



KEY BARRIERS TO WOMEN'S ACCESS TO HIV TREATMENT: A GLOBAL REVIEW



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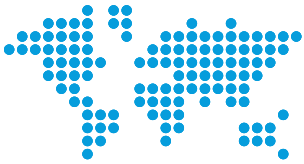


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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome	IPV	Intimate partner violence
ANC	Antenatal care	IRB	Institutional Review Board
ANCs	Antenatal clinics	LMIC	Low and middle-income countries
APN+	Asia Pacific Network of People Living with HIV and AIDS	MHS	Mental Health Survey
ART	Antiretroviral therapy	MSM	Men who have sex with men
ARVs	Antiretroviral medicines/antiretrovirals	NASCOP	National AIDS Control Programme, Kenya
AVAC	AIDS Vaccine Advocacy Coalition	NGO	Non-governmental organization
CAT-S	Community Access to HIV Treatment Care and Support Services	OI	Opportunistic infection
CBA	Community-based assistance	OST	Opioid substitution therapy
CBO	Community-based organization	PEPFAR	The United States President's Emergency Plan for AIDS Relief
DHS	Demographic and Health Surveys	PLHIV	People living with HIV
DREAMS	PEPFAR Initiative for Adolescent Girls and Young Women	PMTCT	Prevention of Mother-to-Child Transmission of HIV
EID	Early Infant Diagnosis	PrEP	Pre-exposure Prophylaxis
eMTCT	Elimination of Mother-to-Child Transmission of HIV	SDG	Sustainable Development Goals
FBO	Faith-based organization	SDOH	Social determinants of health
FGD	Focus group discussion	SRH	Sexual and reproductive health
FP	Family Planning	SRHR	Sexual and reproductive health and rights
GBV	Gender-based violence	START	Strategic Timing of Antiretroviral Treatment
GFATM	The Global Fund to Fight AIDS, Tuberculosis and Malaria	STIs	Sexually Transmitted Infections
GNP+	Global Network of People living with HIV	UNAIDS	Joint United Nations Programme on HIV/AIDS
GRG	Global Reference Group of Women living with HIV	UNICEF	The United Nations Children's Fund
HIV	Human Immunodeficiency Virus	VAW	Violence Against Women
HRBA	Human-rights based approach	VHT	Village Health Teams
HTC	HIV Testing and Counselling	WAPN+	Women of the Asia Pacific Network of People Living with HIV and AIDS
ICW	International Community of Women living with HIV/AIDS	WHO	World Health Organization
		WLHIV	Women living with HIV

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EXECUTIVE SUMMARY

A. Background

In collaboration with UN Women, the ATHENA Network, AIDS Vaccine Advocacy Coalition (AVAC), and Salamander Trust have undertaken a multistage review of the global status of women's access to antiretroviral therapy (ART).

This global review takes place during a turning point in the HIV epidemic where increasing focus is placed on strategic investments in health. Importantly, strategic developments are predicated on the specific characteristics of a region or country's epidemic profile. The strategic investment approach facilitates more focused and effective use of scarce resources. For instance, in sub-Saharan Africa the epidemic continues to differentially impact women and girls. A strategic investment, or invest-for-impact approach, is therefore extremely relevant to women living with HIV. In places with access to treatment, AIDS is no longer a death sentence if treatment adherence is followed. As the global framework for the AIDS response relies ever more intensively on scaled-up ART coverage linked to long-term suppression of HIV, the impact of strategic investments in health holds significant importance for women and girls.

In 2014, UNAIDS "Fast-Track" goals for ending the epidemic promoted the 90-90-90 approach. The objective is that by 2020, 90 per cent of people living with HIV will know their status, 90 per cent of those individuals will initiate ART, and 90 per cent of those on antiretroviral therapy will be virologically suppressed. In 2015, the World Health Organization (WHO) issued new guidelines recommending antiretroviral therapy be offered immediately to everyone living with HIV regardless of CD4 cell count, with priority to symptomatic people and those with a CD4 count less than 350. In addition, it called for people highly vulnerable to HIV infection to begin daily oral pre-exposure prophylaxis (PrEP)

as part of a combination of prevention approaches. These guidelines have been clarified and expanded on in 2016. Early results released from the Strategic Timing of Antiretroviral Treatment (START) study show that early initiation on antiretroviral therapy can lower the chances for people living with HIV to develop AIDS or other illnesses. Additions to the current WHO guidelines include recommending that all people living with HIV begin treatment as soon as possible and remain on treatment for life.

Considering these developments, UN Women and review collaborators identify an urgent need to assess if treatment programmes are reaching women living with HIV, in all their diversities. It is crucial to understand what is known about factors that govern individual choice regarding ART initiation, continuation and adherence/retention in care. It is equally important to identify gaps in knowledge.

This review is informed by a gender-responsive and human rights-based framework to explore the micro, meso and macro level factors that impact women's experiences of treatment availability and their decision-making processes around its uptake. Findings presented in this report address the interplay of structural factors that affect women's overall access to health and resources. The analysis encompasses factors including –but not limited to– poverty, economic security, decision-making, stigma and discrimination. Approaching the construct of treatment access from a gender-responsive and human rights-based approach yields valuable insights into the availability, affordability, acceptability and quality of components. This knowledge is critical to the development of effective, women-owned and women-led care, treatment and support programmes. Without such an approach, expansion of antiretroviral therapy cannot succeed.

BOX 1

Framework: Gender-responsive human rights-based approach

“A human-rights based approach (HRBA) aims to support better and more sustainable development outcomes by analysing and addressing the inequalities, discriminatory practices (*de jure* and *de facto*) and unjust power relations which are often at the heart of development problems.... Elimination of all forms of discrimination is at the core of HRBA. Gender mainstreaming is a key strategy to achieving gender equality and eliminating all forms of discrimination based on sex.” (WHO, 2009)²

Goal - All programmes, policies and technical assistance should further the realization of human rights.

Process - Human rights standards and principles guide programming in all sectors. Important components include:

- Participation and inclusion
- Equality and non-discrimination
- Accountability

Outcomes - Focus on capacity development of duty bearers to meet their obligations and of rights holders to claim their rights.

A human-rights based approach to health aims to realize the right to health and other health-related human rights.

A gender-responsive lens asserts that all genders have rights: “entitlements to the conditions, including access to health care, that will enable them to protect and promote their health; to participate meaningfully in the decisions that affect their lives; and to demand accountability from the people and institutions that have the duty to take steps to fulfill those rights.” (UN Millennium Project, 2005: 4)³

We contend that these findings have profound implications for policy, programmatic and budgetary responses, and interventions that address the needs and rights of women. If policymakers are to ensure that biomedical responses are grounded in human rights-based approaches that reflect, amplify and are guided by the voices of women living with HIV, it is necessary to transform the design of treatment programmes and resource allocation to aid community efforts.

This review of global treatment access is the first of its kind. Few examples exist that place women at the centre of the design and implementation of peer-led and peer-governed analyses of treatment access. This multiphase global review improves our understanding of the experiences, realities, needs, visions and priorities of women living with HIV in relation to treatment access. The review uses an extensive, multiphase methodology and the meaningful participation of women living with HIV.

B. Review Objectives

This review informs the coordinated efforts of stakeholders striving to achieve the UNAIDS “Fast track to end AIDS 2016-2021” strategy.¹ This approach aligns closely with the Sustainable Development Goals (SDGs), a mandate for global collective action to tackle complex problems and improve the well-being of all populations. Ending AIDS is an integral part of the SDG mandate. The UNAIDS strategy recognizes the importance of addressing the holistic needs of people living with HIV. In line with this goal, the primary objectives of this report are to:

- Increase understanding of the dynamics of antiretroviral coverage and access for women globally by adding to current indicators with in-depth knowledge from lived experience.

- Identify key barriers to HIV care and treatment within psychosocial, household, family and community (micro), health service (meso) and national (macro) spheres of influence.
- Renew discussion on measuring treatment accessibility using frameworks that assess women's ability to obtain broader health services.
- Study accessibility barriers in country-level assessments.
- Develop key findings to inform and provide recommendations for policy and programming.

This executive summary highlights findings from:

- **An extensive review of peer-reviewed and grey literature** related to women's access to treatment and an unprecedented analysis of available sex-disaggregated data provided by PEPFAR, GFATM, UNAIDS and other sources.
- **An innovative, participatory, global dialogue with women living with HIV** via country-based focus group discussions (FGDs), one-to-one interviews and a virtual dialogue space. All data collection tools for this phase were designed and implemented by women living with HIV, with oversight from a global reference group (GRG) of women living with HIV.
- **Three country case studies** involving FGDs, literature reviews, and policy scans.

C. Methodology Overview: A Three-phase Approach to Amplifying Women's Voices

A three-phase design guides this global review of women's access to antiretroviral therapy; each stage informed development of the next.⁴ Data collection took place from July – August 2014 (literature review); September – December 2014 (community

dialogues); and April – July 2015 (case study FGDs and interviews). The literature review identified current knowledge about women's ability to access ART and highlighted key knowledge gaps (Phase 1). Emerging themes from the literature review were used to frame discussion guides for 12 community dialogues and nine one-to-one interviews held with women across four countries. An online forum was also available to encourage participant input and discussion (Phase 2). The experiences of women raised in dialogues and interviews were compared with findings from the literature review and provided general themes explored in subsequent case studies of three countries (Phase 3). Further, an updated literature search was conducted between September – December 2016 to include recent studies.

The three interconnected phases of this global project were designed, implemented and/or validated by women living with HIV. At every stage, the research used a multilevel framework of analysis to identify barriers to women's access to antiretroviral therapy in the following spheres of influence: within psychosocial, familial, household and community (micro); health service (meso); and national and geopolitical (macro) spheres of influence. The participatory approaches used in this review placed women living with HIV in leadership roles in designing, implementing and reviewing findings.

Phase 1

An initial literature review was used to identify questions and gaps in the existing peer-reviewed and grey literature related to women's access to treatment. This analysis also obtained unprecedented amounts of sex-disaggregated data from PEPFAR, GFATM, UNAIDS and other sources.

Summary of methodology: Database searches were conducted in PubMed, Popline and Google scholar using key terms (Box 2). Searches also examined national/global datasets (UNAIDS progress reports, PEPFAR, Global Fund) and information gleaned from

BOX 2**Keyword Search Terms (Phase 1)**

Treatment	Stage	Barrier/Factor	Sub/key pop.	Services	Status
Treatment	Women	Gender (in) equality	Injecting drug users (IDU)	Access to service	HIV positive
ARVs/ART	Girls	(Social) norms	Sex workers/ Female sex workers/ Community sex workers	Barriers to services	Living with HIV
ART/antiretroviral treatment[1]	Pregnant/ pregnancy	Violence	Migrants	Experiences of services	
Option B+/ Option B plus		Adherence	Refugees	Community-based	
PrEP		Mandatory testing	Serodiscordant	Assistance with disclosure	
		Retention	Partners of MSM	SHRH	
		Gender-based violence/GBV	Key populations	Family-based care	
		Intimate partner violence/IPV	Marginalized (women)	Peer-to-peer support	
		Disclosure			
		Criminalization			



Completed search & included in review



Searched but found little sex-disaggregated data in these key areas

national health/HIV surveys. Project partners supplemented the exploration by soliciting research from their partners/contacts through listserv requests. We included documents that had been published in the last 10 years, with exceptions for older foundational studies. Simple searches were employed (i.e. treatment + HIV + women), followed by more complex combinations of words to elicit specific information (Box 2).

This review focuses on creating a broader contextual narrative of women's experiences. Except for context-level data, many of the studies included in this literature review are smaller in scale. They provide insight into specific components contributing to the experiences of women and girls living with HIV in accessing and adhering to treatment. These studies

also provide limited material about methodology and information regarding study participants. The review focuses predominantly on small-scale participatory, qualitative studies as a valuable supplement to quantitative data. Participatory methodologies generally promote power sharing over research and findings and encourage openness, clarity of terms, and richness of detail about the context of people's lives.

Phase 2

The literature review findings helped to inform the structure and focus of a discussion guide developed to facilitate peer-to-peer sharing of experiences, concerns, questions and recommendations from women

living with HIV in all their diversities. This discussion guide was used in a series of community dialogues in Bolivia, Cameroon, Nepal and Tunisia, and was adapted for one-to-one interviews with women living with HIV.

Summary of methodology: Community dialogues among women living with HIV were conducted through 12 peer-led FGDs in four countries and more than four languages, nine in-depth one-to-one interviews, and a moderated online community forum from September to December 2014, utilizing peer-developed and peer-reviewed discussion guides. The work was guided by a global reference group (GRG) of 14 women living with HIV from varied contexts, including women at different stages of their lives and a myriad of experiences with using drugs, sex work⁵, conflict, migration and detention and prison. Some participants were also lesbian and transgender women.

The goal of community dialogues was to gain a first-hand understanding of women's experiences accessing and engaging in HIV-related care and treatment. This effort helped to clarify the different contextual barriers (and enablers) to treatment access and adherence women experience at micro, meso and macro levels and how these intersect. The purpose of the dialogues was to validate and reveal any gaps in the literature review and inform country case studies, which constituted a third stage of the review.

The dialogue framework employed a holistic, woman-centred "continuity of care" approach. For instance, it included consideration of basic needs, and quality of services as core elements of accessing and utilizing HIV care and treatment, as well as more traditional considerations such as distance to health-care services, transport costs and child-care. Importantly, a continuity of care approach concerns the quality of care over time.⁶ Discussions and interviews were explored using thematic analysis⁷ and a subsequent framework for Phase 3 FGDs was developed. The findings are intended to be a "living, breathing" picture of how issues play out in

communities and cannot necessarily be generalized. It is possible, however, to build upon the commonality of experiences such a global study of diverse women suggests. Given the multitude of perspectives included in this review, the findings may well reflect the experiences of women from around the world living with HIV.

Phase 3

Themes and issues that emerged in community dialogues and related activities were then used to structure the third phase of country case studies. At this point, further qualitative research was undertaken using updated/adapted FGD guides that reflect the insights generated by community dialogues.

Summary of methodology: Countries and partners identified groups of women from focal areas and participants were selected from these groups for FGDs. Contributors included young women and adolescents, some of whom had acquired HIV perinatally in Zimbabwe, and women accessing ART via Option B+ programmes in Kenya and Uganda. To prepare for the country case studies, the Phase 2 community dialogue framework for guiding discussions was reviewed by Pangaea Zimbabwe AIDS Trust for Zimbabwe and the International Community of Women Living with HIV/AIDS (ICW) Eastern Africa for Kenya and Uganda.

Following the review, an adapted discussion guide for FGDs emerged. The two country, context-specific guides were compared, reviewed by UN Women and, in Uganda and Zimbabwe, submitted for local Institution Review Board (IRB) approval.⁸ The final guide was then submitted for acceptance to the respective IRBs – the Medical Research Council of Zimbabwe and the Uganda Council of Science and Technology. Fieldwork began following approval of the interview guides and consent forms. The Kenya country case study used previously established approaches for community-based participatory research both to inform participants about the study goals and to obtain informed consent. Data were analysed by

social science researchers employed or contracted by the implementing organizations.

Analysis of this project was framed by the three levels of influence that shape women's treatment access: micro, meso, and macro. The micro level looks at individual, household, family and community level issues (i.e. psychosocial, behaviours, norms). The meso level identifies structural issues focused on institutions (i.e. health services delivery). The macro level draws attention to issues at the national level (i.e. laws and policies, conflict, environmental disasters) which are in turn influenced by global geopolitics.

D. Summary of Findings

I. Overall

The three phases of this project exhibit a striking consistency in findings and prioritize the following issues:

- Although there are clear indications of ways to improve access to antiretroviral therapy, data on women's experiences in choosing to start, and stay on, treatment remain scarce. Findings that do exist are not translated into policy and practice.
- Violence against women remains a major barrier to accessing care and treatment, including violence in the home, the community and in health facilities.
- Women in all their diversities welcome the offer of ART in programmes but want this intervention to be presented as a voluntary, informed choice in an environment that is confidential, respectful, supportive, and closely connected to community-based resources for treatment literacy and peer support.
- Many women continue to struggle with transport issues, distance to facilities and waiting times in substandard environments and health facilities that do not respect human rights.

II. Literature Review

The literature review on women's ability to access ART found that:

- Globally, women account for approximately half of all treatment initiations. In some cases, these rates are higher among pregnant women.
- In some contexts, rates of adherence among women are lower than among men. Option B+ roll-out in several countries has been characterized by low levels of retention in care and lower rates of adherence.
- There are major gaps in the data being collected that are essential to guide and monitor a gender- and rights-based approach to antiretroviral therapy including:
 - An absence of and/or gaps in data on treatment uptake, retention in care or adherence data disaggregated by sex.
 - Lack of detailed information on women from marginalized populations such as female sex workers, transgender women, women who inject drugs (or whose partners inject drugs), and wives/female partners of men who have sex with men and who face high levels of stigma and discrimination that impede treatment access.
- There are gaps in national policies and normative guidance regarding ART provision in the context of a gender- and rights-based approach. For example, WHO recommendations are specific to women in some cases (e.g. Option B+). However, these recommendations do not integrate separate concerns about women's access to health care and gender inequality which may inhibit uptake of ART.
- Many women have concerns about the side effects of treatment for themselves and their children and many reported that health-care providers dismiss these concerns.

- Several factors concerning HIV-related stigma *and* gender inequalities mediate women's access to treatment and retention in care including access to income, traditional gender roles, gender-based violence and food insecurity.
- Gender-based violence (GBV)⁹, in the form of stigma and discrimination by health-care staff and poor quality services, is a significant barrier to service –particularly for people from marginalized populations.

III. Community Dialogues

While there has been improvement in access to ART, progress in addressing underlying factors that facilitate starting and remaining on treatment is uneven.

Barriers to Access

- **Violence against women living with HIV**, (including physical, sexual, psychological/emotional, and structural/institutional violence) coupled with fear of violence, was the most commonly cited barrier to access.
- Women experienced **rights violations in health-care settings** in relation to sexual and reproductive health such as ill treatment and human rights abuses and neglect during and after labour, and abuse, coercion, and forced sterilization. These negative experiences led to mistrust of health-care staff.
- **The frequent absence of provider-client discussions** outlining the benefits of treatment, what to take and when, and drug interactions in women's treatment initiation and ongoing care. Women reported **fear of side effects** and the failure to address the full impact of treatment.
- Women identified **inextricable connections between basic needs and access** to HIV care and

treatment. Situated within a framework of social determinants of health (SDOH), poverty, housing insecurity, lack of decision-making in the familial context and inadequate nutrition all remain entrenched barriers to access.

- Women's **lack of autonomous decision-making**, their caregiving responsibilities, and related gender norms and expectations intersect to make initiating and remaining on ART difficult.
- **Violence from partners, family and community members, and employers** in the form of stigma and discrimination also impede ART access. Women mentioned the difficulty in requesting permission from partners and employers to access services during working times and in maintaining confidentiality.

Facilitators to Access

- Women reported **strong positive experiences with peer-led treatment literacy and support groups**, with these interactions directly linked to accessing and remaining on ART over time.
- Women cited building **trusting relationships with health providers as important** to staying on treatment. Participants stressed that access to ART has improved since their diagnosis or since their engagement with ART, including for women who occupy intersecting marginalized identities or contexts.
- 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.
- In summary, participants observed **the distinct value support plays** in helping them to start and stay on treatment. Key sources of encouragement include peers, health-care providers and community and family members.

IV. Country Case Studies

- **Service delivery models in many contexts do not meet women's needs** in terms of accessibility, protecting confidentiality, providing safe, respectful and rights-based care nor do they provide clear, comprehensible and consistent information about antiretroviral therapy regimens, whether for Option B+ or for women who are not pregnant.
- **Programmes fail to meet the needs of women in all their diversities.** Young women and adolescent girls identify impediments associated with utilizing clinics for adult women and in the process of transitioning from paediatric to adult care. Despite WHO guidelines that prioritize key populations, programmatic translation is limited; country-level literature reviews underscore that sex workers and other marginalized women are not well-served by “general population” programmes.
- **Gaps in treatment literacy and in financial support for community-based, peer-to-peer support** (e.g. mentor mother programs) leave many women with unanswered questions about their medications, and/or issues with side effects that can lead to discontinuation or complications with adherence.
- **Roll-out of Option B+ is welcomed** for providing an opportunity for treatment access. However, when the programme is not presented as a choice for women, when male involvement is required, and when it is inconsistently implemented across a country (e.g. different regimens in different districts), it fails to deliver the type of service that women need and want during and after pregnancy.

E. Recommendations: A Six Point Plan for Action

There are detailed, topic-specific recommendations throughout this document. Taken together, and distilled to core issues, we recommend the following six-point plan for action:

- 1) **Human rights:** Expand definitions of access to include rights-based, voluntary and informed choices with full information and appropriate medical guidance. Address gender-related structural barriers to initiate, continue, and adhere to 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, in health and other related settings (e.g. with police and prison staff).
 - Implement gender-based violence prevention and reduction programmes as a core element of HIV and AIDS care and treatment programming.
 - Make delivery of services safe for women through rights-based training for service providers to: improve their ability to address and minimize gender-specific HIV-related vulnerabilities in health-care settings; ensure providers are trained and resourced to offer antiretroviral therapy thereby supporting women's decision-making and providing adequate information and support on treatment uptake and adherence, and on side effect management; make certain mechanisms exist for women to provide feedback on the quality and effectiveness of services; and provide quality lifelong, life stage appropriate sexual and reproductive health care 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 intersections with other structural factors.
 - Develop a rights-based research agenda in collaboration women living with HIV and related to implementation of Option B+, and with new WHO guidelines.¹⁰ This step is urgently needed to provide systematic information on factors affecting voluntary choices around initiation, continuation and adherence/retention in

treatment during pregnancy and lactation and extends to programmes that have yet to incorporate updated and consolidated WHO guidelines.

- 3) **Diversities:** Fill the data gaps that exist across the HIV treatment cascade (care continuum) 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 antiretroviral therapy, including:

- A rapid scan of existing and missing data that are routinely reported by treatment programmes targeting women, e.g. Option B+, test and treat and those for serodifferent (serodiscordant) couples where one partner has HIV and the other does not. Follow with 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 (GFATM), 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.

- 4) **Multiple levels:** Ensure that care and treatment packages include basic needs and account for gender-specific barriers at individual, household, family, community, institutional and national 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, and others).

- 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.

- 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; there remains, however, 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 employ a participatory methodology and a holistic, well-being approach to understanding women's treatment access, adherence and health.

It is our hope that this extensive review catalyses change and encourages robust dialogue at international and national levels in the physical spaces and communities where new and existing forms of antiretroviral therapy are offered. Women's voices are clear, consistent and urgent in their articulation of what must be done to create a woman-centred, rights-based approach to holistic health and well-being. It is also our ambition that the methodology used here will be adapted and expanded upon as a basis for continuing to monitor progress and map gaps in the global HIV response.

DEFINITIONS

Treatment

In the context of this report, **treatment** refers to medicinal responses for the management of HIV through to antiretroviral treatment. In addition, the definition of treatment can extend to medication for the *management of side effects* or related HIV opportunistic infections. The term treatment is used with the understanding that the benefit of taking the medicine is greater than the potential harm it might do. Where possible, in accordance with the basic principles of pharmacology,¹¹ the dose should be kept minimal and with complete understanding of possible side effects, including how to manage these and how, when and why the drug is being taken.

Access

Access is considered the ability of individuals to obtain and utilize services and treatments to improve their health. The universal availability of affordable, high quality, integrated, equitable, comprehensive treatment services in an environment that is safe, well-informed, confidential, and respectful of the individual increases access. Additionally, to ensure high-quality access, health systems and services need to respond to the barriers that women face in different areas of their lives.

Continuum of Care

The **continuum of care** merges the concepts of care and treatment by seeking to link people living with HIV into a holistic and integrated system of care, treatment and support services to enhance

their health and general well-being. Components of the continuum of care are designed to follow patients over time (from diagnosis to achieving virological suppression and good health) and to monitor their progress through a comprehensive set of services. This system comprises, but is not limited to:

- Regular, supportive, and respectful discussions regarding treatment and care pathways between the woman living with HIV and health-care providers.
- Routine medical tests to monitor HIV progression as well as address other opportunistic infections (OIs), health issues and short- and long-term side effects of ARVs.
- Referrals to support groups, psychosocial assistance/counselling and peer support, as well as legal advocacy to defend abuses of human rights.

The above may require a change to the existing medical culture where treatment is a stand-alone pathway separate from a more holistic package of care and support, and where health services are not reliably patient-centred.

Adherence

Adherence refers to the ability of the individual to consistently take medication in the manner intended by health providers. While adherence focuses on compliance with HIV treatment specifically, “retention” considers an individual’s engagement across the entire care continuum.

Coverage

Coverage is the proportion of people receiving antiretroviral therapy out of those eligible for treatment at the same point in time. Coverage numbers are reported nationally and capture a cross-section of people accessing ART at a given moment in time. Coverage, when disaggregated by sex, can provide insight into the gap women face in accessing treatment but it needs to be coupled with adherence and retention measures to fully realize the continued utilization of services to improve care.

The standard measure for treatment access is typically in the form of coverage and is not routinely disaggregated by age or sex. Johnson and Boulle (2010) address concerns about measuring access through coverage. The robustness of coverage figures is challenged by changing eligibility criteria and is not sensitive to programme performance and enrolment. Another method for measuring treatment access is by using a ratio of ART initiation to HIV disease progression: the enrolment ratio. The enrolment ratio does provide the added benefit of not being cross-sectional (as with classic ART coverage calculations) and thus can more accurately monitor performance. This ratio also offers the advantage of not being sensitive to eligibility criteria¹².

Gender¹³

Gender refers to the socially-constructed characteristics of women and men, such as norms, roles and relationships of and between groups of women and men. It varies from society to society and often changes over time and between contexts. While most people are born either male or female, they are socialized to display certain norms and behaviours ascribed to their sex, including how they should interact with others of the same or opposite sex within households, communities

and workplaces. When individuals or groups do not “fit” established gender norms they often face stigma, discriminatory practices or social exclusion – all of which adversely affect health. Gender norms, roles and relations influence people’s susceptibility to different health conditions and diseases and affect their enjoyment of good mental and physical health and well-being. Norms also have a bearing on people’s access to, and uptake of, health services and on health outcomes they experience throughout the course of their lives. It is important to be sensitive to different identities that do not necessarily fit into binary woman or man gender categories.

Violence against women, intimate partner violence and sexual violence¹⁴

“The United Nations defines **violence against women** as any act of gender-based violence that results in, or is likely to result in, physical, sexual or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.”

“**Intimate partner violence** refers to behavior by an intimate partner or ex-partner that causes physical, sexual or psychological harm, including physical aggression, sexual coercion, and psychological abuse and controlling behaviours.”

“**Sexual violence** is any sexual act, attempt to obtain a sexual act, or other act directed against a person’s sexuality using coercion, by any person regardless of their relationship to the victim, in any setting. It includes rape, defined as the physically forced or otherwise coerced penetration of the vulva or anus with a penis, other body part or object.”

Gender-based violence¹⁵

“**Gender-based violence** (GBV) describes violence that establishes, maintains or attempts to reassert unequal power relations based on gender.”

The term was first defined to describe the gendered nature of men’s violence against women. Hence, it is often used interchangeably with “violence against women”. The definition has evolved to include violence perpetrated against some boys, men and transgender persons because they do not conform to, or challenge, prevailing gender norms and expectations (e.g. they may have feminine appearance) or heterosexual norms.

HIV

The human immunodeficiency virus (HIV) infects cells of the immune system, destroying or impairing their function. Infection with the virus results in the progressive deterioration of the immune system, leading to “immune deficiency”. The immune system is considered deficient when it can no longer fulfill its role of fighting infection and disease. Infections associated with severe immunodeficiency are known as **opportunistic infections** (OIs), because they take advantage of a weakened immune system.

AIDS

Acquired immunodeficiency syndrome (AIDS) is a term that applies to the most advanced stages of HIV infection. It is defined by the occurrence of any of more than 20 opportunistic infections or HIV-related cancers.

How is HIV transmitted?¹⁶

“HIV can be transmitted through unprotected sexual intercourse (vaginal or anal), and oral sex with an infected person; transfusion of contaminated blood; and the sharing of contaminated needles, syringes or other sharp instruments. It may also be transmitted between a mother and her infant during pregnancy, childbirth and breastfeeding.”

Gender-based violence against women living with HIV¹⁷

“Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.”

Structural violence¹⁸

Structural violence, a term coined by Johan Galtung and by liberation theologians during the 1960s, describes social structures—economic, political, legal, religious, and cultural—that stop individuals, groups and societies from reaching their full potential. In its general usage, the word “violence” often conveys a physical image; however, according to Galtung, it is the “avoidable impairment of fundamental human needs or...the impairment of human life, which lowers the actual degree to which someone is able to meet their needs below that which would otherwise be possible.” Structural violence is often embedded in longstanding “ubiquitous social structures, normalized by stable institutions and regular experience”. We take for granted these social structures because they seem so ordinary in our ways of understanding the world that they appear almost invisible. Disparate access to resources, political power, education, health care, and legal standing are just a few examples. The idea of *structural violence* is linked very closely to *social injustice* and the social machinery of oppression.



1

LITERATURE REVIEW

ON HIV AND AIDS

19-21 SEPTEMBER 2016, ODESA

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RESPOND



1. INTRODUCTION

Women account for a disproportionately high number of global HIV cases with the highest burden in sub-Saharan Africa among young women and adolescent girls aged 15-24.¹⁹ Progress in curbing HIV worldwide will depend on understanding what factors enable or deter women from accessing HIV treatment. Treatment access depends on complex intersecting structural and social factors across multiple levels: individual, community, service delivery, and national spheres of influence. The complexity of these barriers is compounded by unique obstacles that women face in connection to traditional gender roles and decision-making opportunities. To our knowledge, a full review outlining the details of these obstacles has not been conducted in the specific context of women living

with HIV. Therefore, this review provides a foundation for understanding the barriers women face in accessing treatment and care and highlights key knowledge and implementation gaps related to women's access to treatment.

Women living with HIV experience a range of opportunities and barriers that influence access to treatment and care.²⁰ Women's ability to use and benefit from treatment on an ongoing basis to improve their health and well-being is shaped by these experiences. This literature review draws on global and national data sets as well as academic and civil society-led research studies to provide a comprehensive overview of evidence regarding barriers and facilitators to HIV treatment experienced by women

KEY QUESTIONS

The following questions guided the literature review and community dialogues (see Part 2):

Context: Current international policy and treatment access landscape

- What are the current key global policies on care and treatment that impact, define and set the landscape for women's access?
- How do policies address gender issues in relation to women and girls?
- What is the status currently of treatment access for women?

Micro Level: Psychosocial community-level issues

- What is the role of HIV-related stigma and gender discrimination and inequality in antiretroviral

therapy (ART) access at individual, household, family and community levels?

- Specifically, how do social norms regarding gender and HIV interact to influence access and adherence to treatment?

Meso Level: Health-service level issues

- 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 sphere of influence

- 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?

within their household, their communities and when accessing health services. Further, it explores the impact of macro factors such as policies, legislation and humanitarian emergencies on women's experiences accessing HIV treatment.

A multilevel focus underscores the many factors that condition women's access to treatment, critical care and support services; such an approach also provides opportunity for interventions and solutions targeted at multiple levels. As increasing numbers of women require access to treatment, it is more important than ever to understand and address the factors that prevent women living with HIV from accessing treatment and gaining long-term health benefits.

2. CONTEXT: CURRENT INTERNATIONAL POLICY AND TREATMENT ACCESS LANDSCAPE

2.1 Global and country policies

Key findings

- There is a move towards early initiation of treatment for all individuals regardless of CD4 cell count and especially of children and pregnant and breastfeeding women.
- WHO recommendations can drive policy at a national level. The WHO's HIV treatment recommendations, while specific to women in some cases (e.g. Option B+), do not integrate separate concerns about women's access to health care and gender inequality. The 2016-2021 UNAIDS Strategy links to the SDGs and highlights the need to incorporate gender equality into HIV policies and AIDS policies, yet if or how this will be incorporated into national policies remains unclear.
- Rates of adherence among women are lower than among men, and during Option B+ roll-out several countries have been marred by rapid up-take and below-average rates of adherence.

Recommendations for further research

- A rapid scan of the types of data that are routinely reported or missing from reports by treatment programmes targeting women (e.g. Option B+) and test and treat and programmes for serodifferent (serodiscordant) couples, 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.
- Ensure that lessons learned from the 2013 WHO Consolidated Guidelines on ARVs and the 2014 WHO Guidelines on ARVs for Key Populations are incorporated into implementation of the new 2016 WHO guidelines. Pay attention to recommendations for antiretroviral therapy initiation in women with intersecting identities such as women sex workers and women who inject drugs.

