

UNAIDS Reference Group on HIV and Human Rights

STRENGTHENING HUMAN RIGHTS AT A CRITICAL MOMENT IN THE HIV RESPONSE

Seventeenth Meeting: Geneva, 14–15 October 2015
Meeting report and recommendations

This report was prepared by the Secretariat of the UNAIDS Reference Group on HIV and Human Rights after its seventeenth meeting (October 2015). The views contained herein are the views of the members of the Reference Group and do not necessarily reflect the views of the UNAIDS Secretariat or the Co-sponsors of the Joint Programme.

SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

1. UNAIDS staff as human rights defenders

Recognizing the UNAIDS Secretariat's efforts to ensure that staff embrace their duties to advance HIV-related rights, and given the importance of human rights to achieving the targets in the UNAIDS 2016–2021 Strategy, the Reference Group recommends that mandatory human rights training be implemented for all UNAIDS staff.

2. Middle-income countries

The Reference Group is extremely concerned that external funding withdrawn from middle-income countries (MICs) will not be replaced by domestic sources. As a result, it is likely that services for key populations and other marginalized groups will decline or be discontinued. The Reference Group recommends that modelling exercises be undertaken to demonstrate the likely outcomes for key populations within MICs, the attainment of Sustainable Development Goal (SDG) 3.3,¹ and the attainment of UNAIDS' targets as laid out in Strategy 2016–2021.

3. Data protection and phylogenetic science

The Reference Group is troubled that phylogenetic analysis is beginning to be used to refine treatment interventions, yet it seems unclear UNAIDS has given consideration to the potential human rights consequences of ways in which this data may be used — e.g., in criminal prosecutions of people living with HIV — unless it is adequately protected against such use. We call on UNAIDS to continue to engage with scientific, human rights (including privacy rights), and ethics experts on how to use phylogenetic analysis in research and planning related to HIV and other communicable illnesses in ways that are ethical and protective of human rights, and to consider drafting a guidance note on the matter.

¹ Goal 3.3: “By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.”

4. Drug policy and the rights of people who use drugs

The Reference Group appreciates UNAIDS' effort to conduct high-level meetings on HIV and drug policy issues with national missions in Geneva, New York and Vienna in the lead-up to the UN General Assembly Special Session on "the world drug problem" (in April 2016). It is very important in the spirit of those meetings for UNAIDS also to have a written position to share with national missions that clearly explains both (a) the health and human rights case for comprehensive HIV services for people who use drugs, including harm reduction services, and (b) explains that HIV services are undermined by criminalization of drug use and minor infractions, which leads to the normalization of treating drug use as a criminal matter rather than as a concern of health and social services.

The Reference Group urges that the efforts of the UNAIDS regional office in Bangkok, and its collaborators, to close the compulsory "drug treatment" centres be sustained and intensified until there are more concrete moves to build community-level services and cease abusive detention in the guise of treatment.

The Reference Group further urges that UNAIDS in Eastern Europe and Central Asia do everything possible to ensure that the rights of people who use drugs, their organizations and allies are respected and their meaningful participation ensured in all future planning of regional HIV conferences. UNAIDS should also find alternatives to holding the regional conference in the Russian Federation, which is inherently disempowering for civil society and people who use drugs and is not consistent with UNAIDS' human rights values and goals.

5. HIV prevention

The Reference Group is concerned that HIV prevention efforts have been receiving less focus and funding in recent years, including with respect to the provision of basic prevention materials such as condoms and sterile injection equipment. We therefore support calls for increasing investment in HIV prevention work and the more ambitious prevention targets in Strategy 2016–2021.

We note that the prevention agenda provides many opportunities to advance legal and human rights interventions that are needed in order to reduce HIV-related risks, such as ending police harassment, providing access to justice for human rights violations, and decriminalizing sex work, drug use and same-sex relationships. We therefore call on UNAIDS to work together with the Global Fund to Fight AIDS, Tuberculosis and Malaria and other partners to support legal and human rights interventions that are needed to enhance HIV prevention efforts and access to such services.

We acknowledge the invitation (by Karl Dehne, Chief, Prevention, UNAIDS) to assist with articulating human rights within the comprehensive prevention package. We commit to providing guidance on prevention within the human rights framework, including providing appropriate literature to support the prevention team in elaborating this area of work.

