

UNAIDS Reference Group on HIV and Human Rights

Twentieth meeting | Geneva, 4-5 December 2018

This report was prepared by the Secretariat of the UNAIDS Reference Group on HIV and Human Rights. The views contained herein are those 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

At its 20th meeting, the UNAIDS Reference Group on HIV and Human Rights adopted a number of conclusions and recommendations, as set out below. (The full meeting report, capturing the discussions in more detail, follows.)

UN system reform: ensuring attention to HIV and to human rights

- The UN Secretary General is advancing an agenda for reform of the UN system, including greater coordination and coherence of UN presence and activities at country level. Attention to human rights and gender issues is essential for an effective HIV response. The Reference Group encourages the entire UNAIDS Secretariat, from the Executive Director to relevant country staff, to consistently raise these issues in the process of completing the common country assessment (CCA) and developing the UN Sustainable Development Framework (SDF) for each country.

Defending civil society

- Civil society, and the protection and promotion of human rights, are central to the HIV response, yet in many settings the space for civil society to operate, including in defending and promoting human rights, is closing. In keeping with its [previous recommendations](#) (from its 19th meeting in October 2017), the Reference Group recommends to the UNAIDS Executive Director that the UNAIDS Secretariat should play an active role in raising this issue at the highest levels within this UN system. This could include the development of a joint statement of concern as a proactive measure (which statement could inform a broader discussion within the UN system), and ongoing coordination of efforts with UNAIDS co-sponsors and other UN organizations (e.g., OHCHR) in ensuring that civil society organizations can operate freely and effectively in addressing human rights and health and other social challenges, including HIV. The Reference Group would be pleased to assist with such initiatives.

Intellectual property policy and access to treatment

- As it has previously, the Reference Group recommends that UNAIDS senior management dedicate the necessary resources to ensure that there is capacity within the Secretariat to address the issue of IP-related barriers to access to treatment, including providing support to countries needing to address these barriers.

Recommendations of the IEP on sexual harassment, bullying and abuse of power

- The Reference Group wishes to remain apprised by UNAIDS senior management of the actions it intends to take in response to the IEP recommendations to address sexual harassment, bullying and abuse of power within the UNAIDS Secretariat. The Reference Group will continue to provide its views to UNAIDS senior management and to the PCB regarding the way forward, once it has had an opportunity to review the IEP report and management response, and in light of additional developments that may follow regarding the PCB's response to these. (*Note: Following its meeting, the Reference Group subsequently issued and submitted to UNAIDS management and to the PCB statements regarding the IEP report and its recommendations, which statements were also simultaneously posted publicly on the Reference Group's website.*)

Aligning Global Fund support for human rights programs with global HIV prevention goals

- Many of the barriers to more effective, wider-reaching HIV prevention are structural, human rights-related barriers. The Reference Group therefore encourages the UNAIDS Secretariat and the Global Fund to explore opportunities for ensuring that the catalytic funding for human rights efforts being deployed by the Global Fund can be aligned, where relevant, with the goals of the Global HIV Prevention Coalition.

Continued engagement with OHCHR

- The Reference Group will invite the Office of the UN High Commissioner for Human Rights (OHCHR) to continue to send a representative to attend future Reference Group meetings.
- It will also invite an update from OHCHR on its activities of relevance to the HIV response as a standing item on the agenda of future meetings.

Monitoring epidemic transition: ensuring the inclusion of human rights

- The Reference Group offered two immediate observations to UNAIDS specifically about the initiative of setting targets and measuring epidemic transition and control: (1) human rights measures for assessing epidemic transition should include the specific matter of stigma and discrimination, but should also reflect a broader range of human rights indicators; and (2) it will be important to include trans people, people in prison and other closed settings, and women as populations of particular human rights concern in measuring epidemic transition.
- The Reference Group also expressed its desire and willingness to provide further input as this work progressed, and looked forward to being kept informed by the UNAIDS Secretariat.

Biometrics and surveillance in the HIV response: human rights implications

- The Reference Group decided that it should take up this issue with both a brief statement of concern in the short-term and, over the longer-term, develop some normative guidance that could be used to engage policy-makers, donors, researchers, service providers and others.
- Capacity permitting, the Reference Group will make a submission to the UN Special Rapporteur on the right to privacy regarding the matter of biometrics and their use in HIV surveillance.
- The Reference Group also asked that UNDP involve the Reference Group and the UNAIDS Secretariat in the initiative it is currently heading up that is examining this issue.

Sustaining the HIV response in middle-income countries: planning for donor transitions

- The Reference Group recommends that UNAIDS continue to “sound the alarm” with donors about the need to sustain the HIV response, including for key populations and with respect to human rights, and including in middle-income countries.
- UNAIDS needs to actively engage donors in supporting countries facing a transition out of aid eligibility, and civil society organizations in those countries, to stockpile commodities where feasible in advance of exiting.
- UNAIDS also needs to work at country level, and with other countries (e.g., in regional blocs), to mobilize political support for attention to key populations and to human rights post-transition, thereby increasing the prospects of domestic financial commitments to these.
- As a means of ensuring continued civil society existence and engagement in the HIV response at country level, UNAIDS should promote social contracting, particularly for HIV-related services engaging key populations.
- UNAIDS should also continue to gather data and build the case about the need for such services, particularly for key populations, and hence for their funding. UNAIDS country offices could assist in gathering data about what countries are dedicating by way of domestic funds for the 7 key human rights programs recommended by UNAIDS.
- The Reference Group recommends that the UNAIDS Secretariat convene Joint Programme co-sponsors, the Global Fund and other key partners (e.g., PEPFAR, other donors), as well as civil society, to discuss how to manage the challenges of countries transitioning out of aid eligibility, in particular to sustain programs for key populations and for human rights. The Reference Group would be pleased to participate in such a discussion.
- The Reference Group also decided that, subject to a further consideration of the resources available to it and a full consideration of its priorities for the coming year, it would examine more closely whether the geographical division of human beings—for the purpose of determining their entitlement to benefits, including access to medications in the context of HIV and other epidemics—by reference to classifications of countries into the various income categories is compatible with international human rights law.

Drug policy, HIV and human rights

- The Reference Group was disappointed at the limited action by UNAIDS and the UN Office on Drugs and Crime (UNODC), the Joint Program co-sponsor with the lead on HIV among people who use drugs, to continue advocacy in the Asia-Pacific region for the closer of compulsory drug detention centres, in keeping with the previous joint statement by UN (and other) agencies. The Reference Group urges the UNAIDS Executive Director and the UNODC Executive to direct greater attention by their agencies' representatives in the region to this ongoing abuse of human rights, and will communicate this view to them.
- The Reference Group was disappointed that *no* human rights issues were identified by UNODC as ones it intends to raise at the March 2019 session of the UN Commission on Narcotic Drugs (CND), despite there being a basis to do so in the Outcome Document of the 2016 UN General Assembly Special Session (UNGASS) on drugs, and despite the many human rights abuses against people who use drugs that are undermining the HIV response among this key population. The Reference Group would be pleased to provide advice to UNODC, given its position as a co-sponsor of the Joint Programme, regarding key human rights issues it believes UNODC should raise in fora such as the CND (and which other the UNAIDS Secretariat, other Joint Programme co-sponsors and agencies such as OHCHR should also raise).
- The Reference Group welcomes the initiative to develop *International Guidelines on Drug Policy and Human Rights*, and the involvement of UNDP and the UNAIDS Secretariat, in this initiative. The Reference Group recommends that UNAIDS endorse or co-publish, as appropriate, the International Guidelines when they are released (which is anticipated in March 2019 at the CND).
- The Reference Group will be pleased to review and provide input to UNAIDS Secretariat in the development of its updated *Do No Harm* report for use at the CND.

Universal health coverage (UHC)

- The Reference Group encourages the UNAIDS Secretariat, UNDP (as the UNAIDS co-sponsor with lead responsibility for human rights), and related agencies such as the OHCHR, to intervene proactively with Member States in the negotiation of the outcome of the High-Level Meeting on UHC, to ensure that UHC is understood as a necessary manifestation of the right to the highest attainable standard of health, that addressing HIV and AIDS is essential to achieving UHC, and that the declaration and action plan include attention to human rights and gender determinants of health coverage as necessary dimensions of achieving UHC.
- The Reference Group recommends that UNAIDS country-level staff play a role in ensuring that HIV, and HIV community actors, are part of discussions at the country level regarding advancing UHC.
- The Reference Group will develop a position paper on UHC in advance of the multi-stakeholder hearing on UHC being convened by the President of the General Assembly. This will provide input to UNAIDS Secretariat and the PCB in the preparations for the PCB's thematic discussion of UHC (in June 2019), the multi-stakeholder being convened by the President of the General Assembly (by end of July 2019) and the upcoming UN High-Level Meeting (in September 2019). The position paper should also serve as a resource for others within the HIV sector, since there is a need to raise awareness of the UHC agenda and the importance of ensuring it includes HIV.
- The Reference Group also encourages the UNAIDS Secretariat to actively engage in the multi-stakeholder hearing and more broadly the negotiation of the text of the Political Declaration to be adopted at the High-Level Meeting.
- The Reference Group will strike a working group tasked with the development of the Reference Group's position (noted above) and with continued engagement on behalf of the Reference Group in the UHC discussions.

MEETING REPORT

The 20th meeting of the UNAIDS Reference Group on HIV and Human Rights took place in Geneva on December 4-5, 2018, during which time the Reference Group engaged with various staff members of the UNAIDS Secretariat and representatives from Joint Programme co-sponsors, specifically the UN Development Programme (UNDP) (Reference Group co-managers) and the UN Office on Drugs and Crime (UNODC), as well as observer participants from the Office of the UN High Commissioner for Human Rights (OHCHR) and the Global Fund to fight AIDS, Tuberculosis and Malaria. The Reference Group also met with the two Deputy Executive Directors and the UNAIDS Executive Director to discuss a number of issues related to advancing human rights in the HIV response – including specific discussion of the handling of complaints of sexual harassment, bullying and abuse of power at the UNAIDS Secretariat and the anticipated report of the Independent Expert Panel examining this matter.

This report presents a record of those discussions, and the conclusions, recommendations and other action items agreed by the Reference Group.

