ICW Eastern Africa (International Community of Women Living with HIV/AIDS Eastern Africa) HEPS Uganda (Coalition for Health Promotion and Social Development) • UNASO (Uganda Network of AIDS Service Organizations) • SMUG (Sexual Minorities Uganda) • Health GAP • UHSPA (Uganda Health and Sciences Press Association) • POMU (Positive Men's Union)

Civil Society Statement: Recommendations for Uganda's PEPFAR SDS 2015
May 2015

As a sector civil society appreciates the engagement that has taken place with PEFPAR Uganda during the development of the 2015 COP. **Below are priority recommendations regarding the contents of the draft 2015 SDS and regarding the process for civil society engagement going forward, particularly as the Quarterly Reviews begin.** (Note: where possible we have indicated the section of the SDS that correspond with these comments.)

• Transition plans: We are extremely concerned by the proposed transition to the Government of Uganda 264 HIV testing, treatment and care sites by the end of the U.S. Government Fiscal Year 2016 (September 30, 2016), particularly in Districts with high burden and/or prevalence, and/or hot spots. In these cases, what has PEPFAR done to ensure that low volume and/or low yield reported by implementing partners is due to actual lack of need versus partner performance and/or inaccurate epidemiological data? As a country with a generalized epidemic and persistently high prevalence nationwide, withdraw of services has very different ramifications than in other countries where the epidemic is more focused geographically.

We request information about the services being provided by each of the 264 sites targeted for transition as well as their corresponding location, in order to understand the potential impact of this move. What is the quarter-by-quarter transition plan? What activities will become the responsibility of the Government of Uganda, and how will they be funded?

In addition on p. 18 and 19 the COP describes transition plans for 9 Districts[1] that will result in an estimated 1,233 people with HIV who will not be included in the projected FY2016 total number of people on treatment. These sites never reported PEPFAR funding support for people on treatment not to be reached with treatment (section 4.0) but the COP states that: "PEPFAR will not support newly enrolled (1,233 PLHIV) in transition districts but will ensure supported services are responsibly transitioned to the GoU." Since PEPFAR was providing only national level TA, please list each service that will be transitioned to the government, how they will be funded, and when the transition will take place. *(See Section 3.0, Section 4.1, Table 4.1.2, and Section 5.0.)*

• Results of START trial and unmet need for treatment: The current Uganda HIV treatment guidelines recommend treatment for all HIV positive people in serodiscordant couples, all key populations, all TB-HIV co infected people, all pregnant women, and all people younger than 15 years, regardless of CD4 count. In addition, any person with CD4<500 is also eligible. In practice virtually all Ugandans with HIV are eligible for treatment initiation given those parameters and the high proportion of HIV positive people in discordant relationships.

Moreover, new WHO treatment guidelines will be issued in 2015; given the outcomes of the START trial indicating major clinical benefit to immediate initiation, offering treatment to all people with HIV is very likely to become the new standard—to maximize clinical as well as prevention benefit. However, the COP targets assume that only 80% of people with HIV on pre-ART care have access to CD4 staging, and only 75% of those are eligible (see page 18). We note that these assumptions are most likely incorrect, and the unmet need for treatment is substantial despite the treatment scale up efforts described in the COP 2015. **How will PEPFAR work with the government of Uganda to raise additional funds and with the Global Fund to expand Uganda's access to Global Fund resources in the immediate future?** *See Section 4.4-4.9.*

• Retention, linkage, adherence support and improving quality of adult, pediatric, and adolescent treatment and treatment for pregnant women: Throughout Uganda's COP, poor performance by IPs in

[1] The nine proposed transition Districts are Luuka, Amudat, Abim, Bulambuli, Kapchorwa, Kaabong, Kween, Nakapiripirit, and Napak.

program quality is highlighted. For example: *"September-December 2014 SIMS data showed deficiencies in timely provision of EID (50% red/yellow) and cotrimoxazole (CTX) for HIV-exposed infants (42% red/yellow), and lack of mother- and infant-tracking systems for PMTCT services (45.4% red/yellow)" (p. 26); "September-December 2014 SIMS data revealed gaps in community-facility linkage with 90% of the sites scoring red or yellow for adults and 75% for children. Other weak areas were CD4 monitoring, patient tracking, and pediatric HIV testing" (p. 30); and "September-December 2014 SIMS data showed that 78% of sites assessed lacked systems to track facility-community linkages in large part due to a gap in available community-based services to support adherence, retention, and quality of care" (p. 84).*

