THE PEOPLE'S VOICE OF STATES

PEPFAR COUNTRY OPERATIONAL PLAN 2020



INTRODUCTION

Uganda has an estimated 1,392,742 people living with HIV (PLHIV), consisting of 1,296,000 adults aged 15-64 years (6.2% prevalence) and 96,742 children aged 0-14 years (0.5% prevalence).¹ Prevalence is higher among women (7.6%) than among men (4.7%); and among young people (15-24 years), prevalence is four times higher among adolescent girls and young women (3.3%) than among adolescent boys and young men (0.8%). New infections are estimated at 80,500 people per year: 73,000 adults and 7,500 children. Approximately 83% of HIV positive Ugandans currently access HIV treatment.² Despite important progress made by the country toward the national target of reaching epidemic control, Uganda continues to face major challenges that are weakening the impact of the national response.

Persistently high rates of loss to follow up (LTFU), as illustrated by the loss of 140,000 PLHIV (12% of the overall number of Ugandans on treatment) over the implementation of COP18,³ indicates that the PEPFAR program is not delivering quality, accessible services across implementing partners and Districts and populations. While PEPFAR Uganda TX_NEW targets are being met or exceeded (187,769 PLHIV were newly initiated on treatment), TX_NET_NEW results are poor—only 44,666 patients over the same period.⁴

Treatment initiation and retention for men is particularly poor; there was only a 3% increase in men older than 15 on

treatment over FY18Q4 and FY19Q4—and there was actually a decline of 4% in the percentage of men on treatment between 25-29 years old. 42% fewer men than women older than 15 were put on treatment over the first three quarters of FY19.⁵

Ongoing failure to provide HIV negative Ugandans with effective evidence-based HIV prevention services is a cause for serious concern. While pre-exposure prophylaxis (PrEP) programming is finally expanding (the COP19 PrEP target is 30,000 compared with the COP18 target of 16,481), geographic restrictions have created inequities in access to this critical biomedical intervention, and has stymied national demand. Ongoing

3. PEPFAR COP 2020 Planning Level Letter, Part 2. January 16 2020. https://www.state.gov/wp-

5. Ibid p. 8

2

^{1.} Ministry of Health, Uganda (July, 2019). Uganda Population-based HIV Impact Assessment (UPHIA) 2016-2017: Final Report. https://phia.icap.columbia.edu/wp-content/uploads/2018/07/3430%E2%80%A2PHIA-Uganda-SS_NEW.v14.pdf

^{2.} Uganda Strategic Direction Summary (SDS) 2019, P 4. Available: https://www.state.gov/wp-content/

uploads/2019/09/Uganda_COP19-Strategic-Directional-Summary_public.pdf

content/uploads/2020/01/Uganda_COP-2020_Part-2-of-Planning-Letter-1.pdf

^{4.} Ibid p. 8



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human rights violations such as discrimination, homophobia, transphobia, gender-based violence, and criminalization experienced by PLHIV, key populations, and young women result in avoidable transmission, clinical progression, and grave harm.

Community-led monitoring conducted between January-February 2020 revealed low-quality counseling, inappropriate roll out of index testing, non-existent or insufficient mental health interventions as well as psychosocial support; a yawning gap in treatment literacy; routine stock-outs of essential commodities ranging from family planning to TB-LAM tests; lack of access to prevention tools for adolescent girls and young women; non-availability of friendly services for youth, men and key populations; weak retention in care efforts; insufficient roll out of differentiated service delivery (DSD); prolonged delays in women receiving the test results of their newborns; and community linkage facilitators who had virtually no remuneration, recognition, training or support.

We also unearthed best practices, such as Jinja Regional Referral Hospital's Youth Friendly Corner, which was led by trained, qualified peers. The corner was welcoming, and was felt to be effective in delivering appropriate and supportive services to adolescents with HIV. At Virika Hospital in Fort Portal, one nurse was identified by a focus group of HIV positive mothers as being extremely skilled in training and supporting caregivers to administer pediatric treatment—a non-negotiable component of quality pediatric programming and securing viral load suppression for children with HIV.

However, to address the barriers to quality prevention and treatment that persist, a shift in strategic focus funded by COP20 needs to happen. This policy document, **The People's Voice 2020**, describes this shift and **recommends the country use the remaining implementation period of COP19 and COP20 as an opportunity to "pivot to PLHIV communities.**" This is necessary in order for PEPFAR to deliver against targets in a manner that leads to durable prevention and treatment impact rather than implementing partners merely "chasing numbers" as has too often been the case. Without this shift, the country is unlikely to achieve the 95-95-95 targets. For example, recent analysis shows that national "surge for quality" sites had better rates of viral load suppression than "non-surge" sites,⁶ indicating the essential benefit of support provided through community-led retention interventions. These recommendations were developed by PLHIV and other health advocates through the community-led monitoring that was conducted January-February 2020 at 16 PEPFAR-supported health facilities in 12 districts of Uganda.

FACILITIES MONITORED

NO.	FACILITY	DISTRICT
1	Arua RRH	Arua
2	Buyamba HC III	Rakai
3	Gulu RRH	Gulu
4	Fort Portal DIC Knowledge Room for Men	Kabarole
5	Kabarole RRH	Kabarole
6	Virika Hospital	Kabarole
7	Jinja RRH	Jinja
8	Kalangala HC IV	Kalangala
9	Katwe HC III	Kasese
10	Kyegegwa HC IV	Kyegegwa
11	Kulikulinga HC III	Yumbe
12	Kumi HC IV	Kumi
13	Mbale RRH	Mbale
14	TASO Mbale	Mbale
15	Soroti RRH	Soroti
16	TASO Soroti	Soroti

These findings were supplemented by analysis of national data and PEPFAR facility data from FY19 and FY20, community focus groups, and national validation. The methodology built upon the experiences generated through development of The People's Voice 2019.⁷ Community-led monitoring was aimed to assess the quality and accessibility of HIV service delivery while focusing on the challenges PLHIV experience in getting access to and staying on treatment.

7. https://healthgap.org/wp-content/uploads/2019/03/Peoples-Voice-Uganda-FINAL.pdf

^{6.} Supra note 3, p. 9



COMMUNITY PRIORITY INTERVENTIONS

1. Walk the talk—put communities at the center

1a. COP20 must ensure 100% of PEPFAR supported sites have sufficient funding invested in community-led retention and treatment program quality improvement strategies, prioritizing treatment literacy, stigma reduction and U=U, to ensure access to quality treatment services for all HIV treatment sites and their corresponding communities.

Community-led monitoring found high levels of both external and internal stigma and lack of treatment literacy, poor attitudes of staff, long distances to facilities, long turnaround time for test results and long waiting hours; these issues were all affecting adherence and retention.

In Gulu and Arua, for example, clinic days were only between Monday and Wednesday (same days when district meetings take place), health education was non existent, patients reported long waiting hours, there was a poor health worker to client ratio, reports of incompetent health workers, long distance to access services, fewer or non-existent community linkage facilitators, and high rates of stigma among women using eMTCT services. Three mothers in Gulu reported that their babies seroconverted as a result of stigma and discrimination by their spouses and family members.

