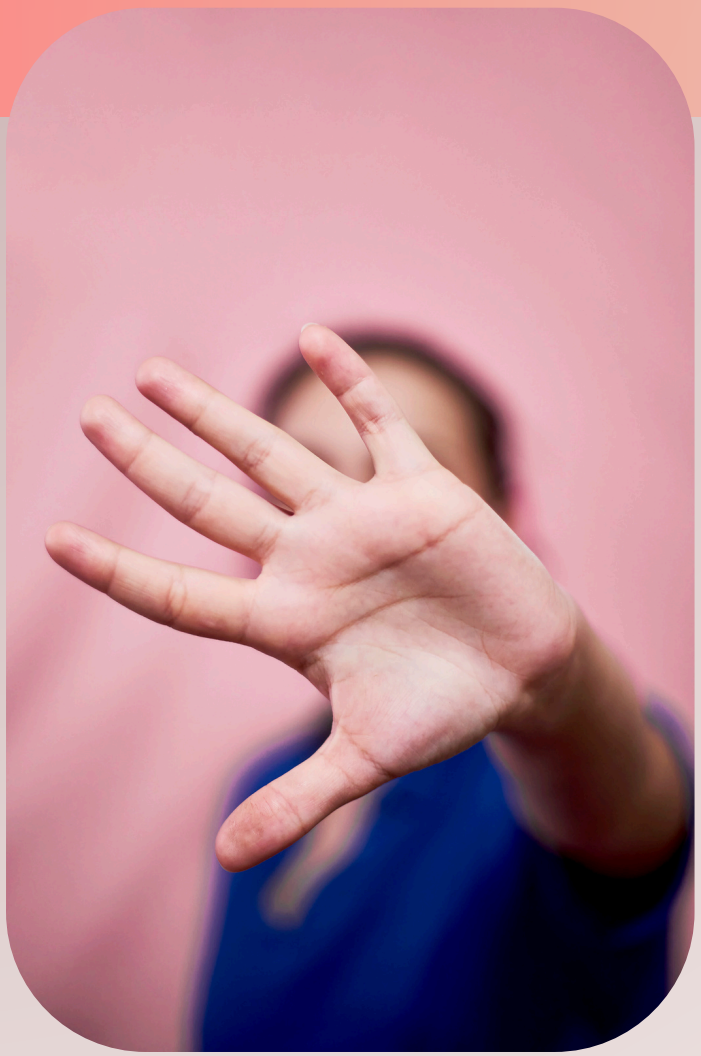
Eurasian Women`s Network on AIDS



OBSTETRIC VIOLENCE AGAINST WOMEN LIVING WITH HIV IN EASTERN EUROPE AND CENTRAL ASIA

COMMUNITY-LED RESEARCH

TBILISI, 2025

Lead author

The Eurasian Women's Network on AIDS (EWNA)[1] brings together women leaders from 14 countries across Eastern Europe and Central Asia and is a key organisation designed to protect the rights of women living with HIV and those who are vulnerable to HIV. EWNA supports women in developing and strengthening their potential and making women's voices heard in decision-making processes at different levels.

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Authors: This report has been developed by the EWNA Research Team under the leadership of **Medea Khmelidze**, EWNA's Director of Programmes.

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The views expressed in this publication are those of the authors and may not reflect the views of the consortiums organisations as well as the RCF. The RCF was not involved in agreeing and approving either the material itself or the possible conclusions from it. The publication is for free distribution.

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[1] www.ewna.org

[2] Eurasian Regional Consortium includes: Eurasian Harm Reduction Association (EHRA), Eurasian Coalition for Health, Rights, Gender and Sexual Diversity (ECOM), Eurasian Women's Network on AIDS (EWNA) and the Sex Workers' Rights Advocacy Network (SWAN)

[3] HIV Justice Global Consortium includes: HIV Justice Network, AIDS and Rights Alliance for Southern Africa (ARASA), Eurasian Women's Network on AIDS (EWNA), Global Network of People Living with HIV (GNP+), HIV Legal Network, Sero Project, Southern Africa Litigation Centre

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Introduction

Violence against women and other marginalized groups takes many forms among individuals and in society. The coexistence of interpersonal and structural violence is especially pronounced in the realm of reproductive autonomy. Reproductive coercion finds its structural-level twin in state policies on reproductive healthcare that are coercive in impact. Communities that are already underserved by the healthcare system and disproportionately affected by anti-choice reproductive health policies, are also the most at risk of reproductive coercion[4].

"Obstetric violence" names a previously unnamed and widely unrecognized harmful social phenomenon: violence and abuse during childbirth in healthcare facilities[5]. It is rooted in a gender-based violence framework and exposes institutional violence in formal maternity care settings[6]. The concept names the everydayness of broadly accepted maternity care services as violence, with a particular focus on approaches to maternity services that dehumanize women. Obstetric violence is a prized political concept with rich transformative potential evidenced in its broader feminist activism across the globe[7] in its introduction into legislation on gender-based violence and in the international recognition of obstetric violence as a particular form of gender-based violence against women[8].

During childbirth, a woman, fearing for her life and the life and health of her child, is as vulnerable and defenceless as possible in front of medical personnel who can stigmatize and discriminate against her. Obstetric violence is one of the types of violence that combines the characteristics of violence against women (targeted at women solely because of being a woman) and institutional violence (the presence of a structural power imbalance in healthcare institutions - between medical staff and patients). Obstetric violence is a so-called umbrella term, as it covers various humiliating, violent and harmful practices that can occur during all types of gynaecological and obstetric care throughout a woman's lifespan (gynaecological check-ups, access to contraception, infertility treatment, when treating miscarriages, during pregnancy, during and after childbirth, etc.).

When women deliver, for healthcare facilities, in addition to providing the high-quality clinical care specific to labour and childbirth, it is utmost important to make sure that the way care is delivered is woman centred and respectful and protects and promotes their rights. Ensuring a continuum of care, regular monitoring and documentation of clinical events, and clear, empathetic, and respectful communication between healthcare providers and clients is essential. In addition, women must be given the information, choices, and support they need to make informed decisions, and a referral plan must be in place should more advanced medical care become necessary. These are all essential elements of good-quality labour and childbirth care that every woman and newborn should receive[9].

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[4] Katz & Tirone, 2015

[5] Lydia Zacher Dixon, 'Obstetrics in a Time of Violence: Mexican Midwives Critique Routine Hospital Practices'(2015) 29 Medical Anthropology Quarterly 437

[6] Michelle Sadler and others, 'Moving beyond Disrespect and Abuse: Addressing the Structural Dimensions of Obstetric Violence' (2016) 24 Reproductive Health Matters 47

[7] Paola Sesia, 'Naming, Framing, and Shaming through Obstetric Violence: A Critical Approach to the Judicialisation of Maternal Health Rights Violations in Mexico' in Jennie Gamlin and others (eds), Critical Medical Anthropology: Perspectives in and from Latin America (UCL Press 2020); Rachelle Chadwick, 'Breaking the Frame: Obstetric Violence and Epistemic Rupture' (2021) 35 Agenda 104

[8] Report of the Special Rapporteur on Violence against Women, Its Causes and Consequences on a Human Rights-Based Approach to Mistreatment and Violence against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence' (UN General Assembly 2019) A/74/137; SFM v Spain [2018] CEDAW/C/75/D/138/2018; NAE v Spain [2019] CEDAW/C/28/D/149/2019; Brítez Arce v Argentina (Inter-American Court of Human Rights)

[9] Operationalizing a Human Rights-Based Approach to Address Mistreatment against Women during Childbirth Zampas; 2020

Violence undermines the HIV response by limiting access to essential services. Violence against women is a human rights violation. Women who experience violence are at increased risk of HIV infection. Women living with and vulnerable to HIV are more likely to experience violence.

According to the findings of the survey conducted by the CO “Positive women”[10] among 104 women living with HIV in Ukraine (2023) regarding their experience of obstetric violence over the past 3 years: 27% of the respondents were denied giving birth due to their HIV-positive status; 44% were asked to pay for free medical services because of their HIV-positive status; 70% reported that their HIV-positive status was disclosed to their inner circle, which in 56% of cases affected further medical support; the HIV-positive status of 55% of respondents was disclosed to the medical staff, which in the case of 72% of respondents had a negative impact on further medical support; 6% experienced physical abuse during pregnancy and/or childbirth due to their HIV-positive status; 34% faced serious consequences for their health or the life and health of their child as a result of obstetric violence.

