Approaching PEPFAR Vision 2025 Strategy through a Gender Equity Lens

September 2021

PEPFAR launched an online survey to provide any additional insights to contribute to its Strategy 2025. Thus it was crucial for all of us, feminist organizations and women living with HIV, to collectively respond to the lack of comprehensive, women-centered, rights based, gender-equitable HIV programs at the center of PEPFAR's new Strategy.

- ➔ *You can read the DRAFT OVERVIEW – PEPFAR Strategy: Vision 2025 https://tinyurl.com/PEPFARstrategy*
- ➔ *Our intervention we made in the 2nd PEPFAR Strategy Listening Session for CSOs and Communities: August 17, 2021 https://tinyurl.com/PEPFARinterventionWLHIV*
- ➔ Our statement that we sent to WHO HIV Dept, that we have also shared with PEPFAR: “5 Approaches to Improve the WHO Global Health Sector Strategies for HIV, Viral Hepatitis and STIs through a Gender Equity Lens”: https://tinyurl.com/WHOHIVstrategygenderrecs
- ➔ Here is the current PEPFAR COP/ROP 2021 Guidance document, in case you have not already seen it. It is much better in some ways than previous versions - eg the language has improved. But there is still much room for improvement. https://www.state.gov/wp-content/uploads/2020/12/PEPFAR-COP21-Guidance-Final.pdf

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1. **The PEPFAR Strategy: Vision 2025 is aligned to the Sustainable Development Goals and Global AIDS Strategy. Are the draft PEPFAR Strategy goals and objectives the priority areas for the program to address? Are any missing or in need of refinement?**

We are writing this from the perspective of women living with HIV in all our diversity from around the world and across our lifespans.We have also worked recently with other global, regional and national networks of women living with HIV to review other international strategies, such as WHO Global Health Sector Strategies for HIV, Viral Hepatitis and STIs and now PEPFAR’S Strategy. We write not ‘just’ to advance the strategy for women or ‘just’ to support women living with HIV. Instead, we seek a person-centered, rights-based gender equitable sustainable response for *all*. This is relevant across the whole strategy, and not ‘just’ in relation to specific sectors such as DREAMS or in relation to pregnancy and potential HIV transmission.

For example, we see the issues raised by other entities such as **MPACT** (https://mpactglobal.org/ensuring-gay-mens-needs-are-addressed-in-the-2020-pepfar-cops/) and applaud their work. We are also their sisters, aunties, mothers, cousins, colleagues and allies - and some of us are also their partners and wives.

We also experience some of the same challenges they raise. For example, in relation to **index testing**, we also highlight the huge challenges faced by women living with HIV, when index testing and/or 'buddy' systems, when our partners are told about our status - either to be tested themselves, during pregnancy, or in order to support our taking our ARVs - results in our rights to confidentiality being violated and our experiencing violence both at home and in the healthcare settings.
Women living with HIV are having to adopt strategies of subterfuge to try to hide their HIV status from partners and other family members, at a time, especially in pregnancy, when they are most in need of care, respect and support from all around them. This increases self-stigma, leaving aside their health care and medical follow-up in order not to lose confidentiality. We call on PEPFAR to address index testing policies and practices around women living with HIV which protect, respect and uphold their rights to confidentiality and informed choice as a matter of urgency.
Community-led monitoring is also a huge issue close to our hearts. We call on PEPFAR to ensure that funds for community-led monitoring designed and led by women living with HIV are in place also.
Investment funds. We also echo MPACT's concerns about ensuring that the majority of funds for specific populations are granted to community-led entities themselves, rather than others such as INGOs. We see this all too often in relation to issues affecting not only our work in advocacy but even our own lives.

By contrast, with PrEP, we have concerns that PEPFAR is *promoting PrEP* use (for example amongst girls and young women and sex workers) without critical supports. These include sufficient funds being also delivered to ensure that they have access to gender transformative social norms change programs, to support them to find and build mutually supportive respectful relationships with intimate partners, and to enable them also to negotiate condom use safely, instead of having to resort to strategies which involve them having to conceal taking PrEP, for example, for fear of violence or as the only resource of HIV prevention. In addition, tenofovir-based PrEP has potential long-term bone density reduction side-effects[1] which are of special concern to girls and women being expected to take PrEP long-term, given that women experience calcium depletion in pregnancy and older women are prone to osteoporosis. In addition, of course, PrEP does not protect against unplanned pregnancy or STIs, both of which can have long term chronic health outcomes. Instead, PrEP should be part of a wide comprehensive toolkit of goods and services available for women and girls as part of their informed choice. But expecting girls to develop strategies of secrecy and concealment, which is what at present PrEP provision for females may be viewed as, should never be seen as a standalone solution. As Joyce Ouma of Kenya said in relation to the dapivirine ring[2]: "Before the availability of the multi-purpose vaginal ring that is still in the research pipeline, there is need to adopt complementing strategies and funding for work led by women, girls and communities,

