

# THE PEOPLE'S VOICE UGANDA

COMMUNITY PRIORITY RECOMMENDATIONS

FOR PEPFAR UGANDA FOR 2021





# INTRODUCTION: DEVELOPING “THE PEOPLE’S VOICE”

Since 2012, communities of People living with HIV (PLHIV), Key and Vulnerable Populations (KVPs) and Civil Society Organisations (CSOs), under the leadership of the International Community of Women Living with HIV Eastern Africa (ICWEA), the Coalition for Health Promotion and Social Development (HEPS-Uganda) and Sexual Minorities Uganda (SMUG) in collaboration with global partners including Health GAP and AVAC have been monitoring and informing PEPFAR Country Operational Planning (COP) processes. At that time, there were no minimum standards for the meaningful engagement of PLHIV, KVPs and CSOs and discussions with the U.S. government regarding Uganda’s COP would take place only in meetings at the U.S. Embassy. PLHIV, KVP and CSOs worked to ensure that the engagement processes became truly community-owned and community-led. They established a structured calendar, clear expectations of civil society and of PEPFAR Uganda, and a shared focus with PEPFAR Uganda on improving the accountability of the HIV response for communities and CSOs.

This is the third edition of The People’s Voice; the first was published in 2019<sup>1</sup> and the second in 2020.<sup>2</sup> Successes resulting from these efforts over the years include: introduction and scale up of Pre-exposure Prophylaxis (PrEP); acknowledgement of the problems that come from poor implementation of index testing; development and implementation of policies and guidelines for harm reduction programs; establishment of a package of harm reduction services for people who use and inject drugs (including Medication Assisted Therapy or MAT); commitment to standardise the package of services provided by community health workers (CHWs) and investment in the Community-Led Monitoring (CLM).

Like earlier editions, this edition outlines recommendations and priorities from PLHIV, KVPs and CSOs. It is built from PEPFAR’s existing promises from COP20 while introducing new recommendations. Communities and CSOs acknowledge PEPFAR for being responsive to the priority areas in The People’s Voice.

This version of The People’s Voice was developed using the following process: Community Led Monitoring (CLM) in 32 health

facilities which are located in 28 districts (see Table A, page 3) during the CLM pilot phase (August-September 2020) and Focus Group Discussions (FGDs) with community representatives. We also undertook a rapid fact-finding assessment on the theme of paediatric treatment access and COVID-19, held consultation and validation meetings with national level CSOs; reviewed PEPFAR and Ministry of Health HIV and TB program performance data; and conducted interviews with key informants from national government and local government. In addition, regional meetings with 13 PEPFAR Implementing Mechanisms (IMs) were convened and attended by CSOs, people living with and affected by HIV, respective Implementing Partners (IPs) and leadership. Consultations with Ministry of Health, Uganda AIDS Commission (UAC), PEPFAR and AIDS Development Partners were held during their annual retreat. We also used these engagements to monitor the implementation status of existing policy commitments made in response to community recommendations from prior years.

This People’s Voice on COP21 focuses on the following critical themes: effective management of COVID-19; rights-based

1. The People’s Voice on COP19 Community Priorities. Available at: <https://healthgap.org/wp-content/uploads/2019/03/Peoples-Voice-Uganda-FINAL.pdf>  
2. The People’s Voice on COP20 Community Priorities. Available at: <https://healthgap.org/wp-content/uploads/2020/02/Peoples-Voice-Uganda-COP20.pdf>



testing; high-impact treatment retention; recruitment and retention of sufficient numbers of professional and community healthcare workers; funding mission-critical treatment literacy efforts implemented by organisations of people living with HIV; and retaining KPIF in COP21 budget that prioritises key population (KP) organisations' capacity building, prevention and treatment. It also focuses on promotion of quality, evidence-

based and human rights prevention interventions; expanding biomedical and structural prevention interventions for women and girls including GBV, economic empowerment and human rights; support for people with disabilities; closing gaps in diagnosis and treatment of children with HIV; PrEP scale up; TB programming; stockouts of HIV and other health commodities; and community-led monitoring.

**Table A: List of health facilities monitored**

Implementing Mechanism (IM)	Districts	Health facilities
1. RHITES E	Pallisa, Mbale	Pallisa General Hospital, Namatala HC IV, Mbale Regional Referral Hospital, Namakwekwe HC III, Maluku HC III,
2. RHITES EC	Bugweri, Bugiri	Busembatia HC III, Bugiri General Hospital
3. TASO Soroti	Ngora, Kumi	Ngora Hospital, Kumi HC IV
4. West Nile	Nebbi, Pakwach	Nebbi Hospital, Pakwach HC IV, Panyimur HC III
5. RHITES Lango	Kwania	Imono HC III, Amach HC IV, Baraapwo HC III
6. RHITES Acholi	Amuru	Kaladima HC III
7. MURP	Mukono, Kayunga, Buikwe	Mukono General Hospital, Bbaale Health Centre IV, Ssi-Bukunja Health Centre III
8. IDI-Kampala	Kampala, Wakiso	Hope Clinic Lukuli HC III, Kajjansi HC III
9. IDI-Hoima	Kikuube, Kiryandongo	Kabwoya HC III, Panyandoli HC III
10. Mildmay	Mityana, Mubende, Kasanda	St. Jacinta, Mubende RRR, Musozi HC III
11. Baylor	Kyenjojo, Kamwenge (Kitagwenda)	Butiti HC III, Ntara HC IV
12. Rakai Health Sciences Program	Masaka, Ssembabule, Kalungu	Bukakata HC III, Ntuusi HC IV, Kalungu HC III, Masaka Regional Referral Hospital, Nyendo HC III, UHRN DiC, AWAC DiC,
13. RHITES SW	Ntungamo, Kabale	Kitwe HC IV, Kamukira HC IV, Biharwe HC III, Nshungenzi HC III, TASO Mbarara





# THE HIV RESPONSE IN UGANDA

As of the end of 2020, Uganda reported 1,431,553 people living with HIV, of whom 88,331 were children younger than 15 years old. Of the 1,275,306 people living with HIV in Uganda, 1,267,521 are on ART, out of which 537,341 are virally suppressed.<sup>3</sup> Approximately 86% ART coverage was reported representing an increase from 83% coverage reported in 2020. National prevalence is estimated at 6.2% among adults and 0.5% among children.

While Uganda is approaching epidemic control, with an estimated 156,247 people who do not know their status, there are serious obstacles preventing the attainment of the crucial goal of ending AIDS as a public health challenge. Importantly, indicators of retention of people living with HIV on continuous, quality treatment shows severe program underperformance, particularly for pregnant and postpartum women, key populations, adult men, children, and adolescents.

Therefore, COP20 set out to scale-up the target of reaching and retaining 1,326,814 people on ART by the end of FY21 (Oct 1, 2021)—which implies that an additional 51,508 people must be reached. Chronic barriers to retaining all people who are enrolled on ART mean that this number will be missed unless there is a massive shift. For example, the TX\_NET\_NEW for FY20 was only 2,862.<sup>4</sup> High rates of treatment interruptions due to loss to follow up mean people are at greater risk of viral replication, drug resistance, sickness and death. As emphasised by the new UNAIDS strategy, social inequalities fuel the continued spread of HIV and clinical progression to advanced HIV disease and death. These inequalities must be tackled as core components of

successful service delivery. Leadership by people living with HIV and key populations (KPs) including people with disabilities are at the foundation of those efforts.

Likewise, indicators of program performance in sexual prevention indicate that the HIV prevention response is off-track. Estimates based on the Uganda Population-Based HIV Impact Assessment (UPHIA) indicate that 73,000 new HIV infections occur annually.<sup>5</sup> Despite an overall decline in the incidence of new infections and AIDS-related deaths, Uganda missed the Fast-Track target for reducing new HIV infections. Adolescent girls and young women (AGYW) endure the most of new infections. Meanwhile, implementation of priority biomedical interventions such as pre-exposure prophylaxis (PrEP) is lagging. For Q1 FY21, the first quarter for COP20 implementation, IPs are already off track in achieving PrEP\_NEW. Annual PrEP targets increased for FY21 as part of COP20 from a very unambitious 30,000 last year to 95,804 for 2020-2021. Only two IPs are keeping up with this surge.<sup>6</sup>

Despite important achievements, chronic problems plaguing the program must be solved if the country is to get on track and

3. SI/HIS Annual Performance Review (APR), PEPFAR Uganda, November 30 2020

4. PEPFAR Uganda Q1 2021 Results, Performance Highlights, March 5 2021, slide 13

5. Ministry of Health, Uganda. Uganda Population-based HIV Impact Assessment (UPHIA) 2016-2017: Final Report. Kampala: Ministry of Health; July, 2019, p 13

6. Supra note 4, slide 17

defeat AIDS nationally. Many of these problems were highlighted in The People’s Voice 2020 and in some cases, PEPFAR Uganda agreed to take on the shifts that were recommended. For example, the 2020 Strategic Direction Summary (SDS) indicates: “PEPFAR will continue to support community, civil society and PLHIV organisations to provide quality peer support services that are targeted to case finding, addressing stigma and discrimination, adherence, treatment literacy, Viral load suppression, and disseminating messages like Untransmittable = Undetectable (U=U)”<sup>7</sup> and implementing “peer-led defaulter tracking, monthly adherence support groups, exploring multi-month drug refills while addressing structural barriers and strengthening ART optimisation: TLD transition for KP, U=U messaging.”<sup>8</sup> But these commitments have not translated into the improvements that Ugandans need.

As noted in the COP21 Planning Level Letter for Uganda, “high levels of treatment interruption, particularly for those newly initiated on ART, large proportions of patients receiving less than three months of ART, particularly for paediatric patients, and significant gaps across the paediatric cascade, starting with two-month EID coverage, through viral load suppression of adolescents” all point to chronic weaknesses that are depriving Ugandans of the HIV of the services they are entitled to.<sup>9</sup> Between 2019 to 2020, 148,563 people were started on treatment, but 97,557 or 66% were lost to follow up (LTFU). PEPFAR reported more than 15% of people experienced interruptions in their treatment, and only 57% of people living

with HIV had 3–6-month prescriptions of ART by Sept 30, 2020. Meanwhile, virtually all children had only one month’s supply of medicine.<sup>10</sup>

Despite agreement by PEPFAR with the evidence and analysis brought forward by communities, we do not see accompanying shifts in program performance. COVID-19 has brought this reality into even sharper relief, with significant reductions in utilisation of outpatient health services, increases in institutional mortality, increases in gender-based violence, teenage pregnancy, unsafe abortion and maternal mortality.<sup>11</sup>

Uganda significantly reduced new HIV infections and AIDS-related mortality during the past decade. However, the country could achieve the 2030 goal of ending AIDS as a public health threat if it prioritises efforts led by people living with HIV to increase retention and poor treatment program quality, scales up service delivery for and funding for the economic empowerment of those who are made most vulnerable due to stigma and discrimination, closes yawning gaps in service delivery for HIV positive children and their caregivers, and rebuilds all aspects of the HIV response that have been harmed by COVID-19 policy restrictions.

