," with experts calling for a "data revolution," capturing a conviction that better, more readily available data will help accelerate development outcomes.⁴⁶ TAP principles can appear very broad, but if they are framed or contextualized in relation to a particular societal or developmental goal, they become more tangible. For example, using a TAP-based approach in relation to the human right to health could mean ensuring that national health strategies and plans of action would not only lead to the opening of health data to the public, but also to getting citizens' inputs in setting priorities, making decisions, and planning, implementing, and evaluating strategies to achieve better health care.⁴⁷

TAP in practice: different approaches, evidence, and lessons learned

In practice, TAP has been interpreted and applied in two main different ways, depending on whether they are initiated by states or by civil society. Governments, apart from holding elections, usually translate TAP into policies aimed to prevent, deter,

and punish corruption, as corrective means to promote accountability and justice.⁴⁸ However, the UN Human Rights Council assures that, while reactive punitive approaches are necessary to fight corruption and mismanagement, they fail to bring justice for those affected by the results of corruption.⁴⁹ Another way of looking at this government-led type of TAP initiatives is by assessing participation. For example, international donors such as the World Bank and the International Monetary Fund provide loans to indebted countries on different conditions, one of which is the extent to which local civil society organizations have participated in the creation of their respective national strategies to combat poverty (Poverty Reduction Strategy Papers or PRSP).⁵⁰

In the context of the HIV response, civil society organizations have led demands for transparency, accountability, and participation by challenging traditional top-down and over-medicalized approaches to health. Yet TAP principles in the context of HIV have been interpreted in the latter sense by focusing on the participation aspects. In their efforts to increase a sense of ownership, international organizations and donors such as the UN, the Global Fund, and WHO, among others, have been creating and promoting different spaces for KPs representatives to participate in policy debates and discussions (such as participation of civil society delegations in their meetings, consultations by UN bodies and human rights mechanisms, and the establishment of country coordination mechanisms (CCMs) with mandatory participation of KPs to manage resources from the Global Fund, among many others). Similar initiatives and spaces of this nature also exist at regional and national levels (such as consultations with civil society organizations and KPs' representatives made by the Organization of American States (OAS) or the African Union (AU), or at national AIDS Commissions/Councils).

As opposed to state or government-led initiatives, civil society-led TAP initiatives focus on increasing social accountability, defined as the extent and capacity of citizens to hold the state and service providers accountable and make them

responsive to their needs.⁵¹ Thus, aiming at progressively enhancing communities' participation in public affairs, conducting activities such as: establishment of multi-stakeholder policy dialogues or consultations, empowering civil society via capacity building, advocacy for the institutionalization of information access, citizen education in public decision-making, and monitoring the delivery of public services. These types of initiatives are based on evidence that patients benefit from being more engaged in public affairs when it concerns access to (or quality of) healthcare, but there are concerns regarding its effectiveness and final impact on health policies or health outcomes.⁵²

Many cases show that enhancing communities' participation in social accountability processes can increase access and coverage to quality health care services.⁵³ However, when assessing the impact of increased information and transparency on citizen engagement and service provision, the main finding is that such interventions can work in some contexts, but not all. Studies show that the success of a particular TAP initiative may depend on the consideration of several factors such as: the perceived legitimacy and ethical components of these TAP initiatives; the inclusion of the needs and further involvement of governmental officials, health care experts, and professionals; citizens' expertise and overall capacities to operate in a particular system; the way in which their concepts, and operationalization strategies and tactics, are defined and agreed by relevant stakeholders; their continuity over time; and the reliability and accessibility of the data used by the actors involved, among others.⁵⁴

Nonetheless, the lack of evidence of success in achieving the specific TAP objectives of such initiatives does not necessarily mean a lack of intrinsic value for the advancement of human rights, or their further potential benefits in improving service delivery, including health care.⁵⁵ A lack of evidence for effectiveness could signify the need for additional research or the inclusion of such lessons learned.⁵⁶ Promotion of TAP and keeping civil society organizations and KPs engaged in public affairs must be sustained and enhanced, as their relevance and connection to human rights remain valid and critical.

