1. Much progress in the fight against AIDS — but many critical gaps remain

Reference Group co-chairs Jonathan Cohen and Michaela Clayton welcomed UNAIDS Deputy Executive Directors Jan Beagle and Luiz Loures (then Director of the UNAIDS Executive Office), as well as Mariangela Simao (Director, Rights, Gender and Community Mobilization Department). Cohen and Clayton noted that, for the second time, the Reference Group meeting was taking place at the same time as the meeting of the UNAIDS Programme Coordinating Board (PCB), providing Reference Group members with an opportunity to participate in the meeting’s thematic segment on non-discrimination. They briefly summarized the agenda of the meeting, highlighting that the Reference Group would focus its deliberations on three substantive issues, each of which has critical human rights dimensions: shared responsibility and global solidarity for the HIV response; the Investment Framework; and scaling up HIV treatment.

Jan Beagle thanked the Reference Group for its advice and reiterated that UNAIDS needs the Group, respects the expertise of its members, and encourages the Group to “speak the truth” and push UNAIDS when it fails to go far enough on human rights. Both she and Loures celebrated the progress made in the fight against AIDS in the last five years, but expressed deep concern about backsliding on some issues, which hinders further progress and puts some of the victories achieved at risk. Concretely, they voiced concern about homophobic laws contributing to further stigmatization of gay men and other men who have sex with men and creating barriers to access to prevention and treatment for them in many countries. Other concerns include Botswana’s regressive draft Public Health Bill; many countries’ failure to fund HIV and human rights programmes and, more broadly, programmes for marginalized and criminalized populations; the rise of stigma and discrimination in some places, despite much improved access to treatment; and the difficulties involved in achieving consensus on human rights issues at the PCB and in many other international fora, resulting in a reluctance to raise difficult issues at the Board level, despite the fact that movement on them is critical for bringing prevention and treatment to those who are currently left out.

Beagle and Loures asked the Reference Group to continue providing much-needed input and to help UNAIDS think about the most strategic way to address the difficult issues that stand in the way of progress on HIV, at all levels. They said UNAIDS was committed to continuing to promote approaches to HIV that are evidence-based and rights-based. Beagle briefly talked about the new UNAIDS/Lancet Post-2015 Commission on the End of AIDS, which would make an important contribution to the debate about AIDS, health and global development post-2015 and which requires a strong focus on human rights issues.

In response, Reference Group members expressed their concern about the current UNAIDS messaging about AIDS, which think about the most strategic way to address the difficult issues that stand in the way of progress on HIV, at all levels. They said UNAIDS was committed to continuing to promote approaches to HIV that are evidence-based and rights-based. Beagle briefly talked about the new UNAIDS/Lancet Post-2015 Commission on the End of AIDS, which would make an important contribution to the debate about AIDS, health and global development post-2015 and which requires a strong focus on human rights issues.

In response, Reference Group members expressed their concern about the current UNAIDS messaging about AIDS, which implies that the end of the epidemic is in sight. They called upon the UNAIDS Secretariat to strike the right balance between emphasizing the impressive progress achieved in recent years and the fact that a lot of very difficult and challenging work remains to be done. Many Group members were concerned that messages about the end of AIDS and an overly optimistic focus on successes send the wrong message to donors – and to young people who often understand the words “the end of AIDS is near” literally, leading to increased risk of
infection and diminished interest in all issues related to AIDS. They noted that what remains to be done will prove more challenging as it will require working with populations that are criminalized and stigmatized. The Reference Group emphasized that human rights messages need to be even more central to the response as we move forward, because the populations that have not yet been reached by HIV prevention and treatment are those that suffer egregious human rights abuses and have been left out, even where governments (and donors) have vastly increased funding for AIDS. In addition, where funding has increased or remained stable, it has gone to prevention and treatment programmes; by contrast, few governments and donors have funded HIV and human rights programmes, leading to a crisis among NGOs trying to take these issues forward.

Several Group members expressed concern about backsliding within the UN family on drug policy issues, noting in particular that references to harm reduction are disappearing from UNODC documents, that opioid substitution therapy is now often described as a “last resort” rather than an integral part of effective HIV programming for people who use drugs, and that the position of Global Coordinator for HIV/AIDS at UNODC, left vacant by Christian Kroll’s departure, needs to be filled by a strong candidate who can ensure that UNODC does its full part for prisoners and people who use drugs.

Other members commented on the absence of discussion about HIV in current talks concerning the post-2015 development agenda, and asked UNAIDS to take an active role in these discussions. In particular, they stressed the need to use the lessons learnt from the AIDS response and to move forward to a larger, transformative agenda focusing on health, development and human rights.

Finally, Reference Group members asked UNAIDS to clarify its position on non-voluntary forms of HIV testing, as well as the “test and treat” approach, noting with concern that some are pushing for implementation of more routine forms of HIV testing that may result in its being used abusively against certain individuals and groups.

Beagle and Loures discussed how the UNAIDS Secretariat could be stronger on drug policy issues, but said that Michel Sidibé had met with UNODC Executive Director Yuri Fedotov and openly discussed concerns about UNODC’s alleged unwillingness to show greater leadership on issues related to drug policy, harm reduction and HIV. They noted that UNODC had recently expressed that the agency remains committed to advocating for all elements of the “comprehensive package” of HIV interventions among people who use drugs, including needle and syringe programmes and opioid substitution therapy. With regard to HIV testing, they said that UNAIDS remains firm in its opposition to any form of involuntary HIV testing, but that it is committed to exploring new forms of HIV testing, including self-testing, that have the potential to further increase people’s access to HIV testing.

They affirmed that the Executive Director is committed to the “test and treat” approach and challenged the Reference Group to provide UNAIDS with advice on what the non-negotiable human rights components of that approach should be.

With regard to the post-2015 development agenda, they said that UNAIDS is committed to being actively involved, including by undertaking a consultation in early 2015 to gather feedback from communities about how UNAIDS should approach the discussions. In addition, the newly created Lancet/UNAIDS Commission would provide opportunities to strategize about how to keep a strong focus on AIDS, while advocating for a broader post-2015 agenda based on human rights, equality and sustainability. They said it would be important to strategically use the Melbourne 2014 International AIDS Conference as a vehicle to highlight the continued importance of the fight against AIDS.