6. Fast-track approach

The Reference Group appreciates UNAIDS' efforts to accelerate access to services for the most vulnerable as a key dimension of the "Fast-Track" approach, and notes that human rights must form an essential part of fast-tracking the response. It welcomes the guidance being produced to ensure that the Fast-Track approach is firmly grounded in human rights, and recommends that such guidance be rolled out in efforts at the national and city levels to accelerate the HIV response.

7. Intellectual property and access to medications

The Reference Group remains deeply concerned about the ability of people to have access to quality essential medicines at affordable prices. Despite substantial progress, it is still the case that less than half of people living with HIV have access to antiretrovirals — and even as UNAIDS and governments commit to prevention and treatment targets that will require further, substantial scale-up of access to ARVs, new barriers are also being raised, including through trade agreements with more restrictive intellectual property rules and other provisions. The Reference Group is concerned that existing action within the UN system has not proven sufficient to date to overcome existing, or forestall new, barriers of this sort.

The Reference Group therefore welcomes the prospect of the UN Secretary-General convening a high-level panel, supported by UNDP, to explore the tension between human rights and trade rules regarding intellectual property, and to propose measures to remedy or alleviate this tension in ways that protect and advance access to existing and new medicines, as essential elements of realizing the right to the highest attainable standard of health. This would be in keeping with the 2012 recommendation of the Global Commission on HIV and the Law (Recommendation 6.1), which the Reference Group has previously endorsed.

Should the Secretary-General convene such a panel, the Reference Group recommends that UNAIDS work with UNDP to support the work of this body, with a view to ensure that its process enables the substantive contribution of all concerned actors within the UN system and by non-UN actors, including civil society human rights advocates and representatives of people living with, and communities most affected by, HIV. The Reference Group in particular encourages UNAIDS and UNDP to support greater flexibility in intellectual property and trade rules for countries, and particularly low- and middle-income countries (who face the greatest burden of disease and the greatest gaps in access) to take measures to advance access, and to support the development of an equitable global system for R&D of health technologies that generates more and better innovation to address global health needs.

8. Civil society

The Reference Group recalls its Recommendation 9 from the 16th Reference Group meeting:

Recognizing the importance of civil society in the HIV response, the Reference Group is concerned that funding for civil society action on rights-based responses to HIV remains dismally low. The Reference Group recommends that the UNAIDS Secretariat address this matter urgently, and advocate with governments and other funders for rapid increases in the funding available to civil society organizations for HIV-related work. Moreover, the Reference Group requests that UNAIDS advocates for civil society funding to be distributed effectively and equitably.

We commend UNAIDS for including commitments to support civil society in the Strategy 2016–2021 and call on UNAIDS to urgently take action to support, fund and empower civil society organizations throughout the world to actively participate in service provisions, access to justice and advocacy activities within the global HIV response.

Moreover, we call on UNAIDS to take steps to ensure that the High-Level Meeting on HIV in June 2016 is a space in which civil society, including members of key affected populations, can engage meaningfully and safely.

9. Increased collaboration with the Global Fund

The Reference Group encourages increased engagement and collaboration between the Community, Rights and Gender Department of the Global Fund to Fight AIDS, Tuberculosis and Malaria and the Law and Human Rights unit of UNAIDS, in order to better advance shared objectives.

We further welcome opportunities to collaborate — formally or informally — with the Human Rights Reference Group of the Global Fund.

STRENGTHENING HUMAN RIGHTS AT A CRITICAL MOMENT IN THE HIV RESPONSE

UNAIDS Reference Group on HIV and Human Rights
Seventeenth Meeting, October 2015
Meeting Report

The seventeenth meeting of the UNAIDS Reference Group on HIV and Human Rights took place in Geneva, 14–15 October 2015. It afforded the opportunity for Reference Group members to learn about new UNAIDS initiatives, engage with various UNAIDS staff members, discuss persistent human rights challenges in the global HIV response, and strategize around effective policies and programmatic intervention to protect the rights of key populations and people living with HIV in the roll-out of the Sustainable Development Goals (SDGs) and UNAIDS’ Fast-Track approach. The report that follows summarizes those discussions. In the course of its deliberations, the Reference Group formulated several key conclusions and recommendations (see preceding “Summary”). The Reference Group looks forward to opportunities to engage with the UNAIDS Secretariat and others regarding the implementation of these recommendations.