The global landscape of HIV response has shifted towards an increasingly biomedical approach. Since the early 2000s, when ART became more widely available, emphasis has been placed on scaling up ART. In recent years, there has been considerable focus on

universal access to ART – ensuring that treatment for HIV is available and accessible for anyone who needs it. According to UNAIDS data for 2015, there are 36.7 million people living with HIV²¹ and only 18.2 million people on ART.²² UNAIDS reports that the estimated

number of people requiring treatment is between 17.6 million and 26.8 million.²³ Current global treatment coverage is estimated to be about 61 per cent, although this varies by country and region.²⁴ Many countries have set a goal for treatment access to antiretroviral treatment of around 80 per cent of those in need.²⁵ However, this figure will depend on the guidelines for treatment initiation a country follows.

More recently, the trend has shifted away from a focus on CD4 cell count as an indication of a person's health and their eligibility to start treatment (historic and existing guidelines recommended initiation at CD4 thresholds of 250 or 300). Now, the focus is on early initiation with an emphasis on achieving viral load suppression. This shift came in the wake of evidence showing that people with a continuous undetectable viral load are unable to pass on the virus.²⁶ This change in focus is accompanied by trends away from universal access and towards a "test and treat" approach.

The shift is reflected in UNAIDS' most ambitious targets to date, 90-90-90 by 2020 (90 per cent of people know their status, 90 per cent of people diagnosed with HIV are on sustained ART and 90 per cent of those on treatment have an undetectable viral load). This strategy was launched at the International AIDS Conference in Melbourne, Australia in July 2014. The approach focuses on achieving an "undetectable" viral load (< 40 copies/ml) within a certain period of initial treatment.

Further impetus for 90-90-90 has come from data from START, a trial which halted randomization in mid-2015 after finding that initiation of treatment, regardless of CD4 cell count, resulted in significantly fewer AIDS-defining illnesses for people living with HIV compared to initiation following current guidelines.²⁷ The latest strategy from UNAIDS, "On the Fast-Track to End AIDS 2016 – 2021," reiterates these goals, and, in line with the latest WHO guidelines recommending early treatment for all people living with HIV, promotes front-loading investments to close the gap in treatment coverage.¹

Universal access

WHO policy documents fail to clearly define access. UNAIDS defines universal access as "maximal coverage of HIV prevention, treatment, care and support services" through interventions that are "equitable, accessible, affordable, comprehensive and sustainable over the long-term".²⁸ The United Nations also recognizes that universal access involves reducing vulnerability and removing structural barriers to services. More explicitly, this involves tackling gender equality and harmful norms, human rights and equity, and health in all policies, laws and regulations.²⁹ However, United Nations monitoring indicators tend to focus on enrolment in HIV care, receiving and retention in care for 12 months following treatment initiation. Adherence, percentage retained on antiretroviral therapy, prevention of vertical transmission, percentage of viral suppression and mortality are given by WHO as additional indicators for monitoring and evaluating the treatment cascade; however, adherence, and particularly retention, are not explained further.³¹

Consolidated treatment guidelines and Option B+

WHO 2013 *Consolidated Guidelines* on the use of ART encourage earlier treatment of people living with HIV when immune systems are still strong at a CD4 count of 500 cell/mm³ or less, as compared to 2009 recommendations of 350 cells/mm³ or less.³¹ WHO's 2013 treatment guidelines also recommend providing ART regardless of CD4 count to all children living with HIV under the age of five, all currently pregnant and breastfeeding women living with HIV, and all partners living with HIV in a serodiscordant relationship whereby one partner has HIV and the other does not.

The 2013 guidelines recommend ART for all pregnant and breastfeeding women living with HIV during the period of risk of vertical HIV transmission and continuing lifelong ART for all women meeting eligibility criteria for their own health, referred to as Option B. The *Consolidated Guidelines*³¹ (Box 3) recommend that women living with HIV who are pregnant or

breastfeeding continue treatment regardless of their CD4 count rather than take a short-term course of ARVs during pregnancy and breastfeeding solely for the prevention of vertical transmission. This is known as Option B+. Option B+ has been piloted in Uganda and Malawi, and is currently being rolled out in a limited number of countries.³⁰

WHO strongly recommends Option B (with “moderate-quality evidence”) and conditionally recommends Option B+ (with little and “low-quality evidence”). Option B+ is based on the principle that treating people with HIV earlier with safe, affordable and easier-to-manage medicines can keep them healthy and lower the amount of virus in the blood, reducing the risk of transmission.³¹ Further, early initiation of ART for pregnant women is “strongly recommended, with moderate quality evidence” that it reduces maternal

mortality and active tuberculosis.³¹ WHO states that if countries can integrate these changes within their national HIV policies, and back them up with the necessary resources, they will see significant health benefits at population and individual levels.³¹ Nevertheless, WHO recognizes the limitations of Option B+ and has made the recommendation conditional in cases where local adaptation has to account for a greater variety in values and preferences or when resource-use makes the intervention suitable for some locations but not for others. This indicates a need for substantial debate and involvement of stakeholders before the recommendation can be adopted as policy.³¹

In November 2013, WHO polled participants attending the WHO Guidelines Dissemination Workshop on their intentions to adopt the new Option B+ recommendations.³² Invitations to the workshop were delivered to

BOX 3

PMTCT (Prevention of Mother-to-Child Transmission of HIV)

In these guidelines, the WHO is moving away from the previous terms, Options A, B and B+. Instead, these guidelines recommend two options: (i) providing lifelong antiretroviral therapy to all pregnant and breastfeeding women living with HIV regardless of CD4 count or clinical stage, or (ii) providing antiretroviral therapy to pregnant and breastfeeding women with HIV during the mother-to-child transmission risk period and then continuing lifelong antiretroviral therapy for those women eligible for treatment for their own health.

In settings that do not implement lifelong antiretroviral therapy for all pregnant and breastfeeding women living with HIV, the distinction between prophylaxis (ARVs given for a limited time during the risk period for transmitting HIV from mother to child) and treatment (antiretroviral therapy) given for the mother’s health, based on current adult eligibility, and to prevent vertical transmission) remains important.

Antiretroviral medicines for women living with HIV during pregnancy and breastfeeding refers to a triple-drug regimen provided to mothers living with HIV primarily as prophylaxis during pregnancy and throughout breastfeeding (when there is breastfeeding) to prevent mother-to-child transmission of HIV. In this option, the mother’s regimen is continued indefinitely after delivery or breastfeeding only if she meets the antiretroviral therapy eligibility criteria for her own health based on CD4 count or clinical stage. Previous WHO guidance referred to this as Option B.

Lifelong antiretroviral therapy for all pregnant and breastfeeding women living with HIV refers to the approach in which all pregnant women living with HIV receive a triple-drug antiretroviral therapy regimen regardless of CD4 count or clinical stage, not only for their own health, but also to prevent vertical HIV transmission and for additional HIV prevention benefits. Previous WHO guidance referred to this as Option B+.³¹

all high-burden and high-priority countries; 62 per cent (90 countries) of low and middle-income countries (LMICs) participated. Of participants, 68 countries announced that they planned to adopt the treatment guidelines for earlier initiation of treatment at 500 cells/mm³ or less. This is a dramatic increase from the seven per cent of nations that had already decided to adopt this recommendation (often as mandatory) for all pregnant women with HIV as of June 2013. In addition, Ethiopia, Namibia, Russia and Zambia declared that their plans of treating all children under the age of 15 and having strong national strategies in place to execute this goal. Before the new recommendations, 12 per cent of Low and Middle-Income Countries (LMICs) at the WHO workshop had policies in place for Option B+ roll-out; as of November 2013, however, 71 per cent of countries stated they would draft policies to implement the programme.

Despite intentions to adopt new recommendations, ranges in national capacities to drive policy and programmatic changes are evident in LMICs. Experiences from past WHO guideline publications show that not every nation has the resources to adopt all recommendations. Some are adopted immediately (or altered to incorporate country-specific risk-benefit ratios), even though the recommendations ideally require greater resources and time for implementation. Yet, 90 per cent of all countries have adopted WHO's earlier 2010 recommendations. This fact highlights the weight of WHO recommendations, ultimately leading to a

dramatic rise in the numbers of women, men and children eligible for treatment.³¹ For instance, in Uganda those who initiated treatment more than doubled from 297,368 individuals in 2011 to 750,896 individuals in 2014.³³

2016 Consolidated treatment guidelines

In 2016, WHO updated their consolidated treatment guidelines to account for current global trends and align with global strategies to eradicate the HIV epidemic. The new guidelines, alongside UNAIDS' 2016-2021 Strategy, respond to changing contexts globally whereby growing inequality, increasing migration, escalating complex human emergencies, changing geographies of poverty and wealth, and improved technological advances complicate current approaches to the HIV epidemic.

2017 Consolidated guideline on sexual and reproductive health and rights of women living with HIV

In 2017, WHO's Consolidated Guideline on the Sexual and Reproductive Health and Rights of Women living with HIV aimed to develop a woman-centered approach which respects women's autonomy in deciding around their health. The guideline used two

BOX 4

A Human-rights based Approach to Antiretroviral Therapy for Women living with HIV

According to the WHO's 2017 Consolidated Guideline on the Sexual and Reproductive Health and Rights of Women living with HIV, all sexual and reproductive health and HIV services, including antiretroviral therapy, should be provided using a human-rights based approach. All women should have access to the necessary information and be empowered to make an individual, informed choice about their HIV treatment.

Women-centred health services should see women as participants and beneficiaries of health systems. They should be provided care in ways that respect their autonomy and decision-making around their health and enable them to make informed choices.

guiding principles, promotion of human rights and gender equality, to provide evidence-based recommendations and good practice statements for the sexual and reproductive health and rights of women living with HIV.³⁴

Moving toward universal “test and treat” policies

In addition to the WHO’s call to initiate HIV treatment early, in 2014 UNAIDS launched their 90-90-90 targets. For World AIDS Day, UNAIDS also launched the “Fast Track” report, which calls for 95-95-95 targets by 2030.²⁹ There is a global drive for early initiation of ART. While there was growing concern regarding the limited evidence as to when therapy should begin,³⁵ interim results from the START Trial indicate that early initiation on ART decreases the risk of developing AIDS or other serious illnesses.³⁶

What are the implications of treatment guidelines for women?

As the global policy environment focuses on dramatically scaling up treatment access, gender and women’s rights advocates contend that understanding women’s accessing, adhering to and benefiting from treatment options is crucial to informing policies and programmes. Gender-focused policies and programmes not only keep women healthy, but also transform the lives of their families.

The new UNAIDS strategy highlights the importance of gender equality in tackling the HIV epidemic. Target 7 in the Strategy aims for 90 per cent of women and girls to live free from gender inequality and gender-based violence to mitigate the risk and impact of HIV. Action in this area remains critical in three areas outlined in the Strategy: “(1) improving access to, and uptake of, sexual and reproductive health and HIV services and commodities; (2) mobilizing communities to promote egalitarian gender norms, engage men and boys, and end gender-based, sexual and intimate-partner violence; and (3) empowering

women, young women and girls in all their diversities, including by investing in women’s leadership in the AIDS response.”²⁹

Despite new WHO guidelines that promote ART access for all people living with HIV and a new UNAIDS 2016-2021 Strategy that stipulates the importance of achieving gender equality to fight the HIV epidemic, barriers to access for treatment remain. Further WHO guidelines entitled *Integrating Gender into HIV/AIDS Programmes in the Health Sector: Tool to Improve Responsiveness to Women’s Needs* (2009) provide a useful analysis of barriers that women face and suggestions for addressing them. Challenges for women (and particularly members of key affected populations) in accessing, initiating and adhering to treatment include:

- **Strict treatment access eligibility criteria:** ability to pay, insurance status, pregnancy, required disclosure, stability of social networks or families as support systems, resident/citizenship status, and/or no substance use.
- A **lack of support and awareness** regarding the need for medications to prevent or treat common OIs, including infections related to reproductive function. In the section of the guide on access to treatment and care, gender-based violence is discussed in relation to disclosure and its impact on women if they are required to disclose their status; GBV is not, however, mentioned in relation to other challenges.
- A **lack of finances** to pay for associated costs for treatment services and to balance the priorities of multiple roles and responsibilities in the household, family, and community can make initiation of treatment difficult.
- **Limited access to nutritional foods** and concerns regarding the side effects to women’s sexual and reproductive health (SRH) and well-being.
- Women’s **lack of autonomy** may result in controlling behaviour from partners who force them to return or share treatment.

While sections of the WHO guidelines include steps for programmes or managers, they are missing directives that health workers might integrate into their work, including ways to help women cope with stigma, discrimination and violence outside the health system. The section on prevention of vertical transmission does not include treatment for women's personal health and well-being. There is inadequate information on the importance of identifying and providing the comprehensive services women need and on links between sexual and reproductive health services and HIV programmes.³⁷ In addition, there remain gaps in information about more recently understood and explored linkages between HIV and gender-based violence, particularly intimate partner violence.

Health specialists, researchers and activists have raised concerns that national and international governing bodies have not adequately addressed key underlying determinants such as weak health systems, poverty and gender inequality. These factors hinder individuals' – and especially women's – access to and their ability to benefit from treatment.^{38,39,40} The WHO recognizes that health systems need a sustained increase in resources. Until this happens and additional demand and supply barriers are addressed, there are concerns that dramatically scaling up treatment by widening the eligibility criteria may undermine treatment acceptance and jeopardize the mental and physical health of people living with HIV. Women, men and children will struggle longer with significant barriers (many of which are described in this review) if they are accessing treatment at an earlier point in their lives.

Additionally, there are concerns that the immediate, medium and long-term ethical, mental and physical health impacts of putting people on treatment earlier than previously recommended have not been sufficiently assessed,^{41,42} nor have ethical concerns about putting people on treatment to minimize transmission to others.⁴³ Research in Australia also documents "significant ambivalence" among health-care staff regarding treatment as prevention for serodifferent couples.⁴⁴

2.2 Current status of treatment access for women

By the end of 2012, 9.7 million people were on ART in LMICs, a 40-fold increase in access to treatment since 2002.⁴⁵ This rapid treatment scale-up has led to significant declines in AIDS-related deaths and lower rates of newly acquired HIV.^{46,47,48} WHO estimates that since 2003, the large-scale roll-out of ART in LMICs has saved approximately 4.2 million lives and prevented 800,000 children from acquiring HIV.²⁵

PEPFAR data from 2013 and 2014 (Table 1 and 2) approximates the total number of people receiving antiretroviral therapy, which is close to 7 million in their partner countries. Nevertheless, these figures from PEPFAR are incomplete since PEPFAR-supported efforts are not comprehensive globally. Since PEPFAR operates exclusively in resource-poor settings, these figures are representative of the circumstances in LMICs where women arguably face the greatest barriers to treatment access. PEPFAR reports that currently 63.75 per cent of individuals on treatment are women.

TABLE 1
Persons Currently on ART, PEPFAR 2014⁴⁹

Age	Number	Per cent
MALE		
<15	244,602	3.58%
>15	2,231,123	32.67%
Total male	2,475,725	36.25%
FEMALE		
<15	260,918	3.82%
>15	4,093,107	59.93%
Total female	4,354,025	63.75%
TOTAL	6,829,750	100.00%

Key findings

- **Datagaps:** There is a dearth of sex-disaggregated data on treatment uptake, retention in care and adherence. UNAIDS and PEPFAR receive reporting from affected countries on their HIV treatment programmes. While some countries provide data disaggregated by sex, others report only estimates. The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFTAM) does not yet have data on treatment disaggregated by sex.
- Women account for approximately half of all treatment initiations, and in some cases the rates of treatment initiation are higher for pregnant women.
- In some contexts, rates of adherence among women are lower than men.
- Option B+ roll-out in several countries has been marred by rapid uptake and below average rates of adherence.

Recommendations for further research

- A system for improved data collection at the national level should be developed and implemented with coordination and cooperation from PEPFAR, GFATM, UNAIDS and other cooperating entities. This system should ensure sex disaggregation of treatment data and should also gather information on access for pregnant versus non-pregnant women, stratified by age.
- A rights-based research agenda developed in collaboration with women living with HIV and related to implementation of Option B+ is urgently needed to provide systematic information on factors affecting decisions to start, stop or stay on treatment during pregnancy and lactation.

Further areas for this project to explore

- Look at ways to identify data analysis of treatment access for sub-groups of non-pregnant women, particularly disaggregated by age and key population.
- Explore further research into the intersection of childcare responsibilities and treatment retention.

Of the individuals who initiated therapy around the globe in 2013, 66 per cent were women (Table 2). When pregnant women are excluded from these calculations, the proportion of women newly initiated on treatment in 2013 falls to 49 per cent. Coverage of ART among pregnant women appears to be higher than among non-pregnant women.

In Kenya and Malawi, of the new enrollees between 2009 and 2011, 66 per cent and 61 per cent, respectively, were women. These data do not account for the potential effect of treatment roll-out for pregnant women, particularly in Malawi where the Option B+ programme has been adopted. In 2012, the Ugandan government also adopted the Option B+ programme which is likely to have contributed to the increase in women initiating ART from 189,701 enrollees in December 2011 to 349,068 in December 2013.³⁶

In other regions, antiretroviral therapy coverage among women varies greatly by country. A six-country survey by WAPN+ in Asia Pacific found that most women (65.1 per cent) were currently taking ARVs. However, the figures ranged from 50.2 per cent in India to 86.1 per cent in Cambodia. Further, women 40 years and older were significantly more likely to be on ARVs than younger women (84.6 per cent versus 59.0 per cent). Most women (85.9 per cent) access treatment from a public health facility. While 30.0 per cent of women stated they had not started ARVs, 17.8 per cent said they had stopped their medication.⁵⁰

The lack of standard metrics for treatment access for women presents challenges in tracking progress. Some reports, including the PEPFAR figures above, state that women appear to be obtaining treatment in higher numbers and percentages than men but

TABLE 2
Persons New on ART, PEPFAR 2013⁵¹

Age	Number	Per cent
MALE		
<15	61,672	4.04%
>15	456,609	29.95%
Total male	518,281	33.99%
FEMALE		
<15	66,406	4.36%
>15	939,997	61.65%
Total female	1,006,403	66.01%
Total non-pregnant	748,552	49.10%
Total pregnant	257,851	16.91%
TOTAL	1,524,684	100.00%

these numbers do not consider losses to follow-up and adherence. In some contexts, losses are worse for women (particularly for pregnant and post-partum women). Understanding these nuances is critical in efforts to address treatment access barriers for women. Without robust baseline figures, monitoring progress will prove difficult.

Women may appear to be accessing treatment at higher rates than men but the influence of prevention of vertical transmission programmes in initiating pregnant and post-partum women may inflate these figures. Especially since vertical transmission prevention programmes notoriously experience high attrition (see the case studies discussed below), the data regarding those currently on treatment may be misleading unless supplemented by sex-disaggregated figures on adherence and retention.

Reporting on treatment uptake, initiation, retention and adherence lacks sex-disaggregated data. Some

organizations charged with monitoring the epidemic and implementing the response fail to report treatment access data disaggregated by sex.

Disaggregated data are dominated by the narrative of prevention of vertical transmission (from mother to child) with little emphasis on women living with HIV in all their diversities at all stages of their lives, including beyond the experience of pregnancy and childbirth. Currently, the lack of available, disaggregated data hinders the work of policymakers and activists to make informed decisions and inspire change to improve the lives of women and girls living with HIV. Moreover, existing systems that collect and report data generally do not report on measures of retention in treatment or adherence to ART regimens. Surprisingly, there is no standard definition of “retention-in-care” either for the purposes of HIV surveillance or implementation research.⁵¹ These data are critical to ensure an effective response and global public health impact.

Organizations such as PEPFAR plan to implement a gender strategy and collect and disseminate sex-disaggregated data. The aim is to more closely monitor who is receiving services and to appropriately address barriers. GFATM developed a similar gender equality strategy in 2008 and its implementation plan in 2014 emphasizes the strategic importance of collecting and disseminating sex-disaggregated data. One of its goals is to continue the commitment to funding gender-focused programmes that address gender-related barriers to deliver an effective HIV response. These policies demonstrate an increased interest in, and recognition of, the value of gender-responsive programmes and efforts.

Adherence and retention

It would be inadequate to focus exclusively on understanding barriers to access for women without also elucidating barriers to adherence and retention. To achieve the goal of virological suppression and positive health outcomes for women globally, the initiation of treatment must be coupled

with efforts to engage and retain women in care. Addressing adherence and retention barriers complements efforts to improve health for women living with HIV.

People living with HIV face several key barriers adhering to ART and maintaining treatment. Shubber and colleagues outline these constraints in a recent systematic review and meta-analysis.⁵² The review cites challenges ranging from forgetting to take medication to health-service related barriers, stigma and depression. Adherence and retention barriers range from individual-level barriers to macro-level constraints, as illustrated in a systematic review of factors affecting initiation, adherence and retention for pregnant and post-partum women by Hodgson and colleagues (2010).⁵³ The barriers listed in the systematic review are identical to access barriers explored in our work. This consistency signifies strong parallels in achieving increased access to care for women and ensuring that they adhere to treatment.

Engagement in HIV care is essential to maximize treatment outcomes; it includes both adhering to ART and being retained in HIV care. Retention in care involves participating in the care continuum. Participation includes attending scheduled clinic visits, immunological and virological monitoring and linkage to counselling for mental health support, as well as to other services aimed at improving health. Retention in care is meaningful in predicting viral suppression and other clinical outcomes.

Adherence measures specifically focus on whether ART medications are being taken regularly as advised. Adherence to medications represents a small portion of overall retention in care. Research on ART adherence dominates the literature but overall adherence measures tend to be less impactful if an individual is not retained in care. Let us clarify this distinction: a person living with HIV who regularly attends their clinic visits but does not yet need ARVs can be described as being *retained in care*. If they do need to start ARVs, but for some reason do not follow their prescribed regimen, they may be described as being *retained in HIV care but not adhering*.

It should be noted that assessing adherence is difficult. Researchers have observed that self-reported measures from participants do not accurately capture their adherence behaviours.^{41,54} It is also widely recognized outside the HIV world that adherence to any medication for any chronic condition is often challenging.⁵⁵ This nuanced perspective is not always reflected in the literature where *adherence* and *retention* are used interchangeably and where there is often an implicit assumption that treatment adherence should be a straightforward process for anyone.

A global meta-analysis of observational studies assessing gender differences in adherence to ART showed that high adherence to the regimen (>90 per cent adherence) was observed to be lower in women than men.⁵⁶ The meta-analysis revealed that studies with a higher proportion of widowed female participants showed the highest percentages of adherent individuals. For men, higher adherence was found in studies with a higher proportion of men who have sex with men (MSM).⁵⁸

As a key affected group, it is plausible that greater adherence among MSM is associated with perceived risk and perhaps also the presence of larger organized support systems. The study also indicated an inverse correlation between viral load and adherence for men: the lower the viral load (that is, the healthier the men), the higher the adherence. By contrast, in the case of women, less healthy women showed a greater adherence to therapy than did men. It is worth exploring whether women are less likely to adhere when they are feeling healthier as this raises concerns regarding early treatment.

Another meta-analysis also confirmed that women had lower adherence than men and their non-adherence was correlated with depression, lack of supportive interpersonal relationships and increased levels of distress.⁵⁷ The meta-analysis researched articles published between January 2000 – June 2011 reporting on ART adherence in developing countries. Women who did not adhere to their regimens stressed the need for approval from their partners considerably more than men who did not adhere.⁵⁹

Overall progress in national antiretroviral therapy coverage masks important access disparities. Treatment gains are not reaching enough key populations, currently defined by UNAIDS as sex workers and their clients, transgender people, people who inject drugs, gay men and other men who have sex with men transgender people, and prisoners and other incarcerated people.³⁰ Injecting drug use is known to negatively impact ART adherence. A study in the United States followed a cohort of women who inject drugs and found that women who accessed any form of drug use treatment were more likely to be adherent than women who did not.⁵⁸ Women over the age of 50 who did not report drug use were more likely to report ART adherence for more than two years in cohorts in Cameroon, Burundi and the Democratic Republic of the Congo.⁵⁹

Prison populations, refugee populations, migrants and mobile workers are also frequently at higher risk of acquiring HIV, yet data detailing the access to ART of these populations remain extremely limited. This is partly because classifying them as key populations can have serious human rights and legal complications in countries in which behaviour associated with key populations is stigmatized and/or criminalized. The intersection of discrimination against marginalized populations and gender inequality is likely to further hinder treatment access for women from these

populations or those whose partners fall into these groups. However, there is a lack of sex-disaggregated data to confirm this hypothesis. Further, refugee and migrant status may hinder both access to ART as well as adherence given both citizenship status and migratory patterns.

Option B+

Option B+ programmes aim to accelerate ART initiation and reduce the risk of vertical transmission of HIV from mother to child (Box 3 on PMTCT in Section 2.1 above). Uganda and Malawi were the first two countries in sub-Saharan Africa to introduce Option B+ on a national scale. The early data from these countries on adherence and retention highlight the importance of supplementing data on numbers of women (or men) initiating treatment with data on retention and adherence to capture an accurate depiction of women's access to treatment.⁶⁰

Option B+ has now been followed by a universal *test and treat* policy recommending that all individuals diagnosed with HIV start treatment immediately and stay on it for life.³¹ However, the issues described in the country examples below are still relevant to this new WHO policy.

BOX 5

Option B+ in Action: Malawi

Malawi's HIV and AIDS estimates for 2015 stated that there are 980,000 individuals living with HIV, and over half are women above the age of 15.⁶¹ Prior to roll-out of Option B+, only 49% of all pregnant women living with HIV were diagnosed, 3% were on treatment, and 2% remained on treatment one year after initiation. Malawi's Option B+ programme, rolled out in 2011, led to a seven-fold increase in pregnant women living with HIV receiving ART in just the first year of the programme.⁶² Despite reductions in vertical transmission from

mother to child with ART initiation, uptake and retention remain problematic. In a cohort study in northern Malawi, nearly half of those who had not started on ART at the beginning of antenatal care not begun by the time they gave birth.⁶³ At the same time, pregnant women who started treatment on the day of diagnosis were observed to be the least likely to follow up in the Malawi Option B+ programme. Thirdly, women who initiated ART during pregnancy were five times more likely not to adhere to their regimen than women who started therapy at a CD4 count of 350 cells/mm³ or less.⁶⁴

BOX 6**Option B+ in Action: Uganda**

In 2012, the government of Uganda adopted the Option B+ programme to curb the vertical transmission of HIV. Financial restrictions have forced Uganda's leadership to roll out the programme in phases. Option B+ was first introduced in 11

high-prevalence districts. PEPFAR committed US\$25 million for the Acceleration Plan.⁶⁵ The increased investment in prevention of vertical transmission was not initially translated into positive programmatic outcomes. Only 20 per cent of women who initiated treatment after labour returned to clinics to receive their CD4 count.⁶⁶

Zimbabwe adopted Option B+ in 2013 and launched a staggered roll-out in 2014. Studies are underway with the aim of improving retention-in-care of pregnant women and mothers living with HIV.^{67,68} In view of the challenges experienced by women described above, it

will be important for the roll-out of the 2016 guidelines to be monitored closely in relation to women's ongoing treatment access issues. See Section 4.1. below for further discussion.

3. MICRO LEVEL: PSYCHOSOCIAL FACTORS AT THE INDIVIDUAL, HOUSEHOLD, FAMILY AND COMMUNITY LEVEL

Key findings

- Many women have concerns about the side effects of treatment uptake for themselves and their children.
- Research has shown that HIV-related stigma and gender inequalities drive several factors that reduce women's access to treatment and retention in care such as access to income, traditional gender roles, gender-based violence and food insecurity.
- Women, who are also part of marginalized populations or partners of men who are at increased risk (such as women engaged in sex work, transgender women, women who inject drugs and wives of MSM), face high levels of stigma and discrimination that impede access to treatment. The data on treatment access, however, is rarely disaggregated by sex.

Recommendations for further 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.

Further areas for this project to explore

- There needs to be a coordinated effort to fill specific gaps in the literature informing programmes and policies. Specific factors to be considered include:
 - Biological factors that may affect treatment for women, including side effects, drug resistance, dosage and effectiveness.
 - The impact of sociocultural ideas regarding gender and sexuality and gender-based violence on treatment access and adherence.
 - Retention and adherence for key populations for which gender is a major factor (e.g. women engaged in sex work, women in prison, women who use drugs).
 - The impact on women of treatment programmes integrated into family or home-based care.
 - The intersection of HIV disclosure by women and treatment initiation.
 - Women's sharing of ART with their partners and other family members.

3.1 HIV-related stigma, gender discrimination or inequality

This section considers how social norms regarding gender and HIV interact to influence women's access to treatment and care. The following factors are caused by, and reinforce, HIV-related stigma and gender-related discrimination and ultimately influence women's ability to initiate and continue ART:

- Physiological factors
- Social and cultural norms
- Women's roles and workload
- Women's access to resources
- Women's decision-making power
- Gender-based violence

Stigma can be a crippling experience for women living with HIV, impacting both mental and physical well-being.⁶⁹ In 2014, UNAIDS conducted a rapid assessment of women's experiences of treatment access in the context of the prevention of vertical transmission. In five high-prevalence countries, results demonstrated that women living with HIV are generally considered to be "immoral" and responsible for bringing HIV into the family.²⁴ Consequently, participants in the UNAIDS study felt that women face greater levels of discrimination than men. There is a perception among both women and men that it is negligent for women living with HIV to become pregnant due to the possibility of passing HIV to their children. See Section 4 on meso-level barriers for information on the pressure placed on pregnant women living with HIV to have abortions or be sterilized.

Women living with HIV are also considered less capable of tending to their children's needs.⁷⁰ Such discrimination can impact women's ability to seek appropriate treatment and care services (including during pregnancy) and can impact their ability to plan families safely, particularly if they internalize such views. In some contexts, women avoided antenatal care (ANC) facilities where testing was carried out due to HIV-related stigma if they tested positive.⁷² Given that women in general have better health-seeking behaviours and (in some contexts) better access to treatment than men, it is worth exploring whether

increased visibility through service access leaves women vulnerable to greater levels of stigma and discrimination.

Fear of stigma and discrimination can also make women living with HIV (WLHIV) reluctant to disclose their status to partners, family and friends or to access services, including through antenatal care.⁷¹ A synthesis of studies looking at rates, barriers and outcomes of HIV status disclosure among women in developing countries found that between 16.7 and 86 per cent of women chose not to disclose their status to their partners.⁷² The majority feared that a negative reaction might result in abuse, violence and abandonment. A more recent study in South Africa's KwaZulu-Natal province showed that women were often more willing to disclose their status to family members than to their male partners.⁷³ Fear of stigma and discrimination and having to keep their status from partners and other family members makes it much harder for women to seek treatment and care and to adhere to treatment regimens for themselves and their children.^{72,74,75}

This literature review includes studies that support a strong link between non-adherence and non-disclosure of status, yet the data are not disaggregated by sex. For example, a systematic review of the inclusion of sociocultural determinants in quantitative studies that examine access to HIV services concluded that in low-income countries lower rates of adherence were associated with perceived lack of familial support, lack of perceived need to disclose to family members and a feeling of depression.⁴² If individuals lacked access to a private storage space, adherence was also impacted by living with extended family members and having to conceal their status from them.⁷⁶ An initiative in the United States to help people with disclosure had a greater impact on women than men regarding their experiences of post-traumatic stress disorder, depression and the physical symptoms of HIV.⁷⁶

In some contexts, levels of disclosure to husbands and partners appear high.^{77,78} Despite significant rates of disclosure, these studies found that women experienced high levels of stigma and discrimination upon

revealing their status. For example, in a study of HIV-positive status disclosure among women attending an ART clinic at the Hawassa University Referral Hospital, South Ethiopia, 59.3 per cent experienced negative reactions upon disclosure.⁷⁹ Experiences of enacted stigma and discrimination seem to vary widely. For example, a 2012 study undertaken in Malawi during the roll-out phase of the national programme to prevent new HIV acquisitions among children found that 40 per cent of women (n=10) who were living with HIV and using services to prevent new cases among children had been divorced by their husbands because of their HIV status.⁷⁹

Partners, however, are not always the main perpetrators. The WAPN+ study found that although many women faced high levels of discrimination upon disclosure of their status, it was usually from mother-in-law's or health-care workers.⁸⁰ We return to the impact of stigma and discrimination within communities and health services on women's access to treatment in later sections.

Physiological factors

Many of the studies looking at barriers to treatment access and adherence stress the concerns of individuals living with HIV about the side effects of lifelong antiretroviral therapy. A study conducted in 2009 by WAPN+ found that 66.6 per cent of women who stopped taking their ARVs did so because of side effects.⁵² These concerns can be significant enough to negatively impact treatment access and adherence.^{52,80,72,76}

Other studies on treatment access and adherence found that worries about, and the experience of, side effects led to discontinued use. While these studies include women, they do not provide a sex-disaggregated breakdown of results or gender analysis. It is evident from reports that women and men have concerns about side effects, yet there remains a low enrolment of women in research trials. Medical investigation into ARVs has devoted less attention to the specific side effects experienced by women, such

as menstrual irregularities, menopausal intensity or acceleration of osteoporosis. Research also explores the impact of HIV diagnosis on an individual's mental health and indicates depression, internalizing stigma, low self-esteem and lack of social support as key factors in determining adherence to treatment regimes. Again, these studies tend not to be gendered although they demonstrate that both women and men are impacted by these factors.

