UNAIDS STRATEGY DEVELOPMENT

UNAIDS STRATEGY REVIEW:

International Community of Women Living with HIV

Global Focus Group on Women and Girls Living with HIV

UNAIDS STRATEGY REVIEW: Focus Group Synthesis template

Please use the template to organize your feedback from the session. Please keep responses succinct and as clear as possible to ensure our synthesis is a reflection of the focus groups hosted.

You can enter your report directly into a form on SurveyMonkey:
https://www.surveymonkey.com/r/3HC9Q6M

If you are not able to enter it on line you can send us a copy via e-mail ***strategyteam@unaids.org***

Would you accept for UNAIDS to make your report publicly available: Yes / No

SECTION 1: Information about the focus group (to be completed by host of Focus Group)

Organization leading discussion: International Community of Women Living with HIV

Date of discussion: August 17, 2020

Theme to be discussed: Gender Equality/Priorities for the HIV Response

Participants: ICW Asia Pacific, ICW Caribbean, ICW Central Africa, ICW Chapter for Young Women, Adolescents and Girls, ICW Eastern Africa, Eurasian Women's Network on AIDS, ICW Latina, MENA Rosa, ICW North America, ICW Southern Africa, ICW West Africa

Country, regional or global focus: Global

Introducing the theme

Please enter the main characteristics of the theme being explored in 5 sentences (please share the presentation if possible by email)

This focus group conducted by the International Community of Women Living with HIV (ICW) explored gender inequalities and identified priorities for women living with HIV within the HIV response. Focus group attendees, discussed the systemic barriers to reaching diverse women living with HIV in programing, human rights violations experienced by women in institutions and their homes, as well as the major gaps and failures of the HIV response and how to address these going forward to achieve progress in the next UNAIDS Strategy.

We want to highlight that our definition of women is any self-identifiying women (transgender and intersex inclusive). The definition is also inclusive of young women and girls, women who use drugs, sex workers, lesbian, bisexual and queer women, women who are incarcerated, migrants, and refugees. ALL WOMEN.

SECTION 2: People-centered response to HIV – key emerging messages

Please enter the main messages coming out, up to 5 points maximum per section

REACHING THE PERSON	
How do we see the current situation?	• Gender inequality is the underlying issue for the advancement of women and girls in the HIV response, undermining their engagement and autonomy in decision-making spaces. • Harmful socio-cultural gender norms continue to constrain the lives and negatively impact many women living with HIV, while also posing practical and structural barriers which make it difficult to reach many women and girls in programs and services.
What concerns us?	• Programs that do not use the GIPA principles including (MIPA), and do not use human-centered design. Instead programs are developed, guided, led, and funding decisions are made, not by women living with HIV but by other individuals, especially those who do not have connections to grassroots communities. Programs focused on prevention have limited room for diverse narratives about treatment and condom adherence or harm reduction. • There is a lack of commitment to developing strong peer role models and champions in the women and HIV movement. Donors, such as UNAIDS, are constantly fragmenting networks of women living with HIV in order to establish and create new networks, reducing opportunities for succession planning, capacity development, using peer support frameworks making the resources to implement these activities limited. • Stigma and discrimination at macro level results in persistent harmful practices and policies in our healthcare institutions, schools, legal systems, and religious institutions. These institutions fuel stigma and discrimination in the daily lives of women living with HIV making it difficult for them to be reached. At micro-level societal stigma leads to self stigma and mental health issues for many women living with HIV. In many patriarchal societies, women do not have economic independence and freedom from their husbands or families. When women do work they are paid lower wages in precarious employment (sellers in the market, domestic labor, textile factory workers). Women often have to make the choice between participating in treatment programs, clinics, groups or her family. Fear of stigma and discrimination prevents many women from advocating for their rights. • Children, adolescents and young women have barriers to accessing both programs and services including treatment and sexual and reproductive health and rights due to age restrictions and parental consent. Parents and adults block young girls from accessing vital information and services in relation to sexual and reproductive health services, particularly sexually transmitted infections including HIV. Outdated, sexist, and misogynistic norms about promiscuity and gender roles create barriers for AGYW in exercising their sexual and reproductive health and other rights including the right to bodily autonomy. • English and other regional colonial languages (French, Spanish, Russian) are predominantly used in the HIV response, over Indigenous and local languages and dialects. This makes it very difficult for many women living with HIV, especially from rural communities to participate in their treatment and/or the HIV response.

