

“I take nine pills, I have a sore throat, for 18 years I am taking tablets – I used to take up to 22 tablets – they are large tablets. ... That’s why sometimes I stopped taking them ... the routine of the drug already has me tired.” INTERVIEW, BOLIVIA

- \* Implement gender-based violence prevention and reduction programmes as a core element of HIV care and treatment programming.
- \* Make delivery of services safe for women, including through rights-based training for service providers to:
  - improve providers’ ability to address and minimize gender-specific HIV-related vulnerabilities in healthcare settings
  - ensure providers are trained and resourced to offer ART, supporting women’s decision making and providing adequate information and support on treatment uptake and adherence, and on management of side-effects
  - ensure mechanisms exist for women to provide feedback on the quality and effectiveness of services
  - provide quality life-long, life-stage appropriate sexual and reproductive healthcare for all women living with HIV, including informed choice in the context of pregnancy and fertility desires.

## 2. Gender: Engage in more analysis of treatment access barriers with gender at the centre, recognizing the intersectionality with other structural factors.

- \* Develop a rights-based research agenda in collaboration with women living with HIV and related to implementation of Option B+. This is urgently needed to provide systematic information on factors affecting decisions to start, stop or stay on treatment during pregnancy and lactation.

## 3. Diversity: Fill the data gaps that exist across the treatment cascade for women in all their diversities. Investigate, innovate and implement the findings of research to fill the existing gaps related to barriers and facilitators of women’s access to ART, including:

- \* A rapid scan of types of data that are and are not routinely reported by treatment programmes targeting women, e.g. Option B+, test and treat and serodifferent (“serodiscordant”) couples’ programmes, followed by a coordinated plan to fill gaps in information, with attention to issues of choice, coercion, supportive services, clinical and psychosocial outcomes for women.
- \* A system for improved data collection at national levels developed and implemented with coordination and cooperation from PEPFAR, the Global Fund to Fight AIDS, Tuberculosis and Malaria, UNAIDS and other cooperating entities. This system must ensure age and sex disaggregation of treatment data and gather information on access for pregnant versus non-pregnant women.

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## 4. Multiple levels: Ensure that care and treatment packages include basic needs and account for gender-specific barriers at individual, household and community levels.

- \* Provide clinic spaces, hours and structures that are accessible to women in all their diversities (women with childcare and family responsibilities during the day, those engaged in sex work, school age girls, etc).

## 5. Gender-based community engagement: Incorporate a gender analysis into expansion of support for community-based service delivery – a core component of UNAIDS’ Fast Track goals.

- \* Track resources allocated to community-based groups to ensure that funding is reaching women-led organizations at grassroots level.
- \* Define gender-specific elements of community-based service delivery in different contexts, to ensure the groups and individuals with relevant expertise and lived experience are in the lead.

## 6. Peer-led involvement: Harness the power and leadership of peer-led and -governed analyses of treatment access as part of a participatory research, implementation and evaluation framework.

- \* Provide peer-support/counselling and mentoring schemes within health services.
- \* Increase funding for networks of women living with HIV, support groups and community-based organizations to provide supportive services along the treatment and care continuum.
- \* This review has focused on available data, but there remains a paucity of rights-based, peer-reviewed literature focused on women’s lived experiences as reported by women themselves. This gap should be filled via strategic support of innovative research projects that utilize a participatory methodology and a holistic, well-being approach to understanding women’s treatment access, adherence and health.

“It motivates me when I look at my children and my other siblings, who are negative, and my father. I have to push on with life.”

INTERVIEW, UGANDA

## The way forward

It is our hope that this extensive review will catalyze change and dialogue at international and national levels in the rooms, clinics and communities where new and existing forms of ART are being offered. Women’s voices are clear, consistent and urgent in their articulation of what must be done to create a woman-centered, rights-based approach to holistic health and wellbeing. It is also our hope that the methodology used to produce it will be adapted and expanded as a basis for continuing to monitor progress and map gaps in the global AIDS response.

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# Key barriers to women’s access to HIV treatment: Making ‘Fast-Track’ a reality

## Background

### An overdue effort

In collaboration with UN Women, ATHENA Network, AVAC and Salamander Trust undertook a global multi-stage review of the status of access to antiretroviral therapy (ART) for women living with HIV.<sup>1</sup> Since the beginning of the HIV epidemic, this is the first ever peer-led global study of care and treatment access for women living with HIV of this scale. It is well overdue.

