



# MAKING WAVES: WOMEN, HIV & THE POWER OF RESEARCH

REPORT ON WAVE WORKSHOP  
AHEAD OF THE 20TH EUROPEAN  
AIDS CONFERENCE

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# MAKING WAVES: WOMEN, HIV & THE POWER OF RESEARCH

## REPORT ON WAVE WORKSHOP AHEAD OF THE 20TH EUROPEAN AIDS CONFERENCE

Women Against Viruses in Europe (WAVE) is an initiative of The European AIDS Clinical Society (EACS). WAVE's mission is to promote the welfare of women living with HIV in Europe. WAVE endeavours to promote equality of access to care and excellence in standards of care for women living with HIV. This includes addressing gaps identified in care for women living with HIV in research and in clinical practice.

This report is an overview of the WAVE workshop entitled 'Making WAVES: Women, HIV & the Power of Research', which took place ahead of the 20th European AIDS Conference (EACS 2025), on 15 October 2025 in Paris, France. Workshop presentations and debates were spread over six sessions and focused on WAVE's activities in 2023-2025 in areas of concern to women living with or vulnerable to HIV in Europe. Clinicians and community representatives presented presentations on the topics of:

- Epidemiology
- Women who are migrants
- Breastfeeding
- Ageing with HIV
- PrEP
- HPV



### Opening remarks

"We are celebrating a decade of WAVE," said WAVE chair Annette Haberl (Germany), opening the morning session with a reflection on the network's growth and achievements since its first workshop at EACS 2015. Over the past ten years, WAVE has expanded to 135 members, accompanied by a steady increase in activities, including seven WAVE workshops and 13 dedicated WAVE Ukraine workshops. Haberl emphasized that WAVE's strength lies in its active working groups, which enable members to contribute according to their expertise and interests. She presented an overview of recent and ongoing work across key thematic areas, including menopause, migrant women, breastfeeding, PrEP, HPV, healthcare perceptions, and the Ukraine response, highlighting a growing body of scientific publications and collaborative projects. Haberl also underlined WAVE's expanding international partnerships, including cooperation with ECDC, EATG, EMAS, and the Japanese Society for AIDS Research.

She concluded by introducing the six thematic sessions of the workshop and encouraging continued engagement and participation within the WAVE network.

# SESSION 1. A CONTINENTAL VIEW: EPIDEMIOLOGY & EMPOWERMENT

## Women with HIV: European Epidemiology by Charlotte Doegan

An epidemiological overview was presented by Charlotte Doegan (European Centre for Disease Prevention and Control, Sweden), who reviewed current trends in HIV among women in Europe. She reported that HIV remains more prevalent among men, with an overall male-to-female ratio of 2.7, though this varies considerably between countries. Women continue to account for a substantial proportion of new diagnoses, particularly among migrants, who represent nearly half of all new HIV cases across the region.

Late diagnosis was highlighted as a major concern, affecting 58% of women newly diagnosed with HIV, with the highest rates observed among older women, those infected through heterosexual transmission, and women originating from sub-Saharan Africa and parts of Asia. Doegan also noted persistently low uptake of pre-exposure prophylaxis (PrEP) among women, with approximately 8,600 female users across Europe, underlining the need for improved access and gender-responsive prevention strategies.

In addition, she drew attention to rising sexually transmitted infection rates among women, including a 177% increase in gonorrhoea notifications over the past decade and a worrying resurgence of congenital syphilis, which continues to rise to levels not seen for more than ten years. Doegan concluded by emphasizing the need for strengthened surveillance, earlier diagnosis, and better targeted prevention and care interventions for women, particularly those from migrant communities.



## **Current situation of women with HIV in Ukraine by Sergii Antoniak (pre-recorded presentation)**

The situation of women living with HIV in Ukraine was presented in a pre-recorded presentation by Sergii Antoniak (Ukraine), infectious diseases specialist at the Gromachevsky Institute of Epidemiology and Infectious Diseases in Kyiv. He reported that as of mid-2025, almost 134,000 people were receiving HIV care in Ukraine, with women representing approximately 45% of all people living with HIV. Due to war-related displacement, the geographical distribution of HIV has shifted from historically high-prevalence south-eastern regions towards central and western parts of the country. Despite these challenges, Ukraine has maintained a robust HIV care cascade, with 88% of diagnosed women on antiretroviral therapy and high viral suppression rates among those with access to viral load testing.