THE CONTEXT OF THE 17TH REFERENCE GROUP MEETING

The seventeenth meeting of the UNAIDS Reference Group on HIV and Human Rights (the Reference Group) was opened by Mariangela Simão, Director of Rights, Gender, Prevention and Community Mobilization. She reflected on the importance of the current political moment. In this regard, she noted the significance of the adoption of the Sustainable Development Goals (SDGs) a mere three weeks prior to the Reference Group meeting, the then-ongoing negotiations towards an updated UNAIDS Strategy for 2016–2021,² and the upcoming High-Level Meeting on HIV (scheduled for June 2016). So while the political environment for enhancing the response to HIV, including addressing the human rights dimensions of the epidemic that require attention, is not encouraging, it is nonetheless a decisive moment for the future of the HIV response.

Luisa Cabal, Chief of Human Rights and Law, provided an overview of the work of her unit during the preceding year.³ A key consideration has been how to raise the profile of human rights in the lead-up to the 2016 High Level Meeting on HIV (HLM). Mainstreaming human rights within the Fast-Track approach also continues to be a focus of her team. In terms of specific programming, advocating for funding for HIV-related human rights programming is one area where the team has been focusing; eliminating discrimination in healthcare settings is another. Cabal also discussed UNAIDS’ response to crises and emergencies: in the past nine months, UNAIDS had engaged in over twenty situations, which efforts usually depend heavily on local offices. Finally, she explained initiatives within UNAIDS to articulate human rights protection as an expectation of all staff, including through the establishment of staff awards and sharing good-practice examples across regions.

On behalf of the UN Development Programme (UNDP), Tenu Avafia, Policy Adviser in the HIV, Health and Development Group, outlined relevant activities, in particular with respect to ongoing follow-up on the recommendations of the Global Commission on HIV and the Law.⁴ Central to these activities have been strategy meetings regarding drug policy, LGBTI persons, and young women and adolescent girls. Avafia also explained that national legal environment assessments (LEAs) are being rolled out in many countries — some have already been completed, many more are in progress or planned. In addition, legal reviews of HIV-specific or HIV-related laws have been conducted in ten countries. UNDP has also supported regional and national dialogues in

² *On the Fast-Track to End AIDS* was adopted at the 37th Programme Coordinating Board Meeting, 26–28 October 2015, and is available on-line via www.unaids.org.

³ The slides and document presented by Luisa Cabal are on file with the Reference Group’s secretariat.

⁴ Tenu Avafia is an official observer on the Reference Group, representing UNDP. His slides are on file with the Reference Group Secretariat.

multiple countries, which Avafia identified as an effective entry point to generate interest in LEAs and reviews of problematic legislation. Another area of work has been trainings and consultations with judges, parliamentarians and law enforcement. Finally, Avafia provided an overview of various knowledge products which had been produced or updated by UNDP over the past year, including implementation tools, a discussion paper on the development dimensions of drug policy, and updating the legal assessment tool to include tuberculosis.

The Reference Group appreciated these presentations and the opportunity to ask about various UNAIDS and UNDP initiatives. Reference Group members noted that some of the activities presented related directly to the discussions and resulting recommendations of the sixteenth Reference Group meeting. As in previous years, with respect to keeping human rights at the centre of the work of the UNAIDS Secretariat and the Co-sponsors, the Reference Group took note of the scope of the task in relation to the resources available, including noting the limited staff complement able to carry out this work and the need for building more capacity and expertise on human rights within the UNAIDS Secretariat and UNDP.

Several Reference Group members raised the critical issue of middle-income countries (MICs) losing external funding for their domestic responses. People will fall through the cracks in these countries if it is left to national governments to fund human rights work and services for key population. Many very poor people live in MICs; per capita national income is not the correct indicator when determining need in relation to poverty or disease. It was suggested that the Reference Group needs to directly address the fact that the impact of lost funding for human rights programming in MICs is not something that can be mitigated. We cannot end the HIV epidemic without human rights programming in MICs.

LOOKING FORWARD TO 2030: “THE END OF AIDS”?

At its sixteenth meeting, the Reference Group had offered its expertise and support through the important Strategy update process. It also drew attention to the importance of focusing on key populations and their critical role in an effective response. Furthermore, in September 2015 the Reference Group sent a letter to Kent Buse, Chief of Strategic Policy Directions, offering eight high-level comments on the draft Strategy text, including guidance on specific issues as well as on overarching issues.

In his engagement with the Reference Group, Buse acknowledged the input provided by the Reference Group for both its substantive and its strategic importance. He noted that what distinguishes this strategy from the previous one is: more focus on location and population, based on better data; rebalancing the perceived over-emphasis on treatment; the notion of front-loading investments; and that it is embedded in the framework of the SDGs. He also noted that member state negotiations define the final document and that push-back had been strong on several issues of particular concern to the Reference Group.