The global review comes at a critical juncture in the epidemic where there is an increased focus being placed on strategic investments in health guided by specific national and regional epidemiological contexts. In late 2015, the World Health Organization updated its guidelines on ART for prevention and treatment, recommending immediate offer of ART to all people living with HIV, regardless of CD4 count or clinical stage.<sup>2</sup> ART is positioned as central to the Sustainable Development Goal of ending AIDS by 2030. Pursuit of this goal is happening in the context of a constrained resource envelope for HIV and health overall.

To achieve current global goals, it is critical to understand and address key barriers to and facilitators of women’s access to HIV treatment.

In this context, it is essential to understand the barriers to and facilitators of women’s access to ART, so that individual choices about when and whether to start, and continue with, treatment translate into positive mental and physical health outcomes for the woman, as well as benefiting public health.

In this review, socio-structural factors<sup>3</sup> were explored at macro-, meso- and micro-levels in order to better understand the experiences women living with HIV have of treatment availability and their decision-making around uptake, and to assess how treatment programmes affect their lives. Removing barriers and changing policies and programmes to align with best practices will contribute substantially to efforts for the achievement of global goals such as the ‘90-90-90’ UNAIDS ‘Fast-Track’ targets<sup>4</sup>.

1. Tenofovir-based pre-exposure prophylaxis (PrEP) using daily dosing of one or two antiretrovirals (ARVs) is being introduced as HIV prevention for HIV-negative men and women. This use is not considered in this review. Here, we only review access to ART by women who know they are living with HIV, in the context of treatment for their HIV.

2. <http://who.int/hiv/pub/arv/arv-2016/en/>

“Most of us live in the far village, which takes one hour to two and a half hours by public transport, which is really costly ... So, some months we don’t visit the hospital to take

ART too, sometimes we manage to get money from a neighbour if we don’t have our own.”

FOCUS GROUP DISCUSSION, NEPAL



“The little money [we have] will buy the cheapest meal for me and the children without thinking of the fruit. Except when a generous partner invites you to the restaurant.”

FOCUS GROUP DISCUSSION, SEX WORKERS, CAMEROON

Conventional measurements of national HIV care and treatment programmes include **coverage** and **access**. Coverage measures are used to quantify the reach of ART at population level, with measures of long-term viral suppression and retention providing proxy indicators of programmatic effectiveness. But there are levels of effectiveness and programme components that are not included in these measures, compounded by gaps in the development of sex/gender-disaggregated coverage data. Improving definitions and filling gaps are both critical to understanding effectiveness in reaching women with services that are delivered in a human

3. HIV-related structural factors are defined as barriers to, or facilitators of, an individual’s HIV treatment behaviours; they may relate to economic, social, policy, organizational or other aspects of the environment. Sumartojo E., *AIDS*. 2000 Jun;14 Suppl 1:S3-10.

4. The UNAIDS Fast Track goals include the following targets: By 2020: 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy; 90% of all people receiving antiretroviral therapy will have viral suppression.



rights framework and provide benefit on an individual and population level.<sup>5</sup>

Access to ART is defined in terms of **availability, affordability, acceptability** and **quality**, with measurement methods including; cost, income, geographic location, cultural and social acceptability, availability of technology, expected health gain, performance of provider and adherence. Current accessibility measures are limited by their focus on health system service delivery and are unable to address the critical points of intersection within the gendered experiences of women. Social, cultural, economic and environmental factors all influence access to treatment for women (i.e. access to economic resources, decision-making power, division of labour in the household, discrimination and stigma, etc.).

This review aims to broaden the conventional understanding of indicators of access to understand women's perspectives and the underlying causes of barriers to access, particularly at household and community levels. The forthcoming full report, available in late 2016, proposes new dimensions and measures of access for consideration, and suggests strategies to address structural factors.

## The review

### A unique methodology: women led and governed

The global review took as its starting point the major gaps regarding information on women's access to HIV care and treatment across the lifecycle, and in particular for adolescent girls and women not currently pregnant.

