



Narrative report of the 2024 in-person meeting of UNAIDS Reference Group on HIV and Human Rights

This report provides a summary of the discussion, recommendations of the independent UNAIDS Reference Group on HIV and Human Rights (RG) at its face-to-face meeting on 28-29 October 2024 at the UNAIDS office in Geneva. It was supported by Article XII, which provides the secretariat services to the RG. The agenda and list of participants are included in annexes at the end of this report. Most RG members attended in person and some joined remotely. Observers from the Global Fund to Fight AIDS, TB and Malaria attended various sessions of the meeting.

Recommendations

The following recommendations emerge from the 2024 meeting of the UNAIDS Reference Group on HIV and Human Rights. Though there are recommendations for the specific agenda item of “Sustainability”, the RG believes that all its recommendations from the 2024 meeting relate to ensuring a sustainable HIV response to 2030 and beyond.

[Note: the term UNAIDS refers to the Joint Programme and work should be led per the division of labor; where the work is for the UNAIDS Secretariat, this is specified.]

Sustainability

Global level

- Human rights are not only critical to a sustainable human rights response, but work must be done to ensure the sustainability of human rights themselves. This will require working to change the narrative around human rights. When discussing integration of HIV services into health systems, all stakeholders should be guided by both country context and the experiences and needs of communities within those countries, using a human rights framework, including but not limited to considerations of equity, availability, accessibility, acceptability, quality and privacy, among others.
- On addressing human rights in sustainable responses, UNAIDS should explore changing the narrative to focus on shared values such as dignity, and individual liberty and couching it within broader societal values and morals to resonate with a broader audience; these messages should be consistent across global, regional and country levels.
- UNAIDS should build on current, existing systems to further human rights within sustainability discussions, developing messaging on human rights that are consistently driven at global, regional and country-levels – these messages should be tailored to funders, as well as to engagements with the private sector that should also be funding the HIV response.
- While the evidence is and should be clear on the need for human rights in a sustainable approach, funding is often not provided for human rights interventions. UNAIDS should develop an investment case for human rights and community programming, assessing cost effectiveness and financial implications of leaving human rights programming behind.
- Access to health technologies, particularly emerging long-acting prevention, will be an absolutely essential element of a sustainable HIV response in the coming years. UNAIDS should lead on the work on access to health technologies and ensure that there are forward-looking strategies and

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targets to ensure that everyone, everywhere can equally benefit from novel innovations – this can include both immediate actions under the current TRIPs flexibilities as well as broader discussions on how the system needs to be restructured to ensure long term access and affordability of health technologies,

- UNDP should develop a resource for countries to protect against rights-related concerns on the scale-up of digital technologies impacting the HIV response.

Country level

- At the country level, guidance is required to ensure that countries incorporate key human rights elements into their response to ensure that it is sustainable. A checklist could be developed by UNAIDS to assess country readiness in relation to sustainability, which encompasses rights-related prerequisites, such as community engagement and feedback mechanisms within health services; engagement of religious leaders; adequate capacity and resourcing to continue to confront stigma and discrimination; protective laws; in addition to the biomedical elements of the HIV response.
- Monitoring and evaluation of human rights elements is critical. UNAIDS should continue tracking core human rights issues such as HIV-related stigma and discrimination and punitive laws and policies – and should work with governments and civil society to ensure that both community and government monitoring are integrated at country levels.
- Civil society participation in the development of sustainability policies formulated on the basis/rationale of a human rights approach is a fundamental step for both the effectiveness and the elimination of stigmas against people living with HIV and other key populations.

Reference Group actions

- RG will develop a public version of their recommendations on sustainability and human rights minimum standards for sustainability of the HIV response. (e.g., key minimum requirements around civil society and sustainability).

Next Strategy

- The RG discussed the development of the new strategy in the context of the 2030 sustainable development agenda, sustainability, emerging health technologies and decreasing funding as well as lessons learned from the previous strategy.
- The RG noted the resistance and push-back in relation to the current strategy and recommended that to avoid repetition of this fracturing, UNAIDS should widely consult on next strategy, including (and importantly) with the “unusual suspects” (e.g., law enforcement and justice sector more broadly, national statistics offices, parliamentarians) as well as those left behind (e.g., young people, etc.). This encompasses discussing with actors who are “difficult” to try and find common ground on how to integrate human rights into the strategy. Consultations should include engagement with regional entities, such as the Inter-American Commission and OAS, African Union and others.
- Noting the continuation of broader concerns that impact on the HIV response, the next strategy should explore intersections with humanitarian actors, as well as stakeholders working on climate change and how to respond to the backlash on human rights.
- While the work on law reform, stigma and discrimination should continue, the strategy should explore more deeply the concept of non-discrimination as a legal obligation, rather than focusing primarily on stigma.