Meeting participants

Reference Group members: Michaela Clayton (co-chair), Joseph Amon (co-chair), Johannes Mokgethi-Heath, Michael Kirby, Raminta Stuikyte, Christine Stegling, Terry McGovern, Daouda Diouf (partial attendance by teleconference), Richard Elliott (secretariat)

UNAIDS Secretariat: Luisa Cabal (Chief, Human Rights and Gender); Emily Christie (Senior Advisor, Human Rights and Law), Mianko Ramarason (Gender and Human Rights Advisor)

UNAIDS Co-sponsors: Tenu Avafia (Team Leader: Human Rights, Law and Treatment Access, UNDP); Kenechukwu Esom (Policy Specialist: Human Rights, Law and Gender, UNDP)

Observers: Ralf Jürgens (Senior Coordinator, Human Rights, Global Fund to fight AIDS, Tuberculosis and Malaria); Leonardo Castilho (Human Rights Officer, Office of the UN High Commissioner for Human Rights)

Tuesday, 4 December

Discussion with UNAIDS senior management

The Reference Group began its 20th meeting by discussing a number of issues with Tim Martineau, A/Deputy Executive Director, Programme Branch, UNAIDS Secretariat:

- ***In-house capacity on human rights and gender:*** The Human Rights and Gender team in the Geneva headquarters was expected to be back up to full capacity soon, with the recent successful recruitment of a senior staff person focussed on gender. In the field, UNAIDS is recruiting community mobilization advisors (whose mandate includes human rights and gender), with a particular focus on eastern and southern Africa, and expects to be up to 32 such staff in the field by mid-2019. The Reference Group welcomed this update.
- ***UN system reform:*** UNAIDS subscribes fully to the UN Secretary General's agenda for reform of the UN system, including greater coordination and coherence of UN presence and activities at country level. One priority for UNAIDS is to ensure that, within the UN Sustainable Development Framework (UNSDF) and the common country assessment (CCA) for each country, which shape the overall plan for UN support (and is negotiated with the country), there is attention to HIV, including its human rights and gender dimensions. As countries develop their UNSDFs through 2019, UNAIDS headquarters and country

offices will seek to ensure attention to HIV and AIDS, whether as a distinct area of attention or as linked to various factors, as may be most strategic in a given context.

- **Universal health coverage (UHC):** Achieving UHC is one of the agreed Sustainable Development Goals (SDG 3.8), and *includes* achieving access to quality essential health care services and to safe, effective, quality and affordable essential medicines and vaccines for all. UNAIDS shares the view of many in civil society that achieving this goal requires understanding UHC not solely in terms of coverage of *medical* goods and services, but should reflect a broader understanding of health and an understanding that attention to more than simply biomedical factors will be needed to achieve even the coverage of medical goods and services. Like many in civil society, UNAIDS is concerned to make sure that HIV and AIDS are integrated meaningfully into the UHC agenda. The UN General Assembly will convene its first high-level meeting on UHC in late September 2019, with the goal of adopting a political declaration negotiated by Member States. The Reference Group welcomed the commitment that UNAIDS will engage in that process with the goal of ensuring HIV and AIDS, and the lessons learned about what attention is needed to human rights and gender in addressing this health challenge, are reflected in the deliberations and outcome of the high-level meeting.
- **HIV prevention:** There remains an urgent need to reinvigorate the HIV prevention agenda and also rethink aspects of HIV prevention, not least given the dramatic impact of treatment as prevention. The Global HIV Prevention Coalition was launched in 2017 to this end, bringing together UN agencies, member states (including the 25 countries with the highest HIV burden), donors and civil society. The Reference Group sought and received assurances that UNAIDS has maintained, and would maintain, the in-house capacity to support the work of this Coalition.
- **Monitoring progress toward 90-90-90 targets of 2020 and defining targets beyond:** The international community has previously committed to efforts to achieve by 2020 the targets of 90 percent of people with HIV having been diagnosed, 90 percent of those people on effective anti-retroviral treatment and 90 percent of those on treatment having suppressed viral loads. As UNAIDS and the international community look beyond 2020, keeping in mind the Sustainable Development Goal (Goal 3.3) of ending the epidemic of AIDS by 2030, there is a need to identify and generate consensus regarding 2025 programmatic targets. This necessarily includes a technical discussion about defining and measuring targets, but also must be an exercise that catches and holds the attention of Member States, policymakers and the public. Given that human rights are central to achieving these targets, and may also be engaged by how targets are set and progress measured, the Reference Group devoted some time specifically to this topic at the meeting and indicated its interest in further contributing to the work of UNAIDS and others in this exercise. It also welcomed the commitment of UNAIDS management to this end.
- **Shrinking space for civil society:** The Reference Group and UNAIDS share an ongoing concern about continued shrinking of space in many countries for civil society to operate—including groups from and within key populations affected by HIV and human rights defenders. Within the UN system, the High-Level Committee on Programs consists of senior representatives from UN organizations belonging to the Chief Executives Board for Coordination (CEB), the longest-standing and highest-level coordination forum of the UN system. The HLCP meets twice annually, and at its next meeting, in April 2019, the agenda includes discussion of this concern. The UNAIDS Deputy Executive Director committed to share the background paper that is being prepared for this discussion, once it is available.

Note: The Reference Group recalls that, at its previous meeting (19th meeting, October 2017), it had formulated a [number of recommendations](#) on this issue to the UNAIDS Secretariat and Executive Director, and to UNAIDS co-sponsors, on this issue, including:

- *raising these concerns directly with governments and in multilateral fora;*
- *issuing a joint statement;*
- *providing direct, concrete support to civil society organizations at country level, including creating secure platforms and spaces for such organizations to meet;*

- *incorporating into country plans the need to address restrictions on HIV-related activities of civil society organizations as part of the plan; and striking a senior-level working group across co-sponsors (and with the involvement of OHCHR) to document the adverse impact on the HIV response of such restrictions and identify measures for UN agencies, member states and donor to take in response.*

In addition, the Reference Group recommended that the PCB request a study into this issue and convene a thematic discussion of this challenge to an effective HIV response.¹

- **Sex work:** The Reference Group was pleased that it appears there is little further discussion about revisiting the common UN position on sex work.
- **Intellectual property issues and access to medicines:** It was noted that a [report](#) was coming before the UNAIDS Programme Coordinating Board (PCB) at its upcoming meeting analysing progress in implementing the UNAIDS Strategy 2016-2021 with respect to overcoming IP-related barriers and other factors affecting access to medicines, and to identify gaps, challenges and best practices to better support countries. The report confirms that this remains an area in which there are constantly new developments and challenges in this area at the heart of UNAIDS’ mandate, and that, in the face of emerging new challenges to treatment access, there is a continued need for UNAIDS engagement and for UNAIDS to “intensify efforts to promote access to affordable medicines across low- and middle-income countries, in accordance with its mandate.” Yet as the Reference Group has noted repeatedly for some years, there appears to be little, and shrinking, capacity within the UNAIDS Secretariat to address this. The UNAIDS Deputy Executive Director agrees, as have previous Deputy Executive Directors and the UNAIDS Executive Director, that there is a need for such capacity but states that this would require sacrificing capacity elsewhere within the Secretariat.
- **Regions falling behind:** With regard to efforts to implement a West and Central Africa “catch-up plan,” UNAIDS reports that there has been encouraging mobilization of civil society organizations in the region, and that some donors are supporting work in the region on ending HIV-related stigma and discrimination. UNAIDS is advocating for the abolition of user fees as a particular barrier to health services and hence a constraint on the HIV response; this is supported by PEPFAR. In Eastern Europe and Central Asia, UNAIDS and others continue to observe small islands of progress and success in the response, but overall the region continues to fall behind and it is a struggle to achieve greater gains, in part given the political and policy environment in a number of countries in the region that hinder effective responses.
- **Global Action Plan for health:** In order to accelerate progress toward the achievement of the health-related SDGs, several member states, with the support of the UN Secretary, convened stakeholders in Berlin in October 2018 to develop a [Global Action Plan for Healthy Lives and Well-being for All](#), to be coordinated by the WHO and uniting the work of 11 leading global organizations active in health, including the UNAIDS Secretariat and co-sponsors, with others expected to join. The final plan is to be delivered in September 2019 at the UN General Assembly. Part of the next phase of the plan is to include engagement of civil society. The Reference Group would welcome being kept informed by the UNAIDS Secretariat about the development of the plan. It also requested that the UNAIDS Secretariat ensure attention to human rights in the development of this plan, and would welcome the opportunity to provide input to UNAIDS Secretariat (and others as appropriate) in the course of its development.
- **Addressing sexual assault and harassment, bullying and abuse of power within UNAIDS:** The Reference Group sought and received an update from the A/Deputy Executive Director regarding the status of, and plans for the release of, the [report of the Independent Expert Panel](#) (IEP) formed to examine the handling of allegations of sexual assault harassment and assault, bullying and abuse of power within the UNAIDS Secretariat. (The Reference Group has previously met with, and [written](#) to, the UNAIDS Executive Director regarding the matter on a number of occasions over the course of 2018.) In particular,

¹ There is brief mention of this in a [paper before the 43rd meeting of the PCB](#), but a more in-depth analysis, discussion and series of recommendations is warranted.

the Reference Group was concerned about the possibility that the public release of the report, which had been promised, would be further delayed. The A/Deputy Executive Director clarified some details about the internal timelines for receiving, reviewing and preparing a management response to the report. He noted that the decision about whether and when to release the IEP report lies with the Programme Coordinating Board (PCB) and its Bureau, not with the management of UNAIDS Secretariat. Similarly, it is up to the PCB to decide how to conduct its upcoming discussions of the IEP report and its recommendations. The Reference Group expressed strongly its unequivocal view that the IEP report (and any response to it) must be made public, and that the UNAIDS Executive Director should also make clearly and publicly an unqualified statement to the PCB and its Bureau to this effect. The Executive Director should similarly make a clear public commitment that there will be open discussion with Secretariat staff and civil society about its contents and that there will be action in response. Transparency is essential to preserving and restoring the integrity of the UNAIDS Secretariat, which must be able to credibly carry out its advocacy for human rights and gender equality, and to engage with civil society, if it is to play its important role in mobilizing the international community to respond to HIV. The Reference Group stated its view that there cannot be further delay from the Executive Director in communicating this commitment to transparency, including the position that the IEP report will be made public. The Reference Group requested that this view be communicated directly to the UNAIDS Executive Director as soon as he was available and noted that it would send a written communication to this effect to him shortly. (That [communication](#) was sent a few hours later and posted publicly on the Reference Group's website.)

Note: The Reference Group was advised later in the day (on December 4th) by the A/Deputy Executive Director that the full IEP report, along with the UNAIDS management response, would be shared with the full PCB by the Bureau by that evening, and that the Board would be voting by the end of December 6th regarding whether these items would be made available publicly right away or whether their release would be delayed until after the PCB meeting the following week at which they are to be discussed. The Reference Group was advised that the UNAIDS Executive Director would be communicating his view to the PCB Chair that it should be shared now, in advance of the PCB discussion, and that this would also be communicated by the Executive Director and UNAIDS in response to media inquiries about the status of the report. (The Reference Group was also advised that by January 2019 UNAIDS senior management would be communicating clearer timelines for the actions UNAIDS plans to take in response to the IEP's recommendations.)

Following the vote of PCB members on December 6th, the IEP report was subsequently [released publicly](#), along with the UNAIDS management response, on December 7th.

Having reviewed the IEP report and management response, the Reference Group issued a [statement](#), shared with the PCB on December 11th (and posted publicly on the Reference Group website), that (i) underscored that UNAIDS plays a key role in mobilizing global attention to the ongoing crisis of the HIV pandemic, including attention to human rights, and (ii) urged the PCB to enable the implementation of the IEP's recommendations as a matter of urgency to ensure that UNAIDS can play this critical role.