Before they moved to the discussion of “shared responsibility and global solidarity for the HIV response”, Reference Group members heard reports from Susan Timberlake, Chief, Human Rights and Law Division, UNAIDS, and Tenu Avafia, Policy Advisor, Health and Development Practice, UNDP, about activities undertaken by the UNAIDS Secretariat and UNDP since the last meeting of the Reference Group in December 2011.

Members of the Group were particularly pleased to learn that, at least partly in response to its recommendation to increase UNAIDS’ human rights capacity, the UNAIDS Secretariat had created a new “human rights, gender equality and diversity and community mobilization” department and, importantly, is undertaking steps to (a) recruit more human rights advisors at regional and country levels; and (b) support all other staff in taking on human rights issues. In this context, members congratulated the UNAIDS Secretariat for preparing guidance for
staff about responding to HIV-related human rights crises at country level, but regretted that one of the Reference Group’s recommendations — about changes in institutional culture and messaging aimed at ensuring that UNAIDS staff at country level are empowered and encouraged to be bold and to speak out on difficult human rights issues — was not reflected in the document.

Members welcomed the development by 12 UN agencies of a joint statement on compulsory drug detention centres, as well as work undertaken by the UNAIDS Secretariat and UNDP to advocate for a fully funded Global Fund to Fight AIDS, TB and Malaria (Global Fund) and to promote implementation of the human rights objective of the new Global Fund strategy.

Members thanked UNDP for its work on the Global Commission on HIV and the Law, praised the Commission’s report, and endorsed its key messages and recommendations, notably that an epidemic of bad laws is fuelling the spread of HIV, resulting in human rights violations and costing lives. They agreed in particular that (i) this epidemic of bad laws is wasting money and limiting effectiveness and efficiency of HIV and health investments; and (ii) that good laws and practices that protect human rights and build on public health evidence already exist and strengthen the global AIDS response, and must be replicated and enforced. Members urged UNDP to work hard to ensure that the Report would not “gather dust in UN basements” and that its recommendations would be implemented. They were pleased to hear that UNDP, in collaboration with the UN and civil society partners, is undertaking work in 59 countries aimed at implementing the report’s recommendations, including legal environment reviews, legislative reform, national dialogues and action planning on HIV and the law, as well as sensitization of the judiciary, media and religious leaders, and work on access to justice. Members suggested that the European Commission’s conference on HIV and human rights be used as an opportunity to promote the Global Commission’s report, including in particular the recommendation to develop an intellectual property regime for pharmaceutical products that is consistent with international human rights law and public health needs.

In this context, Reference Group members expressed alarm about the fact that the current intellectual property regime, coupled with efforts to impose TRIPS-plus protections for patents through trade agreements and the failure of many governments to amend national intellectual property, medicines and competition laws to fully incorporate existing TRIPS flexibilities and/or to create an enabling environment for importing or developing generic drugs, will make sustainable treatment and, by consequence, universal access more difficult to achieve. Members suggested that the Group, at its next meetings, devote more attention to intellectual property and other barriers that stand in the way of ensuring greater and sustained access to medicines.

Timberlake and Avafia ended by thanking the Reference Group for providing substantive input into many UNAIDS documents and processes since its thirteenth meeting in December 2011, including the Guidance on Enablers and Synergies related to the Investment Framework, the operational guidance on Positive Health, Dignity and Prevention, the issue paper on criminalization of HIV non-disclosure, exposure and transmission, and the findings and recommendations of the Global Commission on HIV and the Law.

2. Shared responsibility and global solidarity for the HIV response: human rights considerations

In his introduction, Reference Group member Gorik Ooms recalled the background to current discussions about shared responsibility and global solidarity for the HIV response. He noted that, when antiretroviral medicines became available during the 1990s and gradually turned HIV infection from a death sentence into a manageable chronic health problem for people living in high-income countries, conventional Official Development Assistance (ODA) did not provide a solution to the problems that resulted from the high price of these medicines which made them unaffordable in low-income countries. He highlighted that the implicit convention behind ODA is that it should be temporary and aim to help countries help themselves and become able to ‘sustain’ their own programmes, moving away from financial dependence. But he pointed out that this conventional approach has


been critiqued, and that it has been argued that by creating new funding channels for the fight against HIV and AIDS (like the Global Fund to Fight AIDS, Tuberculosis and Malaria), the international community adopted a new implicit convention, according to which countries should be assisted for as long as needed, and according to the legitimate demand they articulated. This has been seen as the potential beginning of “a new era of shared responsibility for global health”.  

Ooms acknowledged that this new convention of ‘shared responsibility’ remains very fragile, and concluded by saying that one of the main challenges now is to translate the collective duty of the international community into measurable individual duties.

In their interventions, Kent Buse, Chief, Political Affairs and Strategy, UNAIDS, and Luiz Loures highlighted that, in UNAIDS’ view, African dependency on external sources threatens to undermine the AIDS response, resulting in a ‘dependency crisis’, with two-thirds of all AIDS expenditures in Africa coming from external sources at a time of decreasing international investments for AIDS. In this context, Buse and Loures argued that adoption by the African Union, in July 2012, of the “Roadmap on Shared Responsibility and Global Solidarity for AIDS, TB and Malaria Response in Africa” is a great achievement. The Roadmap calls on African governments and development partners to fill the funding gaps together, proposing a ‘fair share’ approach based on ‘ability’ and ‘prior commitments’. It contains three strategic pillars aimed at:

- ensuring country leadership for an orderly and strategic transition to more diversified, balanced and sustainable financing models for HIV, TB and malaria;
- ensuring accelerated access to medicines and health-related commodities; and
- enhancing leadership, governance and oversight for implementing African solutions to AIDS, TB and malaria.

The Reference Group agreed that the adoption of the Roadmap represents an important step towards an improved response to HIV, TB and malaria in Africa. It pointed out that, from a human rights perspective, it is significant that the Roadmap makes specific reference to the need for investment in programmes that support people and communities in preventing HIV, in knowing and claiming their rights and in enabling effective participation in planning and evaluating programmes, as well as the need for ensuring legislative environments that make full use of TRIPS flexibilities. Also of significance is the fact that the Roadmap proposes to increase the impact of basic programme investments by overcoming barriers to the adoption of evidence-based HIV policies and by addressing factors that limit uptake.