"I am in a polygamous marriage and discordant relationship with 3 co-wives. When I delivered my son, I could not carry the syrup in the well known containers of medicines. I had to empty all the syrup boxes not to be associated with HIV. Back home I was discriminated against, and I skipped administering medication to my child. After 6 months during one of our clinic visits, I was told that my son had HIV which he did not have at birth." - Mother in Gulu

In Gulu and Arua mothers were concerned about stigma and discrimination that their children faced in school:

"Our children have started asking us why they are always taking medicine even when they are not feeling sick. We are finding it difficult to explain to children how they are on life treatment on one hand, then they go to school and get rumours from other children whose parents have told their children about our children, our children get stigmatized and they still come back with questions like are we going to die, they say 'AIDS kills' at school, our friends make fun of us, how did we get this disease?" - Parent of 14-year-old.

Kalangala reported an increase in positivity rate among pediatrics which is attributed to poor retention, stigma, discrimination and adherence among migrant mothers including sex workers. The Kalangala district health officer (DHO) reported that the pediatric positivity rate had increased from 2% to 3% over the period of COP18 implementation. In Yumbe District, cases of sero-conversion of children on second PCR were recounted with community monitors.

During the monitoring exercise, interaction with mothers

and caregivers of children living with HIV revealed limited community support for mothers in the eMTCT program. According to one of the leaders of Kalangala Forum of People Living with HIV (KFPLHIV), children of sex workers are the most affected in the District because their mothers are mobile and their caregivers are often not empowered to support their children. Family friendly and stigma-free services for sex workers need to be established and expanded.

In catchment areas of many of the facilities that were visited during the monitoring exercise, ART clients reported being switched to TLD and starting Isoniazid TB preventive therapy (IPT) without being given any counseling or information about the likely side effects and possible adverse effects. Some clients reported having adverse medication side effects and having not received either follow-up nor referral services, forcing some to abandon the treatment. Despite national commitments to fund treatment literacy as part of the national TB preventive therapy (TPT), virtually nothing has been invested in this area to date. Results from the monitoring exercise indicate that patients have remained disempowered as they experience drug toxicities, side effects, or adverse events without any idea of where to go for free, effective management of these concerns. Concurrent roll-out of IPT and TLD has meant that the cause of drug toxicities are difficult to diagnose appropriately and recipients of care because they are not aware of what to monitor for, do not report in time. For example, in Gulu there were reported cases of clients developing hyperglycemia and hypertension, conditions that are not catered for in the initiation package of IPT and TLD. In Kabarole, the acting District Health Officer reported that starting people on TLD and IPT concurrently has negatively affected uptake of TLD and adherence to treatment.

COP20 must dramatically expand funding for treatment literacy and health promotion interventions led by and for communities, caretakers and the end users of treatment. This should include capacity building of communities to interpret, use and communicate client results relating to key concepts such as HIV drug resistance, viral load, the TLD transition and IPT.

COP20 should dramatically increase funding for communityled organizations8 to roll-out interventions focused on U=U, treatment literacy, stigma reduction efforts, psychosocial support and other critical interventions that will improve program quality and impact.

1b. Increase the number of trained, supervised, equipped and adequately remunerated community health workers (community linkage facilitators, expert clients, peer leaders/educators, mentor mothers and peer buddies) supported to facilitate community-facility linkage and follow up for improved retention and treatment outcomes.

8. https://www.unaids.org/sites/default/files/media_asset/what-is-a-community-led-organization_en.pdf

While all the facilities monitored reported having a protocol in place to follow-up clients who miss appointments, protocol implementation is wildly uneven. The number of community health workers is not sufficient and support not adequate to make the phone calls, conduct home based visits, outreaches and other supportive interventions required to ensure adherence and retention of all clients. Some facilities reported delayed and even no monthly facilitation for follow up. Funding for an additional 930 community health workers was recommended in COP19 and action was not taken.

In particular, the community linkage facilitator program, which was a hallmark of COP16, was found to be either partially implemented or no longer truly active. Community health workers are neither remunerated nor given adequate facilitation, tools and training to enable them do their work effectively. At one health center in Kalangala, there was only one mentor mother who was responsible for 500 clients. At Gulu Regional Referral Hospital, 7 linkage facilitators were serving 6,309 clients - an average of a whopping 902 clients per linkage facilitator. In addition, the community health workers have only bicycles, which they have to ride to cover a catchment area extending to 25 kms and beyond.

A facility in Soroti revealed poor retention rates among adolescent young people and women newly initiated on treatment during antenatal visits. This was attributed to stigma, poor counselling procedures and weak follow up, with lack of support for retention and linkage from communities.

In Gulu between October - December there were 821 missed appointments registered of which 278 were confirmed lost 30 days after initiation. This was caused by lack of support for linkage facilitators, no transport means for the linkage facilitators yet some of the distances are as long as 25 km, field telephones and airtime and poor and or inconsistent remuneration for the linkage facilitators).

In Katwe Health Center III in Kasese district, community health workers had not received airtime for follow up calls for the previous month and reported that delays were common. In Kumi, the district health officer reported lack of facilitation for expert clients, linkage facilitators and peer mothers attached to the facilities in the District, resulting in major program challenges and loss to follow up. The DHO indicated that none of the existing partners was providing dedicated funding for community linkage facilitators/expert clients. We learned during a focus group discussion held at Kumi HC IV that only 2 of the 9 linkage facilitators attached to the facility were being given monthly facilitation for follow-up, triaging and counselling.

COP20 must ensure full implementation of the community linkage facilitator program by recruiting sufficient numbers of community health workers, and providing necessary training, support and tools they need to effectively and successfully carry out their responsibilities. This includes an allowance to pay for transportation to conduct home based visits and community outreaches. Community health workers should receive a combined minimum remuneration (through non taxable sources) of 350,000 per month.

Increased PEPFAR COP20 HRH budget outlay for community health worker recruitment should result in at least 1000 additional lay health workers in post by the end of COP20.

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1c. Improve quality and coverage of DSD facility and community models by ensuring fully functional CPPDs, CCLADs, and fast-track clinic lines are available in 100% of PEPFAR supported sites.

The rollout of DSD models in 2018 has improved retention on ART, adherence, reduced stigma and lost to follow up, turn around time of clients, reduced overhead costs at the facility. Despite these improvements, our monitoring revealed major weaknesses in PLHIV access to community-led and facility-based DSD models. These major gaps are undermining the shared goal of defeating HIV.

In many sites, CCLADs were not functioning, CDDPs were non-existent in all the districts visited and clients' prefered DSD model was not provided. In some sites, adolescents and clinically stable mothers were not eligible for community-led DSD models, despite WHO normative guidance to the contrary.