The positive health impacts of treatment motivate women and strengthen their commitment to stay with it. Most female participants of the WHO research in Botswana, Tanzania and Uganda and some participants at the UNAIDS discussion in Uganda reported the positive effects of treatment on their health.^{72,81} It is important to note that the study in Tanzania and Uganda focused on the experience of treatment with ARVs rather than barriers to access. A random sample of women and men living with HIV with high adherence to ART participated in the study, selected through health service patient lists.

Research participants in South Africa, most of whom were women, also saw ARVs as “lifesaving” and expressed their long-term commitment to adhere.⁸² There remains, however, scant research exploring how to overcome barriers to treatment access on the one hand while ensuring that treatment improves women's health on the other. It is vital to understand these issues if we are to develop successful strategies to increase the uptake of ART and minimize adverse events, while also upholding women's rights to informed choice.

Social and cultural norms

Women can have side effects related to certain ARVs that interact with sociocultural norms regarding gender and sexuality. This experience could affect adherence, particularly as women's perceived or “felt” sexual attractiveness is often linked to certain body images.⁸³ Side effects can differ for women during puberty, adolescence, at childbearing age and during the postmenopausal years.⁸⁵ WHO highlights that

pregnant women may face additional barriers in adhering to ART due to “worries about the effects of drugs on their babies, additional nutritional requirements associated with pregnancy, and conditions such as nausea and vomiting that may be exacerbated as side effects of ARVs.”⁸⁵ There is also emerging evidence that women experience side effects from ART differently than men – for instance, in relation to osteoporosis and menopausal changes.

Women living with HIV may also experience specific illnesses related to their reproductive systems. For example, they are more at risk of vaginal fungal infections, genital warts, pelvic inflammatory disease, menstrual irregularities and cervical cancer than are women without HIV.⁸⁴ Sociocultural norms that discourage the discussion of women’s reproductive and sexual health may prevent women from recognizing that these conditions are abnormal or may lead to a sense of shame regarding the experience and discussion of such issues with health providers. This can, in turn, lead to delays in seeking appropriate treatment and care.⁸⁵ In addition, women living with HIV may be affected by reproductive roles and gender norms that undermine their own access to nutritional food, since women prioritize providing food for their children, partners and families. For example, women living with HIV often have a higher prevalence of anaemia than men. Anaemic women tend to show worse survival rates, since anaemia has been linked to disease progression (regardless of CD4 count) in Africa and Europe.⁸⁵

Traditional gender roles and unpaid care work

Women’s multiple roles and responsibilities in the household, family and community impact their ability to take time out to visit health centres. For women living with HIV, access and adherence to treatment is limited by multiple trips to health centres. The situation often also involves long travel and waiting times that do not fit into busy routines (see Section 4, on meso level barriers). Employment in formal sector work can inhibit adherence to treatment due to a lack

of privacy. For example, many women living with HIV and involved in UNAIDS rapid assessments reported that they lacked the time to visit health centres or that they had no one to take care of their responsibilities in their absence.⁷² Taking multiple doses of ARVs in a day (particularly at a specific time) may not fit in with women’s workloads or may cause tiredness and other side effects which impair women’s ability to carry out tasks effectively.^{77,85} For instance, a study in Tanzania showed that women’s routines made it easier for them to remember and take pills, yet it is important to note that in this small qualitative study, the four people who missed pills over the last month were all women.⁸⁶

Women’s roles in the household, including the care of children and other family members, are underpinned by gender inequalities that undervalue their contributions.⁸⁷ WHO suggests that in households where several family members are sick, women prioritize care and treatment for their children and other family members.⁸⁵ In many contexts, it is generally believed that women’s roles as caregivers may lead to better health-seeking behaviours than in men. In fact, women consistently expressed concern about their children and older relatives, explaining the need to stay alive to look after them was a key motivating factor in taking ARVs.⁸³

The reasons for pushing an agenda of greater access to treatment for women are rooted in their relationship to the health system through their reproductive roles and their identification as a priority group (to prevent vertical transmission).⁸³ However, what motivates and conditions access is often context-specific. A cross-sectional, correlational study among 269 Colombian women found that women who had children living with HIV and a high viral load, were less likely to adhere to treatment. This may be due to the strain on their time caring for children.⁸⁸

Gender norms that govern men’s roles in many cultures do not encourage male involvement in the reproductive sphere. UNAIDS found, in their rapid assessments, that male involvement in women’s visits to ANC and access to HIV-related services was limited. This lack of

involvement might constitute a barrier to testing and accessing treatment, since pregnant women living with HIV need help with transportation to clinics and receiving and taking antiretroviral drugs. Women also wanted emotional support, particularly in the face of stigma from family members or the community at large. Men reported that their lack of involvement was due to a fear of social embarrassment, stigma and exclusion at health clinics, or simply a lack of interest in what was considered “woman’s affairs”.²⁴

Women’s access to resources

Gender norms regarding women’s roles and responsibilities influence their access to, and control over, resources. As a result of unequal power dynamics that disadvantage women and girls, women generally have less direct access to resources, meaning they must rely on other more powerful family members to access required resources.⁸⁹ Limited access to resources produces barriers such as the cost of transportation, doctor’s fees, lab tests and procedures, and out-of-stock drugs. The situation holds obvious implications for women’s ability to cover the opportunity and other costs associated with accessing and adhering to HIV treatment and care, particularly for women living in poverty or lacking access to independent resources.^{83,85,90,91}

In Colombia, researchers found that adherence was five times lower for women from low socioeconomic groups.⁹⁰ An APN+ study of 3,000 people in the Asia Pacific region explored the experience of accessing ART and other HIV-related health-care services for people living with HIV, including women, MSM, transgender people and those who inject drugs. Results found that over 80 per cent of women reported not having adequate income to sustain health needs.⁹² In South Africa, a cross-sectional study of over 300 women revealed that women who did not receive money from their spouse showed very poor adherence compared with women with strong financial support.⁶¹ Further, a study in Uganda concluded that “almost all respondents cited the need to locate funds for the monthly clinic visit as a constant source of stress

and anxiety, and lack of money for transportation was a key factor in cases of missed doses and missed medical appointments” (p. 778).⁹² Participants also struggled with competing demands between transport costs and other necessities such as food, housing and school fees.

The relationship between economics and adherence is not always directly correlated. Two studies in Colombia showed an interesting relationship between income and ART adherence.^{90,93} Women who were poor showed a rate of adherence five times that of women from higher socioeconomic status groups.⁹⁰ Although women with medium wealth had relatively good adherence, women with high income did not.⁹⁵ Women with greater resources stated that they were more afraid of stigma and were forced not to disclose their status. In Uganda, a recent study found that financial obligations and economic barriers remained even with increases in income, suggesting there are further complexities that impact women’s ability to access treatment.⁹⁴

The association between food security and ART adherence is strong. Studies have shown the significance of food assistance in order to achieve optimal adherence and have illustrated that individuals with low food security experience higher ART attrition.^{77,95} The need to ensure a nutritional diet when on treatment was a concern of women in poverty and living with HIV in Kenya, Tanzania, Argentina, Cambodia, Moldova, Morocco, Uganda and Zimbabwe.^{96,97} The lack of food particularly affects adherence for women due to their lower access to resources. Additionally, in many settings, women are expected to eat after feeding their children and families and nutritionally rich foods are preferentially given to male members of the household.⁸⁵ As discussed earlier, in low-income nations, anaemia is associated with poor nutrition, malaria and poor fetal health; women living with HIV have a higher prevalence of anaemia compared to men. These factors are linked to disease progression, regardless of CD4 count, in Africa and Europe.⁸⁷

Water access is also important, but information was not found for this review.

Women's decision-making power and autonomy

Unequal gender relations and women's socio-economic dependency limit their decision-making power regarding access and adherence to treatment. Traditional gender roles place men as the heads of household with the power to determine women's access to health care.^{89,98} Women who participated in ICW qualitative studies in Kenya and Tanzania stated they experienced problems in accessing services because their partners often refused them permission to seek treatment.^{98,99} In Kenya this was because men feared that health providers would want them to go for treatment as well.⁹⁸

Women interviewed in UNAIDS 2014 rapid assessments said that male partners or other family members sometimes refused to allow pregnant women to visit ANC clinics because they did not trust the efficacy of the services, did not want to pay for associated costs (for transport or services) or, in the case of husbands and partners, feared the stigma that might be directed at them if their own HIV-positive status were discovered through their partner's service access.

Such constraints may also stop women from accessing health services when they are in critical need, showing obvious challenges for their ability to promote and maintain their health and, if pregnant, that of their baby during pregnancy and beyond.²⁴ The People Living with HIV (PLHIV) Stigma Index research found that women presented late for treatment because they were more likely to seek testing only after a partner or family member became ill. In Nepal, this was observed in 40.6 per cent of women as opposed to 4.5 per cent of men.⁹⁹

Older research also indicates that some women may be forced or compelled to share their drugs with their partners, who use their wives' HIV status as a proxy for their own.⁸⁵ In a study of access to ARVs and adherence in five districts of Zambia, more than 21 per cent of women shared their regimens with a non-tested husband.¹⁰⁰ This study is dated and it may be the case that better education has reduced the instances of sharing. However, it remains an issue worth exploring.

The ICW study of women's access to treatment in Kenya and Tanzania also highlighted the pressures on women to share treatment with partners who were reluctant to get tested themselves.^{98,99} Women in Tanzania said even when they hid their treatment, their partners would find and steal it. There is a lack of recent evidence exploring whether pressures to share treatment remain a concern and whether women's increased access as compared to men's in many countries leads to greater pressure to share or hand over all ARVs. A more recent study found that relatives on similar treatment regimens stole treatment from women in their family.⁷⁷

Gender-based violence

It is increasingly recognized that stigma and discrimination represent forms of violence against women living with HIV.¹⁸ Gender-based violence (GBV) exerts a disproportionately detrimental impact on the lives of women and experiences of violence are particularly prevalent in countries with a high rate of HIV. Studies reveal the strong forward and reverse correlations between GBV and HIV; HIV acquisition is a risk factor for GBV and vice-versa. Women who experience GBV are four times more likely to be at risk of HIV and sexually transmitted infections (STIs).¹⁰¹

Sociocultural influences that breed unequal gender dynamics both drive GBV and present challenges in capturing the true magnitude of GBV experienced by women. A significant proportion (35 per cent) of women over 15 years of age worldwide has experienced either physical and/or sexual intimate partner violence or non-partner sexual violence.¹⁰² It is worth noting, too, that prevalence would be much higher if violence against girls under the age of 15 were explored; such consideration would include, prenatal sex selection, female genital mutilation, child marriage and exploitation, among others.¹⁰³

A recent global survey of women living with HIV shows that 89 per cent of respondents reported having experienced GBV.¹⁰⁴ GBV has been shown to hinder women's ability to access treatment and care

and adhere to ART.¹⁰⁵ There is concern that greater access to treatment through ANC services may leave women at increased risk of family tensions and violence in cases where men lack such access.⁸²

A number of studies demonstrate that fear of GBV (abuse and abandonment) leads many women to conceal their HIV status, treatment and care-seeking behaviour from their partners which, in turn, impacts adherence.^{74,82,106} A study of antiretrovirals access and adherence in five districts of Zambia showed that 76 per cent of women did not adhere to their ART regimen as prescribed because they were trying to hide their pills.¹⁰² Further studies show that fear of violent reaction results in women not accessing treatment and care services at all, including those for the prevention of vertical transmission.^{107,108,109} Certainly, recent findings confirm that GBV remains a barrier to accessing treatment.¹⁰⁶ A 2012 study in South Africa showed that women may regret accessing health services because of the GBV they subsequently experience.¹¹⁰

The fear of negative consequences among women living with HIV is not without foundation. Small- and large-scale exploratory studies have found that women may experience high levels of stigma and discrimination, including physical violence and post-disclosure abuse.^{79,108,110,111,112} Experiences of intimate partner violence are associated with negative HIV-related clinical outcomes, possibly due to a decrease in HIV care, adherence and retention and an increase in depression and anxiety.^{110,113} A United States study found that abusive partners sometimes sabotaged women's efforts to seek care, keep appointments or take medications.¹⁰⁹

However, not all studies show that women living with HIV experience high levels of violence and abuse. A baseline quantitative study of a planned longitudinal study of 1,598 HIV positive people from 15 districts of Nepal found that 8.9 per cent of women versus 9.9 per cent of men had experienced verbal abuse in the past 12 months and 4.3 per cent of women versus 3.5 per cent of men had experienced violence in the past 12 months.¹¹⁴ Other Community Access to HIV Treatment

Care and Support Services (CAT-S) studies from Laos and Indonesia also indicate similarly low levels of verbal abuse and violence for men and women. It is not clear from the studies who is perpetrating the abuse; it is possible that the CAT-S studies only record stigma and discrimination by non-family members or doctors.

Solutions for tackling GBV in the context of HIV are manifold. However, including men and boys in the solution is key. In a 2013 review, researchers found that working with men and boys to promote gender-equitable attitudes and behaviours is a promising programmatic approach to addressing violence against women in the context of HIV.¹¹⁵

3.2 Rights violations of marginalized groups

In this section, we extend UNAIDS' definition of key populations to include other populations whose work, circumstances or lifestyle make them especially vulnerable to acquiring HIV.³⁰ This includes the partners of MSM, those seeking asylum, truck drivers, miners, fisher folk and migrant workers and their families. Many people from key affected populations, and their partners, encounter multiple barriers at the individual, household, family and community level in accessing treatment services, as well as at the institutional level. For many of these people, a punitive legal environment accentuates the barriers.

At the micro level, women from key affected populations will often experience a double burden of social marginalization and gender discrimination, in addition to HIV-related stigma and discrimination. They are likely to face extreme social and institutionalized stigma, discrimination and harassment and fear adverse consequences if their HIV or marginalized status is disclosed.²⁵ These factors significantly impact their treatment access, adherence and retention in care.

Transgender women

Transgender women face a unique set of barriers to uptake of and adherence to ART.¹¹⁶ In the United States, transgender women are four times more likely to “fail ART” if they have experienced trauma.¹¹⁷ Factors correlated with lack of adherence in transgender women include low social support, coerced sex and low self-efficacy.¹¹⁹ In their research on the experience of accessing ART and other HIV-related health-care services for women, MSM/transgender people and those who inject drugs, APN+ found that 59 per cent of women who inject drugs and 46 per cent of MSM and transgender respondents were reported to be in need of ART. Among these, an average of one in three MSM and transgender people who inject drugs reported a lack of access to treatment for OIs.⁹⁴ Unfortunately, APN+ does not disaggregate data between MSM and transgender respondents.

Research from the United States demonstrates through multivariate models, that ART adherence is related to age, stress, self-assessment of transphobic experiences, gender affirmation, and adherence to hormone therapy.¹¹⁸ An earlier study used five focus group discussions and 20 interviews to find that transgender women face substantial challenges in adhering to HIV care and treatment, including the avoidance of health care due to stigma and past negative experiences, the prioritization of hormone therapy and concerns about adverse interactions between antiretroviral treatment for HIV and hormone therapy.¹¹⁹

Sex workers

The nature of sex work creates contextual factors that impact uptake and adherence to antiretroviral therapy. This population faces a variety of structural barriers to accessing services¹²⁰ as highlighted in a 2012 study of female sex workers’ experience of HIV prevention and treatment in Orissa, India. Differences between types of sex work impact barriers. For instance, studies show that young brothel-based sex workers face

issues surrounding restricted mobility and a lack of social support while non-brothel-based women experience violence, stigma and discrimination at more than twice the rate of brothel-based women (48 per cent of non-brothel-based sex workers versus 23 per cent brothel-based).¹²¹ Women who engage in sex work face individual-level barriers (stigma, drug use, and violence) to obtaining services and practicing HIV prevention and harm reduction.

Three studies, including a systematic review of ART uptake, attrition, adherence and outcomes among women sex workers living with HIV reported various factors that inhibit adherence including: running out of pills; not being at home to take them; feeling sick when taking pills; and potential loss of clients if seen taking ART during work hours.¹²² A recent study on human rights violations against sex workers highlights poor working conditions, violence, police harassment, and discrimination as barriers to HIV prevention and treatment.¹²³

Migrant and undocumented workers

Migrant and citizenship status also weigh heavily on an individual’s ability to access ART and remain on treatment. Some members of key affected populations are not always covered by national HIV programmes due to their insecure legal status. For example, in Thailand migrants without labour certificates are unable to get free ARVs or other services; many do not use services for fear of being identified as illegal immigrants. Once they do access services, there are mixed experiences of care and support; in some cases, migrants who tested positive for HIV through routine testing were sent home.⁵²

The lack of appropriate documentation or legal status can create environments of fear that prohibit people from engaging with health-care systems. For instance, undocumented immigrants fear deportation after accessing care. A woman who was originally from Mexico and living undocumented in the United States participated in a qualitative study and stated, “...I think when I try to access

[care], I get scared that they might send me back” (p. 129).¹²⁴ This study concluded that this fear does not dissipate over time. Moreover, individuals who are undocumented tend to work more demanding jobs with long, unregulated shifts. These individuals struggle to balance the maintenance of their employment with their retention in care. As a 42-year-old woman living with HIV shared: “...she [her employer] was very strict and did not allow me to take any medical appointments. I didn’t follow up on medical [care] because I didn’t have any opportunities...” (ibid.).¹²⁶

Three barriers were identified in a study in Philadelphia with undocumented immigrants from Africa who sought medical care in the United States: access issues, language barriers and the stigma of being African in the United States.¹²⁵ Access issues are due to a lack of appropriate documentation to receive health insurance, qualify for welfare or social assistance programmes and to seek employment. Additionally, confusion about navigating the medical care system and about which services are government-supported can act as deterrents for accessing antiretroviral therapy.¹²⁷ There is evidence that the partners of high-risk individuals face even greater barriers regarding access to treatment services. For wives of migrants in India, fewer than 20 per cent of women return to collect their results.¹²³

A lack of national identification cards constitutes a large obstacle for individuals attempting to access treatment. A study exploring human rights and HIV among transgender women in Colombia revealed that they were unable to access services from national health-care centres because of a lack of national identification cards. An ongoing issue for transgender women is a lack of official, legal documentation that reflects their gender.¹²⁶

Female partners of migrant workers also struggle to access information and health care for STIs and ART, due to low decision-making ability, limited household income and high transportation costs to distant facilities. Fear of disclosure is a recurring theme in qualitative interviews.¹²³ Perceived

stigma and fear of identification is a major barrier to accessing social and/or economic benefits such as travel allowances and pension schemes. The Das study in India concluded that the socioeconomic costs of a positive HIV status are borne at twice the rate by women.¹²³

Adolescent populations

A review of published literature from Africa and Asia indicates that more than 70 per cent of adolescent and young adults (12-24 years of age) living with HIV and receiving ART adhered to therapy. Lower rates of adherence were shown in Europe and North America, at 50-60 per cent.¹²⁷ Young women may also experience problems with access and adherence to treatment. In Ukraine, low adherence among pregnant women was associated with the following related factors: women living with their extended family; women living without a partner; and younger women with an unplanned pregnancy.⁷⁶ A qualitative review by WHO suggests that, as with adults, male and female adolescents face a range of barriers to access, adherence and retention.¹²⁸

Adolescents identified both positive and negative factors that facilitated access and adherence to ART. Positive, trusting relationships with and between parents or guardians and health-care providers and the availability of counselling and support were the primary factors facilitating adolescents’ access to care. Provider and community stigma, as well as inadequate or incorrect information about HIV were found to be major barriers to using available services. Free or low-cost medications, an electronic reminder, family and peer support, developing self-esteem and empowerment skills were positively associated with adherence as were incentives like taking medication regularly so that “people won’t know I’m sick”. Adolescents also feared re-infection or super-infection if they did not take medication regularly. The primary barriers to ART adherence for adolescents living with HIV were depression, regimen fatigue, weak health-care systems, a lack of youth-friendly services, privacy, and incorrect information.

Missing data

CAT-S studies on treatment delay and adherence in Bangladesh, Indonesia, Laos, Nepal, Pakistan, the Philippines, and Vietnam focused on key affected populations, including people who inject drugs, women who engage in sex work, MSM, internally displaced persons, domestic migrant workers and transgender people. Unfortunately, the data on key populations are not disaggregated by sex. These studies underscore the problem with accessing treatment particularly for migrants and people who inject drugs. However, MSM, transgender people, women who engage in sex work and people who inject drugs were more likely to miss a dose than migrants. Among the 119 women in the study who needed services for the prevention of vertical transmission, 44.5 per cent did not access them. Women participants who inject drugs were also less likely to use ANC services.

Further, while there are several studies on the experiences of people who inject drugs, they tend not to disaggregate data by sex. There is little information, therefore, on female partners of MSM. However, the Stigma Index found that female partners of men who engaged in high-risk behaviour tended to get tested only when their partners or they themselves became seriously ill.¹²⁹

3.3 Community-level cultural and social barriers

In this review, we have already explored how gender norms operate at the level of the household and family. This section considers the role of the community in facilitating women's access to treatment-related services. There are several examples that illustrate how community-level discriminatory attitudes and behaviours against women living with HIV impact their access to treatment.

An International Planned Parenthood Federation (IPPF) analysis of the *PLHIV Stigma Index* found that women living with HIV were more likely than men to be subject to, and fear, gossip since they were more likely

to be embedded in the life of the community.¹³⁰ The Stigma Index highlights the pressures on both women and men to modify their behaviour but focuses particularly on women. For example, in Nepal 30 per cent of men living with HIV decided not to get married as opposed to 47 per cent of women and 77 per cent of transgender people. Regarding celibacy, 7 per cent of men and transgender people felt pressured to be celibate, as opposed to 35 per cent of women.¹⁰¹ Between 1.8 per cent (Uganda)¹³¹ and 11.5 per cent (Malawi)¹³² of women felt pressure to be sterilized. In Bangladesh, over half of women living with HIV have experienced stigma by a friend or neighbour, 87 per cent have decided not to get married as a result of their HIV status and nearly a fifth have felt suicidal.^{132,131}

Some key informants of the UNAIDS rapid assessments believed that people with HIV should not take ARVs because it makes them look healthy and thus “free to infect others”. At all UNAIDS assessment sites, participants held the view that women living with HIV should not get pregnant in the belief that the mothers would soon die and the babies would be born with HIV.⁷²

Participants of the ICW treatment mapping conducted in Namibia believed that stigma and discrimination against women and men living with HIV was greater in urban areas because of tribal divisions and a lack of the community cohesion experienced in villages.¹³³ Worries about such stigma and discrimination from community members undermine service access. Several studies on health service access underscore the fear that accessing services or the presence of indiscreet health workers might alert community members to an individual's status. This can leave pregnant women vulnerable to vertical transmission.^{72,98,112}

Cultural belief systems operating at the community level are also instrumental in determining what kind of services women access. In the Democratic Republic of the Congo, India, Nigeria and Uganda, a general mistrust of modern medical interventions discouraged women from visiting ANC facilities and from using HIV prevention and treatment services. Women in rural sites frequently accessed traditional birth

attendants instead of official health providers since the former were considered more familiar, friendlier, more culturally aware and less expensive.⁷² Women in South Africa also reported exploring other traditional methods of treatment rather than adhering to ART.⁷⁷

Throughout the history of the HIV epidemic, community support groups have provided invaluable support to women (and men) living with HIV, including improving their understanding of HIV, offering services and treatment options, aiding with adherence, managing side effects and giving resources to aid access. Participants of the ICW treatment mapping in Kenya said that the most effective source of care and information on treatment was from support groups.

A study in South Africa also found that community-based organizations (CBOs) and non-governmental organizations (NGOs) were better placed to respond to the realities, rights and needs of women than were other agencies.¹¹² Other sources of care and support (including financial) are provided by NGOs and faith-based organizations (FBOs) within the community, as well as from women (often living with HIV themselves) who provide care in the community.⁹⁸ FBOs are the largest single group providing health-care services for HIV and, in some countries, they contribute up to 50 per cent of facility-based and community care.¹³⁴

Levels of support vary across and between communities. Participants in ICW's treatment mapping in Tanzania expressed worries that support groups in rural areas channelled less accurate information about HIV than those in urban areas.⁹⁹ Further, there remain contexts in which women felt they did not receive any or adequate care and support from family members, communities or workplaces.^{99,112} In a rural household study in India, men living with HIV reported greater medical and social support, whereas women living with HIV stressed that HIV limited their ability to care for others.¹³⁵ Finally, some individuals reported being discouraged by their faith groups from accessing or continuing with treatment.⁷²

Due to the huge potential of the community to support or hinder women's access and adherence to antiretroviral therapy, the United Nations Children's Fund (UNICEF) acknowledges the importance of working with communities to improve service uptake, adherence and retention. UNICEF underscores the importance of combining community activities with quality facility services (in the context of rolling out Option B+) to achieve an effective community-facility linkage and provide health benefits.¹³⁶

4. MESO LEVEL:

STRUCTURAL ISSUES FOCUSING ON HEALTH SERVICES AND HEALTH KNOWLEDGE

Key findings

- Knowledge about HIV, ART and treatment among women is generally low.
- The cost and location of services are factors in whether a woman decides to continue treatment.
- Stigma and discrimination by health-care staff and poor quality services are significant barriers to service access, particularly for people from marginalized populations.
- Eligibility criteria may impact men and women differently if there are disclosure requirements.

Recommendations and further areas for this project to explore

Many countries are expanding access to ART by raising the CD4 threshold for initiation,

implementing Option B+ and/or offering immediate treatment to individuals living with HIV in serodifferent (serodiscordant) couples.

In this context, there is an urgent need to gather, report, consolidate and act on the following data:

- Women's understanding of treatment and their treatment and care needs.
- The quality of information provided by health-care workers about treatment, risks and benefits.
- Gender differences in the impact of ART care eligibility.
- Women's experiences across the treatment and care continuum and how these experiences affect their mental and physical well-being.

4.1 Women's awareness of treatment options, HIV knowledge and care services

Gender norms may shape how women understand HIV, treatment and care options, and services. Data

suggest that comprehensive knowledge about HIV and AIDS is low among women. Data from a range of demographic and health surveys (DHS) show that in lower income countries, 24.5 per cent of women had comprehensive and correct knowledge about AIDS. When assessed by region, the lowest value was in Central Asia, at 12.5 per cent, and the

highest in Latin America/Caribbean, at 33.93 per cent. In every geographic region, young women (between 15 and 24 years of age) showed higher knowledge than all women (between 15 and 49 years of age). Sub-Saharan Africa had the second highest score, at 29.69 per cent. Women also participate in networks and support groups more readily than men, and such groups can be a valuable source of information.¹³⁷

There is strong evidence indicating a lack of information or misinformation regarding treatment and related services available to women living with HIV. For instance, some participants of UNAIDS rapid assessments in Democratic Republic of the Congo believed ARVs to be sedatives or vitamins.⁷² Other participants of UNAIDS rapid assessments stated that they had never heard of ANC services or were unaware that HIV could be transmitted from mother to child; still others expressed disbelief that it was possible to prevent new HIV cases among children.⁷² In Ghana, 29.5 per cent of women who did not access counselling and testing services in ANCs said they had not been told about these services.¹³⁸

The APN+ study of 3,000 people living with HIV in the Asia Pacific region found that 33 per cent of the women did not know whether HIV could be treated, and one in three women also did not know the names of their antiretroviral drug regimens.⁹⁴ A 2009 WAPN+ study revealed that 17.8 per cent of 1,222 female respondents (ranging from 6.0 per cent in Cambodia to 31.9 per cent in China) said they did not know why they had to take ARVs every day and at regular intervals.⁵² Further, many participants did not realize the difference between HIV and AIDS and many others were unable to distinguish between ARVs and OI drugs. The reasons provided for suboptimal adherence by women enrolled in a prevention of vertical transmission programme in South Africa included therapy misconceptions and/or misunderstandings.⁷⁷ Although information was given verbally in Zulu, the instructions on the medication were written only in English and duplicate medications were sent to the homes of women in rural areas.

Women who participated in the ICW treatment access mapping in Kenya, Tanzania and Namibia said one barrier to treatment was a lack of information or misinformation regarding the following: the rights of people living with HIV, medical advice and guidelines for HIV and OIs, healthy motherhood, sexual and reproductive health rights (SRHR) and related services available to them.^{98,99,135} This was especially true for people living in rural areas.⁹⁹ For instance, there was little knowledge about what first- and second-line treatment might mean.⁹⁸ The reasons given for this lack of knowledge and understanding included language barriers in instructions and on medications as well as inadequate counselling.

4.2 How do health services impact women's access to treatment?

This review looks at studies that consider how health services facilitate or inhibit treatment services for women. The review covers the following areas:

- Location of services
- Payment for services and associated costs
- Eligibility criteria
- Treatment by staff and lack of confidentiality
- Treatment by staff of marginalized populations
- The quality and availability of services
- Provision of related services

Location of services

Participants of all main studies exploring women's access to treatment cited transportation (cost, time taken, poor roads) to service sites as a key barrier to treatment access and adherence.^{72,80,92,98,99} Transport costs are often mentioned in studies that do not provide a gendered analysis, suggesting that it is a factor for both women and men. As discussed, access to resources may be more limited for women. Given the importance of transportation to service in facilitating access, location is critical. One third of pregnant women living in the city of Durban travelled an average of

30 minutes on foot to seek care at an antenatal care facility.¹³⁹ As a woman proceeds through her pregnancy, distance becomes a greater burden. Without appropriate resources and support, it can lead to a lack of follow-up.

Inadequate service location is a significant barrier particularly for women living in rural areas and slums.^{52,72,98} In WAPN+’s study in six Asian countries, women who lived in the capital cities were significantly more likely to have easy access to ARVs than women in rural areas (61.5 per cent versus 50.8 per cent).⁵² In the UNAIDS rapid assessment, some women were referred to clinics that were inconvenient, while other women did not seek testing at all since they knew the difficulty of accessing services. Further, women in both the UNAIDS and ICW studies reported a lack of resources and services within their nearest health centre and fear of being witnessed accessing HIV services forced them to journey to health centres farther from their communities.^{72,98} Lack of transport was also highlighted as a major barrier for many women to access treatment in rural south-eastern United States.¹⁴⁰

In rural areas, public transportation is often limited or unavailable so women rely on personal modes of transportation. In contrast, rural women linked to a clinic for the prevention of vertical transmission in Northern KwaZulu-Natal had treatment delivered to their homes.⁷⁷ The association between lower access and non-adherence, however, is not always connected with living in rural areas. For instance, according to one study, adherence in Nepal is higher in rural areas; unfortunately, the information on this is not disaggregated by sex.¹¹⁶

Payment for health services and associated costs

All significant studies cited the cost of treatment and associated services as a barrier to access. Payment criteria compromise adherence to treatment for everyone, especially in poor households.¹⁴¹ The disadvantage may be compounded for women, who

typically have less access to, and control over, financial and other resources, and are less likely to be insured than men.¹⁴² In Thailand, women adhering to ART noted that having access to free treatment is a significant reason why they remain in care. These women continued to adhere despite suffering side effects.¹⁴³ The payment for treatment services may affect women more adversely than men.⁸⁷ A centre in India – one of the largest ART clinics assessed – requires patients to pay a user fee to access services and treatment. Women were highly underrepresented with only 20 per cent female patients, despite comprising 40 per cent of people living with HIV in India.

Many studies also cited indirect costs as a barrier to treatment access, adherence and wider health care. A systematic review found that indirect health-care costs were negatively associated with treatment adherence for women and men.⁴² A 2009 WAPN+ study on access to reproductive and maternal health care for women living with HIV in six countries of the Asia Pacific region showed that cost (transportation, lab tests and procedures and doctors’ fees) was the most important reason given by women for stopping or not seeking treatment.

The 2013 WAPN+ study on women’s treatment access found the same results. The 2009 study also underscored the problem of having to pay for treatment for OIs and to return regularly to clinics for repeated prescriptions.

Similarly, the ICW Kenya treatment mapping highlights that even where services are free, associated costs may be prohibitive for women (and men) living with HIV. In 2006, although treatment was free in government hospitals of Kenya, there was an enrolment fee of 100 Kenya shillings for the treatment programme and treatment for opportunistic infections and diagnostic tests was not free. All treatments and tests were provided completely free of charge through PEPFAR funded programmes, although they tended to fill up quickly.⁹⁸

Studies also illustrate how badly implemented policies, bureaucracy and corruption affects service access.

In Tanzania, women spoke of having to pay bribes to receive health services.⁹⁹ Bureaucracy in China means women from low-income families struggle to access reimbursements for treatment.⁵² Despite the Zambian government's declaration in 2005 to make the whole ART service package free of charge in the public health sector, Human Rights Watch found that the policy was not uniformly applied in the two provinces studied. Respondents indicated that while ART was free of charge, they had to pay for CD4 counts and diagnostic tests.¹⁰⁸

In Namibia in 2006, treatment was free for those who could not afford it but criteria for eligibility were unclear thereby leading many poor people to miss treatment.¹³⁵ Noting the disparity between men and women in access to educational and literacy programmes, women risk being underserved when policies and criteria are not transparent. For this review, we noted a lack of recent research exploring the gendered impact of policies, bureaucracy and corruption regarding eligibility for free treatment and care.