The People Living with HIV Stigma Index[11] across Eastern Europe and Central Asia (EECA) reveals persistent discrimination against women living with HIV, particularly in reproductive healthcare. In Kazakhstan (2022), 15% (51 women) reported being advised to terminate their pregnancy due to HIV. Pressure was also reported regarding delivery methods (7%) and infant feeding choices (9%). A similar trend was observed in Kyrgyzstan (2022), where 12% of respondents were encouraged to terminate their pregnancies, and 10% faced pressure in choosing their delivery method and feeding options. In Tajikistan (2021), 21 women were advised to terminate their pregnancy. Additionally, 12 women experienced pressure in choosing their delivery method, and 16 women felt compelled to follow certain infant feeding practices. In Moldova (2023), 21 women were advised against having more children in the past year, and 8 women were pressured or encouraged to undergo sterilization. Overall, 45 women reported being advised to terminate a pregnancy due to their HIV status. In Belarus (2022), 28% of respondents reporting pressure from medical professionals to terminate their pregnancies, 24% experiencing coercion regarding delivery methods, and 24% facing pressure about infant feeding choices. Similarly, in Armenia (2023), 22% of women were advised to terminate their pregnancies, while 9% faced pressure in choosing both delivery and infant feeding methods. 18% of women were pressured to terminate their pregnancies, 17% experienced coercion in delivery choices, and 20% were influenced in infant feeding decisions. Meanwhile, in Azerbaijan (2024), the situation remained critical, with 20% receiving medical recommendations to terminate their pregnancies in the past year. Additionally, 27% of women faced pressure about delivery methods, and 26% were influenced in their feeding choices.

These findings reveal the ongoing discrimination faced by women living with HIV in multiple countries. Stigma and coercion in reproductive healthcare, including pressure to terminate pregnancies, forced sterilization, and restricted choices in delivery and infant feeding, continue to undermine the autonomy and rights of women living with HIV.

Institutional violence negatively impacts women’s health. It manifests itself in states adopting laws and establishing rules that limit women’s access to health services and lead to discrimination. In most EECA countries, HIV-positive status, substance use, sex work, gender identity and their intersection increase the degree of discrimination against women in the healthcare system.

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[10] Policy Brief: Obstetric Violence Against HIV-Positive Women in Ukraine, 2023; Positive Women
[11] https://www.stigmaindex.org/

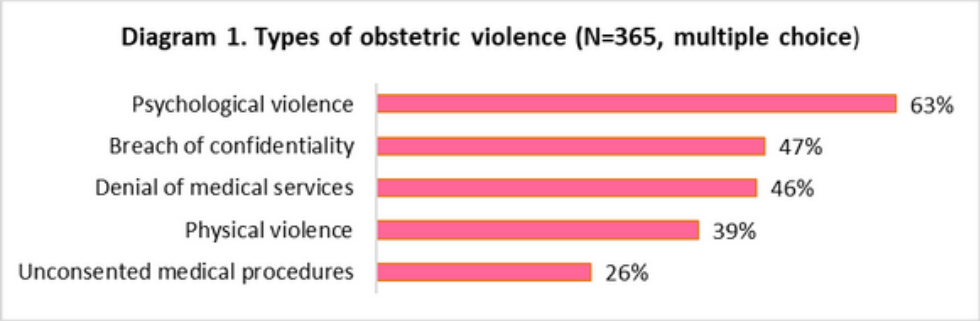
Executive Summary

Obstetric violence is a form of institutional violence that occurs in the context of obstetric and gynaecological care. It includes physical, psychological, verbal and emotional violence, as well as neglect and humiliation that women may experience during pregnancy, childbirth and the postpartum period. This phenomenon seriously limits women's access in general, but especially women living with and vulnerable to HIV, to health services, the effectiveness of the HIV response, undermines their rights and dignity, and worsens their mental and general health.

Obstetric violence has a profound impact on the health and well-being of women living with HIV, increasing their vulnerability to stigma and discrimination. Women living with HIV often face biased attitudes from healthcare staff. This may include derogatory language, denial of care, or coercion to undergo procedures, even such as sterilization, without their consent. Such treatment violates a woman's right to be treated with respect and dignity. Doctors often ignore clinical guidelines regarding breastfeeding or methods of delivery, depriving women of their right to make informed choices. This not only violates standards of care but also increases feelings of powerlessness and discrimination among patients. Constantly emphasizing the "risks of HIV transmission" to the child in a rude or humiliating manner traumatizes the woman, destroying her confidence and ability to make informed decisions about her health and the health of her child. Dismissive attitudes, denial of timely medical care, and failure to adhere to prevention protocols significantly increase the risk of vertical transmission of HIV. Instead of support, women face barriers that could be removed with high-quality and respectful care.

The community-led study, conducted by the EWNA team, examined experiences of obstetric violence against women living with HIV in 13 countries of EECA: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Moldova, [redacted] Tajikistan, Ukraine and Uzbekistan through 365 respondents who participated. The study revealed numerous cases of violation of rights of women living with HIV (Diagram 1):

- **Psychological violence**: 63% of respondents reported various forms of psychological violence, including humiliation (33%), isolation and ignoring requests for help (21%), intimidation (33%), pressure to undergo medical procedures without consent (14%).
- **Breach of confidentiality:** 47% of women experienced unconsented disclosure of their HIV status to third parties, including other healthcare workers (36%) and family members (19%).
- **Denial of medical services:** 46% of women reported being denied services, including pain relief (19%), breastfeeding support (15%), and abortion (12%).
- **Physical violence:** 39% of women experienced physical violence, including ill-treatment (27%), forcing into a particular delivery position (9%) and pushing the foetus out (7%).
- **Unconsented medical procedures:** 26% of women reported cases of medical procedures performed without their consent, including caesarean section (10%), amniotomy (5%) and surgical sterilization (2%).



Although a substantial majority (87%) reported having **autonomy to decide whether and when to have children**, 13% indicated they lacked this autonomy, suggesting potential barriers to empowerment in reproductive decision-making. Obstetric violence increases **stigma and discrimination**, creating barriers to timely access to healthcare and support. The intersection of various factors of discrimination is particularly evident in the EECA region. 66% of respondents faced discrimination in healthcare settings, primarily due to HIV status (64%), but also related to socioeconomic status (12%), drug use history (11%), and other intersecting factors. Women living with HIV, women who use drugs, sex workers, migrants/refugees face double or multiple stigmas. Additional social determinants such as ethnicity, disability, comorbidities and experience of incarceration, experience of violence including at war, further exacerbate their situation. Together, these factors create an environment where violence is not only a result but also a cause of limited access to vital health and social services, reinforcing the vicious circle of vulnerability. Despite having had the experience, only a third of respondents (33%) reported of abuse, out of whom only 30% mentioned that some actions had been taken. In most cases, reports go to hospital/clinic management (45%) and family members or friends (40%), while 15% of cases were reported to a representative of a public or human rights organisation. Only two cases were reported to the police/lawyer.

The survey findings also reflect a significant portion of respondents encountering challenges or unmet expectations in **the quality of healthcare services** and once more stresses the diversity of systemic and individual experiences one might face the EECA region as well as within countries due to the combining factors of level of development, democracy, human rights perspectives on one hand but vulnerability, marginalization and access to resources on the individual level. Satisfaction with the medical services received: 11% were very satisfied and 24% were satisfied, while 36% expressed neutral feelings. However, dissatisfaction was notable, with 22% being dissatisfied and 7% extremely dissatisfied.

The effects of violence and discrimination on mental and emotional well-being reveal a range of experiences among respondents: 31% reported moderate psychological effects (depression, loss of confidence), 18% severe effects (trauma, severe depression), and 29% provided qualitative descriptions reflecting significant distress. The impact on future decisions to seek sexual, reproductive, and maternal health services highlights substantial barriers to care: 21% hesitated to seek care, 41% avoided certain providers, and 7% stopped seeking reproductive health services altogether due to past experiences of discrimination. Most women (67%) have received **community support** at some level, with 29% always having access to peer-driven assistance. However, enhancing awareness efforts can ensure the remaining 10% who are currently unaware can benefit from available resources.

This community-led study underscores the urgent need for integrated, rights-based healthcare models that address intersectional vulnerabilities of women living with HIV and for systemic reforms to rebuild trust and accessibility in healthcare services. Strengthening access to reproductive autonomy and community support is essential. Healthcare systems must combat discrimination and address the multifaceted issues through a holistic, rights-based approach that enforce informed consent, protects confidentiality, and provide equitable care for women living with HIV, ensuring their dignity and well-being. Hence, the key recommendations[12] include addressing **legal, policy, and practice reforms, healthcare system improvements, and community engagement and women's empowerment**.

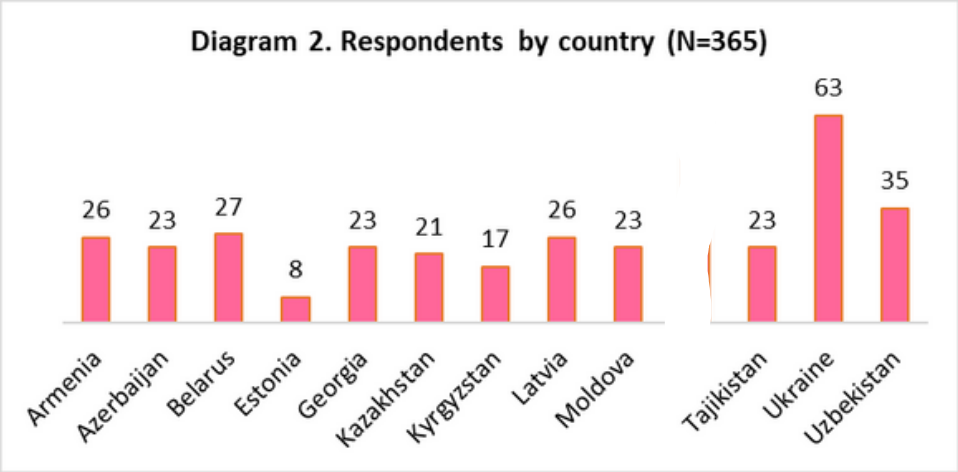
[12] See in detail in the "Recommendations" section

About the Study

The community-led study “Obstetric Violence Against Women Living with HIV in Eastern Europe and Central Asia” was conducted by the Eurasian Women's Network on AIDS as part of the regional campaign “No excuse for violence!”[13].