Buse indicated that overall he felt that human rights were quite strong and prominent in the most recent draft of the updated Strategy. In particular, he emphasized that focusing resources on those who are being left behind and addressing the root causes of their exclusion was a central theme. Moreover, explicit language on discrimination, removing punitive laws, and the GIPA principle are now included. He noted that an excerpt from the preamble to the United Nations’ Charter is featured on the cover to emphasize that the HIV response has to be undertaken within the human rights framework.

Pradeep Kakkattil, Senior Adviser — Office of the Chief of Staff, updated the Reference Group regarding plans for the High Level Meeting on HIV, which he confirmed would take place in early June 2016. The HLM will feature a three-day General Assembly session and a number of side events. A mechanism has been requested to provide for civil society engagement, and a parallel meeting of city mayors may also take place. Regional consultations are to begin in January 2016. Momentum towards the HLM is expected to build through various events happening in the interim, including the Programme Coordinating Board adopting the renewed UNAIDS Strategy for 2016–2021, the Human Rights Council discussion on HIV and human rights in March 2016, and the UN General Assembly Special Session (UNGASS) on “the world drug problem” in April 2016.

Kakkattil acknowledged that there are a number of risks associated with the HLM, including maintaining the political space for HIV, engaging new leaders who do not have a history with AIDS, the challenges facing countries transitioning to middle-income status, the potential shortfall in needed financial resources, and

articulating the new vision of the AIDS movement. The HLM will need to address these issues and produce tangible results to which we can hold states accountable.

In the discussion that followed about the future of human rights in the AIDS response, the political nature of these inter-governmental processes and the role of UNAIDS was interrogated. Does the organization soften its expert opinion for political expediency? With seemingly everything up for negotiation, do we not risk losing earlier victories? If what needs to be done to end AIDS is politically unpopular, how can UNAIDS navigate the waters to negotiate a solid Strategy without endorsing or perpetuating irrational or unscientific attitudes of political leaders? One Reference Group member offered the cautionary note that if the Strategy and Political Declaration are palatable to all states, then UNAIDS will not be any different from other UN agencies. It is important to remind States that this is about an effective response. The Strategy must provide a vision, not the lowest common denominator.

DRUG POLICY AND HUMAN RIGHTS

Drug policy and the right of people who use drugs remain a critical concern of the Reference Group — and are particularly important at this time because of the upcoming UNGASS on the world drug problem. Joanne Csete, chair of the Reference Group’s sub-committee on drug policy, provided an overview of the sub-committee’s work to open the Reference Group discussion on drug policy. That work included the group’s submission in May 2015 to the Office of the UN High Commissioner for Human Rights (OHCHR) as part of that office’s first study of human rights and drug policy issues, as well as ongoing engagement on various matters with Monique Middelhoff, Senior Advisor, Vinay Saldhana, Regional Director for Eastern Europe and Central Asia, and Steve Kraus, Regional Director for Asia and the Pacific, who were present to address the Reference Group.

Middelhoff explained that while text negotiations for the UNGASS declaration will not begin until January 2016, the strategy is already being developed with various briefings and meetings taking place. Mariangela Simão further explained that UNAIDS has been positioning itself to engage in the discussions under the broader rubric of health issues (and not just HIV) on the drug policy agenda, where there is a lack of political leadership. She noted that harm reduction, as previously suggested by the Reference Group, is clearly something for which UNAIDS will advocate — harm reduction within the broader context of health and human rights, in a people-centred approach aimed at securing better health outcomes for individuals and public health.

Kraus reported to the Reference Group on the January 2015 Asia-Pacific intergovernmental meeting on HIV and AIDS. At least 18 of the 20 countries reporting had articulated recommendations to improve their policy environment with respect to HIV and had included the need to address drug use in their review. They decided to continue undertaking national reviews on law and policy barriers, to undertake national consultations to promote access to medications and diagnostics, and to continue looking at national investment and sustainability plans.

He also reported on progress towards closing compulsory drug detention centres in the region, including commitments made a month prior at the Third Regional Roundtable on Compulsory Detention Centres for countries to make data on their detention centres available — number of centres, number of detainees, average length of detention, and intention to retain or close centres. He was pleased to report that at this same meeting, all nine countries agreed to a strategy to transform compulsory treatment centres into voluntary centres and to report annually on progress toward this goal. The Reference Group welcomed this development, noting however that considerable work still needs to be done in order to meet the commitments.