In COP20, communities made recommendations that were frequently adopted in the final Uganda Strategic Directions Summary. According to community analysis, the PEPFAR Uganda COP20 had a score of 59.7%, implying it had “reasonable inclusion” of civil society demands (see Figure 2, below).<sup>12</sup>

Figure 2: Summary Assessment by CSOs of Uganda’s COP20



COP shows reasonable inclusion of civil society priorities.

Table 7. Inclusion of civil society priorities from Uganda’s People’s Voice in PEPFAR’s COP20 Strategic Direction Summary. For greater detail, including composite parts, [see the full data table for Uganda](#).

Priority Area in People’s COP	2020 Grade
1. Walk the talk—put communities at the center	30.6%
2. Key populations programming	55.0%
3. Social enablers must be implemented	68.8%
4. High impact prevention must be expanded through COP19 and COP20, focusing on adolescent girls and young women (AGYW), key populations, pediatrics and men	63.9%
5. Expand pediatric HIV diagnosis and quality treatment access	100.0%
6. Stop stockouts	70.0%
7. Address persistent human resources for health barriers	75.0%
8. TB/HIV service delivery	66.7%
9. Community Led Monitoring for Advocacy	55.5%

7. Uganda 2020 COP Strategic Direction Summary, p 82

8. Ibid p 69

9. Uganda Planning Level Letter. PEPFAR January 13, 2021, p 3

10. Ibid p 5

11. Tumwesigye, Nazarius Mbona et al. Effects of the COVID-19 Pandemic on Health Services and Mitigation Measures in Uganda. Working Paper 571 March 2021.

12. Measuring Up: Tracking PEPFAR’s Accountability to People Living with HIV 2020–21, p 20. Complete side-by-side analysis of Uganda’s COP20 contained in the report is available here.







# COMMUNITY PRIORITY INTERVENTIONS FOR COP21

## 1. COVID-19

On March 21, 2020, Uganda reported its first COVID-19 case. The government responded by instituting a lockdown and other severe restrictions, such as a ban on the movement of public and private vehicles except with expressly issued permits, and a halt to schooling. Uganda experienced some of the most restrictive responses to COVID-19 of any low-income country. International COVID-19 financial assistance provided to Uganda was not used to buffer economic shocks experienced by ordinary Ugandans or to address the increased rates of violence and disruptions in access to medical care they experienced. COVID-19 policy responses also did not prioritise these issues.

CLM findings indicated that facilities operated under restricted hours, high volume departments became COVID-19 emergency response teams, often compromising the quality of care for patients. While medical services were deemed “essential” and were expected to continue, the government—and PEPFAR—did not develop the means to respond to ongoing needs for non COVID-19 medical services.

Moreover, social services were deemed “non-essential,” and as a result interventions that children and adults living with HIV children depend on were severely interrupted. Policy focus was diverted from existing comorbidities in the population that had no relationship to COVID-19. Clinic utilisation declined, sexual reproductive health and rights (SRHR) services such as family planning were even harder to obtain. Gender based violence, rape, incest, unplanned pregnancy, unsafe abortion, maternal mortality and teenage pregnancy rates all increased. Catastrophic loss of income became commonplace because wage earners lost their markets.

**1a. Investments through COP20 reprogramming and COP21, including new PEPFAR COVID-19 emergency funding, must prioritise community recovery from the effects of lockdowns and restrictions on movement, particularly for children with HIV and their caregivers, adolescent girls and young women, people who have experienced gender-based violence, key populations, and others who are most vulnerable.**

Whereas COP20 committed to social support activities such as economic empowerment for adolescent girls and young women (AGYW), intensified screening for gender based violence (GBV), provision of post-violence care, asset building, financial literacy, and more,<sup>13</sup> the response to COVID-19 has thrown these approaches off balance. In addition, treatment retention, already

a weak aspect of the national AIDS response, has been further undermined during COVID-19. The POART Q1 COP21 analysis shows that between Quarter 1 FY2020 and Q1 FY2021, 62,871 people were lost to treatment, leaving the country with a “net new” increase of only 2,862, almost like the previous year’s.<sup>14</sup> As a matter of priority, COP21 must redress these harms. Key populations were also targeted by law enforcement, with arrests, detention and torture of 21 LGBTQ people using the pretence that they were violating COVID-19 procedures.

**COP21 TARGET:** PEPFAR should use COP20 and COP21 resources (including emergency COVID-19 funding) to put in place comprehensive programs to recover from the COVID-19 crisis, prioritising the communities that experienced the most harm, such as targeted community cash transfers for the most vulnerable, access to justice for those who experienced violence. Communities must be consulted in developing and implementing this response.

**COP21 TARGET:** PEPFAR must increase investment to direct IPs to find and support the return to care and treatment of the 62,871 people who were LTFU between Quarter 1 FY2020 and Quarter 1 FY2021.

**1b. Successful community-led adaptations to COVID-19 should be directly funded, strengthened and taken to scale nationally.**

Against long odds, communities led efforts to adapt essential health interventions to COVID-19 restrictions. Examples include: communities doing home delivery of ART and family planning refills and carrying out community based social support and providing cash transfers.

The Support on AIDS Helpline (SALT) provided COVID-19 safe HIV information and referrals. Door to door delivery of ART was led by the National Forum of PLHIV Networks in Uganda

13. *Supra* note 7, cf pp 51, 52, and 57.

14. *Supra* note 4, slide 13.



(NAFOPHANU), Uganda Young Positives (UYP), Uganda Network of Young Positives Association (UNYPA), and social network coordination by key population (KP) peer networks. These interventions used a client-centered approach to deliver essential services and peer-led support. Unfortunately, these were largely treated as “boutique” rather than integrated into the national COVID-19 response and taken to scale. For example, one community-developed model was built out of necessity: by Q1 COP20, public transport had been partially reopened but the cost was unaffordable for young people who had just spent three months without working. HIV positive peers provided door-to-door delivery of medication, helping young people prevent ART interruptions, linking them with routine viral load and CD4 testing. It also helped young people who had little or no access to food adhere to ART. Drug deliveries were done thrice a month at a very minimal cost (fuel, car servicing, masks, sanitiser, and payment of staff). Monthly costs were estimated to be: \$405 for a reach of 196 people.

These community models have proved to be effective not only in providing drug refills but also in carrying out treatment literacy, support for GBV, and other peer-to-peer community engagement regarding disclosure support, among others. However they were not well funded or given the infrastructure they required to have national impact.

IPs did not provide cash transfers to buffer the shock of COVID-19 restrictions; therefore, they could not reach clinics and obtain food during the pandemic. PEPFAR should remedy this using COVID-19 emergency relief currently available at PEPFAR Headquarters level.

***COP21 TARGET: PEPFAR should fund effective community COVID-19 adaptations so that they can be taken to scale nationally.***



## 2. Expand high-impact treatment retention efforts

Lifelong, uninterrupted HIV treatment requires the availability of quality retention-in-care investments available to all adults and children living with HIV. COVID-19 has revealed and underscored the insufficient support for community-led HIV treatment retention interventions in Uganda, such as all prongs of differentiated service delivery (DSD) being available nationwide with fully functional ART support groups, CDDPs (Community Drug Distribution Points) and C-CLADs (Community Client-led ART Delivery); options for fast track drug refills; 6-month supplies of ART; comprehensive treatment literacy programs designed and implemented by organisations of people living with HIV; and adequate concentrations of sufficiently remunerated, well trained and managed community and professional health workers. PEPFAR should require that 100% of IPs implement all minimum standards already decided during the COP20 Regional Planning Meeting.

Treatment interruptions are common in Uganda but are most often reported when people start ART—the period when treatment literacy and peer-led counseling and solidarity are particularly critical.

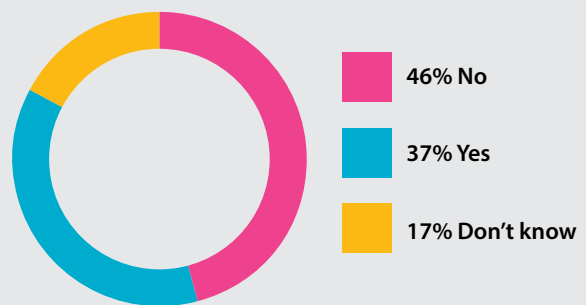
COP20 made a series of commitments in response to People’s Voice 2020 recommendation that: *“COP20 must ensure 100% of PEPFAR supported sites have sufficient funding invested in community-led retention and treatment program quality improvement strategies, prioritising treatment literacy, stigma reduction and U=U, to ensure access to quality treatment services for all HIV treatment sites and their corresponding communities.”* Unfortunately these interventions have not yet been implemented; TX\_NET\_NEW is now at only 2,862 compared with Q1 FY20. COVID-19 has further undermined an already untenable situation.

### 2a. PEPFAR should directly and adequately fund organisations of people living with HIV to design and implement ongoing, comprehensive, high-impact treatment literacy and peer-led support programs instead of one-off marketing or “messaging” campaigns

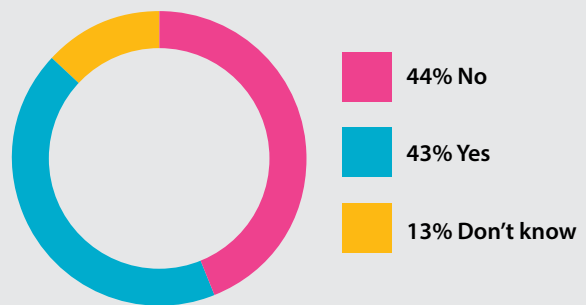
This problem of treatment retention has been raised multiple times during RPMs by civil society. Each time PEPFAR commits to various policy shifts, such as expanding Community Drug Distribution Points (CDDPs). Nonetheless, these efforts have not resolved the problem. CLM has shown us that there is one massive barrier to treatment retention that has not been prioritised nationally—the lack of treatment literacy interventions designed and implemented by networks of people living with HIV.

For example, Joint Adherent Brothers and Sisters against AIDS (JABASA) surveyed HIV treatment literacy in 5 PEPFAR-supported facilities. Of 120 clients interviewed only 9 knew the treatment regimens they were on, 15 knew what viral load measured and the importance of viral load monitoring, only 3 knew the meaning of HIV drug resistance and only 3 could explain what undetectable viral load means. Similarly, the CLM pilot data showed that only 43% of patients surveyed knew that undetectable viral load means that ART is “working well.” In addition, only 37% of patients surveyed knew that undetectable viral load means a person is “not infectious.” Knowledge gaps regarding viral load suppression and its importance point to overall unmet need for treatment literacy.