Antoniak highlighted pregnancy outcomes as a continuing priority, noting that over 1,100 women living with HIV gave birth in 2024. While the majority were on ART before pregnancy, nearly 30% were diagnosed during pregnancy, and most of these diagnoses occurred after the first trimester, increasing the risk of vertical transmission. Nevertheless, post-partum treatment continuation was high, and most women received integrase inhibitor-based regimens. Antoniak concluded by emphasizing that, despite war-related disruption, Ukraine continues to provide essential HIV care with particular attention to women and children, while acknowledging the need for further improvements in early diagnosis and antenatal care. He expressed gratitude to Ukrainian healthcare workers and international partners supporting women living with HIV during the ongoing conflict.

## **Discussion with Tetiana Melnyk & Dagny Krankowska. Moderator: Annette Haberl**

The discussion, moderated by Annette Haberl, brought together perspectives from Tetiana Melnyk (Ukraine/France) and Dagny Krankowska (Poland) and focused on the care of Ukrainian women living with HIV who have migrated to other European countries following the outbreak of war. Melnyk reported that in France, access to HIV care for Ukrainian migrants was ensured from the first day, even in the absence of documentation, allowing immediate continuation or initiation of antiretroviral therapy. While treatment regimens sometimes needed adjustment due to drug availability, continuity of care was generally well maintained. In contrast, Krankowska described more mixed experiences in Poland, where the large influx of Ukrainian migrants has been accompanied by cases of treatment interruption and re-entry into care with advanced HIV disease.

Both speakers highlighted late diagnosis as a persistent challenge, particularly among women, heterosexual individuals and older age groups, echoing trends presented in the epidemiological data. A subsequent exchange with ECDC addressed rising gonorrhoea rates among women and the ongoing issue of late HIV diagnosis in older women, underlining gaps in testing beyond reproductive health settings. The discussion reinforced the need for sustained, gender-sensitive testing strategies and coordinated European responses to ensure uninterrupted care for migrant women living with HIV.

# SESSION 2. JOURNEYS OF STRENGTH: MIGRANT WOMEN'S REALITIES

## SERAY Project by Giota Lourida

The SERAY Project was presented by Giota Lourida (Greece) on behalf of the WAVE Migrant Women Working Group and explored barriers to HIV prevention and testing among women who are migrants in Europe. Building on earlier WAVE work, including a systematic review and a survey of service providers that identified individual, sociocultural, and structural barriers to care, the SERAY Project was designed to directly capture women who are migrants their perspectives. The feasibility study was conducted in Greece, Italy, and Poland through a co-production model involving local NGOs and used an anonymous, culturally sensitive online survey available in multiple languages and supported by cultural mediators.

Eighty-seven women who are migrants participated, representing diverse ethnic and socioeconomic backgrounds. Although most respondents reported access to free healthcare and recent contact with health services, substantial gaps remained, with high proportions of women never having been tested for HIV and many reporting precarious living conditions, financial dependence, or experiences of violence. Sensitive topics such as sex work and violence were disclosed, reflecting a high level of trust achieved through the co-production approach. Lourida highlighted the CROSS framework underpinning the project—co-design, refinement, organisation, support, translation, scale, and sustain—as a reproducible methodology for inclusive research. She concluded by outlining plans to expand the survey to additional countries and to develop a practical screening tool to improve HIV prevention and early diagnosis among migrant women, particularly in the context of global HIV funding constraints.

## Personal journey Story telling by Seray

The woman who inspired the name of the migrant women project shared her personal journey in a powerful and touching presentation.



# SESSION 3. MOVING FORWARD: FEEDING CHOICES FOR PARENTS LIVING WITH HIV

## European guidelines on HIV and breastfeeding by Amy Keane

European guidelines on HIV and breastfeeding were reviewed by Amy Keane (Ireland), who presented findings from a WAVE-led analysis of national guidance across Europe. This work followed the 2022 WAVE breastfeeding survey and aimed to collate existing guidelines, support countries without formal recommendations, and inform future guideline development. Of 23 countries contacted, 19 had national breastfeeding guidelines for women living with HIV, although no two were identical; Austria and Germany were the only countries sharing joint guidance. While most guidelines continued to recommend formula feeding, the majority supported breastfeeding under strictly defined “optimal” conditions.

Keane outlined common criteria for supported breastfeeding, including sustained viral suppression, good ART adherence, and regular viral load monitoring during breastfeeding. Multidisciplinary care was emphasised, with many guidelines recommending involvement of HIV specialists, paediatricians, obstetricians, midwives and lactation consultants. Monthly viral load monitoring for both the breastfeeding parent and the infant was commonly advised, although this intensity of monitoring was acknowledged as potentially burdensome in the postpartum period. Key areas of inconsistency included definitions and management of mixed feeding, infant post-exposure prophylaxis regimens, handling of mastitis and viral load “blips,” and recommended duration of breastfeeding, which was often limited to six months despite WHO guidance supporting longer breastfeeding periods.