However, the Reference Group also pointed out certain risks associated with the implementation of the Roadmap:

- Contrary to its stated aims, the Roadmap may present development partners with an opportunity to pull back on assistance in Africa, particularly insofar as the global compact that it suggests makes development partner assistance dependent on verifiable progress by countries on meeting agreed target levels for domestic investment, which are determined in turn by projected government revenue and the size of the burden of the three diseases. It can be anticipated that these target levels may well not be easy to agree on.
- The Roadmap provides for increased country ownership. In principle, this is a positive and much-needed development. However, as country ownership increases and international assistance and engagement decrease, countries may have “more space” to ignore the needs of under-served and criminalized populations.

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(such as sex workers, gay men and other men who have sex with men, people who use drugs, and detainees) in the design and financing of programmes.

- The Roadmap may also result in development partners reducing their funding for HIV-related human rights work on the basis that increased domestic financing should be used to support this work. It is, however, naïve to assume that NGOs can rely on governments to fund work that is often by its very nature critical of government.

- Some members of the Group were concerned about the elements required to make treatment sustainable that were missing from the Roadmap. For instance, intellectual property policy is an important component if treatment sustainability is to be achieved. But the Roadmap is silent on other essential elements of industrial policy required to make sustainable and affordable local pharmaceutical production a reality. Members also said that the lack of policy coherence at the African Union Secretariat would make it difficult to operationalize the Roadmap, citing the creation of the Pan-African Intellectual Property Organization, whose objectives lie in stark contrast to what is required to facilitate local pharmaceutical production.

The Group noted that, in some ways, the African Roadmap nevertheless is the most progressive African Union document on HIV and human rights developed so far, and that there is language in the Roadmap that can be used for advocacy and to hold governments accountable. It noted that one of the main challenges now will be to translate notions such as “fair share”, “ability”, and “prior commitments” into a reliable partnership and to develop a joint understanding of what “shared responsibility” actually means. The Reference Group called upon UNAIDS to (a) cost the response and to clearly indicate the respective responsibilities of both donors and recipient countries; and (b) speak more clearly about the obligations of both donors and receiving countries in human rights terms, including core support for civil society working on HIV. Finally, members reiterated that rights-based approaches to HIV, TB and malaria are both cost-effective and efficient, while approaches that infringe human rights are a waste of resources.

On behalf of the UNAIDS Secretariat, Buse and Loures thanked the Reference Group for providing critical feedback on the Secretariat’s messaging on shared responsibility and the role it is taking on in promoting the concept. They noted that it is not the Secretariat’s intention to downplay the human rights responsibility of rich countries to continue contributing in a major way to the HIV response in poor countries. In particular, they acknowledged that key populations at risk of HIV infection may be left behind, as domestic funding rarely addresses their needs, and they asked for advice about what the UNAIDS Secretariat can do to ensure that, in practice, this will not happen. They further asked for advice about how similar roadmaps could be developed in other regions. Timberlake noted that neither donors nor recipient countries want to be held accountable for any human rights obligations in the context of financing the response to HIV.

Reference Group members agreed to form a working group to issue a statement on shared responsibility and global solidarity and, more broadly, to advise UNAIDS on related issues in the future, including by providing input on how to develop indicators for monitoring the implementation of the three pillars of the Roadmap.

**Recommendations**

1.1 The Reference Group agrees that it is important to highlight countries’ own responsibility to progressively realize the right to health of their people. However, it is concerned that the Executive Director’s own statements and the UNAIDS Secretariat’s messages more broadly sometimes fail to adequately address donors’ responsibility to continue to contribute their fair share, which is not mutually exclusive of national obligations. The Reference Group strongly feels that there is an urgent need and obligation to continue to scale up programming and, in particular, to vastly increase the number of people who can access HIV treatment. In part, this can be done through reprogramming, and in part, it can be done by countries increasing their own contribution; but it cannot be done unless donors recognize their ongoing responsibility to provide adequate funding, and in fact to increase this funding. **UNAIDS should therefore continue to advocate strongly for development partners to fulfil their own responsibilities in ensuring universal access to prevention, treatment, care and support, including by providing funding in middle-income countries for key populations at risk.**
1.2 In this regard, UNAIDS should encourage states to reaffirm their shared responsibility to realize the human right to health by adequately funding the HIV response. As at previous meetings, the Reference Group stressed that the economic crisis is in many ways a crisis of priorities, wherein billions continue to be diverted away from meeting basic needs, including life-saving health interventions.

1.3 UNAIDS should actively support African countries to implement the Roadmap, while monitoring it carefully and ensuring that it does not lead, in practice, to development partners’ pulling back on assistance in Africa or to decreased attention to the needs of key at-risk populations.

1.4 UNAIDS should advocate for greater policy coherence at the African Union on issues related to sustainable access to treatment.

1.5 UNAIDS should contribute to developing and promulgating clear standards on shared responsibility as a matter of legal and ethical responsibility, namely:

(a) the duty of solidarity of countries bearing the obligations of support and assistance, having helped to begin the funding of health care for people living with HIV and AIDS, to continue and expand such health care to the recipients and those in like position; and

(b) the duty of solidarity of countries bearing the obligation of support and assistance — toward their own nationals and those within their borders – to conform to the international law of human rights, including how this concerns key populations more vulnerable to HIV infection, namely sex workers, people who use drugs, gay men and other men who have sex with men, transgender persons, prisoners and other people in places of detention, and migrants, women and children.

1.6. UNAIDS should assist other regions in developing roadmaps.

1.7. UNAIDS should convene an expert group to guide its advocacy and action on the matter of innovative long-term funding mechanisms for the global HIV struggle. The priority should be to position HIV as a priority for funding that may be generated from financial transaction taxes (FTTs) or other innovative sources of funding.

3. Discussion with UNAIDS Executive Director, Michel Sidibé

Jonathan Cohen and Michaela Clayton summarized the main outcomes of the first part of the meeting. In particular, they highlighted the importance of UNAIDS contributing to the development and promulgation of clear legal standards on shared responsibility, on the part of both rich and poor countries, with a special focus on the needs of the most marginalized populations.

