

# ENDING AIDS IN UGANDA: WHAT WILL IT TAKE?

## Priority Actions for Government, Donors and Technical Partners

### Civil Society Shadow Report to Uganda's 6<sup>th</sup> Joint Annual Review of the AIDS Response • 19-20 September 2013



**CEHURD**  
social justice in health

**UNYPA**  
UGANDA NETWORK OF YOUNG PEOPLE LIVING WITH HIV/AIDS



**HEALTH  
GAP**  
GLOBAL ACCESS PROJECT  
[www.healthgap.org](http://www.healthgap.org)



Action Group for Health, Human Rights and HIV/AIDS (AGHA) Uganda • African Sex Worker Alliance • Center for Health, Human Rights and Development (CEHURD) • Coalition for Health Promotion and Social Development (HEPS) Uganda • Freedom and Roam Uganda • Global Coalition of Women Living with HIV/AIDS Uganda • Health Global Access Project (Health GAP) • Health Rights Action Group (HAG) Uganda • Human Rights Awareness and Promotion Forum (HRAPF) • International Community of Women Living with HIV/AIDS (ICW) East Africa • Kanaa Foundation for Outreach Programs • National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) Rainbow Health Foundation Mbarara • Sexual Minorities Uganda (SMUG) • Spectrum Uganda • The AIDS Support Organisation (TASO) Uganda • Uganda Harm Reduction Network • Uganda Health and Science Press Association (UHSPA) • Uganda Network of Young People Living with HIV/AIDS (UNYPA) WONETHA Uganda

## INTRODUCTION

**Taking stock of an off-track AIDS response:** During 2011-2012, Uganda attracted concern—and criticism—as a result of its troubling epidemiological trends, indicating an off-track response to HIV.<sup>1</sup> The Uganda AIDS Indicator Survey showed that prevalence had risen from 6.4 to 7.3% between 2006 and 2012 and incidence also rose during the same period. Condom use by men and women declined starkly over the same period—reported condom use during sex with a non-cohabitating partner declined significantly between 2005 and 2011 from 47% to 29% and from 53% to 38% among women and men, respectively.<sup>2</sup> Importantly, Uganda was the only PEPFAR “Focus Country” reporting rising HIV incidence—all other PEPFAR focus countries have consistently reported declines in incidence as well as prevalence in recent years.<sup>3</sup>

At the same time, recent game-changing scientific advances in HIV prevention and clinical care are making it possible for all high-burden countries to begin to achieve an “AIDS Free Generation,” defined as a halt to sexual transmission, an end to disease progression for those who are HIV positive, and an end to perinatal transmission. In particular, recent data show that HIV treatment is not only life saving but is also one of the most powerful prevention tools available—groundbreaking new research shows that earlier treatment of HIV positive people—at CD4>350—results in 96% reduction in the risk of HIV transmission through sex with an uninfected partner,<sup>4</sup> is highly cost effective,<sup>5</sup> and provides significant clinical benefit.<sup>6</sup> Uganda’s faltering response means an attaining an AIDS Free Generation will take stronger, more urgent action—with bolder leadership.

For example, new models of Uganda’s epidemic published on World AIDS Day in 2012 revealed the acute need for Uganda to deploy earlier and faster initiation of HIV treatment, medical male circumcision, elimination of mother to child transmission (EMTC) including access to treatment for pregnant women regardless of CD4 count (known as “Option B+”), and scaled up access to HIV testing and condom access for key populations where most new infections are occurring, and/or key populations that are most at risk because of their criminalized and excluded status—including fishing communities, serodiscordant couples, sex workers, adolescent girls, truck drivers, men who have sex with men, and drug users.

According to that analysis, published in the “Blueprint for an AIDS-Free Generation”,<sup>7</sup> the impact of combination prevention interventions on Uganda’s epidemic would be dramatic—between 2012 and 2016, new HIV infections could be reduced between 43-60%. An estimated 101,700 AIDS-related deaths would be averted during the same period. Importantly, these data also show how a “surge” in effective combination prevention spending in Uganda over the coming two years would rapidly generate a major reduction in costs. According to this estimate, “the impact of these upfront investments [in combination prevention] lead to a decline and then flattening of out-year costs, as fewer new services are required and the number of newly infected individuals falls substantially.”<sup>8</sup> The negative impact of inaction would also be dramatic: an alarming continued rise in new infections, while deaths increase along with ever increasing costs.