The three phases of the review included: 1) **A literature review** related to women's access to treatment and an unprecedented analysis of all available sex-disaggregated data from PEPFAR (United States President's Emergency Plan for AIDS Relief), Global Fund for AIDS, Tuberculosis and Malaria, UNAIDS and other sources; 2) **Community dialogues** via focus group discussions (FGDs) in Bolivia, Cameroon, Nepal and Tunisia of 175 women (175); consultations with all 14 **Global Reference Group** (GRG) members (14); one-to-one interviews with 8 of them and 1 additional woman (9); and an online discussion group with GRG members and 7 extra women (7). Thus a total of 197 individual women were consulted in this phase; 3) **Country case studies** undertaken in Kenya, Uganda and Zimbabwe with in-depth focus groups (10, 10, 16), one-to-one interviews (0, 7, 10) and country-level policy scans to provide a fuller picture of women's access in specific contexts. Younger and older women were purposively sampled. Numbers of participants by country (women living with HIV, men living with HIV): Kenya (84, 20) Uganda (80, 19) Zimbabwe (118, 0). The International Community of Women Living with HIV East Africa led the case study work in Kenya and Uganda. Pangaea Zimbabwe AIDS Trust worked with members of the GRG to conduct case study work in Zimbabwe.

**“I was really in favour of early treatment and to have this Option B+. But now my worry is: are we being given this as an option or is this being pushed on us with no option?”** INTERVIEW, ZIMBABWE

### Few examples exist of HIV treatment access analyses in which women with HIV are placed at the center of design and implementation.

Women living with HIV led the design and implementation of the review as they are best positioned to frame and prioritize the issues and areas that should be interrogated as part of an effort to fill these gaps. **A Global Reference Group (GRG)** of women living with HIV was constituted to guide the project throughout all phases. The 14 GRG members represent 11 countries and a range of diverse identities and experiences. The GRG was included in the development and revision of parameters for the extensive literature review, framing of priority topics and questions for a discussion guide used for FGDs and one-to-one interviews led by GRG members and other women living with HIV. Some GRG members are also involved in the final phase of the project, in-depth country case studies that probe issues and concerns raised in the previous phases.

**This project is one of a limited set of investigations** of women's perspectives of why they choose to initiate and remain on or discontinue treatment. The project did not engage women who had never accessed ART, one of several areas for additional investigation.

## Findings

### Uneven progress in access and adherence

There have been improvements in access to ART and scale up of treatment programmes, but progress in addressing underlying factors that facilitate not only starting but remaining on treatment is uneven. Women face complex experiences accessing treatment; violence and discrimination from family, community members and healthcare professionals act as barriers to ART access.

### Data gaps

- \* There are major gaps in the data collection. These include an absence of and/or gaps in data disaggregated by age and sex/gender at every stage of the treatment cascade (with the exception of women receiving ART as part of peri-natal services). There are also information gaps on ART access for women in their full diversities (i.e. sex workers, transgender people, adolescent girls, young women and women of any age who are not pregnant).
- \* Further gaps exist in relation to documentation of women's experiences as patients, especially in relation to confidentiality, treatment literacy, disrespect and abuse.
- \* Based on available sex/gender-disaggregated data, women initiate ART more frequently than men, but many women do not remain on ART and may even have lower retention rates over the long-term than men.<sup>6</sup> Option

6. Women's Working Group of APN+ (2009). "A long walk – challenges to women's access to HIV services in Asia: Participatory action research".

7. Ortego, C., Heudo-Medina, T.B., Santos, L. et al. (2012). "Sex differences in adherence to highly active antiretroviral therapy: a meta-analysis". *AIDS Care* 24(12): 1519-1534. See also: Puskas, C.M., Forrest, J.I., Parashar, S., et al. (2011). "Women and vulnerability to HAART non-adherence: a literature review of treatment and adherence by gender from 2000 to 2011." *Current HIV/AIDS Reports* 8(4): 277-287.