Eligibility criteria

In some settings, eligibility criteria require that people who initiate treatment disclose their serostatus to at least one person or require that people demonstrate their ability to adhere to treatment protocols as ascertained by proxy measures such as having stable social networks or families, resident/citizenship status, or no substance use.^{144,145} Such criteria may limit access to treatment and care for women who do not want to disclose due to fears of violence from partners. In addition, these criteria limit access for single women, migrant women and women who inject drugs, all of whom may lack support and social networks.^{85,146}

The criterion requiring that a partner be present or informed can have mixed outcomes. In WHO's *Guidance on Couples HIV Testing and Counselling including Antiretroviral Therapy for Treatment and Prevention in Serodiscordant Couples 2012*, states that couples' HIV testing and counselling may improve the uptake of

and adherence to ART, benefiting the individual living with HIV as well as the partner without HIV. Couples testing has many benefits and supports HIV-negative partners who are in relationships with people living with HIV. Such testing may also benefit the partner with HIV, since sharing their status with their partner(s) helps in accessing and adhering to treatment and/or making plans for having children safely, minimizing the risk of transmission to their partner and child.

Couples testing could shift the dynamic of the global AIDS response regarding treatment of women through the prevention of vertical transmission.¹⁴⁷ However, there are multifaceted complexities with enforcing couples testing. There is anecdotal evidence to suggest that women are sometimes pressured to attend services with their partners based on these guidelines, particularly within the context of the roll-out of Option B+. These women face discriminatory treatment from health providers if they do not attend with their partners. In Uganda, some women reportedly find a "boda" driver (taxi driver) to attend testing with them to avoid telling their husbands.

Some women might prefer to be tested individually, since many women experience violence when returning home with an HIV-positive diagnosis. Women may also be ashamed to reveal to health providers that they do not have a regular partner, are sex workers, or are not married. A study in Tanzania of 245 women enrolled after pre-test counselling and prior to the collection of test results found that many women lack the autonomy to make decisions about HIV testing. In this study, 52 per cent of women feared their partner's reaction regardless of their HIV status; principally, they feared abuse or abandonment. Only a small percentage of women's male partners said they would get tested, regardless of the women's serostatus.¹⁴⁸

Additional guidelines have targeted women who are pregnant or breastfeeding to tackle mother-to-child HIV transmission. Several countries have identified pregnant women with HIV and new mothers with HIV as groups eligible for priority access to antiretroviral

therapy for their own health needs, apart from receiving ARVs as prophylaxis to prevent the transmission of HIV to their infants.^{146,147} While this benefits pregnant women and mothers, it may also result in the exclusion of women who are not pregnant, including younger women or older women who have completed childbearing.⁸⁵ There is recent evidence suggesting that women who are not pregnant find it harder to access services; the situation also raises questions about fertility treatment for women living with HIV who are finding it difficult to conceive.¹⁰⁶

Though eligibility criteria can be helpful for outlining target populations and streamlining services, they can also create exclusionary practices. It is worth exploring whether certain groups of women experience exclusion because they do not meet relevant criteria. The consequences of exclusionary criteria for women's adherence open an avenue of exploration. With the scale-up of treatment, such eligibility criteria, including a commitment to adherence, may be abandoned.

Treatment by health-care staff, confidentiality and the importance of peer support

A lack of sensitivity in health services, poor communication, breaches in confidentiality and discrimination by health service providers are cited as problems in all studies that focus on the sociocultural determinants of treatment access that lead to non-utilization of services by women living with HIV.^{42,52,72,98,99,111,112,135,140} In fact, stigma in health-care settings is cited as a reason health workers living with HIV often do not access treatment themselves.¹⁴⁹ Even simply visiting a clinic associated with HIV services may undermine an individual's ability to protect their confidentiality.^{84,152}

Concerns that health service providers do not protect confidentiality also inhibit service access for both women and men. Alarming numbers of people report either breaches in confidentiality or a lack of certainty regarding whether their status was kept confidential.^{80,116} In some circumstances, antiretroviral therapy is administered publicly and clearly breaches

confidentiality. Participants in the recent UNAIDS study noted that a perceived (and sometimes actual) lack of confidentiality, along with possible community stigma and discrimination deterred them from accessing or continuing with treatment and services to prevent new HIV acquisition in children.⁷²

Properly implemented community-based assistance (CBA) initiatives can, in certain contexts, aid treatment access and adherence. A study in South Africa showed considerably better ART outcomes for adults who received community-based adherence support. Though these data are not sex-disaggregated, they do illustrate the impact of community-based workers in addressing household challenges affecting adherence. The five-year cohort of individuals who received CBA had higher adherence, lower mortality, decreased loss of follow-up and a greater number of individuals with virological suppression compared to those who did not receive community-based care and support. Reasons cited for improved outcomes for CBA patients included improved knowledge of HIV and AIDS, better psychosocial health leading to improved behaviours related to adherence, reduction in stigmatization, and greater social capital or community relationships.¹⁵⁰

Locations where peer support is present differ remarkably from facilities in which there are many barriers to access, adherence and retention. In response to shortages of health-care staff in resource-poor settings, a recent study suggested scaling up community-based support workers.¹⁵³ In a systematic review of health system barriers and enablers for ART for pregnant and post-partum women living with HIV, researchers named poor communications with health-care staff as a factor for non-adherence to treatment and decreased follow-up in PMTCT services.⁴¹ Right from the point of testing, women report a lack of sufficient counselling that would enable them to make informed choices about their treatment options. In some cases they feel pressured by doctors, family members or partners to take up treatment before they are ready.^{52,94,140}

In their study of women's treatment access in six Asia Pacific countries, WAPN+ identified a lack of adequate counselling as having an impact on adherence.⁵² All Indonesian focus group discussion participants said they only had one session to prepare them for lifetime therapy. In Vietnam, doctors rarely give advice or examinations, but rather dispense prescriptions. Some women started ARVs under pressure from their doctors but did not believe they were concerned about their mental preparedness. Some women felt blamed by doctors for their poor response to regimes of ARV. Research by the International Treatment Preparedness Coalition in Argentina, Cambodia, Moldova, Morocco, Uganda and Zimbabwe highlights the focus of vertical transmission services on preventing transmission to babies rather than prevention, counselling, care and treatment services (including support for adherence) for women and children.¹⁵¹

It is important to note that, conversely, some studies report low levels of discrimination. The CAT-S in Asia found that women do not always experience high levels of negative reaction or experience such reactions more frequently than men. However, discriminatory behaviour may not be obviously identified as such in cultural contexts where such discriminatory behaviour is normalized. For instance, a baseline study in Laos found low levels of reported stigma and discrimination, yet 77 per cent of women living with HIV were advised by health-care providers to not have children.¹⁵²

The evidence outlined so far in this section does not enable an understanding of how treatment within the health-care setting is experienced differently (or similarly) by women and men. Nevertheless, there is documentation of discriminatory behaviour related to women's reproductive roles and it is reasonable to hypothesize that the fear of being forced to take up (or denial of) crucial pregnancy-related services could lead women living with HIV to avoid such services altogether. There are many examples of violence, coercion and denial.

A community dialogue of 150 women living with HIV in Namibia identified 40 women who felt they had been pressured by health staff into undergoing

sterilization.¹⁵³ Additionally, the WAPN+ study in six Asia Pacific countries found that 30 per cent of surveyed women were encouraged to consider sterilization; 61 per cent of such recommendations came from gynaecologists and HIV clinicians based on women's HIV status. Of women who were no longer pregnant, 22 per cent reported having an abortion due mostly to their HIV status, and 29 per cent of women who had undergone the procedure stated that their pregnancy had been wanted. In the same study, 42 per cent of women surveyed had difficulty finding a gynaecologist to care for them during pregnancy due to their status.⁸⁰

The Winchester study on the intersection of intimate partner violence and HIV treatment in Uganda focused on how health-care workers perceive and address this problem.¹⁴⁸ Most health-care workers appeared to appreciate the significant constraints faced by women in accessing and adhering to treatment, particularly their economic dependence on men and their difficulties in finding resources for food and transport. However, they felt powerless to deal with such "structural" injustices. Nevertheless, researchers witnessed some health-care workers providing economic resources to the poorest service users. Other providers hinted (rather than outwardly stated) that women were to blame for their own "burdens", while others were more sympathetic. Although health-care workers understood that for many women disclosure might lead to blame, arguments, violence, separation and a lack of support, several counsellors still strongly promoted disclosure as a means of improving treatment adherence.

Attitudes of staff towards key affected populations

Individuals from key affected populations report high levels of stigma and discrimination by health workers at clinics, including against sex workers, transgender individuals, MSM and migrants. In some situations, this constitutes a breach of confidentiality, while in others women and men are either coerced to take up services such as HIV testing or denied services.⁹⁴ For example, 30 per cent of MSM and/or transgender persons living

with HIV in some countries in the Asia Pacific Region report denial of medical services and even physical assaults by health-care providers when accessing ART and other HIV-related health-care services.⁹⁴

Additional studies underscore the pervasive influence of discrimination within health-care settings. Restricted mobility, violence, stigma and discrimination are common experiences for women engaged in sex work in Orissa, India.¹²³ In a recent study, women sex workers in Orissa reported that their inability to initiate antiretroviral therapy and attend regular medical appointments was due to prior negative experiences with the health-care system, the stigmatizing attitudes of medical staff and the fear of adverse consequences as a result of others knowing their HIV status and occupation.¹²⁴ A qualitative study among women who engage in sex work in Zimbabwe found that, along with travel times and financial costs, discrimination from medical staff and shame or anxiety about sex worker identity reduced the ability of women to attend treatment services. Finally, a study of the experience of women who engage in sex work in Russia found they were vulnerable to abuse from health-care providers.¹⁵⁴ Past experiences of poor treatment, fear of disclosure and perceived stigma were all reasons for neither testing nor seeking treatment services. All interviewed women had had at least one HIV test, with many taking place in settings with mandatory testing such as jails, hospitals and drug rehabilitation. None of the women were on ART.

Additional concerns about services that impact treatment initiation include a lack of understanding of HIV treatment, language barriers with health-care providers, the belief that lengthy counselling is required, worry about informing individuals of an HIV-positive test result and a lack of knowledge about HIV and potential risk behaviours.^{123,155} Long wait and travel times may represent a potential loss of work and income; they act as an additional barrier to services for those in employment, such as migrant workers and women who engage in sex work.¹²⁴

For young people, the successful transition to adult services can be particularly challenging. This transition

time for young adults is formative in ensuring continued access to care; thus, the relationship between adolescents and health-care providers is especially crucial.¹³⁰

Treatment availability in weak health systems

Women with HIV are concerned about out-of-stock ARVs, long waiting times and poorly-resourced (undersized, underequipped and understaffed) health services. Indeed, several studies state these factors as impediments to access and treatment.^{42,72,98,99,140,80,156,157} Women interviewed for the WAPN+ study also said that treatments for OIs were often not available. Stock-outs led eight per cent of women in the WAPN+ study in six Asian countries to change treatments.⁵²

By contrast, in the United States women who attended clinics offering comprehensive care and relatively short wait times showed a high rate of retention in HIV care. In addition, clinics offering flexible wait times showed a proportionately higher level of retention among women.¹⁴²

A review of studies looking at access to ANC and prevention of vertical transmission services underscores the lack of available, accessible, acceptable and affordable resources, and concludes that these factors negatively influence decisions and actions toward services for the prevention of vertical transmission.¹⁵⁸ A recent review found that poor communication and coordination among health system actors, poor clinical practices and gaps in provider training were also key factors for the persistent dropout along the maternal ART cascade of women living with HIV.⁴¹

With increasing numbers of people eligible for treatment under new WHO guidelines, questions have been raised about whether health systems are ready to ensure a lifelong supply of treatment. During discussions to understand the perspectives and experiences of women with HIV in Malawi and Uganda regarding Option B+, participants raised concerns that the health system was not ready to

maintain a regular supply of treatment.⁸² In this more recent study and the 2006 study conducted by ICW, women expressed their worry that donors might pull their funding and thus undermine treatment access for life.^{82,98}

A further neglected area of care for women and men living with HIV is in health monitoring follow-up on any problems encountered during treatment. This is a critical and worrying casualty of weak health systems, particularly given the concerns about how treatment side effects might impact access and adherence. One woman who participated in the ICW Kenya treatment mapping in 2006 was told that her local clinic did not stock second-line treatment, and that she had to travel to Nairobi to get it.⁹⁸ Most of the participants of the ICW mapping in Tanzania were on ARVs but had not been advised about various aspects of treatment and care, such as the difference between first- and second-line combinations or possible side effects and interactions with other medications.⁹⁹ A study focusing on women's experiences of ART service in Ghana found that a lack of follow-up was a key barrier to antiretroviral therapy centre attendance.¹⁶⁰ We know little about how a lack of treatment follow-up and monitoring influence women's experiences and their decisions regarding treatment.

Provision of related health services

A thorough examination of the links between HIV treatment services and other health services is beyond the scope of this review; however, the service delivery model design also has implications for supporting women living with HIV in navigating the maternal ART cascade.⁴¹ Service delivery models for pregnant women living with HIV can be categorized as *integrated* (ART and ANC services offered together), *proximal* (ART and ANC offered separately but close to each other, usually in the same facility) and *distal* (ART and ANC located at different facilities, requiring referral and travel). Many studies claim the benefits of the

integrated model but few studies systematically compare more than one mode of integration. Evidence is mixed regarding which model of integration is superior for delivering maternal ART.

A lack of service integration may undermine the ability of women and men to make use of a range of relevant treatments and services to improve their health more broadly.⁷² For example, many health facilities offer ANC but not HIV services or vice versa.⁷² Members of the Global Reference Group of Women Living with HIV (established to guide this review) strongly emphasized the importance of providing treatment for co-infections such as tuberculosis and hepatitis C or cervical cancer, contraception, and testing and treating for OIs, among others. These silos have detrimental effects on the accessibility of treatment for women living with HIV and co-morbidities. Evidence shows that different service setups suit varying needs; people want to make an informed choice regarding service provision, whether it is integrated or stand-alone.¹⁵⁹

In the WAPN+ study, focus group discussion participants (including women who engage in sex work and women who inject drugs) in Cambodia and China described how the failure to integrate services led to problems in terms of travel, time spent waiting for doctors and discrimination from health-care workers, especially those not used to treating people with HIV. Women living with HIV who also want reproductive health services or treatment for tuberculosis or hepatitis must visit several different clinics or hospitals. One woman in China said that she had to visit five hospitals to receive the different services she needed.⁵²

In addition to living with co-morbidities, many women face GBV, poverty and insecurity. In such contexts, even women who can afford HIV care may not prioritize it.¹⁶⁰ Without adequate training, time or resources to take a full individual case history, service providers find it difficult to comprehend the intersecting experiences and subsequent needs of women living with HIV.

5. MACRO LEVEL: NATIONAL SPHERE OF INFLUENCE

Key findings

Bureaucracy, corruption, fragility, conflict and laws criminalizing HIV and marginalized groups impact the treatment experiences of women and men living with HIV. We do not yet fully understand the gendered implications of such macro processes.

Recommendations and further areas for this project to explore

National case studies will provide further information about policy environments and their impact on women's treatment access.

All policy analysis regarding access to care and treatment should be gendered.

This section explores the impact of national policies and laws, corruption, conflict, natural disasters, internal displacement, health system shocks (e.g. Ebola) and political turmoil on women's treatment access. Due to the large scope of these questions, the themes discussed in this section will be explored chiefly through country studies and consultations.

Discriminatory legal frameworks

Discriminatory laws that restrict the rights of women may inadvertently undermine their health-seeking behaviour. For example, restrictions on the ability of women to inherit property and other assets may limit women's ability to access services and pay for these themselves. Some discriminatory laws directly punish women living with HIV. In Zambia, divorce was granted to a man because his wife went for voluntary counselling and testing and was on ART without his approval.¹⁰² The HIV Prevention and AIDS Control Bill in Uganda, signed by President Yoweri Museveni, forces pregnant women who visit ANC centres to undergo routine HIV blood testing. This clause is likely to breed discrimination in health-care delivery, increase stigma and discourage

women from seeking health care and receiving treatment. In addition, the law does not require providers to maintain confidentiality about an individual's HIV status thereby increasing women's risk of assault and abuse by intimate partners and other family members.

Laws criminalizing certain behaviours such as HIV transmission, homosexuality, drug use and sex work drastically reduce the ability of people living with HIV to access treatment.^{161,162,163} A global assessment showed that 78 governments and civil society organizations in 106 countries report existing laws and policies that present obstacles for key populations.¹⁶⁴

Prejudice and stigma against injection drug users, MSM and people who engage in sex work preclude governments from implementing laws.^{165,166} The impact of criminalization on treatment access may be worse for women (and transgender people) who also inject drugs, have same-sex relationships and/or engage in sex work due to gender inequalities. In the absence of a supportive legal environment, services will not be tailored to meet their specific needs. Moreover, displaced populations, young people and migrants, and anyone at the intersections of these

and other marginalized identities may face additional legal barriers regarding treatment access.

A major focus of literature on the criminalization of HIV transmission has been the impact on MSM populations, since these groups often face parallel legislation that outlaws same-sex practices. HIV criminalization, however, also has a huge impact on the ability of women to look for and obtain health care. A political analysis outlined three reasons why HIV criminalization laws are more likely to prosecute women than men:

- Women are more likely to seek care and know their HIV status;
- Women are more likely to be blamed for transmitting HIV to others; and
- Women may be prosecuted for vertical transmission of HIV.¹⁶⁷

In addition, women are less likely than men to have access to resources that would enable them to contest legal proceedings brought against them.¹⁶⁸

Impact of natural disasters, epidemics and violence

Emergency public health crises may create barriers for women who need access to HIV treatment. The Ebola outbreak in West Africa is an important example. The World Health Organization reports from March 25, 2014 to February 14, 2016 there were 28,646 confirmed cases of Ebola, and 11,323 confirmed deaths from Ebola.¹⁶⁹ Ebola has had a differential impact on women: 75 per cent of those who have died from Ebola in Liberia, one of the worst-affected countries, are women.¹⁷⁰ There are two important reasons for the situation. First, women have increased exposure to Ebola due to their gendered roles caring for the sick and dealing with burials. Second, to contain and control the infectious disease, widespread quarantines have been established in affected regions.

These containment measures have led to an unanticipated barrier for women living with HIV. ICW reported that women living with HIV under the Ebola quarantine have not been able to access their ART. Even women

who are not in quarantine are immobilized by fear and do not seek out care or obtain their ART at health clinics. Overwhelmed by the Ebola response, many clinics are closed or unable to accommodate women who do arrive in need of HIV care and treatment. In Sierra Leone, women with HIV report feeling afraid to go to the hospital and, if they do, say that they have been forced to disclose their status. Women under quarantine cannot get their ARVs and claim they do not get attention because the medical staff are also afraid.¹⁷¹

Conflict and fragility may severely impact women's and men's ability to access treatment. In addition, security risks and potential sexual violence against women may prevent them from accessing services. The burden of conflict, emergency or political instability also jeopardizes the stability of health delivery services. Médecins Sans Frontières has stated that national insecurity disrupts ART programmes, causing patients to interrupt their care and increasing the chance they will develop resistance to ARVs.¹⁷² In Ukraine, the recent annexation of Crimea by the Russian Federation has led to the immediate cessation of services, such as opiate substitution and the interruption of antiretroviral therapy.¹⁷³ Following the presidential election of Mwai Kibaki in Kenya, widespread violence and disruptions erupted. Programme leaders at AMPATH, managing 19 sites across Kenya reported that only five per cent of patients on ART refilled their prescriptions in the wake of post-election violence.¹⁷⁴ Operation Murambatsvina in Zimbabwe revealed that one of the top reasons (at 13.5 per cent) for ART termination was displacement.¹⁷⁵

Over a decade of civil war, political instability, and violence in the Democratic Republic of the Congo has resulted in a weakened and overburdened health sector. Conflict has also prevented local and international organizations from running HIV-sensitization programmes in rural areas. Thus, many people are unaware of the risks of acquiring HIV and are unable to access the limited care and treatment programmes available.¹⁷³ Only 18 per cent of eligible pregnant women receive HIV treatment for their own health and 21 per cent of adults and children on treatment are lost to follow-up after one year.¹⁷⁶

6. CONCLUSION

HIV treatment is being scaled up as a global policy. Data show that treatment access for women worldwide is higher than for men, partially due to the provision of ARVs to pregnant women. Women living with HIV increasingly face treatment over much longer time frames. Yet the literature to date has focused on the number of people with HIV receiving treatment rather than on the quality of their care or retention, and on treatment initiation alone rather than on that and support for adherence as a component of care. Considering what we know about treatment adherence and retention in care for pregnant and post-partum women in countries with Option B+ roll-out, it is likely that reported numbers of women initiating treatment do not reflect those maintaining regular access to, and benefiting from, ongoing treatment. Moreover, treatment access and adherence debates give limited focus to human rights violations, gender inequality and discrimination in care.

Further evidence demonstrates that there remain significant barriers to accessing treatment and care for women. There is also confirmation that women from key populations continue to face particular barriers in accessing and benefiting from treatment. The need to reach women in key populations is a reality that must no longer be ignored. Thus, it is vital to interrogate all barriers rigorously to ensure that women – and particularly marginalized women – experience long-term and positive physical, psychological and sexual health impacts.

Evidence to date strongly indicates that gender inequality related to cultural, economic and human rights issues poses considerable barriers to women's choices regarding access and adherence to HIV care and treatment services. Women's decision-making on disclosure is significantly influenced by gender-based violence, including the fear of negative reactions, abandonment and abuse. This can, in turn, limit their ability to access care and to start and adhere to treatment. The costs to women of overcoming barriers at the household, family

and community level are exacerbated by the discriminatory attitudes of health-care staff and weak health systems, including poor treatment supplies, a lack of counselling and long wait times. Negative health impacts such as side effects and having to take ARVs with food challenge women with HIV and inhibit the decision to access care and maintain treatment. Crucially, a lack of understanding remains regarding what women with HIV believe would help their mental and physical health.

While this review has gone some way to highlighting several gaps in our comprehension of the many barriers women face to accessing HIV treatment and care, it is critical to note that there remains a *widespread lack of sex-disaggregated data or a significant focus on health and human rights outcomes for women in the HIV treatment literature*.

Further, the treatment literature lacks a focus on women living with HIV who are also members of key populations, such as women who inject drugs, partners of MSM, displaced and migrant women, girls and young women. Our Global Reference Group members were chosen specifically for us to learn from them about the experiences of women living with HIV from several diverse groups (such as women who inject drugs and transgender women). We wanted to better understand the range of barriers faced by women living with HIV.

It is important to also note a paucity of data from fragile and conflict-affected states, particularly regarding HIV treatment for women. We will learn more as we move forward into the country case studies phase of this Global Review which includes Kenya, Uganda and Zimbabwe. Only by first understanding the constraints diverse women face can we then design truly effective programmes and strategies to improve access to HIV treatment. Indeed, realising the “Ending AIDS” agenda depends upon how well we listen to women's experiences and translate this knowledge into solutions that leave no woman behind.



2

FINDINGS FROM COMMUNITY DIALOGUES

1. INTRODUCTION

The goal of community dialogues was to gain a first-hand understanding of women's experiences accessing and utilizing HIV-related care and treatment. This effort clarified the different contextual barriers (and enablers) to treatment access and adherence that women experience at micro, meso and macro levels and how these intersect. The purpose of the dialogues was to validate and reveal any gaps in the literature review, and to inform country case studies in the third stage of the review.¹⁷⁷

1.1 Context and approach

It is crucial that HIV treatments for people with HIV last a lifetime. There are exceptions in the context of programmes seeking to prevent vertical transmission such as those when women are initiated on ART for limited periods of time. These programmes are largely being replaced as countries shift towards Option B+ and other immediate initiation strategies. Otherwise, lifelong treatment is an essential basis for programmes. Therefore, this consultation on treatment access explored potential barriers to initial treatment access and to continued adherence. The examination of HIV treatment in the short- and long-term is essential to a woman-centred approach to enhancing the longevity and well-being of those living with HIV around the world.

A comprehensive definition of access to ART includes not only initiation (e.g. access to ARVs in the first place) but also the ability to obtain support services at the clinic level and community level to meet adherence commitments. The need for such consistent, lifelong adherence may present major challenges for many if faced with any psychological, physical or financial challenges. Even adults with conditions such as heart disease or diabetes find it hard to adhere daily to treatment for the rest of

their lives, without having additional worries about secrecy, hiding pills or negative reactions from family members or clinicians.¹⁷⁸ Certainly, women with HIV often face more severe psychological, physical and financial barriers than those with other conditions, owing to the stigma associated with HIV. These barriers exacerbate the challenges of regular, lifelong sustained treatment access. In this global review, we address lifelong adherence issues as part of a thorough interrogation of the challenges around treatment access.

The community dialogues framework was designed by the global reference group (GRG) following the pre-consultation exercise. The community dialogues were wholly designed, developed and delivered by women living with HIV as a qualitative consultative element of the overall review. The framework was structured to gauge levels of knowledge among women in different contexts and to promote discussion around recommendations for improvements. We used neutral, open-ended questions to promote discussion. The overall aim was to understand the relationship between the care and treatment that respondents receive as well as the barriers to accessing treatment with ARVs and quality care and adherence support.

1.2 Priority areas of concern

The findings from community dialogues are structured following the analytical model used for the overall global review. We examine barriers at the individual, household, family, and community level (micro); at the level of services and infrastructure (meso); and within broader societal contexts determined by economic, environmental, legal and policy factors at the national level, which are in turn influenced by global geopolitics (macro). Key questions under each of these

KEY QUESTIONS

Micro Level: Psychosocial community-level issues

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

Meso Level: Health-service level issues

- How do 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 sphere of influence

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

areas are summarized above. In tandem with the community dialogues, these questions were explored in the literature review (see Part 1). They also reflect the priorities, experiences and concerns that were raised through the pre-consultation exercise with the Global Reference Group.

1.3 Methodology

In the literature review we identified gaps in knowledge about the barriers, facilitators and general experiences of women and girls living with HIV and trying to access treatment. Phase 2 continued this work by seeking further information and recommendations that are critical to realizing many of the individual and public health benefits of effective

long-term quality HIV care, treatment access and coverage. The primary objectives of Phase 2 community dialogues, one-to-one interviews and virtual dialogue space were to:

- Ensure the meaningful involvement of women living with HIV, informed by and speaking to their lived realities and priorities and promoting two-way discussion and learning.
- Provide safe physical and virtual spaces for these discussions to take place (this experience is, on its own, an empowering and potentially transformative process).
- Validate and/or reveal gaps in knowledge from the previous literature review.
- Renew discussion on the measurement of treatment accessibility relative to frameworks measuring women's access to broader health services.
- Develop key findings which inform country-specific case studies in Phase 3.

The community dialogues comprised a listserv discussion from September to December 2014 with 18 women from 12 countries, 12 FGDs in four countries (Bolivia, Nepal, Tunisia and Cameroon) and nine one-to-one interviews with women in eight countries, all facilitated by members of the GRG who advised and supported every aspect of the review.

Through peer outreach, every effort was made to ensure that women in all their diversities were meaningfully involved, including young women, women in sex work, women who inject drugs and experiencing other potentially marginalizing factors such as living in poverty. All women who took part in the focus groups, listserv discussions and one-to-one interviews were already accessing ART; they shared their experiences and insights regarding barriers and facilitators to accessing treatment. (See Annex 1 for more details on the methodological approach and ethical framework.)

The dialogue framework utilized a holistic, woman-centred “continuity of care” approach, which included consideration of basic needs, and quality of services as core elements of accessing and utilizing

HIV care and treatment. The framework also included more traditional considerations such as distance to health-care services, transport costs and childcare. Although the findings were intended to be a “living, breathing” picture of how issues play out in communities, they are limited in their generalizability. This section presents the findings of the community dialogues.

1.4 Limitations

The primary limitation of the community dialogues was that they were designed to be a small-scale snapshot of how women living with HIV in diverse settings experience treatment, care and support, with a focus on questions of access and adherence. This process was developed, led and implemented by women living with HIV and was on a short timeline with a modest budget.

In addition, participants were all women living with HIV who had already started on treatment with ARVs and had relatively good access to services. This implies that whatever primary barriers and challenges to treatment access the participants identified were ones that they have been able to manage or overcome. Thus, the findings represent almost a “best

case scenario.” For women who do not have access to treatment and care, or have been unable to maintain good treatment adherence, there may be additional barriers that we are missing, or the severity of the challenges mentioned here may be even greater.

A further limitation was that women who participated in the one-to-one interviews and listserv discussion are all women who have been living with HIV for ten or more years and who are seasoned advocates for the rights of women living HIV. As such, their personal experiences do not reflect most women living with HIV. Participants were, however, able to provide a long-term view, comparing the situation facing women now with that of ten or more years ago. The benefit of this perspective was a clear understanding of advancements and progress, resilience and agency over the past few decades that may be useful in shaping forward-looking recommendations.

It is also worth noting that these participants may have access to information, support and resources that are not common to all women. For instance, one of the contributors to the listserv discussed how participation in the International AIDS Conferences had opened a world of knowledge to her. Clearly, this level of engagement is only available to a very small proportion of women living with HIV globally.

2. OVERVIEW OF FINDINGS

The analysis of the community dialogues illustrates the interwoven complexity of women's lives. These findings highlight barriers and difficulties women face as well as areas of progress and factors that increase women's resilience, support and agency. It is important to understand the barriers and challenges, as well as positive aspects that increase or improve women's access and adherence to ART and overall health outcomes. We hope that by focusing on effective strategies currently in place we can develop a more comprehensive understanding of what is working, what could work, and target areas for advocacy groups and researchers.

Importantly, this analysis seeks to reflect the ways that women involved in the community dialogues attended to the various issues affecting access and adherence to HIV treatment and care. This prioritization was determined by the number of times particular issues were mentioned in the different discussion platforms described in the introduction. It is also important to note that issues that are categorized below as "micro-, meso- or macro-level" may reverberate across all three levels in the experience of women living with HIV. This reflects the intersectionality of women's lives and treatment access, uptake and adherence across all three levels. Where

relevant, there are notes in the text or footnotes to explain the placement of an issue in a particular section of the report.

2.1 Structure of the following sections

Sections 3-5 of Part 2 focus on micro, meso and macro levels. Each section starts with key findings outlining the barriers and challenges experienced most commonly among the community dialogue participants. These key findings are followed by a description of emerging concerns and questions for further investigation, as raised by participants. The issues point to questions that need further exploration to obtain a deeper or more nuanced understanding of women's realities in relation to HIV care and treatment access. They may also serve to identify possible gaps in terms of available information on community and peer support, activism and treatment literacy. These gaps and emerging issues will be explored more thoroughly during the in-depth country case studies in Phase 3 of this review. Finally, we include examples of positive findings, improvements and areas of resilience, including support and agency.

3. MICRO LEVEL: PSYCHOSOCIAL BARRIERS AT THE INDIVIDUAL, HOUSEHOLD, FAMILY AND COMMUNITY LEVEL

3.1 Key findings at the micro level

Gender-based violence against women living with HIV

The most commonly cited concern for women living with HIV remains the physical, sexual, emotional/psychological and financial violence they face in their homes, communities, workplaces and in the health-care system, including structural and institutional forms of violence.¹⁷⁹ This often means it is either physically or psychologically difficult to make appointments, collect and/or take medication.

There are additional dimensions of violence that encompass experiences beyond the use of physical force or power. These dimensions are critical to interrogate as they impact women's access to treatment. Consequently, this review adopted a comprehensive definition of gender-based violence, offered by the Declaration on the Elimination of Violence Against Women (Article 1), as any act that "results in or is likely to result in, physical, sexual or psychological harm or suffering."¹⁸⁰ Hale and Vasquez narrow this definition for women living with HIV as "violence against positive women is any act, structure or processing

in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV."¹⁸¹

As the review notes, violence encompasses both use of physical force as well as threatening or controlling behaviours, expressions of HIV-related stigma or other types of blame and verbal abuse on the part of family, community and/or service providers. It also interrogates financial violence in terms of withholding resources that a woman requires to access services and support her health. Women living with HIV cite physical, sexual, emotional/psychological and financial violence as their most common concerns. These can be multiple and overlapping, as reflected in quotes throughout this section.

Over the course of these dialogues, the women also described experiences with these different forms of violence in multiple spaces of their lives: homes, communities, the workplace and the health-care system. Participants' narratives were structured around the barriers in various environments rather than the types of violence experienced. The document also uses the WHO definition of violence against women to frame experiences of physical, sexual and mental harm or suffering.

