

# Global Treatment Access Review

## Participatory Methodology

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1. ATHENA Network, AVAC, and Salamander Trust with UN Women, undertook this multi-stage review of the global status of access to antiretroviral therapy (ART) for women living with HIV
2. This is the first international study of care and treatment access issues for (and by) women living with HIV
3. This global review takes place at a critical point in the HIV epidemic where increased focus is being placed on strategic investments in health - based on the specific national and regional epidemic contexts and commitments, in parallel with the rollout of new World Health Organization treatment guidelines, which promote early testing and treatment.
4. Currently, little is understood regarding access of women living with HIV to care and treatment across the lifecycle, in particular, for adolescent girls and women not currently pregnant. This multi-phase global review was carried out to understand on-going and emerging barriers that women living with HIV in all of their diversity face in accessing HIV-related care and treatment
5. This review is informed by and interrogates the interplay of structural factors that affect overall access to health and resources of women with HIV. These structural factors must be addressed in a human rights-based approach to policy, programmatic and budgetary responses and interventions that consider the visions, needs and rights of women living with HIV.

## Presentation overview

- What research exists?
- Research questions
- Theoretical Framework
- Key review principles
- Methodology
- Emerging themes from 'Holistic-wellbeing' pre-consultation exercise

## Doing things differently

- Major **gaps** in research and data exist
- Few **inclusive** studies exist
- **Women with HIV are best placed** to frame and prioritize issues and areas to be interrogated
- Each phase of this project looked at macro-, micro- and meso-**levels**

1. There are major **gaps** regarding information on women's access to care and treatment across the lifecycle, in particular for adolescent girls and women not currently pregnant. – We need to disaggregate data beyond age and sex to recognise and track **diversity**
2. Few **inclusive** examples exist of peer-led and -governed analyses of treatment access in which women with HIV are placed at the centre of design and implementation and almost nothing **beyond** tx access for pregnant women
3. Women living with HIV are **best placed** to frame and prioritize the issues and areas that should be interrogated as part of an effort to fill these gaps. **critical** to include evidence-based interventions grounded in human rights, to have any hope of achieving global targets such as **Fast Track**
4. This multi-phase global review, in order to explore barriers and enablers to women accessing HIV care and treatment, sought to address this gap, ensuring a better understanding of the experiences, realities, needs, visions and priorities of women with HIV in relation to treatment access. This was conducted within the framework of a robust model for the meaningful involvement of women living with HIV. At every phase, ' **micro-** ' **meso-** ' & **macro-level** ', barriers and facilitators were considered, and the analysis interrogates the interplay of structural factors that affect overall access to health and resources of women with HIV.

## Learning from past research



- **Grassroots-up** research design with on-going community involvement, is *essential* to address an epidemic effectively

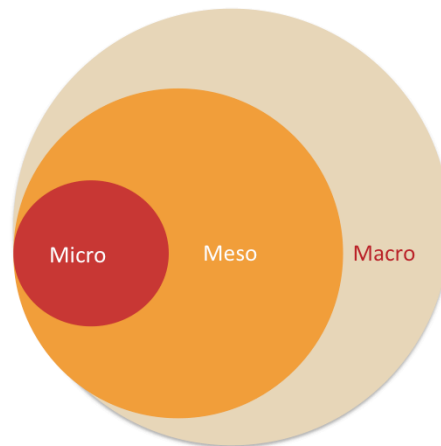
- Quantitative not enough – **mixed method** approaches key
- **Qualitative precedes and informs** quantitative
- Intrinsic and instrumental benefits of **MIWA**
- Women living with HIV are **early warning systems** – not anecdote

