**Closing the gaps for a person-centred WHO Global Health Sector Strategies on HIV, Hepatitis and Sexuality Transmitted Infections**

## 1. Preamble

Thank you for inviting comments on your second draft.[1] We are sorry that these comments have arrived a week later than requested. However, we have no funding to work on draft strategies such as these, in a year which has been particularly crowded with strategic planning by several global entities. Time for our work on them has to be found in evenings or at weekends, on top of our usual work commitments.

In addition, late October is half term time for many women in different parts of the world, where they often want or need to take time off from work to care for their children.

We request WHO to consider such issues in advance. We are deeply committed to supporting the Dept. to produce the best strategy it can, but meaningful consultation can only take place if those involved are properly funded, with sufficient time to commit to the process. Since women living with HIV constitute 53% of all adults living with HIV globally, we see our involvement in this process as critical.

The comments we have made below are an overview summary of our thoughts, made in addition to those we submitted in relation to draft one.[2] They are *not* an in-depth review of the 80+ pages you sent us. However, we highlight some major gaps that we still see in the current draft.

We request a special call or series of conversations with the WHO Department of Global HIV, Hepatitis and Sexually Transmitted Infections Programmes to discuss its strategy, and to focus more in-depth on the issues raised here.

Below we start with some overall considerations. We then highlight some specific Actions which cause concern. We then add in the comments from Erika Castellano made on your call on 29 October.

## 2. Person-centred care across the board

[1] WHO (2021) Global Health Sector Strategies on HIV, Viral Hepatitis and Sexually Transmitted Infections 2022-2030 https://cdn.who.int/media/docs/default-source/hq-hiv-hepatitis-and-stis-library/who_draft_ghss_hiv_hep_stis_2022-2030_for-comments.pdf?sfvrsn=d49c7b49_7

[2] Add reference to '5 Approaches…' here?

In our statement 5 Approaches to Improve the WHO Global Health Sector Strategies for HIV, Viral Hepatitis and STIs through a Gender Equity Lens we advised that the WHO strategy, in accordance with the latest UNAIDS strategy[3], take a person-centred approach to women in all of their diversity and throughout their lives. In political and policy declarations, there is now universal agreement that the individual citizen should be at the center of the health system.[4] On political, ethical, and practical grounds, a person-centered approach has been supported, and it is thought to benefit service users, health professionals, and the health system as a whole.[5] We are pleased to note that the theory of change incorporates people-centered health service delivery, customized to varied populations and situations and engaged and empowered communities to improve accountability. However, as the call you hosted on 29th October showed, civil society organizations also agree across the board that, in terms of addressing the underlying structural causes of poor health outcomes, there is still much to be done. We are hoping that this declaration enacts dramatic reforms in WHO processes as well as in global and national epidemic responses.

One current topical example highlights the need for individualised care. Growing numbers of women globally are concerned about unwanted weight gain on certain ARTs, so much so that some are missing doses in order to regulate their weight. There is no space in current WHO guidelines to report back on side effects such as these, and yet it is clear that this is a major concern for the women concerned, as well as a challenge to drug resistance.[6]

In addition, we remind you that WHO has committed to work on and achieving SDG target 3.8, which focuses on achieving Universal Health Coverage; including financial risk protection, vital health-care services, and safe, effective, high-quality, and affordable necessary medications and vaccinations for all, and to ensure a people-centred health system, with primary care as its foundation[7].

**Gender Inequality**

The strategy continues to fall short on addressing gender inequality as a driver of the epidemic and crucial to the responses success. We would like to draw attention in particular to Box 4.3 which states:

