Develop a rights-based research agenda in the intersectionality with other structural factors.

- 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 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-research 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.

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.

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).

Background
An overdue effort
In collaboration with UN Women, ATHENA Network, AVAC and Salamander Trust undertook a global multi-stakeholder review of the status of access to antiretroviral therapy (ART) for women living with HIV.1 Since the beginning of the HIV epidemic, this is the first ever peer-led global study of care and treatment 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.2 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 factors1 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 of ART, 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’ targets3.

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

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 programme 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 way.

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 treatment. Sunckel-Cotterell, A., AIDS, 2009, Jun 15, Suppl 1: S3-S10.

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 antiretroviral therapy; 90% of all people receiving antiretroviral therapy will have viral suppression.

1. Tenovus-based pre-exposure prophylaxis (PrEP) using daily dosing of one or two antiretroviral ARVs is being introduced as HIV prevention for HIV-negative men who have sex with men. The terms PrEP and ART are used interchangeably in this review. There, we only review access to ART by women who know they are living with HIV, in the context of treatment for their HIV.

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 who are 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, Tuberculosis, Malaria, UNAIDS and other sources; 2) Community dialogues via focus group discussions (FGDs) in Bolivia, Cameroon, Nepal and Tanzania of 175 women [175], consultations with the 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 interviews and FGDs were included in this phase; 3) Country case studies undertaken in Kenya, Uganda and Zimbabwe with in-depth focus groups [10, 10, 14], one-to-one interviews [6, 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): 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 East Africa. Pangea Zimbabwe AIDS Trust worked with members of the GRG to conduct case study work in Zimbabwe.

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 has been 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 sex-disaggregated data in dis-aggregated 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 they relate specifically 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.* Option B+

1. Human-rights: Define, implement and evaluate access in a rights-based framework that encompasses availability, affordability, acceptability and quality of care, to address health system 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.

2. 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).


8. options: the lack of cloning, to be able to answer questions, side effects not being discussed, and being pressurized to make quick decisions without adequate information.

9. 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 caregivers 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 impedes 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 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 health system 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.

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