### BACKGROUND NOTES –

1. **Grassroots**, research - The challenge of research is often the need to think of social and behavioural contexts more than medical; to succeed, we must better understand which routines and methods work best for women in stressful daily conditions.
2. [If the offered methods are not used, then researchers must rethink their approach or at-risk women will continue to acquire HIV, and the epidemic will spiral. A clear example of this was the **VOICE** trial - Most of the women who participated in the VOICE study did not use the tablets or gel, but those who did were protected. In other words, the study failed not because the products didn't work but because they weren't used. The researchers said the women had "lied" about their use of these. Such language is unacceptable. As Professor Ida Susser explained, bad workmen blame their tools. The research strategy was not fit for purpose and the researchers clearly did not adequately understand what was going on in the women's lives. Most people lie for a reason – because they fear telling the truth will land them in trouble or danger. If people don't tell the truth those in power have to try to understand *why*, instead of just blaming them. ]
3. The power of using **mixed methods** approaches – A good example of this is from Raab and Stuppert's: Evaluation of Evaluations of VAWG programmes for DFID 2014: recs re mixed methods approaches. Kim quote from this: page 20 (from "Participation also...)
4. **Qualitative informing quantitative** – An example of this is from the JHU international Wave Study on urban adolescent girls' sexual health in 5 different sites. Qualitative preceded quantitative. The strength of this was clear when the JHU team realised they had to "tear up our quantitative questionnaire and start again" after the qualitative study. Dr Kristin Mmari, Jan 2015, UNFPA meeting on SRH of 15-19 year old girls. (They used Photovoice, community mapping & in-depth interviews in the qualitative research.)
5. MIWA – both intrinsic **RIGHT** and also instrumental – as....
6. **Early warning system** – see lessons learnt from the 2004 tsunami - Wiltshire, Alison (2006). [Developing Early Warning Systems: A Checklist](#) (PDF). Proceedings of the 3rd International Conference on Early Warning EWC III, Bonn (Germany),.

## Research question: "What are the treatment barriers that women are experiencing?"

Exploring Treatment Access at different levels



The structure of the findings from this review follows the analytical model, examines barriers at the individual, home and community level (micro); at the structural level of services and infrastructure (meso) and at the broader societal level determined by economic, environmental, legal and policy factors at the national level, which are in turn influenced by global geo-politics (macro). Key questions under each of these areas are summarized below.

### Key Questions asked in this review were as follows

#### Micro-level: psychosocial community-level issues

Key question for women:

What is the role of HIV-related stigma and gender discrimination and inequality in antiretroviral treatment (ART) access at the individual, household and community level? Specifically, how do social norms regarding gender and HIV interact to influence access and adherence to treatment?

#### Meso-level: health-service level issues

Key questions:

How does knowledge and access to information on HIV shape access to treatment options, care and services?

How do health services enable or obstruct continued access to treatment?

#### Macro-level: national-level, big picture issues

Key question:

What is the impact of national policies and laws, corruption, conflict, natural disaster, internal displacement, health system shocks (e.g. Ebola) and political turmoil on treatment access?

“I am living with HIV since 2007; **married** and I’ve got two sons. After several years of marriage, my husband was very ill and his health deteriorated so much, we went to the hospital and after doing lot of tests and analyses proved to us that he was infected with the **virus**, and a few days after **his death**, doctors have conducted tests for me and my sons. I was **shocked to discover my disease** and since started my journey with the torment of society that does not have mercy on the one hand and on the other hand, **his family refused to accept us, me**. It did not stop at that, even my sister accused me of moral corruption because of the virus and then she and **my brothers kicked me off** from my father's house, where I didn't go there since. I was also exposed to many cases of stigma and discrimination, for example; while I had to stay in hospital for several days, and specifically in **the Department of Rheumatology** the medical team put a banner reading: “**Beware sick with AIDS**’.”

Tunisia

## Key principles of Global Review

KEY DOCUMENTS: WHO 2001; ICW 2004

Further key elements:

- MIWA
- Appreciative Inquiry
- Interactive – building on experiences
- Dual learning
- Grounded in diverse realities

**WHO 2001: Ethical and Safety Recommendations for Research on Domestic Violence Against Women**

**ICW Ethical and Safety Recommendations for Research on Domestic Violence Against Women**

## Participation in the review:

“At the end of every discussion everyone felt very happy to share their experiences ... They recommended that every discussion and problem they shared should be implemented for advocacy ... They want that the next generation should not face the same problems that they are facing now: We hope, and our expectation is, for not only a change but a huge revolution in the place where we belong.”

**GRG Facilitator, Nepal**



## Methodology

### Facilitated by women living with HIV

A **Global Reference Group** of 14 women living with HIV in all their diversities guided the project

- **Phase I** discussion to set parameters for an extensive literature review
- **Phase II** discussions to further investigate key themes and to gather new information on women's experiences of treatment access.....

A Literature review, listserv of women living with HIV, a pre consultation of the Global Reference Group and additional desk research enabled us to identify important **GAPS between** what is documented in the **literature** and the **real lived experience** of our peers.

We realised that we needed to approach this in a way that allows for the gaps to be seen and **not just to ask the same 'barriers to treatment' questions** as have been asked for many years, which would elicit the same answers.

**Research fatigue is a reality** and by developing a more encompassing approach we hoped to have discussions that are relevant, meaningful and useful for the groups in each country as well as feeding into the Global Review.

