SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

1. UNAIDS Secretariat and the Joint Programme: the critical importance of attention to human rights

A key theme throughout the meeting was how UNAIDS can reflect in its programmatic work the importance of human rights, which is identified by the organization, including its senior management, as central to its mission and identity, and critical for an effective HIV response. Members of the Reference Group urged the Secretariat to recognize that as budgets are cut among civil society organizations working on human rights and HIV, as well as for human rights work in the UNAIDS Secretariat and field offices, and as repressive governments restrict the space for civil society organizations to engage with criminalized and marginalized populations at risk of HIV infection and frequently denied access to care, UNAIDS should ensure its commitment to human rights is not just rhetorical, but is adequately supported and integrated into all major initiatives. Despite the challenges and potential pushback from some states, Reference Group members called upon UNAIDS to be bolder in challenging those who suggest success in the fight against HIV can be achieved without attention to rights. The Reference Group recommends action in three specific areas:

- **Increase the resources dedicated to human rights**

The work of the Joint Programme on human rights is more seriously under-resourced than ever before. Reference Group members were appreciative of the work being done by the small unit within the UNAIDS Secretariat that is dedicated to addressing law, human rights and now also gender issues, and of initiatives by Joint Programme co-sponsors such as UNDP to advance human rights. However, staff vacancies and diminished budgets affect UNAIDS’ ability to engage in a timely way on critical rights issues, both globally and in country-level implementation. The stated commitment to human rights is not matched by the human and financial resources dedicated to this work within the UNAIDS Secretariat and across the Joint Programme. Reference Group members reiterated their willingness to serve as a resource, collectively and individually, to support those efforts, but call upon the UNAIDS Secretariat and the Joint Programme co-sponsors to increase the resources they dedicate in-house to working with governments, program implementers and civil society to remove the human rights barriers that continue to impede the HIV response.
Integrate human rights more consistently into the work of UNAIDS across the board

The Reference Group is concerned that there does not appear to be a systematic integration of human rights into the work of the UNAIDS Secretariat, including in initiatives to implement the “fast-track” approach. Human rights are central to an effective HIV response. UNAIDS needs to be able to articulate both why this is, and the important role of UNAIDS (both the Secretariat and the Joint Programme as a whole) in advancing human rights in the response.

This is all the more important in light of the “repositioning” of the UN development system to deliver on the 2030 Agenda for Sustainable Development. The Reference Group is firmly of the view that the UNAIDS Secretariat, and the Joint Programme as a whole, are key institutions in the UN system and in the HIV response—and the protection and promotion of human rights is a central reason why. At this time, there is weak or strained capacity on human rights within many of the Joint Programme’s co-sponsors (for all of whom HIV is but one facet of their organizational mandate), and there is little capacity to address HIV-related human rights issues within the Office of the UN High Commissioner for Human Rights (OHCHR). Meanwhile, the UN Secretary General has eliminated the regional Special Envoys on HIV/AIDS, some of whom had been key ambassadors for human rights in the HIV response. In numerous countries, including some of those most burdened by HIV, there is a retrenchment on human rights of key populations, and a deliberate effort by governments to undermine the operations of civil society organizations that are essential to protecting and realizing human rights and to a successful HIV response. There are also worrisome indications of donors losing interest in HIV; furthermore, as UNAIDS and others have documented previously, even within the overall HIV funding envelope, there has been little funding available for human rights programmes and initiatives.

The Reference Group wishes to underscore that, in a global environment of growing conservatism, challenges to multilateralism, restrictions to civic space and reduced funding for HIV and for human rights in particular, (1) the UNAIDS Secretariat has a vital role to play in ensuring that rights-centered approaches to HIV get the requisite attention within the work of Joint Programme co-sponsors and of other key UN system bodies, including OHCHR; and (2) more broadly, the Joint Programme can function to keep HIV on the agenda, globally and at the country level (including through Joint UN Teams on AIDS). One of the strengths of the Joint Programme is that its multi-faceted, multi-layered structure can enable attention to human rights, including at country level, where a single UN agency might find it more challenging to engage on these difficult issues.