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- Strategy must address access to health technologies, both the game changers that are upcoming, as well as potential breakthrough innovations such as a vaccine or cure, to ensure affordability and access for everyone, everywhere – in alignment with this, the strategy should:
 - Emphasize that access to essential health products as a right, derived from the right to health (article 25 of the Universal Declaration of Human Rights);
 - Include language that encourages access to health technologies, emphasizing the use of TRIPS flexibilities, technology transfer, and developing local production capacity;
 - While recognizing the role of voluntary licenses, it should avoid over-reliance on voluntary licensing and other mechanisms that limit national policy leverage; and
 - Prioritize faster and more comprehensive delivery of innovative health products to ensure they are available, affordable and accessible to all.
- UNAIDS should engage with diplomatic missions for advocacy on HIV and human rights issues within UN human rights mechanisms.

Access to Health Technologies

- In light of recent and upcoming developments on HIV prevention and treatment, the RG suggested that UNAIDS should ensure that access to health technologies remain a major element of their work, and should collaborate with key UN actors such as WHO, UNITAID, UNDP, and with governments that have been or may be excluded from voluntary licensing, key production countries and civil society to discuss strategies of accessing new health technologies, focusing on intellectual property issues.
- The RG was very concerned with the pressures of powerful countries and companies against the use of TRIPS flexibilities that already exists and believes the UNAIDS, WHO, UNDP and the UN in general should create strategies in order to prevent and avoid the use of economic and other sanctions against countries that exercise their right to use TRIPS flexibilities and their national laws to guarantee the right to health.

Summary of Discussions

Topic: Updates – UNAIDS, UNDP and Reference Group Members

Christine Stegling, UNAIDS Deputy Executive Director, Umunyana Rugege, UNAIDS human rights team lead, and Boyan Konstantinov, UNDP, presented on the work of UNAIDS and UNDP, respectively. The speakers provided updates on the work of UNAIDS and UNDP in 2025 and planned work for 2025 and the current state the HIV response and (insufficient) progress toward the 95-95-95 and 10-10-10 goals.

UNAIDS highlighted the fact that the world is at a crossroads regarding HIV – the HIV response has had many successes but the gains are fragile. The challenges for the future, and sustainability, of the HIV response are serious – including waning financial and political commitment, as well as in funding the multilateral system more broadly in the fact of increasing opposition to multilateralism, democracy and human rights. However, there are opportunities to try to reverse these trends and renew commitments, including target setting and the next Global AIDS Strategy, the High-Level Panel reviewing the Joint Program and medical and technological breakthroughs. Human rights must be at the heart of all these discussions.

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In the conversation following the presentations, RG members raised concerns regarding the progress (or lack thereof) related to decriminalization, lack of focus on the Middle East and North Africa region's HIV response despite rising numbers of new infections, funding for HIV work – including in MENA and also Eastern Europe and Central Asia – and the need to ensure human rights work continues to be funded in an environment with shrinking budgets for HIV.

In terms of RG member updates, several members gave substantive updates on the various processes in which they are engaged. These included updates on the Global Fund's work, the MTAG meeting, WHO advisory group on vertical transmission, PEPFAR and its sustainability work and engagement in the UNAIDS High Level Panel.

Topic: Human Rights in a Sustainable HIV Response

The RG discussed the critical importance of human rights in developing a sustainable HIV response. Sustainability is not possible without human rights and a rights-based approach since otherwise the stigma and discrimination against key populations will make the respective public policies ineffective. To frame the overall discussion, a couple key themes were highlighted by the RG members: first, was the importance of religious and spiritual groups of promoting and advocating for human rights within sustainable responses, as well as of interfaith and intercultural collaboration. Political leadership and the willingness of governments to engage with civil society and community-led organizations was another core component, alongside the need to meaningfully engage women at all levels to ensure sufficient consideration of gender-related issues. Members also highlighted how sustainability is not a new conversation as it has been happening for years in places such as the Global Fund and PEPFAR – the concern now is how to ensure funding for human rights remains in the HIV response. Donors need to fund this work to remind governments of their obligation to deliver on the right to health, as well as to have accountability mechanisms when they aren't meeting their obligations.