B+ rollout in several countries has been characterized by high levels of 'loss to follow up' and lower rates of adherence.<sup>7</sup>

## Barriers

### Micro-level (individual)

- \* **Violence against women living with HIV:** this, coupled with fear of violence, were the most commonly cited barriers for women.
- \* **Fear and experiences of stigma and discrimination:** this leads to non-disclosure of status, which is linked to lower adherence and higher rates of depression. This effect is amplified among women. Lack of privacy was also cited in relation to having no safe space at home or work to take medications.
- \* **Side effects of HIV treatment:** these were consistently cited as a barrier to treatment access in the form of long-term adherence for women, and some side effects – especially changes in body shape – had mental health or emotional repercussions, particularly around gender norms and expectations for women's bodies and sexuality.
- \* **Inability to meet basic needs:** including livelihoods, food security, nutrition and housing, and each of these in turn served as a barrier to HIV treatment access and adherence. In the case of food security and nutrition,

**“I do not want to have a stable job because I think they will just fire me. I could not have enough leave to pick up the medication, make checks and other things.”** FOCUS GROUP DISCUSSION, BOLIVIA

women reported prioritizing children over themselves making it difficult for women to access the healthy diets they need to take treatment effectively.

### Meso-level (household, health service and community)

- \* **Gender roles and responsibilities:** including women having to ask permission from husbands or other family members to seek services. This is a significant barrier to treatment access, as is the related lack of access to and control of resources that would allow women to move freely.
- \* **Violations of rights to privacy, confidentiality and bodily integrity in healthcare services:** these were frequently cited as barriers to accessing treatment, particularly for women from key populations. Violations include: disclosure of HIV status in front of family members and other staff and clients; refusal of treatment and care for themselves and their children; human rights violations during and after labour, as well as forced and coerced sterilization.
- \* **Poor communication in healthcare:** limited time with and effort by healthcare providers to address women's concerns and deliver full information, including outlining the benefits and complications of treatment, what to take and when, and drug interactions that are frequently ignored or dismissed by healthcare staff. Women cited a lack of counselling, being unable to ask questions, side effects not being discussed, and being pressurized to make quick decisions without adequate information.
- \* **Mental health and self-stigma:** women described experiencing internalized stigma resulting in depression, low self-esteem and self-worth, and other mental health

problems. These can impact on their health-seeking behaviours, including treatment access and adherence.

- \* **Care-giving responsibilities:** women's expected role of caregiver was cited as a barrier to treatment. Women described taking children to the clinic due to unavailable or unaffordable childcare, and missing appointments due to family caregiving responsibilities.
- \* **Stigma and discrimination:** women from marginalized groups (i.e. women engaged in sex work, transgender women, women who inject drugs) or partners of men who are at increased risk of HIV, face high levels of stigma and discrimination in healthcare settings and the community that impede their access to treatment.

### Macro-level (national and policy)

- \* **Punitive laws, including criminalization:** these exacerbate structural and community violence against women living with HIV and/or from key affected populations and impede access to treatment.

## Facilitators

- \* Women reported strong positive experiences with peer-led treatment literacy and support groups, with these experiences directly linked to accessing and remaining on ART over time.
- \* Women cited building trusting relationships with healthcare providers as important to staying on treatment.
- \* Many women reported finding strength, value and motivation from their roles within families as mothers, partners and caregivers, as well as leaders within their communities.

## Recommendations: a six point plan for action

There are detailed, topic-specific recommendations throughout the full report, organized around women's experiences at micro-, meso- and macro-levels. However, a key finding of the review is that progress is hampered by narrowly defined approaches focused on a specific intervention (testing, ART, adherence support) or level (individual, community, structural). There is overlap in issues, themes and experiences. ATHENA, AVAC and Salamander Trust have therefore developed an over-arching six point action plan relevant to the whole process at all levels and across all interventions.

### 1. Human-rights: Define, implement and evaluate access in a rights-based framework that encompasses availability, affordability, acceptability and quality of care, to address gender-related social and structural barriers. This must include rights-based, voluntary and informed choice, with real options for women, so they can decide if and when to start, and how long to stay on treatment.

- \* Implement a minimum package of services including ensuring that "Know your rights" and treatment literacy programmes are available to all women on treatment in the community, and in health and other related settings (e.g. with police and prison staff).

5. Leigh F. Johnson and Andrew Boule. "How should access to antiretroviral treatment be measured?" *Bulletin of the World Health Organization* 2011;89:157-160.