The aim of the study was to gather comprehensive data on the experiences of women living with HIV during pregnancy, childbirth, and postnatal care, during last five years, with a focus on obstetric violence in the EECA region. Authors aimed to identify instances of obstetric violence and discrimination and assess the quality of care provided. The result of this study therefore contributes to the development of recommendations for strengthening health systems and community services in support to inclusive and non-discriminatory sexual and reproductive health policies and programmes. The study sought to identify barriers to equitable maternal healthcare and inform strategies to enhance services for women in the region.

The study, conducted by the EWNA team, examined experiences of obstetric violence among women living with HIV in 13 countries of EECA, namely: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Moldova, Tajikistan, Ukraine and Uzbekistan through 365 respondents who participated (Diagram 2).



Participants were recruited based on specific eligibility criteria to ensure the relevance and integrity of the data. Eligible individuals included women, who had experienced pregnancy and childbirth while living with HIV. Participants needed to have given birth within the past five years, be at least 18 years old, and have resided in the named countries during their most recent pregnancy. They were also required to provide informed consent, complete the study in a language they understood, and participate without compromising their safety or well-being.

The community-led study was crucial not only in generating information but also in structuring the research process effectively. First, the Research Reference Group convened to review the initial draft of the questionnaire, which was subsequently refined based on their recommendations. Next, all questionnaires were translated into national languages with the direct involvement of country coordinators, who also tested their comprehensibility before the official launch. Prior to the survey's dissemination, a webinar was conducted to provide clear guidance on information distribution.

[13] EWNA Narrative Report of the regional campaign “No excuse for violence!” (in Russian)

Additionally, a dedicated "Guide for Country Coordinators on Dissemination of the Survey: Obstetric Violence Against Women Living with HIV in Eastern Europe and Central Asia" was developed specifically for the webinar[14]. All steps, including development of the final recommendations based on the findings, were carefully planned and reviewed in close collaboration with country coordinators, ensuring their direct involvement and enhancing their sense of ownership over the process.

Serving as both the Data Controller and Data Processor, the team including the local coordinator for each country, facilitated community mobilization and further data collection through digital platforms, including smartphones, tablets, and computers, followed by thorough analysis and reporting. EWNA adheres to the United Nations "Personal Data Protection and Privacy Principles" adopted by the UN High-Level Committee on Management (HLCM) on October 11, 2018. Thus, participation in this survey was entirely confidential.

As mentioned, data collection involved a detailed questionnaire available in all national languages, addressing topics such as socio-demographic characteristics, access to healthcare, experiences of obstetric violence, and the impact of HIV on pregnancy and childbirth[15]. To maintain confidentiality, all responses were anonymized, securely stored, and accessible solely to the research team. Participants retained the right to withdraw at any stage, with any associated data promptly deleted. Although the study posed minimal risks, participants who experienced emotional distress while recalling adverse experiences were offered referrals to counselling services.

Overall, the insights gained from this research are expected to drive significant improvements in maternal healthcare for women living with HIV across the EECA region. By highlighting participants' lived experiences, the study aims to advocate for systemic changes, reduce obstetric violence, and foster the development of inclusive, patient-centred care practices.

Reflections of the National Coordinators:

Kazakhstan: "*A woman living with HIV approached the NGO "Life Despite" (Astana, Kazakhstan) near the end of the survey. She had learned about the survey through a mailing list and wanted to share her story about pregnancy and childbirth. Due to poor treatment at the polyclinic, she opted for an alternative—paid pregnancy care at a private clinic. However, when it came time to give birth, the clinic refused to assist her. She had to negotiate with a regular state maternity hospital, where she faced multiple challenges. The staff treated her poorly, were hesitant to approach her, and failed to maintain confidentiality. When she learned about our study, she was surprised that someone was actually addressing the problems faced by women with an HIV diagnosis. In our organisation, she was given detailed information about the study and women's rights organisations that advocate on such issues. Moreover, at the time she reached out to the organisation, she was experiencing domestic violence from her husband, who was demanding a divorce and threatening to take away her child and strip her of parental rights. He disclosed her HIV status to mutual acquaintances and claimed that her antiretroviral therapy made her mentally unstable. She was emotionally devastated and afraid of going to court alone. At "Life Despite", she was able to receive professional psychological assistance. Thanks to legal support from the organisation's lawyer, the court ruled in favour of the mother*".

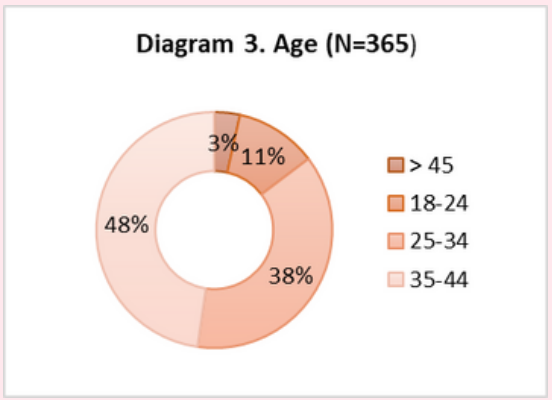
[14] Annex 1
[15] Annex 5

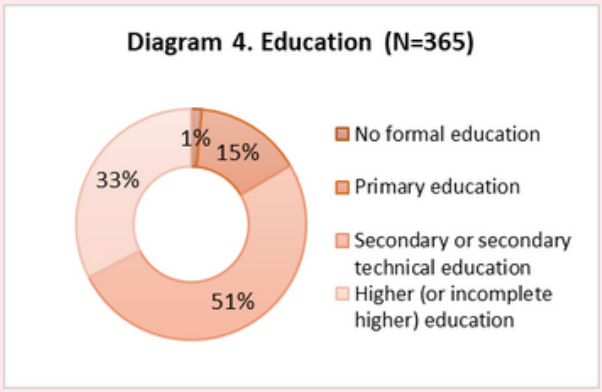
Latvia: "*The findings of this study have already been utilized to advocate for improvements in healthcare settings. One example is the submission of a formal letter to the National AIDS Center in Latvia by the country coordinator for Latvia, outlining the documented cases of obstetric violence experienced by women living with HIV. This letter, based on the study's preliminary results, highlighted key violations such as psychological and physical violence, breaches of confidentiality, unconsented medical procedures, and denial of essential medical services. The letter served as an important step in raising awareness among national stakeholders and policymakers about the intersection of HIV, gender-based violence, and institutional discrimination in maternal healthcare. In particular, it emphasized the heightened stigma and barriers faced by women from marginalized groups, including Roma women and women who use drugs. By sharing these research findings with relevant institutions, the study has not only documented critical issues but also initiated discussions on potential policy changes and improvements in service provision. This example demonstrates how community-led research can be translated into concrete advocacy efforts, informing decision-makers and pushing for systemic change to ensure respectful and rights-based maternity care for all women, especially those living with HIV*".

Overall Findings

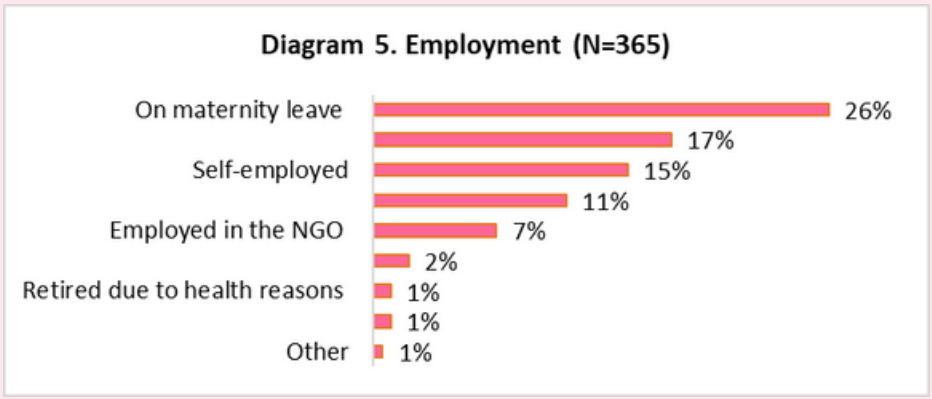
Socio-demographics

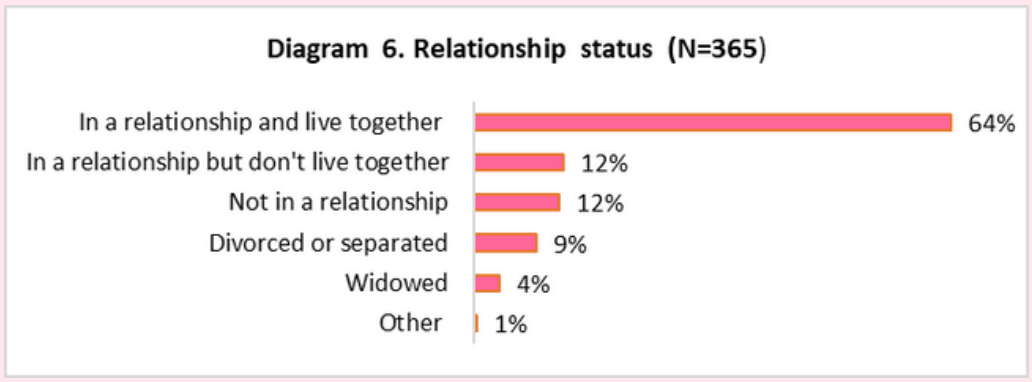
A total of 365 respondents participated in the survey, with the 35-44 age group 47.7%, followed by 25-34 that was 37.6%. Younger participants aged 18-24 made up 11.2%, and those aged 45 and over, represented the smallest group at 3.5% (Diagram 3). Educational attainment was relatively high, with 51% having secondary or secondary technical education and 32.5% having higher or incomplete higher education. Only 1.5% reported no formal education (Diagram 4).



