

FROM MEMBERS OF THE POWER GROUP



27 August 2024

Dear Ambassador Dr John Nkengasong and colleagues

Many thanks for inviting us to join your Town Hall Meeting on 6 August about COP 25.

We members of the POWER [Group](#) have now had time to reflect on the call and wish to share with you some of our thoughts about your proposed strategy.

We appreciate all the groups you identified as priority groups moving forward (men, youth, key populations and children). However, we wish to express our great dismay that women living with HIV were hardly mentioned on the call, except in brief passing in the context of 'PMTCT' programs, in response to a question about infants aged 0-8 months. We explain why we are so concerned about this below.

A. Why Prioritise Women?

Women living with HIV have both an *intrinsic* right to our sexual and reproductive health and rights (SRHR) (see bottom of page 12); and it also makes *instrumental* sense for policy makers, donors and programmers to ensure care, respect and support for women living with HIV. We all play key roles as primary caregivers in our families and communities around the world. Without our unpaid work in our families and communities, children, youth, men and indeed members of key populations (to whom many of us also belong) would fare much worse than they already do. We are disappointed that our message has not yet been heard, so we will try to explain this again here.

A1 Our intrinsic SRHR...

Women living with HIV make up over half the adult population of people living with HIV [globally](#); and women in all our diversity continue to face long-term violations of our sexual and reproductive health and rights (SRHR) in many different settings [globally](#). For example, this latest report from ICW and UNAIDS highlights this [clearly](#).

Although 'PMTCT' programs feature in every country's HIV response, the core values of their approach lie in their name: these programs still view, and focus primarily on, women as vectors and vessels of disease. The [language](#), attitudes and practices involved are regularly blaming and punitive and even still include [sterilisation](#) and criminalisation of women. As UNAIDS states in its latest Global AIDS Update report (page 28): "*Reaching women with prevention of vertical transmission services has not changed in the past 10 [years](#).*"

Meanwhile, there are still very few programs that recognise and support women living with HIV *across our lifespans* into old [age](#), and outside the context of pregnancy and childbirth. Moreover, *women with disabilities* remain unseen and uncatered for in HIV programs.

So while in terms of mere *quantity*, women *appear* to be well served by the HIV response, in reality, the services provided often [violate](#) our SRHR, during a very limited part of our lives, rather than supporting us to enjoy quality long, productive lives.

A2 Our instrumental roles

WHO states that: "*[h]ealth workers are the backbone of any functioning health system... implementing key interventions to protect the health and safety of health workers contributes to increasing the resilience of health services in the face of outbreaks and public health emergencies and contribute to strengthening the performance of health [systems](#).*" Just as airlines state that we must put on our own oxygen mask before helping others, so it is with healthcare staff.

However, there is always far more to healthcare than what happens in formal healthcare settings. As the World Bank states, our unpaid care work, ie healthcare at home and in communities, where we look after partners, children, teenagers, elderly relatives, our neighbours, friends and wider family members... is predominantly undertaken globally by [women](#) (see eg slide 14).

Yet although it is implicitly taken for granted that women will be there to provide this care and support for others around them (since this is a global social norm), the *importance of keeping women healthy and safe*, in order to enable us to *perform* these caring roles is never mentioned *explicitly* in HIV-related policies or programs.

B How this situation affects your proposed strategy

We see a critical lacuna at the centre of your strategy for 2025-2030: namely an apparent complete lack of consideration of this role of women in the societies whom you seek to support. Here are some examples below.

B1 Men and women

Your graph on slide 5 clearly demonstrated that the main group of adults not taking ARVs are men aged around 20-40.

We understand this and agree that it is a major concern. However, since the launch of your MenSTAR program in 2018, we have questioned the logic behind your response to this - and wish to do so again here.

As you rightly say on the MenSTAR [site](#):

“Engaging men with HIV services is critically important to bringing the HIV epidemic under control. Men have their own distinct health needs and vulnerabilities.

And caring for men can benefit everyone—including women and girls.”

However, what you *do not* say there - and did not say in your Town Hall presentation either - is how critical it is to address the *gender inequities* between women and men, in order to enable an effective holistic response.

From many of our own experiences around the world, we have seen that men are often in denial about possibly having HIV and fear going to be tested or to start on treatment, for fear of being alienated by their peers. We are sure you are aware that men’s reluctance to seek out healthcare is a global phenomenon (see eg [here](#)), not just related to HIV.

Yet as women living with HIV, despite facing much violence from partners, we see the solution *not just in healthcare settings but also in communities*.

No matter how good a tailored health service is, if people do not want to use it, they will do their best to avoid it.

Women living with HIV are *also affected personally* by men's reluctance to seek out their own care. We also care for our partners and want the best for them too, even if we are experiencing violence from them (see below). This is why we as women living with HIV have created ways of working with and supporting our partners and other men, to begin to go and get treated - and to start and *stay* on treatment for themselves.

As one example, in Malawi, back in 2012 or so, COWLHA established that its members (women living with HIV) across the country were experiencing poor mental health, and they could not access ARVs. This was because their male partners were refusing to let them access treatment services, through the men's fear of shame and humiliation among their peers. So COWLHA members adapted the gender-transformative *Stepping Stones* programme and rolled it out across 144 sites where their members lived, across 12 districts. They created a [film](#) that showed how the programme enabled men in the communities to talk *openly* about how they now realised that their behaviour towards their wives/ partners was abusive; that they now supported the women to access treatment - and that they have themselves decided to get tested and, if testing positive, have now themselves started on treatment...