Knowledge test – Undetectable viral load means a person is not infectious



Knowledge test – Undetectable viral load means the treatment is working well



TLD transition concerns among people living with HIV also point to the need for comprehensive, PLHIV-led treatment literacy efforts. While “mentoring efforts” for health workers and other supportive programs implemented by the Collaborative for Quality Improvement (CQI) are welcome, they will not be sufficient to scale up access to information among all people living with HIV. This is a matter of serious concern. For example, anecdotal evidence points to people living with HIV being given only the option of TLD, and abandoning treatment because of lack of information and peer-led support to answer their questions. While many older women have transitioned successfully to TLD and the medication is working well for them, with good viral load suppression, young women report that they are still afraid and confused about whether TLD is safe for them.



*“Before transition to TLD, random blood sugar (RBS), liver function tests (LFT) and other relevant tests should have been conducted as some clients suffer from diabetes and high blood pressure but these services are not rendered in our health facilities.”* —Community Health Worker, Kwanja

One client was concerned that a new version of TDF+3TC+EFV (TLE), with a lower dose of efavirenz, was weaker than the existing version—people living with HIV have many questions. By ignoring these questions, the health system foments distrust, leading to treatment abandonment.

*“As a woman who has been living with HIV for 28 years, I have had certain health complications like diabetes, I have undergone several operations for fibroids where I also lost my uterus due to an accident and suffer other complications of the kidney. I take many tablets a day. However, recently when I went to the health center for my HIV drugs, I was told the drug I’m on was stocked out and was switched to DTG which did not react well with the many health complications and the many drugs I’m already taking. The health facility has not been able to support me to stabilise, what can I do?”* —HIV-positive client, Fort Portal

One community member described an HIV-positive young person who never missed his appointment but had an unsuppressed viral load: *“On visiting his home in Rwampara, the boy’s bedroom was full of tins that had never been opened for several months. Adherence is beyond picking medications regularly. Awareness raising to ensure self-acceptance needs to be given a priority.”*

These programs also fight stigma and discrimination by supporting a national cohort of communities, living openly with HIV, demanding to be treated with dignity and respect all people deserve. COP2021 must fund treatment literacy with the resources it deserves for PEPFAR to finally address the most stubborn program gaps.

COP20 committed to “enhanced treatment literacy among KPs and their families (“undetectable=untransmissible” or “U=U” messaging), strengthening peer navigation and monitoring systems, reducing stigma and discrimination in both KP-specific ART sites and within the more mainstream clinical sites.” COP20 also committed: “In addition, PEPFAR will continue to support community, civil society and PLHIV organisations to provide quality peer support services that are targeted to case finding, addressing stigma and discrimination, adherence, treatment literacy, VL suppression, and disseminating messages like U=U.” But these programs have not materialised. Importantly, PEPFAR has plans to roll out the development of messages regarding treatment literacy—such as its “Social Behavioral Change Activity” program (under development). But these approaches are fundamentally different from truly community-owned and community-led treatment literacy. The Social Behavioral Change Activity is a media campaign, not treatment literacy.

**COP21 TARGET:** PEPFAR must invest in a new, comprehensive treatment literacy program implemented by networks of people living with HIV to ensure people are empowered and informed to demand quality services.

## 2b. Community Health Workers

Ensure all IPs recruit, retain and pay a sufficient number of Community Health Workers (CHWs) no less than the same minimum compensation (\$50/month), with funding in addition for airtime, allowances, job tools and more. Community contacts, whether for HIV testing or re-engagement with care, should not be “monetised.” Poorly performing sites where CLM shows long clinic wait times and





*“People are being transitioned without caution and investigation done on diabetes and high blood pressure. We recently lost one of us. He was transitioned and few months into using DTG, the late presented with diabetes which was not managed leading to his death.” —HIV-positive client, Namakwekwe HC III Mbale*

poor staff attitudes should be required to spend additional resources on clinical staff serving clients.

PEPFAR agreed in COP20 to formalise a cadre of community health workers and to “work with CSOs, and GoU to review and standardise the approach to remuneration across the various PEPFAR IPs and continue to work with GoU on a sustainable community staffing approach.”<sup>15</sup> PEPFAR Uganda carried out a mapping effort to standardise remuneration, but their recommendation, of a minimum of \$50/month, according to CLM and other social accountability efforts have shown that not all IPs are in compliance.

For example, recent focus group discussions in Mbale, for example, showed some key population community health workers being paid per client contact on an erratic (eg every 3-month) basis. This approach leads to inconsistent and poor quality engagement, and increases the risk of unethical or coercive engagement with communities. It has also contributed to the low rate of return of lost clients as the linkage facilitators are not motivated enough to continue doing the follow ups and return to care.

*“We have not been paid since last year in December [2020] when EGPAF pulled out.” —Community Health Worker, Nshungyezi Health Center III*

CLM has also indicated congested facilities without the personnel required to provide quality services, where IPs were not investing their program budgets on professional health workers. In one HC IV in Lira, monitors found a client who had been prescribed a nevirapine-based ART regimen since 2013, and whose reports of nevirapine-induced toxicities had gone unheeded by staff. When monitors encountered her, she had given up and was demanding a clinic transfer, which the clinic did not provide. Patient data was poorly managed, so staff consistently lost her viral load test results, making it impossible for the clinic to determine whether her treatment was working for her before switching her to a

recommended regimen. The entire ART clinic had only one clinical staff. PEPFAR should carry out multiple steps to address the HRH crisis, which is a chronic obstacle to ending AIDS.

**COP21 TARGET:** Ensure all IPs pay CHWs a minimum of \$50/month, with no per-client “incentives” permitted

**COP21 TARGET:** PEPFAR must develop enough standard CHW-to-client ratio for quality service delivery and use that ratio to direct IPs to use their budgets to recruit and deploy enough CHWs accordingly

**COP21 TARGET:** Require IPs to increase their spending on staff providing clinical services in poorly performing clinics

**COP21 TARGET:** Work with the Government of Uganda (GoU) to urgently revise outmoded health worker norms and salary structures

## 2c. Provide all prongs of DSD, nationwide

According to PEPFAR Q1 FY2021 POART data, only 47% of adults and children have access to multi month dispensing. Anecdotal reports point to IPs as being concerned that stock outs will occur, despite PEPFAR’s pledge that by COP20, Uganda would have six months of ART buffer supply in the country for the very first time in order to reduce stockout risks.

CLM showed that other aspects of DSD, such as community- and facility-based support groups, exist in name only. Too often, there are insufficient staff to carry them out or they are not seen as benefiting patients. In one clinic, people living with HIV had organised their own support group in order to better address their needs.

**COP21 TARGET:** PEPFAR must scale up provision of 6-month ART refills, with an emphasis on vulnerable and/or mobile communities

15. *Supra* note 3, p 149.

## 2d. Stop requiring transfer letters—provide quality services to highly mobile adults and children including refugees, migrants, truckers, and fisherfolk

The CLM assessments reveal bureaucratic requirements around the country when highly mobile populations sought treatment in new communities. IPs would delay support until they received a piece of paper, and often would make no effort to contact a client's home clinic in order to expedite the process. In the most extreme examples, this resulted in needless delays, and in at least one case, the death of an 11-year-old girl who had drug-resistant TB. This was exacerbated by COVID-19, when people were trapped in new communities or had limited recourse to seek clinical care.

PEPFAR Uganda should mandate IPs in COP20 and COP21 that no client is turned away who is seeking care, and that the complement of “welcome back services” be provided

immediately. Health workers must be expected to establish treatment history at the same time as clients' urgent health needs are attended to; no client should be berated or disrespected by clinic staff.

PEPFAR and the Ministry of Health should develop and publish a directory of all ART centers with their contacts and have copies in every ART clinic to facilitate inter-facility communication on follow-up of self transferred clients.

**COP21 TARGET:** PEPFAR and GoU must actively facilitate inter-facility transfers and require all IPs to commit never to turn away a patient seeking care for lack of a transfer letter.

*PEPFAR must formally investigate and implement IP and program-wide policy changes in response to the death of an 11-year-old patient seeking HIV and TB care at TASO Masaka, who was turned away from critical care because her caregiver had no transfer letter. Investigation results should be made available to the community.*

## 3. Expand quality prevention for women and girls in all their diversity

Women and girls are uniquely vulnerable to HIV acquisition, and represent the population at greatest risk of new infections in Uganda; UPHIA and the ECHO trial revealed unacceptably high HIV incidence among AGYW. Despite commitments by PEPFAR to expanding human rights based approaches including promoting women and girls' prevention interventions, limited implementation has taken place.

As part of HIV prevention efforts across the globe, PEPFAR introduced and is implementing the DREAMS initiative in selected parts of the country. Currently, 20 districts in Uganda are participating in DREAMS. However, this program has several challenges including limited scope (coverage and content), lack of concentration in urban centres where most new HIV infections are occurring, limited capacity to follow up with those who eventually graduate from the program, and the exclusion of AGYW living with HIV from from the program.

One of the biggest challenges in the HIV response in Uganda is that the most commonly used current biomedical HIV prevention methods are not controlled by women yet women are more vulnerable to HIV infections and have limited bargaining power. New prevention interventions that are controlled by women—oral PrEP, the dapivirine ring, and long acting injectable PrEP—have not been fully integrated into Uganda's HIV prevention strategy. The dapivirine ring and long acting injectable PrEP are not yet in the country. Oral PrEP is still not fully integrated into Uganda's combination prevention package.

In addition, STIs continue to be a major problem among women and girls at risk of and living with HIV. An estimated 72% of women living with HIV present with STIs but treatment is not addressed: STI drugs are prioritised for management of other conditions like pneumonia and minor surgeries.

PEPFAR Uganda has allocated \$5 million to renew cervical cancer screening and treatment among women living with HIV in

response to high rates of cancer. As per PEPFAR guidance, Uganda planned to screen HIV-positive women every two years with 260,619 women targeted for screening during COP20.

### 3a. “Dream bigger with DREAMS”

Extremely high dropout rates and poor completion rates for the DREAMS program in Uganda point to the need for further overhaul of the program building on the COP20 shifts. There is a new need for a pivot: because of the serious increase in HIV infection risk among AGYW due to restrictions imposed by the COVID-19 response on access to community services, access to education, as well as a surge in gender-based violence. This effort to “dream bigger” must be driven by community consultations about what DREAMS clients need and are not currently receiving. In addition to the corrective actions already described in the Planning Level Letter<sup>16</sup> we support the call to use funds to expand DREAMS to include targeted high incidence areas of Kampala, along with other urban areas such as in Wakiso and Mukono.