The RG then broke into four different thematic groups to discuss the following questions:

- How do we center human rights and take rights-based approaches within each topic?
- What's the role of communities and how do we continue empowering key and vulnerable populations?
- What evidence do we have for convincing governments and other stakeholders to center human rights and take rights-based approaches (highlighting both good and bad practices)?

The groups reported back and highlighted the following:

Group 1: Future of HIV in health systems and services (e.g., peer-led, integration, primary health care and UHC, etc.)

- When countries discuss whether their HIV responses are sustainable, there should be human rights elements that are prerequisites to sustainability – this include, for example, whether there are community-focused/feedback components of health systems, whether health systems engage religious leaders, whether there are protective laws in a country, etc.
- Decisions relating to integration of services must take into account the needs of communities within each country. In some situations, integration may make sense but in others, integration may be ineffective, creating more barriers to services access. Human rights must be a framework for making these decisions – ensuring that any change improves enjoyment of the right to health for all.

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- Regarding evidence for the impact of human rights, the group noted the existence of a substantial body of evidence to convince governments and other stakeholders to center human rights (e.g., Stigma Index, NCPI, etc.), but they may not want to listen. Human rights are fundamental to effective and equitable health systems. Consideration should be given to highlighting the economic evidence relating to the cost effectiveness of human rights-based approaches to health.

Group 2: Sustainable human rights programming, including addressing pushback and maintaining gains

- In terms of discussing human rights and sustainability, it is important to look at the sustainability of human rights in general given the current attacks on human rights. There is a necessity to change the narratives – it's important to explain the moral grounds on human rights and centering on human dignity and individual liberty as shared values (and fundamental rights in several Constitutions worldwide).
- The role of communities must be protected and strengthened. Their engagement is fundamental for public health policies and should be institutionalized – ensuring community engagement is embedded in systems and structures.
- In terms of evidence on human rights issues: the RG suggested focusing on the economic costs of criminalization and cost of lives of criminalization of key populations. It's also important to keep making the legal arguments that we already make for decriminalization, but also be prepared to take a pragmatic approach and be cognizant of the limited impact that this evidence has for opponents.

Group 3: Funding, financing and investments - national and international - for biomedical and societal enablers

- UNAIDS should work to ensure that human rights activists are part of budget discussions and advocacy considering the worldwide persecution, stigma and discrimination against human rights activists. Within the same discussions, UNAIDS could develop a minimum package of human rights interventions that are needed to ensure sustainable responses.
- Given the reducing capacity and resources, existing structures and systems should be utilized for work on sustainability, including in relation to advocating for political leadership on human rights issues through existing mechanisms such as the Human Rights Council and PCB. UNAIDS' data and modeling could result in producing investment cases for human rights programming.
- In terms of messaging for human rights and sustainability, it's essential to embed human rights messages consistently across global and country levels, as well as between and among Cosponsors of the Joint Program.

Group 4: Equitable access to health technologies

- Access to health products and commodities are key to sustainability. Human rights are essential to this work; access should be for everyone, everywhere. The group discussed the limitations of voluntary licensing, leaving a large group of countries without affordable access. Additional work needs to be done to bring countries and UN agencies into discussion around access to technologies, for example, in implementing TRIPS flexibilities and also reforming of systems and laws for longer-term gains. The role of communities and CSOs is important here and UNAIDS needs to continue to support CSOs and community orgs within this type of work.

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- The key issue here is about choice, that people should have the opportunity to choose which option works for them in terms of prevention and treatment, meaning access to technology work needs to be across the board.
- In terms of evidence, there is a need to document case studies with numbers/financial impact, highlighting economic and public health outcomes resulting from access (or lack thereof) to health technologies – this evidence might spur more political leadership from countries and UN institutions on this topic.

Topic: Overview of Next Global AIDS Strategy, including Human Rights Targets

The session then turned to discussion on the development of the new targets for 2026-2030 and the Human Rights targets specifically. Representatives on the Global Task Team to develop the targets framed the discussion. While it seems the societal enabler targets will remain, one human rights target under discussion is: the percentage of key populations who experience arrest or incarceration within the last year. Another proposed target is around community-led monitoring (CLM) though it's less clear what element of CLM the target will focus on. The speakers noted that it can be quite challenging to develop human rights-related indicators because it can be hard to measure consistently across countries. Another challenge is aligning the perspectives of human rights and community activists with the modelers.