The way forward: Enhancing TAP as means to promote human rights of KPs and improving the HIV response

Enhancing community access to information and participation in health care policymaking has the potential to improve equitable access, quality, and coverage for health care. Efforts to address the HIV epidemic require that KPs are able to overcome exclusion and can become active participants in the formulation of inclusive and effective health and HIV policies.⁵⁷ In all regions of the world, there are positive examples of community-led responses to HIV that advance health and promote human rights in the context of HIV.⁵⁸ However, these experiences remain limited in scope and coverage and are often underfunded and marginal.

Efforts to expand the HIV response and to reach the 2030 targets will require scaling up TAP initiatives in the context of HIV. TAP initiatives designed and implemented with a high involvement of KPs could allow them to: demand compliance with the international commitments made by their governments to fight the epidemic; participate meaningfully in the formulation of inclusive and effective health policies; track-down the allocation, disbursement, and use of public financial resources; monitor public contracting (from planning to implementation); access national and local financial resources from their governments; request the publication of health related information and the prices of medicines; and take actions to sanction non-performance or corrupt behavior by those in power.

If future HIV-related TAP interventions are to be successful and hold up to their potential, they should be: contextually grounded, formulated, and agreed-upon by relevant stakeholders; focused on empowering KPs with the technical expertise required for them to become agents of positive social change in their own communities; and aimed at achieving gradual long-term goals aimed at achieving systemic change instead of trying to "fix" service delivery. The following sections will explore the steps that could lead to the formulation of TAP programming in the HIV response, based on the collected evidence of TAP initiatives in the health sector.

Build the field: Establishing HIV-TAP communities of practice

Having been in existence for nearly 20 years, current TAP initiatives have both diversified and specialized in different fields, ranging from multi-stakeholder initiatives by sector—such as the Extractive Industries Transparency Initiative (EITI), the Construction Sector Transparency Initiative (CoST), and the Global Initiative for Fiscal Transparency (GIFT)—to the establishment of international standards—like the International Aid Transparency Initiative (IATI) and the Open Government Partnership (OGP)—and innovation fund mechanisms seeking to harness the potential of new technologies—such as the Transparency and Accountability Initiative, the Global Partnership for Social Accountability (GPSA), and Making All Voices Count (MACV).⁵⁹ This means that, even when they may seem different in nature, there are plenty of experiences and lessons that can be incorporated into the fight against HIV/AIDS.

As a first step, spaces and opportunities should be created for the formulation of joint strategies to tackle the lack of TAP in the health sector specifically, which is increasingly affecting the fight against HIV. Establishing international, regional, and local platforms formed by the different stakeholders involved in the HIV response—such as non-governmental organizations, KPs' organizations, pharmaceutical companies, and private health care providers, universities, and research institutes, international organizations, and governments—could enable the sharing of technical knowledge and the framing of common challenges and objectives.

Ideally, such platforms would need to be open to actors that are not directly working on HIV/AIDS, to foster cross-cutting creative collaborations between different professional sectors. Building such bridges to connecting different fields of expertise and social movements under the TAP umbrella can also catalyze innovation and potentially lead to the formulation of new frameworks, tools, and methodologies for the advancement of human rights and enhance KPs' participation in the HIV response.⁶⁰

As an example, there are opportunities for the HIV response to be strengthened by harnessing the potential of “open data”—machine-readable information that anyone can freely access, use, modify, and share—and learn from the “open government” social movements advocating to expand demand for and access to public information, particularly from governments.⁶¹ According to WHO, opening access to sound and reliable health data and information to the public domain is an essential feature of any effective health system.⁶² Accessing this information enables individuals and communities to promote their own health, participate effectively in decision-making, claim quality services, monitor progressive realization of their rights, expose corruption, and hold those responsible to account. Recent evidence shows that these types of initiatives have a direct positive impact when applied to procurement processes in health, such as achieving better value for money, and lead to innovations in the monitoring of health care service delivery (including HIV interventions).⁶³