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[1] Young MSM may not completely recover from PrEP-related bone density loss, *Healio*, June 14, 2019 https://www.healio.com/news/pediatrics/20190614/young-msm-may-not-completely-recover-from-preprelated-bone-density-loss
[2] Ouma, J (2020) Let's talk about the dapivirine vaginal ring, *Making Waves*. https://makingwaves.network/2020/08/20/lets-talk-about-the-dapivirine-vaginal-ring/

since the dapivirine ring potentially exposes women who will use it to social harms such as Intimate Partner Violence (IPV) and potential side effects of the ring. There is a critical need to invest in the long term objective of building trust and mutually respectful relationships among women and their partners, including work to claim rights, develop relationship and communications skills, and supporting adolescent girls and young women in protection from STIs, violence and unintended pregnancies."

In relation to children and adolescents, we also advocate for a PEPFAR strategy which wholly supports these young people to start and stay HIV-free and, if they acquire HIV at birth or later, to be supported with testing and treatment in rights-based, gender equitable ways, including community-based and health and social care services tailored specifically to their priorities. We also recommend that PEPFAR wholly supports the UNESCO Technical Guidance on age-appropriate Comprehensive Sexuality Education, in line with children's and young people's rights to evidence-based education. Several countries curb access to this or leave out key elements, or promote abstinence before marriage, to the detriment of children and young people. We also call for children's and young people's meaningful involvement in all policies and programmes which affect their lives, including community-based programs to end VAC and promote gendered, child rights policies and practices.

Again, as women we have a critical role to play, as their sisters, mothers, aunties, cousins and older colleagues. In particular, we see it as essential that PEPFAR explicitly sees the link between our own SRHR as women living with HIV across the perinatal journey and our delivery of babies born HIV-free. As the WHO Comprehensive Guideline on SRHR of women living with HIV made clear, if we are happy, healthy, safe and supported throughout our pregnancies, then we are far more likely to feel respected and supported by all around us, and feel able to access good healthcare, adhere to treatment, maintain an undetectable viral load and deliver our babies HIV-free. Unfortunately, the long-term focus on 'PMTCT' has placed the HIV status of the baby as the top priority, rather than ensuring the SRHR of the woman (or eSRHR for short). It has also prioritised a healthcare focus on women as vectors and vessels of disease, rather than looking at our own SRHR priorities across our life-span. In some countries, forced or coerced sterilisation of women is still taking place (nb there is no mention throughout the whole current PEPFAR guidance to this). In this situation, women often feel powerless regarding bodily autonomy, desperate to keep their babies safe and well and free from HIV, and at the same time shamed and blamed by all around them.

We recommend that PEPFAR endorses and promotes the Respectful Maternity Care Charter. We see our SRHR both as fundamental and intrinsic in its own right, and *also* as strategically valuable, in terms of providing support to others around us, in our ascribed lifelong caring roles.

We are also far more likely to remain engaged in the healthcare system once our babies are born, if we are able to see our healthcare providers as our allies rather than our critics. This is why we call so firmly and repeatedly for an end to structural violence in healthcare settings, IPV

at home and VAWG in general, and why these issues feature so largely in the WHO Guideline as well as in other UN-commissioned reports that we have produced.[3]

In addition, as lifelong unpaid carers, if we are free of violence at home and in healthcare settings, we are also best placed to ensure that our own biological children, orphans and other vulnerable children placed in our care, and those in the communities where we live are best able to grow up free of the adverse childhood experiences which so often cause lifelong damage to children's lives[4]. There is a growing evidence base that shows that ACEs have a direct adverse effect on teenagers' mental and physical well-being and health seeking practices. Again, this is why we call for a holistic, gender-equitable rights-based strategy which explictly identifies the links between violence against children and violence against women, which works to end them both, and which actively promotes the SRHR of women in all our diversity *across our lifespans*.