## Methodology contd.

### **Phase II discussions** involved:

- FGDs in 4 countries by women with HIV with 175 women
  - listserv discussion with 19 women from 12 countries
  - in-depth interviews with 9 women from 8 countries
  - **197 individual women with HIV in all their diversities from 17 countries involved**
- **Phase III** in-depth **country case studies** – Zimbabwe, Uganda, Kenya
    - in-depth FGD and key informant interviews using tools refined by experience with Phase II
    - policy analysis of key parameters (also defined by Phase I, II)
    - and epidemiological background

## Women living with HIV across the life-span in all our diversities

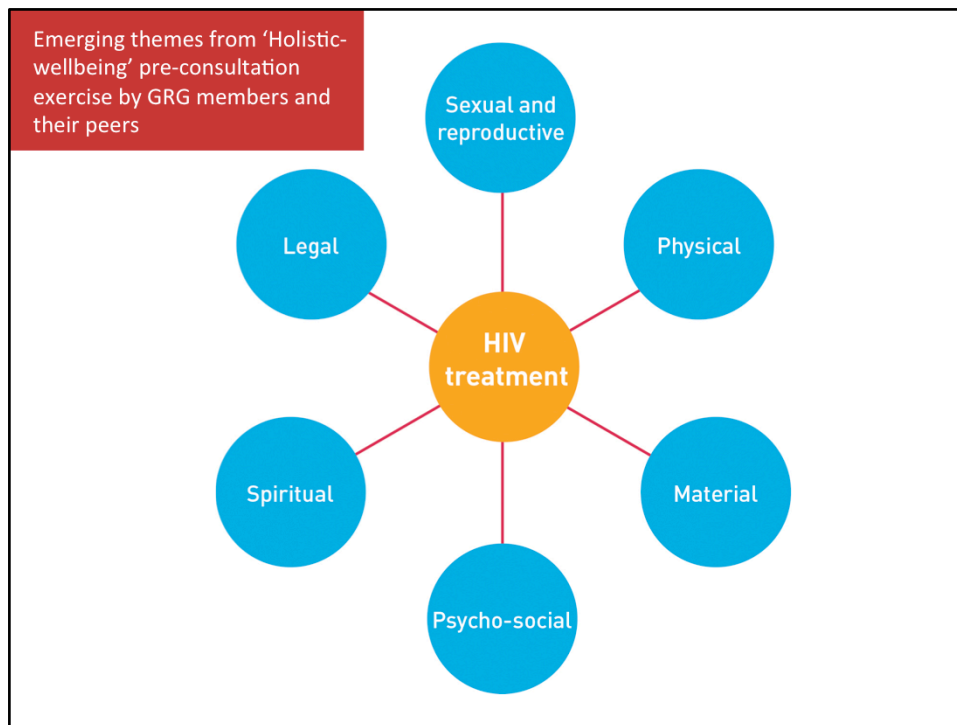
- Inclusion of women with HIV in all our diversity!
- Women with lived experience of treatment
- Phase I and II informed Phase III



“If the messaging about treatment, adherence and healthy living starts young and continues, it is easier for us to understand why it [treatment] is important. ... There is nothing for children or young people about this.”

Interview, Nepal

1. Through peer outreach, every effort was made to ensure that women in all their **diversities** were meaningfully involved: including young women, women with experience of sex work, drug use, trans women, widows of migrant workers and other potentially marginalizing factors such as living in poverty.
2. All women who took part in the focus groups, listserv discussions and one-to-one interviews **are accessing ART** and shared experience regarding **barriers** to accessing treatment.
3. Findings framed in-depth “country case studies” (**Phase III**) which has provided a deeper look at the context of access in specific locations.

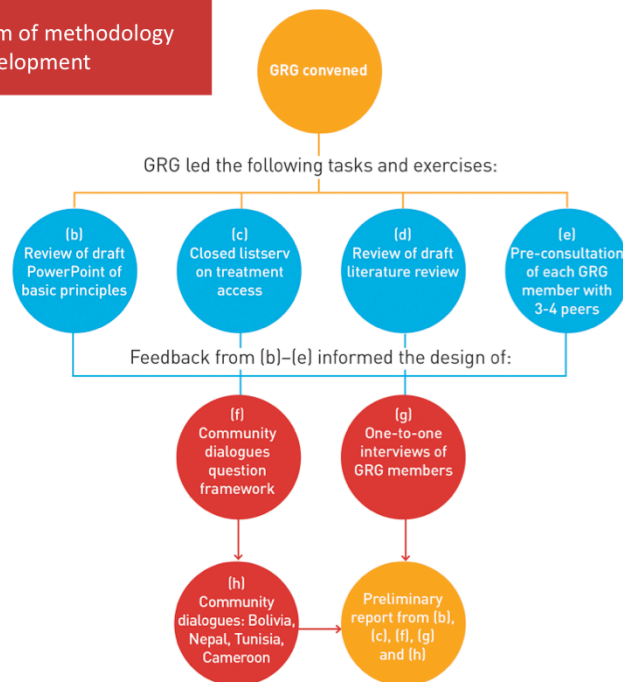


a) To start everything off, we conducted what we have called a “holistic well-being” pre-consultation exercise with GRG members and 3-4 of their peers, to produce emerging themes around tx barriers and enablers for women living with HIV in all their diversities.