## REASONS FOR HOPE?

**During the last year, Uganda has defied expectations and lodged important progress in scaling up an evidence-based response to HIV.** Uganda has substantially increased the pace of treatment enrollment estimated between June 2012 and June 2013. Enrollment has expanded from 372,785 patients on treatment in June 2012 to 566,460 on treatment by June 2013—an additional 193,675 people were added over just a one-

---

<sup>1</sup> See for example, PEPFAR, The Blueprint for an AIDS-Free Generation, December 1 2012: “Although Uganda was one of the first countries to launch a high-profile national response to the AIDS crisis, in recent years policy and programmatic issues have hampered attempts to accelerate VMMC, PMTCT and ART programs,” p 10 and “The Change we Need to End AIDS in Uganda,” October 16 2012. Available at:

<sup>2</sup> Uganda AIDS Indicator Survey 2011. Ministry of Health. Kampala. August 2012.

<sup>3</sup> PEPFAR Focus Countries have received the highest levels of US government prevention, care and treatment funding since PEPFAR was started in 2003. They are: Botswana, Côte d’Ivoire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, Vietnam, and Zambia.

<sup>4</sup> M. Cohen et al (2011). Prevention of HIV-1 Infection with Early Antiretroviral Therapy. The New England Journal of Medicine 365:493-505

<sup>5</sup> K. Freedberg et al. The cost-effectiveness of treatment as prevention: analysis of the HPTN 052 trial. FRLBC01—Oral Abstract.

<http://pag.aids2012.org/abstracts.aspx?aid=21242>

<sup>6</sup> B. Grinsztejn et al. Effect of early versus delayed initiation of antiretroviral therapy (ART) on clinical outcomes in the HPTN 052 randomized clinical trial. THLB05—Oral Abstract. <http://pag.aids2012.org/Abstracts.aspx?SID=16&AID=21278>

<sup>7</sup> See “PEPFAR Blueprint: Creating an AIDS-Free Generation,” December 1, 2012. Available at:

<http://www.pepfar.gov/documents/organization/201386.pdf>

<sup>8</sup> Supra note 7, p. 13

year period. By contrast, the increase in patients on treatment between 2010-2011 was approximately 68,195 new patients and the increase between 2011-2012 was approximately 43,725 new patients.<sup>9</sup> The 2012 surge in newly enrolled patients on antiretroviral treatment include many pregnant women enrolled through national scale up of EMTCT programs using Option B+. This change has been due to the hard work of all partners, including effective advocacy by civil society. However, major challenges remain, including:

- Resistance to adopting the World Health Organisation's new HIV treatment guidelines recommending a change in clinical eligibility for HIV treatment from CD4<350 to CD4<500 for both the clinical benefit of people living with HIV as well as a prevention benefit to their communities;
- Major weaknesses in HIV treatment program quality, resulting in avoidable loss to follow up among patients. This is particularly critical among EMTCT programs implementing Option B+, where research in countries in the region has already shown that the risk of loss to follow up among women who are breastfeeding is high;
- Persistent shortages, interruptions and stock outs of critical and life-saving commodities—from antiretroviral medicines to HIV test kits and condoms to blood and blood testing reagents;<sup>10</sup>
- Parliamentary consideration of Bills including the HIV/AIDS Prevention and Control Bill, the Anti Homosexuality Bill, and the Narcotic Drugs and Psychotropic Substances (Control) Bill that would undermine an effective response to HIV by intensifying stigma, criminalization and discrimination;
- Lack of meaningful consultation with civil society and other key partners in establishing the terms and parameters for a new "AIDS Levy" in Uganda;
- Unwarranted government criticism of an important, highly targeted biomedical prevention strategy known as "Pre-Exposure Prophylaxis" (PrEP) that could have an important role in halting sexual transmission among groups at highest risk of HIV infection;
- Lack of a nationally driven, nationally owned, costed strategic plan to achieve Uganda's ambitious medical male circumcision targets;
  - Insufficient progress in reaching most at risk populations with testing, high impact prevention and treatment programs—despite identification of these populations as a priority in the National Strategic Plan; and
- The need for stronger engagement between legislators, civil society and other and key stakeholders in supporting a human rights-based approach to ending the AIDS crisis in Uganda.