**COP21 TARGET:** PEPFAR should commit to “dream bigger” with an overhaul of the DREAMS program, to address new HIV infection risks that AGYW are experiencing because of COVID-19 restrictions as well as chronic underperformance of the program. This overhaul should be guided by AGYW.

16. *Supra* note 9, p. 22





### 3b. Choice-centered and integrated prevention

Biomedical and structural prevention interventions for women and girls in all their diversity must be rapidly expanded. PEPFAR programs should ensure that evidence-based interventions are available for prevention of new HIV infections and other STIs among women and girls living with HIV. As these girls and young women continue to age, the continuum of prevention and treatment services must remain intact and choice-centered. According to recent program data, integrated HIV and FP prevention services are still not the norm among PEPFAR Uganda supported IPs.<sup>17</sup>

COP21 should leverage EMA and WHO recommendations to expand prevention options for women and girls including the dapivirine ring and cabotegravir.

**COP21 TARGET:** PEPFAR and GOU should start regulatory

*approvals for the dapivirine ring and, eventually, long-acting cabotegravir for prevention while simultaneously preparing for roll out by developing program models, establishing training needs and civil society roles in leading communications and program design*

**COP21 TARGET:** PEPFAR must at least double its funding for STI treating and tests in order to address chronic facility-level shortages (see recommendation 11)

**COP21 TARGET:** PEPFAR should scale up cervical cancer screening and treatment for all women living with HIV rather than only the 25-49 age group, as was already agreed to during the COP20 Regional Planning Meeting in Johannesburg

**COP21 TARGET:** All AGYW receiving prevention or treatment services must be offered FP with method mix on-site, including informed consent and client-centered counseling.

17. *Supra* note 3, slide 23





*“Drop in Centres (DICs), are preferred service spots especially for KPs however drugs for STIs are always stocked out. There is a need to widen the scope of services provided at DICs, for instance services addressing violence. We sex workers are normally harassed but the DICs cannot even provide the first aid kit package.”* —Key Population member, Fort Portal region

## 4. Treatment and prevention for key populations (KP)

KPs experience disproportionate risk for HIV infection and poor clinical outcomes due to stigma, discrimination, poor staff attitudes, criminalisation, homophobia, poorly designed programs, and lack of access to prevention commodities. PEPFAR should build on its promise to completely overhaul the program in COP20, with further shifts in COP21.

We acknowledge and appreciate the growth in the KP program over the years, from PEPFAR’s start of the MAT clinic at Butabika Referral Hospital to expanded PrEP targets. However, the MAT clinic is currently only serving clients in and around Kampala. Therefore, PEPFAR should proceed with the initiative and rollout to other areas—Wakiso, Arua, Kibale, Iganga, Jinja, Mbale, and Tororo as agreed to during 2020 RPM.

### 4a. Drop-in Centers

Since COP20, PEPFAR has funded additional community-led DICs that are accredited to provide priority services. Icebreakers Uganda (IBU) and Lady Mermaids Bureau both now have community clinics that are registered by the Ministry of Health, and the expansion of SPECTRUM’s toll-free line is also taking place. However, we need this model to be improved. CLM has shown that community DICs are not able to provide the comprehensive package of services that key population members require. Currently, clients are expected to accept a referral to a hospital to access critical services, when on-site,

continuous availability of services is what is needed. DIC guidelines are not friendly to KP-led, community organisations; the service package in the guidelines is limited to DICs within a facility setting, rendering limited options for community-based DICs.

All services available in facility-based DICs should also be devolved to the community-based DICs, so that KPs can have “one-stop” treatment and prevention service delivery.

**COP21 TARGET:** *All community-based DICs must be accredited and equipped to provide on-site, 24-hour medical HIV treatment and prevention. The current model of referral between community- and facility DICs are not serving the needs of communities. The DIC model that works best is one where the DIC is anchored in a known, KP-led organisation’s office or site.*

*DICs should be expanded beyond the current number, focusing on retaining current DICs while rolling out this approach in USAID supported regions/sites.*





*“The support to the KPs is still minimal due to wrong attitudes by most stakeholders. IPs still have a lot of work to do regarding KPs.”* — District Stakeholder, Hoima District

#### 4b. KP Program Funding

PEPFAR committed to building the capacity of KP-led organisations through COP20 and the Key Population Investment Fund (KPIF). We found that resources for capacity development have been internally focused on IPs themselves, rather than through partnership with communities.

We call for meaningful and strategic partnerships with key population organisations to ensure effective implementation of programming. Program scale up should reflect USAID and CDC-funded sites. USAID sites tend to be left out because KPIF was implemented only by CDC.

*“We are not consulted, we are not involved and therefore it becomes difficult to serve us.”*  
— Key Population focus group discussion participant, Mbarara

**COP21 TARGET:** KPIF funding (\$10 million for two years, implemented by CDC) should be retained

*in the COP21 budget—there must be no cuts to KP budgets even though the KPIF is ending. These resources should prioritise capacity building of key population-led organisations, and the tools should be nationalised so that USAID-funded regions/sites are not disadvantaged.*

#### 4c. Support for decriminalisation

PEPFAR is carrying out a legal environment assessment as committed to in COP20. But this is not enough—we already know that the current legal and policy environment is not favorable to protection, promotion and defense of the human rights of all Ugandans. Decriminalisation is a key tool to support accelerated scale up of quality services. We call for expanded investments by PEPFAR in advocacy to support decriminalisation in Uganda.

**COP21 TARGET:** We restate our recommendation from COP20: PEPFAR should publicly and actively support decriminalisation of HIV and of KPs to increase uptake of life-saving services, decrease new infections, and ensure evidence-based response in Uganda.

## 5. Index testing and human rights

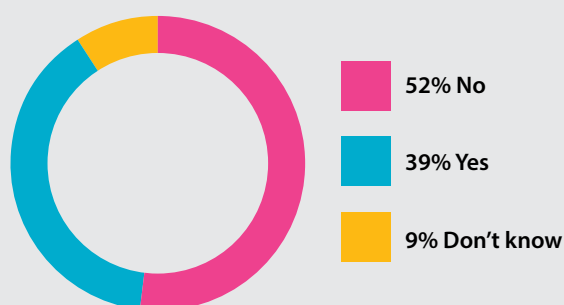
In COP20, PEPFAR committed itself to several changes to ensure that the index testing program does not violate human rights. These include: “Assess quality of service according to WHO and national guidelines at different levels and with different key stakeholders. Key areas that will be assessed mainly at site level include index testing acceptance levels and documentation of refusal rates, availability of index testing implementation materials, minimum package for post-violence care, training of service providers in index testing and IPV, systematic documentation and reporting of APN related IPV, and evidence of provision of post-IPV care; Communicate clear expectations with implementing partners to achieve HTS\_TST and HTS\_TST\_POS targets rather than strictly focusing on achieving testing modalities’ targets; Strengthen adverse event monitoring; Assess and review the quality of overall counseling services; Assess and certify index testing sites and index testing providers; Assess and review the quality of overall counseling services;”<sup>18</sup> among others.

### 5a. Safeguarding the human rights of Ugandans

CLM reveals that while most patients are providing the contacts of their sex partners, 52% of surveyed patients do not know they can refuse to give those to provide those details to a health worker. In Uganda, 1,064 health facilities implementing index testing were assessed for safe and ethical practices, and of those, 90% passed. A closer look at the assessment results indicated that testing sites were weakest in the areas of greatest concern to CSOs such as the ability of testing sites to respond to intimate partner violence and to adverse events caused by index testing.

Approximately 28% of RITES-E’s index testing sites for example, failed the standard queries regarding assessment of intimate partner violence. During CLM, communities uncovered incidents where index testing sites that had recently passed their assessment were nevertheless unable to provide monitors with answers to questions, such as “where would you refer a client if she reported she was at risk of violence?”

Health worker informed clients that they are free to refuse to give the names of sexual partners or children for HIV testing



In COP20, PEPFAR committed to remove sub targets for IPs for any testing modality, including index testing. But these targets appear to have remained as described in Uganda’s POART data. Finally, during COP20 PEPFAR committed to implementing a robust adverse event reporting system wherein all cases of gender based violence reported through the index testing program should be formally reported monthly to MoH, PEPFAR HQ, and civil society (as is the case with AEs caused by VMMC. This would include cases of gender-based violence that were not associated with index testing but which were reported by clients to HTS providers and therefore required follow up.

Incentives for index testing, in communities and in facilities, have been associated by IPs with violence in communities. No money should be given to Village Health Teams (VHTs) or other CHWs carrying out index testing based on the number of contacts successfully recruited for testing. It is unethical. Likewise, index testing cannot ethically be carried out in confined or closed settings.

**COP21 TARGET:** All sites that failed their 2020 assessment regarding IPV and/or adverse event reporting should be temporarily halted from carrying out index testing until appropriate standards are put in place at the site level.

**COP21 TARGET:** Site assessments for 2021 should be done by an independent entity.

**COP21 TARGET:** No monetary or other incentive should be provided as part of index testing services— instead all Community Health Workers should receive a standard level of remuneration, \$50/month.

**COP21 TARGET:** IP-level testing sub targets should not be communicated.

**COP21 TARGET:** A formal mechanism for high level reporting of adverse events and IPV must be developed.

**COP21 TARGET:** CDC should stop carrying out index testing in UPS.

18. *Supra* note 7 p. 41





## 6. People with disabilities

Civil society's CLM pilot revealed that 10% of the clinic users interviewed reported any form of disability. Many deficiencies regarding access to HIV care services among people with disabilities (PWDs) were reported. During a recent focus group discussion in Gulu, an HIV positive PWD noted that although there were registers at health facilities that capture the information of people with disabilities, there was little being done to address challenges they face in accessing HIV, TB and other health services. In a subsequent meeting with the Gulu District Community Development Officer (DCDO), the officer noted that although the fact that the barriers to access that people with disabilities experience are "often discussed" at different fora, "nothing is being done to resolve them." At the Regional Dialogue in Kampala and during the CSOs meeting on priority setting for the People's Voice, representatives for PWDs continued to decry how services are inaccessible to PWDs with a major focus on structures and IEC materials.