Sidibé thanked the Reference Group for its advice and for bringing “reality and honesty to the debates within UNAIDS”. He reflected on the impact of globalization and the crisis of multilateralism, saying that contrary to what we had hoped for, globalization is not leading to more inclusive societies. On the contrary, we are seeing a trend towards increased protectionism and “mini-lateralism”, or small groups of countries coming together to reach agreements on certain issues. In this context, reaching agreement on countries’ human rights obligations is proving more and more difficult. In addition, AIDS has fallen off many agendas, requiring us to “elevate AIDS” and leverage the post-2015 development agenda. Sidibé committed to continue strengthening UNAIDS country offices, recognizing that much of the most difficult work needs to happen at country level. And he restated his commitment to putting human rights at the centre of the response, noting however that UNAIDS will have to become more creative in demonstrating that an approach that is rights-based and inclusive of the most marginalized is not only the right thing to do, but also cost-effective.

Reference Group members thanked Michel Sidibé for his leadership on human rights and his willingness to take on difficult issues and talk about them openly. Craig Mokhiber from the Office of the High Commissioner for Human Rights (OHCHR) noted that, now that human rights are under attack in so many places, it is more
important than ever to have a human rights advocate as Executive Director of UNAIDS. He agreed that in the context of HIV, it is important to demonstrate the instrumental value of human rights-based approaches, while strongly emphasizing that such an approach is good *per se*.

Sidibé encouraged the Reference Group to continue being a critical voice and to push him and UNAIDS, as well as to engage early on and be proactive about identifying where the Reference Group’s advice is most needed. The Group welcomed this encouragement, and noted that more regular interaction between the Group, or at least its co-chairs, and the Executive Director and members of the executive team, would enable it to contribute on a more regular basis and in a more systematic and meaningful way.

### 4. Human Rights and the Investment Framework

Reference Group members, joined by Dr. Bernhard Schwartländer, Director for Evidence, Strategy and Results, UNAIDS, and Dr. Amrita Patak from the Prime Minister’s office, Mauritius and Vice Chair, UNAIDS Global HIV Monitoring and Evaluation Reference Group (MERG), discussed the essential role of human rights and gender equality in the context of the Investment Framework, the new strategic tool that calls for a more targeted approach to investment in the response to the HIV epidemic. Schwartländer recalled that the Investment Framework is designed to help countries and implementation partners focus and prioritize their efforts to achieve the targets of the 2011 United Nations Political Declaration on HIV and AIDS. As such, the Investment Framework emphasizes three categories of investment: “basic programme activities”, “critical enablers” (interventions that create an enabling environment for achieving maximum effectiveness) and “development synergies” (programmatic efforts in other health and development sectors related to HIV/AIDS). According to Schwartländer, a shift towards focused investments in the global AIDS response could enable countries to make more rapid progress in stopping new infections and keeping people alive. In addition, it would increase the likelihood of mobilizing the additional resources required to fill the funding gap, since it would help stakeholders demonstrate that programmes are implemented efficiently. He emphasized that the Investment Framework signifies a transition to a new paradigm, which emphasizes achieving and measuring results in order to collect evidence critical for demonstrating effectiveness.

Reference Group members expressed concern about the risk that, in the context of the current funding crisis, “critical enablers” will be seen as less “critical” than other elements of the Investment Framework, both in the proposed allocations of financial support they will receive and in their strategic centrality, trivializing the lessons learnt over three decades about the need for human rights protections to be central and integral to HIV responses. They welcomed the efforts of the special working group convened by UNDP to explore the links between basic programmes and critical enablers and synergies, as well as the development of the paper entitled “Understanding and Acting on Critical Enablers and Development Synergies for Strategic Investment.” This paper includes country examples that illustrate how basic programmes have been strengthened through support to critical enablers and states that human rights and gender equality are essential considerations across the Investment Framework. It further says that “strategic investments posit a human rights-based approach in which all the activities and programmes are delivered in a manner that is universal, equitable, and ensures inclusion, participation and information consent and accountability”. Reference Group members were particularly pleased that the document includes an explicit commitment by UNAIDS to produce separate discussion and guidance materials on the gender and rights dimensions of the investment approach and implementation of investment thinking. Members strongly emphasized the importance of human rights and the need to understand them as an element of best practices, a measure of quality, and an indispensable principle for how programmes and interventions should be structured.

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Schwartländer emphasized the need to “collect the strong and compelling evidence base necessary to convince even the most reluctant interlocutors that human rights interventions are not only the right thing to do, but also help achieve better results”. He said that, to date, we have not done enough to measure the contribution of gender and human rights, and that we need to be “smarter and demonstrate the economic impact of human rights violations in the context of HIV”.

Reference Group members agreed that it would be helpful to gather additional evidence, but pointed out that, in most cases, it is unlikely that governments will be moved by evidence to change policies that reflect deeply held prejudices.

Reference Group members expressed a wish to collaborate closely with the UNAIDS MERG, such as by defining together what kind of data and evidence should be collected. Both Patak and Schwartländer agreed and made a commitment to ensuring the groups would collaborate in future.

Finally, members noted that, while UNAIDS has been successful in defining and positioning human rights as critical enablers, it should be borne in mind that human rights go beyond the set of seven rights-based programmes that UNAIDS has articulated, as well as the other critical enablers being posited. Human rights are a set of fundamental principles and binding commitments, a framework for accountability, and “a language that is empowering and resonant with communities”. Reference Group members emphasized the need to be clear about what is meant when we say that we need more evidence of the impact of human rights-based approaches. We may need evidence of the health impacts of certain programmes if we argue they should be funded using health funding, but we should emphasize that there are many other reasons related to human rights goals and protections, beyond health, why these programmes could and should be funded.

Reference Group members noted that the Declaration of Commitment and subsequent unanimous declarations of the General Assembly assert that a commitment to human dignity in the response to HIV is of incontrovertible importance, independent of considerations of programme efficiency, concluding that it would be a great step backward for the Investment Framework to promote the idea that economics and efficiency trump human dignity and rights. It would also be a distortion of the integral link between HIV, human rights and health which the Reference Group views as part of the origin and legacy of UNAIDS.