Furthermore, public information needs to be presented in ways citizens can easily comprehend and analyze in relation to their needs, and with a clear understanding of the risks associated with the liberation of such data (for example, violation of privacy rights and possible misuse or misinterpretation of data).⁶⁴ To mitigate such risks, alliances can be formed between KPs and *infomediaries* (that is, agents who can take complex data and translate, package, and contextualize it for use by wider segments of society, such as international organizations, NGOs, information and communications technologies (ICT), and open data experts and activists, journalists, and watchdogs), to fill gaps in the supply and demand chain of information. In the case of the HIV response, *infomediaries* would ensure that KPs use government-published data effectively and in a responsible and well-informed manner.⁶⁵

Building “cross-sector” alliances and communities of practice, shared between the KPs engaging in the HIV response and *infomediaries*, could also help in bridging those conceptual gaps and increasing the limited capacities that KPs and communities

experience when trying to engage meaningfully in complex decision-making processes. For example, if a sex worker living with HIV wants to engage with the National AIDS Council, this person would need to not only overcome the stigma and discrimination attached to his or her medical condition and/or behavior in order to participate, but would also need to be fully prepared with the right knowledge and tools to do so effectively. Providing spaces and resources for knowledge exchange could lead to the development of shared agendas, and new narratives and practices around TAP principles in the context of the HIV response could be truly beneficial to enhance its sustainability and effectiveness. *Infomediaries* could employ user-centered approaches to develop technologies and tools to facilitate open data collection and analysis (for example, new software applications for mobile phones and tablets), which could allow KPs to better harness and benefit from the “data revolution.”

KP-led TAP mechanisms key to financial sustainability and effectiveness

Along with including TAP strategies in the response, and raising the awareness about the importance of such principles to overcome the main challenges of the HIV response, further steps need to be taken to enhance KPs’ participation. As the people affected by HIV and the potential agents of change, KPs’ participation can revitalize the effectiveness of the global efforts against HIV. Their input is necessary to adequately set the priorities and strategies of effective HIV programming.

Given increasing financial pressure, KPs need to have a say in how donors will transition out of their countries, how their governments will channel public budgets to fund national HIV plans, and how to ensure that the promises made for 2030 become a reality.⁶⁶ This would require further cooperation from the different actors involved in health governance. States must fulfill their human rights obligations by repelling discriminatory regulations, and take steps to have transparency and social accountability mechanisms in place where KPs can participate. The international community, and donors in particular, should stress their role to support governments and

KPs in advancing human rights.

Furthermore, international donors and funders need to better plan their strategies and consult KPs as they transition out from middle-income countries, to avoid creating further gaps in the funding of HIV prevention and treatment services. Their support would also create pressure for governments to: increase funding to sustain the HIV response under specific funding streams and budget lines in their national health strategies and programs to address HIV; increase efficiency, transparency, and accessibility of information for constituents on how national resources are being spent; ensure inclusivity and effectiveness in the planning phase of budget allocation and contracting; and monitor implementation of their national HIV plans by including citizens and KPs.

Conclusion

Achieving the Sustainable Development Goals and the end of AIDS before 2030 requires placing human rights and TAP principles on the agenda’s main priorities, as a social justice imperative, and as tools to improve the sustainability and impact of public health care delivery. By fully endorsing TAP while funding from international donors remains in place, KPs could prepare to harness the potential of new technologies, open data, and open governments. This will aid them to demand well-funded and inclusive national responses against HIV, to adequately monitor budgets and progress of governments’ political and legal commitments to respect their human rights, and to participate meaningfully in decision-making.

Evidence shows that in order for the HIV response to become more effective and sustainable, it is necessary to overcome inequality and discrimination against KPs. Thus, policies should focus on prioritizing KPs needs and human rights and targeting the underlying causes (or social determinants) that drive the epidemic. Comprehensive health care must become accessible and affordable for all people without discrimination of any kind, yet meaningful involvement of KPs in the governance structures of the HIV response (particularly

at the national level) is a key element of the solution but remains unattended.

Promoting alliances across different development sectors, and particularly with activists focused on access to information, would help to promote TAP in the HIV response. The goal is to find ways in which data can be collected, analyzed, and made accessible to fit the needs and rights of KPs. Financial and health data must be fully accessible to KPs and NGOs in user-friendly formats, as a way to better monitor government actions, curb corruption, and successfully advocate for change.