For his part, Saldanha spoke about UNAIDS’ continuing engagement in Russia and the efforts to maintain UNAIDS’ influence and independence within the region. The Reference Group used this opportunity to highlight its concerns regarding the 5th Eastern Europe and Central Asia AIDS Conference (EECAAC), to be held in Moscow from March 23–25, 2016. Members emphasized that an alternative venue for this important conference must be found in future and the meaningful participation of key populations must be ensured.

The Reference Group is committed to supporting the UNAIDS Secretariat and regional staff in preparing principled, public health and human rights-based positions for the EECAAC and the UNGASS. Noting the

excellent paper prepared by OHCHR for the UN Human Rights Council,⁵ the Reference Group urged UNAIDS to prepare a bold position paper on drug policy and the rights of people who use drugs. UNAIDS has the opportunity to take control of the discussion on harm reduction and HIV, making a strong statement about the difficulties of providing harm reduction in oppressive environments. The UNGASS is a unique opportunity to set a new tone and content for global drug policy.

AFFORDABILITY OF AND ACCESS TO COMMODITIES

At its sixteenth meeting, the Reference Group had expressed its extreme concern that the 90-90-90 treatment target would not be met without addressing the challenges posed by intellectual property laws and issued five recommendations to the UNAIDS Secretariat. Following up, at this meeting Tenu Avafia, Policy Advisor, UNDP, and Carlos Passarelli, Senior Expert, Treatment, UNAIDS, reported back to the Reference Group on progress towards advancing the intellectual property (IP) agenda within the Joint Programme and responding to the Reference Group's recommendations.⁶

In terms of key developments from 2015, some of the items highlighted by Avafia and Passarelli were:

- Several key guidance documents have been released, including competition law guidance and guidelines on examining pharmaceutical patents.
- There has also been a reasonably successful effort to ensure the inclusion of consistent language within the renewed UNAIDS 2016–2021 Strategy regarding the use of TRIPS flexibilities, attention to trade agreements, and advocacy on these issues to advance access to treatment.
- The Equitable Access Initiative (EAI) had been launched by the Global Fund (with eight international organizations), examining alternatives to Gross National Income (GNI) as the sole indicator to use in categorizing countries' ability to fund responses to HIV (and TB and malaria) domestically and their potential eligibility for support from the Global Fund. It was noted that Michael Kirby, a member of the Reference Group, is a member of the EAI.
- The TRIPS Council of the World Trade Organization (WTO) has been debating extending a waiver of TRIPS obligations with respect to pharmaceuticals for least developed countries; the current waiver runs until the end of December 2015. UNDP and UNAIDS issued a statement in favour of an indefinite waiver for LDCs.⁷
- After several years of non-transparent negotiations, an agreement was reached by the negotiators of the Trans-Pacific Partnership (TPP), including numerous "TRIPS-plus" provisions. (The final text was not yet released officially, but had been leaked.⁸) Both UNDP and UNAIDS had previously produced materials outlining the harmful consequences of TRIPS-plus provisions in such agreements, and in July 2015, UNAIDS issued a news release calling on states to preserve flexibilities in TRIPS and specifically expressing its concern about the TPP. Domestic ratification of the TPP is anticipated to be difficult in some countries, including possibly in the United States as a result of considerable opposition, including in the Congress.
- Recommendation 6.1 of the Global Commission on HIV and the Law called for the establishment of a high-level panel to recommend a new intellectual property regime for pharmaceutical products. As reported previously to the Reference Group, UNDP had been pursuing this recommendation with the UN Secretary-General and those efforts were continuing.⁹
- The UNAIDS Secretariat convened a "think tank" on access to medicines and IP, which meeting was held

⁵ Office of the High Commissioner for Human Rights, *Study on the impact of the world drug problem on the enjoyment of human rights*, UN Doc. A/HRC/30/65 (September 2015).

⁶ Presentation slides on file with Reference Group secretariat.

⁷ Note that in November 2015, following the Reference Group's meeting, the TRIPS Council approved a decision extending the waiver with respect to pharmaceuticals, but only until 1 January 2033.

⁸ The final text of the TPP as negotiated was released officially in November 2015.