In response to those who demand “evidence” to support critical enabler programming, Reference Group members emphasized that programmes need to be demand-driven and designed by and with full involvement of people living with HIV as well as members of other key populations. In addition, as there is pressure to demonstrate results and value for money of interventions, much more needs to happen to capture and report on the positive impacts of critical enabler programming, with a view to inspiring more action and investment. In this context, the Reference Group highlighted the need to expand the definition of “evidence” and to place explicit value on human rights outcomes, quality of services, and the qualitative experiences of people living with HIV and members of key populations.

The Reference Group expressed that it would be happy to assist UNAIDS (and the Global Fund) in developing any further guidance on critical enablers, in a way that underscores what history has proven to be the crucial place of human rights in AIDS programmes at any resource level and with any level of linkages to other priorities.

### Recommendations

2.1 The investment approach, in the implementation of its three aspects (basic programmes, critical enablers and development synergies) should adhere to a rights-based approach, as indicated in the original Lancet article on the subject. This should be spelled out in concrete terms in all documents relating to the investment approach.

2.2 UNAIDS must do more to develop the notion of “critical enablers” in explicit human rights terms and to advocate strongly for more resources for programmes that are indeed critical for protecting, promoting and respecting the human rights of people tested and treated for HIV and those in prevention programmes. Rights-related critical enablers should not be seen as discretionary or context-specific; rather, they are indeed critical firstly to ensure that human rights are protected and respected in the context of HIV and secondly to enable basic programmes to achieve health.
2.3 The UNAIDS Executive Director and other UNAIDS and co-sponsor leaders should state clearly that “faster, better and smarter” results in the global response are impossible without strong financial and political support for human rights measures already identified by UNAIDS (including removal of punitive laws and law enforcement that impede HIV responses, access to justice, anti-discrimination laws and their enforcement, stigma reduction, gender equality measures and others).

2.4 Discussion of critical enablers should be much more specific in describing the nature and content of the programmes, particularly with regard to the specific programmes that UNAIDS has identified as key programmes for supporting human rights and which the 2011 Political Declaration on HIV/AIDS enumerates.

2.5 UNAIDS should make a strong statement that the implementation of the investment approach must be inherently and at all times a rights-based approach — not just when the national authority determines that human rights measures are warranted in the particular package of “critical enablers” because of the way the national epidemic is understood by those in power. That is, centering policies and programmes on human rights always makes them more respectful, more effective and more sustainable. If UNAIDS (or the Global Fund) sends a message that this is not the case, ground will be lost. The case has also been made by UNAIDS that key human rights measures — enabling people to know their rights and gain access to legal services, reducing gender-based violence, reducing stigma, reforming unjust laws, helping health workers and police to work in human rights-centred ways — are central determinants of the effectiveness of HIV responses.

5. Scaling up HIV treatment: human rights issues and considerations

Dr. Badara Samb, UNAIDS, spoke about a planned, new UNAIDS initiative on access to treatment. Reference Group members generally welcomed an initiative to re-energize efforts to provide access to treatment to everyone in need, but expressed many concerns about what was being proposed concretely in the draft document about the initiative prepared by the UNAIDS Secretariat and sent to Reference Group members in advance of the meeting. In particular, members repeated concerns already expressed during the meeting about UNAIDS messaging on the state of the epidemic, suggesting that UNAIDS, and particularly the Secretariat, should be much more balanced between achievements and “end of AIDS” messages and the very hard issues that still need to be addressed as we move forward. Members felt that the UNAIDS Secretariat should not shy away from, and indeed has an obligation with regard to, conveying hard messages, including that:

- further scaling up access to HIV testing requires addressing the fear, discrimination, social exclusion, discrimination, punitive laws and injustices that keep people from taking up testing, as well as the lack of mechanisms and support to move people from testing to treatment in a timely fashion;
- those who are not yet on treatment include marginalized and often criminalized populations — new ways to reach them and to overcome political and legal discrimination against them will have to be found to expand treatment;
- insufficient resources, both from donors and from implementing countries, are being made available to achieve the rapid treatment scale-up required to ensure everyone in need can access treatment;
- many people on treatment are dropping off, for reasons that require serious and concerted action;
- developments regarding intellectual property are going to impede treatment access, particularly for people who will require second- and third-line antiretroviral therapy.

Members requested that UNAIDS keep the focus on these difficult issues, rather than playing them down and pretending that we could “end AIDS” without addressing them, if we are to reach the millions currently without

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access to treatment across multiple barriers, including human rights violations and injustice. With regard to statements made about “the end of HIV activism”, Reference Group members said this was a simplistic analysis that failed to acknowledge the incredible activism that still exists and the fact that it is currently seriously threatened by funding cuts to the groups carrying out such activism. The Reference Group urged UNAIDS to advocate strongly and strategically for serious and sustained financial support for civil society, including groups taking on human rights issues. It further urged UNAIDS to ensure that its staff at country level are fully apprised of barriers to treatment access, are in contact with those in need of treatment who are not getting it and are acting as their vocal champions.

The Reference Group next heard from Dr. Rachel Baggaley, WHO, that access to treatment for marginalized populations in certain settings, such as Eastern Europe and the Middle East, remains “shockingly low”, and that at the same time as people in desperate need are denied treatment, mandatory testing proposals are creeping back onto government agendas. They questioned the focus on attempts to massively increase the number of people tested for HIV, when data clearly show that so many of those tested fail to be linked to care or, if they are, fail to be retained in care. Members emphasized that, to reach the next half (and more when treatment guidelines change), things will have to be done differently by UNAIDS, governments and civil society. They urged the UNAIDS Secretariat to flesh out these challenges and corresponding actions, rather than painting a “rosy picture” of the epidemic. In this context, they urged UNAIDS to continue defending treatment as a human right, rather than characterizing it as a “pathfinder for social justice”. While members recognized that social justice is an important concept, they also pointed out that it carries with it no legal obligation or political punch as do human rights.