In COP20, activists called on PEPFAR to support interventions to address the needs of women living with HIV and disabilities, with an initial emphasis on infrastructure as well as sign language interpretation. PEPFAR's only current commitment in this area is to "In COP19 PEPFAR funded four CSOs to address PWID and will expand this in COP20; PEPFAR will explore minor infrastructure modifications in COP20 and seek partnership with GoU and GF for broader systematic supports and sign language interpreter support."<sup>19</sup>

**COP21 TARGET:** Invest in community and facility infrastructure that will enable people with disabilities to access services without any structural barriers:

*priority investments are community facility linkage designed for people with disabilities.*

**COP21 TARGET:** Carry out an assessment of the needs of people with disabilities who are living with HIV to establish a baseline regarding gaps in service quality and accessibility, with a focus on establishing the unique needs of this community.

**COP21 TARGET:** HIV materials should be made accessible for people with disabilities, such as sign language captions on posters, and sign language interpreters and captions for videos.

19. *Supra* note 7 p 151





*“My son kept crying for food and whenever I gave him ARVs without enough food. He got dizzy and cried. The situation has left me so depressed. Whenever we didn’t have food, we skipped our medicines.”* —Mother of a 3-year-old child with HIV, Iganga District

## 7. Paediatrics

Despite progress in prevention of paediatric HIV infection, children with HIV remain at increased risk of death, non-suppression of viral load, treatment interruptions and rapid clinical progression. PEPFAR must prioritise closing gaps in access to timely paediatric testing, treatment, comprehensive treatment and supportive care services for children, their mothers, and other caregivers. COP21 must prioritise ending the persistent crisis in lack of quality treatment and care by rapidly implementing all the COP20 policy and program shifts, and taking on new priority recommendations.

### 7a. Children and caregivers left behind by lockdown

During COVID-19, barriers to treatment were exacerbated for children and their caregivers. A rapid assessment in four regions of 88 caregivers and their children carried out by community monitors revealed families largely abandoned during lockdown, suffering interruptions in treatment and access to essential support.<sup>20</sup>

*“My work closed during lockdown and this left me with no income at all to support the child. I opted to take him to different friends’ and relatives’ homes for his support but they would ask me*

*to take him away after a few days. I eventually decided to take him to the grandfather’s home where he spent most of the lockdown period but there was no one there to support him take his ARVs. I didn’t disclose his status; his relatives don’t know about it. Therefore, he often missed taking his ARVs and his health deteriorated. His grandfather called me to take him to hospital, and I decided to stay and struggle with him.”*— Caregiver of a 10-year-old child with HIV, Ntungamo District

20. Health GAP, NAFOPHANU, HEPS-Uganda. “Left Behind By Lockdown.” April 2021.



*“I experienced stock outs of one of my son’s combination drugs; there was a stock out of abacavir for 4 months, only lopinavir was available. I had to travel a 27 kilometers round trip to the health center and I would only be given monthly emergency refills. I used to get permission letters from the Local Council to use a boda-boda. Though there was a time when I had no money for transport, my son had to swallow his tablets. I had no income during lockdown, I couldn’t afford to feed my child well, his viral load even went up during lockdown. I didn’t get any support from the government, but I am glad his viral load is now stable again.”* —Father of an 8-year-old child with HIV, Mbarara District

**COP21 TARGET:** PEPFAR must dedicate a funding stream to returning paediatric clients and caregivers to treatment, and provide direct cash transfers to address profound economic shocks that have undermined HIV treatment outcomes.

**COP21 TARGET:** All children living with HIV should be linked to comprehensive OVC services starting in FY20 and continuing to FY21. Functional family support groups should be established for all sites providing PMTCT services, along with 100% coverage of the Mother Baby Care Points and Mentor Mothers approaches, which have been shown to result in higher levels of viral load suppression and better retention in quality care.

**COP21 TARGET:** Introduce a transport voucher system for caregivers with children living with HIV to counter the impact of COVID-19.

## 7b. POC EID Testing

While Early Infant Diagnosis (EID) coverage has slowly expanded in Uganda, timely access to results is all too rare. WHO has finally announced new testing guidelines instructing

all countries to roll out universal point of care (POC) EID for all HIV exposed infants <18 months.

Mortality for HIV positive children peaks just months after delivery. Without treatment access, half of all children with HIV die before their second birthday. The proposed COP21 target of 45% of all tests being POC is inadequate and inconsistent with WHO guidelines.

**COP21 TARGET:** PEPFAR should budget and plan for providing universal POC EID testing for children exposed to HIV <18 months old.

## 7c. Accelerate paediatric DTG roll out, with complete phase out of nevirapine-based treatment regimens

CLM has found continued use of suboptimal nevirapine based regimens for children; the new dispersible DTG formulation for children <10kgs must be rolled out as a matter of urgency.

**COP21 TARGET:** Urgently implement shift to new paediatric DTG formulation for children <10kgs.

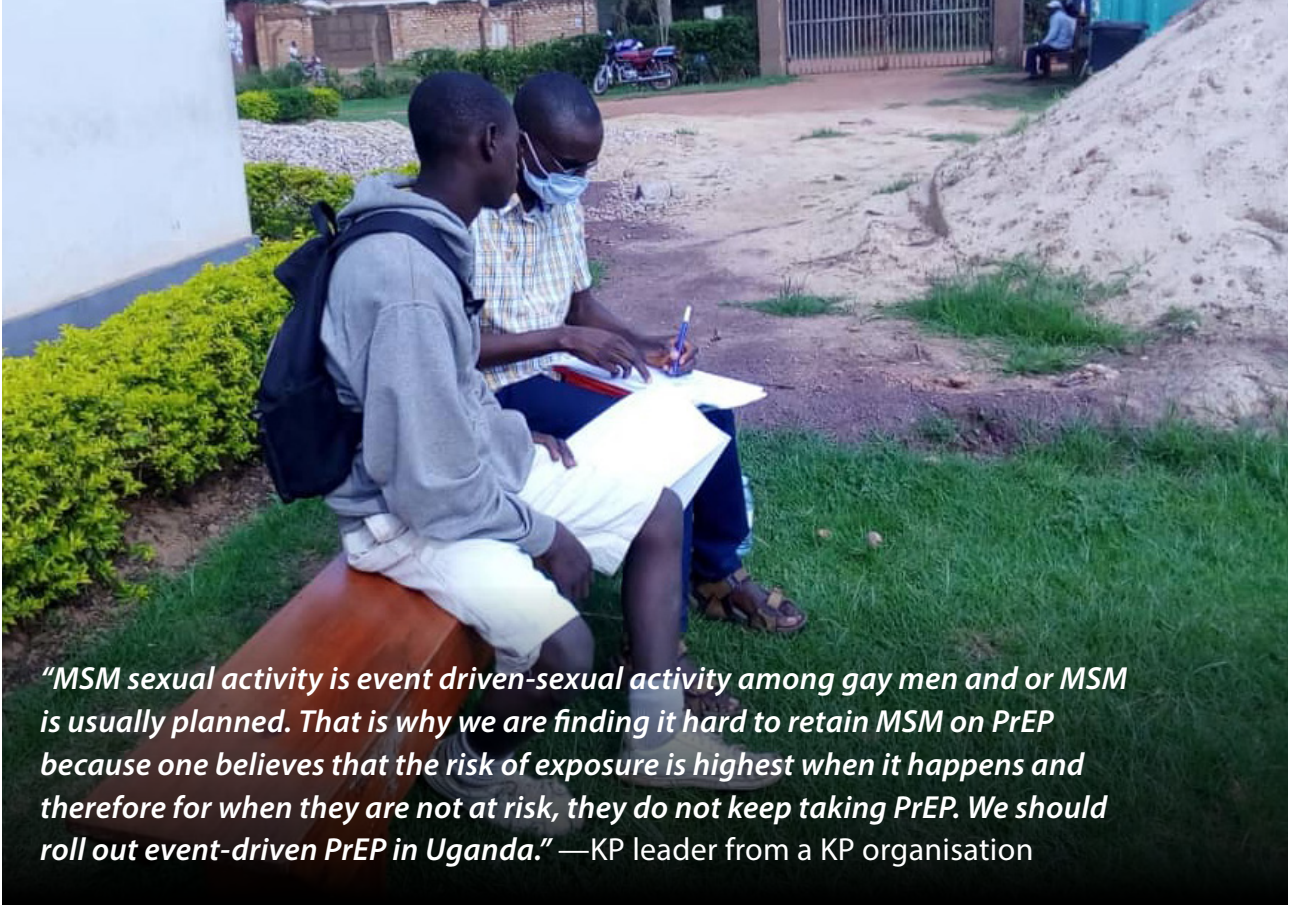
## 7d. Comprehensive, stigma-free treatment and care services, for all people living with HIV, children, caregivers, including Key Populations

The COP21 new program proposal for a standalone OVC program designated for the “Children of KPs” is raising community concerns. While the intentions might be good, key populations who are parents and caregivers were not consulted in its design and are not being proposed as key partners in implementation. Program descriptions reveal the extremely stigmatising orientation of the program. For example, that lack of access to services for children of KPs will create “another KP”<sup>21</sup> We also question the assertion that such a program should be implemented by the OVC Program, which has no record of accountability to or meaningful partnership with the KP community and their children, rather than the KP program.

We appreciate that the proponents of this program have learned about the problem of unmet service needs among the children of KPs, but KPs have been calling for family-friendly services for years. Unfortunately, this has not been a priority for PEPFAR, agencies, or IPs.

**COP21 TARGET:** Implementation of the proposed “Children of KPs” program should meaningfully consult first with caregivers who are KPs, including mothers and fathers, on all aspects of design, implementation, budget and accountability.

21. “Prevention: Children of Key Populations Request.” Slide 4.



*“MSM sexual activity is event driven—sexual activity among gay men and or MSM is usually planned. That is why we are finding it hard to retain MSM on PrEP because one believes that the risk of exposure is highest when it happens and therefore for when they are not at risk, they do not keep taking PrEP. We should roll out event-driven PrEP in Uganda.”* —KP leader from a KP organisation

## 8. PrEP

PrEP has not been implemented as a core part of the combination prevention program in Uganda. Instead, each year the program grows, without being adopted or integrated nationally. This is causing persistent challenges in PrEP literacy (among health workers and communities), PrEP uptake and retention, and overall prevention impact. As at the beginning of FY21, PEPFAR recognised PrEP as one of its Minimum Program Requirements (MPRs) but implementation requires expanded effort in COP21/FY22.

### 8a. National PrEP scale up—now

Health officials in Soroti, Mbale and Jinja all called for PrEP to be part of a national program, rather than an intervention limited to a subset of PEPFAR-supported sites. A recent assessment reveals very low PrEP literacy among health workers; only 10% of surveyed health workers had “perfect knowledge” of PrEP.<sup>22</sup> During CLM regional meetings, a District Health Team member in Bullisa District asked the CLM monitors “what is PrEP?” Community members and health workers also have inaccurate perceptions about PrEP. According to community peer educators, PrEP retention for drug users and MSM is low. Some health workers are discouraging people from seeking PrEP, indicating a sore need for PrEP literacy beyond communities.