Keane concluded that while European guidance has shifted towards conditional support of breastfeeding, significant gaps remain, highlighting the need for clearer, harmonised and evidence-based recommendations that balance safety with feasibility and parental wellbeing.

## Discussion with Mojgan Hessamfar & Yvonne Gilleece. Moderator: Annette Haberl

The discussion, moderated by Annette Haberl, with contributions from Mojgan Hessamfar (France) and Yvonne Gilleece (United Kingdom), focused on the global diversity of approaches to breastfeeding in women living with HIV and the challenges of translating guidelines into clinical practice. The INFORM Plus initiative was introduced as a collaborative effort bringing together women living with HIV, clinicians and researchers from high-, middle- and low-income countries to promote equity in infant feeding support. Speakers highlighted the tension between cautious European recommendations and the realities of resource-limited settings, where frequent viral load monitoring is often unfeasible and breastfeeding remains essential for infant survival. Experiences from Germany, Austria and France illustrated a gradual move away from rigid monthly monitoring towards more individualised, adherence-focused follow-up, supported by multidisciplinary care and, in France, a national registry documenting breastfeeding outcomes. Audience discussion emphasised the absence of a universal “gold standard,” the need to pool international data to strengthen the evidence base, and the importance of involving obstetricians, midwives and families in care pathways. Several participants stressed that women’s preferences and informed choices must remain central, noting that effective communication and supportive environments are critical to reducing fear and stigma and enabling safe, individualised breastfeeding decisions.



# SESSION 4. HER FUTURE, HER TERMS: AGEING WITH HIV

**Improving care for women with HIV as they age by Anna Hachfeld & Nneka Nwokolo. Moderator: Susan Cole-Haley**

The session on ageing and women living with HIV, moderated by Susan Cole-Haley, brought together community, clinical and policy perspectives through presentations by Anna Hachfeld (Switzerland) and Nneka Nwokolo (United Kingdom). Opening the session, Cole-Haley shared a community perspective grounded in lived experience, highlighting the lack of information, fragmented care, and emotional distress frequently reported by women ageing with HIV. She emphasised that women living with HIV are not a homogeneous group and that intersecting factors such as migration status, racism, stigma, and socioeconomic disadvantage compound challenges as women age.

Menopause emerged as a key unmet need, with many women reporting that symptoms are poorly recognised, dismissed, or misattributed, and that access to hormone replacement therapy (HRT) remains inconsistent despite safety evidence. Cole-Haley stressed the importance of meaningful co-production, joined-up care, early menopause discussions, mental health support, and genuine listening to women's priorities.

From a clinical and research perspective, Hachfeld highlighted that women with HIV age differently to men, with menopause representing a critical transition associated with metabolic changes and increased cardiovascular risk. Data from Switzerland and other Western European countries indicate that the majority of women with HIV are now peri- or post-menopausal. However, cardiovascular risk in women is often underestimated, and commonly used risk calculators underpredict events. Despite these risks, research on menopause and ageing in women with HIV remains scarce, with few studies incorporating hormonal status and very limited data from low-income settings. Hachfeld also noted major knowledge gaps among women and healthcare providers, contributing to underdiagnosis and undertreatment. She presented WAVE-developed educational materials on HIV and menopause as an example of effective co-production and called for better representation of women in ageing research, routine consideration of hormonal status, and improved implementation of existing evidence into clinical practice.

The session concluded with a presentation by Nneka Nwokolo outlining a strategic collaboration between the European AIDS Clinical Society (EACS) and the European Menopause and Andropause Society (EMAS). This partnership aims to integrate menopause expertise into HIV care and ensure that HIV considerations are reflected in broader ageing and menopause research, education, and policy. Nwokolo highlighted the potential benefits of this collaboration for improving symptom recognition, reducing stigma, enhancing holistic care, and strengthening the evidence base through joint research and educational initiatives.

Overall, the session underscored ageing and menopause as central issues for women living with HIV and called for coordinated, gender-responsive, and community-informed approaches to care.