The Reference Group therefore welcomes some recent initiatives by the UNAIDS Executive Director to improve awareness and understanding of human rights within the Secretariat, including training for all staff. However, such training needs to be accompanied by clear directions to all department heads and regional and country directors to ensure that they integrate attention to human rights into their work—from developing country plans for fast-tracking the achievement of HIV prevention, testing and treatment targets, to engaging with governments and civil society, to providing technical support in developing human rights initiatives at country level, to considering the human rights dimensions of how epidemiological surveillance modelling is carried out. Reference Group members noted in particular the continued need to strengthen UNAIDS’ work at country-level in defending and advancing human rights; the experience remains highly variable across different countries and more consistent, sustained and robust engagement should be the goal. Resources need to be dedicated appropriately to ensure this capacity exists at country level.
The Reference Group recalled that, during some of its previous meetings, it had previously engaged with UNAIDS regional offices and staff via online conferencing; this is an opportunity to raise the profile of human rights issues across the Secretariat and contribute to efforts to integrate human rights into the programmatic work of UNAIDS. Although the coordination of these calls can be challenging, we strongly feel that this engagement, or other opportunities, are vital. The Reference Group stands ready to assist UNAIDS at every level in building the awareness, knowledge and capacity of UNAIDS staff on human rights issues.

- Lead boldly on human rights, and build a stronger and visible partnership with OHCHR

The Reference Group underscores the importance of leadership on human rights issues from the most senior levels of the Joint Programme. The Reference Group welcomes the steps taken on several occasions by the UNAIDS Executive Director and other senior leadership to raise human rights concerns directly with various governments, both publicly and privately, including in response to particularly disturbing developments such as initiatives criminalizing key populations or attempting to silence or otherwise interfere with the work of community organizations and human rights defenders. In light of the current global environment, in which numerous governments appear emboldened to deny or infringe human rights, thereby undermining an effective HIV response, it is essential that there be institutional voices within the UN system defending human rights.

The Reference Group recommends that the UNAIDS Executive Director demonstrate leadership by consistently incorporating the central importance of human rights to the HIV response into his public and private advocacy. The most senior voice within the UN system with a mandate to address the ongoing global HIV pandemic must be a champion for human rights, including being willing to raise issues that may be provocative and controversial but that must be addressed if the world is to ultimately end the HIV pandemic. Such leadership is consistent with the Reference Group’s other recommendations above for strengthening attention to human rights issues by and within the UNAIDS Secretariat and the Joint Programme as a whole. The Reference Group recommends the UNAIDS Executive Director consider ways in which he could regularly highlight, to staff, co-sponsors and the broader public, human rights issues of concern in the HIV response. This could include some sort of regular bulletin or update on such issues and the work being done to address those, including by UNAIDS.

Recalling its previous discussions with the UN Deputy High Commissioner for Human Rights (at its eighteenth meeting in December 2016), the Reference Group also suggests that UNAIDS develop a more visible and significant partnership with the Office of the UN High Commissioner for Human Rights (OHCHR) to advance a programme of work on HIV and human rights. The Reference Group previously benefited from the regular participation of an observer from the OHCHR but this has been discontinued in recent years, as OHCHR eliminated its sole position that had been dedicated part-time to engaging on HIV-related human rights issues. The Reference Group reiterates its concern that work on HIV-related human rights issues is not adequately resourced within OHCHR. Just as the Reference Group urges UNAIDS to strengthen its in-house capacity to address human rights, so too does the Reference Group urge OHCHR to reinstate some dedicated in-house capacity to working on HIV.
2. Shrinking space for civil society is undermining the HIV response

The Reference Group is deeply concerned about the growing number of countries, including some of those heavily burdened by the HIV pandemic, in which civil society organizations representing and working with key populations affected by HIV, and organizations advocating for human rights, are being deliberately targeted by governments seeking to silence or otherwise impede their work.

Numerous governments have enacted new laws impeding or restricting the ability of non-governmental organizations—particularly those working with or representing key populations such as LGBTQ+ people, sex workers and people who use drugs—to legally register as such, as well as laws declaring organizations receiving funding from abroad as “foreign agents” and laws prohibiting the receipt of funding from external foundations or donors that support human rights programs. In some countries, civil society organizations representing key populations affected by HIV and/or engaged in human rights work have been politically targeted with audits, or staff and volunteers have been arrested or otherwise detained without legal basis.