⁹ Note that, a few weeks after the Reference Group is meeting, the UN Secretary-General announced the creation of a High-Level Panel in keeping with the Global Commission's recommendation: see <http://www.unsgaccessmeds.org>. The Panel is to be supported by UNDP, in collaboration with UNAIDS. Reference Group member Michael Kirby has been appointed as a member of the panel and will chair its Expert Advisory Group; Richard Elliott, member of the secretariat to the Reference Group, has been appointed to the Expert Advisory Group.

in May 2015. Christine Stegling, chair of the Reference Group’s sub-committee on intellectual property and access to medicines, and Richard Elliott, of the Reference Group’s secretariat, participated. The group focused its discussion on exploring better integration of intellectual property and access to medications policies and activities into the joint programme. UNAIDS’ senior management has expressed support for the proposed workstreams: advocacy, technical support and mainstreaming IP within UNAIDS. Critical venues for advocacy include the upcoming High-Level Meeting on HIV, the WTO Ministerial Conference, and the 2016 International AIDS Conference.

The Reference Group congratulated Passarelli and Avafia on these multiple initiatives and the emerging success with respect to advancing the IP and access to medications issue within the United Nations. During the subsequent discussion, Reference Group members discussed the opportunities and challenges at the various venues and with different agencies (e.g., WHO, WTO, Medicines Patent Pool, etc.) The group agreed that the Reference Group sub-committee on IP and access to medications should discuss next steps and priorities.

VARIOUS INITIATIVES AIMED AT ACHIEVING THE FAST-TRACK TARGETS

At its sixteenth meeting, the Reference Group had expressed concern that the Fast-Track strategy was rolling out without a clear road map or proper consideration of human rights. The Reference Group therefore welcomed presentations on various initiatives and the opportunity to engage with key staff members regarding their human rights content and/or challenges.

An overview of the Cities Initiative was provided by Michael Hahn, Chief of Global Financing and Partner Coordination. He conceptualized Fast Track as a movement to find the gaps and accelerate access to services for the most vulnerable. Recognizing that significant changes to legal frameworks are a necessary but longer-term goal, the immediate focus is on promoting practices that can be implemented immediately. Examples include lay-person HIV testing, making available three-month supplies of medications (rather than one-month), community service delivery, and working closely with police to provide safer spaces at drop-in centres and clinics. Hahn indicated that building consensus to tailor services for high-priority groups, and updating the narrative about HIV testing and HIV/AIDS, are the biggest challenges within this approach.

Martina Brostrom, Technical Adviser — Office of Special Initiatives, updated the Reference Group on progress with the 90-90-90 treatment agenda. She noted that as a result of the last engagement with the Reference Group, the Reference Group co-chairs had been invited to join the Scientific and Technical Review Committee (STAC) and the Reference Group’s input on the first 90 (i.e., HIV testing) was considered.

She identified two current priorities for the treatment agenda. First is the issue of human resources for health. Given the objective of doubling the number of people on treatment, they have recognized that it is not possible without equipping and strengthening health systems differently. Task-shifting has remained limited, in part because it is not sustainable when primarily of a voluntary nature. Moreover, it is critical to ensure that task-shifting does not result in compromised quality of care — mechanisms must be put in place to ensure that patients benefit from new delivery models. Finally, as treatment expansion continues, it becomes more of a chronic care model (as opposed to an infectious disease model) and therefore remote monitoring, self-care by stable patients and similar changes are expected in order to alleviate some of the long wait times and high costs that currently pose barriers.

The second priority relates to pediatric treatment expansion. Treatment coverage for children has lagged behind that for adults; UNAIDS is therefore attempting to address the specific challenges that have resulted in this ongoing disparity. In this regard, they have been successful in negotiating lower prices for early infant diagnostic technologies, appointed a new ambassador for the pediatric treatment agenda, and helped mobilize PEPFAR resources for pediatric treatment.

The report to the Reference Group on community mobilization and engagement was delivered by Chris Collins, Chief of Community Mobilization. Collins identified getting more money into communities for service provision and advocacy as a priority. To this end, the community mobilization department had collaborated with the Stop

AIDS Alliance to produce *Communities Deliver*,¹⁰ providing the evidence base and best practices for community provision of services, and was also producing several advocacy documents to help make the case for investing in communities. He also reported that the recent survey on financing of civil society organizations (over 400 responses) demonstrated that 41% had seen a decrease in funding since 2013, with 50% experiencing a decrease in core funding, and drew to the attention of the Reference Group the report of this research and a related consultation (in which some Reference Group members had participated).¹¹

Collins further reported that activities were being undertaken to support civil society advocacy, including producing a Q&A series and increased communications to civil society; UNAIDS had also hosted an advocacy meeting on Fast Track in May 2015. He also spoke about specific activities with faith leaders, youth, country offices and community engagement in the development of WHO guidelines for the elimination of vertical transmission.