b) **Availability, affordability, acceptability and quality of care** components can be explored in ways that yield information critical to the development of effective, woman-owned and –led care, treatment and support programs, when the construct of access is viewed from a gender-responsive and human rights-based perspective. Only with such an approach, will expansion of and adherence to ART succeed.

c) These structural factors must be addressed in a **human rights-based approach** to policy, programmatic and budgetary responses and interventions that consider the visions, needs and rights of women living with HIV.

Flow diagram of methodology  
process development



# Thank you

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“The participatory methodology is an exercise of empowerment at individual and community level. There are no experts, saviours or victims when we use this methodology, we learn and help one another. In all areas of life, women are the experts.” Violeta Ross



# Global Treatment Access Review Findings

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Dorothy Namutamba  
ICW East Africa  
Programme Manager  
*Phase III Case Studies, Uganda and Kenya*



## Presentation Overview

- Introduction: Findings from Global Treatment Review
- Data Findings
- Progress in access & adherence
- Micro-Level barriers
- Meso-Level barriers
- Macro-Level barriers





## Introduction

- **First ever global study** of care and treatment access for women living with HIV of this scale led by and for women living with HIV
- Deepening our understanding to achieve global goals including 90-90-90 and “Fast Track” targets
- Information helps women understand **when, whether** to start and **continue** with treatment

1. Before this current research, there has been almost no interrogation from women’s perspectives of *why* women are choosing not to continue with treatment - This study is overdue – As a woman living with HIV – I was involved in facilitating the FDGs in Zimbabwe and we did not learn anything new – women have been saying the same things for years but no one has been listening and documenting their challenges and concerns – for the first time this study provides us with this space to finally put down as part of the formal evidence base the challenges that we are facing in our homes, communities, health care centers and lives
2. global goals - To achieve global goals such as **Fast Track** we need to understand and address key barriers to and facilitators of women’s HIV treatment – especially in light of **START** study findings
3. As the UNAIDS document on START emphasizes “Protection of human rights is critical to effective health responses. In the context of HIV, access to antiretroviral therapy is a fundamental aspect of the right to health and to life. Recognition of this right calls for redoubling efforts to ensure early access to antiretroviral therapy for everyone, everywhere. The implementation of expanded access to antiretroviral therapy should uphold key human rights principles such as **informed consent, privacy, confidentiality and non-discrimination. Under no circumstance should efforts to expand HIV testing or treatment involve coercion or mandatory approaches. It is critical that individuals be provided information to allow them to make informed decisions about treatment initiation.**
4. Removing barriers and changing policies and programs 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. The UNAIDS “Fast-Track” goals include the following targets: By 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.

"I take 9 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



"Some husbands do not want their wife to go to the hospital. In this case the woman goes to hospital secretly ... she will miss the appointment if she can't justify the reason to go out the day that she is supposed to collect medicine."

FGD among Muslim women, Cameroon

Dorothy added her own experience about pill burden (and length of time on pills daily) & confidentiality issues

## Findings: Data

### Data on ART initiation & retention:

- not disaggregated by age and sex/gender

### Uneven progress in access & adherence:

- Initiation: more (peri-natal) women than men
- Retention: more men than women

### Extra data needed for gender- and rights-based approach to ART:

- Sex workers, trans men & women, adolescent girls, young women - *women of any age who are not pregnant/lactating*
- Documentation of women's experiences as patients:
  - confidentiality, treatment literacy, disrespect, abuse

1. There are major gaps in the data being collected. 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).
2. Uneven progress in access and adherence – Although Women emphasized that access to ART has improved, sometimes dramatically, since their diagnosis many years ago but there is **much room for improvement** —progress in addressing underlying factors that facilitate not only starting but *remaining* on treatment is uneven. As ART programs have scaled up, women have had complex experiences accessing treatment, facing violence and discrimination from family and community members and from professionals in the health system, each of whom act as barriers or enablers to ART access.
3. **Major gaps in the data** There are major gaps in the data being collected. 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 gaps in information regarding ART access for women in many of their diversities—sex workers, transgender men and women, adolescent girls, young women and indeed 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. Although (based on available sex/gender-disaggregated data) women initiate ART more frequently than men, many women do not remain on ART and may even have lower retention rates over the long-term than men. Option B+ rollout in several countries has been characterized by high levels of “loss to follow up” and lower rates of adherence.