In Mbale, communities reported that there were no adherence clubs at the Mbale Regional Referral Hospital—because the intervention is not being supported by the implementing partner, RHITES-E. Indeed, of the facilities reached, only TASO Soroti and Arua Regional Referral Hospital had adherence support clubs; the rest (numbering 14) did not have them.

In Gulu, 100 CCLADs were established but only 23 were functional, with no CDDP. Adolescents are not eligible for community led models of DSD. In Yumbe, CDDP had been rolled out in Bulomoni, Egamara and Bangatuti attached to Kulikulinga HC III, but facility models were not functioning and there were no youth friendly DSD services. In Soroti no community DSD models were functional. In Kumi community-led models were non functional (Kumi HC IV). In Mbale community models (CCLADS & CDDPs) exist but no health education was being provided during the refill for treatment support.

All PEPFAR supported sites should increase funding for the three prongs of DSD so that all DSD options are available at all sites, and CCLADs and CDDPs are fully functional. IPs must increase their budget allocation for DSD implementation in COP20.

1d. Urgently address gaps in access to services and loss to follow up for Kalangala through accreditation of all HCs.

Access to quality services remains a huge gap in the island for fishing communities, their sex partners and surrounding communities. Kalangala District with 84 islands has the highest HIV prevalence by District in the country. Of its 20 health facilities (12 Health Center IIs, 6 Health Center IIIs and 2 Health Center IVs) only 9 were accredited to provide integrated ART services. The long distance required to access services, migrant community, high numbers of sex workers including from neighbouring countries (Tanzania, Kenya and Rwanda) and limited support for a sex worker-friendly family centered model must be resolved during COP20 through accrediting all remaining health facilities to prescribe ART.

COP20 should fund accreditation of all remaining HCs in Kalangala for integrated ART and aggressively manage the IP (Rakai Health Sciences Project) to improve retention in care, 100% access to client-friendly services, particularly for pediatrics, and sex workers and their families.



2. Key populations programming

2a. COP19 and COP20 must support a strategic overhaul of programs for Key Populations across implementing partners, with accompanying revisions of service delivery models, targets, and strategies.

Key populations in Uganda experience disproportionately high rates of HIV infection as well as poor clinical outcomes featuring low rates of linkage to treatment, lower rates of viral load suppression, and lack of access to effective HIV prevention methods such as PrEP, condoms and lubricant, as well as U=U messages, treatment literacy, and STI testing and free STI treatment.

Community led monitoring revealed troubling indications of the lack of strategic direction for key population prevention and treatment programs in Uganda. This is reinforced by PEPFAR FY19 Q4 Key Populations program performance data, for example indicating overall KP linkage rates of only 42%, with only 1% linkage among men who have sex with men.⁹ On the positive side, KP networks have undertaken best practices in coordination such as the establishment of the Uganda Key Populations Consortium (UKPC), a new platform for policy advocacy regarding HIV, health rights, and access to quality services.

In the 2019 SDS, PEPFAR committed to a DREAMS-style approach to "layering" service delivery for key populations.¹⁰ Furthermore, the country committed to rolling out key population service delivery through 38 "Drop In Centers" (DIC) at Districts with "identified hotspots."¹¹

However by contrast, community-led monitoring as well as interviews with key District health officials, service providers and service users showed that DICs were nonexistent or just a room with no services offered at all.

In all of the facilities visited, services for key populations who

are not sex workers (men who have sex with men, transgender women, WSW and people who use drugs) existed at best in name only. For example, the Jinja Regional Referral Hospital is funded to house a DIC for key populations by the Global Fund to Fight AIDS, Tuberculosis and Malaria and PEPFAR. Instead of a DIC, on the day of their visit, community monitors found an empty, locked room. After immediately contacting the Administrator of the DIC, it became clear that substantive activities were not taking place on a daily basis. The monitor reported: "The DIC was just a small room with a desk, 2 chairs, 1 file cabinet, and a note board. It's found in the most crowded area in the referral hospital. It leaves so much to be desired! There is a need to have a proper DIC put in place at the referral hospital and the community."

In 75% of facilities visited, clinic and hospital management as well as front line health worker staff exhibited poor attitudes toward key populations, commenting that Key Populations "do not exist here." In Gulu Regional Referral Hospital, the DIC provided risk reduction counseling services and information as well as STI testing and treatment but ART clients had to be referred to the main clinic.

Implementing partners funded to deliver KP services such as testing, linkage and treatment were leaning heavily on local, small key population-led community based organizations to carry out the bulk of this work, without well-planned programs that are designed and owned by communities, and without adequate remuneration or protection of the KP outreach workers who were carrying out the actual work at the sub-partner level.

COP20 must fund a complete redesign of Key Population programs in Uganda being implemented through COP and Key Population Investment Fund (KPIF) support. The programs are out of step with the needs of HIV positive and HIV negative Key Populations in Uganda.

Across the country, Drop in Centers (DIC) must be subjected to "community audit" and should be replaced with community designed interventions that respond

^{9. &}quot;PEPFAR Uganda FY19 Q4 Stakeholders Update Slides," available at: https://drive.google.

com/file/d/1Ausr5mEdxTGZcJeW4bmfQ6Z8RRRqncih/view?usp=sharing

^{10.} Supra note 2, p. 59

^{11.} Ibid.



to the priorities of key populations, including minimum components such as a: District level key populations coordinator whose cell phone number is known to communities and can be available on a routine basis to address client needs; a center staffed by at least 3 paid, trained counselors, a professional clinician, and providing a minimum package of quality services including on site access to PrEP, STI screening and free treatment, counseling and support, viral load testing, and condoms and lubricant.

COP20 should fund continuous professional and community health workers to improve client satisfaction. The impact of training must be measured through anonymous surveys to determine whether or not health worker attitudes and high rates of stigma are actually improving.

2b. Support expansion of treatment and prevention services in prisons

Lack of access to prevention services for Ugandan prisoners should be addressed through innovative, evidencebased services such as peer-led prevention programs and treatment literacy outreach. Despite a challenging legal environment, Ugandan inmates deserve protection and treatment particularly given very high rates of HIV, tuberculosis and other infectious diseases.

COP20 should fund a pilot with Uganda Bureau of Prisons and other partners to implement an

HIV prevention and treatment literacy program, modeled on the MAT/harm reduction program being implemented in partnership with Butabika.

2c. Support decriminalization of key populations

A recent increase in violence targeting key populations is a worrying trend in Uganda. COP20 should prioritize promoting, protecting and defending the health and human rights of all Ugandans.

PEPFAR should publicly and actively support decriminalization of HIV and of KPs in order to increase uptake of life saving services, decrease new infections, and ensure evidence based response in Uganda. PEPFAR should fund establishment of rapid response mechanisms for violence elimination (either community or IPV) through phone-trees or whatsapp links, with a protocol for how to support KPs who are in trouble.

Human rights interventions should involve some basic legal literacy, particularly referral mechanisms for legal assistance. Community health workers/ peer navigators should be empowered to provide these services. Human rights interventions should also involve improving safety and security systems and processes, as well as sensitization work in local communities where services are located/provided.