The Reference Group then heard presentations by Carlos Passarelli, Senior Expert, Treatment, UNAIDS, and Tenu Avafia, UNDP, on the UNAIDS Secretariat’s and UNDP’s work on intellectual property challenges and issues. The presentations demonstrated that very important work is being undertaken, but the Reference Group was struck by the fact that there does not appear to be sufficient collaboration, joint strategizing and clear messaging on shared issues regarding treatment in general and intellectual property in particular among the UNAIDS Secretariat, WHO and UNDP.

In conclusion, the Reference Group appreciated and applauded the willingness of UNAIDS and UNDP to have serious dialogue with the Group and its members, as well as other partners, on efforts to scale up HIV treatment and, in particular, a new UNAIDS initiative that would support and bolster such efforts. Among other things, members expressed concern about the up-to-3.5-times increase in cost as people move from first- to second-line treatment, and the up-to-23-times increase in cost for people requiring third-line treatment; the generally very high prices of drugs in Eastern Europe, Latin America and the Caribbean and the enormous disparity in pricing of the same drug in different countries; and barriers to treatment access beyond intellectual property, including corruption and lack of competition. They noted that, as more and more middle-income countries in Eastern Europe and Latin America become ineligible for support from the Global Fund, a strategy for ensuring greater access to treatment in those regions urgently needs to be developed.

Members emphasized that treatment expansion is the human rights imperative of the epidemic and said that it was right and critical for the UNAIDS Secretariat and co-sponsors to make treatment expansion a priority. They highlighted that UNAIDS can and should offer to this effort the ability to be bold, direct, challenging and concrete about the serious challenges that need to be addressed. Members concluded by urging UNAIDS to provide such leadership and committed to providing more detailed comments on the draft UNAIDS Secretariat treatment agenda in writing before the end of January 2013.12

Beyond the issue of pricing, Reference Group members were concerned about the fact that the current intellectual property regime fails to adequately stimulate innovation for antiretroviral (and many other) drugs. They challenged the UNAIDS Secretariat, WHO and UNDP to move forward quickly and strategically on the recommendations related to access to medicines in the Global Commission’s report, noting that putting a reconfiguration of the intellectual property regime on the global agenda will be a huge, but critical, task.

They suggested that it might be a good idea to invite a new member to join the Reference Group, one with extensive knowledge of the technical issues related to intellectual property and other barriers to treatment access.

and they urged UNAIDS to support efforts to increase communities’ capacity to advocate effectively on these complex issues.

**Recommendations**

3.1 **The Reference Group strongly advises the UNAIDS Secretariat to rethink its messaging and communications strategy to be much more balanced between achievements and the difficult work that remains to be done.** This will be critical to sustaining support and engagement in the AIDS response. In particular, the Reference Group strongly calls upon the UNAIDS Secretariat to speak out about the hard issues (and the actions needed to address them) that stand in the way of treatment access for all. Such leadership is the Secretariat’s niche, comparative advantage and raison d’être. In short, the UNAIDS Secretariat and any documents on scaling up treatment access need to engage in much more “plain speaking” and express articulation of the human rights necessities of the epidemic.

- This should start by expressly recognizing and affirming as vital, not only in their own right but as essential strategies to inform the work necessary for an effective response, the human rights to life, health and non-discrimination. **Any new treatment initiative should defend treatment as a human right.**

- Specifically, **UNAIDS needs to take on intellectual property issues; stock outs; inequitable and inadequate delivery; state-level denial and discrimination against people living with HIV and other key populations and marginalized groups; stigma and discrimination in health care systems; and punitive laws and law enforcement that impact treatment and/or promote low self-esteem, stigma, discrimination, retaliation, and risks of violence and imprisonment suffered by people living with HIV who are marginalized and criminalized.** Any new treatment initiative should spell out concretely what the UNAIDS Secretariat plans to do about these issues.

3.2 **UNAIDS should do more to promote key programmes to support human rights which will also support treatment.** UNAIDS made a significant breakthrough in recent years by capturing in a practical list the seven key programmes that can dramatically improve the likelihood of scaling up HIV services from a human rights perspective: stigma reduction, legal aid, law reform, legal/human rights literacy, human rights sensitization of police, human rights training of health care workers, and reduction of harmful gender norms and violence against women. The expansion of such programmes at country level will help a great deal to address the fundamental exclusion and inequities faced by exactly those populations that make the remaining scale-up of testing and treatment so challenging. The expansion of such programmes also serves to direct sufficient funding to civil society groups who are no longer receiving it.

3.3 **UNAIDS should speak in explicit terms about the unjust application of criminal law and its consequences on treatment expansion.** Unjust application of criminal law to sex- and drug-related behaviours is a major barrier to testing and treatment access in many parts of the world. UNAIDS should explicitly recognize this, and any treatment initiative should include recommended actions addressing this.

3.4 **UNAIDS should be explicit, and serious, about the problems with the patent system.** A large part of the problems related to access to and affordability of drugs stems from the patent system steering research and development not towards medicines with important therapeutic applications for under-served needs like HIV and co-infections, but towards the ever-greening of existing block-buster medicines. UNAIDS needs to provide leadership and take an active role on this, in particular by pushing for some of the structural and potentially long-lasting solutions proposed in the Report of the Global Commission on HIV and the Law, including innovation prize funds, a binding international treaty on research and development and open source drug discovery. In addition, any treatment initiative should attend also to preventing and reversing some of the

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13 UNAIDS. Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses. Guidance note. 2012.
developments on intellectual property that we know are going to impede treatment access. As a minimum, UNAIDS should support efforts by people in low- or middle-income countries (LMICs) who are calling for their governments to incorporate, and where necessary, use TRIPS flexibilities to increase and sustain treatment. Countries considering passing legislation that may restrict treatment access (e.g., so-called anti-counterfeiting legislation) should be pressured not to do so. Countries that have already passed such legislation should repeal it, or amend it to ensure that access to affordable and sustainable treatment is not impeded. LMICs involved in bilateral, regional or multilateral negotiations should not agree to TRIPS-plus commitments or to provisions that may restrict their ability to use TRIPS flexibilities. UNAIDS and UNDP should support the proposal by Haiti, currently before the WTO TRIPS Council, to exempt all least developed countries (LDCs) from having to apply the TRIPS Agreement as long as they remain LDCs.

3.5 **UNAIDS and partners need to address children’s (lack of) access to treatment more forcefully.** The disparity of treatment between adults and children is a major human rights issue. UNAIDS and its partners should take this on as a priority.