For adolescents and pregnant and breastfeeding women, access to information about PrEP is poor. While revised PrEP policy guidelines include provision for AGYW and pregnant and breastfeeding women, persistent knowledge gaps around PrEP still exist. PrEP materials aren’t available at facility level. During HIV testing, clients report that PrEP is hardly discussed.

Moreover, PrEP choice is limited. COP21 should leverage EMA and WHO recommendations to provide for expansion of woman-

controlled prevention options including the dapivirine ring. Long-acting injectable PrEP is an important option that must be explored and made accessible in Uganda.

Finally, gay men and other men who have sex with men report daily administration of PrEP as a barrier to consistent use.

**COP21 TARGET:** *PrEP should be rolled out nationally as a core part of combination prevention in Uganda, with further expansion of targets beyond 95,000, and program adaptations such as same-day initiation.*

**COP21 TARGET:** *adopt WHO guidelines for event driven PrEP for MSM, along with a communication strategy and demand creation activities.*

**COP21 TARGET:** *Accelerate roll out of the dapivirine ring and cabotegravir, along with a communication strategy and demand creation activities.*

**COP21 TARGET:** *Generate demand for PrEP services, particularly among at-risk AGYW and pregnant and breastfeeding women (PBFW). Integrate PrEP education in curricula that are used for parents and communities of AGYW.*

22. *Supra* note 7, p 75.



## 9. Structural interventions: GBV, economic empowerment, and human rights

Women represent the most of the clients tested and started on treatment within the PEPFAR platform, and maintaining their level of involvement in these interventions is critical. Evidence has shown that GBV and violence against women act as barriers to accessing HIV services and adherence.

### 9a. GBV

GBV is high among women across all PEPFAR Implementing Mechanisms (IMs). For example, PEPFAR FY20Q4 program data revealed high rates of sexual violence.<sup>23</sup> This correlates with rampant GBV resulting from COVID-19 restrictions. The data also show serious missed opportunities to provide preventive services to clients who have experienced sexual violence. There were 35,723 reported cases of sexual violence and only 5,442 of these received HIV prevention (PEP) interventions during the period. What happened to the remaining 32,281? Were they struggling to navigate police and legal processes? Anecdotal community testimony as well as findings from community scorecards reveal that one of the barriers to accessing PEP is the time spent following police protocols, when the window for efficacy is only 72 hours.

**COP21 TARGET:** PEPFAR must scale up funding for comprehensive GBV programming and trauma-informed services across the program, focused on and platforms where more women seek health care services.

### 9b. Economic empowerment

There is a strong relationship between economic empowerment and risk for HIV infection. Economically empowered persons are less likely to suffer human rights violations as demonstrated by the DREAMS model. However, most people living with and at a higher risk of acquiring HIV are economically disempowered. Over the years, CSOs and other community representatives have demanded for economic empowerment of vulnerable populations; and we do appreciate the support through the DREAMS Initiative. COP20 planned investment to accelerate pathways to economic independence with more emphasis on entrepreneurship (increased funding: \$4,465,320).

The proposed package included financial literacy, savings groups, and entrepreneurship/apprenticeships; economic independence encompassing extensive market assessments to identify opportunities and guide intervention package; and enhanced market-relevant training. It also entails

bolstered start-up support (matching grants and start-up kits); leverage GOU structures like operation wealth creation; ongoing mentorship and peer networking; adaptation of evidence-based models used in Uganda; and Empowerment & Livelihoods for Adolescents Women's Income Generating Support (WINGS). However, these efforts are confined to one program; therefore, they are insufficient. We call upon PEPFAR to allocate more resources towards fostering economic independence.

**COP21 TARGET:** PEPFAR should either through its IPs or other appropriate channels provide funds to improve the economic status of targeted populations namely PWDs, AGYW, KPs, women living with HIV and other high-risk groups.

### 9c. Stigma and discrimination

HIV-related stigma and discrimination has persistently undermined access to HIV and TB services, the quality of treatment outcomes and national achievement of the 95-95-95 targets for all people living with and at high risk of HIV. There are various drivers of stigma and discrimination including existing laws, policies, practices, socio-cultural norms, and religious beliefs. Discriminatory and stigmatising attitudes toward people living with HIV are common in Uganda. Low levels of knowledge about how HIV is and is not transmitted are also widespread.<sup>24</sup>

**COP21 TARGET:** PEPFAR should fund HIV-positive religious leaders who are active in the faith-based sector in Uganda to develop and implement evidence-based interventions to fight HIV stigma and discrimination and who espouse progressive principles and values.

*These interventions will first target other religious leaders and will become a robust and high-impact engagement of the faith-based sector in fighting against all forms of stigma and discrimination that harm people living with HIV and key and vulnerable populations.*

23. *Supra* note 3, slide 22

24. *Supra* note 5, p 104







## 10. TB

About 38% of Ugandans living with TB are also HIV positive, and 15,000 of TB cases are undiagnosed.<sup>25</sup> According to the national health reporting system, TB case finding for people living with HIV has increased from 1.4% to 2% in FY 2019. CLM data indicate these priorities for co-infected clients: most people with TB who are coinfecting are diagnosed at late stage; and people living with HIV who are diagnosed with TB find it challenging to manage treatment for the both ailments. Nutrition support is a priority for co-infected people, as is stigma, high pill burden, lack of treatment literacy materials, and stigma at the health facility and community. Community systems to manage co-infected clients are poor, systems for early TB case detection are weak and there is a lack of comprehensive approach to managing TB cases beyond presentation at the health facility level. CLM also uncovered a disconnect between TB and HIV interventions at community level, with TB community interventions grossly underfunded. TB and HIV interventions should be integrated at the community level. PEPFAR and the GoU needs to address these issues to increase the survival rate for the co-infected clients.

The Government of Uganda and PEPFAR should improve mechanisms for early detection beyond those who present at the health facilities and provide essential interventions that are required for uninterrupted TB treatment such as food and funding for associated costs of care such as clinic transport. Human rights violations, especially those experienced by women and girls, must also be addressed.

In addition, stockouts reported 2020 of TB LAM kits will worsen unless supplies are increased, especially given rollout of new WHO guidelines.

**COP21 TARGET:** PEPFAR should close the funding gap for nutrition support and other essential supportive services for people living with TB and HIV.

**COP21 TARGET:** PEPFAR should dramatically increase funding to carry out integrated, community-led TB/HIV community support services to intensify case finding and save lives.

**COP21 TARGET:** Accelerate uptake of TB LAM and urgently increase supply of TB LAM commodities.

## 11. Stockouts and Medicines Shelf Life

CLM findings show that clients were routinely unable to obtain essential medicines, especially STI treatment, at clinics due to insufficient stocks. Clients were made to purchase essential medication out-of-pocket, or go without. This was prohibitively expensive, especially for sex workers. Stocks would run out because of the tremendous demand for STI treatment for all uses (such as non-sexually transmitted bacterial infections). Supplies of essential medicines must be expanded for all indications for Ugandans to prevent continuous recurrence of this problem. Currently PEPFAR reports spending only \$3 million for a combined “other drugs” category of cotrimoxazole, INH, STI/OI drugs, and B6.<sup>26</sup>

In Lira, CLM showed persistent stock outs of medicines for paediatric HIV patients, particularly during COVID-19 restrictions in 2020. HIV positive women who were postpartum told CLM community clinic that nevirapine syrup for paediatric prophylaxis for HIV-exposed infants as well as paediatric atazanavir/ritonavir were “never available at the clinic.” They were told by health workers that they had to buy them from private clinics, although they had no money.

In other districts such as Pallisa, there is typically drug redistribution among facilities when stockouts occur and clinics are waiting to receive National Medical Stores (NMS) deliveries. However, some facilities reported excessive supply of tenofovir-

lamivudine-dolutegravir (TLD) with short expiry dates.

**COP21 TARGET:** PEPFAR must at minimum double its funding for STI treating and tests to address chronic facility-level shortages.

**COP21 TARGET:** The practice of people being told they must buy HIV medicines from private clinics violates PEPFAR’s Minimum Program Requirement (MPR) of “elimination of all formal and informal user fees.” PEPFAR must increase funding to focus on ensuring medicines reach communities, on time and in full at 100% of its supported sites.

25. *Supra* note 4, p 52

26. *Supra* note 7, p 28.



*“Community-Led Monitoring gives the power to the beneficiaries to design and define their own destiny” —Chief Administrative Officer, Soroti District*

## 12. Community Led Monitoring (CLM) for Advocacy

Global PEPFAR guidance states that OUs are “required to fund the development and implementation of community-led monitoring activities.”<sup>27</sup> Uganda has begun implementing a national CLM starting with a pilot program in 2020 (COP19) and extending to national roll out during COP20.

COP21 must continue to fund CLM, building on the lessons learned from different CLM models in Uganda, establishing routine, comprehensive, ongoing clinic and community-based monitoring of the quality and accessibility of HIV services, covering enough PEPFAR-supported sites to represent a significant portion of people currently on treatment. Priority indicators for people living with HIV and their communities include, in particular: staff attitudes towards patients, clinic waiting times, shortages of essential commodities, and interventions for patients with treatment interruptions.