In relation to heterosexual men also, we are glad to see PEPFAR promoting the need to have testing and treatment access services tailored to heterosexual men. Again we are their sisters, mothers, cousins, partners, aunties, daughters, nieces and colleagues. If they are tested and, where needed, on treatment or accessing condoms, we are also potentially healthier. At the same time, it is important to note that men too need and want community-based gender transformative social norms change programs which will enable them to overcome the fear, stigma, hurts and needs that often drive the multiple forms of violence that we face from them in our relationships, which damage our own lives and those of our families. Supporting men to be tested and treated, while important, is not enough unless there is complementary support beyond the biomedical and clinic door in the communities where the men live and work, and interact with us in different ways. Similarly, we too have been calling for many years for services tailored to our own priorities, based on holistic, trauma-informed women-centred care, respect and support, reflecting our multiple complex physical and psycho-social challenges across our lifespans from a rights-based and gender equitable perspective.[5]

Criminalisation of HIV and of Key Populations. We also see criminalisation of people for transmitting HIV and of people from key populations as major barriers to a successful HIV

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[3] Orza, L. Bass, E. Bell, E. Crone, T. Damji, N. Dilmitis, S. Tremlett, L. Aidarus,N. Stevenson, J. Bensaid, S. Kenkem, C. Ross, G. Kudravtseva, E. Welbourn, A. (2017) In Women's Eyes: Key Barriers to Women's Access to HIV Treatment and a Rights-Based Approach to their Sustained Well-Being, *Health and Human Rights Journal,*
https://www.hhrjournal.org/2017/12/in-womens-eyes-key-barriers-to-womens-access-to-hiv-treatment-and-a-rights-based-approach-to-their-sustained-well-being/

[4] Robert F. Anda, MD, MS, Vincent J. Felitti, MD, FACP, J. Douglas Bremner, MD, John D. Walker, MD, Charles Whitfield, MD, Bruce D. Perry, MD, PhD, Shanta R. Dube, MPH, and Wayne H. Giles, MD, MS. The enduring effects of abuse and related adverse experiences in childhood: A convergence of evidence from neurobiology and epidemiology
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3232061/

[5] Women and HIV Research Program at Women's College Hospital. (February 2020). Caring for Women Living with HIV: Women-Centred HIV Care: Ontario, Toronto: Women and HIV Research Program at Women's College Hospital. https://cep.health/media/uploaded/CEP_HIVTool_Clinician_Nov24.pdf

response. We recommend strongly that PEPFAR actively seeks to support all governments to ban policies and practices which promote criminalisation of HIV transmission, of sex work, of drug use and LBTI+ communities, including so-called 'conversion therapy'; and supports harm reduction strategies, safer working conditions for sex workers and tailored health and social care programs for all concerned.

Last but not least, in our own right, as women living with HIV in all our diversity, we call on PEPFAR to uphold our SRHR and across our lifespans, in line with in line with the call of ICW's Gender Equity Officer, a young women from Latin America born with HIV, in the 2nd listening webinar held in August 2021[6]

2. What does the PEPFAR program look like at sustained epidemic control of HIV? What are the main threats to maintaining epidemic control of HIV?

We see HIV as part of a complex range of issues that affect our lives (see for example the HOUSE model which many of us created from our global values and preferences survey in 2014, commissioned by WHO to inform its 2017 Guideline on our SRHR[7]. We can only see a sustained epidemic control of women's and girls' vulnerability to HIV and our ability to live positively with HIV if the other issues that we face are also addressed in women-centred, gender-equitable, rights-based ways. HIV does not exist in a vacuum. In particular the co-morbidities of violence against women and girls, at home and in the healthcare, and ther associated mental health issues we face, are major factors for us. Ultimately, not only social concerns affect us greatly, but also economic equity where not all women have the privilege of access to transportation to medical appointments, clean water, education, proper nutrition, access to a roof over their heads, a stable job, among many others. There are also, as unequal child custody rights for women with HIV, not only because of their status but also because of their economic condition - and this has been worsened by COVID. The HIV epidemic and COVID-19 pandemic has thrown women's and girls' lack of secure property rights into stark relief. When mothers and fathers die, orphaned girls may not have the right to inherit their parents' property and widowed or separated women are often denied access to their shared home and land.[8]

There is not enough research on children born with HIV or young women with HIV in many regions, especially in Latin America. Usually, the studies of women have been complemented by young women but these have never been the special focus of research nor are there state

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[6] ICW & Salamander Trust (2021) PEPFAR's strategy https://b9787f34-af4e-4de5-a742-c9add66b069a.filesusr.com/ugd/682db7_4bfdddff4fab48d29d206dd8d64cba94.pdf

[7] Salamander Trust (2014). Building a safe house on firm ground: key findings from a global values and preferences survey regarding the sexual and reproductive health and human rights of women living with HIV. WHO, Geneva https://salamandertrust.net/wp-content/uploads/2016/09/BuildingASafeHouseOnFirmGroundFINALreport190115.pdf

[8] UNAIDS, Securing Women's Property And Inheritance Rights https://data.unaids.org/gcwa/gcwa_bg_property_en.pdf

indicators to follow up on this population. ICW Latina's Youth Area is launching a report on their research project based on data collection on young women living with HIV in the Latin American region where one of the conclusions is that there is little or no data disaggregated by age and sex.