3. Social enablers must be implemented

3a. Immediately halt implementation of policies that violate human rights

Baseline rates of violence are extremely high. The 2016 Violence against Children Survey (VACs) shows 59% of women and 68% of men (aged 18-24) experienced physical violence before the age of 18. A recent survey of adult women with HIV reports intimate partner violence at a rate of 32.1%.¹² Introducing index testing in a country where violence is so common, should raise major alarms—yet index testing expansion was a COP19 priority, and community concerns were assuaged with assurances that counselors would be properly trained.

We have found that index testing is being administered to women and key populations inappropriately by implementing partners who disregard risk of violence and other risks to their health, human rights and well-being. PEPFAR's halt of index testing has not reached all communities, particularly women living with HIV, and the emphasis in Uganda's COP20 Planning Level Letter on index testing scale-up for children living with HIV without consideration of the risk of violence and other potential human rights violations is a major concern. Implementing partners must be held to a strict standard so that index testing does not undermine clients' safety. A number of the facilities visited during community led monitoring reported cases of violence resulting from index-testing interventions. While facilities have tools to record these harmful outcomes, service providers reported to monitors that they did not take any corrective action.

At Kumi Health Center IV, people reported being too afraid to bring their partners to test. In Kalangala, mothers in the PMTCT program reported violence when they offered HIV self-test kits to their partners.

Community monitors also interacted with one person living with HIV in Bwaise who is a mother and a sex worker, who was abandoned by her husband while she was pregnant as a result of a counselor disclosing her status to her husband without her consent. As a result, she fell out of care during her pregnancy and one of her twins became HIV positive. Despite living relatively near to multiple Kampala-based PEPFAR funded implementers, she is not receiving treatment literacy, counseling, or facilitation to reach her clinic visits which are only accessible over extremely bad roads. Her other children have not been tested for HIV, although she told monitors she wanted that service. PEPFAR must immediately redesign index testing tools and protocols and monitoring based on community feedback.

PEPFAR and the government of Uganda must not fund implementing partners to restart index testing anywhere without a restructuring of the program to resolve fundamental barriers to

12. https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-019-0831-1

quality - client centered testing - and to protect human rights. Our concerns must be resolved.

3b. Address stigma and discrimination as key barriers affecting women living with HIV in the HIV response

HIV/TB-related stigma has over time been known to "devalue' people either living with, affected by or at risk of HIV and TB. And it is usually accompanied with discrimination which subjects PLHIVs and TB patients to unfair and unjust treatment. The Uganda National HIV Prevention Strategy (2011-2015) and National HIV Strategic Plan (2015-2020) identify stigma as a key driver of the epidemic. Under the outcome of strengthening a sustainable enabling environment, the NSP prescribes efforts to mitigate underlying factors that drive the HIV epidemic including mitigating stigma and discrimination in all spheres.

However, the efforts to address stigma and discrimination are either non-existent or have not been fully explored. Stigma and discrimination continue to undermine program impact in the country; Retention on ART remains a major challenge and is estimated at 72% at 12/12 following ART initiation with majority of LTFU occurring in the first 3-6 months. Contributory factors include inadequate psychosocial support to address stigma, and non-disclosure which is also a result of stigma. The face of stigma and discrimination was seen among a discordant couple in Arua where a woman with HIV reporting suffering ridicule, scorn and disrespect from her partner: "He at some point started bringing other women in the house," she recounted.

Recent focus group discussions with over 100 women living with HIV from 14 districts (Kasese, Bundibugyo, Kampala, Arua, Yumbe, Pader, Kitgum, Moroto, Amudat, Kaabong, Kotido, Napak Nakapiripiriti and Abim) reveal that stigma and discrimination is sidelining women and girls living with HIV from fully utilising the available health services, access to quality and comprehensive SRHR services and information; skills building programs, access to financial instruments, and employment opportunities.

One intervention that should be explored by IPs is supporting "stigman free champions." Monitoring revealed that in Arua, Kabarole, and Jinja revealed **"Mr. & Mrs Y+" groups of empowered young people living with HIV were making major strides as "Stigma Free Champions."** They are ambassadors who are ensuring that young people with HIV live healthy and dignified lives. Their roles at facility level include; referral, linkage, follow up, triage, and adherence support through counselling.

COP20 must invest in programs to reduce stigma and discrimination at all levels. Other than the stigma index survey report which is a one time off that offers recommendations on how to challenge and address stigma and discrimination, there is no mechanism in place that captures stigma and discrimination in real time for immediate action. We therefore need facility and community level tools to assess and capture occurance of stigma and discrimination for immediate action.

3c. Addressing GBV and other forms of violence against women, girls and children living with and affected by HIV

Uganda's National HIV Strategic Plan (2015-2020) recognises gender inequalities and GBV as one of many factors contributing

to the high HIV incidence in Uganda. As described above, violence against women, girls and children is associated with FGM, forced early marriage, teenage prenancy; as well as structural risk factors such as poverty, poor legal protection measures, illiteracy, and unemployment. GBV, violence against children living with HIV is a two dimensional risk factor; women, girls and children can be the victim of violence due to their HIV status, for example violence perpetrated against women living with HIV as a result of index testing. At the same time, women may suffer sexual violence with its associated implications including HIV infection, STIs, and unplanned preganancies.

The NSP does not prescribe plans for responding to GBV. Neither gender inequality or GBV are adequately addressed. There is not sufficient allocation for addressing negative gender norms yet evidence shows that integrating a gender perspective into the HIV response improves program outcome and impact.

Monitoring reveals that Integration of these issues in HIV programming was not taking place. Some facilities did not have gender focal person, no gender register and even when gender cases are brought before a dest, there were no protocols in place to address exposure to violence. Screening for gender based violence were not priorities. One health worker at a facility in Mbale illusted thatoffered; "We only offer physical examination and treatment to clients for cases of sexual assault we offer PEP and emergency contraception and dressing or treatment for any other physical injuries where never cases are brought here. But screening for potential exposure, no we do not do that."

COP20 must invest in programs to reduce policy and legal barriers that worsen women's inequality and perpetuate violence that further impacts the HIV response.

COP20 should support interventions to address the needs of women living with HIV and disabilities with a priority focus in Year 1 on infrastructure and sign language interpreters.