3.6 **UNAIDS should highlight the fact that many are still dying of AIDS.** They have become a “lost group” without a voice, including in the many reports that UNAIDS has been issuing. UNAIDS should try to recognize the reality of the lives of those not on treatment (and who are either dying or threatened with death), as well as depict the experience of those who are on treatment but experience (i) huge burdens of travel, money and time commitments to get short stocks of drugs; (ii) discrimination at point of delivery; (iii) lack of nutrition support; (iv) continuing stock outs; (v) requirement to “pay” even where treatment is supposed to be free of charge at point of delivery; and (vi) pressures by family members to share drugs. UNAIDS should propose to expand treatment based on the real experience of those without treatment and of those barely able or completely unable to remain on treatment. An important part of UNAIDS’ role and that of its staff at country level is to find, work with, advocate for, support the engagement of, and identify solutions with those without treatment and those unable to sustain treatment. UNAIDS staff should be seen as their champions and the “go to” people in the UN.

3.7 **UNAIDS should strongly affirm that civil society action and engagement has been a crucial driver of the response.** Such civil society engagement is not dying for lack of interest or need, but is being threatened by less and less funding being made available to continue good and vitally needed work. This is a major crisis that threatens the entire response, including treatment expansion. **UNAIDS should champion the specific forms of political and financial support that civil society needs to enable it to advocate for policy and legal changes and adjustments in government spending, as well as to provide patient support, community mobilization and service delivery.**

3.8 **The UNAIDS Secretariat should collaborate and coordinate closely with WHO treatment efforts and UNDP intellectual property efforts.** The Reference Group urges the UNAIDS Secretariat, WHO and UNDP to work together closely to present a solid, united, rights-based and strategic front on the political, technical and funding challenges presented by treatment expansion.

6. Discussion with Mariangela Simao, Director of Rights, Gender and Community Mobilization, UNAIDS

Jonathan Cohen and Michaela Clayton summarized the main outcomes of the meeting. They welcomed the creation of the new department on rights, gender, and community mobilization and said that the Reference Group would like to provide the department with any assistance and support it may need as it moves forward its important agenda, including advice on how to develop cross-cutting initiatives that will link the rights, gender and community mobilization teams and broadly support the demand for rights-based approaches, and advice on how to achieve greater in-house visibility, acceptance and participation in discussions on the priorities of the UNAIDS
Reference Group members briefly summarized the main issues and concerns discussed during the meeting, highlighting once again the concern about UNAIDS messaging that obscures the fact that the epidemic is far from over and that serious barriers stand in the way of further progress, in particular the failure to address the needs of the most marginalized and criminalized populations. The Reference Group urged UNAIDS to ensure adequate followup to the recommendations in the report of the Global Commission on HIV and the Law.

Simao thanked the Reference Group for its active engagement and honest feedback. She committed to seeking Reference Group feedback in a more timely and consistent manner, at earlier stages of the preparation of key initiatives and documents. She asked the Group to be as specific and concrete as possible in its feedback, to clearly articulate the human rights issues that are not getting the attention they need, and to push UNAIDS when it fails to say and do the hard things. It was suggested that, to a greater extent than has been done to date, UNAIDS Secretariat staff should be invited to participate as observers in relevant sessions of Reference Group meetings. In addition, the need for participation of UNAIDS communications staff in meetings was stressed.

Reference Group members expressed a desire to be more actively engaged in UNAIDS activities in-between meetings. This should include meetings between the co-chair and senior UNAIDS staff, as well as participation in regional consultations and on other working groups and commissions, including the Lancet/UNAIDS Commission and the Monitoring and Evaluation Reference Group.

With regard to the next meeting of the Reference Group, members discussed the possibility of dedicating a session to follow up on the Global Commission report, specifically its recommendations on access to medicines, and suggested that it would be important to start engaging with UN Women. They agreed that another important focus should be the UN General Assembly special session on drugs scheduled to take place in 2016, which will look at the relevance of drug conventions in today’s world, and that the Reference Group should make recommendations to UNAIDS about how it should position itself in the events leading up to the special session.
Appendix 1

31\textsuperscript{st} UNAIDS Thematic Segment on “Non-discrimination”

On 13 December, the members of the Reference Group participated as observers in the UNAIDS Programme Coordinating Board meeting’s thematic segment on non-discrimination. The thematic segment focused on responses to HIV-related discrimination in a variety of sectors, including health care, employment, education, justice, and community. An important part of the meeting was devoted to exploring effective strategies for expanding programmes to reduce HIV-related discrimination in national AIDS responses, such as models for integrating such programmes into national HIV responses, funding such programmes, and putting people living with HIV and other key populations at the centre of efforts to reduce discrimination.

Reference Group members participated actively, speaking to each agenda item to highlight a wide range of problems and to suggest what should be done programmatically to address them. At the end of the day, Reference Group co-chair Jonathan Cohen summed up the event (see below).

Reflecting on the day’s outcomes, Reference Group members felt that they had been able to get important messages across, and that having done this twice had been a significant opportunity to interact with the Board. However, it was also felt that the Reference Group should follow up with the UNAIDS Secretariat regarding whether the Reference Group should participate in future PCB thematic segments or instead hold its meetings at a less busy time, while exploring other ways of engaging with the Programme Coordinating Board. These could involve such things as sharing the Reference Group papers with the Board and/or getting presentations by Reference Group members on the agenda of Board meetings.

Summary of the Thematic Segment

Jonathan Cohen
Co-chair of the UNAIDS Reference Group on HIV and Human Rights

Thank you, Nisha. Thank you, Mr. Chair. Thanks to the UNAIDS Secretariat. And let me also recognize my fellow members of the UNAIDS Reference Group on HIV and Human Rights.

Nisha, at the beginning of this session, you challenged us to walk away with at least one new idea about discrimination that we’ve never heard before. I have to confess I struggled with this challenge for the precise reason that Justice Michael Kirby has already so eloquently stated something we’ve known from the earliest days of this epidemic — that discrimination drives HIV, and that the way to deal with the epidemic properly is to work respectfully with the communities most at risk. So I was not terribly surprised to hear today that in every walk of life — in health care, education, employment, travel, the justice sector, banking and personal finance, parenting, and marriage — people living with HIV and those affected by it are denied basic benefits and privileges that most of us take completely for granted. Not for any good reason, but because of simple fear and ignorance.