The politics of the HIV response and the need to repoliticize this work emerged as a key concern of the Reference Group. The official Fast-Track discourse seems to privilege good news stories and successes, including considerable self-congratulation for the number of people who are on treatment. However, the Reference Group is concerned that the real barriers that continue to exist, and the reasons those barriers exist, is not something much discussed. One Reference Group member suggested that focusing on identifying barriers to testing and treatment results in an important shift to focusing on structural factors and governmental responsibility. Human rights contribute to identifying the barriers. Patient rights and accountability for quality of care are key components of this human rights-based approach. Listening to key populations and hearing the barriers they identify should be inherent components of the refocusing and targeting which is central to Fast Track.

The Reference Group noted the disconnect between the Fast-Track ambition and the reality of what is happening on the ground. Human rights and key populations are not popular topics with many governments. So while presentations such as these in Geneva say “the right things,” that same messaging is often not heard at the regional level or in-country.

External funding is needed to sustain community services and advocacy, to reach marginalized populations and support grassroots mobilization. A fundamental question then is how to change the politics of funders. Until we figure out how to better support civil society, we are not going to reach the 90-90-90 targets and we will not “end AIDS.”

We all want to see a united and effective response. For that, we need to very consciously put civil society and human rights at the centre of the push to “fast-track” the response and the achievement of the prevention targets and 90-90-90 treatment targets.

IMPLEMENTATION SCIENCE AND HUMAN RIGHTS

Peter Godfrey-Faussett, Senior Advisor, Science Panel, prefaced his presentation with the comment “UNAIDS is not primarily a science organization, but the response does need to be based in science.” He explained the basics of phylogenetics — the analysis of molecular sequencing data to study evolutionary relationships among groups and organisms (in this case, strains of HIV). He noted the many different issues implicated, including such things as privacy rights. He noted that sub-typing analysis is validating some of what we already know about HIV transmission, and also providing some new insights.

Phylogenetic analysis has particular relevance to achieving prevention and treatment targets because it can be used to show where clusters of transmission take place. Such information can be useful in terms of knowing where “test and treat” approaches can be effective or where it may be a priority to make pre-exposure prophylaxis

¹⁰ UNAIDS and Stop AIDS Alliance, *Communities Deliver: The Critical Role of Communities in Reaching Global Targets to end the AIDS Epidemic* (2015), online: http://www.unaids.org/sites/default/files/media_asset/UNAIDS_JC2725_CommunitiesDeliver_en.pdf.

¹¹ *Sustaining the Human Rights Response to HIV: Funding Landscape and Community Voices* (October 2015), online: http://www.unaids.org/sites/default/files/media_asset/JC2769_humanrights_en.pdf.

(PreP) readily available. It can also help provide useful information with respect to drug resistance, developing tailored treatments, and vaccine effects. At the same time, developing a more precise understanding of how transmission is happening makes it more likely that the source of infections can be identified. It makes it possible to show whether different communities are intermingling. This, however, can be highly sensitive information.

The Reference Group, and in particular members who had been at an earlier New York consultation on the use of phylogenetic analysis,¹² advocated for caution when making such data available. Concerns were expressed about the failure to consider the possible impacts of their research into phylogenetics and the very real possibility that it can lead to further stigma and criminalization — particularly for sex workers, people who use drugs, gay men and other men who have sex with men (MSM), and people living with HIV. The Reference Group emphasized the importance of considering how this research is done and who has access to it and for what purposes.

INTENSIFYING HIV PREVENTION

Prevention is a key element of the global HIV response, and the Reference Group expressed concerns that the scale-up of a range of evidence-based HIV prevention interventions should not be sidelined in the excitement over “treatment as prevention” (TasP). A presentation by Karl Dehne, Chief of Prevention, kicked off the Reference Group’s dialogue about the need to revive the push for “prevention as prevention.”

Dehne noted that the updated UNAIDS Strategy 2016–2021 contains ambitious prevention targets, including a 75% reduction in new infections by 2020 and 90% coverage of combination prevention for key populations. Yet how will this be achieved? The 2015 prevention target was missed.¹³ New infections are not falling fast enough and prevention investments are insufficient.¹⁴ The prevention issue highlights the fact that the epidemic does not have a solely technological fix. Dehne requested the Reference Group’s assistance in understanding the human rights interventions that need to be included as part of “combination prevention” (alongside structural, behavioural and biomedical interventions).

