

January 13, 2020

Dear Ambassador Birx:

Under your leadership, PEPFAR has shown a commitment to following medical science and developing, implementing, and evaluating programs utilizing the best evidence available to have the greatest impact for people living with HIV and those most at risk of infection. We are grateful for this commitment and for your strong partnership with civil society as part of PEPFAR planning and implementation.

In this spirit, we write to you in advance of the FY2020 COP Guidance, which we anticipate this week, to reiterate concerns about the approach to index testing laid out in the draft version shared in late 2019, and about ongoing adverse events and human rights violations resulting from implementation of the COP 2019 guidance. We hope and trust you will act while there is still time to shift the COP2020 guidance language and to immediately mitigate risks to people living with HIV and to the broader AIDS response where PEPFAR plays such an essential role.

We and other civil society partners have shared these concerns over the past two years, and in meetings with OGAC, CDC, USAID, DoD, and country teams last month. To date, no action from your office has been communicated to civil society. Given the urgency of the situation, we are writing in advance of the revised guidance to re-state the critical demands:

- **The requirement to achieve 30-50 percent proportion of HTS\_TST\_POS through the index testing modality is suspended in order to immediately institute procedures to prevent human rights violations and the requirement to achieve a specified proportion of HTS\_TST\_POS is removed from the FY20 COP guidance;**
- **All implementing partners must begin to individually certify that each facility providing index testing is able to implement such programming in compliance with the [WHO's Self-Testing and Partner Notification Guidelines](#) - including for members of key populations receiving services in facilities serving the general population. Until this certification process is implemented, sites should either perform a self-assessment and fill the gaps identified, or suspend index testing immediately. For any contacts of members of key populations, population by population risk-benefit analyses must be done to determine whether the benefits outweigh the risks of contact tracing for key populations.**
- **All certified programs continuing to implement index testing should have minimum client refusal rates of at least 15% for index testing services - a proxy for voluntarism. Any site achieving index testing acceptance rates above 80% should be**

**flagged for immediate review of the consent procedures being implemented at the facility level.**

- **Implementation of index testing will, going forward, take place in the context of a civil-society monitoring committee per district/county that can receive concerns, conduct monitoring, and activate appropriate responses.**
- **Guidance on the minimum standards and the process to certify a facility as capable of safely implementing index testing services will be developed in collaboration with civil society organizations, women living with HIV, and representatives of key populations in the coming months and require in-country engagement by the country teams.**

We make these urgent demands on the basis of numerous reports received from various countries. We have removed the country information in the summary below, but believe these instances are indicative of violations happening on a broader scale.

- Several reports of pregnant women being denied services or having fees assessed until they bring their spouses/partners in for HIV testing;
- Reports of violence against sex workers who have named their clients;
- Reports of violence and blackmail of men who have sex with men who disclosed their sexual contacts;
- Reports of sex worker program sub-recipients being ordered by their prime partner to obtain a minimum of 3 contacts for each individual testing positive or face having their funding withdrawn;
- Reports of sex worker programs being ordered to halt hotspot HIV testing as the high positivity rate in such testing was undermining achievement of proportionate based index testing targets;
- Reports of facility/clinic vehicles going to MSM contact's houses without consent of the contact and reporting the exposure - some of these men have wives who are unaware;
- Reports of sex workers being denied PMTCT services due to refusing to identify client contacts. In one particular instance, “They denied me PMTCT services as a result of not giving the contacts of my sexual partners. I at last gave birth to a baby boy who died after a few months for having been infected.”

These and other accounts represent experiences across at least four countries and a combined total of 40-50 facilities. These are not cherry-picked, isolated incidents identified after large-scale investigations. Deeper and more thorough investigations would establish many more rights violations stemming from this program. Preliminary data from an additional 35 site visits conducted by civil society revealed that only 25 sites included IPV screening as part of their

index testing process. Of those, 18 reported that they contact the partners regardless of the outcome of the IPV screen.