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[3] Global AIDS Strategy 2021–2026 End Inequalities. End Aids, Unaids 2021
https://www.unaids.org/sites/default/files/media_asset/global-AIDS-strategy-2021-2026_en.pdf
[4] OECD Health Ministerial Meeting, 2017; World Health Organization, 2016; World Health Organization Regional Office for Europe, 2015
[5] Dieterich, 2007; Duggan et al., 2006; Richards, Coulter & Wicks, 2015.
https://www.euro.who.int/__data/assets/pdf_file/0010/455986/person-centred-health-systems.pdf
[6] https://www.clinicaloptions.com/hiv/programs/2021/individualized-art/clinicalthought/ct1/page-1#
[7] WHO (2018) The Thirteenth General Programme of Work, 2019–2023
https://apps.who.int/iris/bitstream/handle/10665/324775/WHO-PRP-18.1-eng.pdf

*'Priority populations for HIV. Certain populations are disproportionately affected by epidemics as a result of biological, behavioural and structural factors that increase their risk and vulnerability. Global evidence indicates that for HIV, five key populations – men who have sex with men, people who inject drugs, sex workers, transgender people, and people in prisons and other closed settings – are disproportionately affected as compared to the general population in almost all settings. These populations are important to the dynamics of HIV transmission and essential partners in an effective response.'*

Women and girls are invisibilized in this paragraph, although they are present in all but the first group - and can often be married to or partnered with men in the first group. All are adversely affected not only by being in one (or multiple) groups but also by the prevailing gender inequities they face. We also urge WHO to recognize and include the disproportionate impact of HIV on adolescent girls and young women in this list, and that women and girls constitute 53% of all people living with HIV[8].

The WHO strategy should prioritize confronting gender inequality and provide specific strategies to address gender-specific challenges and opportunities and to reflect the priorities of marginalized women.

**3. Respectful care**

To achieve person-centered care, it must come from all levels. It is about strengthening the movement for the rights of women living with HIV, and to change the narrative (See your draft ACTION 3 especially) from ending "Mother to Child Transmission" (eMTCT) to safeguarding and ensuring our Sexual and Reproductive Health and Rights (eSRHR) for the rest of our lives.[9] Women have long called for and led a shift away from biomedical approaches to disease prevention which have been based on "elimination of mother-to-child transmission", toward a woman-centered, gender-equitable, rights-based approach to "securing our SRHR", as spelt out in the WHO 2017 Consolidated Guideline on our SRHR. Within the strategy, perinatal care continues to focus on tests, examinations and medications; it does not mention the vital importance of respectful care. This means working with and on the psychological, emotional and spiritual needs of the perinatal woman. Physicians, HIV-related organizations, and organizations focused on housing, immigration, domestic violence, mental health, and other

[8] UNAIDS (2020) Global HIV & AIDS statistics — Fact sheet https://www.unaids.org/en/resources/fact-sheet
[9] 4M Mentor Mothers Network
https://4mmm.org/

issues affecting women's lives must work closely together. It is essential to have a collaborative and holistic approach that includes not only our bodies, but also our brains and spirits.[10]

We urge you to defend HIV-positive women's rights and to protect our sexual and reproductive rights during pregnancy and throughout our lives, as well as to create an atmosphere that allows women to thrive and work, to ensure *primarily* that our SRHR are upheld throughout the pregnancy journey, instead of (almost only) focusing on prevention of disease transmission.

**4. Mindfulness in use of language is important**

It is crucial to use appropriate language. It has an impact on how we feel, think, act, and react. It also has a physiological impact on our body, which affects all of our vital organs.[11] We have repeatedly asked for this too over the years.[12] We would like to flag your Box 1.1, which states: "...their partners account for 62% of the people newly infected worldwide, yet these populations face many barriers to service access". The issue remains a major source of concern, as seen, once more, in the 2017 WHO Guideline on SRHR of Women Living with HIV, as well as in the UNAIDS Terminology Guide. Both clearly advise avoiding the unnecessary term "HIV-infected persons."