The international community needs to find strategies to ensure and maintain HIV interventions—both prevention and treatment—in the immediate future and even beyond 2030, by remaining well-funded by governments, the private sector, and international donors in a transparent and accountable manner. International investments in human rights-based programming should continue as long as stigma and discrimination of KPs remain. Further, local and international HIV programming should be budgeted annually by all governments, and integrated within integral health policies (including sexual and reproductive health) until the epidemic is finally controlled.

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References

1. B. Ki-moon, UN Secretary General, *Report for the UN General Assembly High-Level Meeting on Ending AIDS*, UN Doc. A/70/811, par. 6.
2. Although the term Key Populations is contested, and allows for different interpretations (particularly at country level), we acknowledge that the term in some cases has also been loosely used to refer to other vulnerable groups, such as: migrants, people in prisons, and young women and girls. See more at: UNAIDS, *Terminology Guidelines* (Geneva: 2015, p. 31). Available at: http://www.unaids.org/sites/default/files/media_asset/2015_terminology_guide-lines_en.pdf.
3. World Health Organization, *Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations*. (Geneva: WHO, 2014). Available at http://apps.who.int/iris/bitstream/10665/128048/1/9789241507431_eng.pdf?ua=1&ua=1.
4. UNAIDS (2015, see note 1).
5. Ibid.; The Global Fund to Fight AIDS, Tuberculosis and Malaria. *Key Populations Action Plan 2014-2017* (Geneva: GFATM, 2013), pp. 5–6. Available at https://www.theglobalfund.org/media/1270/publication_keypopulations_actionplan_en.pdf.
6. UN Human Rights Council, Resolution No. 17/14, The right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN Doc. No. A/HRC/17/L.16 (2011); UN Human Rights Council, Resolution No. 16/28, The protection of human rights in the context of HIV and AIDS, UN Doc. No. A/HRC/16/L.22 (2011); UN Human Rights Council, Resolution 12/27, The protection of human rights in the context of immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), UN Doc. No. A/HRC/12/L.24 (2009).
7. UN General Assembly, Transforming our world: the 2030 Agenda for Sustainable Development, UN Doc. A/RES/70/1, par. 20-b (2015). Available at http://www.un.org/ga/search/view_doc.asp?symbol=A/RES/70/1&Lang=E.
8. UNAIDS, *Global AIDS Update 2016* (Geneva: UNAIDS, 2016), p. 3. Available at http://www.unaids.org/sites/default/files/media_asset/global-AIDS-update-2016_en.pdf.
9. W. Haidong, T. Wolock, A. Carter, G. Nguyen et al, “Estimates of global, regional, and national incidence, prevalence, and mortality of HIV, 1980–2015: The Global Burden of Disease Study 2015,” *Lancet HIV*, 3/8 (2016), pp. e361–e387.
10. Global Commission on HIV and the Law, *Risks, Rights and Health* (Geneva: UNDP, 2012). Available at <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>; UN General Assembly. *Political Declaration on HIV and AIDS: On the Fast Track to Accelerating the Fight against HIV and to Ending the AIDS Epidemic by 2030*, UN Doc. No. A/RES/70/266 (2016). Available at: <http://www.refworld.org/docid/577a04324.html>.
11. The Global Network of People Living with HIV/AIDS, *A Multi-Country Study of the Involvement of People Living with HIV/AIDS (PLWHA) in the Country Coordinating Mechanisms (CCM)* (Amsterdam: GNP+, 2004). Available at <https://www.gnpplus.net/resources/multi-country-study-involvement-people-living-hiv-aids-plwha-country-coordinating-mechanisms/>; S. Nemande, K. Esom, R. Armstrong, 2015. *Key Populations Experiences within the Global Fund's New Funding Model in Sub-Saharan Africa* (Johannesburg: AMSHeR, 2015). Available at <http://www.globalfundadvocatesnetwork.org/>

wp-content/uploads/2015/11/keypopulationexperiences_within_the_globalfund.pdf.