In addition, some donors have imposed or expanded restrictions on potential funding recipients that negatively affect NGOs working on HIV. An example is the expanded version of the United States’ “Mexico City policy” (also widely known as the “global gag rule”), which requires foreign non-governmental organizations receiving US global health assistance to certify that they do not use their own non-US funds to provide abortion services, counsel patients about the option of abortion or refer them for abortion, or advocate for the liberalization of abortion law. The expanded version of the policy extends restrictions to an estimated $8.8 billion in US global health assistance, including funding support for HIV/AIDS through The President’s Plan for Emergency Relief for AIDS (PEPFAR).

Such measures only undermine the HIV response—not only efforts to achieve zero discrimination and full respect for human rights, but also efforts to fast-track the achievement of HIV prevention and treatment targets. The Reference Group therefore welcomes efforts by UNAIDS to support documentation of the impact of such restrictions and to advocate against them as measures that undermine effective response to HIV, such as the recent study of the situation in several East African nations. The Reference Group recommends the following:

- The UNAIDS Executive Director and the heads of co-sponsor agencies of the Joint Programme should speak out, jointly and individually, against such measures. This includes raising concerns directly with governments, raising them in multilateral fora where HIV and/or human rights are relevant, and providing technical and other support to organizations challenging such restrictions. The Reference Group urges the UNAIDS Secretariat, UNDP and the other Joint Programme co-sponsors, as well as other relevant agencies and programmes (e.g., OHCHR), to issue a joint statement outlining how such restrictions on the work of civil society organizations contravene human rights standards and undermine the HIV response. (The Reference Group stands ready to assist in formulating a joint statement.)

- The UNAIDS Programme Coordinating Board should request a study into such restrictions and convene a thematic discussion of this challenge to an effective HIV response.

- The UNAIDS Secretariat and Joint Programme co-sponsors should collaborate to determine ways in which they can, as UN agencies, provide concrete support to civil society organizations at country
level with the activities needed for an effective HIV response, including human rights programmes such as those recommended by UNAIDS. They should also actively create secure platforms and forums for civil society organizations to exchange information and strategies on how to function despite such restrictions, including by identifying and addressing them in country plans being developed by UNAIDS.

The UNAIDS Executive Director should convene a working group, with the involvement of senior leadership from the UNAIDS Secretariat and relevant co-sponsors, as well as OHCHR and the Reference Group, to document the adverse impact of shrinking space for the operations of civil society organizations and identify measures that UN agencies, member states and donors can take to counter such restrictions that are undermining the HIV response.

The Reference Group also noted a concern, particularly in light of constrained resources and shrinking space for civil organizations, that UNAIDS and other UN agencies should be conscious of not duplicating the role of civil society organizations. Rather, part of the important role of the Joint Programme co-sponsors is to support the development of capacity within civil society (including to advocate for human rights) and to engage politically with governments to defend or open up space for civil society involvement in the HIV response.

3. Collaboration with Global Fund to fight AIDS, Tuberculosis and Malaria

The Reference Group welcomed additional information about the initiatives being taken by the Global Fund to fight AIDS, Tuberculosis and Malaria to scale up funding for human rights programmes. This represents an historic opportunity to remove human rights barriers to effective HIV responses, by supporting the key human rights programmes recommended by UNAIDS and, in at least some countries, taking them to scale. The Global Fund initiatives can build human rights capacity on the ground in places where it is sorely needed to address those human rights barriers, while also building capacity and expertise on human rights issues within the Global Fund itself, the world’s largest multilateral source of HIV funding.

The UNAIDS Secretariat is a key technical partner in such efforts, as are some Joint Programme co-sponsors. For example, in many countries, co-sponsor UNDP is a principal recipient of Global Fund grants as well as providing technical expertise on human rights issues. The Reference Group urges increased coordination between the Global Fund and UNAIDS (both the Secretariat and co-sponsors), at the level of both headquarters and at country level.