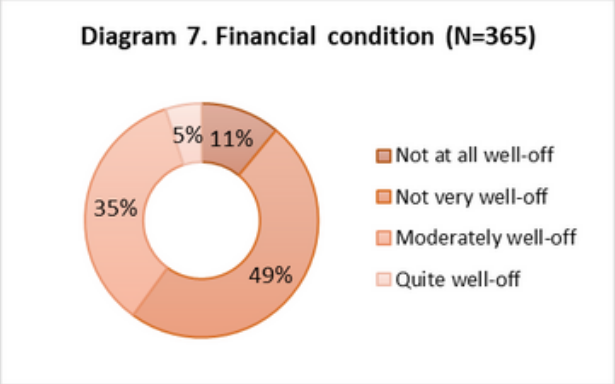


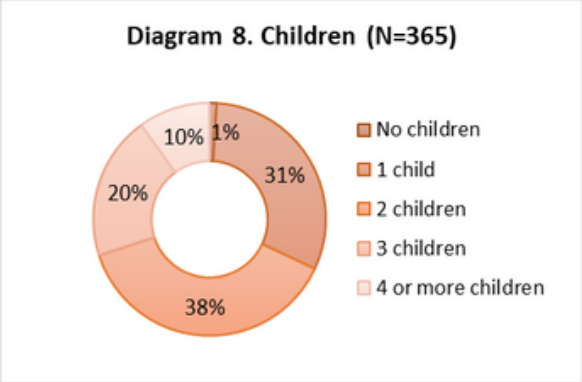
In terms of employment, 26% were on maternity leave, while 21% were unemployed. Other significant groups included those employed in the private sector (17%), self-employed (14.5%), and employed in the public (11%) or non-governmental sectors (7%) (Diagram 5). Most respondents (64%) were in relationships and living with their partner, while 11.5% were single, and 12% were in relationships but not cohabiting (Diagram 6).



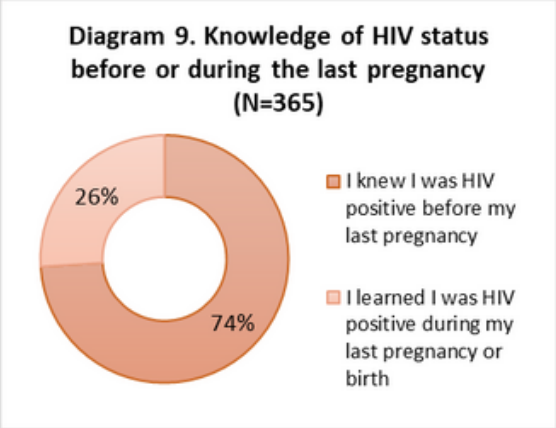


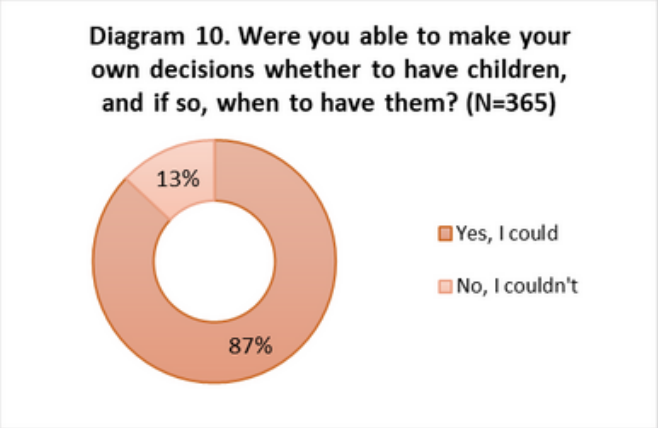
Financially, nearly half (49%) described themselves as “not very well-off”, with 11% reporting being “not at all well-off”. Most respondents had 1 or 2 children (69%), while larger families with 3 or more children accounted for 30% (Diagram 7). The pie chart illustrates the distribution of respondents based on the number of children they have. The 38% have two children, followed by 31% with one child, 20%with three children and 10% have four or more children. As expected the smallest proportion, 1%, reported having no children. (Diagram 8).





In terms of HIV status, 74.2% of respondents knew they were HIV positive before their last pregnancy, while 25.8% learned of their status during pregnancy or childbirth, indicating gaps in pre-pregnancy testing (Diagram 9). Regarding reproductive decision-making, a substantial majority (87%) reported having autonomy to decide whether and when to have children, although 13% indicated they lacked this autonomy, suggesting potential barriers to empowerment (Diagram 10). These findings highlight the importance of improving access to HIV testing and strengthening support systems for reproductive health and autonomy, especially for those facing economic and social challenges.





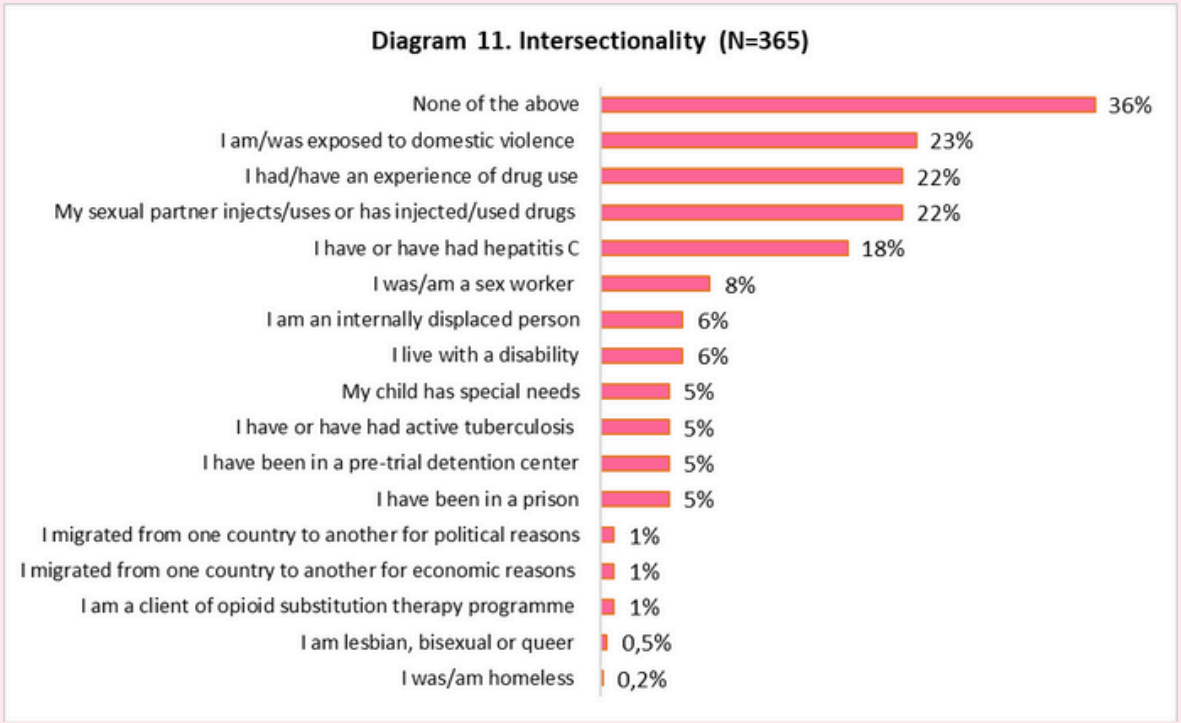
Intersectional characteristics and experiences

The data highlights the complex and overlapping challenges faced by respondents, where multiple intersectional characteristics contribute to their lived experiences. These characteristics do not sum to 100%, as women often identify with more than one category, reflecting the multidimensional nature of their vulnerabilities (Diagram 11).

Drug use and closed settings: 22% of respondents reported having experience with drug use, while an equal proportion (22%) indicated that their sexual partner uses or has used drugs; 1% of respondents are clients of opioid substitution therapy. 5% had been in prison and/or pre-trial or temporary detention, showcasing a linkage between drug use and incarceration. These findings underline the need for integrated services addressing drug use, incarceration, and rehabilitation.