12. UNAIDS, *Fast-Track Update on Investments Needed in the AIDS Response* (Geneva: UNAIDS, 2016), p. 3. Available at http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Reference_FastTrack_Update_on_investments_en.pdf.

13. Transparency International, *Corruption in the Pharmaceutical Sector, Diagnosing the Challenges* (2016). Available at <http://www.transparency.org.uk/publications/corruption-in-the-pharmaceutical-sector/>.

14. G. Backman, P. Hunt, R. Khosla et al., "Health systems and the right to health: an assessment of 194 countries," *Lancet* 372/9655 (2009), pp. 2047–2085.

15. UNAIDS, *Global AIDS Update 2016* (Geneva: UNAIDS, 2016), p. 3. Available at http://www.unaids.org/sites/default/files/media_asset/global-AIDS-update-2016_en.pdfpaper8.pdf.

16. UNAIDS (2016, see note 12).

17. J. Seeley et al, "Addressing the structural drivers of HIV: A luxury or necessity for programmes?" *Journal of the International AIDS Society*, 15/1 (2012). Available at: <http://www.jiasociety.org/index.php/jias/article/view/17397>.

18. The Global Fund to Fight AIDS, Tuberculosis and Malaria, *Overview of the Allocation Methodology (2014-2016) The Global Fund's new funding model* (2014). Available at http://www.theglobalfund.org/documents/fundingmodel/allocations/2014-2016/FundingModel_Allocations2014-2016_Methodology_en/.

19. UNAIDS, *Prevention Gap Report* (Geneva: UNAIDS, 2016), p. 13. Available at http://www.unaids.org/sites/default/files/media_asset/2016-prevention-gap-report_en.pdf.

20. UNAIDS, *Sustaining the Human Rights Response: Funding Landscape and Community Voices* (Geneva: UNAIDS, 2015); Transparency International, *Global Corruption Report 2006* (London: Transparency International, 2006); V. Bhargava, The cancer of corruption, in *World Bank Seminar Issues* (Washington DC: World Bank, 2015), pp. 1-9; Transparency International, *Global Corruption Report 2015* (London: Transparency International, 2015); J. Michaud, J. Kates, and S. Oum, *Corruption and global health: Summary of a policy roundtable* (Menlo Park: The Henry J. Kaiser Family Foundation, 2015). Available at <http://kff.org/report-section/corruption-and-global-health-summary-of-a-policy-roundtable-issue-brief>.

21. Transparency International (2006, see note 13); World Health Organization, *World Health Report 2010* (Geneva: WHO, 2010), p. 61; J. Gee and M. Button, *The financial cost of healthcare fraud 2015 – What data from around the world shows* (London: PKF Littlejohn LLP, 2015). Available at <https://www.pianoo.nl/sites/default/files/documents/documents/thefinancialcostofhealthcarefraud-september2015.pdf>.

22. UNAIDS (2011). *A New Investment Framework for*

the Global HIV Response. Issue Brief (Geneva: UNAIDS, 2011). Available at: <http://icssupport.org/wp-content/uploads/2012/02/3-Investment-Framework-Summary-UNAIDS-Issues-Brief.pdf>; UNAIDS, *Prevention Gap Report* (Geneva: UNAIDS, 2016). Available at http://www.unaids.org/sites/default/files/media_asset/2016-prevention-gap-report_en.pdf.

23. The Global Fund to Fight AIDS, Tuberculosis and Malaria, *Domestic Financing* (2016). Available at <http://www.theglobalfund.org/en/domesticfinancing/>.

24. J. Kates, A. Wexler, E. Lief, *Financing the Response to HIV in Low- and Middle-Income Countries: International Assistance from Donor Governments in 2015* (Menlo Park and Geneva: The Henry J. Kaiser Family Foundation and UNAIDS, 2016), p. 7. Available at <http://files.kff.org/attachment/Financing-the-Response-to-HIV-in-Low-and-Middle-Income-Countries-International-Assistance-from-Donor-Governments-in-2015>; UNAIDS (2011, see note 22).