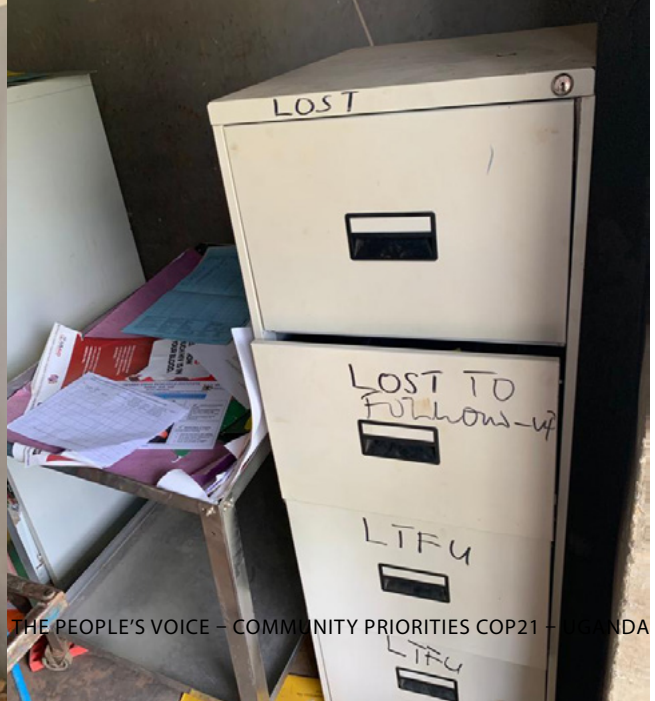
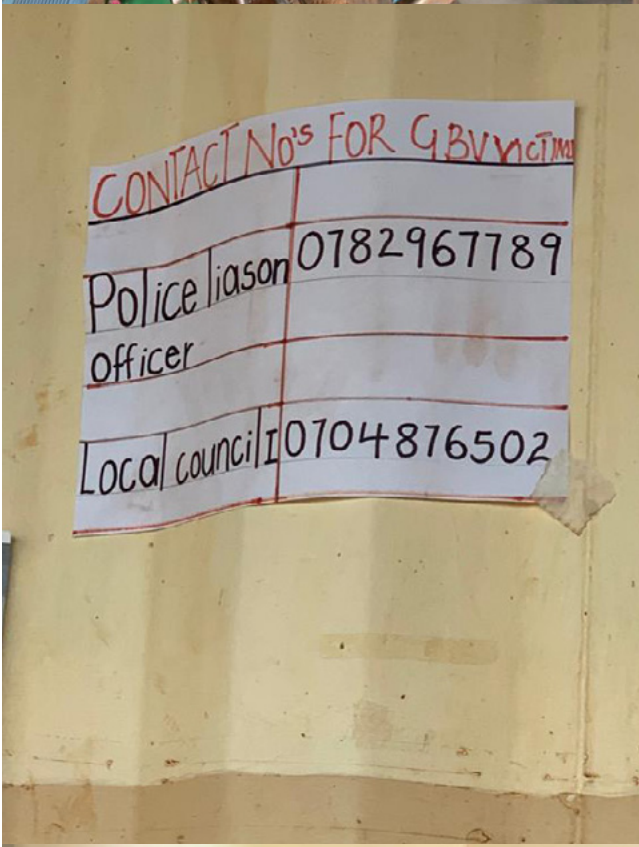
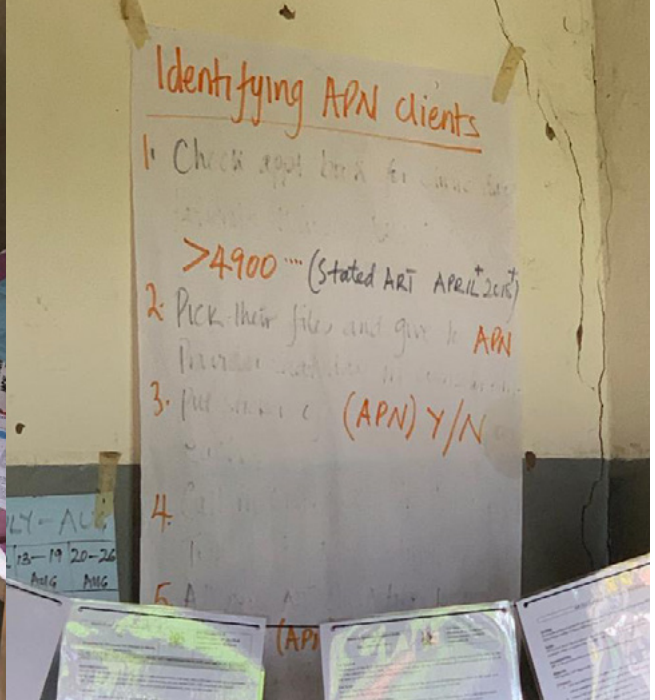
Monitoring results must trigger accelerated responses from the Ministry of Health, PEPFAR and implementing partners to address the priorities that are identified by community evidence. Chronic issues will be the focus of advocacy efforts at local and national levels, engaging local and national government at all stages. Resources will be required for staffing,

travel, communication, data analysis and documentation, and other costs to allow community groups to carry out these vital efforts. Advocacy will be used to support community-led responses to problems that are not resolved through information sharing. Communities will focus on high priority areas such as health worker attitudes, protection of health and rights, commodity shortages, delays in return of test results, and more. Independence, transparency, and the community-led nature of successful CLM will continue to be prioritised.

**COP21 TARGET:** PEPFAR should continue CLM funding at COP20 levels (1.56 million for the CLM program) for independent, community and PLHIV-led monitoring of quality and accessibility of services at PEPFAR-funded sites. Increased funding should be explored for expanded coverage.

27. PEPFAR COP/ROP 2021 Guidance, p 125





# SPECIFIC LANGUAGE REQUESTED IN COP21

LANGUAGE TO INCLUDE IN COP21 SDS	COP21 TARGET
<b>1. Recover faster—and stronger—from COVID-19</b>	
<b>1a. Investments through COP20 reprogramming and COP21, including new PEPFAR COVID-19 emergency funding, must prioritise community recovery from the effects of lockdowns and restrictions on movement, particularly for children with HIV and their caregivers, adolescent girls and young women, people who have experienced gender-based violence, key populations, and others who are most vulnerable</b>	
<p>PEPFAR will use COP20 and COP21 resources (including emergency COVID-19 funding) to fund programs that support recovery from the effects of COVID-19 restrictions.</p> <p>These will include, for example, direct cash transfers, access to justice for people who survived violence, and more.</p> <p>Interventions needed to locate the large numbers of new and existing adults and children on treatment who lost to follow up and return them to quality care will be prioritised by IPs.</p>	<p><b>COP21 TARGET:</b> PEPFAR should use COP20 and COP21 resources (including emergency COVID-19 funding) to put in place comprehensive programs to recover from the COVID-19 crisis, prioritising the communities that experienced the most harm, such as targeted community cash transfers for the most vulnerable, access to justice for those who experienced violence. Communities must be consulted in developing and implementing this response.</p> <p><b>COP21 TARGET:</b> PEPFAR must carry out a surge in investment to direct IPs to find and support the return to care and treatment of the 62,871 people who were LTFU between Quarter 1 FY2020 and Q1 FY2021.</p>
<b>1b. Successful community-led adaptations to COVID-19 should be directly funded, strengthened and taken to scale nationally</b>	
<p>PEPFAR will roll out national adoption of community-led programs developed in response to COVID-19 restrictions, such as door-to-door drug delivery, peer counseling, and peer-led treatment education. Efforts to bring treatment, support and prevention closer to communities are vital measures to correct Uganda's chronic loss to follow up crisis.</p>	<p><b>COP21 TARGET:</b> PEPFAR should fund effective community COVID-19 adaptations so that they can be taken to scale nationally.</p>
<b>2. Expand high-impact treatment retention efforts, with a requirement that 100% of IPs implement all minimum standards already decided during the COP20 Regional Planning Meeting</b>	
<b>2a. PEPFAR should directly and adequately fund peer led treatment literacy</b>	
<p>PEPFAR will directly fund organisations of people living with HIV to design and implement ongoing, comprehensive, high-impact treatment literacy and peer-led support programs—not one-off marketing or “messaging” campaigns</p>	<p><b>COP21 TARGET:</b> PEPFAR must invest in a new, comprehensive treatment literacy program implemented by networks of people living with HIV to ensure people are empowered and informed to demand quality services.</p>
<b>2b. Community Health Workers</b>	
<p>PEPFAR will ensure all IPs recruit, retain and pay enough Community-Health Workers (CHWs) no less than the same minimum compensation (\$50/month), with funding in addition for airtime, allowances, job tools, etc. Community contacts, whether for HIV testing or re-engagement with care, should not be “monetized.” Poorly performing sites where CLM shows long clinic wait times and poor staff attitudes should be required to spend additional resources on clinical staff serving clients.</p>	<p><b>COP21 TARGET:</b> Ensure all IPs pay CHWs a minimum of \$50/month, with no per-client “incentives” permitted; a best practice for minimum concentration of CHWs for quality programming should be rapidly established and IPs instructed to recruit and deploy staff accordingly.</p> <p><b>COP21 TARGET:</b> PEPFAR must develop a sufficient, standard CHW-to-client ratio and use that ratio to direct IPs to use their budgets to hire enough CHWs.</p> <p><b>COP21 TARGET:</b> Require IPs to increase their spending on staff providing clinical services in poorly performing clinics.</p> <p><b>COP21 TARGET:</b> Work with the Government of Uganda (GoU) to urgently revise outmoded health worker norms and salary structures</p>
<b>2c. Provide all prongs of DSD, nationwide</b>	
<p>PEPFAR will provide all prongs of DSD nationwide, at 100% of its supported sites.</p>	<p><b>COP21 TARGET:</b> PEPFAR must scale up provision of 6-month ART refills, with emphasis on vulnerable and/or mobile communities.</p>



LANGUAGE TO INCLUDE IN COP21 SDS	COP21 TARGET
<b>2d. PEPFAR will stop requiring transfer letters</b>	
<p>Quality services should be provided to highly mobile adults and children including refugees, migrants, truckers, and fisherfolk without bureaucratic hurdles.</p>	<p><b>COP21 TARGET:</b> PEPFAR and GoU must actively facilitate inter-facility transfers and require all IPs to commit never to turn away a patient seeking care for lack of a transfer letter.</p> <p>PEPFAR must formally investigate and implement IP- and program-wide policy changes in response to the death of an 11-year-old patient seeking HIV and TB care at TASO Masaka, who was turned away from critical care because her caregiver had no transfer letter. Investigation results should be made available to the community.</p>
<b>3. Expand quality prevention for women and girls in all their diversity</b>	
<b>3a. Dream bigger with DREAMS</b>	
<p>PEPFAR will carry out further program overhaul of DREAMS to address extremely high dropout and poor completion rates for DREAMS in Uganda.</p> <p>The serious increase in HIV infection risk among AGYW due to restrictions imposed by the COVID-19 response on access to community services, access to education, as well as an surge in gender-based violence will require strategic program shifts . This effort to “DREAM bigger” will be driven by community consultations about what DREAMS clients need and are not currently receiving. PEPFAR will use funds to expand DREAMS to include targeted high incidence areas of Kampala, along with other urban areas such as in Wakiso and Mukono.</p>	<p><b>COP21 TARGET:</b> PEPFAR should commit to “dream bigger” with an overhaul of the DREAMS program to address new HIV infection risks AGYW are experiencing because of COVID-19 restrictions as well as chronic under performance of the program. This overhaul should be guided by AGYW.</p>
<b>3b. Choice-centered and integrated prevention</b>	
<p>PEPFAR will make choice-centered and integrated prevention a centerpiece of prevention for women and girls.</p>	<p><b>COP21 TARGET:</b> PEPFAR and GOU start regulatory approvals for the dapivirine ring and, eventually, long-acting cabotegravir for prevention while simultaneously preparing for roll out by developing program models, establishing training needs and civil society roles in leading communications and program design</p> <p><b>COP21 TARGET:</b> PEPFAR must at minimum double its funding for STI treating and tests to address chronic facility-level shortages (see recommendation 11)</p> <p><b>COP21 TARGET:</b> PEPFAR should scale up cervical cancer screening and treatment for all women living with HIV rather than only the 25-49 age group, as was already agreed to during the COP20 Regional Planning Meeting in Johannesburg</p> <p><b>COP21 TARGET:</b> All AGYW receiving prevention or treatment services must be offered FP with method mix on-site, including informed consent and client-centered counseling.</p>
<b>4. Treatment and prevention for key populations (KP)</b>	
<b>4a. Drop In Centers</b>	
<p>PEPFAR will improve service accessibility and quality for key populations by ensuring community-based DICs are able to provide the same package of clinical services provided in facility-based DICs.</p> <p>The current model of referral between community and facility DICs do not adequately cater for the needs of communities. The DIC model that works best is one where the DIC is anchored in a known KP-led organization's office or site.</p>	<p><b>COP21 TARGET:</b> All community-based DICs must be accredited and equipped to provide on-site, 24-hour medical HIV treatment and prevention.</p> <p><b>COP21 TARGET:</b> DICs should be expanded beyond the current number, focusing on retaining current DICs while rolling out this approach in USAID supported regions/sites.</p>