## PRIORITIES FOR CHANGE

For 2013-2014, the period of the 6<sup>th</sup> Joint Annual Review of the AIDS Response, the evidence is clear—Uganda must further accelerate its scale up of high impact HIV prevention and treatment in order to rapidly bring about a "tipping point": the point at which more people are being initiated on HIV treatment than are becoming HIV positive. Attaining this target is an important indication that a country is poised to get ahead of its epidemic by significantly halting new infections, saving more lives, and eliminating pediatric HIV. All partners should tackle each of these challenges systematically, in order for Uganda to re-claim its position as a leader in the fight against HIV, and finally begin to end AIDS.

**Civil society has the following priority recommendations for key actions to ensure Uganda attains the achievable goal of ending the AIDS epidemic:**

**1. Uganda must implement the new WHO treatment guidelines—make earlier treatment a reality for people with CD4<500, all serodiscordant couples and all children under 5—alongside pregnant women and people co infected with tuberculosis. Routine viral load monitoring must also become a reality.** In June 2013, WHO released new HIV treatment guidelines, recommending all resource poor countries adopt changes to clinical eligibility guidelines for treatment for adults and children, and that they implement routine viral load monitoring in order to ensure ongoing suppression of viral replication. The new WHO treatment guidelines recommend all people CD4<500 should be offered treatment. Also, several populations should be offered treatment regardless of CD4 count: people co-infected with tuberculosis, serodiscordant couples, pregnant women, and children under 5 years old.

While Uganda has already adopted treatment for pregnant women regardless of CD4 count and treatment for all people co-infected with tuberculosis, the change in CD4 threshold for treatment eligibility, treatment for all

<sup>9</sup> Annual Performance Report of the National HIV and AIDS Strategic Plan 2011/12-2014/15. October 2012. Uganda AIDS Commission, p 23.

<sup>10</sup> "AIDS Drug Shortage Hits Government Hospitals," *The New Vision*, August 1 2013.

people in serodiscordant partnerships, and treatment for all children <5 years old has not yet been adopted. In particular, civil society is troubled by reports that the Ministry of Health is not supportive of a change in Uganda's eligibility threshold to CD4<500. The Ministry should urgently consult with civil society and all partners and establish a timeline and workplan to adopt this critical new global standard of care. Likewise, routine viral load monitoring is a crucial component of program success, particularly in order to ensure Option B+ and earlier treatment are actually suppressing viral replication and delivering maximum clinical and preventive benefit. Uganda should also update its national targets and national gap estimates based on this change in best practice.

Uganda should not use the issue of a funding gap as an excuse not to take action—the country can afford this change in eligibility. For example, the substantial national expansion in HIV treatment enrollment during 2012–2013 happened with almost no increase in HIV funding. Moreover, apart from being scientifically justified, earlier access to treatment has been proven to be highly cost effective in setting such as Uganda's—considering the cost savings from infections averted and increased productivity associated with clinical benefit of treatment.<sup>11</sup>

Successful implementation of the WHO guidelines will require stronger, higher quality treatment and care programs. In particular, Uganda will require expanded community driven, non-facility based interventions that will ensure people are retained in care, as more people are initiated on treatment—including asymptomatic people with HIV—for longer periods. New data from Uganda show that high rates of retention among healthier, asymptomatic patients are possible<sup>12</sup>—but barriers to patient follow up must be removed.

**2. Urgently improve the program quality of EMTCT—so that Option B+ delivers maximum benefit for women and their babies.** Uganda's commitment to rolling out Option B+ as a cornerstone of EMTCT in Uganda should be applauded. But there are troubling reports that program quality is suffering because HIV positive women and their communities are not being directly engaged in program design and demand creation, and there is no minimum expectation among implementing partners for non-facility based patient follow up for pregnant and breastfeeding women has not been established.

Without improvements to program quality immediately, Option B+ will fail to deliver the benefit women, their families and communities require. Women will be started on treatment but will be lost to follow up and face the likelihood of developing drug resistance and disease progression, as well as transmission of HIV during the period of breastfeeding.

Importantly, without rapid improvement to the quality of Option B+ within EMTCT, earlier initiation of treatment for non-pregnant women and adult men will also suffer. The very same non-facility based support and prevention of loss to follow up is needed for all people with HIV, not only pregnant women.