The IEP report and UNAIDS management response were discussed by members of the PCB on December 11 at the 43rd meeting of the Board. At that time, the UNAIDS Executive Director advised the PCB that he would be stepping down from his position in June 2019 following the 44th meeting of the PCB.

In [decision points adopted at its meeting](#), the PCB: called for immediate implementation of the management response; established a working group to oversee this and to further discuss the IEP report and management response, and propose options to the next PCB meeting for strengthening the PCB's monitoring and evaluation role vis-à-vis the UNAIDS Secretariat; decided to discuss the report of the IEP at a special PCB meeting to be held no later than March 2019, at which time it may bring forward specific recommendations to the UN Secretary General; and called for the immediate initiation of the selection process for the next UNAIDS Executive Director.

Conclusions and recommendations

- The Reference Group encourages the UNAIDS Secretariat, from the Executive Director to relevant country staff, to consistently raise human rights and gender issues, to which attention is crucial for an effective HIV response, in the process of completing common country assessment(s) and developing UNSDFs for each country.
- The Reference Group encourages the UNAIDS Secretariat, UNDP (as the UNAIDS co-sponsor with lead responsibility for human rights), and related agencies such as the OHCHR, to intervene proactively with Member States in the negotiation of the outcome of the High-Level Meeting on UHC, to ensure that UHC is understood as a necessary manifestation of the right to the highest attainable standard of health, that addressing HIV and AIDS is essential to achieving UHC, and that the declaration and action plan include attention to human rights and gender determinants of health coverage as necessary dimensions of achieving UHC.
- In keeping with the centrality of civil society, and of protecting and promoting human rights, in the HIV response, and in keeping with its [previous recommendations](#) (from its 19th meeting in October 2017), the Reference Group recommends to the UNAIDS Executive Director that the UNAIDS Secretariat should play an active role in raising this issue at the highest levels within this UN system. This could include the development of a joint statement of concern as a proactive measure (which statement could inform a broader discussion within the UN system), and ongoing coordination of efforts with UNAIDS co-sponsors and other UN organizations (e.g., OHCHR) in ensuring that civil society organizations can operate freely and effectively in addressing human rights and health and other social challenges, including HIV. The Reference Group would be pleased to assist with this.
- As it has previously, the Reference Group recommends that UNAIDS senior management make efforts to dedicate the necessary resources to ensure that there is capacity within the Secretariat to address the issue of IP-related barriers to access to treatment, including providing support to countries needing to address these barriers.
- The Reference Group wishes to remain apprised by UNAIDS senior management of the actions it intends to take in response to the IEP recommendations to address sexual harassment, bullying and abuse of power within the UNAIDS Secretariat. The Reference Group will continue to provide its views to UNAIDS senior management and to the PCB regarding the way forward, once it has had an opportunity to review the IEP report and management response, and in light of additional developments that may follow regarding the PCB's response to these.

Work on human rights and law of the UNAIDS Secretariat and UNDP

Tenu Avafia (Team Leader: Human Rights, Law and Treatment Access, UNDP) presented an update regarding the work of UNAIDS co-sponsor UNDP over the past year, and some of the priorities for the agency in 2019. Among other things, he noted:

- continued follow-up on the recommendations of the Global Commission on HIV and the Law in its original 2012 report, as well as the release at AIDS 2018 of a [supplementary report](#);
- the adaptation of UNDP's HIV-focussed legal environment assessment (LEA) tool to facilitate such assessments regarding the TB response, with a further updated tool, also incorporating viral hepatitis, anticipated in 2019;
- raising the issue of TB and human rights at the World Lung Health conference;
- partnership in the implementation of regional grants from the Global Fund;
- collaborating with civil society as the co-lead on the development of [International Guidelines on Drug Policy and Human Rights](#) (to be launched in March 2019 at the UN Commission on Narcotic Drugs); and

- continued work on access to treatment and efforts to advance the recommendations of the UN Secretary General's [High-Level Panel on Access to Medicines](#) (noting the need for in-house capacity within UNAIDS Secretariat to strengthen joint work on this).

Challenges for the work of defending and advancing a human rights-based response to HIV include: increased nationalism; shrinking civil society space; the adoption of new punitive laws, policies and practices targeting key populations (e.g., in relation to sex work and sex workers); reduced funding for HIV and human rights; migration and increased vulnerability to HIV of migrants. UNDP also shares the growing concern for human rights (including privacy rights) raised by digitization and the collection and use of biometric data; this will be a topic for further work by UNDP in the coming year. Other priorities for UNDP's work on human rights issues related to HIV for 2019 include: greater effort on addressing HIV among adolescent girls and young women; the launch and follow-up on the forthcoming *International Guidelines on Drug Policy and Human Rights*; and continued engagement, including with civil society, in resisting HIV criminalization.

Luisa Cabal (Chief, Human Rights and Law, UNAIDS Secretariat) provided the Reference Group with an update regarding the work of the UNAIDS Secretariat in 2018 according to three core priorities of her team:

- With respect to *catalysing political leadership and commitment to gender equality and human rights in the HIV response*, she noted the work of the UNAIDS Secretariat in relation: the UN Human Rights Council's 2018 resolution on human rights and HIV; the resolution from the Commission on the Status of Women regarding women, girls and HIV; engagement with the African Commission on Human and Peoples' Rights to produce the Commission's first report on HIV and human rights; collaboration with the Gender Secretariat within each of the African Union and the Southern Africa Development Community; the promotion of dialogues on HIV and human rights between regional human rights systems; monitoring and contribution to common UN positions on sex work and drug policy; and collaboration in developing the forthcoming *Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination*.
- With respect to *advancing rights based on gender-transformative country action*, UNAIDS Secretariat continued to: compile, synthesize and present evidence supporting the need for, and effectiveness of, responses to HIV grounded in human rights and gender equality; respond to human rights crises and provide technical assistance at country level, including informing laws, policies and programmes in more than 20 countries; develop and promote tools for gender-transformative, rights-based national responses to HIV (e.g., the Gender Assessment tool kit); document shrinking civic space and its adverse impact on the HIV response; collaborate with partners in the scale-up of the 7 key human rights programmes in the 20 priority countries in which the Global Fund is supporting intensified efforts in this regard.
- With respect to *harnessing the power of partnerships, movements, and communities to advance human rights and gender equality*, UNAIDS Secretariat continued to: collaborate with scientific experts and civil society organizations in addressing HIV criminalization (e.g., the release at AIDS 2018 of the global Expert Consensus Statement on the science of HIV in the context of the criminal law); build bridges across movements (e.g., collaborating with ICJ in convening the May 2018 Geneva meeting of jurists on misuse of the criminal law); and the development and implementation of the engagement in the [ALIV\[H\]E Framework](#) (Action Linking Interventions on Violence Against Women and HIV Everywhere), which aims to expand the evidence on what works to reduce VAW and to ensure that evidence is applied in the implantation of responses to both HIV and VAW.

Members of the Reference Group thanked UNDP and the UNAIDS Secretariat for their presentations and their work to advance human rights. Group members offered a number of reflections based on the presentations:

- Even where there has been increased funding in some countries to support human rights programs (e.g., from the Global Fund), in some cases there is a challenge with capacity at the country level to implement and scale-up such programs.

- With respect to the ALIV[H]E Framework, it would be helpful to have more evidence from evaluations of the effectiveness of alternatives to the use of the criminal justice system as a response to gender-based violence.
- As has been noted consistently for several years by the Reference Group, there is definitely a need for greater capacity within UN agencies, including the UNAIDS Secretariat, to address the IP-related challenges to treatment access. Countries continue to face pressure to not use the flexibilities that are ostensibly open to them under international law (e.g., the WTO TRIPS Agreement). Note that the new Global Action Plan for Healthy Lives and Well-being for All (“the Berlin Plan”) includes an entire section on sustainability of such efforts, and perhaps this provides an opportunity for UNAIDS and others to make progress on these issues of IP policy, as this is central to the sustainability of global health efforts, including, but not only, in relation to HIV.
- The experience of the past year again demonstrates that there is a need for more systematic, coordinated effort between agencies (e.g., the UNAIDS Secretariat and UNDP) to respond to human rights crises when they arise, such as Tanzania’s recent crackdown on LGBT people and organizations. The Reference Group should consider whether it should or can play a role as well in mobilizing in response to such situations.

Conclusions and recommendations

- The UNAIDS Secretariat and the Global Fund should explore opportunities for ensuring that the catalytic funding for human rights efforts being deployed by the Global Fund can be aligned, where relevant, with the goals of the Global HIV Prevention Coalition, since many of the barriers to more effective, wider-reaching HIV prevention are structural, human rights-related barriers.
- The Reference Group should invite the Office of the UN High Commissioner for Human Rights (OHCHR) to continue to send a representative to attend future Reference Group meetings, and should include an update from the OHCHR on its activities of relevance to the HIV response as a standing item on the agenda of such meetings.

Monitoring epidemic transition: ensuring the inclusion of human rights

The Reference Group welcomed Peter Ghys, Director, Strategic Information and Evaluation (UNAIDS Secretariat) and Laurel Sprague, Chief, Community Mobilization (UNAIDS Secretariat) to share an update on current and planned work regarding the related tasks of (1) setting global targets for 2025 in the HIV response, and (2) monitoring and planning for “epidemic transition”.

Setting targets for 2025 in the HIV response

Most of the programmatic targets currently guiding the HIV response are set for 2020. To keep decision-makers and other actors engaged beyond then, there is a need to identify 2025 targets, on the road to achieving the Sustainable Development Goal of ending AIDS by 2030. The purpose is not to change the 2030 impact targets, but there is a need in setting 2025 targets to incorporate considerations and metrics for the anticipated and desired transition in epidemics. Similarly, the target-setting exercise needs to consider how the HIV response is integrated with other health services and the response to other public health challenges through 2030. Targets must also factor in the potential or desired impact of future technologies (e.g., long-acting ARVs, vaccines). The exercise is not simply one of modelling, but to describe and inform a full response at the country-level, a response that includes actions to be taken by various government actors but also by civil society, in order to achieve the identified targets.

The goal is to influence: national plans and strategies on HIV and AIDS; a possible High-Level Meeting on HIV in 2021 (although this meeting remains to be confirmed); a new UNAIDS Strategy 2022-2026; the Global Fund replenishment efforts for 2019-2022 and 2023-2026; and the engagement of other actors and donors (e.g., PEPFAR). To this end, the task involves identifying programs for which impact has been established through evidence, but UNAIDS recognizes that a comprehensive response will also need to include programs where there may at this time be less research data available regarding impact. The exercise

also needs to measure the impact of advocacy and other social enablers of the HIV response (e.g., policy impact of advocacy and mass media in low-prevalence settings) and ensure they are costed in order to be able to identify and show the cost-effectiveness of improving social enablers (e.g. through human rights programming).

UNAIDS has struck a steering committee for this week, and is convening a series of technical meetings to address target-setting in various areas, including:

- 1) HIV testing and treatment;
- 2) primary prevention;
- 3) social enablers [which meeting is to happen within the first quarter of 2019];
- 4) costs and resources;
- 5) integration (of the HIV response with other efforts); and
- 6) new technologies and their implications.