We saw a riveting story of a business person who thought that he was making a routine stopover in Qatar, only to be pulled aside by security guards who donned black gloves in order to search him, detain him, and send him home, forcing him to disclose his HIV status to his employers because of an HIV-related travel restriction. We saw a video from Human Rights Watch that showed a health care worker clearly unprepared to counsel an HIV-positive deaf person, probably out of an unfounded assumption that deaf people don’t have sex. And we heard a litany of examples from Ruth Morgan Thomas of sex workers prohibited from opening bank accounts, from getting pensions, from registering their children and sending them to school, simply because of their mother’s or father’s choice of employment.

I can’t say that I was surprised either to hear that fighting discrimination is not just a human rights imperative, but a public health imperative as well. We gather today at a critical moment in the HIV epidemic. As Michel Sidibé reminded us when he opened this session, despite everything we know about the therapeutic and preventive benefits of antiretroviral treatment, there are 6.8 million people who have not been reached with ART. Even in the wealthy nation of the United Kingdom, 47% of new diagnoses in 2011 were late diagnoses. Why is this? We learned from our Mexican colleagues that men who have sex with men and transgender individuals don’t want to be diagnosed with HIV because they fear discrimination. We heard from the MSM Global Forum that this is a global trend: 2/3 of their survey respondents said that they couldn’t access condoms, lubricant, testing or treatment because of their criminalized or marginalized status. We learned from the UN Development Programme...
and the Global Commission on HIV and the Law, whose report we are all encouraged to read, that prosecution of people living with HIV for the so-called “crime” of not disclosing their HIV status deters them from seeking testing and treatment. The Office of the High Commissioner for Human Rights summed it up well when they described stigma and discrimination as “vectors for the virus”.

Finally, it wasn’t terribly surprising to learn that while anti-discrimination laws are certainly a critical part of the response, there remains a great gulf between laws and their enforcement. So that even in a place like Germany, with strong anti-discrimination protections, we are faced with the challenge of dentists denying care to people living with HIV. Or in China, where we have a law prohibiting discrimination and mandating free schooling for children living with HIV, it is parents who protest the enrolment of their HIV-positive neighbours. Or in India, where there has been a law since 2005 protecting people living with HIV from discrimination, people simply don’t come forward to claim their rights because they are afraid of stigma.

We spent a lot of time discussing the challenges of discrimination, but equally we spent a lot of time discussing the solutions. Michel Sidibé called discrimination the “hardest zero,” a view that was echoed by a number of speakers today. But fighting discrimination is not impossible, and there is no excuse for inaction. We heard today that there has been real progress in introducing legal accountability for violations of the universal human right to non-discrimination. In Kenya, a recently created HIV Equity Tribunal has already concluded 14 cases at its young age. In Brazil, a recent court decision reversed the burden of proof in job discrimination cases. We heard that 42 countries have accepted an International Labour Organization recommendation that broadly defines discrimination as being on the basis of not just of HIV status, but also on the basis of stereotypes and membership in key populations.

We learned a lot today about attitude change, and Nisha, you pushed our speakers very hard on this issue. We learned that attitude change is hard, but not impossible. Many positive examples came from the education sector, from countries as diverse as Israel, Norway and Argentina. We learned that innovative and interactive school-based interventions can succeed in addressing homophobia among teachers, in increasing students’ comfort level with HIV among their classmates, and in emboldening gay, lesbian, bisexual and transgender kids to express their sexual and gender identity. From El Salvador, we learned that an important Global Fund-funded project to provide antiretroviral treatment in prisons not only provided profound therapeutic benefit but, amazingly, also contributed to greater respect for transgender prisoners. We learned in Mali that street theatre conducted by sex workers led to greater acceptance of that community. We learned, although we knew, from Jane Bruning, that it is more powerful to learn about discrimination from a person who experiences it, than from the didactic account of a teacher.

Perhaps most importantly, we learned that it is communities who are standing up, fighting back, and taking discrimination into their own hands and claiming their human rights. So that, as Ruth Morgan Thomas very eloquently described, sex worker communities are responding to not being able to open bank accounts, by opening their own banks; or not being able to come to an AIDS conference, by holding their own conference; or not being able to send their children to school, by starting their own school.

We are left with what Ralf Jürgens described as a paradox. Michael Kirby spoke of the “AIDS paradox,” but there is also the discrimination paradox, which is that the more we seem to talk about discrimination, the less we seem to do about it. The more we seem to agree and reach consensus on discrimination, the less we seem to invest in it. So that while it is very heartening that many of the examples we learned of today come from governments and are funded by governments, by bilateral donors or by the Global Fund to Fight AIDS, TB and Malaria, too many of these interventions have either lost funding recently or never got beyond the status of pilot projects. I suppose this is no surprise given what we learned from Christine Stegling, that while many national strategic plans for HIV mention human rights, rarely do they include comprehensive evidence-based programmes, such as all the ones that were described today. Now, we know that the Global Fund will, going forward, be funding programmes based on national strategic plans, so we have to ask ourselves what this lacuna means in terms of the prospect of the Fund being able to fund anti-discrimination work. We heard from the Global Fund that such plans will not be considered technically sound if they exclude human rights, and that the Fund will be asking countries to show that they are addressing equity and non-discrimination.

But for now, the reality is as it was described by people like Alessandra Nilo, Terry McGovern and Ralf Jürgens, which is that these programmes are not being funded; that organizations leading this work are going into debt; that foundations, bilaterals and other donors are shifting their priorities. But we also know that this is not just a question of money; it’s a question of policy, of commitment, of political will and of courage.
Ladies and gentlemen, next year, the UN Secretary General will report to the General Assembly on the progress made against the anti-discrimination target in the latest Political Declaration.

Let us conclude by asking ourselves this: will this be yet another report where we observe the continuing impact of discrimination and mention that something can and should be done about it? Or will this be the report where because of real money, real commitment and real courage at all levels, we finally made progress against the hardest zero?

Thank you.