Violence in the home

Psychological and financial abuse

Seven out of the nine women who were interviewed, as well as participants in most of the focus groups, reported experiences of violence and/or fear of violence in the home. This came from multiple family members including, but not limited to, intimate partners, siblings and in-laws. Specifically, women described threatening or controlling behaviours and/or instances of verbal abuse conveying HIV-related stigma and blame, slander and rejection.

“My father ill-treated me and my son, where he refused to support us financially [and] also prevented me from sitting with the family around the table for eating or watching TV, or using anything in common with them because of their fear of transmission of the virus.”

(FGD in Tunisia)

In some instances, women and their children were abandoned by their husbands, in-laws and family members, leading to homelessness and destitution. Some women described this violence as resulting in serious deterioration of their mental and physical health. Additionally, such experiences greatly impact women’s ability to overcome the direct and indirect costs of accessing treatment, care and support for their HIV-positive status.

Physical violence

Reports of physical violence within the home varied geographically. Women in focus groups in Tunisia reported very high levels of intimate partner and domestic violence. The experiences of intimate partner and domestic violence acted as a barrier to women’s ability to care for themselves, and to access treatment, care and support in the context of their HIV status. Violence in the home is rarely a one-off event but is instead a chronic long-term condition, creating major physical and/or psychological barriers to treatment access.

“I am living with HIV since 2004 and I was infected by my husband, he made my life with him a living hell. Every day I live in a state of terror and fear because of beatings and various kinds of insults and verbal abuse.”

(FGD in Tunisia)

“After the death of my husband I started my journey with the suffering when his family repudiated me and my children and they attacked and beat us. Then, we were fired from the house. We are now living in the street homeless, depending on the righteousness and charity of some people, and sometimes we lodge in the open without food or clothing.”

(FGD in Tunisia)

Violence in the community: additional layers of marginalization

Psychological violence

Many women described psychological violence in the community as an extension of experiences in the home: slander, rumours, stigma and discrimination.

Physical violence

While intimate partner violence is often discussed as the primary source of physical threats to women living with HIV, we must recognize that women living with HIV from key affected populations¹⁸² may face exacerbated levels of violence within the community as well as at home. These women face multiple forms of marginalization and layers of stigma, whether they are sex workers, transgender women, or members of other at-risk groups. An interview with a transgender woman in the United States revealed how fear of violence acts as a strong and immediate disincentive to accessing care and treatment:

“If just simply leaving the house increases the chance of being assaulted or being killed versus not taking medication and starting later, which one do you think they would choose?”

(Interview in the United States)

Experiences of violence in the community and at home discourage women from care-seeking behaviour, especially those facing multiple forms of marginalization.

Violence in the workplace: stigma, discrimination and involuntary disclosure

Psychological and financial violence

In community dialogues, women living with HIV identified several fears post-disclosure including fear of job loss or never working again. In places where HIV treatment requires multiple visits to the hospital and/or clinic and where it is accessed in HIV-specific sites the very act of seeking and acquiring treatment may be a signal of HIV status, resulting in involuntary disclosure. Further, women tend to be employed in informal sectors where there is little recourse in the face of stigma, discrimination, involuntary disclosure or related forms of violence.

Formal and informal workplace violence impacts women’s livelihoods both psychologically and financially. When a woman cannot work well, loses her job or compromises her health to conceal her HIV status from co-workers, she will ultimately lose income. Sometimes the linkages are even more direct. An interviewee from Uganda explained that stigma against sex workers living with HIV is so extreme that those who are not living with HIV may deliberately disclose the status of another sex worker living with HIV to “poach” clients. Women engaged in sex work, therefore, experience further disincentives to access services or carry medication for fear of raising suspicion among their colleagues regarding their HIV status:

“When a client comes they will shout out ‘she is HIV positive don’t take her, take me’.”

(Interview in Uganda)

Physical Violence

In sex worker communities, women and transgender women living with HIV are particularly vulnerable. One transgender woman interviewed in Bolivia said that a sex worker “*would be lynched*” if her HIV-positive status is known. “*Discrimination is huge*,” she claimed. Such fear of violence and discrimination within the community where (in this case) transgender women work creates a significant barrier to access and adherence to treatment.

Women’s gender roles and responsibilities

Building on the discussion of violence, the community dialogues highlighted how the need to gain permission (from home, school or work), or to take time out of routines (education, remunerative employment, subsistence work, domestic work) to attend health services intersects with the challenge of maintaining confidentiality in those settings. For some women, having to ask permission from husbands or other family members, or fear of rousing suspicion caused by regular hospital visits, presents significant constraints to treatment access and leads to missed appointments or defaulting on treatment. Gender norms around women’s roles and responsibilities within the household further compound the situation when routines such as childcare, housework and family meal preparation are expected to take priority over the concerns of individual women.

In some settings, formal workplaces lack the flexibility to accommodate taking time off work to attend frequent clinic or hospital appointments, especially where long waiting times and/or stock-outs are common.¹⁸³ Frequent, regular or lengthy absences from the workplace may also lead to involuntary disclosure.

“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.”

(FGD in La Paz and El Alto, Bolivia)

“Some husbands do not want their wife to go to the hospital. In this case, the woman goes to hospital secretly. If not, 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 in Cameroon)

One woman in Nepal described how she had to ask permission from her mother-in-law, who would respond by telling her that hospital visits were a waste of time:

“She always used to say that I am going to die because of my status so no need to go.”

(FGD in Nepal)

In addition, women’s lack of control over resources is coupled with the expectation that women require permission to seek health-care services. This demonstrates the interrelationship between gender norms, women’s ability to make decisions regarding their own health and access as well as adherence to HIV treatment and care.

“Most of us are dependent on husbands or family so we have to get permission because only [then will] they give us cost for bus fare and hospital procedures.”

(FGD in Nepal)

Another limiting component of traditional gender roles and responsibilities for women is their assumed role as caregivers. Women in two focus groups in Bolivia described how the inaccessibility of childcare (due to cost or availability) meant that their children must accompany them to the clinic. A small number of women across the focus groups also reported missing appointments because they were caring for other family members, including elderly parents, and could not always leave their homes long enough to attend appointments.

Women living with HIV participating in the community dialogues referenced their caregiving roles and motherhood as both a challenge and a motivation that held both positive and negative implications for their access to care and adherence to HIV treatment. Children were alluded to as a great strain on resources while also being a motivating factor for maintaining health, and a source of happiness and inspiration:

“My son is my happiness.”

(FGD in La Paz and El Alto, Bolivia)

Treatment side effects

Physical side effects (including lipodystrophy and neuropathy) were cited in many of the FGDs, during interviews and on the listserv discussion as barriers to adherence. Most impacts were physical, but some of these – especially changes in body shape – had mental or emotional repercussions, particularly around gender norms and expectations for women’s bodies and sexuality. Participants cited mood swings, changes in libido, nervousness and anxiety, difficulty sleeping or staying awake, lethargy and loss of memory as negative side effects of treatment. Side effects may act as a disincentive to treatment uptake or adherence, bring about treatment fatigue or lead to depression and low self-esteem.¹⁸⁴ One participant no longer felt desirable due to the side effects of HIV treatment:

“What affected me most is that I do not feel attractive to my husband. He does not say anything, but that is how I feel and that is why I get depressed.”

(FGD in Cochabamba, Bolivia)

Such perceptions may be rooted in societal expectations around women’s bodies and sexuality, fueling negative self-perceptions if one does not meet these standards.

Focus group participants in Nepal noted a range of side effects:

“After starting ARVs my hips became narrow and my stomach became big, so its looks bad.”

“I can’t stay awake for 10 minutes after taking ARVs. For me, it’s a sleeping tablet.”

“I severely suffer from diarrhea whenever I eat meat.”

“After starting ARVs I have lost muscle in my cheeks [face.]”

“I feel like vomiting when I smell any food cooking - I don’t want to eat anything.”

“After I started ARVs I have gained unnecessary muscle on [the] back [of my] neck, like a lump.”

(FGD in Nepal)

Although most women in the FGDs did not report that side effects had caused them to interrupt their treatment, women in one FGD said that those who were not given clear counselling about side effects were likely to stop their treatment altogether when

side effects started; others spoke about treatment fatigue (see 3.2 below).

In two cases, women reported side effects that were so severe their doctors advised them to stop taking the treatment. One woman switched to an alternative regimen and found that the symptoms disappeared. This example highlights the importance of having a range of treatment options available.

Basic needs

Poverty and financial insecurity

Most of the women involved in the focus groups and three of those interviewed described experiences of poverty and financial insecurity. These experiences reflect the global gender gap in socioeconomic status. HIV status deepens this gap (see discussion on experiences of violence in the workplace). Participants in paid employment often reported being on very low salaries compared to national averages. Lower wages for these women are part of a general trend of lesser pay for women, combined with unreliable funding patterns for civil society organizations. Several of the participants worked in the HIV NGO sector where their organizations were underfunded and frequently lacked the resources to pay wages.¹⁸⁵

“The basis of this reality is poverty. We earn little and then, after paying rent, it is hard to afford good nutrition and the school fees for our children.”

(FGD in Nepal)

For other women, their earning potential has been reduced by the physical weakness resulting from HIV. Combined with the costs of seeking treatment and care, HIV was viewed as an entry-point into a cycle of poverty.

“I am very weak. I can’t contribute more effort in the field so I am unable to earn sufficient income to fulfill my basic requirements.”

(FGD in Nepal)

Nutrition and food insecurity

For a small number of women in Tunisia, Uganda and Zimbabwe, there was great uncertainty as to where their next meal would come from. For most FGD participants, food was available but many said they were unlikely to be able to supplement basic food with more nutritious elements (e.g. many missed fruit) or with dietary supplements in the form of vitamins. Again, this mirrors the food insecurity that women face more broadly and, in most cases, gender norms and cultural expectations dictate that women place family needs above their own.

“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”

(FGD with women sex workers in Cameroon)

3.2 Emerging questions and areas for further investigation at the micro level

Mental health, self-stigma and its effect on access and adherence

It is important to gain a better understanding of the relationship between mental health, self-stigma and adherence. Across all community dialogues, women described a variety of past and present

situations impacting mental health, causing depression, anxiety, stress and a lack of motivation to go on living. Among these, several women described how experiences of stigma might be internalized and result in depression and other mental health problems. These have detrimental effects on women’s self-esteem, sense of worth and, in turn, on their health-seeking behaviours, including treatment access and adherence. One interview with a transgender woman from the United States illustrated how depression impacted her ability to access treatment:

“I didn’t feel the motivation to take care of myself... I was losing the will to live.”

(Interview in the United States)

A community dialogue participant in Bolivia abandoned her TB treatment because of the depression caused by the lack of support from her boss:

“I was so depressed at that situation I stopped the treatment and I have not retaken it until now.”

(FGD in Bolivia)

Women and men are less likely to access and adhere to treatment if they are experiencing mental health problems; these may also be caused by stigma, discrimination and violence, financial stress, and treatment side effects, among others.^{71,106} For example, poor mental health due to intimate partner violence was a strong factor for no or low treatment adherence in a Coalition of Women Living with HIV and AIDS in Malawi (COWLHA) Malawi baseline GBV study.¹¹³

How treatment initiation timing and preparedness affect access and adherence

In relation to mental health, women's own feelings about their diagnosis and treatment itself may present a psychological barrier to accessing treatment in the first place, while treatment fatigue (also related to side effects, see Section 3.1) may impede adherence. While many women in the community dialogues said that starting treatment as soon as possible was desirable, others described having struggled emotionally with the uptake of treatment. One woman described the day she started taking treatment as *"the saddest moment of [my] life."* (FGD with women sex workers in Cameroon)

One interviewee from Uganda expressed the belief that women may need time to come to terms with their diagnosis before starting treatment. Others have struggled with long-term adherence, sometimes dealing with "treatment fatigue" as well as a range of side effects.

"[S.] tells us how she was on strike in 2010. 'For five months she was tired of swallowing tablets, even now, she is not happy to take it'."

(FGD with Muslim women in Cameroon)

"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, until now the ddl [didanosine] one I have to chew. That's why sometimes I stopped taking them, occasionally I stop them, the medication, it is the routine of the drug that already has me tired."

(Interview in Bolivia)

"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 in Zimbabwe)

The issue of women's individual "readiness" to start taking treatment becomes especially relevant where new treatment approaches such as Option B+ are being rolled out.^{186,187} In addition, rapidly growing evidence indicates reduced rates of AIDS-defining illnesses and/or increased long-term health benefits from initiation of HIV treatment regardless of CD4 cell count. With the release of data from the START trial, in which roughly one-third of participants were women, there is now additional evidence for the potential individual benefit if a person is ready and able to remain on treatment. However, the findings from Option B+ programmes show that initiation and long-term retention in care are not a given.

There may be consensus on "when" to start from a clinical perspective but there are major gaps in research and programmes that define "how" to start so that an individual can take her or his medications as prescribed over time. Data from Malawi on women stopping treatment after they give birth and/or being "lost to follow up"¹⁸⁸ raise questions about whether, when and how women living with HIV "become ready" to start lifelong treatment. Given the challenges of general adherence to long-term treatment for any condition,¹⁸⁹ the feedback raises important questions about how best to help women prepare to embark on lifelong treatment.

In conclusion, further work is needed to understand the beliefs women hold about the benefits and harms of treatment, and the advice they receive at the service level (see also the sub-sections on treatment literacy, information and advice available to women, under Section 4.1). Additionally, we need evaluations of the effectiveness of programmes that both initiate treatment and support individuals who are on treatment. Such evaluations of emerging ART programmes should examine the long-term outcomes of different approaches to initiation in varying contexts. Further, individual readiness to begin treatment as well as support for access and adherence must be better integrated within existing quality-of-care approaches.

3.3 Positive findings: areas of improvement, resilience, agency or support

Supportive family, friends and peer groups

Support from family, friends and, in particular, contact with other women living with HIV is fundamental to supporting women and giving them a reason to live. Many of the women interviewed said having access to other women living with HIV made an immense difference to their lives. This sentiment also came up repeatedly during FGDs. Women reported that support groups and the opportunity to share experiences with other women living with HIV made them feel “normal” and helped with treatment adherence.¹⁹⁰

“If it wasn’t for the Grupos de Ayuda Mutua (support groups) I do not know where we would vent, the GAMs are like a family.”

(FGD in Cochabamba, Bolivia)

Many of the women interviewed had also played an activist role at some point since diagnosis, often in conjunction with support groups and networks of women living with HIV. This work also provided a sense of purpose and agency in relation to their diagnosis.

“Being an activist gave me the purpose that I didn’t have for a long time. [This] drives me to take better care of myself.”

(Interview in the United States)

Motivation to survive and adhere to medication after having children

Some women explained that having children was a huge motivation to persevere, fight for their lives and take and adhere to medication. This held true even though having children put pressure on mothers in other areas: household finances, managing childcare when collecting medications and protecting children from different forms of violence (i.e. physical, psychological).¹⁹¹ In some cases, women related how being able to have children and start a family brought a welcome sense of normality to their lives. Women felt as though they had “achieved” adulthood by acquiring the social status of motherhood after the turmoil, uncertainty and sense of isolation and “difference” that many women described following diagnosis.

“It motivates me when I look at my children and for my other siblings who are negative and my father, I have to push on with life. As long as you are taking your treatment well, you are no different from the rest.”

(Interview in Uganda)

4. MESO LEVEL: BARRIERS WITHIN OR RELATED TO HEALTH SERVICES, ACCESS TO INFORMATION AND STRUCTURAL AND INFRASTRUCTURAL BARRIERS

4.1 Key barriers at the meso level

Rights violations in the health-care setting

Stigma and discrimination by health professionals

Attitudes of health-care workers towards people in their care affect their clients' health-seeking behaviours.¹⁹² Often, there can be logical reasons for clients not accessing or adhering to treatment, but these might not be obvious to health-care providers.¹⁹³ Stigma, discrimination and abuse by health professionals was raised as a serious concern in about half the focus groups discussions—particularly in Bolivia and Tunisia—and in two of the interviews. Participants described experiences that included breaches of confidentiality whereby HIV status was disclosed in front of family members, other staff and clients. In some cases, this resulted in stigma and discrimination and potentially placed women at risk of intimate partner or domestic violence, as described above.

Women also mentioned instances in which they or their children were refused treatment and care by health professionals based on their HIV-positive status. Some participants expressed fear of revealing their HIV status when seeking care for a non-HIV-related issue in case they were turned away. For all these reasons, women may avoid accessing health services altogether.

“I have the problem of cervical cancer, but I’m afraid to say that I have HIV. Will they see me if I say that?”

(FGD in La Paz and El Alto, Bolivia)

Transgender women living with HIV are particularly vulnerable to violence and rights abuses within health settings. In a FGD for transgender women in Nepal, participants described facing double stigma within services, partly because service providers “don’t

know how to deal with them, they don't know how to treat them." Participants explained that transgender women are often seen and treated as MSM or as sex workers. There are no specialist services or facilities for transgender women. This makes hospitals potentially threatening places where transgender women can face stigma and discrimination from staff and other service-users.

"There is no separate transgender ward. If we are admitted in the hospital, then they put us in the male ward which is hard for us and if we go for the counselling then they say in a rude way that we are sex workers."

(FGD in Nepal)

Sexual and reproductive health and human rights violations

Interrelated and overlapping with quality of care and attitudes of health-care workers are additional sexual and reproductive health and human rights violations experienced by women living with HIV when they become mothers. These, too, serve as barriers to ongoing access to treatment, care and support. Women in FGDs in Tunisia and Bolivia commonly reported experiencing human rights violations when seeking care, especially prenatal care and during pregnancy/delivery, or in relation to their sexual and reproductive health more broadly. They saw this lack as having an inevitable negative effect on the likelihood of initially accessing or continuing to access relevant medication for themselves or their unborn children.¹⁹⁴

Some participants of FGDs, interviews and listserv discussions cited having had little or no access to information about access to treatment for the prevention of vertical transmission. Such information is considered critical for deciding whether to have children. This contention was particularly common among participants who had been living with HIV for

a greater length of time (ten years or more) and had been diagnosed earlier in the HIV response.

Among clients and providers there also appeared to be widespread disparities in up-to-date knowledge on guidelines, recommendations and good practice around clinical care and treatment for women living with HIV who wanted to have, or were having, children. For instance, an informant from Kampala who had recently given birth reported that women living with HIV in Uganda are only offered Caesarean sections which carry an additional cost. By contrast, in the United Kingdom, women living with HIV who are on treatment (including an informant for this review) have vaginal deliveries with over 99 per cent of the babies being born free of HIV.

In some instances, women reported that there is still a belief or attitude among service providers that women living with HIV should not conceive, have children, or even have sex.

"I was told not to get pregnant by doctors there, 'you don't have to use family planning methods, you must stop having sex'."

(Interview in Uganda)

A few women said they continue to be discouraged from having children despite the existence of clinical guidelines and treatment to prevent vertical transmission. In some cases, they reported the advice of service providers goes far beyond discouragement and moves into ill treatment, abuse and violence against women living with HIV who are pregnant, delivering or in post-partum care. Participants cited examples of women being neglected during pregnancy and labor, stigmatized by health workers, receiving poor quality care, being forced to undergo or refused abortion, being forced or coerced into sterilization or witnessing the neglect of their children.

“When they did a vaginal examination, my water had broken and they left me there all night, the doctor left an order to do a caesarean but the doctor who has entered the shift change when he learned, he did not want to take over. ‘How come? She has HIV!’ ... Nobody helped me; they left me on the floor. ... The nurse told me that children with HIV would die very quickly. And she told me that medication would give me welts.”

(Interview in Bolivia)

As we illustrate below, other women reported that good support is available for women living with HIV who want to have children.

Quality of care

The positive impact of treatment literacy

About half of the focus groups and two-thirds of the interview participants described having a limited understanding of HIV treatment protocols and reported low levels of treatment literacy among themselves and their peers. They underscored the importance of treatment literacy or broader health literacy as a tool for autonomy and informed decision-making in accessing treatment. Some participants regarded treatment literacy as the entry point for women to engage in a two-way conversation about their care and treatment plans and pathways. However, this is not the reality for most women:

“Most conversations ignore the fact that people living with HIV need to have increased health literacy.”

(Interview in the United States)

Several participants in one-to-one interviews described how they had spent a great deal of time and energy building their own treatment literacy through online resources, conversations with health professionals, networks and support groups and their work as HIV advocates. They reported this as essential in enabling them to making decisions about when to start treatment and how to manage their lifelong commitment to accessing treatment. Consolidating this individual experience could prove a promising practice in strengthening women’s treatment literacy, engagement and overall access and adherence for improved health outcomes.

“All the information was gathered from [the] Internet ... [Later] participation in HIV conferences opened a new world of information for me. ... I [then] felt informed, and ... could discuss with the doctor my treatment options and make decisions for myself.”

(Listserv discussion in Portugal)

One of the interview participants, born with HIV, believes that for parents and caregivers looking after children with HIV, information about treatment is inaccessible. It can be hard enough for any adult to persuade their child to take medication, even harder if it tastes bad and singles the child out from his or her siblings.¹⁹⁵ Lack of available information or support about how to medicate children effectively can thus result in a parent ceasing treatment delivery.

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

(Interview in Nepal)

One participant expressed the perception that treatment literacy – traditionally a strong element of treatment advocacy – has been eroded by the onset of greater treatment availability. As treatment access has increased, treatment advocacy has waned and with it the treatment literacy that was a fundamental part of mobilizing community activism.

“I think once treatment came, treatment literacy and advocacy took a step back and now there is very little.”

(Interview in Zimbabwe)

This dearth points to an important ongoing role for civil society, including support groups and networks of women living with HIV to be involved with peer treatment literacy and adherence support.

The barriers of gender and power dynamics in health facility-based decision-making about starting and remaining on treatment

Regarding gender norms and power dynamics between health-care providers and women patients more broadly, as well as evidence gaps around the effect of ART on women, community dialogues suggest that, in many places, advice given to women in health settings is often missing or inadequate. Women do not understand the benefits of treatment, what to take and when, associated care, and interactions and side effects. In relation to health-care providers, women in the FGD in Nepal observed:

“They ignore counselling about treatment.”

(FGD in Nepal)

Many women explained that they were told very little, if anything, about any side effects they might experience. Consequently, women felt unprepared to deal with side effects once they started on treatment. “For

me it was an ordeal to adjust to the medication,” (FGD in La Paz and El Alto, Bolivia). Side effects may have a strong impact on women’s motivation to continue with treatment. Some women felt that the lack of counselling, information, monitoring and support for common side effects could act as a strong disincentive for treatment adherence.

“When they have the first side effects, or do not understand, they just leave it.”

(FGD in La Paz and El Alto, Bolivia)

Women in Bolivia explained there is little or no information given about treatment regimens, and in some cases women were denied other services if treatment was refused. How treatments are distributed at the health-service level, and what information, explanation and support accompany them to promote women’s agency are meso-level issues.

“All women are put on Tenofovir, Efavirenz, Lamivudine (TEL), sometimes without assessing the side effects. It is almost mandatory to start treatment, there is no choice. If you say you do not want to start, then they do not want to see you.”

(FGD in Cochabamba, Bolivia)

A question that begs further enquiry is: how does a lack of choice affect treatment access, adherence and positive health (including mental health) outcomes for women?

Another concern that women in FGDs raised was a lack of linkages to care and integration of services (e.g. for side effects, opportunistic infections, co-morbidities or other health concerns). Women in Cameroon explained that at the three-month consultation with

their doctor (for which they pay) they felt that she or he did not have time to listen to concerns not directly linked to HIV or ART.

“As soon as they see that you are an HIV-infected person, then they don’t take care of you, they just send you to take your [ARVs] treatment well.”

(FGD among Muslim women in Cameroon)

The dialogues revealed connections between the overall quality of care, rights abuses within health services and the ability or willingness of service providers to give appropriate information and advice to clients, specifically to women. Several FGD participants complained that health-care providers were not taking the time to ensure that they had understood how and when to take medications, which can have serious implications for adherence. In some cases, it may lead to women quitting their treatment when they experience adverse side effects or if their health improves. This issue may be further exacerbated for clients who are non-native speakers or who have other communication barriers.

“They started giving me triple therapy without explaining to me what it is or the symptoms of side effects. In addition to that I did not get the meaning and significance of therapeutic education.”

(FGD in Tunisia)

“There are women who speak Aymara¹⁹⁴[and not Spanish], who cannot complain. There is discrimination against these women because of their traditional dress, they are afraid, they are mistreated because they come from rural areas...They say [they] have understood for fear of the doctor, but really have not understood.”

(FGD in La Paz and El Alto, Bolivia)

Distance, transport and waiting times

Women in nearly all the focus groups raised concerns over the high cost of transport and the distance to facilities. They described both as barriers to initial access and to adherence, particularly for women living in rural areas. Many women related having to ask for money from family members or borrow from neighbours or co-workers to be able to travel to the hospital or clinic. If they could not get the money, they would miss their appointments and this could result in defaulting and/or hostility from service providers when the women tried to re-schedule.

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

(FGD in Nepal)

“The biggest problem is for those who are from rural areas. They have to travel far and sometimes they don’t get seen, and this is why they stop their treatment.”

(FGD in Santa Cruz, Bolivia)

A smaller number of women explained that these challenges also arise because women may choose to attend health clinics that are farther away. This is done to avoid involuntary disclosure and/or meeting people from their local community in the clinic or because the women perceived the alternative clinic offered a higher standard of care.

Further, women in Cameroon and Nepal spoke about the need to visit their health facility monthly for treatment refills. This puts a strain on limited resources where higher transport costs, longer distances and

waiting times, stock-outs and the need to take time off from work and/or pay for childcare come into play.¹⁹⁷ As one woman notes:

“In all that, you have to go to the health centre every month for supplies.”

(FGD with women sex workers in Cameroon)

“Health services are a little bit far from where we live so we have to travel by public transport which takes 15-30 minutes. [This is] affordable because most of us are employed. But if we talk about the situation in the village, then it takes one day if we travel by public transport which is not affordable because there we are dependent on house work. And if we ask help for money then no one is ready to give it to us. So, because of this situation we are unable to go hospital to take ARVs which leads to treatment interruption for one month.”

(FGD in Nepal)

Related to the issue of quality of care, some women also reported very long waiting times. They noted this could result in defaulting if, for example, they were consequently unable to access treatment and return to the health centre the following day.

“There are very large queues in the government hospital [for everyone] to see a doctor. We have to wait in line with 25-30 people.”

(FGD in Nepal)

As these narratives imply, the combination of long waiting times, extensive journey times and the cost of public transport can be insurmountable barriers to accessing treatment, especially for women who fear

disclosure, are in controlling or violent relationships, or risk losing their livelihood if they miss work.

Availability of monitoring

For women in Nepal and Zimbabwe, a lack of free CD4 testing was reported as an issue, while in most of the other countries it was available. However, a more widespread issue was the limited availability of free viral load testing (or lack of equipment to do the test) and other exams such as for bone density, liver or kidney function (all of which can be adversely affected by ARVs) for women in Cameroon, Ukraine, Uganda, Nepal and Zimbabwe. Without these tests, women have a harder time monitoring their progress while on ARVs. This, in turn, limits incentives for women to continue adhering to ART. As explained above, if women can see that their treatment has a positive effect on their CD4 count and viral load, this encourages efforts to access and take ARVs despite other ongoing challenges. Such monitoring is also good clinical care.

4.2 Emerging questions and areas for further investigation

Treatment literacy

A small number of women raised questions about health provider knowledge regarding interactions between ARVs and other medications required by women living with HIV, particularly those from key affected populations. This needs to be explored both in relation to linkages to care (to ensure that co-morbidities are detected and given appropriate care) and treatment.

“Methadone and brupenofren need to be very controlled with ARVs, tuberculosis [treatment]. The doctor’s confidence depends on geographical areas and depends on treatment literacy. There is low motivation among doctors to teach patients and time constraints.”

(Interview in Ukraine)

We need further investigation into what advice and referrals women are given around treatment interactions and co-morbidities. For example, the development of cervical cancer through Human Papilloma Virus (HPV), tuberculosis (TB) and malaria co-morbidities all have gendered dimensions, which are to date largely under-researched. This is not directly related to our review of women's access and adherence to HIV treatment, but it has been cited as a gap that should be integrated into any such effort by members of the Global Reference Group.

Care and treatment access for women in prison or detention

A couple of interviewees raised issues regarding the interruption of treatment for women in prison or detention, which they said was a common experience:

"In prison, there are issues about people's medication being discontinued or interrupted due to the time between arrest and people accessing services."

(Interview in United Kingdom)

This feedback raises particular concerns for the population of women sex workers. These women frequently face short-term detention or arrest and may be held overnight and then released without charge, a harassment tactic used by police. It can also be a problem for female sex workers living with HIV to take medication in prison or detention in front of their colleagues for reasons of disclosure and subsequent discrimination, as explained in Section 3. An interviewee from Uganda pointed to the important role civil society organizations play in training police and prison or detention staff on treatment literacy and adherence:

"We train paralegals so that when sex workers are arrested, they can call the paralegals and get legal support. We also ensure they have access to their meds for sex workers in prison. We are working on sensitization about treatment access with the police force."

(Interview in Uganda)

Access and linkages to sexual and reproductive health services

The community dialogues raised questions around family planning, fertility, pregnancy and related co-morbidities that merit further exploration under the rubric of the quality and nature of advice given on HIV treatment including referrals and informed choice. Given the connection between mental health, meeting fertility desires and adherence,^{71,187,189} this topic has potentially wide-ranging implications for access to care and treatment.

Related considerations include:

- Women's concerns about the effects of ARVs on unborn children;
- Potential interactions between hormonal contraceptives and ARVs;
- Timing of starting treatment when one wants to have a baby; and
- Abortion services.

Access to treatment among health staff living with HIV

The clear majority of front-line health-care workers globally are female. An important gap in the data gathered to date through this review is about health staff living with HIV¹⁵² and any specific barriers or enablers they face regarding self-testing and self-treatment and adherence. While this was not explicitly discussed in the community dialogues, it is an important topic for future research.¹⁹⁸

4.3 Positive findings: areas of improvement, resilience, agency or support

Trust in, and rapport with, health-care staff

In one-to-one interviews women from the United Kingdom, United States, and Russia described how building a good relationship with a doctor through mutual trust and respect had been an essential element in their accessing treatment, understanding side effects and adhering to medication. This relationship enabled them to ask questions about treatment, which in turn allowed them to develop their own knowledge, gain a sense of autonomy and safety, build confidence in the advice that they were given and become better positioned to advocate for effective treatment, information and care. Additional components of this positive relationship included communication, responsiveness and more equal power relations between the provider and patient or client.

“My doctor is very accessible. I have his mobile phone and his email. Once I was out of the UK and I wanted to take an antibiotic I wasn’t sure about so I texted him and he replied straight away. I don’t think most people have that kind of access. I think overall I have access to the best health care in the world.”

(Interview in United Kingdom)

Unfortunately, this sort of relationship is likely to be out of reach for many women in more resource-constrained settings where the burden of HIV is higher. Women living with HIV in these settings generally have less access to education than their male counterparts or than health staff, resulting in unequal power and knowledge relations. Directly connected to treatment access and adherence in the context of HIV is

the lack of confidence to ask questions about health, especially about sexual and reproductive health as these are widely considered taboo issues.

Individual treatment literacy for women with HIV

Several women living with HIV who took part in one-to-one interviews and the listserv discussion spoke about treatment literacy as a key component in supporting them to make informed choices. FGD participants and interviewees described how women’s access to information about HIV treatment and care is often linked to their ability to find support groups and networks of women living with HIV.

“Share among yourselves, seek information, don’t isolate yourself, do not sit with folded arms to die.”

(FGD in Cochabamba, Bolivia)

“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 in United Kingdom)

Women have many questions for health workers about potential drug interactions between ARVs and contraception and viral load in relation to having sex. It can be extremely hard for women to raise such issues with male health staff.

“There is lack of special female doctors so [it is] hard to be open with problems.”

(FGD in Nepal)

5. MACRO LEVEL: BARRIERS CREATED BY LAWS, POLICIES AND THE BROADER ENVIRONMENT

5.1 Key barriers at the macro level

Criminalization of HIV exposure and transmission, sex work, drug use and same-sex practices

A small number of women who took part in interviews isolated the legal environment as a set of barriers to accessing treatment where the transmission of and/or exposure to HIV is classed as a criminal offence. In addition, laws that criminalize drug use, sex work and/or same-sex practices create extra constraints to women from key affected populations. These laws often exacerbate structural and community violence against women living with HIV. (Section 4.1 describes how violence constitutes a barrier to accessing and benefiting from appropriate treatment and care.)

“The legal environment in Uganda and the ‘HIV prevention and control law’ ... many people know about this and it has created lots of fears. Already, people who were strong and accessing medication 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 in Uganda)

A woman’s legal status (e.g. women who are migrant workers, women seeking asylum or women who have relocated to another country for other reasons) may also be a barrier to accessing care and treatment.