*"Acknowledge the importance of language: Positive, inclusive language creates new opportunities for advancement and collaboration, instead of exclusively focusing on ending existing problems. For example, discussing "promoting health" instead of "ending disease" can create opportunities to think about the next steps in health promotion, in addition to responding to concerns of ill health. SRHR programmes should use language that puts people ahead of disease, such as saying "people living with HIV" instead of "HIV-infected people" or "HIV-positive people". HIV or AIDS should be used instead of HIV/AIDS, thereby disassociating the virus and the clinical syndrome. "Acquire" is a more neutral term than "infected" when referring to the transmission of HIV. Comprehensive prevention of "vertical transmission" can be used instead of saying "mother-to-child transmission" (or MTCT), to reduce possible blame that women living with HIV may experience. This is central to creating an environment that promotes SRHR." (pg. 19)* [13]

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[10] 4M Mentor Mothers Network CIC (2020) From elimination of MTCT to ensuring SRHR https://4mmm.org/wp-content/uploads/2020/12/4M_July2020_Advocacy_Brief_combinedbriefs_final.pdf

[11] Salamander Trust (2019) The power of language. https://salamandertrust.net/project/the-power-of-language/

[12] Dilmitis, S., Edwards, O., Hull, B., Margolese, S., Mason, N., Namiba, A., Nyambe, M., Paxton, S., Petretti, S., Ross, G.V., Welbourn, A. and Zakowics, A. (2012), Language, identity and HIV: why do we keep talking about the responsible and responsive use of language? Language matters. Journal of the International AIDS Society, 15: 17990. https://doi.org/10.7448/IAS.15.4.17990

[13] Consolidated Guideline on SRHR of women living with HIV (WHO 2017), http://apps.who.int/iris/bitstream/handle/10665/254885/9789241549998-eng.pdf?sequence=1

Recognize the significance of language in your discussions, and use positive and inclusive terminology. When defining language that refers to or addresses specific communities, keep in mind that those communities should be the ones to define their own language.

**5. Increase resources**

A profound lack of resources, capacity, and support, as well as challenging legal, social, and policy environments, are all obstacles that might restrict the influence and effectiveness of women's networks and CBOs. Increased long-term and sustainable investments in network capacity are needed to address these persistent practices typically experienced by women living with HIV at the national and global levels.

According to the WHO Accelerator Discussion Frame, (which was developed to present the central role of accelerators in driving progress toward the health-related SDGs, opportunities and bottlenecks to closer coordination, roles and implications for relevant organizations, and preliminary frameworks for joint action), rapidly improving the generation, allocation, and utilization of ***funds*** for health is one of the most effective strategies to meet the SDG3 targets.

However, Universal Health Coverage (UHC) and the larger set of SDG3 targets will not be achieved if business as usual continues. Meanwhile, in countries where healthcare is chronically under-funded, under-resourced and affected by shortages of medical professionals, equipment and medicines, the introduction of UHC is unable to positively impact the general population, let alone marginalised and criminalised populations.[14]

The lack of channels to bring together civil society and community organizations working on various aspects of health at the global and national levels encourages walled thinking and limits efforts to catalyze synergies and realize their full potential. From policy formulation to service delivery and accountability, a more coordinated approach among global health organizations might better exploit the unique role of communities and CSOs in achieving SDG3+.[15]

The Accelerator also reiterated the need to:

- short-term coordinated actions among global health organizations by establishing investment targets and ensuring synchronization of CSO support in health-related investment cases,
- map and disseminate global health organizations' investments in CSOs,

[14] NSWP (2018) Briefing Paper: Universal Health Coverage: Putting the Last Mile First. https://www.nswp.org/resource/nswp-briefing-papers/briefing-paper-sex-workers-access-comprehensive-sexual-and-reproductive

[15] WHO (2018) Accelerator Discussion Frame: Accelerator 3. Community and Civil Society Engagement https://www.who.int/docs/default-source/global-action-plan/accelerator3.pdf

- increase investments (and coordination of investments) in developing civil society groups' capabilities, particularly at the country level and through south south/south-north networks, to enable them to engage more effectively in the health sector, and
- review and organize the funding methods of global health organizations to help CSOs gain access to resources and build long-term resource mobilization strategies.

Lastly, there is a need to incorporate a strong accountability framework into the strategy to ensure transparency and accountability at all levels - with a clear role of communities.