The goal is to identify targets that are global and relevant for all countries. One key issue that has already arisen is whether the targets should be disaggregated and differentiated for different regions or countries, reflecting the different starting realities of their epidemics. However, the conclusion to date has been that targets should not be set lower in the cases where regions or countries have been falling behind, but rather to set ambitious universal targets and enhance investments and make additional effort in such regions and countries to support them in achieving these targets.

Estimates of the resources needed to meet 2025 targets will focus initially on low- and middle-income countries, but there may be some exploration of adding high-income countries into the analysis as well. The exercise also needs to include some measures of the cost of inaction or insufficient action on HIV, reflecting both the experience to date where targets have been missed because of this as well as projections of the future impact of not meeting targets. UNAIDS aims to have initial estimates of impact by mid-2019 and continue this work on target-setting with a view to a possible High-Level Meeting on HIV in 2021 as a key moment at which international consensus on such targets may be achieved and endorsed.

Epidemic transition or control

Closely related to the question of setting new targets for 2025 is the task of defining and measuring transition in a country's HIV epidemic as progress is achieved, and when it might be possible to determine that the epidemic is "under control" in a given setting. At its previous meeting, the Reference Group held a discussion of how to define and measure the concept of "epidemic control" or transition, and received then an update from a technical meeting that had recently been convened by UNAIDS (in Glion, October 2017). At that time, the Reference Group had noted a concern about how epidemic "control" is discussed and could be interpreted (i.e., in ways that encourage punitive approaches to achieving the desired epidemiological outcome), and also questioned the utility of trying to devise a single quantitative measure as the indicator of progress toward achieving "control" of the epidemic. It was pleased to receive an update and continue the discussion at this meeting.

UNAIDS recognizes, including from the context of efforts to "validate" elimination of vertical transmission, that human rights must be taken into account in assessing whether a country has succeeded in getting its HIV epidemic "under control." The experience to date with HIV, and with other epidemics of infectious disease (from polio to Ebola), is that failure to attend to the social and political context will also mean efforts at bringing an epidemic under control will fail or be undermined. These must, therefore, be factored into indicators used to determine whether a country has achieved "epidemic control" or is on track to do so. Mr. Ghys noted that, at the October 2017 technical meeting in Glion, it was recognized that epidemiological measures of epidemic transition should be accompanied by: (1) improved measures of trends in HIV-related stigma and discrimination; (2) a policy "cascade" that measures whether an enabling legal and policy environment is in place for efforts to eliminate stigma and discrimination. By way of follow-up, he noted that the UNAIDS Monitoring Technical Advisory Group (MTAG) had convened a task team in March 2018 for the development of summary measures of HIV-related stigma, discrimination and enabling policy environment for an effective AIDS response. (One of the Reference Group co-chairs is a member of that task team.) It was noted that UNAIDS' report [*Miles to Go*](#), released in July 2018, identifies many areas in which

action is still needed in order to reach the 2030 target, and includes discussion of numerous human rights-related barriers, which could inform the development of indicators about the “enabling environment” that are useful in assessing epidemic transition or control.

Mr. Ghys explained that UNAIDS was continuing work on developing indicators for measuring epidemic transition and progress toward epidemic control, which would be shared with the task team. A further e-consultation was anticipated, with a plan to have developed a final measure by June 2019. Ghys also noted that the framework for measuring stigma and discrimination would be aligned with the focus areas set out in the [Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination](#), about to be launched (on December 10th) by UNAIDS and partners – i.e., health care settings, workplaces, educational settings, the justice system and households. At the moment, the focus is on four key populations: people living with HIV, men who have sex with men, sex workers and people who use drugs. Another question that remains unresolved at this stage is whether a single composite index will be suitable (and if so how to construct it), or whether it is important to have more visibility for specific elements or issues that should be considered in assessing progress in a given country toward epidemic control.

Mr. Ghys invited the Reference Group to provide feedback regarding: (i) the proposed process, including ensuring broad civil society engagement; (ii) the parameters to be considered in developing a summary measure or measures of epidemic transition and progress toward epidemic control; (iii) particular questions or issues to be considered in the process and perhaps included in the planned consultation. He also invited the Reference Group to identify any “red flags” with what was being proposed by UNAIDS.

Conclusions and recommendations

The Reference Group offered two immediate observations specifically about the initiative of setting targets and measuring epidemic transition and control:

- Human rights measures for assessing epidemic transition should include, but not be limited to, the narrow matter of stigma and discrimination, but should reflect a broader range of human rights indicators.²
- It will be important to include trans people, people in prison and other closed settings, and women as populations of particular human rights concern in measuring epidemic transition.

The Reference Group also expressed its desire and willingness to provide further input as this work progressed, and looked forward to being kept informed by the UNAIDS Secretariat.

Biometrics and surveillance in the HIV response: human rights implications

The Reference Group welcomed: Keith Sabin, Senior Advisor, Epidemiology, UNAIDS, for an update regarding UNAIDS’ work on biometrics in various contexts; Jantine Jacobi, UNAIDS Country Director in Kenya, to discuss recent experience there with concerns regarding the collection and use of such data; and Laurel Sprague, Chief, Community Mobilization, UNAIDS to offer some perspectives from key communities.

Mr. Sabin noted that to date, there is some, but limited, guidance from UNAIDS on the appropriate collection and use of biometric data in HIV surveillance, research and program evaluation. In particular, there is a UNAIDS resource published as [The Privacy, Confidentiality and Security Assessment Tool](#) released in November 2016 to assist in the protection of personal health information (which does make reference to fingerprints and other biometric data), and there are the [Biobehavioural Security Guidelines](#) for populations at risk of HIV, developed by the Global HIV Strategic Information Working Group and released in September 2017 by WHO, UNAIDS and other partners (which also refers to biometric data such as fingerprint codes and under what circumstances these can be considered anonymous data because they cannot be used to reconstruct the original fingerprint images). Sabin offered the view that so far in HIV research, any biometric data being gathered has been fingerprints, not other data.

² The 2017 Guidance issued by UNAIDS, [Fast-Track and human rights — Advancing human rights in efforts to accelerate the response to HIV](#), and in particular the checklists provided therein regarding HIV prevention, testing and treatment services, would be one useful source of potential indicators.

He observed that *biobehavioural surveys* may sometimes find the collection of biometric data useful, but they are not essential, and concerns such as avoiding duplication can be largely addressed via other elements of survey design. The case for gathering some sort of unique identifier information (perhaps biometric data) is stronger with respect to *HIV surveillance* systems, specifically in the context of reporting HIV cases, where there is a higher risk of duplicate reports, particularly the more widespread HIV testing is. The collection of identifying information alongside risk behaviours in case reports may also allow the creation of cohorts useful for further study that can inform HIV responses. However, while capturing risk behaviours in unique case reports may be useful, they are not essential. Finally, gathering unique identifier information is important in efforts to track *engagement with services* across different providers, in order to enable measuring accurately the uptake and coverage of these services (e.g., for combination prevention of HIV); without such data, his view was that there would be a loss of efficiency and effectiveness in combination HIV prevention efforts. But even here, a unique identifier need not necessarily be biometric data; it could instead, as has been done in some settings, be a unique object provided to participants. While taking issue with certain claims in the [background paper](#) by Kavanagh et al³ that was before the Reference Group, Sabin generally concurred that their analytical framework for determining when biometric data might be legitimately gathered was useful and could be applied, with some additional considerations, by UNAIDS. That framework considers 4 scenarios, based on an analysis of both the level of stigma and the legal environment in a given setting, recommending that biometrics only be used in a context of low stigma and adequate legal protections (e.g., for privacy, against discrimination).

Ms. Jacobi presented on experiences gained in Kenya regarding integrated bio-behavioural survey (IBBS) efforts. In pursuing programmes to address HIV among key populations, the Ministry of Health is preparing new estimates of the size of such populations. However, in Kenya key populations are criminalized and face serious societal stigma and discrimination, as well as the risk of violence. UNAIDS had provided advice to the ministry outlining some operational and human rights considerations, and made recommendations to address the concerns raised by key populations. Following this, the IBBS was put on hold and it was agreed to develop a national policy on data privacy, and to identify safe storage of data. The ministry has agreed key populations should be involved in developing this policy. The criminalization of, and societal stigma and discrimination against, key populations remains an ongoing challenge that must be addressed in this process. She noted that UNAIDS would find helpful the support and input from the Reference Group in addressing this issue.

Ms. Sprague noted that the international networks representing key populations have been unanimous in insisting on the need for vigilance against misuse of HIV-related data that identifies individual people. She noted an emerging concern about “molecular HIV surveillance” being used to “support” people in achieving viral suppression: such data can easily be used, and has been used, to also “justify” very punitive approaches and interventions targeting people living with HIV.

Reference Group members shared a number of observations:

- The Reference Group is very concerned about the potential for harmful access to personal health information and its misuse in punitive fashion against people living with HIV and members of other key populations. This concern is heightened in contexts of high levels of stigma and discrimination, and particularly in contexts where key populations are criminalized. Furthermore, even where there may be legal protections restricting law enforcement’s access to personal health information (such as HIV status, viral load, risk behaviours which may be criminalized or at least stigmatized, etc.) that is gathered in the context of HIV surveillance, research studies or the provision of services, police may still be able to exploit the lack of knowledge of this fact on the part of individuals detained or with whom they are interacting. This underscores the need for legal literacy (“know your rights”) programs and access to legal services to help defend rights. It also underscores the need for researchers, policymakers, service providers and others involved in collecting personal data – particularly data, including biometric data, that

³ M. Kavanagh et al., Biometrics and public health surveillance in criminalised and key populations: policy, ethics, and human rights considerations, *Lancet HIV* 2019; 6(1): PE51-E59 (e-published October 7, 2018), DOI: [https://doi.org/10.1016/S2352-3018\(18\)30243-1](https://doi.org/10.1016/S2352-3018(18)30243-1).

can be used to identify unique individuals – to ensure these human rights considerations are taken seriously in their policies and practices.