5.2 Positive findings: areas of improvement, resilience, agency or support

Access to HIV-related treatment and care has improved

Most women who took part in the community dialogues noted that access to ART and other HIV-related services has improved, especially for women who were diagnosed over ten years ago. This includes women from key affected populations.

“Since 2005 OST [opioid substitution therapy] exists. MARPs (most at risk populations) have access to rapid testing through outreach and don’t need to go into medical settings.”

(Interview in Ukraine)

In addition, it was noted that improvements in laws regarding human rights for people living with HIV have led to more choice and better quality of care for all women living with HIV. In Ukraine, women who use drugs can now access opioid substitution therapy as well as rapid HIV testing done through community outreach.

“We have changed our AIDS law – we now have a new version of the law that is more [reflective of the] HR (human rights) protection of personal data, [there is] more opportunity for women’s SRHR access to reproductive technologies where before it was prohibited.”

(Interview in Ukraine)

Community dialogue participants reported a range of approaches vis-à-vis their level of choice in terms of both when to start and stop treatment options. The range of approaches was also noted by many women participating in e-discussions and is also reflected in country guidelines.

While guidelines at the macro level are helpful for streamlining treatment uptake, they can also be perceived as barriers to initiation. Some women in the one-to-one interviews attributed their delayed uptake of ART to ineffective national-level guidelines. For instance, one participant of an FGD in Cameroon explained how she had been impatient to start treatment but her health provider had made her wait until her CD4 count dropped to below 300, in accordance with the national guidelines. Normative guidelines

implemented at the national level frame much of what happens within health services. Although such guidelines can be effective streamlining frameworks for treatment uptake, some of the women in this review described how their experiences attempting to begin treatment had been thwarted by these guidelines.

In Bolivia, women illustrated how the situation has changed over time. Drug shortages have been a problem both at the meso and macro levels due to logistics and supply issues at the health service level and ineffective health policies at the national level. During past drug shortages women would “*take what was available*” and sometimes this meant pediatric ARVs funded by other countries or foundations. Since the Global Fund to Fight AIDS, Tuberculosis and Malaria support started in Bolivia in 2005, ARVs are generally more available.

The HIV treatment availability, access and adherence landscape is under rapid change. New evidence is emerging that points to a reduction in negative health outcomes and improved long-term health outcomes with immediate or early initiation of ART. At the same time, there continue to be funding cuts which will affect HIV treatment access in numerous countries. This is in part due to withdrawal of funding to countries designated by the World Bank as Middle Income Countries. For example, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the UK Department for International Development (DFID), and the United States President’s Emergency Plan for AIDS Relief (PEPFAR) are changing their funding priorities, with some countries becoming ineligible for resources.¹⁹⁷ Time will reveal the consequences of these funding shifts.

6. CONCLUSION

The community dialogues, although relatively small in scope, present a unique model for qualitative, textured dialogue by and among women living with HIV. These examples provide a framework for exploring and understanding how women may be best supported in their need to commit to a sustained lifelong treatment journey. An exploration of immediate barriers and enablers related to HIV treatment access and maintenance is crucial to making sure policies, programmes and strategies truly reflect the needs of diverse women.



3

COUNTRY
CASE STUDIES

1. INTRODUCTION

In the final phase of this review, women living with HIV helped to guide and implement in-depth country case studies in **Kenya, Uganda and Zimbabwe**.^{200,201}

The case studies contained in this section provide a thorough exploration of the experiences of women living with HIV in deciding to start, remain on, or come off ART. The primary purpose of this approach was to highlight core themes identified by women and make room for women's experiences. As the literature review underscored, women's voices are markedly absent in research to date. Although we include limited quantitative data, the purpose of our analysis is to reveal new critical insights into the challenges faced by women living with HIV in response to treatment scale-up programmes.

Context-specific versions of the Community Dialogues Discussion Guide were developed from guides used in Part 2, as well as related in-depth one-to-one interview tools. The focus group discussion guide developed and adapted by each of the country teams

stressed a conversation that was often conducted by or with the assistance of a woman living with HIV.

Methods for each country case study included a focused literature review on country-specific issues, a policy and epidemiological scan, 10 to 16 FGDs, and select key informant interviews with health providers. Some FGDs in Kenya and Uganda included male partners. A space was created for women to safely express themselves. Through this process, areas of resilience and challenge were identified.

All the transcripts were analysed and coded to identify emerging core themes. The findings, presented below, both validate and give additional texture and detail to the first two phases of this global review. It is essential these results form the basis of further operational research based on both qualitative and quantitative information. In this way, we can ensure the right questions are asked of the right people at the right time.

2. KENYA CASE STUDY

2.1 Kenyan women living with HIV – an overview of epidemiology and experience

Although Kenya has seen an overall decline in HIV incidence since the mid-1990s, rates remain disproportionately higher in women than in men. Overall, women constitute 57 per cent of people living with HIV in Kenya. The per cent of women testing in antenatal clinics has increased substantially from 2009 (68.3%) to 2013 (92.20%). The percentage of pregnant women living with HIV who received ART remained stable over that same period, while the absolute number of pregnant women receiving ART declined. Roughly 55 per cent of women with an HIV diagnosis reported using ART at the time of delivery. Between 2009 and 2013, there was an upward trend of women using ART during breastfeeding. Over this period, the number of infants who acquired HIV perinatally remained the same.^{202,203}

While the epidemic is driven through heterosexual partnerships, key populations remain disproportionately affected. Female sex workers have a prevalence rate at 29.6 per cent, more than five times higher than the national average. Their uptake of HIV testing and knowledge of HIV status is, at 68 per cent, lower than the average for women accessing antenatal care where testing rates are above 90 per cent. Adolescent girls and young women between 15-24 years of age are another vulnerable population, accounting for 21 per cent of all new infections in Kenya.¹⁹³ Approximately 3 per cent of young Kenyan women and men (or 2 per cent for young women only) are living with HIV.¹⁹³

The Kenyan government tracks retention in care for up to 60 months following ART initiation but does not disaggregate these numbers by sex. Perinatal initiation does not include long-term retention levels.

There is, therefore, limited information on barriers and facilitators to remaining in care and on ART over time for both women and men. A recent population-level survey tracking the HIV cascade and incidence found that women were more likely to be retained in care compared to men. This investigation was the first in Kenya to follow the 2013 WHO recommendation for initiating antiretrovirals at CD4 cell counts of 500 or above—a policy shift that increased the number of individuals eligible for ART.²⁰⁴

As summarized in the sections that follow, the lived experiences of women, as documented in this project, fill in some of the data missing in the peer-reviewed literature and add to previous efforts led by and for women living with HIV. Documenting their experiences helps to explain some of the gaps in the treatment cascade that begins with uptake of testing and ends with a decision about when and whether to take ART.

2.2 Highlights from recent literature

Overall

- Documentation on women's access to ART highlights factors at the macro, meso and micro levels. Multiple studies underscore the relative contributions of logistical meso level barriers (distance to clinic, costs associated with attending) versus meso level constraints at the psychological/emotional level (stigmatizing attitudes or psychological violence displayed by health-care workers) and micro-level barriers (depression, shame, fear of partner abandonment). The effects of many of these factors apply to all women, regardless of their HIV serostatus, and therefore strategies for addressing these issues would have an overarching benefit for all women accessing any healthcare services.

- The prevalence of data available about women who access ART pertain to women who are pregnant. Adult non-pregnant women, adolescents, sex workers and transgender women are not accounted for in most analyses of treatment cascades in Kenya.
- There is scant information on barriers and facilitators to remaining in care (as opposed to initiating ART) as data often cover a limited period following delivery, even in the comparatively well-studied realm of Option B+ programmes. There is also a limited amount of data on women who are not linked to care, or who are offered and choose not to start ART.

Selected studies²⁰⁶

An evaluation of social factors influencing the uptake of programmes to prevent vertical transmission in rural Kenya probed the influence of referrals and acceptability, HIV-related stigma, observed discrimination and knowledge of violence.²⁰⁷ Most women living with HIV reported stigma and nearly half reported shame if they were associated with someone living with HIV. Shame was significantly associated with decreased likelihood of HIV testing, a complete course of maternal ARVs and infant HIV testing. The authors conclude, “interventions that seek to decrease maternal depression and internalization of stigma may facilitate uptake of PMTCT (Prevention of Mother-to-Child Transmission of HIV).”

A small study examining linkages to ART among women living with HIV who received a diagnosis in antenatal care found that 85 per cent of women who were eligible did not register for ART after their diagnosis.²⁰⁸ Enabling factors associated with registration included knowing someone with HIV, not having to pay for transport to a hospital, and having received enough information to decide to have an HIV test. Barriers included stigmatizing attitudes perceived or anticipated in women’s social support networks, interactions with health workers and health facility characteristics.

Another study looking at factors that influenced delivery in a facility found that cost, distance, and fear

of harsh treatment were the primary disincentives for both women living with HIV and women who were HIV negative.²⁰⁹ HIV-specific stigma indicators were not cited as additional factors for women living with HIV in this study. Pregnant women living with HIV who delivered in hospitals were more likely to know their partner’s HIV status, to have disclosed to their partners, to be on ART, and to have higher education and socioeconomic status compared to women living with HIV who did not deliver in a medical facility.

Women living with HIV have been, and continue to be, a source of valuable data on experiences within the health-care setting, with rich documentation and recommendations on the specific challenges and rights violations faced by all Kenyan women²¹⁰ including those living with HIV.²¹¹ A 2015 report produced by the International Community of Women Living with HIV (ICW) and the Global Network of People Living with HIV (GNP+) provides an in-depth and first-hand exploration of Kenyan and Namibian women’s experiences with programmes to prevent vertical transmission. The research focused particularly on barriers and facilitators related to the uptake of early infant diagnosis.²¹²

The studies included in this literature review identify instances where supportive health workers assisted women in making decisions and accessing service with positive outcomes. There are few such accounts in the literature. This is, in part, an artefact of a barriers-oriented research approach. It is also a reflection of over-taxed health systems and holes in the training provided to health workers. Negative results on women include harsh treatment, breaches in confidentiality, and refusal of services and threats – all forms of psychological violence.

At least one evaluation of the relative impact of factors related to the health facility versus stigma on women’s linkage to ANC to prevent vertical transmission concluded that “health systems are more influential than stigma” in terms of uptake.²¹³ There is also a paucity of literature on the support provided to frontline, mostly female health workers that can help improve care and mitigate the stressors of their workplace, including the profound stigma against women living with HIV working in health-care settings.²¹⁴

TABLE 3
Status of HIV and Treatment in Kenya²⁰⁵

Demographics	
Population	42,961,187
GNI per capita	US\$2,780

Prevalence	
Number people living with HIV	1,366,771
HIV prevalence	3.18%
Women	6.6%
Men	4.9%
HIV PREVALENCE BY KEY POPULATIONS	
Men who have sex with men	18.2%
Female sex workers	29.3%
People who inject drugs	18.7%
Fishing people	26.2%
Adolescent girls/young women	3%

Incidence	
New HIV acquisitions	56,355
Incidence rate	0.13%

Treatment access	
Total coverage	63% (857,472/1,366,771)
Pregnant women	74% (55,400/74,470)

Treatment cascade	
Total people living with HIV	1,366,771
Tested for HIV	7,956,018
Diagnosed HIV positive	215,123
Initiated on ART	165,138
On ART	857,472
Retained on ART at 12 months	746,000
Viral suppression at 12 months	726,370

Treatment cascade: pregnant women	
Total people living with HIV	74,470
Tested for HIV	1,233,462
Diagnosed HIV positive	61,510
Initiated on ART	28,983
On ART	55,400
Retained on ART at 12 months	No data
Viral suppression at 12 months	80%

The literature reviewed for this report also highlights structural issues impacting treatment uptake and retention. These include persistent silos between services for HIV prevention, treatment and care, and those for contraceptives. One study to assess need and demand for integrated HIV/STI prevention and contraceptive programmes identified gaps in provision of needed services for both men and women in Kenya.²¹⁵ Interestingly, this paper focused solely on the use of condoms for HIV prevention despite other available options. In an expanding landscape, which includes ART for people living with HIV and Pre-exposure Prophylaxis (PrEP) for people who are HIV negative (and, for men, established interventions like voluntary medical male circumcision), revisiting questions of strategic programmatic integration with a lens to where and how newer strategies are made available is also a necessity. Combined with previous research that informed the implementation of new ART guidelines (see below), the shifting landscape of the HIV response is opening new and unexplored avenues for research, even as well-mapped, entrenched issues at the health systems and society levels remain identified but unaddressed.

In 2013, the WHO issued its consolidated guidance document on the use of antiretrovirals for treatment and prevention. Articles published following the release of these guidelines respond specifically to data gaps regarding barriers and facilitators to ART access for individuals who may be reached through test and treat, Option B+, or expanded testing initiatives. Some, though not all, of these papers provide sex-disaggregated data.

A Kenyan survey of linkage to care following home-based counselling and testing found that women who expressed fear of violence or relationship breakup were less likely to link to care.²¹⁶ Women who had disclosed their HIV status to their families were more likely to link to care. Another Kenyan study of sero-discordant couples offered immediate ART as part of their participation in open label trials offering ART and PrEP. The study identified a range of concerns associated with initiation regardless of CD4 cell count, including a strong association related to historic HIV public awareness campaigns, that ART was for people

who were sick and taking ART was an indication of “being near the grave.”²¹⁷ The data in this study were not sex-disaggregated. Of note, this is one of the few sources on Kenyan women that provides insight into women who are *not* encountering ART in the context of antenatal care.

There are limited resources available regarding the experiences of women on ART in all their diversities. A study exploring the impact of antiretroviral introduction on women sex workers focused primarily on perceptions of ART’s impact on HIV and on women’s HIV risk behaviours. Motivations for starting and staying on treatment, including having children and a strong religious faith, were noted in passing.²¹⁸ There remains a dearth of information that examines the interconnectedness of women who occupy multiple marginalized social locations and/or identities.

2.3 Policy landscape

As summarized in Table 3, Kenya has a range of policies and strategic frameworks touching on issues affecting access to ART for women living with HIV. The frameworks do not provide consistent, in-depth identification of issues related to interventions or targets for women in all their diversities. Notably, Kenya tabled a portion of a law that would criminalize HIV transmission; however, this law was not enacted.

The Public Benefit Organizations Act,²¹⁹ which is pending but not yet operational, is another concerning piece of legislation. The Act proposes changes in how NGOs are governed, extending government control over NGO engagement in the political sphere. As civil society engagement and peer-initiated advocacy, service delivery and safe spaces are essential to the ongoing fight against the HIV epidemic, this could have detrimental impacts for women living with HIV. The Act has been the subject of critique and concern from civil society organizations; expanded government powers to register and de-register NGOs could have a chilling effect on vigorous advocacy and activism.

In terms of policy affecting provision of and access to services, the new Kenyan Constitution devolves health service management and provision to the provincial level, where specific challenges affect service delivery such as health-care worker strikes or province-specific resource allocation decisions. In addition, PEPFAR, which makes its biggest grant to Kenya, is pursuing a geolocation approach to service provision that is supported by Kenya's own national AIDS policies. While this tactic focuses resources on high burden areas, it also reallocates resources away from those areas that do not have an overall high burden but may have significant impact on social issues, such as profound stigma and discrimination.

A directive from President Uhuru Kenyatta to publicly disclose the names of people living with HIV, including creating a register of children living with HIV, is currently under challenge in the Kenyan high court. As well, the issue of forced and coerced sterilization of women living with HIV is before the court. At the time of this review, a lawsuit had been brought forward by women who were coerced into sterilization without consent.²²⁰

2.4 Methodology overview

ICW Eastern Africa staff members reviewed Elimination of Mother-to-Child Transmission of HIV (eMTCT) programme performance indicators including loss to follow-up, percentage of newborns and infants diagnosed with HIV and ART coverage rates for the general population. This case study is based on one high- and one low-performing district. Interview tools and informed consent forms for women living with HIV, their male partners and health facility staff were developed in consultation with UN Women and collaborating partners, and aligned with the Community Dialogues tool. A total of 10 FGDs were carried out, 5 per district. FGDs in each district were organized into three categories: 2 FGDs with women aged 18-29, 2 with women aged 30 and older, and one with men. Participants were identified via members of ICW Eastern Africa (ICW EA) and some of these participants were members of other organizations

of women living with HIV. FGDs were led by ICW EA members and informed consent was obtained using an approach consistent with community-based participatory research ethics (see Annex 1 for details). Findings are organized so the micro level addresses individual, household and community factors; the meso level includes health service availability and delivery factors; and the macro level contains national policies and institutions, while recognizing that such factors often move between and co-exist at multiple levels.

2.5 Findings from focus group discussions

Micro level Issues

Stigma, neglect and violence from male partners: Some men refuse to use condoms, do not attend ANC with their wives or spouses, and resist getting tested for HIV. A significant number of women respondents stated that they risked violence if they disclosed their HIV status to a male partner.

“It is very difficult for the woman to tell the man that today I have gone to the health facility and I have tested positive. You will get so many blows and you will not believe yourself.”

(FGD in Kenya)

Food insecurity/poverty: Many women reported low-income and food insecurity as a major barrier to accessing treatment. Similarly, respondents counted on food supplies promised by the hospital only to find someone else had claimed them.

The cost of transport to clinics can be a barrier: Many women found transport costs as well as expenses incurred at the clinic (see below) a challenge to care access.

Meso level Issues

Observance of sexual and reproductive health and rights for women living with HIV is inconsistent:

Respondents reported that mothers are not given an opportunity to choose a Caesarean-section instead of having a vaginal delivery. Women also identified gaps in information about infant feeding options, including the right to decide to breastfeed. Health-care workers interviewed seemed to be aware of women's rights, but a consistent programme to educate women about their rights concerning family planning and related issues is not in place or, if it is in place, is insufficient.

"Yes, you can choose for yourself, but the emergency C-section can only be recommended from our doctor."

(FGD in Kenya)

"It depends. If the mother is in good condition she delivers normally. But if she has complications this is when you get this mother taken to get a Caesarean. Normally in our Busia County and Referral hospital, few are taken to get a Caesarean. The majority are delivering normally."

(FGD in Kenya)

ANC is the primary drive for women to seek care at the clinic:

ANC represents a point of entry for women to engage in more comprehensive health care, especially if they test positive for HIV. Indeed, most women learn their HIV status after coming to the clinic for ANC. Women's experience at this crucial visit can consolidate or alienate their continued involvement with the health-care system.

Lack of resources, especially stock-outs of drugs, and limited medical supplies, constrain the services of some clinics: Stock-outs of ARVs present a major

challenge to the delivery of care in health facilities. Kenyan participants reported stock-outs on "many occasions." Kenya's focus group discussion also outlined problems with transportation and delivery which interfered with the distribution of needed drugs and other supplies. Further, many prescribed drugs, except ARVs, must be paid for out-of-pocket. Respondents felt it was imprudent to give up a day of work to go to the clinic only to find they could not pay for the drugs prescribed.

"You might be sick or admitted in the ward. So, you are supposed to use money. Some of us are widows, we must go and work – like her, she is a supplier of water. If she is in bed, she will not have money. So, if you got to Kakamega County Hospital you have to be with money because every drug prescribed you have to buy, but you lack money. We don't buy ARVs but other drugs we have to buy."

(FGD in Kenya)

Understaffing can limit the availability of individual counselling:

This sometimes leads to group sessions instead and tired, irritable health workers. Respondents held overworked, inadequately trained staff responsible for a range of complaints from insensitive counselling to forced sterilization. In fact, the issue of insufficient staff at health facilities was listed at the top of barriers to access in Kenya. Participants claimed staff are rude and very slow when attending women living with HIV, and show discriminatory attitudes.

"It has been a challenge for us – health workers' negative attitudes toward mothers who are positive."

(FGD in Kenya)

“I delivered by Caesarean section and the TL (tubal ligation) was done without telling me. I was told later that the TL was done because I was not supposed to have more children. I was told to sign without knowing what I was signing for...so I was forced.”

(FGD in Kenya)

Delayed start of ANC: On average, most pregnant mothers living with HIV attend their first ANC when four to five months pregnant, contrary to the recommended first trimester. Many continue to give birth outside the hospital, circumventing wider engagement with health-care services, including elimination of mother-to-child-transmission (eMTCT) programmes and Option B+.

Long distances and long waits at health-care centres: It is not unusual for women to spend hours traveling to a clinic and then encounter long waits before they are seen; this undermines their interest and motivation in visiting the health centre. Long delays while waiting for care mean women living with HIV go the day without a meal, miss work, and experience multiple other indirect costs to visiting health centres.

Limited capacity for effective follow-up: Many women stop coming after four or five ANC visits. Health facilities need to be able to call or visit women living with HIV who have not returned to the clinic to support women’s continued participation in treatment.

Early infant diagnosis (EID) at the clinic level is effective: For those women living with HIV who gave birth in hospitals, EID is a priority. Most health facilities provide EID as early as 6 weeks in line with national policy. The test is done again 6 weeks after cessation of breast feeding (mothers are advised to stop breast feeding at six months) and at 18 months, a *polymerase chain reaction (PCR) test* is done.

Basic testing is effective: The infrastructure and services required for eMTCT, such as lab tests (CD4), hemoglobin (Hb), urinalysis and virological HIV

testing in infants for polymerase chain reaction (PCR) are done at the health facilities visited.

Couple support groups improve adherence: In Kenya, women who had accessed the limited array of support groups for couples reported that they offered much-needed counselling and support to women living with HIV and their male counterparts and, as a result, facilitated success with treatment for ARVs.

Macro level issues

Gender roles and poverty: Participants explained that gender roles influence the ability of men to care for themselves or support their partners and children. Men tend to be a highly mobile and migratory population, looking for employment. Generally, their place in the economy as low-wage workers, “scrambling for a day’s pay”, undermines their involvement in health-seeking behaviors for themselves and their families. Women respondents proposed incentives such as health talks for couples, male-oriented health kits or supplies and financial incentives as a complement to current programmes such as the ‘Maama kits’ (for mothers).

Understaffing and inadequate staff training: Health workers are overworked and not well-trained on prevention of mother-to-child transmission and elimination of mother-to-child transmission. Often, they have limited knowledge of the rights of women living with HIV.

“Nurses ... seem not to understand. Some of our mothers who turned out to be positive for the first time were initiated on ART. She is not given the right instructions [for] the medication that mother has to take.”

(FGD in Kenya)

The discriminatory and unethical conduct of some health workers toward women living with HIV was a major concern across all participants.

Limited knowledge about the full objectives of eMTCT, Option B+, and sexual and reproductive health and rights: Very few of the respondents in Kenya understood the scope of eMTCT and Option B+, which includes the provision of care, keeping mothers alive, and the *choice* to initiate ART regardless of CD4 cell count. eMTCT is widely understood to include ANC, the right to give birth in a clinic and ARVs to prevent the transmission of HIV from a mother living with HIV to her newborn.

Respondents learned what they know about eMTCT from television shows and the news, more local district-initiated efforts such as the launch of the provincial eMTCT programme by the provincial governor in Kakamega district²²¹ and on-site counselling at clinics. These efforts, however, deliver only a portion of the message; almost all the men and women living with HIV who participated in the FGD were entirely unaware of the other life-saving elements of the eMTCT programme. The FGD coordinator noted that *“none of the women and men living with HIV in Kenya articulated a single eMTCT/PMTCT policy, not even the then popular strategic framework for eMTCT. It was therefore not surprising...women living with HIV had limited knowledge”* of eMTCT programme provisions.

By contrast, respondents were familiar with an extensive list of family planning interventions including condoms (the most preferred because usage does not

involve hormone regulation), levonorgestrel implants, depo, implanon, oral contraceptive pills, injectables, tubal ligation, and dual protection.

2.6 Recommendations

- **Comprehensive rights-based education targeted to women, men and health-care providers.**
Education should underpin models of women-centred service delivery that reduce stigma and discrimination and facilitate informed choice.
- **Investments in treatment literacy and literacy on specific issues, topics and guidelines** including eMTCT policies, guidelines and strategies so that women can demand adequate services and hold health-care workers and people who hold office accountable.
- **Investment in novel service delivery models that bring care closer to women**, thereby reducing pressure on infrastructure and the long and costly distances that women (and men) living with HIV have to travel to reach these facilities.
- **Facilitate, motivate and train village health teams (VHT), peer or mentor mothers, peer educators** and women living with HIV themselves so they continue to support women living with HIV to access eMTCT services.

TABLE 4
Policy Mapping in Kenya

Policy	Policy objective (overall)	Policy focus related to women	Strengths	Shortcomings	Notes/Analysis
NASCOP treatment policies	To provide HIV care, treatment and support to those living with and affected by HIV.	Reproductive health services including STI prevention and treatment in Minimum Package of Care. Guidelines detail when and how to start treatment for pregnant women.	Minimum Package of Care in HIV Services Provision; sexual and reproductive health (SRH) care, family planning (FP) services and cervical and breast cancer screening included in package of care. In Guidelines, ANC promoted for pregnant women – especially early access. HIV Counselling and Testing (HCT) highlighted as necessary for women who opt out of testing during pregnancy. Screening for cervical cancer is highlighted as essential for HIV+ and sexually active women. Guidelines for ART Treatment do, however, discuss SRH for women living with HIV, noting that “choice of contraceptive methods in [women living with] HIV women is the same as in HIV uninfected women” and choice of contraceptive should consider ART regimen for HIV+ women to ensure safety.	Minimum Package of Care: requirements for service provision only specify pregnant women. Even in the Adolescent Health section, SRH care and FP is only discussed in context of pregnant adolescents. In guidelines for HIV treatment, management of infection is only in the context of prevention of vertical transmission. Doses and regimens are based on “efficacy in prevention of transmission” and do not incorporate other contextual factors. Abstinence is promoted for women living with HIV to reduce risk of acquiring Human Papillomavirus (HPV).	Non-pregnant, young women still need access to FP and SRH services, which is not highlighted.
Kenya NASP 2009/10-2012/13	Guidance for HIV interventions in Kenya over four years. Aims to achieve Kenya’s Universal Access targets for quality integrated services at all levels to prevent infections, reduce new infections and prevent death.	N/A	Small section on gender dimensions of the epidemic highlights its “feminization”.	Results Framework Logic Chain Outcomes aims to increase abstinence among youth and unmarried women. Clear linkage discussed between urban poor and women at risk of HIV due to lack of control of human capital, rights, information, and denial/ lower quality of education and care – highlights need to target even hard to reach groups such as young, out-of-school women. 0% per cent of total funding allocated to “Women’s Policies & Guidelines” under <i>Enabling Environment</i> .	Prevention (Px) programmes for youth have contributed to delayed sexual debut but for young women who are sexually active, they have failed to make a difference. A lot of discussion of gender disparities, high prevalence among young women and high risk of HIV but no planned interventions for these target groups outside of pregnant women for PMTCT. One target mentioned to reduce GBV but no intervention proposed.

Policy	Policy objective (overall)	Policy focus related to women	Strengths	Shortcomings	Notes/Analysis
Kenyan AIDS Strategic Framework 2014/15 – 2018/9	Provide guidance for addressing the HIV and AIDS epidemic in Kenya.	Women mentioned as a priority group (in addition to key populations) along with adolescents, boys and girls.	<p>Highlights women as disproportionately affected by HIV vs. men and “therefore are a key vulnerable population to be prioritized in this strategic framework”. Young women are also a priority in this HIV response. Adoption of strategic framework for PMTCT with clear targets.</p> <p>Interventions, recommended actions and responsible parties/ leading agencies outlined for adolescent and young women specifically as well as pregnant women. Additionally, proposes behavioural interventions aimed at reducing stigma. Targets set for reducing levels of sexual and GBV by 50%. Interventions proposed for various sectors to remove barriers to access services including empowerment of women, and use of media to reduce gender-related violence.</p>		Programme gaps identified include low programme priority to address HIV stigma and discrimination and violence against key populations (including women). IPV and GBV to be integrated in HIV survey.
Vision 3030 (focus on second Medium Term Plan 2013 – 2017)	Kenya’s development programme that aims to create a globally competitive and prosperous nation with a high quality of life by 2030.	Youth and women identified as high priority. Government commits to increasing support for policies and institutions devoted to promoting gender equality and will allocate resources to enterprises led by youth and women.	Strategy outlined for female empowerment, gender equality (including reducing GBV) and improving livelihoods developed. Strategy outlined includes objectives, outcomes, implementing agencies, deadlines, financing and annual budget allocations until 2018.	Neither health- nor HIV-focused.	Focus on empowering women and ending GBV which would enable access to care but no specifics on women and HIV care and treatment. Improvement in HIV and AIDS response is not gendered, some focus on adolescents but not women or young women.

Policy	Policy objective (overall)	Policy focus related to women	Strengths	Shortcomings	Notes/Analysis
Declaration of Commitment on HIV/AIDS (Kenya follow up 2003 & 2014 review by General Assembly)	Guiding framework to combat HIV and AIDS. Outlines governmental commitments to address HIV and AIDS and take action.	The Declaration calls for policies to ensure equal access for men and women to prevention and care. Emphasizes access to vulnerable populations.	Gender and AIDS Taskforce has made recommendations to ensure equal access. It also states that promotion of the rights of women at-risk of HIV have been included in legal framework and addresses gender dimensions that place women and girls at-risk. Aims to mainstream gender issues into Kenya's National AIDS Strategic Plan.	2014 update reports on successes and shortfalls of implementation but it is not sex-disaggregated. Discussions on "recommendations" made but no details on what they are and no targets/strategy outlined. States "inclusion in legal framework" but no details on how and where.	Kenya's PMTCT strategy has led to reduction in new cases of HIV in children. Women not considered under "vulnerable high risk population" category.
PEPFAR COP 2013	Focus on treatment scale-up, strengthening supply chain, increased collaboration and integration.	eMTCT and Option B+ are a large focus.	Targets set for counselling pregnant women and provision of ARVs. For non-pregnant women, strategies to increase testing and re-testing identified. Great data collection and reporting on HIV prevalence that are sex- and age-disaggregated. PEPFAR resources also committed to providing support services to women for disclosure. PEPFAR Team has an inter-agency Gender Working Group that drives the gender agenda and realizes that barriers to care are "social, educational, legal and economic." Targets set for: increasing gender equity in HIV activities and services; reducing violence and coercion; addressing male norms and behaviours including increased engagement of men in PMTCT; counselling and testing; and care and treatment services.	Significant focus on pregnant women regarding access to treatment with specific, time-bound targets. Disclosure support provided to women as part of a strategy to increase male enrolment in care and support services and not for the purpose of providing support to women post diagnosis. Some focus on women in prison but only in the context of pregnancy while incarcerated.	Goals to provide women with entrepreneurship skills training create enabling environment for women to access care by increasing empowerment. Targets and interventions for non-pregnant women are discussed but mostly around prevention (condom negotiation, safe sex negotiation, etc.) and not on treatment, service, resource access once positive. This is highlighted as a key issue but no dollars or targets attached to them. Cervical cancer screening for women.
Kenya Health Policy 2012-2030	Provides direction to improve health in Kenya. Coordinated alongside Vision 3030, the Constitution and other global commitments.		Policy objective to increase literacy among women (under social determinants of health Policy #6).	Limited focus on HIV apart from calling for an increase in coordination with other STI control efforts (led by National AIDS Control Council). Epidemiological data presented but not disaggregated and no response outlined for women.	Highlights stunted growth and low BMI for women in rural areas with obesity (and diabetes) burdening women largely in urban areas.

3. UGANDA COUNTRY CASE STUDY

3.1 Ugandan women living with HIV – an overview of epidemiology and experience

In Uganda, as in the rest of sub-Saharan Africa, HIV prevalence is higher among women (8.3%) than men (6.1%). The prevalence rate increases with age until it peaks at age 35-39 for women (12%) and at age 40-44 for men (11%). Among young adults, four per cent aged 15-24 are living with HIV, and a staggering 75 per cent of these young people are women.^{222,223} Once heralded as a success story for steadily decreasing prevalence and incidence rates, Uganda now stands out from its neighbours as rates have increased in recent years.

Women in urban areas have a higher HIV prevalence than those in rural areas, with prevalence highest among widowed women and lowest among unmarried women. The country's most recent Demographic and Health Survey found that nearly two-thirds of all Ugandan women experienced physical violence, sexual violence or both at some point in their lives, and most of these women experienced this violence in intimate partnerships.²²⁴ The *People Living with HIV Stigma Index Report: Uganda* highlights the pervasiveness of stigma, including the verbal and physical abuse of people living with HIV.²²⁵

Uganda and Malawi were the first two countries in the region to adopt the Option B+ under the eMTCT programme. In Uganda, the adoption of these programmes was prompted because Uganda has one of the highest fertility rates in the world. Asking

women to start and stop antiretroviral therapy around pregnancy was, therefore, considered infeasible and suboptimal for individual health outcomes for women and children. Rates of testing women in ANC settings have surged since the programme was introduced, as have rates of women being initiated onto Option B+ regimens. As documented by ICW East Africa and others, however, Option B+ is hampered by poor implementation. Women do not get enough support to make informed, voluntary, and confidential choices. For instance, they endure stigmatizing attitudes from health workers and receive inadequate pre-test counselling most often conducted in groups. Concerns about the poor quality of programmes arose following their introduction, indicating that many eMTCT programmes could not support retention in care or adherence and thus resulted in high rates of loss to follow up.