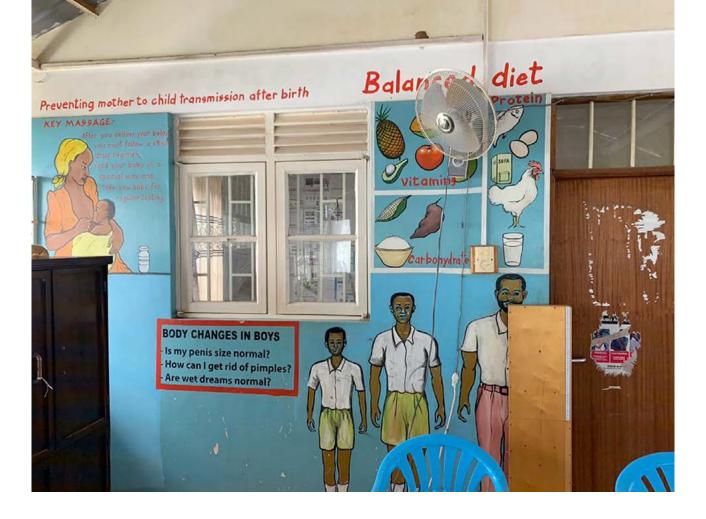
COP20 must invest in the development of a gender integration framework which will offer strategies for addressing GBV responses including; prevention & management of GBV (including safe houses for post GBV interventions), peer support for GBV survivors, and GBV protocols for all IPs to implement.

3d. Expand comprehensive services for women living with HIV

Major service gaps for women living with HIV were revealed during the community monitoring exercise. These included; information gaps especially in relation to DTG, poor and/or no integration of family planning into HIV, lack of protocols for assessing exposure to violence, limited ineritance of property rights[1], gender based violence for women mostly in polygamous families[2], social and cultural norms undermining women of their sexual rights and making them prone to STIs..

COP20 must improve access to quality and comprehensive SRHR services and information for women and girls living with HIV. All women and girls (irrespective of gender identity or sociocultural or economic status) should access, utilize and enjoy quality SRHR. (reference to WHO SRHR guidelines for women living with HIV)

COP20 should support interventions to address the needs of women living with HIV and disabilities with a priority focus in Year 1 on infrastructure and sign language interpreters.



4. High impact prevention must be expanded through COP19 and COP20, focusing on adolescent girls and young women (AGYW), key populations, pediatrics and men

4a. PEPFAR and the government of Uganda must prioritize programs that address socio-economic, legal and structural barriers to increase service uptake by Adolescent Girls and Young Women

COP20 community-led monitoring found that in many facilities, AGYW programs were either non-existent or had been phased out and were now non-functional. Where youth friendly services existed, major gaps included: no standard service package for AGYW, no adherence support clubs for young people, limited Family Planning services, and no age appropriate materials for young people. Poor viral load suppression rates were reported among AGYW especially those in school.

A Comprehensive program and/or package for AGYW could include the following: access to vocational training; programmes that target AGYW's partners and their children,, meaningful involvement of AGYW in the implementation of adolescent friendly health services, literacy programmes on health, legal, policy and human rights, programmes that prevent rape and defilement; early/child marriages and interventions that address GBV in schools.

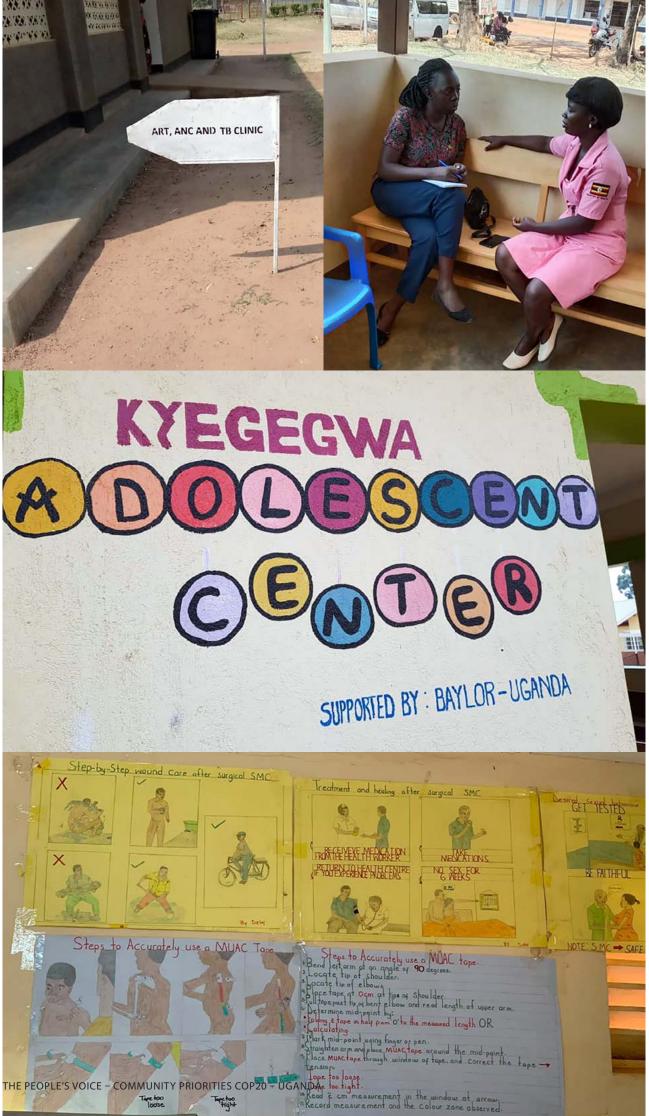
COP20 should invest in programs aimed at improving the quality of services delivered by and for young people, by rapid expansion of the YAPs model nationally. COP20 must ensure increased access to FP services and comprehensive sexuality education for young people. PEPFAR COP20 should prioritize interventions for reducing stigma and discrimination in schools targeting both boys and girls.

4b. PrEP scale up must be supported through COP20

HIV prevention in Uganda has been undermined by continuous foot-dragging in PrEP implementation, with multiple years of low targets, poor demand, and geographic restrictions. PrEP should be available everywhere, and the Ministry of Health should be supported to release a circular informing health workers about national PrEP roll out, and what is expected of health facilities that are still waiting for supplies.

PrEP must be rolled out nationally, with public promotion of this high impact prevention tool. COP19 and COP20 should fund a pivot away from geographic and population restriction, instead offer PrEP to all people at substantial risk of HIV infection, everywhere, including adolescent girls and young women (AGYW) and pregnant and breastfeeding women.

Health workers must be trained to offer stigma free screening for PrEP eligibility, and supply forecasting must be adjusted in order to ensure adequate PrEP supply and appropriate national coverage.



4c. Expand quality harm reduction services

In COP19, PEPFAR invested in MAT services in Kampala targeting 300 people who inject drugs (PWIDs) at Butabika National Referral Hospital working with PWID-focused CSOs.

Community monitoring revealed that in all facilities visited, harm reduction services were limited to condoms, STI screening and management. Information about harm reduction and how to reduce risks associated with drug use is scanty. At facility level, care providers' understanding of services for PWID is limited to referrals for mental health and rehabilitation.

COP20 must support expanded community based harm reduction services including psychosocial interventions for MAT clients, scale up of the hub and spoke model for PWID in prisons and other closed settings, stronger community models for referral and linkage to MAT and other HIV services; and education and training of health care providers, caretakers, families and PWID communities about harm reduction.