We are deeply concerned that there is no surveillance system in place to identify these harms. They happen outside the facility in most cases. The COP 2019 guidance on the minimum program requirement of “ensuring consent procedures and confidentiality are protected and monitoring of intimate partner violence (IPV) is established” has not been implemented systematically, and neither the Guidance nor the implementation tools relating to PEPFAR’s index testing program adhere to WHO’s implementation or ethical guidelines.<sup>1,2</sup> As one example, no criteria exist for certifying that facilities or programs implementing index testing must have IPV and GBV services available to clients.

Under your leadership, PEPFAR has transformed the ways that country programs pursue and assess progress against the 90-90-90 goals. PEPFAR is uniquely able to test and iterate on approaches to testing, differentiated service delivery and primary prevention. The evidence to date strongly suggests that this index testing emphasis will—without substantial modification as described above—put the credibility of testing programs of all sorts at risk. These stories also get communicated amongst communities themselves and drive clients away from our programs. If PMTCT services are denied because of concerns about naming clients, resulting in the death of their infant, that patient is unlikely to remain in HIV care, and will tell others.

We stress again the urgency of this situation and the need for clarification from your office that includes suspending all index testing targets as a proportion of new diagnoses. Again, we identify the targets and the threat of having funding withdrawn as the driving force motivating these rights violations. We recognize that the responsibility to implement active accountability and monitoring is incumbent on the agencies as well, and we will continue to engage the agencies and implementing partners directly.

We look forward to your response to this request.

Sincerely,

Access Care Treatment and Support Ghana  
American Jewish World Service  
Anna Foundation Uganda

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<sup>1</sup> WHO, *Self-Testing and Partner Notification Guidelines*

<sup>2</sup> WHO, *WHO Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies*, ISBN 978 92 4 159568 1

APHA  
AVAC  
BAR HOSTESS EMPOWERMENT AND SUPPORT PROGRAM  
CENTA  
CHANGE (Center for Health and Gender Equity)  
COALITION OF WOMEN LIVING WITH HIV AND AIDS  
Coast Advocacy Network  
Community Health Response Taskforce, Nairobi  
Community Recovery Empowerment and Advocacy Tanzania  
Consolation East Africa  
Council for Global Equality  
DACASA  
Dandelion Kenya  
Dandora community Aids support ASSOCIATION  
DARE ORGANIZATION  
Diakonia Institute, Nairobi  
Differentiated Service Delivery Umoja Tanzania (DSDUT)  
Dignity and Well being Women Living with HIV Tanzania (DWWT)  
Emthonjeni Counseling and Training  
Focus for the Future Generation  
Good Women Association (GWA)  
HASDI+  
Health GAP  
ICWEA  
ICW - Kenya Chapter  
ICWWA  
JAAIDS Nigeria  
JONEHA  
Koinonia Community, Nairobi  
Life Health and Development Organisation  
Mambokaaje CBO  
Mother Kevin PMTCT Support Group  
Mouvement pour les Libertés Individuelles  
MPact Global Action for Gay Men's Health and Rights  
National Council of People living with HIV and AIDS  
NSAMBYA HOMECARE  
NYP+, Tanzania  
Out & Equal Workplace Advocates  
Pghccc adults

PLAN Health Advocacy and Development Foundation, Nigeria  
Public Health International Consulting Center (PHICC)  
Sauti Skika  
SISTERLOVE, INC.  
Survivors Self Help Group  
TanPUD  
Tanzania Health Education and Services for Youth (TAHESY)  
Tanzania Network of Women Living with HIV and AIDS  
The Botswana Network on Ethics/Human Rights, Law and HIV/AIDS (BONELA)  
Union Congolaise des Organisations des PvVIH (UCOP+)  
Womenplus Against TB and HIV in Kenya  
World Provision Centre  
Wote Youth Development Projects  
Kirumba Movement for Harm Reduction  
Youth Health Connect 360