## Findings: Micro- (Individual) Level Treatment Barriers

- **Violence** & fear of violence most commonly cited barriers – partner; family; community
- Includes stigma and discrimination
- Side effects of HIV treatment: eg appearance; sexuality
- Inability to meet basic needs: housing, food security, livelihoods – women prioritising children & others

*“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*

1. Violence against women living with HIV: this, coupled with fear of violence, were the most commonly cited barriers for women.
2. In the home, 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.
3. 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<sup>10</sup> – had mental health or emotional repercussions, particularly around gender norms and expectations for women’s bodies and sexuality.
4. 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, women reported prioritizing children over themselves making it difficult for women to access the healthy diets they need to take treatment effectively.

## Findings: Meso-Level Treatment Barriers

- Gender roles and responsibilities
- Violations of rights to privacy, confidentiality and bodily integrity in healthcare services
- Violations during and after labour, including forced and coerced sterilization
- Poor communication in healthcare

1. 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.
2. 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
3. violations during and after labour, as well as forced and coerced sterilization.
4. 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.

## Findings: Meso-Level Treatment Barriers

- Lack of counselling and discussion
- Mental health and self-stigma
- Care-giving responsibilities
- Stigma and discrimination



1. Women cited a lack of counselling in health settings, being unable to ask questions of healthworkers, side effects not being discussed with health staff, and being pressurized to make quick decisions without adequate information by health staff.
2. 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.
3. 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.
4. In healthcare settings: 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

## Findings: Macro-Level Treatment Barriers

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

*“The Legal environment in Uganda and the ‘HIV prevention and control law’ has created lots of fears. People who were strong and accessing medication they are now hiding away because of the fear of being seen and known to be HIV positive now that you can be criminalized for HIV transmission” Interview Uganda*

1. Criminalisation of HIV transmission, of drug use, of sex work and of sexual orientation

“Most of us live in the far village, which takes 1 hour to 2 ½ hours by public transport, which is really costly and some us live nearer to hospital. So some months we don’t visit the hospital to take ARTs too, sometimes we manage to get money from a neighbour if we don’t have our own.”

FGD Nepal



Dorothy added personal comment here



## Findings: Facilitators of Treatment Access

- **Peer-led treatment literacy and support groups** - directly linked to accessing & remaining on ART over time
- **Better adherence** through community support groups
- **Building trusting relationships with health providers** – important to staying on treatment
- **Gaining strength, value and motivation from roles** within families as mothers, partners and caregivers, and as leaders within their communities.



“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

Dorothy added personal comment

# Thank you

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“We do need targeted programmes to develop treatment literacy and treatment advocacy skills and as much as we work in partnership, we do need women only spaces as well because there are very gender specific issues to treatment, not just around pregnancy.” **Interview, UK**



# Global Treatment Access Review

## Recommendations: six point plan

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Alice Welbourn  
Salamander Trust



## A six point plan for action

1. Human-rights

2. Gender

3. Diversity

4. Multiple levels

5. Gender-based community engagement

6. Peer-led involvement

*"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*

## 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.**

**\*\* SERVICES** 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).

**\*\* GBV** Implement gender-based violence prevention and reduction programmes as a core element of HIV care and treatment programming.

**\*\* TRAINING** 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
- **ACCOUNTABILITY** ensure mechanisms exist for women to provide feedback on the quality and effectiveness of services
- **LIFE-LONG** 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.

**\* \* RESEARCH** 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

**\*\* MORE DATA & DISAGGREGATED DATA** 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.

**\*\* BETTER DATA COLLECTION SYSTEM** 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 nonpregnant women.



## 4. Multiple levels

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

**\* \* DIVERSE WOMEN-FOCUSED** 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.**

**\*\* RESOURCE ACCOUNTABILITY** Track resources allocated to community-based groups to ensure that funding is reaching women-led organizations at grassroots level.

**\*\* WOMEN LED** 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.**

**\*\* PEER-LEAD COUNSELLING** Provide peer-support/counselling and mentoring schemes within health services.

**\*\* FUNDING** 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.

**\*\* MORE WOMEN-LED RESEARCH** 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.

# Thank you

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# Global Treatment Access Review

## The Way Forward

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Deirdre Grant  
AVAC



## The Way Forward

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

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Interview, Uganda