Unfortunately the only intervention described to correct this serious obstacle to epidemic control is budgeting of an additional $12.70 per patient in Scale up 1, 2 and Maintenance 1 Districts, with a further $1.30 budgeted for each key population patient. Such additional funding is necessary but not sufficient—what is the *strategy* for fixing these chronic issues? Will PEPFAR enforce a requirement that all IPs to deploy a minimum package of interventions based on best practices and the goal of epidemic control—eg implementation of service delivery models that have been shown to increase retention in care, increase viral suppression, and improve clinical outcomes? For example in eMTCT programs, this would include a requirement for use of compensated HIV positive mentor mothers in all sites, family support groups, and active defaulter and case tracking for mother-baby pairs. Historically, IPs have had multiple service delivery approaches, with different priorities and using different models. This has led to less accountability and has not improved outcomes. That is why a minimum set of consistent expectations that all IPs and partners can be held accountable for is needed—building on successful, community owned approaches leveraging expertise of HIV positive people. *See Appendix B, Section B.2, Resource Projections. See also "PMTCT quality and service delivery models," below.*

• eMTCT quality and service delivery models: Uganda has the largest Option B+ program in the world and has registered important successes. However program quality issues have been identified consistently since roll out in 2013, and have not been resolved. SIMS data show IPs are not investing sufficiently in service delivery models that ensure all women and all newborns are supported, tracked, and motivated to adhere in care. We also note the existence of the national real-time Option B+ reporting platform that generates weekly reports through an emergency operations center (see p. 26). Civil society plays a crucial role in monitoring the quality of eMTCT programs at the community level. For example, ICW Eastern Africa recently completed assessments of eMTCT care in Kanungu, Ntungamo, and Bullisa that provided invaluable feedback for a national conference on poor performing Districts in eMTCT. ICW Eastern Africa had not been formally invited to the meeting—nor were any civil society members (who are not IPs/grantees) invited in advance. Will PEPFAR work with the Ministry of Health, Uganda AIDS Commission, and civil society to ensure all policy setting bodies overseeing the Option B+ program *include* technical experts from civil society, and that civil society have timely access to weekly reports data from the real-time Option B+ reporting platform? Specifically, when civil society is not present in a meaningful way at such meetings, PEPFAR should publicly express concern and request that such oversights be immediately rectified. *See Section 4.4.*

We also note with concern the removal from "Core Activities" and "Non Core" designation of cervical and breast cancer screening for HIV positive eMTCT patients (p. 59). In addition, moving to "Near Core" the screening of pregnant and breastfeeding women HIV positive women for intimate partner violence is astonishing, considering extremely high risk of Option B+ patients to domestic violence, and the linkage between poor clinical outcomes and high loss to follow up among women confronting violence in their homes. Both of these options are core components of quality service for pregnant women—they are not simply 'nice to do,' they are necessary for addressing priority co morbidities women with HIV are at high risk of, and they are necessary for responding to the structural barriers that make HIV positive women and their HIV positive children at much greater risk of treatment failure (e.g. domestic violence). *See Appendix A, Table A.1.*

• Lab capacity and viral load monitoring: Supporting rapid scale up of viral load monitoring through the Early Infant Diagnosis hubs is critical to the success of the COP 2015 strategic pivot. What is the year on year coverage target for viral load monitoring and what is the roll out strategy? Given persistent quality concerns and the size of the patient population on ART, we would want to see a more ambitious viral load monitoring target for year 1. *See Section 4.8, p. 32.*

Civil Society is also concerned about how the country is prepared to handle outcomes of rolling out viral load monitoring. With VL monitoring there is a high likelihood of increased cases of patients failing on 2nd line treatment who will require 3rd line treatment. Currently the country has no third line treatment policy but there

are a growing number of patients needing third line treatment. Medicines used for third line such as darunavir are not registered in Uganda, causing unnecessary delays in importation.

We are concerned that the current central lab will be over burdened, given that it is used for EID as well. Regional labs are needed, as well as aggressive scale up of Point of Care labs in the high burden and high prevalence districts. Finally, the structure of the service contracts for GeneXpert machines may undermine ongoing maintenance of this vital diagnostic tool.

• **Meeting the prevention and treatment needs of women, including adolescent women and girls:** The COP 2015 indicates that gender will be 'integrated' in Scale up Districts (p. 25), but there is no clear description of how that will happen, or why the South African modules are expected to succeed in Uganda, and how adaptation of these modules will occur. We are also concerned that gender will not be a priority for prevention in non Scale Up Districts. *Section 4.2*

HIV treatment needs of HIV positive young women (eg outside the treatment bracket of 15 years and younger) are not sufficiently prioritized in the COP. On p. 32 the COP notes "PMTCT/ART integration and DREAMS funds will establish adolescent-friendly services and identify more adolescents living with HIV, respectively, and link them to care and treatment"—but what is the specific treatment target for this population? What is the allocation for 15-24 year old women living with HIV? *Section 4.8*.

In addition, we are concerned that the commitment in the COP to mainstream gender is not reflected in program priorities, for example, Option B+ roll out has come with a surge of domestic violence. Fear of violence leads to loss of HIV positive women from clinical care. If the COP does not address domestic violence, eMTCT and epidemic control efforts will be undermined, while women's rights are violated.