4d. Improve services for men

Uganda committed through COP19 to expand engagement of men, particularly those age bands with lowest levels of knowledge about their status, those in HIV care but with high rates of loss to follow up, and those who are not virally suppressed. These commitments included: developing and scaling up friendly services for men, ensuring testing outreach for partners of pregnant women, cultivating the President as a champion for increased access to HIV treatment and prevention through the Presidential Fast Track Initiative.

The 2019 Strategic Direction Summary states: "Multiple platforms will be leveraged to reach men aged 20+, including exploitation / utilization of Uganda's Presidential Fast Track Initiative which seeks to reposition the role of country leadership in the HIV response. Increasing access to services for men is among the key priorities of this initiative." In our recent field engagements and data validation activities, it was unclear that this commitment had taken effect. PEPFAR should facilitate initiatives like the Male Action Groups (MAGs) that were established by the Ministry of Health with support from the Global Fund, and should expand "Male Knowledge Room" clinics beyond Kampala and the region of Southwestern Uganda.

5. Expand pediatric HIV diagnosis and quality treatment access

COP20 must ensure all HIV positive and HIV exposed infants, their caregivers and families have access to timely diagnosis, optimized treatment, and comprehensive services that are required in order to deliver viral load suppression, retention in care, and a long and healthy lifespan.

Program data reveal that Uganda has much work to do to address the 95-95-95 targets in HIV-infected children. For children aged 0–14, based on UPHIA data of parental reports and detection of ARVs in the blood, only 56 percent were known to be HIV-positive, 54 percent were on ART, and 24 percent were virally suppressed.

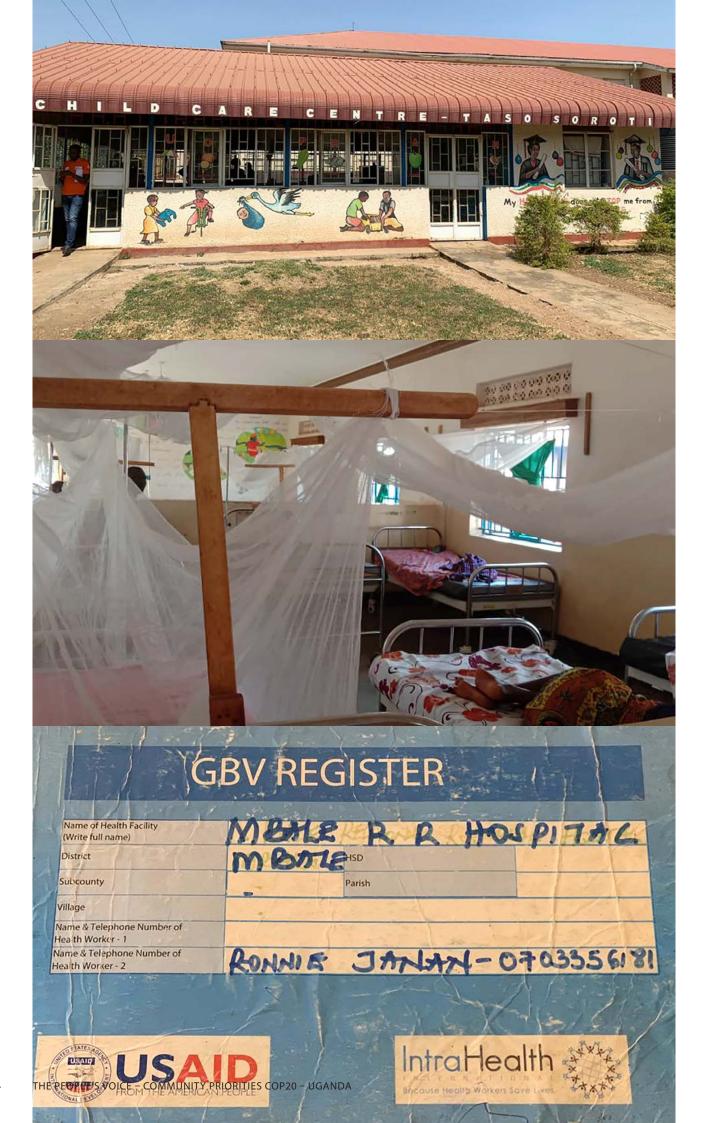
According to COP2019, children <15 years represent the population group with the highest unmet need for HIV diagnosis and treatment. Furthermore, among children under the age of 15, successful VL suppression only reaches 39.3 percent. The COP20 Planning Level Letter notes that "HIV positive children in OVC programs had better VLS outcomes than those in general pediatric treatment." But children living with HIV represent only a minority of many IPs' OVC beneficiaries.

100% of children living with HIV should be linked to comprehensive OVC services starting in FY20 and continuing to FY21. Functional family support groups must be established for all sites providing PMTCT services, along with 100% coverage of the Mother Baby Care Point and Mentor Mothers approaches, which have been shown to result in higher levels of VL suppression and better retention in quality care. Uganda's pediatric HIV epidemic is showing worsening trends, with an overall vertical transmission rate of 7.9% at the end of breastfeeding. At the current rate, Uganda will not achieve its goal of virtual elimination (transmission rate of <5%) by 2022. The proportion of children that received an EID test within 0-2 months of age is still very low (51%).

COP20 should expand Point of Care EID to cover all HIV exposed infants in order to improve rapid case detection and linkage to treatment.

IPs must budget for service delivery models that increase pediatric treatment retention through treatment education and support for caregivers, HIV positive women, children and adolescents.

Increasing new pediatric infections in Uganda must be tackled through better quality treatment and prevention programs that suppress the viral load of HIV positive pregnant and breastfeeding women and provide PrEP and retesting services for HIV negative pregnant and breastfeeding women.



6. Stop stockouts

Routine stockouts of TLD, Xpert MTB/RIF Ultra test cartridges, STI treatment, TB-LAM test kits, Aluvia, nevirapine syrup for pediatrics, cotrimoxazole, and other essential commodities were widely reported in all facilities monitored. All districts visited in Rwenzori region (Kyegewa, Kabarole and Kasese) were experiencing DTG stockouts and some clients had to be switched back to efavirenz-based combinations due to delayed supply by National Medical stores.

Cases of drug resistance were found in Kegegya, Kalangala and Soroti as a result of inconsistent drug supply. In Kumi HC IV at the time of the visit there were no new clients initiated on DTG. Kyegegwa clients refused to be switched back to efavirenz based combinations and opted to wait for a new stock of DTG. During facility visits, monitors saw health workers lacking training related to issues ranging from the rollout of DTG for women of reproductive age, to engaging community in treatment literacy in order to increase adherence to lack of monitoring for adverse effects including hyperglycemia following DTG transition, and hepatotoxicity following TPT initiation. Pharmacovigilance was nonexistent, health workers lacked competence regarding these grave issues, and the concerns of recipients of care were ignored. In Soroti at the regional referral hospital, a client reported toxicity after starting DTG and IPT. End user surveys or monitoring of ART toxicity levels to provide feedback to the care providers were nonexistent.

The government and PEPFAR must work towards eliminating treatment interruption resulting from stockouts of ART for adults and children. Communities must be supported to monitor stockouts at every step of the supply chain.