- It was noted that in some cases, those raising concerns about the human rights implications of gathering biometric data or other identifying information have come under pressure from other actors in the HIV response (e.g., public health authorities, researchers, policymakers) to set aside these concerns because they are characterized as undermining the country’s HIV response.
- The UNDP regional office in Eastern Africa convened a meeting recently where the issue of privacy of personal health information, including biometric data, was a common concern among participants; representatives from 6 of 12 participating countries indicated this was an issue that had arisen. In some contexts, there is a perception that this demand is donor driven (i.e., by PEPFAR), which puts substantial pressure on communities and governments needing resources for their HIV response.
- UNDP and WHO are co-chairing program on sexual and reproductive health and developing a guidance on this. One issue under discussion is self-initiated interventions. Questions are also being raised – as they also were in the context of preparing the recent supplement to the report of the Global Commission on HIV and the Law – about the privacy of data gathered from online apps (e.g., social networking apps used by gay, bisexual and other MSM) and whether police could gain access to and use such data to target communities and individuals, particularly in contexts where they are criminalized.
- The UN Special Rapporteur on the right to privacy will present a report to the UN General Assembly by October 2019 on improving safeguards and remedies for the privacy of health data. The Reference Group may wish to share its concerns in relation to HIV with the Special Rapporteur.
- Donors such as the Global Fund and PEPFAR should have clear policy on this that takes human rights into account. But this is also part of a larger societal conversation regarding the right to privacy, and HIV advocates perhaps need to connect better to broader privacy rights advocacy. Furthermore, one concern is certainly the information that the state may capture, but concerns arise equally in relation to private actors such as corporations gathering, having access to and potentially misusing personal information, including health information. These should also inform any initiative on this issue the Reference Group may wish to take.
- Reference Group members are concerned about the pressure from donors regarding data collection, including its digitalization and compilation into large databases, the security of which has sometimes been breached but which are not necessarily useful. This pressure can come not only from international donors, but also sometimes from government funders of programs (e.g., in the name of grantee accountability, the Romanian government has been requiring providers of needle and syringe programs to gather the passport data of service users).

Conclusions and recommendations

- The Reference Group decided that it should take up this issue with both a brief statement of concern in the short-term and, over the longer-term, a process of developing some normative guidance that could be used to engage policy-makers, donors, researchers, service providers and others.
- The Reference Group will, capacity permitting, make a submission to the UN Special Rapporteur on the right to privacy.
- The Reference Group asked that UNDP involve the Reference Group and the UNAIDS Secretariat in the initiative it is currently heading up that is examining this issue.

Sustaining the HIV response in middle-income countries: planning for donor transitions

The Reference Group welcomed Iris Semini (Senior Advisor, Fast Track Efficiencies) and Nertila Tavanxhi (Technical Lead, Transitions and Sustainability) to discuss UNAIDS’ thinking and approach to sustaining the HIV response in middle-income countries.

Ms. Semini noted that, as reflected in UNAIDS’ *Miles to Go* report, there has been substantial progress regarding both HIV prevention and treatment, but many challenges remain and the HIV response in middle-

income countries (MICs) is in a precarious position not only because of the overall funding gap in the HIV response (of about 20% of the estimated resources needed for the global response in 2017), but also in light of donors transitioning out of supporting countries they deem no longer eligible for support. While there may in theory be domestic resources available for the HIV response, and in some cases there is a greater mobilization of a domestic commitment, we cannot lose sight of the fact that is still primarily international funding that is supporting work specifically to address HIV among key populations. Nor does eligibility for support necessarily take into account the burden of disease in that country and therefore the level of resources required. Similarly, programs on human rights and gender quality are inadequately funded, and the funding available is still primarily from international sources. As a result, one specific issue emerging in MICs in the face of dwindling donor support is the turn to user fees for services; these present a false economy and reinforce inequities in access to care, and represent a specific concern that UNAIDS, with support of the Reference Group, needs to take up as a right to health issue.

Donors who are exiting certain countries need to plan their exit better. It is misguided to base transition solely or primarily on GNP/GNI; other factors must be considered. PEPFAR includes consideration of disease burden; the Global Fund has an allocation formula that comprises multiple factors. But many donors have a less sophisticated approach. Transitions that are poorly planned and executed disproportionately affect key populations, adolescent girls and young women and the “enabling environment” interventions that rely heavily on donor funding. For example, transitions from international assistance in some eastern European and central Asian countries badly compromised their HIV responses—to such an extent that the countries again became eligible for Global Fund support. Common issues arising include:

- the unwillingness of national governments to fund key population programmes;
- a lack of technical or regulatory capacity (e.g. legal mechanisms for contracting HIV services through civil society and community groups);
- unforeseen external events which place countries under too much financial pressure to fulfil prior commitments;
- the lack of formal country-level fora across government and implementers to examine and make sound decisions on transition challenges;
- the devolution of power and budgets to subnational country partners with limited capacity for effective HIV planning, financing and implementation; and
- the lack of funding for human rights work, including advocacy.

In order to sustain the global HIV response, it is essential to tackle “the risky middle.” Almost 70% of people living with HIV will be living in MICs by 2020. There is a growing awareness that GNI per capita alone is an insufficient measure of transition readiness, and MIC experiences in transitioning to domestic funding have not all been successful, despite their apparent ability to pay. If the global community is serious about achieving the SDGs, a tailored approach is needed for the “risky middle” to incentivize domestic resource mobilization in line with countries' abilities to absorb the costs, while avoiding service disruptions.

There are four main components to UNAIDS' proposed “sustainability framework” for responding to HIV and achieving the SDG goal of ending AIDS by 2030:

- unwavering political commitment to shared responsibility;
- investing for impact and robust national strategies;
- delivery for sustained results; and
- sustainable financing.

UNAIDS and donors needs to assist all countries in applying this framework, and need to consider, including in decisions about donor support, several factors:

- rights and equity status;
- ability to pay;
- the disease burden;
- the pace of progress towards control of the epidemic; and

- how much progress the country is making toward universal health coverage (UHC).

Countries in the "risky middle" require tailored support to address emerging gaps created by decreasing donor funding. Technical support should be provided to all countries to develop and introduce tailored and integrated sustainability plans and to establish roadmaps that can help them stimulate domestic resources at their own pace. Special attention and technical support must be in place to support transitions—especially “within-country transitions” which often occur quickly and without prior warning. Monitoring frameworks and revised metrics to measure progress towards sustainability are required.

The Reference Group could support the call for developing a sustainability plan for every country that takes these factors into account. It was noted by the Reference Group that in many countries, we are also seeing the loss of a national-level platform (such as a National AIDS Council or a Country Coordinating Mechanism constituted for purposes securing Global Fund support) for efforts to sustain and coordinate a multisectoral HIV response, let alone advance the broader agenda of UHC.

Ms. Tavanxhi noted that transition planning for the HIV response needs to ensure (i) financial sustainability, (ii) programmatic sustainability, and (iii) inclusive, multi-sectoral governance of the response. Many countries facing transitions (i.e., reductions) in international donor funding for HIV are also introducing major health systems reforms in light of goals such as UHC; it is essential that the HIV response be brought into those processes to protect gains made and sustain a future response. All efforts need to be made to avoid “transition cliffs” – this needs to be reflected in donors’ policies, by donors contemplating partial transition versus complete exist, and by coordinating transition changes between donors. It should also be recognized that long-term assistance will be needed from partners even after transition – e.g., continued access to discounted prices for medicines. It is essential that donors and governments, with the support of technical partners such as UNAIDS, ensure that funding and mechanisms are put in place at country level for sustaining programmes for key populations most at risk – including through “social contracting” of service delivery to key populations by civil society organizations.

As discussant, Reference Group member Raminta Stuikyte noted that the elements of the HIV response that suffer most in MICs when donors and partners exit include:

- services for key populations;
- data, including HIV surveillance data that can inform the ongoing response to be effective;
- the capacity for advocacy for human rights, including legal reforms where necessary;
- community organizing and mobilization more generally; and
- spaces for political dialogue and engagement with policy-makers, such as Global Fund-supported CCMs.

A good illustration is the experience with harm reduction. An estimated 55% of people who inject drugs live in upper MICs, but donor investment in harm reduction is far below what it needs to be, and has been shrinking. The primary source of funding that does exist for harm reduction services is the Global Fund, which is providing two-thirds of international funding for harm reduction. But how will the Global Fund be able to maintain such support in the countries where it is urgently needed, in light of its eligibility policy and its approach to allocations of funding? The future of already-limited harm reduction services in countries where they are needed is bleak, particularly given the frequent lack of domestic political will to invest funds domestically to sustain such elements of the HIV response, often accompanied by a punitive and discriminatory legal and social environment.

This experience underscores that sustainability must be understood as extending beyond donor transition: this needs to include sustaining some engagement and advocacy with governments even after transition, and promoting dialogue between NGOs and government. Opportunities also need to be found where they exist to continue vital support in countries – such as the use by the Global Fund of the “NGO rule” and of regional grants.

To assist with transition, she suggested that UNAIDS can and should:

- Sound the alarm, particularly with donors
- Where possible, create a safety net to soften the impact of donors' policies and exiting (e.g., leave commodities, bring other donors to the table to fund specific things)
- Mobilize political support and influence to increase the likelihood of services needed by key populations, and attention to human rights, being part of the HIV response after the exit by donors supporting these
- Mainstream "social contracting" as part of encouraging governments to support civil society organizations to deliver the services and interventions needed, including for key populations
- Gather and use data and other evidence about the impact of interventions that work, and of the adverse impact of those services going unfunded and undelivered

As an additional discussant, observer Ralf Jürgens, (Senior Coordinator, Human Rights, Global Fund to fight AIDS, Tuberculosis and Malaria), offered a number of observations from the Global Fund's perspective:

- The Global Fund wants to ensure funds flow to where the needs are, and these allocations and decisions should not be based solely on GNI and disease burden, otherwise key populations are left behind. However, we also need to be careful in re-opening current eligibility criteria, as some donors do not necessarily agree with this approach.
- The Global Fund is taking the issue of transition and sustainability a lot more seriously. For example, until the last allocation round, under multi-country and regional grants, Global Fund monies could not be used to pay for direct purchase of commodities; but this has now changed, in part recognizing the need for countries to build up supplies in anticipation of transitioning out of eligibility.
- The main issue is the overall inadequacy of funding, and not just in MICs but also in LICs.
- In some instances, there has been a success in increasing funding – such as the Global Fund's commitment to matching funds for human rights programs and key populations, and the specific initiative to intensify human rights programs in 20 countries. One aspect of this initiative is to encourage countries to commit domestic funds to these programs as well, but in some cases there is no baseline data about the level of domestic support, making it a challenge to measure the increase. Assistance from UNAIDS in getting this data at country level would be welcome.
- This commitment to funding human rights programs in the 20 priority countries has led to a desire to establish stand-alone programs, but in the interests of sustainability, it is perhaps better to think from the outset how to integrate such programming into existing HIV prevention and treatment service.
- This initiative includes a monitoring and evaluation component, with a view to building an evidence-based case for governments to take on these programs longer-term.
- Also, while the Global Fund creates an incentive through its grant-making approach for governments to fund human rights programs as key elements of a comprehensive response, it also recognizes there are some elements governments are very unlikely to fund. The Global Fund is therefore seeking to create alliances with other donors to ensure these programs are sustained longer-term.
- He also noted that the Global Fund is training its staff on sustainability, and perhaps this training would be useful for UNAIDS Secretariat staff as well.
- Another aspect of the challenge for sustainability is that as countries are re-categorized into higher-income levels, this will in some instances translate into higher prices for ARVs and other medicines depending on what stance is taken by suppliers when it comes to negotiated price discounts.