The discussion underscored the importance of human rights interventions — such as the seven programmes identified by UNAIDS¹⁵ — as key to efforts to intensify HIV prevention. Reference Group members and UNAIDS discussed how human rights norms and framing should inform, and can strengthen, the prevention agenda. For example, the right to the highest attainable standard of health includes the right to access to harm reduction commodities, the right to accurate sexual and reproductive health information, and the right to be free from violence, to name a few elements. The Reference Group cautioned against using the term “right to prevention” as opposed to referring to the internationally recognized “right to health”— which includes prevention. In the context of the upcoming UNGASS on drugs, it was noted that UNAIDS has an important opportunity to reframe the discourse on prevention (and treatment) in ways that highlight the human rights barriers to achieving HIV-related targets. For example, the ongoing criminalization of people who use drugs impedes efforts to maximize the HIV prevention benefit of various harm reduction interventions (some of which are also criminally prohibited in some countries); it also impedes efforts to achieve among people who use drugs the “first 90” of the 90-90-90 treatment targets (i.e., 90% of those who are HIV-positive get diagnosed).

The prevention challenge should not be seen only as a problem of access, but also often the inability to put prevention into practice (e.g., because of lack of information, gender-based violence, legal restrictions, etc.) Reference Group members also noted, however, that there are many human rights interventions relevant to HIV prevention that do not require law reform. While eliminating punitive laws is a necessary objective, on both

¹² “HIV 2015: Using Phylogenetics to Enhance the HIV Response,” June 4, 2105, hosted by UNAIDS and the New York Academy of Sciences; see http://www.unaids.org/en/resources/presscentre/featurestories/2015/june/20150608_phylogenetics.

¹³ The target set at the 2011 UNGASS was a 50% reduction in new infections by 2015. The actual reduction was about 13%, resulting mostly from declines in high prevalence African countries.

¹⁴ According to Dehne approximately 25% of the budget should be devoted to prevention but currently only 10-20% goes to prevention.

¹⁵ The interventions that UNAIDS identified as key for every HIV response are: stigma and discrimination reduction; HIV-related legal services; monitoring and reforming laws, regulations and policies relating to HIV; legal literacy (“know your rights”); sensitization of law-makers and law enforcement agents; training for health care providers on human rights and medical ethics related to HIV; and reducing discrimination against women in the context of HIV.

human rights grounds and for practical public health purposes, it is also important to implement human rights programming to the extent it is possible and it can have an important beneficial impact even as law reform efforts continue to be pursued. The local context often dictates the appropriate interventions.

There was broad agreement that there is an urgent need to revive the prevention agenda, and to do so with the explicit understanding and articulation, including by UNAIDS, that there is an obligation to provide people with the prevention commodities (e.g., sex workers should have condoms, people who use drugs should have access to harm reduction materials). Simão also noted that UNAIDS would be launching a call for investments in prevention at the Programme Coordinating Board meeting. The Reference Group welcomed Dehne's invitation to work with him in developing a human rights-based approach to prevention.

EMPOWERING CIVIL SOCIETY

A recurring theme throughout the meeting was the critical importance of civil society to the HIV response. So many of the initiatives discussed — from providing community-based testing options to making prevention materials available to everyone — require an active and effective civil society. Yet civil society is in a very fragile state right now, often working in repressive environments, lacking funding and unable to gain access to important policy venues. The Reference Group takes the voices of those on the front lines very seriously. Lip service is not enough — we must ensure that civil society and key populations are able to participate and demand accountability.

Financing is an overarching challenge. Funds do not seem to be reaching grassroots organizations or civil society organizations who have previously been leaders. Many organizations are finding it extremely difficult to provide services to key populations, and as external funding is withdrawn from countries transitioning to middle income status (MICs), services will be discontinued. As one Reference Group member noted: “It is not the natural course of this disease for it to become a disease of the most marginalized people in the world. If that is what it has become, it is because of how it has been treated.” AIDS activism must be supported.

There is no “technical fix” to HIV. The Reference Group consensus is strong: 90-90-90 is unachievable without civil society; we will not end AIDS without civil society; and we cannot celebrate increased numbers of people being tested and treated if human rights violations are taking place and key populations are being left behind. The Reference Group implores the Executive Director and the entire Joint Programme down to the field offices to engage and support civil society.

CONTINUING OUR ENGAGEMENT

In closing the meeting, Mariangela Simão expressed her appreciation to the Reference Group. She invited Reference Group members to continue alerting the Executive Director when there are situations or issues about which that UNAIDS needs to be making a statement. Finally, she underlined that the High-Level Meeting in June 2016 will be extremely important to the AIDS response.