Health and chronic conditions: 18% of respondents reported having or having had hepatitis C, a condition often associated with drug use. 5% experienced active tuberculosis, and 6% identified as living with a disability. These health conditions highlight the compounded vulnerabilities of respondents, particularly those with histories of incarceration or drug use.

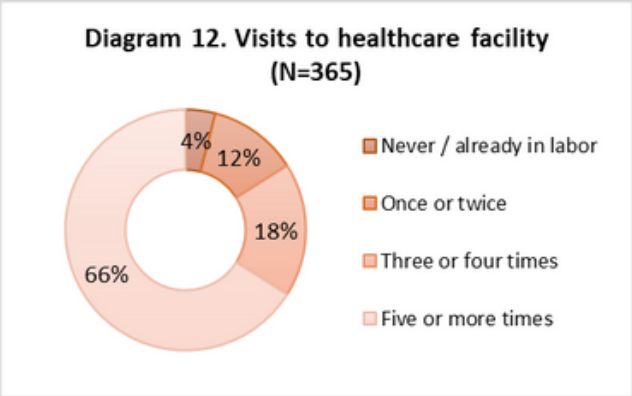
Violence, social vulnerabilities, economic and migration challenges: 23% of respondents reported being exposed to domestic violence, indicating a significant prevalence of gender-based violence within the population. 8% identified as having engaged in sex work, a group particularly vulnerable to violence and health risks. Two respondents identified as lesbian, bisexual, or queer, adding layers of marginalization and social stigma. A small percentage reported migration for economic (1%) or political (1%) reasons. 6% identified as internally displaced persons. 5% had children with special needs, highlighting the need for targeted support services. One respondent reported homelessness, emphasizing extreme social vulnerability.

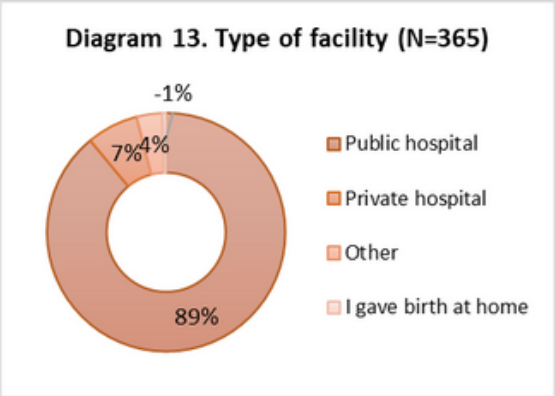


Women living with HIV face significant challenges due to their HIV related vulnerabilities, but these are further exacerbated by intersecting factors that amplify marginalization. The data reveals that respondents often experience multiple overlapping challenges, such as a history of drug use coinciding with incarceration, hepatitis C, and gender-based violence. These intersections deepen their vulnerability, creating barriers to accessing essential services and exacerbating inequality. While 36% of respondents indicated that none of the listed vulnerabilities applied to them, underscoring that a substantial minority does not face compounded challenges, the majority experience these overlaps, which complicate their lives significantly. This highlights the urgent need for integrated service delivery models that holistically address intersecting issues like drug use, incarceration, health conditions, gender-based violence, and economic instability to ensure equitable support for all women living with HIV.

Experience of receiving health services

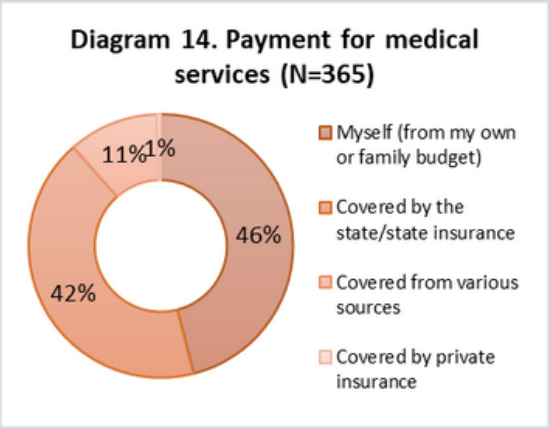
Most respondents (66%) visited a healthcare facility five or more times during their last pregnancy, indicating regular engagement with maternal healthcare services. However, 18% visited three or four times, 12% visited once or twice, and 4% did not visit a medical facility until labour (Diagram 12). Most respondents (89%) gave birth or received pregnancy-related services at a public hospital, while 7% used private hospitals. Only 2 respondents gave birth at home, and 3.5% reported using services of both public and private facilities (Diagram 13).

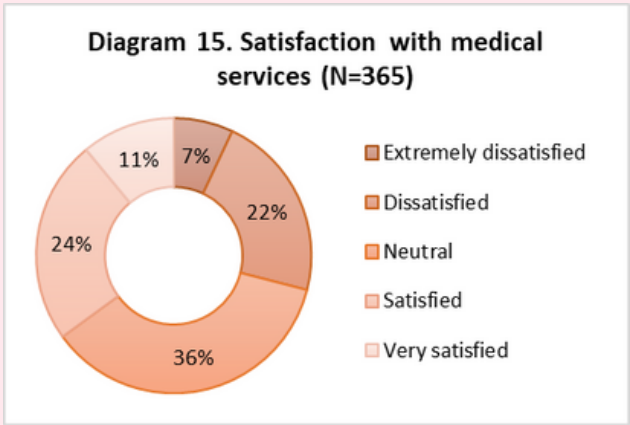




When it came to covering the cost of pregnancy-related medical services, nearly half (46%) paid out of their own or family budget, while 42.5% benefited from state coverage or state insurance. A small minority (0.5%) relied on private insurance, NGO support, or fundraising. 11% reported using various funding sources (Diagram 14).

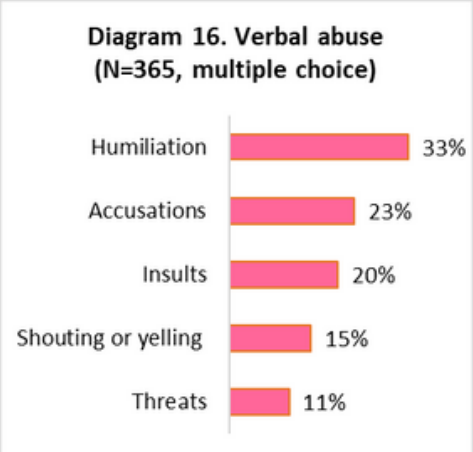
Regarding satisfaction with the medical services received, 11% were very satisfied and 24% were satisfied, while 36% expressed neutral feelings. However, dissatisfaction was notable, with 22% being dissatisfied and 7% extremely dissatisfied (Diagram 15). These findings reflect a significant portion of respondents encountering challenges or unmet expectations in the quality of healthcare services and once more stresses the diversity of systemic and individual experiences one might face the EECA region as well as within countries due to the combining factors of level of development, democracy, human rights perspectives on one hand but vulnerability, marginalization and access to resources on the individual level.

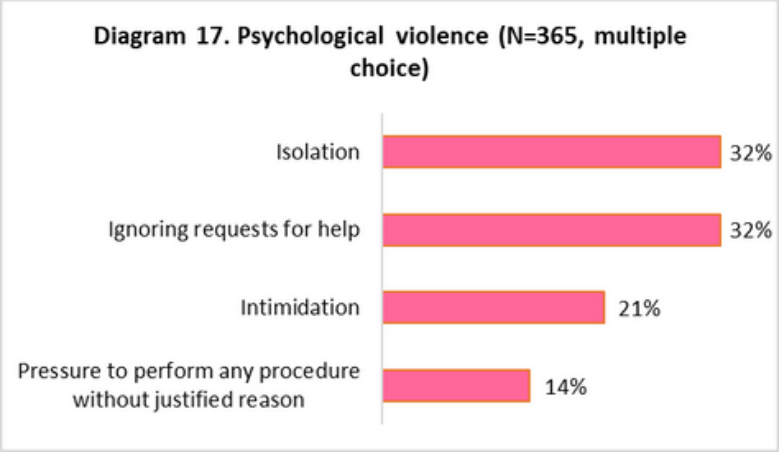




Experience of obstetric violence and discrimination

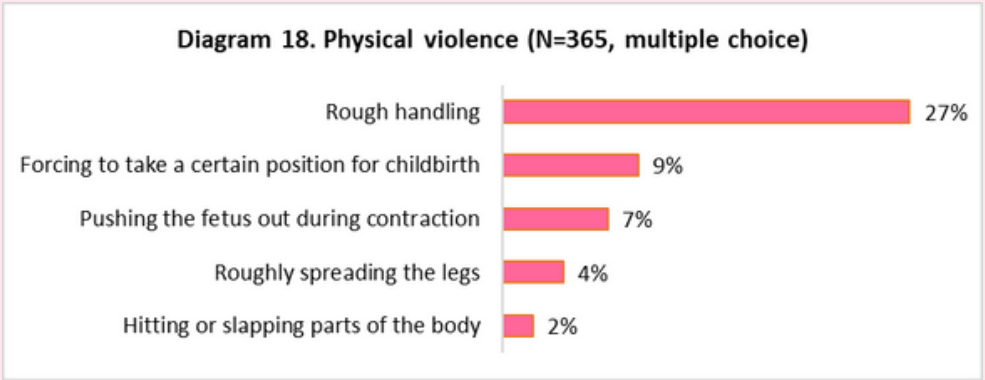
The experiences of women living with HIV reveal profound challenges in the healthcare system, marked by various forms of abuse and discrimination. Over half (56%) of respondents reported experiencing at least one form of verbal abuse. Commonly reported forms included shouting or yelling (15%), insults (20%), accusations (23%), and threats (11%). Among these, the most prevalent was humiliation, experienced by 33% of respondents, making it the dominant form of verbal abuse encountered (Diagram 16). Psychological abuse was even more widespread, with 63%, indicating they had experienced at least one form of this type of mistreatment. Intimidation was reported by 21%, while 14% faced coercion to undergo medical procedures without valid justification. Additionally, isolation and the ignoring of requests for help emerged as the most common forms of psychological abuse, each affecting 32% of respondents (Diagram 17).