## **Models of care for women living with HIV in Europe: a scoping review by Duaa Rao**

Models of care for women living with HIV in Europe were reviewed by Duaa Rao (Germany), who presented findings from a WAVE-led scoping review examining existing care pathways and guidelines. The review was prompted by previous WAVE data showing a mismatch between perceived and actual care for women ageing with HIV, with disparities most pronounced in Eastern Europe. After screening more than 8,000 records, only 17 relevant studies were identified, the majority originating from the UK, with minimal representation from Eastern European countries.

Rao outlined ten key components of effective care models, including retention-focused HIV care, peer support networks, meaningful involvement of women living with HIV in service design, tailored and flexible services, integration of social and mental health support, multidisciplinary teams, culturally appropriate care, healthcare worker training, and gender-responsive research. While emerging work addresses ageing and menopause, significant regional gaps remain.

Rao concluded that incorporating these core components into health systems is essential to delivering holistic, equitable care for women living with HIV across Europe, and highlighted the urgent need for research and models reflecting the diversity of healthcare settings and lived experiences.

## **Discussion by Anne Hachfeld, Nneka Nwokolo, Susan Cole-Haley, Duaa Rao. Moderator: Ellen Moseholm**

A formal discussion following the presentations on ageing and models of care for women living with HIV could not be held due to time constraints. Participants were instead encouraged to continue exchanges informally during the break with the speakers, including Anna Hachfeld, Nneka Nwokolo, Susan Cole-Haley and Duaa Rao.



# SESSION 5. PROTECTION, POSSIBILITY, POWER: REWRITING THE NARRATIVE WITH PREP

## Prevention of HIV, PrEP options for women by Yvonne Gilleece

HIV prevention and PrEP options for women were reviewed by Yvonne Gilleece (United Kingdom), who highlighted both historical challenges and recent breakthroughs in HIV prevention research for women. She outlined the failure of several early prevention trials, including FEM-PrEP, VOICE, tenofovir vaginal gel and the dapivirine ring, noting that low efficacy was largely driven by adherence barriers rather than biological inefficacy. These findings underscored the limitations of prevention strategies that did not adequately reflect women's social realities, particularly among young women aged 15–24 years who face the highest risk of HIV acquisition.

Gilleece presented compelling evidence for new prevention modalities that have transformed the landscape for women. Data from the HPTN 084 study demonstrated that long-acting injectable cabotegravir was 88% more effective than daily oral PrEP, with high acceptability and persistence among women, including younger age groups. Similarly, the PURPOSE 1 trial of six-monthly injectable lenacapavir reported zero HIV transmissions in the active arm, representing a major advance for women who face challenges with daily pills or covert use. In settings where injectables remain unavailable, emerging data on intermittent oral PrEP were highlighted, with four-day weekly dosing achieving over 94% pharmacokinetic efficacy, offering a more flexible alternative to daily dosing.

The potential role of doxycycline for STI prevention was also discussed. While doxycycline post-exposure prophylaxis has shown substantial benefit in men who have sex with men, evidence in cisgender women remains limited, with modest reductions in chlamydia and no clear effect on gonorrhoea or syphilis, likely reflecting adherence challenges rather than biological limitations.

Gilleece emphasised that effective HIV prevention for women must extend beyond biomedical interventions to include peer support, community-designed services and integrated care models, such as the Women's Health Hub initiatives in Brighton and Liverpool. She concluded that expanding prevention choice, co-designing services with women, and embedding PrEP within trusted care pathways are essential to closing persistent gender gaps in HIV prevention.

## Educational needs assessment: PrEP in trans communities by Amanita Calderon-Cifuentes

An educational needs assessment on HIV prevention and PrEP among trans communities was presented by Amanita Calderon-Cifuentes (Germany), HIV research and advocacy officer at Trans-Europe and Central Asia (TGEU). The study was developed in collaboration with trans community members and researchers and aimed to assess PrEP-related knowledge across diverse trans populations in several European countries, including Armenia, Denmark, Germany, Italy, Romania, Slovenia and the United Kingdom. The survey focused on further marginalised groups, including trans sex workers, migrants, people who use drugs, individuals with a history of incarceration, and trans youth.

Overall PrEP knowledge did not differ by gender identity; however, marked differences were observed across socioeconomic and structural factors. Trans sex workers and trans people who use drugs demonstrated the highest levels of HIV prevention knowledge, reflecting the impact of sustained, peer-led community interventions.

In contrast, trans youth under 20 years of age and undocumented migrants, asylum seekers and refugees showed the lowest levels of knowledge. The least understood topic across groups was PrEP on-demand, particularly regarding its effectiveness and applicability based on body type, highlighting significant confusion due to inconsistent messaging and limited trans-specific data.