HIV testing in ANC settings has become mandatory, an approach that has been critiqued for violating human rights principles. Women have also reported differential treatment depending on whether they attended the clinic with a male partner or alone. In some settings, those who cannot, or who choose not to, bring a male partner face additional abuse and criticism from health staff.⁸¹

Women from key populations also face increased discrimination. Sex workers are disproportionately affected by HIV with an overall prevalence of nearly 40 per cent²²⁶ and yet their work remains criminalized. Moreover, they are underserved and subjected to high rates of physical and psychological violence in many health-care settings.

Uganda has one of the richest bodies of literature, regionally, on the lived experiences of women with HIV. There are several comprehensive documents that review the status of eMTCT and programming in relation to key populations. There are many recommendations to shift programming towards rights, dignity, and positive health outcomes (including informed, voluntary and confidential choices). Unfortunately, policies, funding and programmes have not always aligned with documented best practices or recommendations by informed and engaged civil society.

3.2 Highlights from recent literature

Uganda has one of the most extensively researched epidemics in sub-Saharan Africa, with a history of government, national NGO and international partner engagement that dates to the mid-1980s when some of the first people with HIV on the continent were identified in the Rakai District of southwestern Uganda.

It is difficult to find issues that have not been addressed or explored by academic groups, many with longstanding ties to Uganda. However, programme decisions and implementation are often guided by politics instead of the research-based findings of science. Key findings from trials conducted in Uganda have triggered policy changes and programmatic work in neighbouring countries, while interventions have yet to be implemented in Uganda.²²⁸

Uganda has a robust civil society presence, including several groups led by and for women living with HIV and/or people living with HIV, including ICWEA, NAPOPHANU, NACWOLA, HEPS Uganda, Mama's Club, and many others. These groups have produced documents, position statements and campaigns focusing on a range of issues. These have included advocacy to ensure that Option-B+ is truly presented as a *choice* for women attending ANC and to decriminalize HIV. The latter issue has included galvanization of support for Rosemary Namiburu, a nurse living with HIV, who

was imprisoned after being charged with negligence while executing her duties. This charge was made possible under the HIV Care Act that criminalizes HIV transmission.

There is also a broad coalition effort focused on improving maternal health and calling attention to tragic and preventable morbidity and mortality associated with pregnancy and childbirth among Ugandan women. Specifically, the literature review shows:

- An abundance of evidence for—and yet lack of— a national approach to community-based peer support for women (and men) using antiretroviral therapy.
- Gendered dimensions of treatment and care are addressed inconsistently in various guidance documents.
- There is a disproportionate focus on pregnant women who access ART via eMTCT programmes. Evidence and research on the experiences of sex workers, adolescents (including those who acquired HIV perinatally) and women accessing ART via adult clinics does exist and provides recommendations that could be operationalized or piloted in various settings. However, the preponderance of information, particularly on barriers and facilitators to ART, focuses on women who initiate ART via eMTCT programmes. Documentation from ICW EA and GNP+ suggests that such eMTCT programmes may not present the immediate initiation of ART as a *choice* to pregnant women.
- Despite the huge quantity of research that has been conducted over the years in Uganda, there remain significant gaps in its focus and impact. Key questions remain unanswered in some areas, while in others a wealth of information has yet to trigger policy change.²²³

TABLE 5
Status of HIV and Treatment in Uganda²²⁷

Demographics	
Population	35,660,500
GNI per capita	US\$670

Prevalence	
Number people living with HIV	1,403,103
HIV prevalence	7.3%
Women	8.2%
Men	6.1%
HIV PREVALENCE BY KEY POPULATIONS	
Men who have sex with men	13.7%
Female sex workers	33%
People who inject drugs	N/A
Fishing people	14% - 20%
Adolescent girls/young women	10%

Incidence	
New HIV acquisitions	100,000
Incidence rate	0.3%

Treatment access	
Total coverage	53% (742,537/1,403,103)
Pregnant women	63% (83,150/131,325)

Treatment cascade	
Total people living with HIV	1,403,103
Tested for HIV	8,511,752
Diagnosed HIV positive	260,706
Initiated on ART	167,721
On ART	742,537
Retained on ART at 12 months	153,293
Viral suppression at 12 months	135,769

Treatment cascade: pregnant women	
Total people living with HIV	131,325
Tested for HIV	1,626,134
Diagnosed HIV positive	41,701
Initiated on ART	4,608
On ART	83,150
Retained on ART at 12 months	18,616
Viral suppression at 12 months	2,878

Selected studies

The literature generated in this review of Uganda-specific literature has identified several studies that explore facets of ART care and gendered experiences often neglected in the wider global literature.

A prospective, randomized study of quality of life for Ugandan people living with HIV who are on first-line regimens found that gender was the only variable impacting scores on the Mental Health Survey (MHS) tool used to evaluate depression and psychological outcomes. Women on Nevirapine-containing regimens have lower MHS scores than men after all other variables were controlled for.²²⁹

A qualitative study by Kastner and colleagues explored how women's experiences accessing ART affected their pregnancies.²³⁰ The study found that while the counselling messages from health providers regarding intention to have children were "largely dissuasive," treatment literacy (messages regarding ART and the potential for remaining healthy and having a child born without HIV) contributed to optimism and an increased ability to navigate social expectations regarding childbearing. The study recognizes the conflicting messages—discouraging childbearing but then promoting ART in women who choose to become pregnant. However, the study fails to explore the impact of initially dissuasive messages on women who may choose to become pregnant and be deterred from accessing services due to fears of stigma and abuse about their pregnancies, as has been documented in several studies.²³¹

Another qualitative study examined concepts of "therapeutic citizenship" among Ugandan men and women on antiretroviral therapy. The goal was to explore the multifaceted experiences of ART after initiation. The study showed peer support, experiences in the community, and experiences in health settings can strengthen or complicate resilience, positivity and the ability to remain on antiretroviral therapy.²³²

A 2013 study by Adakun and colleagues explored the impact of early initiation on ART as recommended by WHO.²³³ They found that higher baseline CD4 cell

counts at the time of initiation predicted viremia (a continuing detectable viral load) and treatment interruptions in a rural cohort. Interestingly, 70 per cent of their participants were women. This underscores the need for messaging, programmes and peer support systems specifically designed to promote informed choice regarding beginning ART and treatment maintenance.

An in-depth exploration of "personal barriers"²³⁴ to ART adherence, drawing upon interviews with members of a rural Ugandan prospective clinical cohort, looked at issues facing both men and women, as well as young people. This study underscores, in both dimension and data, the need for ongoing counselling and peer support to address specific barriers including "health and sexual life concerns, desire to have children and family instability."²⁴¹

A study of the integration of PMTCT programmes into maternal and newborn health clinics found that it worked solely in clinics where extra guidance was provided on how to manage the process.²³⁵ While the policy for such integration exists on paper and was in place for all clinics in the study, newly integrated enrolments could only be achieved through additional support. This underscored the need to invest in capacity building to help policies become practice.

Many of the issues identified in these peer-reviewed publications are echoed in both the current FGD findings and in an earlier report by ICW EA and GNP+ on understanding the perceptions of women living with HIV regarding Option B+.⁸¹

3.3 Policy landscape

As described in Table 6, Uganda has also developed and adopted a range of policy documents covering a large array of issues related to HIV treatment and care. These documents include comprehensive guidance on the use of ART, early adoption of Option B+, guidance on home-based care, and instruction on the management of sexually transmitted infections in women sex workers. These materials exist alongside a collection

of annually updated reviews, a ‘dashboard’ on eMTCT that is updated monthly, and five-year national strategic plans for addressing the epidemic. In a trend seen across the countries surveyed in this project, however, the frameworks do not provide consistent, in-depth identification of issues defined by women in all their diversities, nor do they offer interventions for, or objectives created by, women themselves.

Recent shifts away from community-based service delivery have been prompted by PEPFAR’s “rationalization” process undertaken to streamline service delivery by implementing partners. Civil society has documented concerns over this shift as it could potentially undermine current efforts to tackle the epidemic. Indeed, there is an ongoing effort by civil society to ensure that funding and planning contribute to a better ART service delivery approach – one that supports voluntary, confidential, informed choice regarding initiation and continuation of treatment, and reinforces community partners and peer support programmes. Unfortunately, there is still no national policy, broadly-adopted best practice, or implementer-based approach (e.g. via PEPFAR) for this type of model overall, let alone for women.

Uganda’s HIV Prevention and AIDS Control Act features a range of components that are supported by civil society. However, the Act also contains a provision criminalizing attempted and intentional transmission of HIV. Even prior to its passage, portions of the penal code related to HIV were enforced in a high-profile case mentioned above. The case involved Rosemary Namiburu, a nurse living with HIV. Namiburu received a jail sentence following a high-profile suit brought by the parents of a child in her care, after a needle stick injury that did *not* result in the child testing positive for HIV. Both the existence of the law and its enforcement will likely have a chill effect on disclosure, testing, treatment and care.

3.4 Methodology overview

ICW EA staff members reviewed eMTCT programme performance indicators including loss to follow up, percentage of newborns and infants diagnosed with HIV,

and ART coverage rates for the general population. They selected one high- and one low-performing district as the study focus. Interview tools and informed consent forms for women, male partners and health facility staff were developed in consultation with UN Women and collaborating partners, aligned with the community dialogues tool, and submitted for and received IRB approval. A total of 10 FGDs were carried out, 5 per district, 2 FGDs with women 28 years and younger, 2 with women 30 years and older, and 1 with men. Additional one-to-one interviews were conducted with health providers and eMTCT coordinators. Findings are organized so that the micro level addresses individual, household and community factors; the meso level includes health service availability and delivery factors; and the macro level contains national policies and institutions.

3.5 Findings from focus group discussions

Micro level Issues

Stigma and emotional/physical violence at the household level: Women living with HIV report a significant fear of stigma and violence associated with disclosure. The women acknowledge that involving men is difficult due to patriarchal norms and the threat of male violence. In addition, some men refuse to use condoms, most do not attend ANC with their wives or spouses, and many resist getting tested for HIV. One respondent said he sent his wife for testing to determine his own HIV status.

Food insecurity/poverty: The low-performing district encompassed trading centres in and around fishing communities with a relatively arid landscape that made farming and growing food very difficult. Most women reported having to buy food, earn money by cutting grass, selling fish and pursuing other informal economic activities. Their very low income made it difficult to obtain regular, nutritious food and many reported maintaining a healthy diet as a barrier to remaining on ART: “*you cannot take medicine on an empty stomach but we try to take it.*”

Access to healthy food: In the Kanunga district, women were unhappy that a programme offering rice, mandazi, and soda was no longer provided at health facilities. Some women told stories of going all day without eating while waiting to be seen at the clinic.

Costs: Women identified at least three categories of costs incurred with accessing ART that were significant barriers to care: (1) the cost of transportation to clinics; (2) often, prescribed drugs (except for ARVs) must be paid for and respondents said it was not wise to give up a day of work to attend the clinic, only to find they cannot pay for the drugs prescribed; (3) and most pregnant mothers are not provided an opportunity to select their preferred delivery method. While most women deliver vaginally, prolonged labour often results in a Caesarian section and a charge of UGX 50,000-300,000 (US \$15-90).

Meso level Issues

Stigma at the community level: In the low-performing district, women reported that support groups were held mainly in the villages, not in the health-care facilities. They mentioned they avoided joining these groups out of fear of stigma and discrimination should their status become known.

ANC is the primary drive for women to seek care at the clinic: Antenatal care represents a point of entry for women to engage in more comprehensive health care, particularly testing for HIV and accessing treatment. Most of the women learn their HIV status after coming to the clinic for ANC. For many women, this visit is crucial as it can consolidate or alienate their continued involvement with the health-care system.

Discrimination by clinic staff: Respondents complained about overworked, inadequately-trained staff. The case study revealed that insufficient staff at health facilities was at the top of the list of barriers to testing and treatment access for Ugandan women in this case study. Participants claimed that staff were ill-tempered and displayed poor attitudes toward women living with HIV.

Delayed start and attrition of ANC: As in other contexts, many expectant mothers delayed their first ANC attendance until they were four to five months pregnant, contrary to the recommendation that the initial visit occur during the first trimester. Additionally, many continue to give birth outside the hospital, circumventing wider engagement with health-care services, including eMTCT and Option B+, and thereby increasing the potential of PMTCT.

“Some mothers come for the first antenatal visit at 18 or 20 weeks, although others come in the first trimester to confirm pregnancies. The number of pregnant mothers who come for ANC services reduces at the fourth visit compared to the first visit. The number of mothers who come to deliver in the health unit also reduces when compared to the number that attends ANC services. I have been here for only two months and have observed that the number reduced by one half.”

(Interview with health workers in Rugyeyo Health Centre III, Kanungu District, Uganda)

The aspects of health centre capacity identified as areas of concern are:

Inconsistent hours: Some Ugandan health facilities offer ANC and family planning services daily from Monday to Friday while others maintain inconsistent hours based on the availability of medical supplies and prescription drugs.

Follow up: Some facilities have the added capacity to telephone or send Village Health Teams (VHT) or peer educators to visit women who initiated ART but missed appointments. The role of direct contact in these circumstances is highly valued.

Confidentiality/privacy: Limited space requires staff to double up in workplaces and this can infringe on patients' privacy. Most health centres appear to

competently handle testing but are constrained by space needed for other services.

Long distances and long waits at health-care centres: It is not unusual for women to spend hours travelling to a clinic and then encounter long waits before they are seen; this undermines their interest and motivation in visiting the health centre.

“Most of them come very far. A client from Rutenga Sub-County wakes up at 5 a.m. and reaches the health centre at 10 a.m., spends more than four hours at the health unit, and reaches home in the night. And yes, some clients do not come back because of the delays at the health unit.”

(Key Informant Interview with health workers in Rugyeyo HCIII, Uganda)

Stock-outs and expired drugs: Stock-outs of drugs are a major challenge to the delivery of care in health facilities. Ugandan participants reported stock-outs of septrin, testing kits, Maama Kits and other family planning methods such as oral contraceptive pills.

Understaffing undermines effective counselling: Women reported that short-staffed health centres sometimes need to resort to group counselling, a response regarded as inadequate.

“The mothers are not getting adequate counselling which has caused mothers to drop out and stop treatment. This is mainly due to health workers being jumpy, doing other services, and attending other cases...”

(eMTCT Coordinator in Kanungu District, Uganda)

Discriminatory incentives: To incentivize men's participation, some health clinics allow women arriving with their male partners to bypass the queue for service. Women living with HIV whose spouses are not supportive, or do not have spouses, view this policy as unfair.

Inconsistent observance of sexual and reproductive health and rights for women living with HIV: Respondents reported a lack of informed choice about modes of delivery (C-section vs. vaginal delivery), with little detail provided about the risks and benefits of the methods and few opportunities to select one method versus the other. Mothers in the FGDs also felt that there was a gap in information about infant feeding choices, including clear and accessible information about the risks and benefits, that reinforced their right to choose the strategy they preferred—including breastfeeding.

Health-care workers felt ill-equipped implementing programmes and approaches to educate women about their rights in the context of decision-making around contraceptives and while pregnant and after delivery.

“I cannot tell where I learnt them from but I have heard about them from meetings and trainings. I have been a trainer for reproductive health since 2001. What I know about rights most health workers don't know because they rarely talk about them.”

(Interview with health worker/PMTCT Coordinator in Kanungu District, Uganda)

“We got information from school and the Ministry of Health gives charts but we don't have them in this health unit. Most health workers are not trained in Family Planning and eMTCT, the government should also take the obligation to train health workers, not leaving it to implementing partners.”

(Interview with health worker in Kanungu Health Centre, Uganda)

Ineffective early infant diagnosis (EID) at the clinic level: FGD participants who delivered in clinics or hospitals reported an emphasis on early infant diagnosis by health staff. This was reinforced in interviews with health providers who were familiar with the testing algorithm for confirming infant HIV diagnosis.

“We do PCR (Polymerase Chain Reaction) at 18 months...those babies are also brought monthly by their mothers who come to be part of the baby home care package where we meet the mothers.... We also provide prophylaxis for children that are exposed, as well as cancer screening because those HIV positive mothers are likely to get cancer of the cervix.”

(Health provider in Uganda)

Basic testing is effective: The infrastructure and services required for eMTCT, such as lab tests (CD4, HB, urinalysis and virological HIV testing in infants or PCR) are done at the health facilities visited. For the most part, mothers tested in the Ugandan health centres are cooperative and counselled successfully to enroll in care when testing positive.

Availability of a range of maternal delivery services: Women in Uganda are advised to give birth in a health centre where several precautions are undertaken to prevent transmission of HIV to newborns during labour and delivery: ART before delivery, avoiding and minimizing prolonged labour, minimizing vaginal exams, avoiding artificial rupture of membranes, avoiding unnecessary trauma and the use of aseptic techniques when disinfectants are available.

Small male action groups (SMAGS) promote ART adherence: Small male action groups known locally as *Emanzi*, which means ‘the brave’, offer social support and much needed counselling to men living with HIV, thus enabling them to succeed with ARVs treatment.

Macro level issues

Gender Roles and Poverty: Male involvement was a major challenge reported by women living with HIV and health workers. Women FGD participants often linked these challenges to HIV-related stigma; health workers emphasized economic factors.

“The men are not involved so much. Out of 20 women, only one couple comes. Maybe they feel going to the ANC clinic, that’s part of the mother. If you ask the mother, she says ‘my husband has gone for work’. Men feel that they don’t need to go to the health facility or it’s not part of their work to escort their women.”

(Health worker in Uganda)

“The main reason for low male involvement is that most families are below the poverty line and men are always on the move serving as casual labourers. Most men don’t stay with their families and are known to have poor health-seeking behaviours.”

(FGD in Uganda)

“Some men do support their wives but most them are against it. Few men in Kanungu support their wives to go for these services, although we are trying. Still, the number is low because we are at 25%.”

(Health worker in Kanungu, Uganda)

“For us mothers we are very good ... but these men, some of them are very bad. They don’t support their wives. If you want to understand most of these problems, go to the discordant couples, where the mother is HIV positive and the man is HIV negative. Whenever you go to ask for assistance of transport, like when you have to go to the clinic, he will ask you: Did I send you to look for HIV?”

(FGD in Uganda)

Increasing male participation depends on deliberate incentives; however, these can backfire (see meso level issues of discriminatory incentives). Women respondents reported success with community-based programmes that involved peer outreach and women supporting each other in negotiations with partners. They also recognized that financial and other incentives could help bring men to the clinic.

“Our husbands are not interested in escorting us to the clinic. They say they are always busy. I think if Taata kits can be introduced the same way as Maama kits were introduced, men could go to health units to get them.”

(FGD in Uganda)

“We have cards, invitation cards for partners so when we come across a mother who is under denial or fears disclosure we give her that card.... the card is a bit important [because] when the husband sees that card he says: Let me go the doctor....so they come....[Now the] percentage in Busia County and Referral Hospital [is at] 65% for couple counselling.”

(A mentor mother in a FGD for older women in Busia, Kenya)

Limited knowledge about the full objectives of eMTCT, Option B+, and sexual and reproductive health and rights: Respondents learned what they know about the eMTCT from doctors and nurses in health facilities and hospitals, and from VHT members, radio programmes, churches, books, friends and local leaders. Workshops and trainings provided by the Ministry of Health and NGOs were another identified source of information. Service providers pointed to continuous professional development courses as the source of their knowledge of eMTCT

policies and guidelines. These efforts, however, only deliver a portion of the message as the men and women living with HIV who participated in the FGD were unaware of the full scope of the programme – including the provision of ART regardless of CD4 cell count and the emphasis on the woman’s health. A narrow definition of eMTCT focused on the prevention of onward transmission was common.

“eMTCT means stopping children from acquiring HIV from their mothers. Only one in four midwives in our health centre has ever got training on eMTCT. The rest of us have only read leaflets and got on-the-job training.”

(Health provider in Uganda)

“I understand that PMTCT is a programme set to help mothers living with HIV so that they can get drugs (ARVs) to make sure they do not infect their newborns. [They are also given] advice or some kind of trainings on how to feed the children [in case they are] excluding breast feeding to avoid affecting the children.”

(FGD in Uganda)

Uganda’s health workers and service providers, interviewed in coordination with the FGDs, were unaware of the sexual and reproductive health and rights of women living with HIV. However, FGD participants were familiar with an extensive list of family planning interventions including condoms (the most preferred because it does not involve the regulation of hormones), levonorgestrel implants, depo, implanon, oral contraceptive pills, injectables, tubal ligation, and dual protection. Women were routinely advised to use dual protection.

3.6 Recommendations

- **Invest in, and standardize, minimum packages of layered services at facility level and in surrounding communities** including support for transportation, Maama kits, community-owned peer-based support and approaches to care that minimize repeated clinic visits, especially as women near their delivery date.
- **Tailor specific services to the socioeconomic context in which a clinic is operating** such as clinics in districts with drought, limited food supply, high levels of poverty and food insecurity may require different, intensive approaches and linkages with programmes in the community.
- **Anticipate, track and mitigate the impact of donor and implementer transitions in service provision.** Coordination with national government, GFATM, PEPFAR and community-based organizations, particularly women's groups, must be standardized and prioritized.

TABLE 6
Policy Mapping in Uganda²³⁶

Policy	Policy objective (overall)	Policy focus related to women	Strengths	Shortcomings
National HIV prevention strategy	Guide national efforts to reduce HIV infections by about 30% by 2015.	Strengthened, sustainable enabling environment that mitigates epidemic's underlying factors.	Highlights women's emancipation. Independent decision-making about SRH or jointly with partners is a key indicator. Focus on substantially reducing GBV. Aims to increase linkages to support (and increasing capacity of health and social services to provide support) for women experiencing GBV. Sets targets and timelines to change harmful sociocultural and gender norms, beliefs and practices. Promotion of male involvement.	Outcomes measured are not disaggregated by sex. Examples include reports of reduced transactional sex, testing access and others reported as "men and women" combined.
National strategic plan for HIV/AIDS	Achieve universal access targets for HIV/AIDS prevention, care, treatment and social support and protection by 2015.	Mainstreaming gender, SRH rights	Infection rates for pregnant women considered a key indicator in progress of epidemic. Gender Policy recognizing social and physical vulnerability of women to HIV. Development of national SRH-HIV integration strategy to champion FP efforts. Provision of legal/social services to protect women against GBV highlighted as a strategic action to scale up social support and protection to vulnerable populations of people living with HIV.	Focus on women is largely in the context of pregnant women with very little on other diversities.
PEPFAR SDS	Achieve epidemic control (in 79/112 districts) in 2 years. Follows UNAIDS 90-90-90 principle.	Pregnant women and young women (primarily through DREAMS)	Integration of gender using Stepping Stones and C-Change approaches. Targets young women (15-24), married adolescent girls, young women who have given birth by age 15 and those reporting transactional sex. Expansion of FP/HIV integration and increases access to treatment for PMTCT (likely through Option B+). Details provided for treatment cascade for pregnant women.	HTC strategies focused only on pregnant women and ANC. DREAMS initiative and districts briefly discussed but no details outlined outside of pregnant women. GBV screening and provision of post-GBV care is not a core activity.
Annual NSP performance review	Assesses progress of implementation for the financial year (2011/2012). Part of good M&E practices.	GBV support and improving family planning.	Suggests revision of national targets to include pregnant women on ART. Emphasises importance of training community leaders (e.g. teachers) on counselling and recommends including HIV/AIDS and GBV in counselling course. Calls for strengthening screening and linkages to care and support for GBV by mobilizing communities. States that there is unmet need for FP and calls for action. Strategic Action 2.3.3 aims to build capacity of providers and empower communities to support people living with HIV in their SRH choices.	Does not call for Monitoring and Evaluation in terms of PMTCT adherence/retention in care, only treatment (Tx) data is currently about initiation or not disaggregated. Little discussion about women who are not pregnant or breastfeeding.

Policy	Policy objective (overall)	Policy focus related to women	Strengths	Shortcomings
Vision 2040	Strategies to transform Uganda from low income country to competitive upper middle income country within 30 years.	Gender equality and women's empowerment for socio-economic transformation.	Guarantee of equality between men and women before the law. Commitment to eliminate female genital mutilation. Acknowledges high fertility and aims to keep women in school.	Outlines vision but does not provide solid policies, strategies or targets to monitor progress. States that "efforts will be made to ensure gender responsive policies, programmes and actions" but no details shared. Does not discuss family planning investments or promotion to address fertility concerns.
National Policy Guidelines and Service Standards for SRHR	Obtain highest level of health for all through development of appropriate reproductive health policies, objectives and strategies.	Increase service coverage and safety for reproductive health and improve access for adolescents.	Provides details on components of SRH and has service policy guidelines, service standards and outlines priority groups. Defines reproductive health in Uganda, training and implementation and provides goals, targets, guidelines for obtaining consent and Monitoring and Evaluation for FP and contraceptive delivery. Emphasises the importance of integrating HIV and AIDS into reproductive health services. Outlines service standards and M&E for combating GBV.	Published in 2001. Great framework. Could be strengthened with revision.
Health Sector Strategic Plan II	Overall framework for health sector. Aims to contribute towards accelerating economic growth and reducing poverty	Youth-friendly reproductive health services include contraceptives, ANC and postnatal services.	Recognizes need to provide youth-friendly services to improve health for young people. Key policies/strategies: strengthen SRH, building institutional capacities at national, district and community levels for reproductive health, expands SRH services, strengthen adolescent reproductive health services. Suggests reviewing and updating current policy environment to promote delivery of SRH. Several policies/objectives to build capacity of health workers to manage GBV, create awareness for GBV and strengthen monitoring and evaluation for GBV.	
National Population Policy and Social Transformation and Sustainable Development	Plan for and invest in the increasing population and address consequent challenges.	Decreasing unplanned pregnancies (excludes women from productive economic and social activities).	Recognizes reproductive health as a basic human right. States that current reproductive health services are insufficient and identifies weak health system due to lack of human resources to provide care. Lists role of government in the following: increasing skilled birth attendants, ANC, family planning, adolescent reproductive health and strengthening referrals/integration. Advocates for linkage of reproductive health and HIV and AIDS programmes. To reduce unmet need to FP, strategies outlined to promote reproductive health commodity security and the provision of affordable, accessible FP through education and advocacy.	Does not talk about social norms, discrimination or stigma around FP or GBV.

4. ZIMBABWE CASE STUDY

4.1 Zimbabwean women living with HIV – an overview of epidemiology and experience

According to the UNAIDS Gap Report 2014, Zimbabwe remains among the countries with the highest HIV infection rates. The nation carries the third largest HIV burden in Southern Africa and has one of the highest rates of premature adult mortality, largely due to HIV-related illnesses. The latest estimates place adult HIV prevalence at 14.7 per cent, which brings the estimated number of adults over 15 living with HIV to 1.3 million, and 63.4 per cent of these are on ART. There are about 77,000 children under 15 living with HIV, and 54.8 per cent of women receiving ART.^{237,238} The report further estimates that women represent 62 per cent of adults living with HIV in the country. Recent studies have found that upwards of 50 per cent of sex workers in Zimbabwe are living with HIV.²³⁹ In one study of 870 female sex workers from across the country, only 25 per cent with laboratory-confirmed HIV were accessing antiretroviral therapy.²⁴⁰

Violence against women is endemic in Zimbabwe. The country's first comprehensive baseline study on the prevalence of intimate partner violence²⁴¹ reports that 2 in 3 Zimbabwean women have experienced some form of gender-based violence in their lifetime. 1 in 4 women reported an experience of violence in the 12-month period prior to the study.

The fear and reality of violence is exacerbated for women living with HIV who must also deal with HIV-related stigma.²⁴² Despite a high level of awareness, HIV and AIDS remain highly stigmatized in Zimbabwe. People living with HIV are often perceived as having done something wrong. Discrimination is frequently directed at both them and their families. Many people are afraid to get tested for HIV for fear of being

socially alienated and losing their partner or their job. Those who do know their status rarely make it publicly known, suggesting they may not have access to sufficient care and support.

Women living with HIV, particularly pregnant women, continue to account for approximately half of all treatment initiations. In some contexts, they represent the majority of the population on treatment when data are disaggregated by sex. One surge in enrolment has come from the roll-out of an expanded vertical transmission prevention programme. In 2010, Zimbabwe had an estimated 30 per cent rate of mother-to-child transmission during gestation, labour and breastfeeding. In 2015, that rate had fallen to 6.7 per cent.²⁴³ The change reflects women's ability to access and reliably take antiretrovirals during the perinatal and antenatal period, but provides less information about women's experience as individuals, whether pregnant or not.

4.2 Highlights from recent literature

Zimbabwe has seen a massive expansion of its vertical transmission prevention programme over the past five years and, over a slightly longer timeframe, a striking reduction in incidence of new HIV cases. Despite both trends, there is a paucity of information in the peer-reviewed literature that foregrounds or even tangentially addresses the experiences of women in all their diversities as they relate to choosing whether to initiate ART. Nor is there any information on barriers and facilitators to making these choices and long-term experiences of women once in care and/or on ART. This absence is particularly significant given the move to initiation of ART even earlier than previously recommended (offer on diagnosis, per the most recent WHO recommendations.)

Against this backdrop, there are some instances where the experiences of Zimbabwean women have been documented in ways that suggest critical points of action for programme design and community engagement. These include:

- **Engagement with, and leadership by, young women** including those who are HIV-negative and young women who acquired HIV perinatally via the SHAZ! Initiative.
- The **importance of cultural capital**, existing social support structures and new peer support initiatives such as “mentor mother” programmes in improving the overall health and well-being of individuals and communities and in supporting adherence to ART once initiated.

We highlight some of the relevant studies in the next section.

Selected studies

The literature generated in this survey of Zimbabwe-specific papers has identified a few studies of relevance to women’s experiences of ART. These studies are outlined below.

Skovdal and colleagues conducted a qualitative study exploring how masculinity and particularly “male denial of HIV/AIDS” impacts women’s ability to access and adhere to ART.²⁵² The study involved 37 individual interviews and five focus groups with a total of 53 male and female antiretroviral drug users and 25 health-care providers in rural eastern Zimbabwe. Perceptions of HIV as a threat to manhood and dignity emerged as a core component of gendered dynamics within the household, affecting women’s ability to disclose their status and take their drugs (and/or receive “permission” to take medications). The study recommends ART programmes take the gendered nature of household and family dynamics into account in service design and provision.

A cross-sectional study by McCoy and colleagues examines the association between food insecurity and receipt of services in the PMTCT cascade.²⁵³ The study suggests that severe food insecurity may impede pregnant and postpartum women from receiving certain services, and may influence the likelihood that infants will acquire HIV during pregnancy, labour or breastfeeding. The authors note that these relationships need to be confirmed by other observational studies. The overall finding that roughly half of women with a recent birth reported living in moderately or severely food insecure households in the month prior to the survey prompts a strong recommendation for the integration of food support into antenatal settings.

The positive impact of peer-to-peer mentoring programmes was discussed in a project that analysed the impact of mothers living with HIV providing support and advice for other pregnant women living with HIV. The study found that enrolment in a “Mothers to Mothers” (M2M) programme significantly increased women’s adherence to PMTCT regimens²⁵⁴ and retention in care at six to eight weeks after delivery. However, a lack of disclosure to spouse/partner and community contexts (levels of stigma, availability of support, etc.) both affected the likelihood that women would opt into the programme.

A recent study examined the impact of gender norms on expectations of behaviour. The study explored Zimbabwean nurses’ attitudes towards, and treatment of, patients seeking ART based on notions of what a “good” or “bad” patient is, and how this impacts ART adherence.²⁵⁵ The study explores the gendered nature of behaviour expectations, noting that cultural norms of masculinity can make it difficult for men to conform to expectations of a good patient. Norms also impact the ability of men and women to perform specific gendered behaviours to “access good care and ensure continued access to ART.”