"Threats of imprisonment if the baby was born sick, intimidation about giving birth to a "deformed" child, was yelled at me all the time. I was told I was not worth to have children, and that the money spent on my treatment should be given to others..." (Belarus)

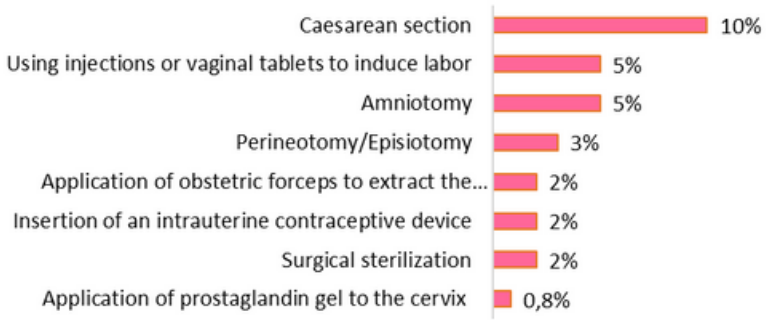
Physical abuse was another significant concern, affecting 38.6% of respondents. This included being forced into specific birthing positions (9%), roughly spreading legs apart during labour (4%), and the application of fundal pressure to forcibly extract the foetus (7%). Alarmingly, 27% of respondents cited "rough handling" as the most prevalent form of physical abuse experienced during childbirth (Diagram 18).



"After taking a blood test, he wore two gloves on top of each other, and when I cramped in pain, the nurse held me down and said "Don't whine, otherwise I won't draw your blood" ..." (Armenia)

Lack of genuine informed consent for medical procedures was another critical issue. Over a quarter (26.3%) reported that they had not given informed consent for at least one procedure. These included perineotomy or episiotomy (3%), the application of obstetric forceps (2%), amniotomy (5%), the use of prostaglandin gel for labour induction (0.8%), labour-inducing injections or vaginal tablets (5%), and intrauterine contraceptive device insertion (2%). Caesarean sections, which were reported by 10% of respondents, remain widely promoted and, in some cases, imposed on women living with HIV as also depicted in comments supporting validation of trends through generated qualitative information. Additionally, 2% of respondents reported undergoing surgical sterilization—a procedure that is irreversible and punishable by law—without consent (Diagram 19).

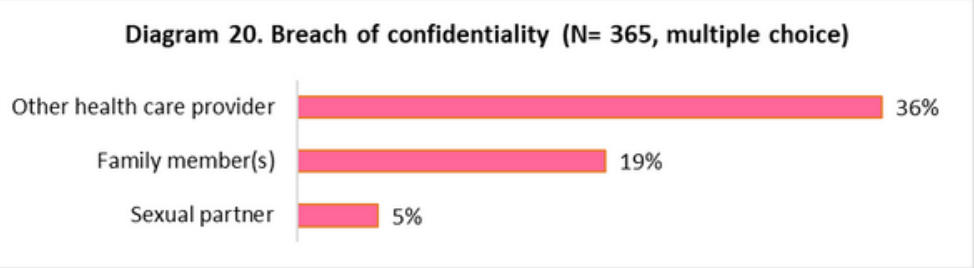
Diagram 19. Unconsented medical procedures (N=365, multiple choice)



"A contraceptive was inserted after surgery without my consent. They argued that with HIV, it's better not to have more pregnancies. Nurses refused to change my diapers because of my HIV status..." (Uzbekistan)

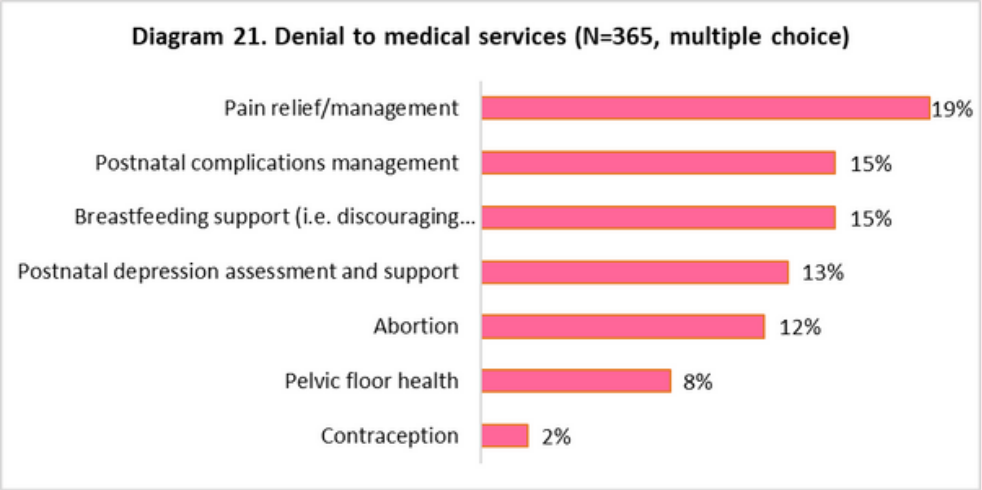
Breaches of confidentiality were also a widespread issue, reported by 47%. Disclosures of HIV status occurred without consent, most frequently to other healthcare providers (36%), followed by family members (19%) and sexual partners (5%) (Diagram 20).

Diagram 20. Breach of confidentiality (N= 365, multiple choice)



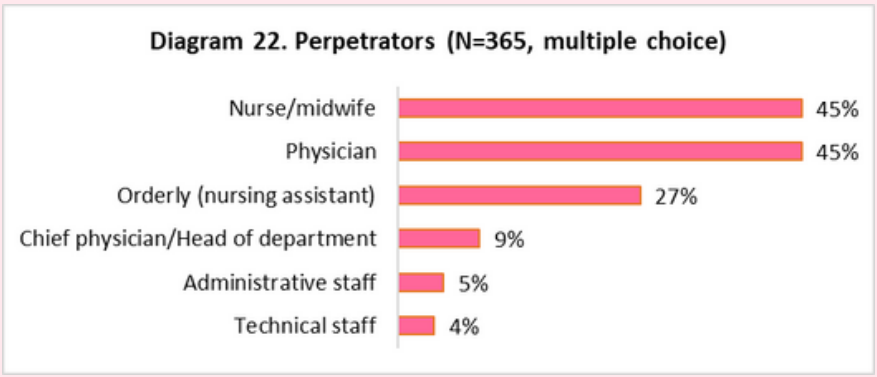
"My mother-in-law found out about my status in hospital, changed her attitude towards me, and even told me to leave the house…" (Kyrgyzstan)

Access to critical medical procedures and services was also frequently denied. Nearly 46% indicated being refused services such as abortion (12%), pain relief or management (19%), diagnosis and support for postpartum depression (13%), and support for breastfeeding (15%). Additional denials included pelvic floor healthcare (8%), contraception (2%), and postpartum complication management (15%) (Diagram 21).



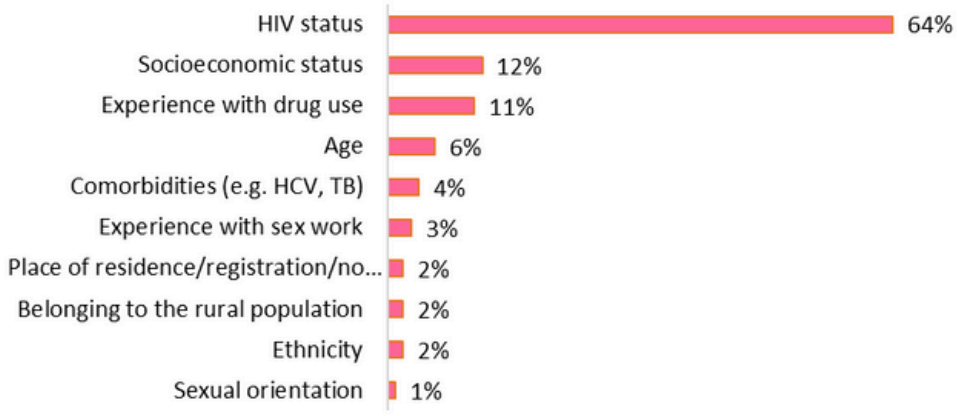
"The doctor told me that a person with AIDS cannot breastfeed a baby, no one explained why or I had an option…" (Georgia)

Obstetric violence was a pervasive issue, with 63.6% stating they had experienced at least one form of mistreatment. The identified perpetrators of this violence included doctors (45%), nurses or midwives (45%), nursing assistants (27%), chief physicians or department heads (9%), administrative staff (5%), and technical staff (4%). While social workers were rarely implicated, with only two cases reported, the overall breadth of violations highlights systemic issues within healthcare institutions (Diagram 22).