What gives us hope?	• The emergence of strong civil society networks led for and by women living with HIV at national, regional and global levels. We see ICW as an essential network at all levels. • The nurturing and investment in ongoing peer-based programs, supporting the long-lerm succession planning for a feminist HIV response that includes consciousness raising and a gender equity approach. • Using innovative technologies and social media platforms to reach women and girls living with HIV in diverse communities through a variety of peer-to-peer supports – such as adherence councilors, health care, educators, mental health advisors. • Prioritizing investment in advocates and activist women living with HIV – including skills development, and financial compensation for their work and contribution to the greater HIV and gender response. • Programs that include an intergenerational and intersectional approach – looking at engagement of women living with HIV through her lifespan and tailoring programs to fit the diverse needs of women. • Reaching women in our communities by working directly network to identify HIV hotspots, and working with diverse women in places that are safe to them – beauty salons, around the kitchen tables, in the clinics, or in the clubs and bars.
What constrains our ability to achieve our goals?	• There is a strong movement to treat the HIV epidemic biomedically and a lack of focus on the holistic well-being of women and girls living with HIV, therefore there is a lack of social support programs led by peers at the community level. • Institutional stigma and discrimination has not been properly or fully addressed, efforts to address stigma and discrimination have not resulted in change or accountability, human rights, and women are often seen as an afterthought to programming development and design. • Self-stigma still poses challenges to women accessing services and engaging in advocacy. • Harmful gender norms continue to restrict advancement in the HIV response. Gender is non-binary and therefore these gender norms create tensions and misunderstandings about who women are and what women can do. These assumptions remain at the core of program development and outreach, overlooking, for example, transgender women and women who do not fit into these pre-assigned molds (such as women from key populations, butches, lesbians). Gender norms also promote gender inequality resulting in lack of education, poverty, early marriage, intimate partner violence, and lack of access to fundamental rights and freedoms.

THE STRUCTURES THAT RESPOND TO HIV	
How do we see the current situation?	• Women in all of our diversity are not represented equally in the HIV response and there is a lack of MIPA in practice. In many contexts, women fear the repercussions of their disclosure and are not able to participate in decision-making spaces. In many examples, the HIV response generalizes our experiences as a homogenous group of ‘women’ and does not acknowledge or make space in our societal structures for marginalized groups

	such as transgender women, women who use drugs, sex workers, queer women or Indigenous women living with HIV making them invisible. Invisibility creates ignorance and fuels stigma and discrimination leading to rights violations in our institutions and our homes. ● Resources are shifted from women and girls living with HIV to programs and services are targeted towards broader key populations. This is a current trend in donor circles. This creates tensions in the HIV response and challenges for networks of women living with HIV to fully participate in decision making settings. In key population communities women living with HIV are also present but they tend to be under served and under acknowledged.We also note that older women living with HIV have also been left out as fewer resources available are channeled to adolescent and young women. ● Legal structures do not prioritize the rights of women and gender equality. There is little recourse for gender-based violence in homes and institutions.
What concerns us?	● The lack of social assistance programs and economic employment programs to support the disproportionate numbers of women living with HIV living in poverty without secure housing are an issue. During COVID-19, for example, we witnessed substantial loss of women's jobs and income. As a result, women were more susceptible to intimate partner violence, and systemic violence in their daily lives. Women from key populations groups seeking relief during the pandemic, such as sex workers, were denied basic supports and food packages from ministries. ● Rights violations in health care settings threaten the lives of many women living with HIV. Programs for women are not always safe for women living with HIV to access and have resulted in numerous and continuous health care violations and abuses. Healthcare programs and services on the other hand are not centered around the women that they support, including trans women, women who use drugs, sex workers and/or young women. ● Older women living with HIV are being left behind. Women living with HIV are dying from preventable HIV related diseases, such as cervical cancer. ● Many countries and educational institutions do not provide comprehensive sexuality education for young people and therefore do a disservice to younger women who deserve accurate information about their sexual and reproductive health and rights. Denials of information and services can result in early pregnancy (leading women to be removed from school), sexual assault, and misinformation about HIV and STIs, especially for young women born with HIV. If there are comprehensive sexuality education programs, young women and adolescents may not have access without parental consent. ● Research institutions do not disaggregate data based on gender. In addition, treatment is often tested on the bodies of men and therefore side effects, and other specific issues that women may experience are less likely to be reported. Most research is not led, guided or influenced by women living with HIV and rarely focuses on the issues that are most pressing and important to the community. Researchers profit off information gathered from the community but most times communities are last to know.