Conclusions and recommendations

- The Reference Group recommends that UNAIDS continue to "sound the alarm" with donors about the need to sustain the HIV response, including for key populations and with respect to human rights, and including in middle-income countries. UNAIDS needs to actively engage donors in supporting countries facing a transition out of aid eligibility, and civil society organizations in those countries, to stockpile commodities where feasible in advance of exiting. UNAIDS also needs to work at country level, and with other countries (e.g., in regional blocs), to mobilize political support for attention to key populations and to human rights post-transition, thereby increasing the prospects of domestic financial commitments to these. As a means of ensuring continued civil society existence and engagement in the HIV response at country level, UNAIDS should promote social contracting, particularly for services engaging key populations. UNAIDS should also continue to gather data and build the case about need for such services,

particularly for key populations, and hence for their funding. UNAIDS country offices could assist in gathering data about what countries are dedicating by way of domestic funds for the 7 key human rights programs recommended by UNAIDS.

- The Reference Group recommends that the UNAIDS Secretariat convene Joint Programme co-sponsors, the Global Fund and other key partners (e.g., PEPFAR, other donors), as well as civil society, to discuss how to manage the challenges of countries transitioning out of aid eligibility, in particular to sustain programs for key populations and for human rights. The Reference Group would be pleased to participate in such a discussion.

Additionally, in the course of the discussion about advancing the UHC agenda and the earlier discussion regarding MICs countries transitioning out of funding eligibility, and further recalling the discussion the previous day of defining targets for 2025 for the HIV response – and specifically the matter of whether targets should be defined universally or by reference to the socio-economic and other characteristics of a given country – an underlying question of considerable concern arose repeatedly: *the human rights implications of classifying countries in this simplistic fashion and hence effectively determining the scope of rights to HIV prevention, treatment and other services*. As it was articulated by one Reference Group member, “we cannot allow people to be categorised out of prevention or out of treatment.” The result is the exclusion of many people living with HIV and of many members of key populations, who end up being left behind, which is antithetical to the very spirit and letter of the Sustainable Development Goals.

The Reference Group therefore endorsed in principle the following resolution, subject to a further consideration of the resources available to it and a full consideration of its priorities for the coming year:

Having regard to

- *the universality of human rights, as expressed in the Universal Declaration of Human Rights and UN treaty law;*
- *the fact that such universal human rights inhere in individual human beings irrespective of their country of nationality, presence or residence;*
- *the acceptance by UNAIDS hitherto of the geographical division of human beings for the purpose of determining their entitlement to benefits, including access to both life-saving and life-enhancing medications and treatment in the context of HIV and other epidemics, by reference to classifications of countries into the categories of “high-income,” “middle-income,” and “low-income” (including “least-developed countries”); and*
- *the inequalities that persist within countries despite their income classifications and that shape the response to HIV, including the achievement of the Sustainable Development Goal of ending AIDS by 2030;*

the Reference Group resolves:

- *to investigate and consider the compatibility of this geographical classification of human rights with international human rights law; and*
- *if it is concluded that such divisions may not be compatible with such law, requests the secretariat of the Reference Group to prepare an options paper on how the actual and potential injustices of the present approach can be reconsidered and corrections or improvements adopted, including by UNAIDS, with a view to the full realization of universal human rights as mandated by international human rights law.*

It was agreed that any such initiative by the Reference Group aimed at rethinking and perhaps redefining classifications of countries by income level, so as to determine how the HIV response is financed and who gets left behind in the context of countries transitioning out of aid eligibility, it would be necessary to link this analysis not only to the SDG on ending AIDS but also to SDGs 1 (on poverty elimination), 5 (gender equality), and 10 (inequality).

Meeting with the UNAIDS Executive Director

The Reference Group members identified a number of specific items that it raised with Michel Sidibé, the UNAIDS Executive Director, during their meeting with him:

- the report of the IEP into sexual harassment, bullying and abuse of power, and the handling of the allegations and the panel's work by UNAIDS management, the damage done to UNAIDS staff and the organization's goodwill, and the need for expeditious action following through on the IEP's recommendations;
- the importance of UNAIDS engaging with donors and MICs facing transition to ensure attention to key populations and to human rights, and the need to convey a more sophisticated message that "ending AIDS" will require such attention;
- strengthening UNAIDS' capacity for response to human rights crises when they arise;
- 'strengthening UNAIDS' in-house capacity for work on IP issues related to access to treatment;
- appointing a new director for the Department of Community Support, Social Justice and Inclusion;
- the human rights dimensions of defining 2025 targets, monitoring epidemic transition and defining epidemic "control";
- the challenging environment of the PCB in 2019, and the importance of UNAIDS and its leadership standing up for human rights, including at the PCB;
- opportunities for integrating human rights into various frameworks and processes (e.g., the "Berlin plan" on global health for all, the UHC agenda), and the need for the presence and engagement by UNAIDS (and its leadership) in such fora and processes as an advocate for human rights (e.g., of key populations, access to medicines).

In the course of the discussion, the UNAIDS Executive Director offered the following observations:

- UNAIDS needs to pay more attention and invest more in the work of the Reference Group, give it greater prominence to assist with the consistent integration of human rights into all aspects of the response.
- He concurs that we need a new narrative for the global HIV response as part of achieving the SDG of ending AIDS. We cannot let HIV and AIDS become thought of simply as a medical issue, when it is not.
- It is clear that progress being made in some areas is jeopardized when governments attack key populations and undermine the ability of civil society to engage in the response, including defending human rights.
- In order to ensure no one is left behind in the HIV response, we also need to encourage governments to address issues they often prefer to ignore. For example, as UNAIDS Executive Director he is encouraging African leaders to rethink punitive drug policies, noting the recent release of the model law by the West African Commission on Drugs.
- UNAIDS also needs to encourage the discussion of UHC to broaden beyond simply the biomedical dimensions and instead reflect a more comprehensive approach to achieving UHC. As Executive Director he supports the idea of a larger meeting, involving civil society groups, that could ensure that HIV – and the lessons from the HIV response – are part of the broader UHC discussion.
- UNAIDS must remain vocal about the gap in financing the global HIV response, and enhance the impact of the message that the world has a window of opportunity to invest that it cannot afford to miss, if the 2030 SDG of ending AIDS is to be achieved. This may also require being more sophisticated in how we use the data that UNAIDS gathers and analyses. UNAIDS must also demonstrate that it is working with countries on transition and sustainability plans, so as to keep donors engaged in the HIV response.
- In the context of the UN system reform agenda of the UN Secretary General, it will be important to ensure that HIV is not conceived of as a health and development challenge solely in biomedical terms. This could result in further weakening of the Joint Programme, particularly if further hoped-for progress on reducing new infections encourages misplaced complacency and is misinterpreted prematurely to conclude there is less need for such an initiative, thereby weakening the HIV response.
- It is now evident that, in the recent restructuring, the Secretariat had lost capacity for attention to IP issues related to access to medicines, and that management needs to act quickly to address this gap.

- There are opportunities for further engaging and mobilizing faith communities with the recent appointment of a new staff person within the Secretariat to lead this work. In response to a specific proposal for the appointment of a higher-level UNAIDS ambassador to faith communities, the Executive Director noted that it would be important to be strategic in engaging in this area by taking into account a shift toward greater engagement of faith-based organizations in a key donor country such as the US.

The Reference Group and the UNAIDS Executive Director also discussed at some length the *report of the IEP into sexual harassment, bullying and abuse of power, and the UNAIDS management response* to the report (neither of which the Reference Group had seen at the time of the discussion as they had not yet been released by the PCB).

Mr. Sidibé noted that the IEP report was very critical of him, but that he nonetheless welcomed many of the recommendations, and has put together a group to implement them. He noted that while he did not wish to present a defensive response, UNAIDS management also identified what it considers to be some inaccuracies or others aspects of the report with which it takes issue, and these are set out in its management response. He noted that the IEP functioned fully independently, and UNAIDS management had not seen a draft of the report before it was finalized, even for purposes of ensuring accuracy—hence the view on the part of management that its response should include some corrections and clarifications where it takes issue with the report.

The Executive Director thanked the Reference Group for its communication the previous day regarding the release of the IEP report and management response, and advised the Group that he had indeed written to the Chair of the PCB the previous evening to express his position that the report should be released without delay, in the interests of transparency. He reiterated that UNAIDS had originally planned to post the IEP report and management response on the UNAIDS website on December 3rd, but there was not consensus on the part of the PCB Bureau with this approach, hence the delay and the Bureau’s eventual decision to put the matter of the timing of the release to a vote by all PCB members by December 6th. The Reference Group welcomed this report from the UNAIDS Executive Director and that he had communicated his support for immediate release of the IEP report; it noted that “in silence there is suspicion” and it was unfortunate that the communications regarding the report and the lack of transparency had contributed to a dominant narrative, including in media, that was unhelpful to the work of the organization as a whole.

The Reference Group urged the UNAIDS Executive Director to ensure that the public message from UNAIDS is that it supports transparency, including the full and timely release of the IEP report and management response, and that management is committed to acting on recommendations from the IEP to address sexual harassment and assault, bullying and abuse of power within the Secretariat. The Reference Group reiterated that UNAIDS senior management must take seriously the concerns that have been raised. The allegations against the former Deputy Executive Director, and the handling of the investigation, have done damage to UNAIDS as an organization, including its relationships with funders and with civil society. The Reference Group’s overriding concern is to ensure that UNAIDS – including its role in mobilizing the global HIV response, including with respect to human rights – is preserved and strengthened, and that it can be a credible advocate for human rights, which necessarily includes reflecting those principles within the organization itself. The Executive Director asked that the Reference Group provide direction to UNAIDS as it moves forward in acting on the findings of the IEP. The Reference Group confirmed that it would do so, continuing to state its reviews and provide recommendations, to UNAIDS senior management and to the PCB.

Update: UNAIDS management and governance

The Reference Group welcomed Gunilla Carlsson (Deputy Executive Director, Management & Governance, UNAIDS) to provide an update on various aspects of management within the UNAIDS Secretariat, as well as external relations, including with respect to resource mobilization.

One major item of discussion was the IEP report. Ms. Carlsson, who had just recently joined the UNAIDS Secretariat, reaffirmed that UNAIDS has put together a very good management response to the report and is committed to addressing staff health and well-being. Management is committed to change in response to the IEP recommendations, and hopes that management’s response will demonstrate this and engender trust. She

agreed that UNAIDS has a unique position in the HIV response, and plays an important coordinating role. UNAIDS has an important convening power, including bringing together civil society and government. UNAIDS needs to be a brave, clear advocate for leaving no one behind. UNAIDS is also a key partner to civil society and others at country level. She noted, for example, that UNAIDS is complementary to the work of the Global Fund, and will be fully engaged in supporting efforts to replenish the fund, which is also an opportunity to communicate how UNAIDS is an important part of the ‘ecosystem’. UNAIDS also needs to focus on a few things and do them better, something that may also take on additional importance if resources are flat or reduced in the wake of the past year’s reputational challenge regarding the sexual harassment allegations. She welcomes the Reference Group’s advice on which things are most important and how best to strengthen UNAIDS.

She also noted that part of the changes in the wake of the IEP report may require some restructuring of the management of UNAIDS, including the position heading up the Department of Community Support, Social Justice and Inclusion (within which the Law, Gender and Human Rights team sits). She would welcome the input of the Reference Group regarding what is needed in this position and in the management team.