3. PEPFAR continues to achieve progress, but COVID-19 has short- and long-term effects. How should PEPFAR plan over the next five years to mitigate the effects of COVID-19 and accelerate toward reaching sustainable, equitable, and resilient epidemic control? How should PEPFAR continue to leverage its platform for broader health outcomes?

COVID-19 has had a major effect on the lives of many women living with HIV. There was a marked increase in IPV and VAWG in general around the globe and some countries reported an increase in incest. It was clear that many countries' COVID responses (based on WHO guidance) were not gender-equitable and also differentiated in terms of the economic consequences that fell more on women.[9]
(see:
https://www.theigc.org/blog/womens-employment-during-the-pandemic-in-ghana-a-tale-of-vulnerability-and-resilience/). However women living with HIV, like so many other women, despite chronic lack of funds, have stepped into the breach, to provide other women around them with continued access to food, contraceptives, ARVs and other essential services when government or NGO staff have been withdrawn. One study conducted by women living with HIV across East and Southern Africa highlighted all this and recommended 7 key areas for an effective response.
(https://i0.wp.com/salamandertrust.net/wp-content/uploads/2020/09/ITPCSalTMW_CFA_ALL_Oct20-1-scaled.jpg?ssl=1)
We also recommend improving and strengthening mental health services, in the context of infectious diseases in clinics, for young women with HIV, since due to the collapse of the health system to respond to pandemic, this area has been neglected.

Another major cause of chronic concern is climate change and we strongly recommend that PEPFAR addresses its enormous effects on women's safety, health and well-being. We already know that climate change increases VAWG with diminishing resources and with this will come further VAWG, including further unplanned pregnancies, STIs and HIV.

We also strongly expect that COVID is only the first of many future pandemics. A global response needs to learn from the COVID pandemic and ensure gender-equitable, rights-based person-centred policies, programs, funds *and people-led early warning monitoring systems* are in place.

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[9] Dzansi, J. Kim, M. Lagakos, D. Telli, H. (2021) Women's employment during the pandemic in Ghana: A tale of vulnerability and resilience
https://www.theigc.org/blog/womens-employment-during-the-pandemic-in-ghana-a-tale-of-vulnerability-and-resilience/

4. We have the technical tools to end AIDS as a pandemic, but inequities, stigma, discrimination, and ineffective policies make our collective job more difficult. What specific strategies should PEPFAR pursue to better confront this challenge?

Over the years, we have repeatedly called for holistic strategies, policies and programmes which ensure our meaningful involvement throughout, to harness our own insights and experiences. A recent article from Stanford describes the power of what it calls this 'proximate leadership' in effective responses.[10]
We also call for our meaningful involvement in all research which affects our lives and this is echoed in WHO's 2017 Guideline on our SRHR in section 6.[11] See also an article which highlights the benefits of community-based participatory research. It concludes: "These findings have implications for building successful CBPR partnerships to address challenging public health problems and the complex assessment of outcomes."[12]

Specifically we recommend that PEPFAR funds of use research implementation frameworkz, such as the UNAIDS-commissioned ALIV[H]E framework on VAWG and HIV, which enables clear recognition of priorities of women living with HIV ourselves, rather than depending on what issues others see as our 'needs' (see eg the experiences of MENA-Rosa[13]). See also, for example, Women for the Global Fund's Accountability Toolkit for community monitoring.[14]

5. Please provide any additional specific feedback on the Strategy?
In sum, we appreciate the opportunity to respond to this consultation through this survey. We would welcome the opportunity for a specific call or series of calls with PEPFAR to discuss its strategy in more detail and to focus in a more in-depth way on the issues addressed here. In addition, there are many technical issues around in-country grant management processes, which we have not even mentioned here.

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[10] Proximate leadership https://ssir.org/articles/entry/effective_change_requires_proximate_leaders).
[11] WHO (2017) Consolidated guideline on sexual and reproductive health and rights of women living with HIV http://apps.who.int/iris/bitstream/handle/10665/254885/9789241549998-eng.pdf;jsessionid=7F5C7856F5BE8231F5CE712606E7D4FD?sequence=1
[12] Jagosh (2015) A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-015-1949-1
[13] Salamander Trust, UNAIDS et ALIV(H)E in Action (2019) Key examples of the Action Linking Initiatives on Violence Against Women and HIV everywhere. https://salamandertrust.net/wp-content/uploads/2017/11/ALIVHE_in_Action_FINAL_Salamander_et_al_March2019.pdf
[14] Women4GlobalFund (2021) A Toolkit to Sustain Global & National Advocacy https://women4gf.org/wp-content/uploads/2021/03/March-2021-W4GF-Accountability-Toollkit-Updated.pdf