• **Meeting the needs of key populations:** Who will be responsible for conducting the "rapid assessment to determine gaps in HIV services delivery for hard-to-reach populations and identify potential opportunities to scale-up services" described on p. 32?The COP states that men who have sex with men in Uganda" are highly stigmatized within a legal and policy environment that inhibits non-discriminatory service delivery." Given this reality, what steps are being taken to ensure the safety and appropriateness of data collection and service delivery for MSM? (p. 4).

The COP contains no action plan for how to improve data collection on key populations. We are concerned that the size estimates for men who have sex with men are serious underestimates. For example on Table 1.1.1 ("Key National Demographic and Epidemiological Data: Key Populations), the MSM population size estimation appears to severely underestimate the true MSM population size outside Kampala. The Kenya AIDS Indicator Survey (AIS), which is used to estimate that only 0.6% of men in the 111 districts outside Kampala are MSM, considered accurate for MSM population size estimation, but is considered a drastic underestimate for female sex workers because, as the COP notes, "people tend to underreport illegal behaviors in a household survey"? Thus, a 2.84 multiplier is applied to every regional AIS estimate for female sex workers but the value of 0.6% for MSM is left intact. Given the well-documented stigma and discrimination faced by MSM, it is reasonable to assume that they are being extensively undercounted outside Kampala. The COP could also be much more explicit in stating the population size estimation assumptions for Kampala. Likewise, normative guidance issued by the WHO on HIV interventions and service delivery for key populations have not been adopted by Uganda and are not mentioned.

It is unclear why the population size estimates for key populations (with the exception of those for the military) differ between the tables on p. 6 and p. 7. Which table is accurate? The COP provides no data for people who use drugs and provides no explanation for why they are excluded from programming. This is concerning given that: 1) Data from neighboring Kenya and Tanzania indicate significant drug using communities with elevated HIV prevalence, and 2) The COP15 guidance requires that drug using communities be prioritized, if and when it is safe to do so.

Coverage targets for MSM (40%), long-distance truck drivers (50%), fisher folk and army personnel (25%) are being set much lower than the 80% targets being set for sex workers, police personnel, and zero-discordant couples. These targets should be corrected and made more ambitious (p. 19).

The COP 2015 notes "general population [treatment] targets were merged with priority and key populations due to a lack of reliable data on key/priority population sizes." We are concerned this will result in insufficient ambition regarding treatment and care. This underlines the limited nature of key populations data in Uganda, yet no clear action plan is presented for future data collection (p. 23). *See Table 4.1.2*.

On p. 24, in Table 4.1.4 ("Target Populations for Prevention Interventions to Facilitate Epidemic Control") it is not clear why population size estimates for key populations are so much lower than the national estimates provided on p.6 (e.g. only 9,115 MSM are being "targeted" compared to a national estimate of 25,460). The COP here appears to be stating (in very confusing terms) that key populations are only being targeted in geographically prioritized districts ("Scale-up" and "Maintenance 1") and not in de-prioritized districts ("Maintenance 2" and "Transition"). If this is the case, this would contradict the COP 2015 global guidance that key populations be prioritized even in geographically de-prioritized areas.

Finally, although less is known regarding HIV risk and baseline prevalence among lesbian and bisexual Ugandans, they also experience discrimination when seeking health services, and it is critical to cater for their needs when building high impact key population programming.

• **VMMC level funding:** the COP 15 funding level is held constant, but the program will shrink to 58 districts (p 17), targeted based on prevalence and unmet need for circumcision. Please provide information about the geographic shift in programs between COP 14 and COP 15. Will this program contraction result in established programs being shut down, triggering inefficiencies? Is PEPFAR working to secure government ownership of the program? *See Section 3.0*.

• **Support for civil society advocacy:** The COP notes the need to expand investment in civil society advocacy: "findings from the SID, SIMS and CSO engagement clearly indicate that community participation and CSO engagement in HIV advocacy, and at service delivery sites is limited and ad hoc, in most cases. PEPFAR will support capacity building of CSOs in advocacy, involve them in assessing and developing approaches to facilitate access to quality HIV services in a non-discriminatory manner to all HIV-affected populations, and reinforce linkages between communities, CSOs, and facilities to ensure that all PLHIV are detected and linked to services" (p. 43). We strongly welcome this acknowledgement of the need to invest in civil society advocacy to achieve Uganda's ambitious HIV treatment and prevention goals. We note that this will require not only additional resources, but also assurance by all partners, including PEFPAR, that civil society is supported as equal partners participating meaningfully in relevant technical bodies that are setting policy, reviewing and analyzing data, and making key recommendations. *See Section 6.3*.

• **Engagement of civil society after COP 2015 approval:** We intend to engage substantially through the new Quarterly Monitoring meetings. In order to ensure success, we request timely access to complete performance data for all implementers, transparently presented and disaggregated by facility and IP. We request meetings be structured so that we both have the opportunity to engage directly with PEPFAR as well as alongside Government of Uganda and Implementing Partners.

We also request ongoing oversight of the DREAMS Initiative to use PEPFAR engagement with civil society as a model, as part of Quarterly Review meetings, and for PEPFAR to share the DREAMS application urgently.