**3. While the pace of treatment scale up has accelerated, so-called “rationalization” has substantially undermined the quality of treatment programs—for adults, pediatric patients, and in the context of EMTCT. In addition, lack of meaningful involvement of people with HIV in design and implementation of all stages of the HIV response has led to serious missteps,** such as the procurement by the Government of Uganda of an extremely bitter, non film-coated version of tenofovir+lamivudine in order to achieve a relatively minor upfront reduction in marginal costs.

“Supply Chain Rationalization” and “Health Systems Strengthening,” two policies pursued by the Ministry of Health with partnership from PEPFAR, have the stated good intentions of maximizing efficiencies and streamlining partner activities in the AIDS response. Unfortunately, they have had the unintended consequences of undermining treatment program quality. In the case of the health systems strengthening rationalization program, mobile outreaches to patients have been shut down; in the case of supply chain rationalization, forbidding facilities from providing buffer stocks of medicines in order to respond rapidly to stock

---

<sup>11</sup> Supra note 5.

<sup>12</sup> Namusobya, J et al. “High retention in care among HIV infected patients entering care with CD4 >350 under routine program conditions in Uganda.” *Clinical Infectious Diseases*, 29 July 2013.

outs at the local level is exacerbating periodic stock outs and shortages of medicines—exacerbating the problem that the policy was intended to correct.

Research by people living with HIV and their partners have uncovered serious drawbacks in planning and implementation of these policies. They must be reexamined and restructured urgently, in order to achieve maximum efficiencies without undermining treatment program quality. Unless patients are consulted, Uganda runs the risk of designing treatment programs that are not acceptable to patients.

#### **4. Uganda needs additional sources of national funding to help support an expanded AIDS response.**

All partners must increase their investments as new tools in the fight against HIV, and an increasing pool of people newly eligible for treatment means the current funding gap will also expand.

An “AIDS Levy” to fund antiretroviral treatment and other life saving commodities is a major priority that has been discussed in Uganda for several years, and has been implementing in other countries. For example in Zimbabwe, a National AIDS Trust Fund (NATF) has been created from a tax on payroll among people employed in the formal economy and has raised substantial amounts of funding.

Despite the fact that the 2012-2013 Aide Memoire passed at the Joint Annual Review of the AIDS Response highlighted the need for action in pursuing an AIDS Levy, progress in developing and passing such a tax through Parliament has been extremely slow. Importantly, people living with HIV and civil society have not been consulted, and existing policy documents describing the proposed AIDS Levy have not been made available. Passage of an AIDS Levy in Parliament in 2014 is possible—but consultation with people with HIV and civil society must be prioritized, particularly regarding priority policy questions, such as what the tax is used to pay for, accountability and transparency in using the revenue raised, and how the funds will be ringfenced in policy and in practice so that they are protected from corruption.

**5. Uganda’s policy and legal environment must be improved to support positive living with dignity and an evidence based, public health approach to fighting HIV—stigma and shame drive people at greatest risk of HIV infection underground, outside the reach of life saving services.** Harmful bills such as the HIV/AIDS Prevention and Control Bill and the Anti Homosexuality Bill must be scrapped, and instead the regional HIV/AIDS act for East Africa—already assented to by the President—should be used as our national standard.

**In addition, more rapid progress by all partners is needed in rolling out evidence-based programs for most at risk populations—**in particular fishing communities, men who have sex with men, sex workers, and other vulnerable populations where evidence shows treatment and prevention service coverage is low, and risk of transmission is high. Uganda should expedite the formulation of a national framework on HIV prevention and treatment service standards for most at risk populations. Access to lubricants should be ensured as part of the national condom policy and as part of condom distribution efforts—for all people, including key populations. Evidence clearly shows that access to condom-safe lubricant is a critical prevention tool, as lubricant reduces the risk of condom failure and breakage.

**6. Donors, in particular PEPFAR, must meaningfully engage a diverse group of civil society in 2013-2014 in design of the Country Operational Plan 2014 (COP2014).** The increased investment from the Global Fund that will come in 2013 and the replenishment period of 2014-2016 as a result of the Global Fund’s New Funding Model must prioritize the unmet demand for services from HIV positive people and those at greatest risk of infection.