So of course this has made a huge difference to the women, who no longer have to look after sick, abusive partners, and can themselves access ARVs, without fear of violence from their partners.... and this in turn of course also means that their children are happier and healthier because they no longer have adults arguing around them.

This example shows how *holistic, inclusive gender-transformative programmes in the community* can bring lasting improvements to the lives not only of the men concerned, but also their wives and partners and older and younger children too.

B2 Children, young people and women

There is ever-growing understanding of the critical dyadic link between a child and its mother. It is now becoming increasingly understood how this relationship between a child and its mother begins in the [womb](#), is critical in the first 1,000 days especially, and has a life-

long effect on a child's social and emotional development and ability to cope with life in general.

The quality of the child's attachment to their primary caregiver is fundamental to this. This role is almost always played by the child's mother. She is best placed in this role if she is supported to feel and be happy, healthy and safe *throughout conception, pregnancy, childbirth and beyond*.

As these children and young people grow to become adults in their own time, they will have seen and feel able to mirror the positive role models of their adults. This will in turn enable them to build resilience to widespread Adverse Childhood [Experiences](#) (ACEs), such as sickness, bereavement, grief, witnessing and experiencing domestic violence, and poverty, that they have faced.

This includes children being more likely to maintain adherence to any medication that they are needing to take themselves, as well as developing self-care strategies that support them to become happy, healthy and safe in their own lives, instead of facing "*long-term dysfunction in [adulthood](#)*".

B3 Key populations and women

We are also mindful that amongst key populations, women who use [drugs](#), women who are lesbian or bisexual, and trans women, as well as women sex workers are often those who are feeling under most stress, most marginalised - and criminalised - by and from society, and least well supported by their communities and by health or other services. In addition, women members of key populations are also significantly affected by deeply gendered social norms [inequities](#).

For example, [UNAIDS](#) (page 4) states: "*Among the 17 countries that report sex disaggregation, the global median prevalence of HIV is 8.5% among men who inject drugs and 15% among women who inject drugs.*"

Once again, women also have a long history of care and support for family members and/or friends who are in key populations. So whilst we are glad the PEPFAR is planning to prioritise key populations in their strategy, we also seek to ensure that PEPFAR recognises and responds to the significant gendered inequities *amongst* those of us who belong to key populations also.

B4 Young women

We are also surprised and alarmed to note that there is no mention of young women in your strategy, despite young women especially still being so vulnerable to HIV acquisition (4,000 a week) - in sub-Saharan African countries [especially](#).

Young women's own dynamism and agency in responding to the HIV pandemic is so critical to an effective response - and yet young women often remain so hemmed in and harmed by the complex intersectional restrictive boundaries placed around them.

C Women's leadership - the evidence base

We were also surprised and dismayed to see your focus on funding governments as the lead partners in your response. As members of key populations clearly pointed out on the call, many governments globally have criminalised key populations. They also have policies and programmes which either ignore or actually violate women's SRHR. We have often seen that programs led by governments are significantly diluted in quality and that services provided are not fit for purpose since they do not match women's needs, desires or [rights](#).

In addition, since women face so much intimate partner violence, which is both a driver and a consequence of a woman's HIV [diagnosis](#), we need to recognise the evidence that clearly shows that the *only* way to reduce violence against women in a country is the presence of a vibrant independent women's rights [movement](#). We cannot expect governments to address these issues successfully. Instead, we urge you to follow the evidence and fund our vibrant civil society movements, including women's rights movements, to effect the change we *all* wish to see.

D Pandemic preparedness and climate change

The COVID 19 global pandemic highlighted the already well-known health and gender inequities which women face. For many, their key role as caregivers increased significantly. For example, women living with HIV are especially vulnerable to acquiring COVID and yet in many countries they organised collective ARV distribution in their communities to alleviate the challenges of accessing them during the [pandemic](#). These challenges included forced disclosure of their HIV status to travel to clinics and the risk of sexual and other violence from guards.

The most recent MPOX global emergency is inevitably increasingly affecting women as primary caregivers and their children in the DRC and other African regions. As WHO states: "*Children, pregnant women and people with weak immune systems are at risk of developing complications and dying of [mpox](#).*"

We also see considerable challenges to our SRHR with increasing extreme weather events, related to climate [change](#). Once again, these have significant gendered implications which are detrimental to our SRHR. We echo Riha et al and call for you to “*engage with women as consumers, producers, and innovators rather than just as [beneficiaries](#).*”

Now as then, we call on PEPFAR to provide flexible funding mechanisms to support us directly, so that we can build on our collective COVID experiences to support our own SRHR and the health of our [communities](#).

In Conclusion...

We are deeply dismayed at your apparent lack of awareness of the work we all do, individually and collectively, to support ourselves, one another and our children, teenagers, partners and friends. For all the reasons explained above, if you ignore and exclude us from your strategy, your efforts will not succeed.

We call on you at PEPFAR to *engage with us, prioritise our SRHR, harness our skills, knowledge, insights, experience and our *leadership* qualities, to work together with you to overcome this pandemic.*

Recognise the work we do, fund our initiatives, support holistic, inclusive gender-transformative, *community*-led responses. Invest in us and you will not be disappointed.

Together we can create an ethical, effective and sustainable HIV response.

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