For example, UNAIDS is prioritizing a number of countries for implementation of the “fast-track” approach, while the Global Fund is undertaking an intensified, multi-year effort to scale up human rights programmes in 20 priority countries. In countries receiving such priority attention by both UNAIDS and the Global Fund, it should be a priority for both institutions to coordinate to maximize the beneficial impact for human rights and hence for the HIV response. Furthermore, at the country level in any country eligible for Global Fund support, UNAIDS Secretariat and co-sponsor staff on the joint UN country teams have an important role to play in working with civil society and governments to secure Global Fund funding for quality human rights programmes. The support of UNAIDS staff in country for the development and implementation of multi-year plans to scale up programmes to address human rights barriers has already been and will continue to be crucial for the success of this initiative.
In this regard, the Reference Group noted as a particular example the need to ensure coordination between the Global Fund’s human rights initiative and the efforts of UNAIDS and other partners in the Global HIV Prevention Coalition. Specifically, in developing and implementing their national HIV Prevention roadmaps, governments should identify initiatives to address human rights barriers, particularly for key populations and including gender-based violence and other gender inequities, to scaling up effective HIV prevention measures. Global Fund funding could and should assist in pursuing such initiatives, and it would be advisable for both UNAIDS and the Global Fund to make sure that this source of potential support for addressing difficult human rights barriers to prevention is part of the discussion in developing country roadmaps.

The Reference Group determined that it would continue to follow UNAIDS/Global Fund collaboration in addressing human rights barriers, including making this a standing item on the agenda of the Reference Group. Reference Group members also agreed to provide support in their capacities as individual experts to the Global Fund’s efforts to scale up funding for human rights programmes.

4. Global HIV Prevention Coalition

The Reference Group welcomed UNAIDS’ initiative in launching the HIV Prevention 2020 Road Map and the convening of the Global HIV Prevention Coalition to help drive this agenda. The Reference Group noted the critical importance of getting donors engaged in this effort to reinvigorate prevention.

The Reference Group observed that the indicators reflected in the Road Map so far seem to be largely quantitative indicators focussed on coverage of HIV prevention technologies and interventions, but did welcome the recognition in the Road Map that the policy environment is key to HIV prevention efforts. The Reference Group further notes that the Road Map calls for countries to (1) address key legal, social, economic and gender-related barriers to the demand for, access to, and uptake of HIV prevention services, (2) identify key policy changes needed to create an enabling environment for HIV prevention, and (3) take remedial action to address those constraints, among others.

The Reference Group urges UNAIDS and members of the Global HIV Prevention Coalition to ensure that human rights barriers to effective HIV prevention, including for key populations, are indeed identified and addressed in the course of implementing the Road Map, and looks forward to further reports from UNAIDS and the Coalition members regarding progress made on these fronts. The Reference Group offers UNAIDS its assistance, including through participation by the Reference Group in relevant meetings as the work of the Coalition progresses, to ensure that steps are indeed taken to protect and promote human rights as a necessary element of strengthening effective HIV prevention.

5. Defining “epidemic control”: human rights cautions

The Reference Group discussed the (now released) report by UNAIDS of a recent meeting in Glion on defining “epidemic control” in order to assist implementers, policy-makers and Joint Programme staff in understanding and driving progress toward the goal of “ending AIDS.” The Reference Group appreciated the opportunity for one of its co-chairs to participate in the recent consultation on the subject convened
by the UNAIDS Science Panel, and the opportunity for further engagement with the UNAIDS Secretariat on the subject.

The Reference Group appreciated the effort to define in concrete terms what the “end of AIDS” looks like, but expressed concerns about the potential human rights implications of how epidemic “control” is discussed and could be interpreted. One particular concern is the adoption of any terminology or framing that may encourage or inform punitive approaches to achieving the desired epidemiological outcome — e.g., measures that could easily feed into stigmatizing and dangerous perceptions of people living with HIV as a threat that must be “controlled” in the interests of the public health goal of ending the epidemic.

The Reference Group also highlighted its concern about the selection of one single quantitative measure as the indicator of progress toward achieving “control” of the epidemic. Specifically, the Group expressed concerns that some of the indicators under consideration, when presented at a national level, may mask alarming and out-of-control epidemics among sub-populations, and that other indicators are not conducive to disaggregation for certain key populations.