Calderon-Cifuentes emphasized that targeted, peer-led educational strategies are urgently needed to address these gaps and announced plans for tailored interventions focusing on trans youth and migrant communities, reinforcing the importance of community-designed education to reduce inequities in HIV prevention access.

## Discussion: Ben Collins, & María Jesús Pérez Elias. Moderator: Nina Weis

Due to time constraints, the planned discussion with Ben Collins (United Kingdom) and María Jesús Pérez Elias (Spain), moderated by Nina Weis, could not take place during the session. Participants were encouraged to engage directly with the speakers informally following the presentations.



# SESSION 6. SILENT THREAT: HPV IN WOMEN LIVING WITH HIV

## HPV screening in women with HIV by Christina Carlander

The silent burden of human papillomavirus (HPV) infection and related cancers in women living with HIV was addressed by Christina Carlander (Sweden), senior consultant at Karolinska University Hospital and chair of the Swedish National HIV Register.

She highlighted that HPV prevalence remains persistently high in women with HIV across the lifespan, in contrast to HIV-negative women, in whom HPV typically clears with age. Women living with HIV face substantially increased risks of HPV-related cancers, including a six-fold higher risk of cervical cancer and a more than fifteen-fold higher risk of anal cancer, largely driven by persistent infection and immunosuppression. While antiretroviral therapy significantly reduces cancer risk, regional differences remain pronounced, particularly where screening coverage is limited.

Carlander reviewed current evidence and guidelines for prevention and screening. HPV vaccination was shown to be highly effective in preventing cervical cancer when administered before sexual debut, with robust immunogenicity also observed in women with HIV, although long-term efficacy data remain limited. For secondary prevention, HPV DNA testing is increasingly replacing cytology due to its high sensitivity, but high HPV prevalence in women with HIV reduces specificity and complicates risk stratification.

Cervical screening programmes have proven effective in preventing cancer when combined with viral suppression and regular follow-up. Anal cancer screening, however, remains challenging, as responsibility often falls between medical specialties and access to high-resolution anoscopy is limited, even in high-income settings.

Carlander emphasized the need for improved access to anal screening, clearer care pathways, and novel biomarkers to better identify women at highest risk. She concluded by underscoring that leveraging existing HIV care infrastructure offers a critical opportunity to improve HPV-related cancer prevention and outcomes for women living with HIV.

**Discussion: Nina Weis, Denmark & Karoline Aebi-Popp, Switzerland. Moderator: Yvonne Gilleece**

The discussion, moderated by Yvonne Gilleece, with contributions from Nina Weis (Denmark) and Karoline Aebi-Popp (Switzerland), focused on persistent gaps in the implementation of anal cancer screening for women living with HIV. Panellists highlighted that responsibility for anal health often falls between medical specialties, with gynaecologists, primary care clinicians and proctologists frequently uncertain about ownership of screening, contributing to delayed action. Stigma surrounding anal disease and limited access to high-resolution anoscopy were identified as additional barriers, even in high-income settings.

Audience contributions from women living with HIV underscored a concerning disconnect between patient advocacy and service availability, with requests for screening sometimes declined due to capacity or lack of clear protocols. Discussion emphasised the need for interdisciplinary collaboration, pragmatic interim measures such as digital anorectal examination, and the development of scalable screening models. Participants also highlighted the importance of leveraging existing HIV care infrastructure, expanding training across specialties, and generating stronger evidence to support guideline implementation.

The session concluded with calls for coordinated action to translate growing evidence on HPV-related cancer risk into equitable, accessible screening pathways for women living with HIV.



## Closing remarks & next steps by Nina Weis

The WAVE workshop concluded with closing remarks from vice-chair Nina Weis (Denmark), who reflected on the breadth of topics covered and the collective progress achieved through WAVE's collaborative efforts. She expressed sincere thanks to all speakers, working groups, and members of the Scientific Committee for their contributions, as well as to the EACS Secretariat for their essential organisational support. Weis highlighted the central role of community involvement across WAVE projects and encouraged continued and expanded engagement of women living with HIV in research, guideline development and service design. Looking ahead, she emphasised the importance of strengthening international collaborations, including ongoing partnerships with organisations such as EMAS and EATG, and proposed exploring a broader scope for WAVE's work beyond HIV to include other viral infections impacting women's health, particularly HPV and viral hepatitis. Finally, she drew attention to the Ask Us Europe study, a community-designed initiative examining equity in access to new antiretroviral treatment options, and encouraged participants to support increased participation by women.

Weis closed by thanking the audience for their engagement and invited continued involvement with WAVE activities at EACS and beyond.





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