TABLE 7**Status of HIV and Treatment in Zimbabwe²⁴⁴**

Demographics	
Population	15,602,751
GNI per capita (USD)	\$924 ²⁴⁵

Prevalence	
Total people living with HIV	1,420,604
Children (<15 years of age)	156,718
Adults (> 15 years of age)	1,2623,887
Women	748,451
Men	515,436
Total HIV prevalence (15 to 49 years of age)	15%
Children	2.37%
Young adults	5.1% ²⁴⁶
Women	5.9% ²⁴⁷
Men	3.8% ²⁴⁸

ADULTS	
Women	18%
Men	12%

HIV prevalence by key population	
Men who have sex with men	16.8%
Female sex workers	28.7%
People who inject drugs	N/A

Incidence	
New HIV infections	62,926
Incidence rate	0.92%

Treatment cascade: Female sex workers	
Total population	85,949
Total PLHA	24,667
Tested for HIV	N/A
Diagnosed HIV positive	~50%
Initiated on ART	~30%
In care	~30%
On ART	~30%
Retained on ART at 12 months	N/A
Viral suppression at 12 months	N/A

Treatment access	
Children	55%
Adults	63.4%
Pregnant women	82% ²⁵⁰

Treatment cascade	
Total PLHA	1,390,211
Tested for HIV	1,664,176
Diagnosed HIV positive	175,568
Initiated on ART	N/A
In care	N/A
On ART	748,882
Retained on ART at 12 months	85%
Viral suppression at 12 months	89.6%

Treatment cascade: pregnant women	
Total population	412,120
Total PLHA	N/A
Tested for HIV	173,916
Diagnosed HIV positive	13,624
Initiated on ART	24,573
In care	N/A
On ART	N/A
Retained on ART at 12 months	N/A
Viral suppression at 12 months	N/A

Global Fund	
HIV grants (# grants; % total)	\$541,607,793 ²⁵¹ (3 grants; 60%)
Gender-related funding	N/A

4.3 Policy landscape

As detailed in Table 8, Zimbabwe has developed several policy documents related to HIV care and treatment. The most pertinent documents include: HIV, Testing and Counselling Guidelines; Adolescent Sexual Reproductive Health Strategy; Zimbabwe National AIDS Strategic Plan; Patient Charter; and the Zimbabwe AIDS Policy. Zimbabwe was one of the early adopters of Option B+ after Malawi.

Recently, Zimbabwe revised their National Strategic Plan 2016 – 2018. This plan has taken additional strides to acknowledge key affected population groups, such as sex workers. The HIV testing and counselling guidelines were recently launched as an attempt to make HIV testing more accessible to a variety of population groups with differing barriers and facilitators to accessing HIV testing. The Adolescent Sexual and Reproductive Health (ASRH) Strategy ended in 2015 and efforts are being made to finalize the new ASRH strategy. This approach aims at establishing youth friendly centres around the country with the hope that this will increase their access to comprehensive sexual reproductive health services. Additionally, increased sensitivity training for service providers is underway to ensure that service provision is stigma-free, equitable and meets the needs of youth.

The major challenge in Zimbabwe, however, is the implementation of these guidelines. The Ministry of Health and Child Care (MoHCC) is undergoing efforts to ensure the implementation of these guidelines and conduct routine follow-ups. To streamline service implementation, the MoHCC has come up with an Operational Service Delivery Manual. Aside from the necessary focus on sex workers, these policy documents do not contain clear and targeted interventions addressing the unique needs of women in all their diversities.

4.4 Methodology overview

The Zimbabwean focus group discussion guide for young women was developed from the “Community Dialogue” discussion guide for Phase 1 of this project. Pangaea Zimbabwe AIDS Trust worked with members

of the Global Reference Group to narrow down the areas of focus for the Zimbabwean guide. The guide was shared with UN Women and collaborators and then submitted to the local Institution Review Board (the Medical Research Council of Zimbabwe) for approval. After authorization for the interview guides and consent forms was granted, fieldwork commenced in the urban settings of Harare and Chitungwiza. Focus group participants were grouped into the following four categories: 1) ages 16-20; 2) ages 20-24; 3) pregnancy within the past year, those with a delivery in the past 12 months; 4) pregnancy within the past year, those with a non-delivery in the past 12 months. A total of 16 FGDs were conducted, with 4 FGDs per criteria and additional one-to-one key informant interviews used to enrich findings and probe specific themes.

4.5 Findings from focus group discussions

This section presents findings from the Zimbabwean case study according to micro, meso or macro levels, although we acknowledge that in most cases these factors move between and overlap at multiple levels to impact the lives of women and girls. Findings are organized such that the micro level addresses individual, household and community factors; the meso level includes health service availability and delivery factors; and the macro level contains national policies and institutions.

Micro level issues

Disclosure remains a major barrier to adherence and applies to both adults and young people. For the young women interviewed, disclosure issues fell into two categories: issues related to involuntary disclosure and those related to voluntary disclosure. The fear of involuntary disclosure, or disclosure against a patient’s consent, is a major barrier preventing individuals from starting and/or remaining on antiretroviral therapy. Young women identified the following constraints in ART adherence related to confidentiality and involuntary disclosure.

Health-facility record keeping that violates confidentiality. At public health facilities, people living with HIV are given green file folders that hold their medical records. These files are different in colour from those seeking non-HIV-related health services. Roughly 36 per cent (43/118) of young women interviewed highlighted the system of green files as stigmatizing and failing to protect client confidentiality.

“Imagine your boyfriend passing through the clinic and sees you holding a green file. Automatically, that relationship is done. There is no way you are going to make him believe otherwise – that you are not living with HIV.”

(FGD in Zimbabwe)

Insufficient resources challenge one’s ability to maintain confidentiality. A lack of resources can lead to involuntarily disclosing one’s status. About 10 of 118 young women interviewed resorted to asking their boyfriends for transport money to clinics and ended up having to disclose the reason why they periodically needed transport money. As one respondent noted, “Initially he (boyfriend) will just give you the transport money but, with time he will get to ask you why you always need transport money to go to town. What is it that you need to get in town that you cannot get within the neighbourhood?” Young women identified the location of the clinic as a further barrier (see meso level findings for more discussion).

Lack of community and individual counselling on disclosure for young women who acquired HIV perinatally. Some of the young women grew up with their HIV status known in the neighbourhood. One woman explained:

“You just hear people talking about you saying, this is the one who grew up sickly, she is actually grown.”

(FGD in Zimbabwe)

Young women also identified the following barriers to voluntary disclosure:

Inadequate support structures in the community: Young women, again, reported limited support structures in their communities. Participants stated that when an individual tests positive for HIV, it is often the case that neither their family nor community is prepared to fully embrace the individual.

“When I was tested for HIV, I went with my husband who came back home and told everyone about how I was living with HIV. I was then chased away from the house because my husband’s family members were afraid I would spread HIV to them. My husband also said he did not want to die.”

(FGD in Zimbabwe)

“It is a bitter pill to swallow but there is nothing that you can do to stop them from passing such comments.”

(FGD in Zimbabwe)

Absence of supportive elements in policies and programmes aimed at the family: In Zimbabwe, it is mandatory for every pregnant woman who goes through antenatal care in public health facilities to get an HIV test. Once a pregnant woman tests positive for HIV, they are immediately initiated on ART regardless of their CD4 count. However, mandatory testing can be prohibitive and strains families. In some communities, young women would reportedly get married without disclosing their HIV status and become pregnant. When they were eventually tested for HIV at the ANC, they would act surprised. A woman testing alone without her partner, who had never been tested, can find herself in a situation where she is accused of having acquired HIV from another person. If there were routine family or couples testing, women may not be in that position.

There were also several issues raised that affected access to treatment, but not specific to voluntary and involuntary testing.

Medication side effects as a barrier to remaining on treatment: 60 of the 118 young women reported that some side effects caused them to default on their medication, and thus became a barrier to adherence. Side effects included skin irritation, eye discoloration, weight gain, and others. For instance, one young woman reported she was nicknamed “*masamba*” (tea leaves) due to the skin rashes that spread all over her face.

Some young women who reacted to ARVs discussed not only their side effects, but societal reactions to those that were particularly visible.

“When I was on Stalanev I used to have persistent headaches and mouth sores. I developed warts on my hands and even to this day, some people do not like to shake my hand due to the warts that are still there despite switching regimens.”

“I also reacted to Stalanev. I had mismanagement of fat deposits. I then started defaulting, then I was switched to Tenolum N.”

“I developed yellow eyes when I was switched to second line [therapy]. I then started defaulting again because people started asking me why I had yellow eyes.”

“I stopped taking Tenolum N because I developed veins on my legs. I was then switched to second line [therapy].”

(FGD in Zimbabwe)

Meso level issues

Inability to protect privacy at accessible clinics: The location and visibility of services are crucial components to accessing care and treatment for young women living with HIV. Around 64 per cent (76/118) of young women interviewed highlighted that public clinics are located close to neighbourhoods and offer little privacy. While clinic locations have been designed for better accessibility and closer to communities to avoid travel times, this inadvertently removes privacy that should be afforded to patients seeking treatment within nearby health facilities. Young women expressed deep concern around the lack of privacy as they visit clinics that are highly visible to the entire neighbourhood, especially if they must wait in long queues outside of the facility to access services.

“One day while I was collecting my ARVs refills, I saw someone from our neighbourhood. They asked me whose ARVs I was collecting and I responded by saying they were my cousin’s ARVs. After that incident, the young woman from my neighbourhood was telling people that she saw me collecting my ARVs at the clinic”.

(FGD in Zimbabwe)

Young women also noted that private clinics, or those operated by NGOs, are usually located away from neighbourhoods and are sometimes even sited within shopping malls where young women can access services unnoticed. Although distances travelled are greater, the privacy offered was an attraction and some clinics run by NGOs also provided transport stipends.

“NGO-operated clinics offer privacy, you just get in and out, and no one will ever know what service you were offered.”

(FGD in Zimbabwe)

Long waiting times at public facilities: Due to the high demand of services, participants reported that they were expected to arrive at public health facilities by eight o'clock in the morning. The high volumes of people seeking care often meant they would not be able to leave the clinic until lunch time. The time burden this places on women living with HIV is extreme. In addition to attending school, work, or taking care of the home, this added demand on their time proved a deterrent to accessing ARVs.

As one young participant confirms: *“At our public clinic you wait for long hours before you are given your refills. You are expected to be at the clinic by eight and usually you leave around one o'clock.”*

This experience differs to NGOs or privately operated clinics that typically operate by appointment and have shorter wait times to see a health-care provider.

“When I was at the public clinic, the service providers used to shout at me when I came for an unscheduled visit or missed my visit. I then explained to the doctor that given that I am still in school, at times I cannot make it for the scheduled visits and the doctor ended up transferring me to a private clinic.”

(FGD in Zimbabwe)

Most young women interviewed felt that private or NGO clinics also offered greater privacy, which they appreciated. All 118 young women preferred to access such services even though they sometimes had to pay. Although payments made at the NGO-operated clinics are minimal, the out-of-pocket fees are still inaccessible for many. As a result, these clinics are often not crowded.

Negative service provider attitudes: 55 of the 118 young women interviewed reported that service providers are neither youth-friendly nor sensitive to their needs. This attitude prevents young women (who are transitioning from paediatric care) from wanting to access services.

75 of the 118 young women agreed that some nurses make comments such as, *“young women are too promiscuous.”* Interviewees also reported privacy breaches. For instance, some nurses would come out where everyone was waiting and shout, *“those who are here to collect ARVs, go to that door.”* Certainly, the underlying attitudes conveyed by the actions of service providers act as a deterrent to accessing health-care services. As one young woman made clear:

“I sometimes don't go to the clinic because of the negative attitudes of the service providers.”

(FGD in Zimbabwe)

Sometimes nurses direct adults and young people to join the same queues at the health facilities. This can be challenging when adults question young women about how they acquired HIV thus making them feel uncomfortable to continue coming and accessing health facilities.

“The nurses just treat us as adults, they expect us to join the queue with adults and the adults will just be asking us questions about how you contracted HIV.”

(FGD in Zimbabwe)

Lack of youth-friendly testing and health services:

Young women discussed feeling uncomfortable when visiting HIV Testing and Counselling (HTC) centres or health facilities to have an HIV test. They felt unwelcome in those facilities as most of the patients were adults seeking HTC services. Young women also described a lack of awareness of the possibility of perinatal HIV acquisition; adults encountered in these settings assumed that anyone living with HIV had acquired it through sexual contact or other risky behaviours. Participants reported that this experience made them shy away from

public health facilities even though some had been prenatally infected. It seemed that some adults did not understand how a young woman could be born with HIV and still live into young adulthood without HIV treatment. Participants believed there is a perception that young women accessing HTC services are promiscuous. Interestingly, this was less of an issue for young women below the age of 16 who require parental consent to access HTC services. The requirement of parental accompaniment, combined with the location of services in paediatric settings, suggests that girls under 16 are not subjected to such public scrutiny.

Involuntary disclosure linked to ART packaging: In Zimbabwe, ARVs shipped to clinics are distributed in the original packaging in which they arrive. This packaging differs depending on the treatment regimen – either packed in boxes or in plastic containers. In this project, older women were less likely to raise the issue of the packaging of ARVs, while it was a concern for most of the young women interviewed, linked to forced disclosure and stigma.

Depending on one's adherence and the level of monitoring necessary, people are given a one-month supply of ARVs. Some are given a two-month supply while those with good adherence history are given a three-month supply. Young women raised concerns around the packaging which they also referred to as bulky and difficult to carry when they went for refills. The size and noise the medicines made in their bags made many young women feel uneasy.

“When I go for my refills, I carry the face of a frog, meaning I do not entertain anyone who wants to talk to me at all lest someone asks me ‘What’s in that big backpack of yours? What did you bring us from town? Can I carry your backpack for you because it seems heavy?’ I will only talk to people once I get home and pack away my drugs.”

(FGD in Zimbabwe)

About 80 young women devised ways of making the packaging less bulky by throwing away the boxes while still at the clinic and rolling the pills in cotton wool: “Once you remove the bulky packaging, no one will ever know you are carrying so many pills.”

52 young women reported that some clinics require you to bring back the original plastic container that the pills came in when returning for a refill. These filled plastic containers make noise and some young women report being questioned about the content in their bags. Young women expressed feeling deep discomfort because they could not answer the question truthfully as they do not want to say what is in their bags. 34 participants reported having to deny the noise coming from their bags while 21 have painfully ignored the question altogether.

One young woman recounted how after refilling her quota for ARVs she met with her boyfriend who offered to carry her backpack. While at the boyfriend's house, the boyfriend became curious about what was in the bag and upon opening the backpack the young woman reacted by shouting, “I don't like people who open my bag – who gave you permission to do so?” and stormed out of the boyfriend's house. This is how she escaped involuntary disclosure but, like most young women interviewed, she felt uneasy carrying around her medication.

Lack of service delivery model to support transitioning from paediatrics to adult clinics: 48 of the 118 young women interviewed initiated ART between the ages of 5 and 10. They reported having enjoyed the experience of accessing treatment care and support at the paediatric clinics where all children under the age of 18 are followed by health-care professionals.

Young women noted that paediatric clinics provide personalized services and pay attention to individual concerns unlike adult clinics. Paediatric clinics also provide support groups where HIV and adherence is explained in simple and animated ways for children to understand what is happening in their bodies. Indeed, facilitators try to make the experience enjoyable for young people. At 18 years of age, people are required to transition to adult clinics.

The transition from paediatrics to adult clinic was noted by those interviewed as a life changing and scary experience. It is representative of a time when many young women start to face adherence issues, with some not returning to access monthly refills of ARVs. One young woman recalls her first visit to the adult clinic at which an elderly man asked her, *“What brings you here young girl? Are you here to pick up drugs for your Mom?”* One young woman recalled attending an adult support group and feeling upset by the content under discussion. For example, one male member said, *“I am not surprised that I am living with HIV. In fact, I deserve it. I have slept with all sorts of women, there is nothing one can tell me about women that I do not know. I have been with all shapes and sizes and this is why I am happy with my HIV.”* This young woman was devastated at hearing this and felt that that support group was not the place for her as she was unable to relate to what was being discussed. She did not return for subsequent sessions.

Lack of affordable and/or free monitoring tests:

About 60 of the 118 young women accessing care and treatment at private clinics reported receiving all HIV-related services free of charge, with transport being provided to and from the clinic for those requiring assistance. Young woman accessing care and treatment at private clinics also receive a CD4 count once every six months. About 60 of 118 young women interviewed were reportedly happy with the services offered at private clinics, were grateful that they did not have to pay and appreciated the support with transportation.

In contrast, the young women accessing HIV care and treatment in public health facilities reported challenges accessing CD4 count tests due to cost and to capacity issues at the facility level. For instance, clinics can only perform a certain number of tests per day. If the daily quota of tests is filled people are told to return the following day. One young woman reported, *“I have never had my CD4 count taken at my local clinic, they always refer me elsewhere. For me, the New Start Centre is the best place to go but you have to go early.*

They only charge US\$ 1 for a CD4 count, then I take the results back to my clinic.” Viral load testing is not available at public health facilities.

Chest X-rays are available at all central hospitals for a fee of US \$20 per chest X-ray. The tests are offered through an outsourcing facility, housed within a central hospital. One young woman said, *“Although chest X-rays are available at Central Hospital and there are usually no queues, the cost is just prohibitive. I was once in need of a chest X-ray and could not get the US \$20 that is required. So, I can say the service is available but not available since we cannot access it.”*

Lack of adequate communication and information from health providers:

55 out of the 118 of young women interviewed reported that when one is given ARVs or has any tests like Full Blood Count (FBC) taken, service providers often do not explain the purpose of the test. The same situation happens when one is pregnant. The service provider gives patients a pill at the onset of labour and are told only that it is to protect their baby from contracting HIV. The consensus among young women was that they are told what to do without adequate explanation. Moreover, some service providers display negative attitudes towards young women with HIV. The situation leaves some participants unaware of the potential consequences of failing to follow their treatment plans.

Macro level issues

Poor quality information and consistency regarding PMTCT programming including Option B+:

Option B+ was introduced in Zimbabwe in February 2012, starting with a few sites and eventually rolled out to all sites initiating ART. The 30 young women who reported a pregnancy in the past year had mixed and inconsistent responses regarding the treatment regimens offered during pregnancy, labour and delivery. Some reported accessing Nevirapine at the onset of labour; others did not. Some reported that their babies were given Nevirapine two weeks after birth, while others reported that their babies were given

Nevirapine six weeks after birth. These reports suggest that Option B+ was offered inconsistently and women were seldom given information about options for preventing onward transmission.

“I was not sure why I was being injected. I had to ask the nurse and was only told that the injection was to protect the baby from contracting HIV.”

(FGD in Zimbabwe)

The young women (30 of 118) were happy to protect their babies from contracting HIV but they wanted to understand what to expect next.

Mandatory testing and ART initiation: As discussed at the meso level, in Zimbabwe, it is mandatory for every pregnant woman who goes through ANC in public health facilities to be tested for HIV. Policy then states that all women diagnosed with HIV should initiate ART. Some young women reported marrying without disclosing to their husbands. The knowledge that an HIV test is required can cause distress, deter testing and lead to efforts to pretend that the young woman did not know her status before, thereby eroding trust between partners.

Criminalization of onward HIV transmission: In Zimbabwe, it is a criminal offense to knowingly infect someone with HIV. This is in accordance with the Constitution, Section 79, and is a documented deterrent to HIV testing.

4.6 Recommendations

- National effort to **systematically address confidentiality and privacy** issues raised at facility level—possibly integrated with PEPFAR Site Improvement Monitoring System (SIMS) audits or other ongoing data collection initiatives.
- **Health worker training** to increase youth-friendly delivery of health services.
- Establishment of **adolescent clinics** where young people transitioning from paediatrics would be able to access health services and be afforded privacy.
- Expansion of the **treatment literacy and peer support programmes** offered as part of ANC programming, Option B+ and immediately after delivery.
- Ministry of Health **monitoring** to ensure consistency in the roll-out of Option B+ takes place at some health facilities.

TABLE 8
Policy Mapping in Zimbabwe²⁵⁶

Policy	Policy objective (overall)	Policy focus related to women	Strengths	Shortcomings
HTC guidelines	Guidelines specify who can access HIV Testing and Counselling services without parental consent. In circumstances where parental consent is required but cannot be obtained, guidelines do spell out viable alternatives.	Guidelines also focus on mature minors, adolescents below the stipulated age but who have assumed adult responsibilities. These “mature minors” do not require parental consent to get HIV Testing and Counselling services.	The policy gives service providers the power “to act in the best interests of the child” when it comes to HIV testing and counselling.	Policy implementation lag in some cases.
Adolescent SRH strategy	The strategy specifies what an adolescent is and the different categories of adolescents. It goes on to spell out which health services adolescents can access.	The strategy realizes that female adolescents will require some SRH services that their male counterparts might not need. It therefore specifies female age groups for certain services.	It stresses the importance of the establishment of youth friendly services for adolescents to be able to access services freely and without intimidation.	The current strategy ended in 2015 and a new one is still in development. The major criticism levelled against this strategy is that it focuses on the establishment of youth-friendly service provision but is weak on developing strategies to support youth health-seeking behaviours.
ZNASP	<ol style="list-style-type: none"> 1) Provide a strategic framework that will guide and inform the planning, coordination, implementation, monitoring and evaluation of the national multi-sectoral and decentralised HIV and AIDS response with the aim of achieving zero new infections, zero discrimination and zero AIDS-related deaths. 2) Articulate national priorities, results and targets to which all stakeholders and partners will contribute. 3) Provide the basis for consolidating strategic partnerships and alliances especially with civil society organizations, public and private sector, and development partners. 4) Establish the basis for Zimbabwe to consolidate efforts to develop sustainable financing mechanisms for HIV and AIDS response. 	<p>HIV incidence reduced from 0.85% for adults to 0.435% by 2015.</p> <p>HIV and AIDS related mortality reduced by 38% from 71,299 in 2010 for adults and 13,393 for children in 2009 to 44,205 for adults and 8,304 for children by 2015.</p> <p>National HIV and AIDS response is effectively coordinated and managed.</p>	The strategy has identified female sex workers as a main key population needing access to services.	<p>The current strategy ended December 2015 and has paved the way for the 2016-2018 National Strategic Plan that will guide work in the coming years. This strategy has these weaknesses:</p> <ul style="list-style-type: none"> • Inadequate implementation of interventions targeting key populations. • Although Zimbabwe has a national BCCC strategy and programme, implementation remains fragmented with inadequate coverage and intensity. • Insufficient coverage, intensity and duration of interventions targeting young people, especially those not in school. • Stigma and discrimination not adequately addressed in the National Behaviour and Communication Programme (NBCP). • Poor and low quality of life skills-based HIV education provided. • Inadequate coverage of workplace-based HIV and AIDS education.

Policy	Policy objective (overall)	Policy focus related to women	Strengths	Shortcomings
Patient charter	Outlines patient rights to access health services regardless of individual circumstances.	Focuses on the rights of all human beings to access health services, whether they are able to pay or not.	Policy clearly states that no one should be denied access to health services.	Published in 1996, the charter is now 20 years old and should be reviewed.
Zimbabwe AIDS Policy	Speaks of a multisectoral approach to managing HIV and AIDS with the National AIDS Council coordinating these efforts.	The policy's efforts are all inclusive and does not single out any strategy for women.	Policy speaks of resource mobilization through all sectors and government to try and combat HIV and AIDS.	This is a 1999 policy that has never been revised despite the changing face of HIV over time.

CONCLUSIONS

Improved AIDS response and room for further improvement

This extensive review presents and amplifies the realities of women and girls living with HIV around the world. It confirms, through qualitative analysis, what epidemiological figures and treatment programme data suggest – that while the HIV response has improved over the past two decades and access has indeed expanded, there remains much more to be done. This work involves a purposeful, well-funded, human rights-based, gender-focused and truly intersectional approach to fully meet the needs of women living with HIV. The approach should include, but not be limited to, women's needs and desires related to informed choices on initiating, continuing, and adhering to antiretroviral therapy.

Quantity and quality; treatment and care

As the report's Phase 1 literature review suggests, HIV treatment is being scaled up as global policy. Data show that more women around the world access treatment than men, at least partially as a result of the provision of ARVs for pregnant women. The focus on initiation of Option B+ in pregnancy means that women living with HIV increasingly face treatment over much longer timeframes. Yet treatment access literature to date has concentrated on the *numbers* of people with HIV receiving treatment rather than on the *quality* of their care or *retention* in care. Furthermore, the words 'treatment' and 'care' are often used interchangeably, masking their different meanings.

Similarly, the focus of service delivery has been on treatment initiation alone rather than on care initiation, with both treatment initiation *and* care and support for adherence as optional components of this care. Indeed, much of what is known about treatment

adherence and retention in care for pregnant and post-partum women, in countries with Option B+ roll-out, suggests there may well be major challenges in supporting women to both initiate *and remain on* ART via 'test and offer' or 'test and treat' programmes – both of which are being rolled out worldwide.

Barriers to access

Diversities of women; diversities of unmet needs

Evidence from this review demonstrates that there remain significant barriers facing women who wish to access and benefit from care and treatment, including particular barriers faced by women from key populations. The need to reach women from key populations is an urgent reality that we can no longer ignore. Thus, it is vital to rigorously interrogate sociocultural and economic barriers to ensure that women – particularly marginalized women – experience long-term, positive physical, psychological and sexual health outcomes from the application of global policies.

Human rights violations

This review's findings from qualitative research that was designed, led and managed by women living with HIV, strongly indicate that human rights violations—in the form of gender inequality, and cultural and economic challenges—pose major barriers to women's choices regarding access and adherence to HIV care and treatment services.

Gender roles in decision-making

Women's decision-making regarding disclosure is heavily influenced by gender roles and gender-based violence, including the fear of negative reactions, abandonment and abuse. This in turn limits their ability to access care and to make an informed voluntary choice about if and when to start, and how long to adhere to treatment.

Barriers at multiple levels

These barriers operate at multiple levels, yet programmes and policies frequently fail to conceptualize a response that cuts across them all. The costs to women of overcoming constraints at the household and community level are exacerbated by the discriminatory attitudes of health-care staff and weak health systems, including poor treatment supplies, lack of counselling and long waiting times in suboptimal environments that do not respect privacy and confidentiality. Health-related issues such as side effects, having to take ARVs with food, and the fear of gender-based violence if seen taking ARVs also present challenges for women with HIV. These concerns are key factors in decision-making around whether and when to access care and for how long. Further, women need sufficient time with health-care providers to raise any concerns and for these to be taken seriously. Women living with HIV require all necessary information to make informed choices about participation and the most appropriate treatment regimens and duration.

Gaps in the literature, guidelines and practice

There remains a broad lack of understanding of these insights and scant recognition of their importance in the development of policies, guidelines or practices. Certainly, there are many studies in peer-reviewed journals on access to care and treatment, adherence, and health outcomes. Our literature review, however, reveals a limited focus on the relation to human rights outcomes for women living with HIV. We illustrate critical gaps in the understanding of the various barriers women face when accessing HIV treatment and care.

The widespread lack of sex- and age-disaggregated data further compounds the problem. *If we are to reach women and girls living with HIV in all their diversities, we must close these research gaps as a matter of urgency. We need to acknowledge that the foundation of an enabling environment and the pursuit of enduring solutions lies in women's insights and resilience.* Women living with HIV know best what has helped to improve and maintain their physical and mental health and well-being. This global review, in addition to identifying gaps, also identified sources of resilience, depth of knowledge, concrete, actionable recommendations and a clear vision of what a rights-based, women-centred approach to ART provision might look like in the near future.

Moving Forward

The recommendations outlined in the executive summary and throughout this document provide a framework for immediate action. The results will be a demand-driven and sustainable service delivery model that addresses gender equality and women's rights at micro, meso, and macro levels.

Using the 'Six Point Plan for Action' would create a transformative shift in the way women's treatment needs are addressed. It would inform policies, guidelines, and programmes and contribute towards achieving the 2016-2021 UNAIDS Strategy to End AIDS. We contend that the Plan would achieve gender equality by improving women's access to and uptake of HIV services; mobilizing communities to promote gender equality; and empowering women globally, including by investing in women's leadership in the AIDS response.¹

BOX 7

The 'Six Point Plan for Action' to address women's gaps in HIV treatment

- 1) **Human rights:** expanding definitions to include rights-based, voluntary and informed choice with options, and addressing gender-related structural barriers to women's informed voluntary choices on initiating, continuing and adhering to/retention on treatment;
- 2) **Gender:** engaging in more gendered analysis of treatment access barriers, recognising intersections with other structural factors;
- 3) **Diversities:** filling data gaps that exist across the treatment cascade for women in all their diversities;
- 4) **Multiple levels:** ensuring care and treatment packages include basic needs and account for gender-specific barriers at household, community, and national levels;
- 5) **Gender-based community engagement:** incorporating gender analysis into expansion of support for community-based service delivery; and
- 6) **Peer-led involvement:** harnessing the power and leadership of peer-led and peer-governed analysis of treatment access as a part of participatory research.

ANNEXES

Annex 1: Ethical framework and principles

The discussion tools designed for the community dialogues phase are grounded in strong ethical principles that relate to working closely with women living with HIV. WHO has placed a high priority on ethics and the need to respect women in research. In the WHO guidelines on research on domestic violence against women,²⁵⁷ the following key principles are noted as essential and reflected in the report:

- **The safety of respondents and the research team is paramount**, and should guide all project decisions.
- Prevalence studies need to be **methodologically sound and build upon current research** experience about how to minimize the under-reporting of violence.
- **Protecting confidentiality** is essential to ensure both women's safety and data quality.
- All research **team members should be carefully selected and receive specialized training and ongoing support**.
- Study design must include actions aimed at **reducing any possible distress** caused to the participants by the research.
- Fieldworkers should be trained to **refer women requesting assistance to available local services and sources of support**. Where few resources exist, it may be necessary for the study to create short-term support mechanisms.
- Researchers and donors have an ethical obligation to help ensure that their **findings are properly interpreted and used to advance policy and intervention development**.
- **Violence questions should only be incorporated into surveys designed for other purposes when**

ethical and methodological requirements can be met.

Throughout the use of the designed tools (focus group discussions, one-to-one interviews and listserv discussions), the team upheld and respected the following principles in addition to those mentioned above:

- **Meaningful involvement of women living with HIV and AIDS (MIWA)**: All discussion was developed and facilitated by women living with HIV through the Global Reference Group (GRG). The MIWA principle is not new but its practice is rare. Early AIDS activists created the "Denver Principles"²⁵⁸ in 1983, when the "GIPA Principle" (Greater Involvement of People with HIV and AIDS in all issues that affect our lives) was initiated.
- **Appreciative inquiry**: The team sought from the outset to build on the resilience of women living with HIV in how they have responded to the challenges around accessing treatment. This approach is based on positive thinking, language and content, turning from problems and needs to visions and solutions. From the outset, this review used a holistic perspective to convey the complex realities that women living with HIV face daily and how they strive to overcome barriers. Appreciative inquiry involves a way of working and soliciting information that strengthens the capacity to understand, anticipate and influence positive potential instead of just focusing on the challenges.

- **Interactive approach:** An interactive, flexible approach was used to ensure that participants were not constrained by the original research framework. Unexpected issues and themes raised by women during discussion were incorporated in subsequent discussion tools, analysis and reports.
- **Dual learning:** All women consulted and interviewed were encouraged to walk away having also gained information and understanding from the discussion and feeling positive about the whole experience of sharing personal and professional life experience around treatment access.
- **Grounded:** A potentially transformative exercise, as described by ICW's *Toolkit on Positive Women Monitoring Change*, was the actual process of developing the tool and working with other groups of women to develop their own. This current work has respected the process, both in the community dialogues phase and in moving into the country case studies phase. This process involves women engaging politically with their own experiences and environments, envisioning a different future and shaping their own messages, indicators or frameworks to reflect a contextualized "ideal". This process helps women analyse their context and situation, and enables ongoing advocacy using a tool over which there is far more ownership than with one that is "ready-made".²⁵⁹
- **Understanding and defining violence against women living with HIV:** Violence against women (VAW) is defined by the WHO as: "Any

public or private act of gender-based violence that results in, or is likely to result in physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion, or arbitrary deprivation of liberty with the family or general community. It includes sexual, physical, or emotional abuse by an intimate partner (known as 'intimate partner violence'), family members or others; sexual harassment and abuse by authority figures (such as teachers, police officers or employers); sex trafficking; forced marriage; dowry-related violence; honour killings; female genital mutilation; and sexual violence in conflict situations."²⁶⁰ This list also encompasses violence by police and clients directed towards sex workers.

A broader definition of Violence against Women, as proposed by women living with HIV, includes structural forms of violence, related to how social, political and legal contexts cause direct and indirect harm to women. This expanded definition of VAW comes directly from women living with HIV who describe it as "any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV."²⁶¹ While this definition was developed specifically by and for women living with HIV, it has broader resonance when it comes to understanding VAW as structural violence. This enables indirect forms of violence and the maintenance of unequal social relationships to be included in the definition of violence. For instance, we may frame the criminalization of women living with HIV, sex workers or injecting drug users as institutional violence.²⁶²

Annex 2: Part 1 Literature Review References

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Josephine Kulea is the founder of Samburu Girls Foundation, a non-governmental organization that works in northern Kenya to end harmful traditional practices such as female genital mutilation, early forced marriages and beading.

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Natalia Kovnir, a woman-activist living with HIV, at the National Women's Forum on HIV and AIDS (19-21 September 2016, Odessa, Ukraine), supported by UN Women and other partners.

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Jon (left), 24, a peer educator, discusses how to prevent HIV/AIDS and other sexually transmitted diseases with a group of adolescents in Barangay Apelo, a slum area in Pasay City near Manila, the Philippines.

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Keren Dunaway, a young woman from Honduras living with HIV, said, "We adolescents and young people should have the space to participate meaningfully in decision-making at all levels, including policy-making and implementation. Governments must work with civil society and young people to ensure accountability. Together we must break the prejudice and stigma so that all young people have access to services."

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