25. UNAIDS, *The Gap Report 2014* (Geneva: UNAIDS, 2014), p. 22; UNAIDS (2015, see note 20).

26. P. Piot, R. Greener, and S. Russell, "Squaring the circle: AIDS, poverty, and human development," in *PLoS Medicine* 4(10), p. e314. Available at doi:10.1371/journal.pmed.0040314.

27. UNAIDS (2014, see note 25).

28. Ibid.

29. P. Piot, S. S. Abdool Karim, R. Hecht et al., "Defeating AIDS – advancing global health," *Lancet* 386/9989 (2015). Available at [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(15\)60658-4.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(15)60658-4.pdf); UNAIDS (2016, see note 19).

30. M.S. Cohen et al, "The spread, treatment, and prevention of HIV-1: Evolution of a global pandemic," *The Journal of Clinical Investigation* 118/4 (2008), pp. 1244–1254.

31. UNAIDS (2016, see note 15), p. 11.

32. UNAIDS (2016, see note 19).

33. Ibid.

34. UNAIDS (2016, see note 15), p. 11.

35. International Council of Human Rights Policy, *Corruption and Human Rights: making the connection* (Versoix: International Council of Human Rights Policy, 2009), p. 7. Office of the UN High Commissioner for Human Rights, *The Human Rights Case Against Corruption* (Geneva: OHCHR, 2013). Available at <http://www.ohchr.org/Documents/Issues/Development/GoodGovernance/Corruption/HRCASEAGAINSTCORRUPTION.pdf>.

36. Transparency International, *Corruption Perceptions Index 2015*. Available at: <https://www.transparency.org/cpi2015>; J. Michaud, J. Kates, and S. Oum, *Corruption and global health: Summary of a policy roundtable* (2015). Available at [http://kff.org/report-section/corruption-and-global-health-summary-of-a-policy-roundtable-issue-brief/Michaud et al 2015](http://kff.org/report-section/corruption-and-global-health-summary-of-a-policy-roundtable-issue-brief/Michaud%20et%20al%202015).

37. The Global Fund to Fight AIDS, Tuberculosis and

Malaria. *Community Systems Strengthening Framework* (2014), pp. 11–17. Available at https://www.theglobalfund.org/media/6428/core_css_framework_en.pdf/.

38. J. C. Kohler, M. G. Martinez, M. Petkov et al. *Corruption in the pharmaceutical sector: Diagnosing the challenges* (London: Transparency International UK, 2016); Transparency International, *Transparency and Good Governance in Global Health* (London: Transparency International UK, 2014); K. Hussmann. *Vulnerabilities to corruption in the health sector: Perspectives from Latin American sub-systems for the poor* (Panama: UNDP, 2011). Available at <http://www.u4.no/recommended-reading/vulnerabilities-to-corruption-in-the-health-sector-perspectives-from-latin-american-sub-systems-for-the-poor-with-a-special-focus-on-the-sub-national-level/downloadasset/2764>; and Department for International Development (DFID), *Addressing Corruption in the Health Sector* (DFID practice paper, 2010). Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/67659/How-to-Note-corruption-health.pdf

39. International Monetary Fund, *Code of Good Practices on Transparency in Monetary and Financial Policies, Part 1—Introduction* (Washington DC: IMF, 2000). Available at http://www.imf.org/external/np/mae/mft/sup/part1.htm#appendix_III.

40. World Health Organization, *WHO Accountability Framework* (Geneva: WHO, 2015) Available at http://www.who.int/about/who_reform/managerial/accountability-framework.pdf.

41. UN Human Rights Committee (HRC), CCPR General Comment No. 25, UN Doc. No. CCPR/C/21/Rev.1/Add.7 (1996). Available at <http://www.refworld.org/docid/453883fc22.html>.

42. T. Carothers and S. Brechenmacher, *Accountability, Transparency, Participation, and Inclusion: A New Development Consensus?* (Washington DC: Carnegie Endowment for International Peace, 2014). Available at http://carnegieendowment.org/files/development_consensus_brief.pdf.