LANGUAGE TO INCLUDE IN COP21 SDS	COP21 TARGET
<b>4b. KP Program Funding</b>	
<p>\$10 million in KPIF will be included in the core KP program budget for COP21. These resources will be used to build on the lessons and evidence from the KPIF in Uganda, prioritising capacity building of key-population led organisations.</p>	<p><b>COP21 TARGET:</b> KPIF funding (\$10 million for two years, implemented by CDC) should be retained in the COP21 budget—there must be no cuts to KP budgets even though the KPIF is ending. These resources should prioritise capacity building of key population-led organisations, and the tools should be nationalised so that USAID-funded regions/sites are not disadvantaged.</p>
<b>4c. Support for decriminalisation</b>	
<p>PEPFAR will carry out a range of efforts to support decriminalisation of people with HIV and KPs in Uganda, as consistent with evidence, best practice, and human rights.</p>	<p><b>COP21 TARGET:</b> We restate our recommendation from COP20: PEPFAR should publicly and actively support decriminalisation of HIV and of KPs in order to increase uptake of life-saving services, decrease new infections, and ensure evidence based response in Uganda.</p>
<b>5. Index testing</b>	
<b>5a. Safeguarding the human rights of Ugandans</b>	
<p>PEPFAR will prioritise safeguarding the human rights of Ugandans through ongoing efforts to ensure IPs are implementing ethical, confidential, and quality index testing. When service providers fail to attain minimum standards, index testing will be halted until their capacity improves. A range of new policies will be implemented in COP21 to ensure this takes place.</p>	<p><b>COP21 TARGET:</b> All sites that failed their 2020 assessment regarding IPV and/or adverse event reporting should be temporarily halted from carrying out index testing until appropriate standards are put in place at the site level.</p> <p><b>COP21 TARGET:</b> Site assessments for 2021 should be done by an independent entity.</p> <p><b>COP21 TARGET:</b> No monetary or other incentive should be provided as part of index testing services—instead all Community Health Workers should receive a standard level of remuneration, \$50/month.</p> <p><b>COP21 TARGET:</b> IP-level testing sub targets should not be communicated.</p> <p><b>COP21 TARGET:</b> A formal mechanism for high level reporting of adverse events and IPV must be developed.</p> <p><b>COP21 TARGET:</b> CDC should stop carrying out index testing in UPS.</p>
<b>6. People with disabilities</b>	
<p>PEPFAR will invest in increasing the accessibility of HIV care and treatment services for people with disabilities.</p>	<p><b>COP21 TARGET:</b> Invest in community and facility infrastructure that will enable people with disabilities to access services without any structural barriers: priority investments are community facility linkage designed for people with disabilities.</p> <p><b>COP21 TARGET:</b> Carry out an assessment of the needs of people with disabilities who are living with HIV to establish a baseline regarding gaps in service quality and accessibility, with a focus on establishing the unique needs of this community.</p> <p><b>COP21 TARGET:</b> HIV materials should be made accessible for people with disabilities, such as sign language captions on posters, and sign language interpreters and captions for videos.</p>



LANGUAGE TO INCLUDE IN COP21 SDS	COP21 TARGET
<b>7. Paediatrics</b>	
<b>7a. Children and caregivers left behind by lockdown</b>	
<p>PEPFAR will ensure children and caregivers left behind by the COVID-19 restrictions are able to recover, through a range of emergency supportive interventions.</p>	<p><b>COP21 TARGET:</b> PEPFAR must dedicate a funding stream to returning paediatric clients and caregivers to treatment, and provide direct cash transfers to address profound economic shocks that have undermined HIV treatment outcomes.</p> <p><b>COP21 TARGET:</b> All children living with HIV should be linked to comprehensive OVC services starting in FY20 and continuing to FY21. Functional family support groups should be established for all sites providing PMTCT services, along with 100% coverage of the Mother Baby Care Points and Mentor Mothers approaches, which have been shown to result in higher levels of viral load suppression and better retention in quality care.</p> <p><b>COP21 TARGET:</b> Introduce a transport voucher system for caregivers with children living with HIV to counter the impact of COVID-19.</p>
<b>7b. POC EID Testing</b>	
<p>POC EID Testing will be rolled out by PEPFAR for all HIV exposed infants, to accelerate the elimination of paediatric HIV.</p>	<p><b>COP21 TARGET:</b> PEPFAR should budget and plan for providing universal POC EID testing for children exposed to HIV &lt;18 months old.</p>
<b>7c. Paediatric DTG roll out</b>	
<p>PEPFAR will prioritise support for paediatric DTG roll out, with complete phase out of nevirapine-based treatment regimens.</p>	<p><b>COP21 TARGET:</b> Urgently implement shift to new paediatric DTG formulation for children below 10kgs.</p>
<b>7d. Provide comprehensive, stigma-free treatment and care services</b>	
<p>PEPFAR will ensure IPs provide comprehensive, stigma-free treatment and care services, for all children and caregivers, including KPs</p>	<p><b>COP21 TARGET:</b> Implementation of the proposed “Children of KPs” program should meaningfully consult first with caregivers who are KPs, including mothers and fathers, on all aspects of design, implementation, budget and accountability.</p>
<b>8. PrEP</b>	
<b>8a. National PrEP scale up—now</b>	
<p>PEPFAR will work with the GoU to ensure PrEP is implemented as a core part of combination prevention in Uganda and becomes a national program. PEPFAR will prioritise increasing PrEP literacy (among health workers and communities), PrEP uptake and retention, and overall prevention impact.</p>	<p><b>COP21 TARGETS:</b> PrEP should be rolled out nationally as a core part of combination prevention in Uganda, with further expansion of targets beyond 95,000, and program adaptations such as same-day initiation.</p> <p><b>COP21 TARGETS:</b> Adopt WHO guidelines for event driven PrEP for MSM, along with a communication strategy and demand creation activities.</p> <p><b>COP21 TARGETS:</b> Accelerate roll out of the dapivirine ring and cabotegravir, along with a communication strategy and demand creation activities.</p> <p><b>COP21 TARGETS:</b> Generate demand for PrEP services, particularly among at-risk AGYW and pregnant and breastfeeding women (PBFW). Integrate PrEP education in curricula that are used for parents and communities of AGYW.</p>

LANGUAGE TO INCLUDE IN COP21 SDS	COP21 TARGET
<b>9. Structural interventions: GBV, economic empowerment, and human rights</b>	
<b>9a. GBV</b>	
PEPFAR will prioritise roll out of comprehensive and trauma-informed GBV services for adults, adolescents and children.	<b>COP21 TARGET:</b> Scale up funding for comprehensive GBV programming and trauma-informed services across the program, focused on and platforms where more women seek health care services.
<b>9b. Economic empowerment</b>	
PEPFAR will implement economic empowerment programs targeting vulnerable communities, PWDs, AGYA, KPs and other women living with HIV.	<b>COP21 TARGET:</b> Provide funds through either its IPs or other appropriate channels funds to improve the economic status of targeted populations namely PWDs, AGYW, KPs, women living with HIV and other high-risk groups.
<b>9c. Stigma and discrimination</b>	
PEPFAR will invest to combat Uganda’s persistently high rates of stigma and discrimination, as described regularly in the UPHIA and the Stigma Index.	<b>COP21 TARGET:</b> PEPFAR should fund HIV-positive religious leaders who are active in the faith-based sector in Uganda to develop and implement evidence-based interventions to fight HIV stigma and discrimination and who espouse progressive principles and values.  These interventions will first target other religious leaders and will become a robust and high-impact engagement of the faith-based sector in fighting against all forms of stigma and discrimination that harm people living with HIV and key and vulnerable populations.
<b>10. TB</b>	
PEPFAR will further scale up up priority TB/HIV services, in especially interventions required to improve timely TB case finding among people living with HIV, and improve their clinical outcomes,	<b>COP21 TARGET:</b> PEPFAR should close the funding gap for nutrition support and other essential supportive services for people living with TB and HIV.  <b>COP21 TARGET:</b> PEPFAR should dramatically increase funding to carry out integrated, community-led TB/HIV community support services to intensify case finding and save lives.  <b>COP21 TARGET:</b> Accelerate uptake of TB LAM and urgently increase supply of TB LAM commodities.
<b>11. Stockouts</b>	
PEPFAR will correct chronic STI treatment shortages which are hindering quality services for people living with HIV and people at high risk of infection.	<b>COP21 TARGET:</b> PEPFAR must at minimum double its funding for STI treating and tests to address chronic facility-level shortages.  <b>COP21 TARGET:</b> The practice of people being told they must buy HIV medicines from private clinics violates PEPFAR’s Minimum Program Requirement (MPR) of “elimination of all formal and informal user fees.” PEPFAR must increase funding to focus on ensuring medicines reach communities, on time and in full at 100% of its supported sites.
<b>12. CLM for Advocacy</b>	
PEPFAR will continue its support for CLM in Uganda. CLM findings will form the basis for program and policy adaptations.  Advocacy will be used to support community-led responses to problems that are not resolved through information sharing. Communities will focus on high priority areas such as health worker attitudes, protection of health and rights, commodity shortages, delays in return of test results, among others. Independence, transparency, and the community-led nature of successful CLM will continue to be prioritised.	<b>COP21 TARGET:</b> PEPFAR should continue CLM funding at COP20 levels (net \$1.56 million for the CLM program) for independent, community and PLHIV-led monitoring of quality and accessibility of services at PEPFAR-funded sites. Increased funding should be explored for expanded coverage.