Discrimination against women living with HIV was also alarmingly prevalent, affecting 66% of survey respondents. The leading cause was their HIV status (64%), often compounded by other intersecting vulnerabilities such as socioeconomic status (12%), drug use history (11%), comorbidities like hepatitis C or tuberculosis (4%), age (6%), ethnicity (2%), rural residency (2%), lack of residential registration (2%), sexual orientation (1%), and experiences in sex work (3%). The data underscores that discrimination rarely stems from a single factor; rather, it is often intersectional, with overlapping vulnerabilities amplifying marginalization (Diagram 23).

Diagram 23. Discrimination factors (N=365, multiple choice)

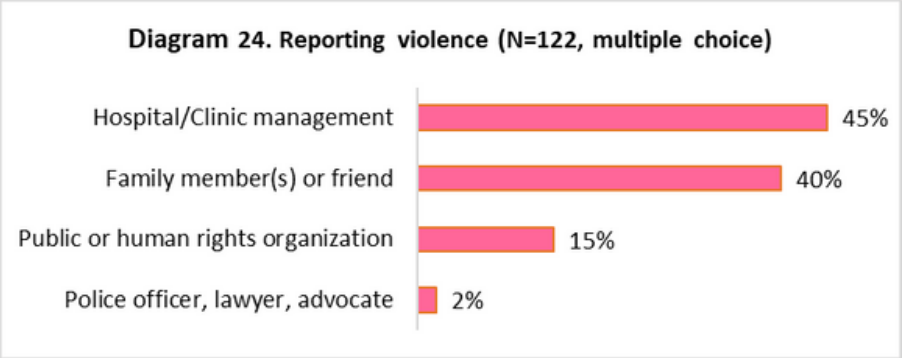


"At the beginning of pregnancy, they insisted I have an abortion, saying "You're old and have AIDS, have an abortion; the child might be born with defects". When I got my maternity card, it had the code "AIDS" written in large red letters. I asked for it to be removed, but they refused, saying it was protocol. After childbirth, I had clots, and the doctors refused to clean them out. They prescribed medications that didn't help, and I had to go to another maternity hospital privately..." (Uzbekistan)

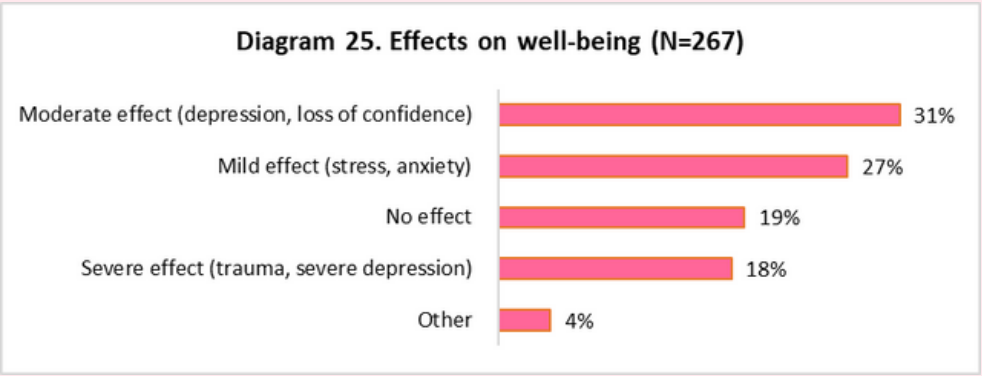
"I was denied medical care because of my HIV status and because I am poor…" (Azerbaijan)

These findings highlight the critical need for healthcare systems to address these multifaceted issues through a holistic, rights-based approach that ensures informed consent, protects confidentiality, and eliminates discrimination and abuse. Integrated service models are essential to meet the needs of women living with HIV and safeguard their dignity, health, and well-being.

Those needs are hard to address if not reported and analysed. Despite having had the experience, only a third of respondents (33%) reported it, out of whom only 30% mentioned that some actions had been taken. In most cases, reports go to hospital/clinic management (45%) and family members or friends (40%), while 15% of cases were reported to a representative of a public or human rights organisation. Only two cases were reported to the police/lawyer. An interesting observation is that, although the reference to organisations is relatively lower, the responsive action is almost the same as when referring to clinics and family members or close friends (Diagram 24).

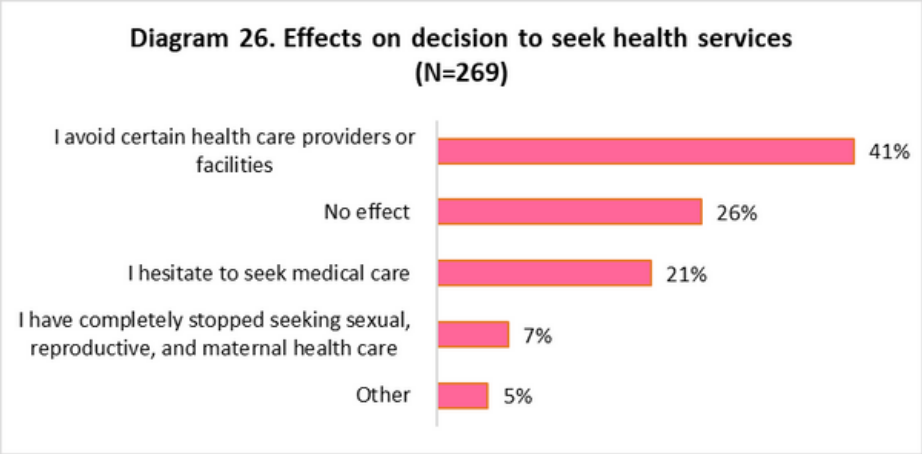


The effects of violence and discrimination on mental and emotional well-being reveal a range of experiences among respondents. 18,7% reported no effect. However, 27,3% noted mild effects, such as stress and anxiety, which highlight the pervasive nature of these experiences. A significant portion, 31,5%, described moderate effects, including depression and loss of confidence, illustrating deeper psychological impacts. Furthermore, 18,4% reported severe effects, such as trauma and severe depression, underscoring the devastating consequences of prolonged or intense exposure to discrimination. Notably, 29% provided additional qualitative responses, which align with the overarching trend that the impact frequently ranges from moderate to severe (Diagram 25).



"Just because I found out about HIV late doesn't mean I'm not human. The negative attitude in the delivery room ruined all my joy about the birth of my child..." (Latvia)

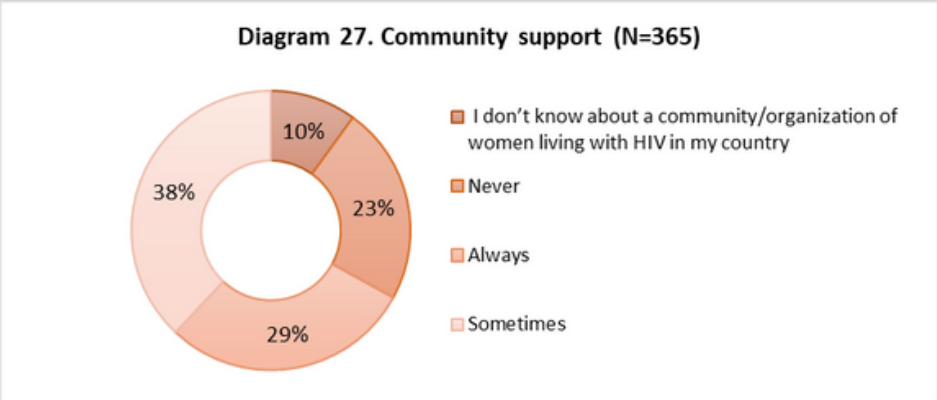
The influence of violence and discrimination on future decisions to seek sexual, reproductive, and maternal health services highlights substantial barriers to care. While 25,7% of respondents indicated no effect on their behaviour, the remaining responses paint a concerning picture. 21,2% expressed hesitation to seek medical care, signalling a breach of trust in the healthcare system. 40,9% stated that they avoid specific healthcare providers or facilities, demonstrating how stigma and discriminatory practices lead to selective disengagement. Alarmingly, 7,1% reported completely ceasing to seek sexual, reproductive, and maternal health services, reflecting the extreme consequences of systemic discrimination. An additional 30% provided qualitative responses, emphasizing diverse, individualized impacts. These findings indicate a critical need for systemic reforms to rebuild trust and accessibility in healthcare services (Diagram 26).



"The way I was treated totally ruined me. I have never gone to any medical service since..." (Tajikistan)

Community support

Support related to pregnancy and childbirth from community organisations of women living with HIV varies significantly among respondents, highlighting both the strengths and gaps in community-led support systems. Approximately 23% of respondents reported never receiving support. On the other hand, 38% indicated that they sometimes received support, and 29% stated they always received support, showcasing the critical role these organisations play for those who can access their resources. Notably, 10% of respondents were unaware of the existence of such communities or organisations in their country, underscoring the need for better outreach and awareness initiatives (Diagram 27).