In response to Ms. Carlsson’s invitation for input regarding UNAIDS management and priorities, members of the Reference Group offered a number of observations:

- The Reference Group reiterated its view that any new Deputy Executive Director must have clear commitment to addressing human rights and ensuring these are central to the work of UNAIDS Secretariat as an organization and of the Joint Programme as a whole.
- The Global Fund welcomed UNAIDS’ commitment to collaboration.
- As a co-sponsor of the Joint Programme, UNDP noted that UNAIDS Secretariat can play and has played an important role as an advocate for communities that are marginalized and often have no voice; this function must be preserved in the broader UN system reform.
- Engaging with faith communities in the HIV response has been and is challenging, but nonetheless important, including to defend and advance human rights.
- The Reference Group has repeatedly stressed the importance of strengthening the capacity of staff, including in country offices, to address human rights issues. There is considerable variability in this regard across country offices. It is important that senior management, including the Executive Director, communicate across the organization, including to country-level staff, the relevance of human rights and that this is part of their responsibility. Staff need to be supported, encouraged and recognized for taking on this task, which can often be challenging.

Drug policy, HIV and human rights

The Reference Group welcomed presentations from Eamonn Murphy (Director, Regional Support Team Asia-Pacific, UNAIDS); Monica Ciupagea (HIV/AIDS Section, UNODC); and Tenu Avafia (Team Leader: Human Rights, Law and Treatment Access, UNDP).

Ms. Ciupagea provided an update regarding the upcoming 62nd session of the UN Commission on Narcotic Drugs (CND) in March 2019, which will also include a high-level Ministerial Segment. She reviewed some of the previous key articulations by Member States of their approach to drugs, including: the 2009 Political Declaration and Plan of Action (which set 2019 as a target date for achieving the goals set out therein, and also explicitly noted the alarming rise in HIV among people who inject drugs); the high-level, mid-term review and Joint Ministerial Declaration adopted in 2014 at the CND; and the Outcome Document from the 2016 UN General Assembly Special Session (UNGASS) on “the world drug problem,” which represents the most recent consensus of Member States. The [2016 UNGASS Outcome Document](#) contains more than 100 operational recommendations in 7 thematic chapters – and specifically mentions ending HIV among people who use drugs, in keeping with the SDG of ending AIDS by 2030. UNODC is coordinating the inter-agency task team across the UN system responsible for operationalizing the Outcome Document.

Mr. Murphy provided an update on UNAIDS work in the Asia-Pacific region regarding addressing HIV among people who use drugs. With respect to the matter of compulsory drug detention centres, he reviewed

the regional consultations on the matter, including the second consultation in 2012 that led to the [joint statement](#) by UN agencies and others calling for their closure, and the most recent, third consultation in 2015. He noted that UNODC and ASEAN member states have been discussing the growing epidemic of problematic methamphetamine/ATS use in the region, and that this may prompt some governments to want to maintain or even expand such compulsory drug detention centres, which is an added challenge. In some countries, there are some pro bono legal service providers who can assist people at risk of incarceration or detention in a compulsory drug detention centre. There have been some positive or encouraging signs in the region: Malaysia is considering decriminalizing possession of drugs for personal consumption, and Myanmar has adopted a new law on drugs that reflects some positive changes. UNODC plans to undertake in 2019 a review of legal and policy barriers, as well as documenting progress and good practices. There is the prospect of an updated global statement by UN agencies, but this has not yet been discussed.

Mr. Avafia noted that UNDP's substantive engagement on drug policy issues began in 2014, in the lead-up to the 2016 UNGASS, with the production of a [report on the development dimensions of drug policy](#). As presented earlier in the meeting, following the recommendations of the Global Commission on HIV and the Law in 2012, UNDP, as the Joint Programme co-sponsor with the lead on human rights, has also taken an active role in collaborating with civil society organizations in developing the forthcoming *International Guidelines on Drug Policy and Human Rights*, which will be launched at the upcoming CND session in March 2019. He noted that UNDP is enthusiastic about the prospect of a new joint UN statement on compulsory drug detention centres, which violate multiple human rights norms, although cautioned that this may not be feasible by the CND in March 2019 since discussion has not yet started.

Members of the Reference Group offered a number of observations and asked several questions:

- There have been some statements by UN agencies at the country level expressing concern about compulsory drug detention centres, but seemingly none of these go as far as the joint agency statement issued in 2012 that included UNAIDS Secretariat and UNODC. In at least one instance, there have been proposals for the introduction of new centres (e.g., in the Philippines), but seemingly there has been no response from UNAIDS or UNODC. The analysis of the abuses these centres involve, and the case for shutting them, has been done and the call has been made. Why are the UNAIDS Secretariat and co-sponsors not keeping up a robust response, even keeping to previously-agreed positions, in the face of this? Why are the UNAIDS Secretariat and UNODC not tracking more carefully the number of centres and the number of people being detained, in order to assist in achieving the goal of closing such centres.
- The 2016 UNGASS Outcome Document makes reference in a number of preambular and operational paragraphs to human rights, including some specific human rights issues. UNODC is the co-sponsor within the Joint Programme with the lead on HIV among people who use drugs and prisoners. The Reference Group was interested to know what specific human rights issues UNODC plans to raise for discussion among Member States and other stakeholders at the upcoming CND. In response, however, UNODC did not identify any specific human rights issues it intended to raise.
- It was noted that the International Drug Policy Coalition (IDPC) has recently released a shadow report tracking the outcomes of the last decade of action on drugs since the 2009 Political Declaration. Yet this report, prepared entirely by civil society, appears to be the only report providing a realistic assessment of the achievements and failures, in order to inform the discussion at the upcoming CND about the direction of drug policy beyond 2019. What will UNAIDS Secretariat and UNODC say at CND about the assessment provided by this report, and how can they use it to advocate at CND and beyond for responses to drugs that are more evidence-based, human rights-based and reflect a public health approach? UNAIDS noted that it would be preparing for the CND an updated "Do No Harm" report, and would welcome the input on the Reference Group on this.

Conclusions and recommendations

- The Reference Group was disappointed at the limited action by UNAIDS and UNODC to continue advocacy in the Asia-Pacific region for the closure of compulsory drug detention centres, in keeping with the previous joint statement by UN agencies. The Reference Group urges the UNAIDS Executive Director and the UNODC Executive to direct greater attention by their agencies' representatives in the region to this ongoing abuse of human rights, and will communicate this view to them.
- The Reference Group was disappointed that *no* human rights issues were identified by UNODC as ones it intends to raise at the upcoming CND, despite there being a basis to do so in the 2016 UNGASS Outcome Document and despite the many human rights abuses against people who use drugs that are undermining the HIV response among this key population. The Reference Group would be pleased to provide advice to UNODC, given its position as a co-sponsor of the Joint Programme, regarding key human rights issues it believes UNODC should raise in fora such as the CND (and which other the UNAIDS Secretariat, other Joint Programme co-sponsors and agencies such as OHCHR should also raise).
- The Reference Group welcomes the initiative to develop *International Guidelines on Drug Policy and Human Rights*, and the involvement of UNDP and the UNAIDS Secretariat, in this initiative. The Reference Group recommends that UNAIDS endorse or co-publish, as appropriate, the International Guidelines when they are released.
- The Reference Group will be pleased to review and provide input to UNAIDS Secretariat in the development of its updated "Do No Harm" report for use at the Commission on Narcotic Drugs.

Human Rights Reference Group: panel for all UNAIDS staff

The Reference Group was pleased to participate in a panel with all UNAIDS staff who could attend, some in person and some remotely online, to discuss the work of the Reference Group and the role of human rights in the work of the UNAIDS Secretariat.

Agenda for Universal Health Coverage: Ensuring attention to HIV and human rights

The Reference Group welcomed Gang Sun, Senior Adviser, Fast-Track Country Support, UNAIDS for a discussion about UNAIDS' engagement in the agenda for universal health coverage (UHC), one of the Sustainable Development Goals for 2030.

Mr. Sun outlined that for UNAIDS, UHC must involve a "pro-poor universalism." All services that are needed for HIV prevention, treatment and care must be available to every person and community, without causing financial hardship. The UNAIDS Strategy 2016-2021 calls for HIV-sensitive UHC schemes to be developed and monitored. This requires community engagement, a robust strategy for ensuring there is the data to develop such schemes, identifying entry points for integrating HIV services, and addressing the underlying social determinants of health that affect coverage.

The UHC agenda is provoking a shift from disease-specific thinking, responses and architecture into a more horizontal, integrated approach. There is the risk of dilution of resources, with the likelihood that vertical, HIV-specific funding streams may be reduced or disappear. Yet there are still disease-specific needs, including attention to human rights issues that have been so central to the course of the epidemic and the response, which must not be lost. UNAIDS and partners need to address this challenge. The framework for UHC includes 16 key indicators, one of which deals with HIV, but there is a need for a better approach to capture HIV-related data that should be part of assessing progress toward achieving the goal of UHC. In the process that is underway of defining UHC packages country-by-country, it is clear that the risk of sidelining HIV-related needs and indicators is clear. A quick survey of 40+ countries' plans so far showed that less than one-third of them included both HIV treatment and prevention services in the package, and often there is little

mention or inclusion of harm reduction services for people who use drugs or of the other needs of specific key populations affected by HIV.

One factor to keep in mind is that there is no clear formula or approach for nationally-owned, inclusive mechanisms to advance the UHC goal, unlike the mechanisms and platforms that have been developed as part of the HIV response (e.g., National AIDS Councils, CCMs for Global Fund grants). In this respect, the HIV response has already done important work on the inclusion of civil society – an advantage and a lesson that should be brought forward in discussions of UHC. Perhaps such existing structures at country level could be evolved into a new, broader model of an “inclusive partnership” platform for advancing the UHC agenda, and this would assist in ensuring HIV considerations are part of those efforts. There is also a need generally to strengthen monitoring and evaluation of health systems, including incorporating human rights standards and principles in that exercise – an area in which the HIV response has already generated considerable thinking and guidance.

UHC Day is December 12th each year, and the UNAIDS Executive Director will be putting out a message and Q&A document to all staff within the Secretariat regarding the goal of incorporating HIV into the UHC agenda. UNAIDS will also be actively engaging in various upcoming fora to this end. At its upcoming PCB meeting in June 2019, the thematic topic for discussion will be UHC – and UNAIDS would welcome the Reference Group’s input as it prepares for this discussion, which will also inform the first-ever [UN High-Level Meeting on UHC](#) (at the General Assembly on September 23, 2019).