What gives us hope?	• Social assistance programs that give subsidized housing and basic support to women living with HIV, in addition to job training programs for economic empowerment and independence. • Strongly supported partnerships with government structures, institutions, and services to allow for women living with HIV to be at the heart of shaping structures in our society. When diverse women living with HIV, who are the direct recipients are part of creating and bettering the structures, all women in society will benefit. • Strong, resourced, inclusive community led networks of women living with HIV to act as spaces for mentorship, decision-making, and advocacy for the HIV response. These spaces must bee inclusive to all self-identified women, including transgender women and women from key populations. • Women living with HIV who have been pioneers in legal changes to push back against health care violations (example, forced and coerced sterilization cases) and punitive laws that harm women and girls making it hard or impossible to access services (such as safe and legal abortions, and contraceptives) in society. • Working directly with religious agents to reform religious institutions and develop their acceptance, understanding of, and support for women's rights and autonomy, including sexual and reproductive health and rights. • Projects that are directed at including rural women living with HIV in service provision plans such as community-based health care and mental health services, and providing bicycles and scooters for nurses and educators in remote areas.
What constrains our ability to achieve our goals?	• Resources for a strong, holistic HIV response that puts gender and the issues that women living with HIV experience at the heart of the epidemic are dwindling globally. Many programs and structures have become catch-all's and do not always include the diverse perspectives or lived experience of women living with HIV. These efforts are often not led by the women living with HIV in the community. • Lack of GIPA and the meaningful engagement of women living with HIV in the development of our societal structures and programs in the HIV responses continues to be a barrier in achieving our collective goals. Women who push back against the patriarchy in the HIV response are often silenced. Sexual harassment and institutional violence cannot end if we are silenced.

CONTEXTUAL ENVIRONMENT	
How do we see the current situation?	• Globally, stigma and discrimination against women and girls living with HIV is still prevalent. Stigma and discrimination in many contexts is codified in harmful legislation that disempowers women, in particular, from key populations. Women who are from key populations, women who are poor, women from racialized groups, and women with disabilities experience greater stigma and discrimination. Stigma and discrimination linked with