43. UNDP, *World Development Report 'Making Services Work for Poor People'* (Geneva: UNDP, 2004); The World Bank, *Making Politics Work for Development: Harnessing Transparency and Citizen Engagement* (Washington DC: The World Bank, 2016). Available at <http://documents.worldbank.org/curated/en/268021467831470443/pdf/106337-revised-PUBLIC-Making-Politics-Work-for-Development.pdf>.

44. UN General Assembly Res. 59/201 (December 20, 2004). Available at <http://www.refworld.org/docid/43f3122f6.html>; United Nations Convention Against Corruption, UN Doc. No. A/58/422(31 October 2003). Available at <http://www.refworld.org/docid/4374b9524.html>.

45. Democracy Reporting International, *International Standards on Transparency and Accountability* (Berlin: Democracy Reporting International, 2014). Available at http://www.law-democracy.org/live/wp-content/uploads/2014/04/Transparency-and-Accountability.final_Mar14.pdf.

46. UN Secretary-General's Independent Expert Advisory Group on a Data Revolution for Sustainable Development (IEAG), *A World That Counts: Mobilising the Data Revolution for Sustainable Development* (2014). Available at <http://www.undatarevolution.org/wp-content/uploads/2014/12/A-World-That-Counts2.pdf>.

47. UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. No. E/C.12/2000/4 (2000). Available at <http://www.refworld.org/docid/4538838do.html>; World Health Organization, *Ottawa Charter for Health Promotion* (Geneva: WHO, 1986).

48. O. Brunelle-Quraishi, "Assessing the relevancy and efficacy of the United Nations convention against corruption: A comparative analysis," *Notre Dame Journal of International & Comparative Law*, 101 (2011). Available at <http://www3.nd.edu/~ndjicl/V211/Brunelle-Quraishi.pdf>.

49. International Council on Human Rights Policy and Transparency International, eds., *Integrating Human Rights in the Anti-Corruption Agenda: Challenges, Possibilities and Opportunities* (Geneva: International Council on Human Rights Policy, 2010). Available at http://www.ichrp.org/files/reports/58/131b_report.pdf.

50. International Monetary Fund, *Poverty Reduction Strategies in IMF-supported Programs Factsheet* (Washington DC: IMF, 2017). Available at <https://www.imf.org/About/Factsheets/Sheets/2016/08/01/16/32/Poverty-Reduction-Strategy-in-IMF-supported-Programs?pdf=1>

51. D. Ringold, A. Holla, M. Koziol et al., *Citi.zens and Service Delivery Assessing the Use of Social Accountability Approaches in the Human Development Sectors* (Washington DC: The World Bank, 2012). Available at <https://www.odi.org/sites/odi.org.uk/files/odi-assets/events-documents/4871.pdf>.

52. M. Stewart, J. Brown, A. Donnor et al., "The impact of patient-centered care on outcomes" in *Journal of Family Practice* 49/9 (2000), pp. 796–804; N. Mead and P. Bower, "Patient-centred consultations and outcomes in primary care: A review of the literature" in *Patient Education and Counselling*, 48 (2002), pp. 51–61; L. Williamson, "Patient and citizen participation in health: The need for improved ethical support," in *The American Journal of Bioethics*, 14/6 (2014), pp. 4–16; J. C. Kohler and M. G. Martinez, "Participatory health councils and good governance: healthy democracy in Brazil?" in *International Journal for Equity* 14/21 (2014); S. Bartlett, "Poverty reduction strategy papers and their contribution to health: An analysis of three countries," in *McGill Journal of Medicine* 13/2 (2011), pp. 22–28. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3371744/>; GNP+ (see note 10); S. Nemande et al. (see note 11).

53. A. M. Garba and S. Bandali, "The Nigeria Independent Accountability Mechanism for maternal, newborn,

and child health,” in *International Journal of Gynecology and Obstetrics*, 127 (2014), pp. 113–116; E. Anbrasi et al. 2015, “Enhancing governance and health system accountability for people centered healthcare: an exploratory study of community scorecards in Afghanistan,” in *BMC Health Services Research*, 15/299 (2015); and M. Björkman and J. Svensson, “Power to the people: Evidence from a randomized field experiment on community-based monitoring in Uganda,” in *Quarterly Journal of Economics* 124/2 (2009), pp. 735–69.