The RG discussed the feasibility of a target on arrests and the ability of measuring it, to support the target discussions happening with the Global Task Team in Gion the next day, including the need to ensure arrests relating to HIV exposure, non-disclosure and transmission are also included.

Topic: Next Global AIDS Strategy

Muleya Mwananyanda, Director, Influence and Partnerships, UNAIDS, and Anne-Claire Guichard, Senior Adviser Policy and Reporting, joined the RG to discuss UNAIDS' work in developing the next Global AIDS Strategy. Victoria Bendaud, Adviser in the Data for Impact team, also joined meeting, specifically on the targets discussion. Anne-Claire presented a high-level overview of the plans for targets development and the process for developing the strategy, with the targets representing the “what” in terms of the 2030 goals and the strategy defining the “how” in terms of operationalization.

RG members noted that, looking forward, it would be important for the consultations to include the “unusual suspects”, including law enforcement, justice system, financing institutions, national data bureaus. Importantly, this also includes the stakeholders who traditionally have not been aligned with rights-based approaches, such as non-aligned faith groups and “difficult” countries. Having discussions with regional-level entities should also be highlighted – all of this engagement will hopefully lead to more buy-in into the new strategy.

Substantively, the RG raised several core topics that could be included in the upcoming strategy. Members flagged that this strategy should be seen as an opportunity to address equitable access to health technologies and products. Looking over the next five years, new developments in terms of drugs and other products, including the possibility of a vaccine or functional cure, will be game changers. Assessing how to support countries to afford such products so there isn't a huge gap between upper, middle- and lower-income countries, as well as how to best use the TRIPS flexibilities, is critical.

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Addressing the impact and intersections between HIV with humanitarian crises and climate change are other important elements. Thinking about how discussions on HIV and human rights might be relevant to other global conversations, such as global health governance and combatting dis- and mis-information, would be important. The strategy must also continue to build on what has worked in the HIV response thus far, such as meaningful community engagement, and focus on elements that have not yet received as much attention, such as non-discrimination (as opposed to stigma) and engaging with parliamentarians on health and rights issues.

In essence, the RG recommended that the development of the strategy could take learning from a Joint Program approach, to engage and center human rights across various thematics – e.g., health, migration, engagement with UN human rights bodies, etc.

Topic: Access to Health Technologies

UNAIDS recently restored the priority area of access to medicines within the secretariat. In alignment with this and the renewed work of the sub-committee on IP and access to health technologies, the RG had a session on access to health technologies. Carlos Passarelli, Senior Adviser, Access to Medicines, UNAIDS and Boyan Konstantinov, Policy Specialist, Human Rights and Access to Health Technologies, UNDP, presented on their respective portfolios of work in this area. To focus specifically on innovation in pre-exposure prophylaxis (PrEP), Heather-Marie Schmidt, Adviser HIV Prevention Programme Implementation, WHO/UNAIDS, provided an overview of the latest developments in prevention technologies, including those related to Lenacapavir.

In the discussion, the RG highlighted the importance of this topic, especially in the context of human rights. The RG discussed that in addition to access, it's also important for key populations and people living with HIV to have choices and preferences about their treatment and care. The core questions are "who's going to access these new products and when?" New products are under patent protection. While voluntary licenses have been issued for more recent developments, they only include lower-income countries. Pricing and affordability are issues even for rich countries, and also certainly for middle-income countries. Members highlighted that now is the time to discuss IP issues for prevention and treatment gamechangers – both the ones in the pipeline now and the ones that may be developed over the next couple of years. The suggestion is to convene a conversation with countries that have been excluded from current and previous licenses – to start to develop strategies to access upcoming products. Such a meeting could also cover issues such as the restrictions related to voluntary licensing (e.g., bans countries from exporting medicines through compulsory license), as well as how to best use the TRIPS flexibilities to improve access.

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Annex 1: Agenda



UNAIDS Reference Group on HIV and Human Rights Twenty-fifth Meeting

28 - 29 October 2024

UNAIDS/WHO Building, Kofi Annan Room
20 avenue Appia, Geneva, Switzerland

Agenda

Please note: Due to security upgrades in the UNAIDS building, you are kindly requested to bring your passports to have your badges made. Badges are issued at the UNAIDS entrance. Kindly allow extra time for this procedure.