Pharmacovigilance systems must be put in place to track adverse events, including at Community Drug Distribution Points. Pharmacovigilance committees at district level should be put in place to monitor side effects of drug interactions and long term use of ARVs.

7. Address persistent human resources for health barriers

Uganda's health system staffing norms are woefully out of date--they were last reviewed 25 years ago, in 1996. At the time, there were fewer Ugandans, including fewer people with HIV, and no public sector treatment program. Over the years, the population has exploded and HIV has become a generalized epidemic.

For instance, Kumi HC IV has not had a medical officer since 2017; the facility is staffed by only 5 nurses and 2 clinical officers; there is no specific nurse assigned to the ART clinic, where expert clients do most of the non-clinical work. In Yumbe, despite the huge number of clients from the community and refugee camps accessing HIV services at Kulikuliga HC III, the facility has only one critical cadre (a clinical officer) to conduct examination, treatment and support community programs extension to the refugee community. As a result, they have limited time to counsel, and clients face long waiting hours and poor quality of services. Kalangala with only a health centre IV as the main facility, receives clients from different lower facilities. The facility is served by 2 doctors and 2 clinical officers, supporting 3,400 clients which has resulted in long waiting hours and limited follow up.

COP20 must prioritize increased funding to deploy additional priority health workers in clinical sites with high volume, high vacancies and poor outcomes and patient satisfaction reported among PLHIV.

Government must increase its funding for the recruitment, equitable deployment and increased remuneration of critical cadres of health workers as part of Global Fund and PEPFAR co-financing agreements, rather than only explore annual allocations for ART.

8. TB/HIV service delivery

8a. TB preventive therapy

An estimated 53,000 people are newly infected with TB in Uganda annually, and the number of new infections has been rising over recent years. TB preventive therapy is proven to reduce morbidity and mortality among PLHIV, and must be considered as a routine and integral part of the HIV clinical care package. Uganda's Ministry of Health launched the 100-day accelerated Isoniazid TB preventive therapy (ITPT) scale up plan in 2019. During the campaign, more than 500,000 PLHIV were started on ITPT were given Isoniazid to prevent the development of active TB in people who may be infected with the bacteria.

Despite the successful enrolment of people on Isoniazid, completion of treatment is a major concern, this is caused by what many PLHIV report as unbearable side effects and long treatment period (6 months). Whereas there has been progress made in improving completion rates from 64% at Q4 FY18 to 77% at Q3FY19 we have not moved fast from the national rate of 72%.

This calls for an urgent shift to the newer 3HP (combination of isoniazid and rifapentine) for adults and 3HR for children (three months of isoniazid and rifampin). The 3HP & 3HR regimens are shorter, safer, and easier for people to complete, and have been shown to be as effective. The Government and PEPFAR should invest in this new drug and aim to put a significant proportion of people with HIV who receive TB preventive therapy on 3HP in COP20.

In addition, children receiving TB preventive therapy should receive the 3HR regimen, which is available in a child-friendly dispersible tablet. Children with HIV requiring TB preventive therapy can receive 3HR if they are on efavirenz- based antiretroviral therapy; children on nevirapine, lopinavir/ritonavir, or dolutegravir-containing regimens should receive isoniazid preventive therapy to avoid drug-drug interactions with the rifampicin in 3HR.

8b. TB LAM testing

People living with HIV are at increased risk of developing TB, and of dying from it—especially when they have advanced HIV disease, or AIDS. The LAM test can rapidly and easily diagnose TB in people living with HIV, and has been shown to reduce deaths among people with AIDS. In 2019, the World Health Organization (WHO) strengthened and expanded its guidance on the use of LAM testing for TB, recommending its use for all people living with HIV, (1) who have signs and symptoms of TB, (2) who are seriously ill, or (3) who have AIDS, with less than 200 CD4 cells/mm3 for inpatients and less than 100 CD4 cells/mm3 for outpatients.

Uganda already rolled out TB LAM testing, however some of the lower health facilities surveyed did not have this service yet and those offering in some places i.e. The Rwenzori region had experienced LAM testing stockouts for two months.

COP20 must invest in expanded TB service delivery including ensuring TB symptom screening, and urine-LAM and Xpert MTB/RIF Ultra testing are being implemented in all settings where PLHIV present for care, including outpatient settings

COP20 must support universal access to TPT for all eligible PLHIV (those currently on treatment who have not previously received TPT in addition to those newly initiating treatment) and household contacts of PLHIV with TB disease, including children. The preferred TPT regimen for adults should be 3HP.

9. Community Led Monitoring and Advocacy

In the 2020 Global Guidance PEPFAR states that "In COP20 all PEPFAR programs are required to develop and support and fund a community led monitoring platform in close collaboration with independent civil society organizations and host country governments."

COP20 must set aside resources to ensure that community led monitoring for advocacy can be more consistently rolled out by the users of services themselves, and that issues identified can be addressed and resolved in a timely and satisfactory manner.

Different models are being used in Uganda, such as a community scorecard approach that integrates with PEPFAR SIMS data to conduct routine quarterly monitoring of selected PEPFAR supported facilities to collect data using standardized observational, patient/PLHIV, and healthcare worker surveys. Expansion of the fact finding approach supporting The People's Voice could be expanded to cover a sufficient number of sites, on a routine (eg bimonthly) basis.

These efforts will help to reveal issues in the quality of HIV and TB service provision at the facility related to waiting times, staffing complements and shortages, staff attitudes, stockouts and shortages of health commodities, facility cleanliness, the state of infrastructure, and more.

Monitoring results must be linked to a model of accelerated

response from the Ministry of Health, PEPFAR and implementing partners to address the priorities that are identified. Chronic issues will be the focus of advocacy efforts at local and national levels. Resources will be required for staffing, travel, communication, data analysis and documentation, and other costs to allow communities groups to carry out routine monitoring.

COP20 should fund independent, community and PLHIV-led monitoring of the state of service provision at PEPFAR supported sites and escalate issues using advocacy interventions. Key areas to be monitored include performance, quality of services, health worker attitudes, health and rights, and stockouts and/or shortages of diagnostics and treatment.

The results of monitoring must be linked to a model of advocacy to ensure an accelerated response from all actors to address the issues identified in order to ensure they are rapidly rectified. The funding mechanism must foster independence and transparency.