	gender inequality are the leading factors in women living with HIV remaining without supports, access to treatment and unnecessarily dying especially young women living with HIV. ● Overall, the lack of funding for women's organizations creates a vacuum that is linked to a lack of knowledge for the preparation and management of projects. Networks of women living with HIV are often under resourced and face significant financial hurdles to implement meaningful projects and programs for their community. Women living with HIV in the response should be paid a living wage for their time and expertise, and to be compensated for their time - including as consultants by partners like UNAIDS.
What concerns us?	● Programs and services are centralized in urban city centers and this poses challenges for reaching women living with HIV in rural and transient communities. These programs may force women to travel long distances which can be time consuming and costly. Often women need to choose between caring for her domestic duties and her HIV treatment. ● Programs for women and girls living with HIV are under-funded causing us to struggle to provide the services that are needed to support a woman to achieve her highest standard of health, with all aspects of her health inclusive of treatment as well as mental health services. ● Young girls have lack of access to quality education therefore reducing the likelihood of her having access to services, programs, and knowledge about HIV and her sexual and reproductive health and rights. In addition, young women miss out on other larger scale projects such as HPV vaccines that are often administered in school settings. By not being in school and not getting the HPV vaccine it opens them open to preventable diseases such as cervical cancer later in life. ● Patriarchy is deeply rooted in socio-cultural practices and traditions making it hard to inform women about her rights. Cultural justifications are also used to harm women particularly lesbian, bisexual, queer and transgender women by deeply stigmatizing them for their gender presentation, sexuality, substance use, economic independence and so on. Harmful cultural norms include early child marriages and sexual debut, female genital cutting, as well as sexist norms regarding the commodification of woman's virginity. Gendered cultural practices are linked to femicide and honor killings of women.
What gives us hope?	● MIPA! When women living with HIV through our networks are supported and given space to speak up and can do it loudly and proudly in all spaces that have impact on the lives of women. Women living with HIV are inspired by institutional shifts in our partner organizations and donors that hire paid positions and consultants representing our community of women living with HIV to lead the HIV response in meaningful ways. ● Treatment advances for women living with HIV including U=U, the ring and other medical advances. This has changed the lives of many. In order to have a larger impact, policy, the law, and social knowledge has to align with the information and science that we know to stop HIV criminalization and other human rights violations ● Advocacy and leadership programming such as the ICW School of Feminism that support women's consciousness raising and sensitize women and

	community leaders about intersectional and community led approaches to the HIV response. Inclusive in our feminism, are conversations on inclusion of diverse women including queer, transgendered and intersex women living with HIV. ● Strong advocacy and global push back against gender inequalities and human rights abuses using innovative technologies and social media as well as direct action. For example, the protests supporting #BlackLivesMatter in the United States looking at racism and police brutality and how this can be applied in the HIV response and our work. We want to see more programs and services led by the underrepresented women in our communities and talk about intersectionality and the impacts of colonization on the global response, this includes women living with HIV first and foremost, women of color, women with disabilities, women who use drugs, sex workers, young women, women who are lesbian, bisexual or queer, transgender and intersex women. ● Working with religious agents to engage in community programs and reduce for women living with HIV in the community. In addition, to push back against harmful gender norms, champion women's rights including sexual and reproductive rights and choice to safe and legal abortions, access to economic empowerment, and the autonomy of a woman's gender presentation and sexuality.
What constrains our ability to achieve our goals?	● Networks and community organizations are struggling to exist because of reduced funding and shifts towards other focuses. In addition, extensive reporting requirements (which often includes high levels of English), and the professionalization of the HIV response limits opportunities for community groups and activists to participate in meaningful ways that are sustainable. When networks of women living with HIV are supported to implement their own programs, services and lead their own research, they are able to make long term changes in their communities and the gender response. We see the defunding of our networks as the work of patriarchy, especially when we know that women, in particular young women, are so greatly impacted by HIV and carry the global burden. ● Ultimately, patriarchy and gender inequality are the core reasons why the HIV movement is failing to reach its goals. Women's experiences of violations in healthcare settings, in their homes, in their workplaces, in their communities, adn in the HIV response is rooted in their unequal treatment in society.

EMERGING PATTERNS:

- Gender inequality and inequity are root causes of the disparate impact that HIV has on adolescent girls and women of all ages. Effective strategies to address gender inequalities remain inadequately prioritized and invested in and this negligence result in stigma, discrimination, unequal power dynamics and a devaluing of women's rights to autonomy and bodily integrity which then manifests in egregious violations of women's

rights. (For example obstetric violence including forced or coerced sterilization and other forms of reproductive oppression).