We welcome all this and trust that the Dept. of HIV, Hepatitis and STIs will also incorporate these points in its strategy.

**7. Human Rights**

Although the WHO strategy identifies human rights as a driver of progress, the inclusion of human rights-based approaches is inconsistent and reveals a lack of understanding about what human rights based approaches entail. For example, a human rights based approach is mentioned with regards to voluntary partner notification but not with regards to addressing discrimination in healthcare settings - which are human rights violations. Further the commitments are weak and lack actionable steps and measures. For example, there have been significant human rights violations persistently documented in the arena of prevention of vertical transmission and maternal health services - yet the relevant action promises only "**promoting gender equality and human rights."** This is not sufficient. WHO must set the standard for human rights and gender equality and go beyond promotion to **requiring** that any interventions that WHO supports, endorses, funds and/or implements are implemented in accordance with internationally accepted human rights and gender equality standards. Healthcare systems must be held accountable for respecting, protecting and fulfilling human rights norms including gender equality.

One key way to do this is to ensure that data generation increasingly tracks and measures progress on key human rights issues including stigma and discrimination but also informed consent practices, Availability, Accessibility, Acceptability and Quality (AAAQ) aspects and provider attitudes and knowledge of human rights principles. [16], [17], [18]

[16] PMNCH et al (2013) Knowledge Summary 23: Human Rights & Accountability
https://www.who.int/pmnch/knowledge/publications/summaries/ks23.pdf?ua=1
[17] WHO & OHCHR (2008) The Right to Health.
https://www.ohchr.org/documents/publications/factsheet31.pdf
[18] The Danish Institute For Human Rights (2012) The AAAQ toolbox
https://www.humanrights.dk/projects/aaaq-toolbox

While Action 54 and complementary actions rightly recognize the critical role that networks of people living with HIV and Key populations play is providing key feedback to health systems, the role of community and other mechanisms for monitoring human rights compliance should be strengthened. Critically, human rights violations in healthcare settings must be monitored, independently assessed and pathways to accountability, remedy and redress for those who experience violations must be identified.

**8. Some specific comments on some of the Actions.**

The comments below are in no particular order. They provide more specific detail in relation to some of your listed Actions, related closely to the general points raised above. They are in no way comprehensive.

**Action 8: Stigma and Discrimination**

The draft strategy states:

***"ACTION 8: Stigma and discrimination in health care settings. Eliminate stigma and discrimination in health care settings and strengthen accountability for discrimination-free health care.*** *The health sector has a responsibility to ensure that everyone can access services for HIV, viral hepatitis and sexually transmitted infections in a non-discriminatory and supportive environment. Key health sector interventions include regular trainings for all health care staff to increase knowledge of these diseases, address misconceptions and underlying fears, and raise awareness about the harmful consequences of stigma and discrimination; and the development and monitoring of standards for health care workers to ensure that all patients are treated with respect, dignity and compassion. Health workers should be educated about patient rights and about how to sensitively provide care to all patients, particularly the key and most affected populations."*

Often this is not just 'stigma and discrimination' but structural violence and human rights violations and it should be named as such. There is extensive evidence from around the world regarding significant levels of violence experienced by women living with HIV. This includes regular confidentiality rights violations (Action 7), blaming and shaming women who do not attend clinic and/or do not take treatment regularly, forced and coerced abortions and/or sterilisations and many other experiences related to gender, race and/or HIV status inequities, with no understanding of the effects of PTSD from violence and/or from the HIV diagnosis itself, or or life-long adverse childhood experiences on women's lives.. Young women who have grown up with HIV can often find services highly abusive and young people in general do not find widespread supportive or youth-friendly services. Women in key populations have additional barriers to safe respectful care.

Health care providers need training in human rights and in trauma-aware care and there need to be accountability mechanisms in place to hold those who do not provide respectful care accountable.

There also needs to be recognition of the critical importance of women-led and -organised peer support in effective healthcare delivery: and funding for this.