54. J. Anuradha, “Do they work? Assessing the impact of transparency and accountability initiatives in service delivery” in *Development Policy Review* (2013), 31/S1 (2013), pp. s29–s48; World Health Organization, *Medicines Transparency Alliance (MeTA): Pathways to Transparency, Accountability and Access Cross-Case Analysis and Review of Phase II* (Geneva: WHO; 2016); E. Lodenstein, M. Dieleman, B. Gerretsen et al. “Health provider responsiveness to social accountability initiatives in low- and middle-income countries: a realist review,” *Health Policy and Planning* 32 (2017), pp. 125–140.

55. S. Molyneux, M. Atela, V. Angweni et al., “Community accountability at peripheral health facilities: a review of the empirical literature and development of a conceptual framework”, in *Health and Policy Planning* 27 (2012), pp. 541–554.

56. F. Guertzovich and S. Rosenzweig, *Bridging the context gap through comparative research* (Washington DC: The Transparency and Accountability Initiative, 2014). Available at <http://www.transparency-initiative.org/wp-content/uploads/2014/08/Context-and-comparison.pdf>.

57. World Health Organization (2016, see note 43, p. 106); World Vision International, *Citizen accountability key to delivering on development targets*, The post-2015 Agenda: Policy Brief #8 (2014). Available at <http://www.wvi.org/health/citizen-voice-and-action-o>.

58. See, for example, AmfAR, The Foundation for AIDS Research. *Lessons From the Front Lines, Effective Community-Led Responses to HIV and AIDS Among MSM and Transgender Populations* (New York: AmfAR, 2010). Available at: http://www.amfar.org/uploadedFiles/_amfarorg/Around_the_World/Lessons-Front-Lines.pdf.

59. F. Guertzovich and A. Shaw, *Supporting international transparency and accountability interventions: Does our existing knowledge help?* (Washington DC: The Transparency and Accountability Initiative, 2014). Available at <http://www.transparency-initiative.org/wp-content/uploads/2013/10/Think-Piece-Guertovich-Shaw.pdf>.

60. F. Guertzovich and S. Rosenzweig (2014, see note 44).

61. European Data Portal, *Open Data in a Nutshell* (Luxembourg: EU, 2017). Available at <https://www.europeandataportal.eu/en/providing-data/goldbook/open-data-nutshell>.

62. World Health Organization. *Everybody’s Business:*

Strengthening Health Systems to Improve Health Outcomes (Geneva: WHO, 2007), pp. v–vi. Available at http://www.who.int/healthsystems/strategy/everybodys_business.pdf.

63. Transparency International. *Making the Case for Open Contracting in Healthcare Procurement* (London: Transparency International, 2017). Available at <https://ti-health.org/content/making-case-open-contracting>.

64. Responsible Data Forum, “Access to treatment for HIV/AIDS patients: Trying to improve public health systems in Buenos Aires” in *Responsible Data Reflection Stories* (2016). Available at: <https://responsibledata.io/reflection-stories/hivaids-treatment-access/>; J. Attard, F. Orlandi, S. Scerri et al., “A systematic review of open government data initiatives”, *Government Information Quarterly* 32/4 (2015), pp. 399–418.

65. B. Carter, *Infomediaries and accountability*. GSDRC Helpdesk Research Report 1347 (Birmingham: University of Birmingham, 2016). Available at <http://www.gsdrc.org/publications/infomediaries-and-accountability/>; M. Janssen and A. Zuiderwijk, “Infomediary Business Models for Connecting Open Data Providers and Users”, *Social Science Computer Review* 32/5 (2014), pp. 694–711; F. Schalkwyk, M. Cañares, S. Chattapadhyay et al. *Open Data Intermediaries in Developing Countries* (2015). Available at: <http://www.opendataresearch.org/dl/symposium2015/odrs2015-paper8.pdf>.

66. P. Tucker, *Accountability Theory: How can it improve the response to health needs in Africa?* Policy Brief #8 (Cape Town: AIDS Accountability International, 2014). Available at http://www.aidsaccountability.org/?page_id=9842.