- Women living with HIV were concerned with the lack of mental health services available to them including peer support, and counseling. Women want to see mental health integrated in advocacy for universal health coverage and comprehensive HIV care.
- Women living with HIV recognize that biomedical approaches are currently prioritized within the HIV response and seek an increase of a holistic focus of well-being along their life-cycle, including but not limited to their reproductive years and capacity, as well as a need to resource and otherwise support peer support networks at the community level.
- Networks of women living with HIV do not feel that a diverse representation of women living with HIV are meaningfully engaged and adequately resourced to participate in the HIV response. Women living with HIV have been leading the HIV response from behind for decades, conceptualizing, implementing, and informally doing the work of monitoring programs and services and calling out human rights violations but their contributions continue to be undervalued and under supported. This has resulted in the loss and/or struggling of many national, regional, and global networks of women living with HIV. Program monitoring and evaluation, particularly around availability, accessibility, acceptability, and quality (AAAQ) framework, stigma, discrimination and other human rights abuses must embody the GIPA principle and engage and be accountable to community and particularly to diverse networks of people living with HIV including women living with HIV.
- Women living with HIV face a scarcity of data about their experiences, a lack of gendered data disaggregation, and a lack of research focused on the issues of concern to women living with HIV remain extremely problematic.

SECTION 3: RECOMMENDATIONS World Café

Please enter the main messages coming out, up to 5 points maximum per section

START	- *START actually promoting and implementing GIPA. Insist that women living with HIV are giving the final say in decisions about gender and HIV. Start doing more work to link gender based violence, women's equality, and HIV.* - *START promoting and resourcing mental health and self-care work.* - *START including overhead and staff costs in your grants and ensure that you allocate resources to grassroots networks of women living with HIV, including transgender women and not just international consultants. Hire peers from among the women living with HIV community to become "remunerated" consultants, with an assistant from the vulnerable community.* - *START funding long term projects for networks and not just short project funding - people living with HIV are not projects. If you say we do not have the capacity, build it.*

	- *START the reflection and production of a gender report on the advancements that UNAIDS has made in regards to gender. We want to see greater accountability and transparency on the work of UNAIDS in regards to gender.* - *START dealing with women and girls living with HIV as human beings and not only numbers and cases.*
STOP	- *STOP dropping networks UNAIDS created and turn around to create another network that looks "trendy". So instead of the first network being able to encompass/do all the activities including activities intended by the new initiative are dividing and harming the community.* - *STOP working in competition with other UN agencies. It's a waste of money, resources, and undermines the HIV response. Align and complement each others' efforts and don't duplicate projects.* - *STOP promoting inequalities among different cultures, origins, genders in practice. Hire diverse women living with HIV in the UNAIDS offices and strongly promote gender equality in the workplace and the field and not just talk about it.* - *STOP saying UNAIDS works with communities while community networks say they struggle to understand what UNAIDS does and how to work with UNAIDS. STOP only working with movement gatekeepers.* - *STOP wasteful meetings and flying people around the world for expensive meetings when this could be put into people power and the response.*
CONTINUE	- *CONTINUE to work with and nurture networks that are led by and for women and girls living with HIV.* - *CONTINUE reporting on human rights violations and promoting gender equality as a strong pillar of UNAIDS. We as networks of women living with HIV, want UNAIDS to support and beleive us when we raise concerns (such as forced and coorced sterilizations and abortions) then support us to document violations, advocate, and change systems.* - *CONTINUE giving trainings and workshops for leaders in country to build capacity and knowledge* - *CONTINUE creating anti-discriminatory and decriminalizing laws and policies for government partners* - *CONTINUE creating spaces for dialogue with civil society, private sector, and governments*

What is the one key recommendation you want to reiterate for strong consideration?	*UNAIDS prioritized gender in their previous strategy, yet, networks of women living with HIV persistently struggle to survive and make their essential contributions to the HIV response. We want more investment where the rubber meets the road in terms of supporting accountability for gender equality, women's rights inlcuding the full spectrum of SRHR, and investments in the key issue impacting women's lives, calling out harmful gender norms, taking action to address sexist and misogynist stigma and discrimination in institutions but also the HIV reponse itself.*

Please share with us any references you think would be useful for the Strategy Development, such as examples of case studies that illustrate the challenges or recommendations you outlined in the discussion report.

Please also share a list of names and email addresses of participants who would wish to continue to be informed of the Strategy development process. Note names and contacts will not be shared publicly or with any third party.