As discussant, Reference Group member Christine Stegling, Executive Director of the International HIV/AIDS Alliance, observed that “the UHC train is moving and the HIV sector has to get on board.” To that end, she shared some reflections regarding the UHC 2030 Global Compact and questions for consideration by the Reference Group as it formulates its view and recommendations to UNAIDS and others:

- “Who is covered?” is a key human rights question. When health schemes require a family connection to a card holder to secure coverage, key populations (sex workers, LGBT people, people who use drugs) are more likely to be excluded. When national health schemes include premiums for coverage, or for specific products of services, this will automatically create a financial barrier to access for poor people.
- There may be greater challenges of monitoring corruption across entire health systems, rather than smaller-scale, more focussed programs.
- “What is covered?” is another key question. Treatment may be covered, but this is insufficient if HIV prevention and other health promotion services are dropped from the essential package.
- It is essential that we not pit the HIV response against the UHC agenda; instead, the HIV sector needs to make the case for integration without losing the principles and approaches that are dear to the HIV community, including attention to human rights and the importance of community involvement, the greater and meaningful involvement of people living with HIV (GIPA) and of key populations.
- It is also essential that HIV advocates share information about what is happening with UHC implementation at country level, to ensure the HIV response is being integrated. At the country level, UNAIDS could support coordination of civil society in this, and also play a role in ensuring that governments include community and key partners in the HIV response in discussions about advancing UHC.
- The upcoming HLM on UHC in 2019 is the key opportunity before the 2020 HIV targets to mobilise political support at the highest level possible for strengthening the HIV response *as part of* the larger UHC agenda. The President of the UN General Assembly will convene a multi-stakeholder hearing, before the end of July 2019, providing an opportunity for non-state actors to feed into the Political Declaration on UHC. It is essential that UNAIDS Secretariat and co-sponsors feed into this. Similarly, the “Berlin plan” on health for all is to be completed by September 2019, as a key element in the UHC agenda, under the leadership of the WHO. As already discussed, the HIV community and UNAIDS must ensure HIV is integrated into this.

Ms. Sprague (Chief, Community Mobilization, UNAIDS) agreed that engagement at country level, and not just efforts to influence the HLM outcome document, will be essential. UNAIDS is looking at supporting community engagement at both levels. At the national level, community needs to be engaged in discussions

about *how* UHC rolls out, *who* will be covered and *what* will be covered. Note that it is not necessarily the case that ARV treatment will be covered in each country, which underscores the challenge that faces efforts to ensure HIV is integrated into UHC efforts. Criminalization of, and stigma and violence against, key populations will also make it a challenge, especially in some settings, for those populations to engage in shaping the UHC agenda and ensuring they are not left behind. Again, UNAIDS has an important role to play here.

Reference Group members also flagged a number of other considerations:

- Modifying bio-behavioural surveys to include some additional questions may be a means of gathering additional data about interventions needed, access to services, etc., that could be useful in efforts to ensure attention to HIV is included in the UHC agenda, including at country level. It could also be a means of monitoring the extent to which this is happening or not.
- Privacy issues are among the human rights concerns that should be raised in a discussion of how UHC is implemented. For example, what documentation (e.g., a national identity card) may be required to access services forming part of the UHC package, and who will have access to this info and for what purposes?
- It was agreed that UNAIDS Secretariat and also co-sponsors have a role to play at country level to ensure the inclusion of HIV and of key communities in UHC discussions and implementation.
- UNAIDS has provided some input previously on the “Berlin plan” but so far it has proven challenging to secure the inclusion of language on human rights. Note that there is language there regarding social determinants and “accelerators” for achieving health for all; these could provide a basis for strengthening language and commitments on human rights issues that need to be addressed to achieve health for all. It was noted that WHO, a Joint Programme co-sponsor, is leading the effort to develop the Berlin Plan – and it will be appropriate and advisable for the Reference Group to communicate with the Director-General of the WHO to ensure the integration of HIV and of human rights in that plan.
- It was also agreed that as the architecture evolves for advancing the UHC and global health agendas, there is an important role for UNAIDS Secretariat, as the convener of the Joint Programme, to try to ensure that key players from different facets of the HIV response are involved.
- UNAIDS Secretariat also has a role to play in getting non-HIV stakeholders to the table for discussion with the HIV sector, which will help facilitate integration of HIV into the broader UHC agenda.
- It was noted that one thing UNAIDS Secretariat brings to the UHC discussion is a familiarity with the need for human rights programs as part of a response to a health challenge – including legal literacy and empowerment initiatives, engagement of legal networks and National Human Rights Institutions.

Conclusions and recommendations

- The Reference Group recommends that UNAIDS country-level staff play a role in ensuring that HIV, and HIV community actors, are part of discussions at the country level regarding advancing UHC.
- The Reference Group will develop a position paper on UHC in advance of the multi-stakeholder hearing on UHC being convened by the President of the General Assembly. This will provide input to UNAIDS Secretariat and the PCB in the preparations for the PCB’s thematic discussion of UHC (in June 2019), the multi-stakeholder being convened by the President of the General Assembly (by end of July 2019) and the upcoming UN High-Level Meeting (in September 2019). The position paper should also serve as a resource for others within the HIV sector, since there is a need to raise awareness of the UHC agenda and the importance of ensuring it includes HIV.
- The Reference Group also encourages the UNAIDS Secretariat to actively engage in the multi-stakeholder hearing and more broadly the negotiation of the text of the Political Declaration to be adopted at the High-Level Meeting.

- The Reference Group will strike a working group tasked with the development of the Reference Group’s position (noted above) and with continued engagement on behalf of the Reference Group in the UHC discussions.

Ending HIV-related stigma and discrimination: the Global Partnership for Action

Luisa Cabal (Chief, Human Rights, Law and Gender, UNAIDS) provided the Reference Group with an update regarding the agency’s work on stigma and discrimination, which has culminated in the forthcoming [*Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination*](#) (to be launched December 10th, on the 70th anniversary of the Universal Declaration of Human Rights).

A year previously, at the December 2017 meeting of the PCB, the NGO delegation called for a “global compact” to address HIV-related stigma and discrimination, building on existing UN human rights treaties, resolutions from UN bodies, and political commitments made on paper but not yet realized. The UNAIDS Strategic Information Team has also been working on targets and indicators related to stigma and discrimination as part of the larger discussion regarding setting global targets for 2025 and for measuring epidemic transition and defining and assessing progress toward epidemic “control.” The PCB NGO delegation, GNP+ and UN Women convened a consultation following the June 2018 PBC meeting to identify recommendations for priorities in a global plan on addressing stigma and discrimination.

Kenechukwu Esom (Policy Specialist, HIV, Health and Development, UNDP) laid out the results of a global consultation to inform the development of plan. This resulted in the identification of five key settings in which to implement and then evaluate concentrated efforts against stigma and discrimination: health care settings, workplaces, educational settings, justice system and households. Subsequently, a sixth domain – emergency and humanitarian settings – was added. In recent months, regional consultations have been convened by civil society in six cities. UNAIDS co-sponsors have been invited to come on board in the development of the plan of action. The plan will be launched with a call for Member States to join the partnership and endorse the commitments in the plan, such as setting up a national group tasked with implementing the plan at country-level. Once the plan is released, UNAIDS and co-sponsors will discuss in early 2019 how to take this work forward at the country level.

The Reference Group welcomed this initiative. It was noted that this should complement, rather than duplicate, work already underway on stigma and discrimination by civil society actors (including engaging faith communities in this effort), and work such as legal environment assessments supported by UNDP or the baseline assessments being undertaken with Global Fund support in the 20 countries prioritised for intensified efforts to scale up human rights programs. It was also noted that this could be an opportunity to ‘refresh’ the relevant guidance from the *International Guidelines on HIV and Human Rights* already put out by UNAIDS and OHCHR. Note also important recent developments regarding stigma affecting specific key populations, such as the ground-breaking [*resolution adopted at the CND in March 2018*](#) calling for action to address stigmatizing attitudes against people who use drugs in the context of health, care and other services. Could the dedicated “key populations” funding announced by US PEPFAR provide support for some of these initiatives to address the stigma and discrimination they encounter? Particularly if efforts to address stigma and discrimination are understood correctly as barriers to HIV prevention and testing and presented this way, this should assist in securing funding for this human rights initiative.

Ms. Cabal noted that health is now a strategic priority again with the work of the OHCHR, so there may be more opportunity to engage them in taking forward this work on stigma and discrimination. Mr. Esom noted that UNDP was prepare a resource with all key instruments with relevant human rights obligations to inform this Global Partnership; the 2018 CND resolution on stigma will be added.

The Reference Group also had a brief discussion regarding reinvigorating the use of the *International Guidelines on HIV and Human Rights* as a key tool in the HIV response—and underscoring at this moment in the HIV response, while approaching 2020 targets and defining targets for 2025, the continued necessity of attention to human rights for an effective and sustainable response. Much of the content remains relevant, although some updates would be likely desirable. UNAIDS could consider, with OHCHR, relaunching the

Guidelines, perhaps with a new foreword – and also packaging it with some other key resources, such as the UNAIDS Guidance Note on the seven key human rights programmes, the recent guidance on human rights and the fast-track approach (including its checklists for applying human rights standards to HIV prevention, testing and treatment services), the recommendations of the Global Commission on HIV and the Law, etc. One possibility might be to consider focussing the relaunch of the Guidelines in the 20 countries prioritised by the Global Fund for scaling up programs to remove human rights barriers to HIV services.

The year ahead for the Reference Group

The Reference Group began the discussion of the year ahead by recalling the clear statement of the UNAIDS Executive Director that the UNAIDS Secretariat must find greater support for the work of the Reference Group. The Reference Group will incorporate this commitment into its follow-up with the Executive Director after the meeting.

The Reference Group also discussed its future composition. The group's Terms of Reference envision staggered rotation of members, to ensure both continuity and renewal. All members serve upon appointment by the Executive Director. Note that at least three members of the Reference Group are stepping down in 2018. The Co-Chairs asked all members to consider whether they wished to continue serving on the Reference Group, and also to consider potential new members who might be nominated for consideration. It was agreed that the Secretariat would send out a follow-up note to all members and compile the results for discussion with the Co-Chairs.

The Reference Group also identified a number of items that would form part of its work plan in 2019 (with others to be identified), including:

- sharing its conclusions and recommendations from this meeting with the UNAIDS Executive Director, senior management, and co-sponsors as appropriate;
- providing input to the UNAIDS Executive Director and PCB regarding implementation of the recommendations of the IEP report on sexual harassment, bullying and abuse of power;
- providing input into the definition of 2025 targets for the HIV response, and to defining and monitoring epidemic transition and control;
- developing a position statement and normative guidance on ensuring human rights in the collection of biometric data in the course of HIV surveillance, research and service provision;
- examine the issue of the compatibility of determining entitlement to human rights such as access to health goods and services base on classification of countries by income level with the requirements of international human rights law, and perhaps develop a position paper on the subject;
- providing input to UNAIDS and UNODC regarding drug policy and human rights;
- the work of a sub-group regarding the UHC agenda; and
- convening for its twenty-first meeting in the latter part of 2019.

Closing

The Reference Group reiterated its thanks to Meena Seshu, Joanne Csete and Raminta Stuikyte for their service as members of the group. It also expressed its thanks to the UNAIDS Secretariat staff, and to the Co-Chairs and Reference Group secretariat for their work in organizing the meeting.