**7. SMC is a critical element of effective combination HIV prevention in Uganda. While there has been important scale up in safe medical male circumcision (SMC) during 2012-2013, further acceleration is urgently needed, in particular increased government support and funding for SMC.** Currently, the US government is funding and driving virtually all of SMC program scale up, with no indication that the Government of Uganda will sustain these efforts. In a recent WHO and PEPFAR-convened review of country progress in SMC roll-out, Uganda was one of two out of the 14 priority countries without a designated SMC



focal person.<sup>13</sup> The country's national SMC plan lacks a budget, annual targets or concrete plans for scale-up.<sup>14</sup> The national SMC task force, which is to have quarterly meetings, met only once in 2012.<sup>15</sup> Persistent contradiction among officials about SMC's role in the response to HIV in Uganda contributes to confusion and delayed action.<sup>16</sup>

**8. Uganda must explore evidence emerging from important PrEP demonstration projects to influence how PrEP is used in the country—rather than reflexively dismissing PrEP.** Particularly given the important potential role for PrEP among serodiscordant couples, statements by the Ministry of Health that PrEP will not be used in Uganda for unspecified “moral” reasons and before the results of PrEP demonstration projects are known—are troubling and premature.

**8. Driving down the price of medicines is an urgent priority in order to reach more people in need, particularly as the number of treatment eligible patients expands—Uganda must use the flexibilities available through the Agreement on Trade Related Aspects of Intellectual Property (TRIPS)** and domesticated in the Industrial Property Law to reduce drug prices, while promoting local innovation and drug manufacturing which will help sustain access to more affordable HIV treatment. In addition, while working to combat counterfeit drugs in Uganda's markets, there is a critical need to pursue approaches that will reduce the spread of illicit, unregistered and unsafe products without hindering access to quality, safe and efficacious medicines – particularly legitimate and affordable quality generic medicines. Uganda must restrict the scope of criminalized activities in the Anti-Counterfeit Goods legislation (2010) to what is prescribed by the TRIPS Agreement which we are party to.

**Civil society demands:**

- National and donor government commitment to dramatically accelerate the pace of treatment scale up, and to change national eligibility guidelines so that all people CD4<500 are offered HIV treatment for clinical and prevention benefit;
- National implementation of routing viral load monitoring;
- Intensified testing campaigns reaching key communities;
- Reverse the troubling trend in reduced condom use, reported by the 2012 Uganda AIDS Indicator Survey, and ensure condoms are available to all, in particular communities most at risk of new infections;
- Government must ensure communities, particularly people living with HIV, are at the heart of an accelerated response—leading counseling, testing, outreach and adherence support efforts, including for Option B+ implementation;
- An end to harmful policies that undermine the right to health and promote exclusion, such as those in the proposed HIV/AIDS Prevention and Control Bill and the proposed Anti Homosexuality Bill;
- Immediate doubling of the national investment in the AIDS response for FY2013/14, with progressive additional increases every year, alongside significant expansion of funding in other priority areas of the health sector such as health worker recruitment and commodities procurement;
- Urgent passage of an AIDS Levy—with revenues *ringfenced* for essential service delivery, in particular for antiretroviral treatment;
- Bold national leadership in urgently scaling up implementation of SMC including a budgetary allocation from the Government of Uganda, streamlined coordination and reporting, and incorporation of non-surgical devices into the SMC program;
- The Ministry of Health must explore evidence emerging from important PrEP demonstration projects in Kasangati and Kabwohe and consult a broad range of stakeholders to generate national consensus on how PrEP is used in the country;
- Use the flexibilities available to Uganda through TRIPS, to drive down the cost and increase the availability of medicines and restrict the scope of criminalized activities in the Anti-Counterfeit Goods legislation of 2010 to what is prescribed by the TRIPS Agreement; and
- Government must stop procurement of the extremely **bitter** version of tenofovir+lamivudine to facilitate adherence and prevent long-term costs that come with lack of patient acceptability.

---

<sup>13</sup> Presentation by Dr. Buhle Ncube, October 15 2012, Joint WHO-PEPFAR Meeting on Accelerating the Scale-up of Voluntary Medical Male Circumcision (VMMC) for HIV Prevention in East and Southern Africa.

<sup>14</sup> Safe Male Circumcision Policy (2010) Government of Uganda Ministry of Health. Accessed October 15 2012 at [http://malecircumcision.org/programs/documents/Uganda\\_MC\\_policy\\_JAN10.pdf](http://malecircumcision.org/programs/documents/Uganda_MC_policy_JAN10.pdf)

<sup>15</sup> Personal Communication, members of the Civil Society HIV Prevention Research Working Group.

<sup>16</sup> Supra note 15.