SPECIFIC LANGUAGE REQUESTED IN COP20

LANGUAGE TO INCLUDE IN COP20 TARGET 1. Walk the talk--put communities at the center COP20 will ensure 100% of PEPFAR Target: 100% of PEPFAR supported sites fund community-led retention strategies. supported sites have sufficient Target: Increase the number of trained, supervised, equipped and adequately remunerated funding invested in community-led community health workers (community linkage facilitators, expert clients, peer leaders/ retention and treatment program educators, mentor mothers and peer buddies) supported to facilitate communityquality improvement strategies, facility linkage and follow up for improved retention and treatment outcomes. prioritizing treatment literacy, stigma reduction and U=U, to ensure access Target: Increased PEPFAR COP20 HRH budget outlay for community health worker to quality treatment services for recruitment should result in at least 1000 additional lay health workers in post by all HIV treatment sites and their the end of COP20, with remuneration (non taxed) of 350,000 UGX per month. corresponding communities. Target: All PEPFAR supported sites should increase funding for the three prongs of DSD so that all DSD options are available at all sites, and CCLADs and CDDPs are fully functional. IPs must increase their budget allocation for DSD implementation in COP20. Target: COP20 should fund accreditation of all remaining HCs in Kalangala for integrated ART and aggressively manage the IP (Rakai Health Sciences Project) to improve retention in care, 100% access to client-friendly services, particularly for pediatrics, and sex workers and their families. 2. Key populations programming COP20 must fund a complete redesign Target: Across the country, Drop in Centers (DIC) must be subjected to "community of Key Population programs in Uganda audit" and should be replaced with community designed interventions that respond being implemented through COP and to the priorities of key populations, including minimum components such as a: District Key Population Investment Fund (KPIF) level key populations coordinator whose cell phone number is known to communities support. The programs are out of step and can be available on a routine basis to address client needs; a center staffed by at with the needs of HIV positive and HIV least 3 paid, trained counselors, a professional clinician, and providing a minimum negative Key Populations in Uganda. package of quality services including on site access to PrEP, STI screening and free treatment, counseling and support, viral load testing, and condoms and lubricant. Target: COP20 should fund continuous professional and community health workers to improve client satisfaction. The impact of training must be measured through anonymous surveys to determine whether or not health worker attitudes and high rates of stigma are actually improving. Target: COP20 should fund a pilot with Uganda Bureau of Prisons and other partners to implement an HIV prevention and treatment literacy program, modeled on the MAT/harm reduction program being implemented in partnership with Butabika. Target: PEPFAR should publicly and actively support decriminalization of HIV and of KPs in order to increase uptake of life saving services, decrease new infections, and ensure evidence based response in Uganda. PEPFAR should fund establishment of rapid response mechanisms for violence elimination (either community or IPV) through phonetrees or whatsapp links, with a protocol for how to support KPs who are in trouble. Target: Human rights interventions should involve some basic legal literacy, particularly referral mechanisms for legal assistance. Community health workers/peer navigators should be empowered to provide these services. Human rights interventions should also involve improving safety and security systems and processes, as well as sensitization work in local communities where services are located/provided. 3. Social enablers must be implemented 3a. Immediately halt implementation Target: PEPFAR and the government of Uganda must not fund implementing of policies that violate human rights partners to restart index testing anywhere without a restructuring of the program to resolve fundamental barriers to guality - client centered testing 3b. Resolve socioeconomic and - and to protect human rights. Our concerns must be resolved. legal structural barriers affecting women living with HIV Target: COP20 must invest in programs to reduce policy and legal barriers that worsen women's inequality and perpetuate violence that further impacts the HIV response. COP20 3c. Expand comprehensive services must improve access to quality and comprehensive SRHR services and information for for women living with HIV women and girls living with HIV. All women and girls (irrespective of gender identity or sociocultural or economic status) should access, utilize and enjoy quality SRHR. Target: COP20 should support interventions to address the needs of women living with HIV and disabilities with a priority focus in Year 1 on infrastructure and sign language interpreters.

4. High impact prevention must be expanded through COP19 and COP20, focusing on adolescent girls and young women (AGYW), key populations, pediatrics and men

4a. PEPFAR and the government of Uganda must prioritize programs that address socio-economic, legal	Target: COP20 should invest in programs aimed at improving the quality of services delivered by and for young people, by rapid expansion of the YAPs model nationally. COP20 must ensure increased access to FP services and comprehensive sexuality education for young people.
and structural barriers to increase service uptake by Adolescent Girls and Young Women PEPFAR COP20 should prioritize interventions for reducing stigma	Target: PrEP must be rolled out nationally, with public promotion of this high impact prevention tool. COP19 and COP20 should fund a pivot away from geographic and population restriction, instead offer PrEP to all people at substantial risk of HIV infection, everywhere, including adolescent girls and young women (AGYW) and pregnant and breastfeeding women.
and discrimination in schools targeting both boys and girls. 4b. PrEP scale up must be	Target: Health workers must be trained to offer stigma free screening for PrEP eligibility, and supply forecasting must be adjusted in order to ensure adequate PrEP supply and appropriate national coverage.
supported through COP20 4c. Expand quality harm reduction services 4d. Improve services for men	Target: COP20 must support expanded community based harm reduction services including psychosocial interventions for MAT clients, scale up of the hub and spoke model for PWID in prisons and other closed settings, stronger community models for referral and linkage to MAT and other HIV services; and education and training of health care providers, caretakers, families and PWID communities about harm reduction.
5. Expand pediatric HIV diagnosis a	nd quality treatment access
	Target: COP20 must expand Point of Care EID to cover all HIV exposed infants in order to improve rapid case detection and linkage to treatment.
	Target: IPs must budget for service delivery models that increase pediatric treatment retention through treatment education and support for caregivers, HIV positive women, children and adolescents.
	Target: Increasing new pediatric infections in Uganda must be tackled through better quality treatment and prevention programs that suppress the viral load of HIV positive pregnant and breastfeeding women and provide PrEP and retesting services for HIV negative pregnant and breastfeeding women.
6. Stop stockouts	
	Target: The government and PEPFAR must work towards eliminating treatment interruption resulting from stockouts of ART for adults and children. Communities must be supported to monitor stockouts at every step of the supply chain.
	Target: Pharmacovigilance systems must be put in place to track adverse events, including at Community Drug Distribution Points. Pharmacovigilance committees at district level should be put in place to monitor side effects of drug interactions and long term use of ARVs.
7. Address persistent human resou	
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8. TB/HIV service delivery	
7a. TB preventative therapy 7b. TB LAM testing	Target: COP20 must invest in expanded TB service delivery including ensuring TB symptom screening, and urine-LAM and Xpert MTB/RIF Ultra testing are being
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	Target: COP20 must support universal access to TPT for all eligible PLHIV (those currently on treatment who have not previously received TPT in addition to those newly initiating treatment) and household contacts of PLHIV with TB disease, including children. The preferred TPT regimen for adults should be 3HP.

9. Community Led Monitoring for Advocacy			
COP20 should fund independent, community and PLHIV-led monitoring of the state of service provision at PEPFAR supported sites and escalate issues using advocacy interventions. Key areas to be monitored include poor performance, poor quality of services, poor health worker attitudes, health and rights violations, and stockouts and/or shortages of diagnostics and treatment.	Target: COP20 supports implementation of a routine, robust, independent community led monitoring system led by monitors who are themselves service users.		
The results of monitoring must be linked to a model of advocacy to ensure an accelerated response from all actors to address the issues identified in order to ensure they are rapidly rectified. The funding mechanism must foster independence and transparency.			













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