Monday, 28 October

Welcome and Opening Discussion

Co-chairs: Jules Kim and Carolyn Gomes

- 9:00 – 9:15 Welcome and introductions
Review of the agenda and meeting objectives by co-chairs
- 9:15 – 10:25 UNAIDS and UNDP welcome and updates
- 10:25 – 10:45 Reference Group member updates

Human Rights in a Sustainable HIV Response

Chair: Jules Kim

- 10:45 – 11:15 **Context setting on sustainability and human rights agenda**
Discussants: Jide Macaulay, Immaculate B. Owomugisha and Allan Maleche
Plenary discussion/Q&A
- 11.30 – 12:30 Small group discussions:

Sustainability, continued

Chair: Jules Kim

- 13:30 – 14:30 Plenary report back, discussion and next steps.

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Overview of Next Global AIDS Strategy, including Human Rights Targets

Chair: Carolyn Gomes

14:45 – 15:15 Overview of Next Global AIDS Strategy and Target Setting Process
Muleya Mwananyanda, Director, Influence and Partnerships, UNAIDS
Anne-Claire Guichard, Senior Adviser Policy and Reporting, UNAIDS

15:15 – 17:00 Human Rights Targets in Next Global AIDS Strategy
Discussants: Jules Kim and Allan Maleche
Recommendations for Target Setting

Tuesday, 29 October

Sustainability, continued

Chair: Carolyn Gomes

9:00 – 10:00 Reflections on Sustainability discussion

Human Rights in the Next Global AIDS Strategy

Chair: Carolyn Gomes

10:00 – 11:15 Discussants:
Mikhail Golichenko
Paulo Iotti
Ricky Gunawan

Access to Health Technologies

Chair: Carolyn Gomes

11:30 – 13:00 **Setting the scene: access to health technologies – key achievements and systematic challenges**

Carlos Passarelli, Senior Adviser, Access to Medicines, UNAIDS
Boyan Konstantinov, Policy Specialist, Human Rights and Access to Health Technologies, UNDP

Latest developments in access to PreP:

Heather-Marie Schmidt, Adviser HIV Prevention Programme Implementation UNAIDS
Discussant: Othoman Mellouk

13:00 – 14:00 *Lunch*

Review of meeting, Recommendations and Next Steps

Chair: Carolyn Gomes

14:00 – 15:00 Review and discussion of draft conclusions, recommendations and action items

Preparation for meeting with Executive Director

Chair: Carolyn Gomes

Wrap-up and Close

16:30 – 17:00 Close

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Annex 2: List of Participants

Reference Group Members

1. Allan Maleche
2. Cecilia Garcia Ruiz
3. Carolyn Gomes (co-chair)
4. Jules Kim (co-chair)
5. Othoman Mellouk
6. Mikhail Golichenko
7. Jide Macaulay
8. Immaculate Owomugisha Bazare
9. Paulo Iotti (online)
10. Cedric Nininahazwe
11. Ivana Radačić
12. Nina Sun (secretariat)

Observers

13. Alexandrina Iovita, Global Fund

UNAIDS and UNDP support of Ref Group team

1. Emily Christie, UNAIDS
2. Boyan Konstantinov, UNDP
3. Umunyana Rugege, UNAIDS
4. Suki Beavers, UNAIDS
5. Tays Yumi Tan Drewes, UNAIDS
6. Simone Salem, UNAIDS (online)

Session Guests

7. Christine Stegling, Deputy Executive Director, UNAIDS
8. Muleya Mwananyanda, Director, Influence and Partnerships, UNAIDS
9. Anne-Claire Guichard, Senior Adviser Policy and Reporting, UNAIDS
10. Carlos Passarelli, Senior Adviser, Access to Medicines, UNAIDS
11. Heather-Marie Schmidt, Adviser HIV Prevention Programme Implementation UNAIDS

Apologies

1. Anand Grover
2. Ricky Gunawan

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Annex 3: List of presentations

Presentation by Umunyana Rugege: *Update for the UNAIDS Human Rights Reference Group: UNAIDS Update 2024*

Presentation by Boyan Konstantinov: *Rights, Laws, Key Populations, Gender and Access: An Overview of UNDP's Initiatives and Partnerships*

Presentation by Anne Claire Guichard: *The 2030 HIV target-setting process*

Presentation by Carlos Passarelli: *Addressing Access to Health Technologies Challenges in the Context of the HIV Pandemic*

Presentation by Boyan Konstantinov: *Fostering Access to Health Technologies*

Presentation by Heather-Marie Schmidt, *The HIV pre-exposure prophylaxis (PrEP) landscape and the promise (and potential challenges) of Lenacapavir*