The Reference Group encouraged UNAIDS to examine the experience of the validation of ending vertical HIV transmission, which incorporated multiple indicators, including legal and policy factors, to assess both “control” and sustainability of that control. The Group also encouraged attention to the example of the process for validating the elimination of trachoma, which similarly requires countries to present measures of both disease transmission and morbidity management. For example, incorporating an indicator such as incidence of HIV divided by the percent of those infected who are virally suppressed would address both the goal of “zero new infections” and achievement of the third “90” of the 90-90-90 targets, and could be disaggregated by key population or geographic region.

The Reference Group also noted the assurances of the Secretariat that the report from the meeting would be the basis for further consultation with key population groups.

6. West and Central Africa “catch-up” plan

The Reference Group welcomed UNAIDS’ decision to devote attention specifically to supporting countries in West and Central Africa to intensify efforts in achieving prevention and treatment targets and in addressing human rights concerns. The Reference Group noted that stigma and discrimination (including gender inequality), criminalization of key populations, and violence are all factors undermining the HIV response in the region. The Reference Group also noted with concern that several countries in the region are experiencing official government hostility to, and restrictions on, the civil society organizations that are essential to an effective response. This underscores the need for UNAIDS —from the Executive Director to country-level staff—to show leadership in addressing both human rights (especially for key populations) and the issue of shrinking space for civil society. All country plans for the region must include attention to the human rights barriers to an effective HIV response. The Reference Group also noted that the 20 countries selected by the Global Fund for an intensified effort to scale up human rights programs in the coming years include several in West and Central Africa; UNAIDS must take advantage of the opportunities this presents to support key initiatives in those countries as part of the UNAIDS “catch-up” plan for the region.
7. Intellectual property and access to medicines

The Reference Group recalls its statement to the Programme Coordinating Board (PCB) during the last meeting of both the Group and the Board (in December 2016) on the importance of addressing intellectual property-related barriers to the goal of achieving universal access to antiretroviral medications and other treatment. The Reference Group reiterates the recommendations made therein for concrete actions that UNAIDS and co-sponsors should take on this front. The Reference Group recalls as well the PCB’s recent thematic discussion of this issue (based on the discussion paper prepared by UNAIDS Secretariat at the Board’s request), as well as the recommendations of the Global Commission on HIV and the Law (previously endorsed by the Reference Group) and those of the more recent report of the UN Secretary General’s High-Level Panel on Access to Medicines.

Given those analyses and recommendations, the Reference Group is, therefore, profoundly concerned that, at a time when such issues should be receiving renewed attention, the UNAIDS Secretariat has instead diminished its already meagre capacity in this regard. The Reference Group reiterated again to the senior leadership of the UNAIDS Secretariat its concern that the capacity in-house to address the important intellectual property policy issues affecting access to medicines appears to be substantially reduced. The Reference Group urges the UNAIDS Executive Director to address this deficiency in relation to a human rights that is of fundamental importance for people living with HIV and for the goal of ending the AIDS epidemic.

8. Future role of the UNAIDS Reference Group

The Reference Group welcomed the continued statements from UNAIDS senior leadership that it values the advice it receives from the Group and that this input informs the work of UNAIDS, but as noted above, is deeply concerned that these assurances are not necessarily reflected in the work and budget of the Secretariat. It appears that the Reference Group, and its recommendations and other advice, are not well known even on the part of some senior staff within the UNAIDS Secretariat. Furthermore, the Reference Group has for some time been concerned about the lack of engagement or utilization of the Group by the Secretariat and the Joint Programme as a whole. It also noted that the existing Terms of Reference are in need of review and likely updating in light of current realities.

The Reference Group therefore decided to establish a committee to work with the Secretariat to review and update the Terms of Reference of the Group, and to bring forward a proposal to the UNAIDS Executive Director for a new model of functioning for the Group, continuing as an independent, expert voice for human rights. In doing so, the Reference Group will seek to ensure: more regular communications by and within the Reference Group, so that it may engage more regularly and proactively on raising human rights issues of relevance to the work of the Joint Programme; more engagement with UNAIDS staff at regional and country level, as well as with the Joint Programme as a whole; and, consequently, a greater awareness of human rights within the UNAIDS Secretariat and among Joint Programme co-sponsors.