**ACTION 9: Communicable and noncommunicable diseases**This should specifically include the menopause which is of growing concern to many women ageing with HIV.[19]

**Action 14: Violence**

The strategy states:

*"**ACTION 14: Gender-based and sexual violence. Prevent gender-based and sexual violence, provide support for people experiencing violence, and create an enabling environment to promote physical, sexual and emotional well-being and safety.** Physical, sexual and psychological violence, fueled by gender inequalities, harmful social norms, and criminalization and other repressive laws and policies, are risk factors for disease transmission, in particular among adolescent girls and young women, and key populations. The health sector plays an important role in providing post-violence care, including post- exposure prophylaxis for HIV and sexually transmitted infections, and broader clinical and psychosocial care and support. Efforts to prevent violence must also involve other sectors, such as to promote law and policy reforms and establish mechanisms to monitor violence and foster the accountability of law enforcement officials."*

This Action completely omits the widespread documentation of the types of violence experienced by women living with HIV in healthcare settings including abuse, violations of bodily integrity and obstetric violence - including forced and coerced sterilization, abortion, contraception and Caesarian-section. It is critical that these forms of violence be urgently and immediately eliminated. Specific steps include human rights violation reporting mechanisms, independent and community-led monitoring, health care provider training and accountability at all levels and remedy and redress for those who have experienced these violations.

Beyond violence in healthcare settings, many women living with HIV *also* experience VAWG upon or after diagnosis, at home, from partners, wider family, community members, workplace and faith-based locations, as well as in healthcare settings. They experience all these even more if they are women from key populations. We note that WHO mentions 'people living with HIV' in its related indicator but this is far too grave an issue just to be mentioned in passing and

[19] Tariq, S (2014) Menopause in women living with HIV in England: findings from the PRIME Study. NIRH (https://www.ucl.ac.uk/prime-study

in a non-gendered way there. The enormity of this issue both in terms of women's own intrinsic rights and in terms of the negative consequences on her access to safe, respectful, quality healthcare. need to be properly acknowledged and embedded in WHO's new strategy.. [20]

**Action 12: Mental Health**

A lot of the mental health[21] issues experienced by women living with HIV, which you have rightly mentioned in Action 12, are closely related to the issues experienced by women, including the VAWG at home and in healthcare settings described above. Together they severely affect women's ability to access treatment.[22]

**Both VAWG and mental health issues are raised repeatedly in the 2017 WHO Guideline on SRHR. We are dismayed that they have not been mentioned at all here.**

**Action 5: Infection prevention and control**

In Action 5, we ask that you specifically recommend the practice of standard Universal Healthcare Precautions[23] with relation to *all* patients. Since 2007, WHO has address the Standard precautions in health care[24] and quality health care that ensures timely, equitable, integrated and efficient services.[25] This will greatly reduce the stigma and discrimination experienced by people living with HIV and/ or people from key populations, if they/we are just treated like all other patients, rather than singled out for extra caution. This is also the most effective method of infection prevention and control.

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[20]Orza, L., Bewley, S., Chung, C., Crone, E.T., Nagadya, H., Vazquez, M. and Welbourn, A. (2015), "Violence. Enough already": findings from a global participatory survey among women living with HIV. Journal of the International AIDS Society https://onlinelibrary.wiley.com/doi/full/10.7448/IAS.18.6.20285

[21] Orza, L., Bewley, S., Logie, C.H., Crone, E.T., Moroz, S., Strachan, S., Vazquez, M. and Welbourn, A. (2015), How does living with HIV impact on women's mental health? Voices from a global survey. Journal of the International AIDS Society https://onlinelibrary.wiley.com/doi/full/10.7448/IAS.18.6.20289

[22] 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 and Welbourn, A. In Women's Eyes: Key Barriers to Women's Access to HIV Treatment and a Rights-Based Approach to their Sustained Well-Being 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/

[23] CDC (2016) Standard Precautions for All Patient Care https://www.cdc.gov/infectioncontrol/basics/standard-precautions.html

[24] WHO (2007) Standard precautions in health care https://www.who.int/docs/default-source/documents/health-topics/standard-precautions-in-health-care.pdf?sfvrsn=7c453df0_2

[25] WHO. Quality of Care https://www.who.int/health-topics/quality-of-care#tab=tab_1

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On behalf of all the networks listed below

**Comments from Erika Castellano on behalf of the WHO Advisory Group of Women living with HIV made on WHO webinar, 29 October 2021**

Thank you for giving me the opportunity to reflect on the draft strategies and provide some advice.
I have been invited in my capacity as the co-chair of the WHO Advisory Group of women living with HIV – Today as I make my intervention I will speak to what we as women in all our diversity feel needs to be included as part of our broader community needs so that together we can move this important strategy forward.

I would first like to recognize the progress that has been made in addressing the epidemics and the efforts to include the voices of communities in various WHO processes. As WHO prepares for the discussions in January, we would like to highlight the following and urge the Executive Board, Director General and Deputy Director-General to:

1. Recognize the expertise and role of communities and foster safe spaces for community engagement, particularly of the communities most impacted by the epidemics.
2. In this same line we urge you to reflect if you are ready to actively listen to us – you hear us because we are stubborn, persistent, and loud – but what we need is to be listened to.
3. Address inequalities from a holistic lens. As adjust the response to the epidemics in this new era, take the lessons learned from our shortfalls and successes and address the inequalities which remain one of the biggest barriers to ending the epidemics, including those related to gender, access, education etc.
4. Translate the statement “people at the center” from words to actions – We celebrate the prominent theoretical positioning of people at the center but we request that this statement goes beyond being politically correct and appealing to the ears and make radical changes both in WHO processes, and the global and national responses to the epidemics. Ensuring to place people at the center throughout the lifespan of the individual and not only on sporadic points in our lives.
5. Consider the priorities of communities and foster integration of services to move us closer to UHC.
6. Integrate considerations around gender-based and intimate partner violence as key elements in the response to the epidemics.

7. Recognize the importance of language in your discussions – ensuring the use of positive and inclusive language. Related to language, when defining language that refers to or addresses specific communities, remember that those communities should be the ones to define their language. For example, it is unacceptable that a group of cis-gender people decide how they will refer to when talking about trans people. We are the experts, if needed request our advice and then when we do give it to you please act on this
8. Incorporate a strong accountability framework into the strategy to ensure transparency and accountability at all levels with a clear role of communities.
9. To end, do not tick the box of community engagement, with having me speak in the webinar today, you can tick the box only if and after you have acted on our requests.

**CO-SIGNATORIES**

| NAME (IF PERSONAL SIGN-ON ONLY) OR YOUR ORGANISATION | COUNTRY/REGION/ GLOBAL |
|---|---|
| ICW Global | Global |
| WHO Advisory Group of Women living with HIV | Global |
| 4M Mentor Mothers Network CIC | UK |
| Advocacy for Quality Health Uganda (AQH-Uganda) | Uganda |
| Eurasian Women's Network on AIDS | EECA |
| ICW Asia Pacific | AP |
| ICW Central Africa | Regional |
| ICW Latina | Latin America |
| ICW North America | Regional |
| ITPC- MENA | MENA |
| Jacquelyne Ssozi Foundation | Uganda |
| Jamaica Community of Positive Women | Jamaica |
| Making Waves Network | Global |
| National Federation of women living with HIV AIDS | Nepal |
| Pan African Positive Women's Coalition | Zimbabwe |
| Positive Women | Ukraine |
| Positive Women's Network | India |
| Positive Young Women Voices | Kenya |
| Positively UK | UK |
| Priscilla Simon Ingbian, Community Health Support and Empowerment Initiative COHSEI | Nigeria |
| Salamander Trust | UK/ Global |

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| Seres (con) viver com o VIH | Portugal |
| Sophia Forum | UK |
| Srijansil Mahila Samuha | Nepal |
| The POWER Group | Global |
| Women's Network of Key Communities of Kyrgyzstan | Kyrgyzstan |
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