These findings align with earlier trends, demonstrating that while non-governmental organisations and community groups are highly supportive, their impact is contingent on individuals being able to reach out and engage with them. This mirrors observations that reports of violence and discrimination often elicit high levels of responsive action from non-governmental organisations, rather clinic management and family. It highlights the importance of strengthening referral pathways for women to connect with community organisations, ensuring their needs are addressed effectively and comprehensively.

Insights from Open-Ended Responses

The following statements reflect the severe stigma and human rights violations experienced by respondents of the research. Please be aware that this excerpt may be distressing and triggering.

"After a caesarean section, the nurse told me that I needed to stay in a separate paid hospital ward. However, since I didn't have the financial means, I was transferred to a free private ward. When I asked the nurse why I was being isolated, she said it was because I had an infection..." (Armenia)

"I had a difficult delivery, and there were complications afterward that I needed to treat. The doctor told me it was my fault for not thinking about the consequences with HIV, even though I had prior experience giving birth. She said I would soon die, and my children would be taken away. This caused constant panic attacks..." (Belarus)

"Do abortion, give birth, feed with breast, do not feed with breast… everyone decides instead of you… I was just tired …" (Georgia)

"During my caesarean section, the anaesthesiologist constantly asked questions about my status, like what I had used, why, and how my husband lived with me without being afraid. He mocked me. When an injection was needed, he refused to administer it into my arm, even though my veins were fine, and instead made me strain my neck to inject there, joking, "Why are you scared? You've injected yourself before..." (Kazakhstan)

"At 31 and 32 years old, I was told I was too old to give birth. I was accused of burdening the state by having a child while being HIV positive..."

"Labour didn't start naturally, so they induced contractions with oxytocin and pills (I don't remember the name), constantly reminding me that I contracted HIV and had so many abortions that I should "shut up and wait" for the contractions to begin. After 12 hours with no dilation, following a scandal I caused at the maternity hospital, they took me for a caesarean section..."

"You can't raise a child, they said, because you're a drug addict with HIV and too old..." (Tajikistan)

"Throughout my pregnancy, the doctor at the clinic kept threatening that I would give birth to a child with abnormalities or defects. Even at a late stage, they suggested artificial termination. At the maternity hospital, the doctor simply told my mother, "Your grandchild is fine; she didn't infect him." By then, my husband had already passed away..." (Uzbekistan)

"The doctor who performed my caesarean section was unqualified. She said many unpleasant things about my diagnosis..." (Ukraine)

"I was told I had no right to choose how to feed my child because I was sick..." (Ukraine)

"The health centre doctors refused to perform an abortion. No one came to check on me in the maternity hospital the second time, and eventually, they moved me from the general ward to isolation, where again, no one came to help. I had to seek help from a doctor I was acquainted…" (Tajikistan)

"I was called a dirty gypsy, a drug addict, and was denied help with managing pain..." (Latvia)

"I was denied medical care because of my HIV status and because I am poor…" (Azerbaijan)

"I went to private clinic in Russia, because there was no other mean I could get the service there, but when I returned home, I went to state hospital, I felt humiliated everywhere…" (Azerbaijan)

"At the maternity hospital, they treated me especially badly because of my status and the fact that I had no money..." (Kyrgyzstan)

"They treated me badly, saying I was too old to give birth and questioning why I was having a baby being with HIV…" (Kyrgyzstan)

"In the maternity hospital, syphilis was detected, first HIV, then this…and I faced judgment and humiliation during a conversation with the doctor…" (Moldova)

"Prohibition from going out into the corridor, placement in isolation, and being in a delivery room with the worst conditions having no information about how my kids were… I was really worried as I had been using drugs by then for a long time, doctors say many unpleasant things and threatened … no one paid attention…" (Moldova)

"I heard a nurse say that all drug addicts and people with HIV should be shot. It's terrifying to seek help because it means revealing your status and what's happening in your family, which would lead to the entire town gossiping about you. It's also frightening to think that this could later prevent you from finding a job or lead to other consequences…" (Estonia)

The narratives presented illustrate the profound intersectionality of stigma and discrimination experienced by women living with HIV in healthcare settings. These experiences reveal how overlapping factors such as socio-economic status, gender, ethnicity, substance use, and health conditions compound the harm inflicted during critical moments like childbirth. HIV stigma emerges as a central driver of dehumanizing treatment, from visible identifiers like "AIDS" marked in red letters on medical records to outright refusals of care. Women are disproportionately affected, often stripped of autonomy over their reproductive choices through coerced abortions, forced contraception, or denial of the right to breastfeed. Such actions perpetuate societal beliefs that women with HIV are unworthy of motherhood and reinforce systemic gender inequities.

Structural violence within healthcare systems exacerbates these challenges. Financial barriers push marginalized individuals into substandard care, often isolating them physically and socially. The lack of empathy and ethical care is evident in the degrading remarks, forced procedures, and humiliating treatment described by participants. For example, in Kazakhstan, a patient was mocked and physically mistreated during a caesarean section, reflecting the misuse of power by healthcare professionals. Isolation practices, such as forbidding access to corridors or placing patients in substandard facilities, further stigmatize individuals based on their health status, eroding their dignity and amplifying psychological harm. These institutional practices combine with societal attitudes to create environments where women feel unsafe seeking care, fearing exposure of their status or personal circumstances.

The psychological and emotional consequences of such treatment are profound, leaving individuals with long-term mental health challenges such as panic attacks, depression, and internalized stigma. Many patients describe a loss of agency and pervasive fear of societal exclusion, leading to delays in seeking necessary medical care. These experiences highlight the urgent need for systemic reform to address intersecting forms of oppression. Healthcare systems must prioritize empathy and equity, implementing mandatory training to combat stigma and enforcing anti-discrimination policies. Advocacy efforts must adopt an intersectional approach, addressing not just HIV-related stigma but the broader socio-cultural factors that perpetuate discrimination. Only through such comprehensive reforms healthcare systems can ensure that all women are treated with respect and dignity, regardless of their HIV status.

Recommendations

1. Legal, policy and practice reforms

1.1. Enact and enforce laws explicitly prohibiting obstetric violence, ensuring clear definitions of mistreatment, abuse, and negligence in maternity care, building the knowledge of accountability on violation of rights.

1.2. Establish independent regulatory bodies to monitor and investigate cases of obstetric violence

1.3. Mandate reporting of obstetric abuse cases, with penalties for healthcare providers and institutions found guilty.

1.4. Create anonymous and easily accessible platforms run by community workers, for reporting obstetric violence, such as hotlines, applications or online portals with clear reporting and response mechanisms.

1.5. Offer free legal assistance, counselling, and rehabilitation for survivors of obstetric violence.

1.6. Establish patient ombudsmen or advocates within healthcare facilities to address violations in real time.

1.7. Enable community-led monitoring systems to document abuses and ensure accountability in maternity care.

2. Healthcare system

2.1. Develop clear, evidence-based guidelines for respectful maternity care for women living with HIV including pain management and informed consent.

2.2. Address financial and systemic barriers such as understaffing and inadequate infrastructure that contribute to mistreatment for women living with HIV, who use drugs and sex workers, migrants.

2.3. Ensure that patients are fully informed about medical procedures and have the right to refuse interventions without coercion or threats.

2.4. Respect patients' birth plans and follow up preferences, including the choice of birthing position, pain management, breastfeeding.

2.5. Provide emotional/psychological support to patients throughout pregnancy, delivery and postpartum care.

2.6. Integrate respectful maternity care and anti-stigma training into medical and midwifery curricula.

2.7. Provide regular professional development sessions on patient rights, diversity sensitivity, autonomy and social justice, integrity, confidentiality and access to quality of care.

3. Community engagement & women's empowerment

3.1. Educate the public/community about obstetric violence, patient rights, and respectful maternity care and autonomy through peer educators, community outreach and media campaigns.

3.2. Develop/strengthen paralegals' networks of women living with HIV with particular expertise to address obstetric violence.

3.3. Ensure community of women living with HIV activists' meaningful engagement in policy making related to their health (protocols, standards, guidelines, national SHRH and HIV programming etc).

3.4. Resource community to advocate for systematic change including submissions of alternative/shadow reports to the UN treaty bodies and anti-stigma/discrimination/violence campaigns.

3.5. Facilitate support groups and peer networking for women to share their experiences and provide peer support.

3.6. Train healthcare providers on intersectionality to address vulnerabilities related to ethnicity, socioeconomic status, health conditions, disabilities etc.

3.7. Design community-led interventions for marginalized women to facilitate their access to healthcare, including women living with HIV, women who use drugs, sex workers, violence survivors, women affected by mobility and displacement.

3.8. Equip women with a guidance on navigating insurance, accessing state-funded healthcare, and avoiding exploitative medical costs to advocate for themselves in healthcare settings including against economic violence.

3.9. Address economic barriers to accessing quality maternal healthcare through subsidies or financial aid.

Annexes

Annex 1. Guide for country coordinators on dissemination of the Survey

Guide for country coordinators on dissemination of the Survey
“Obstetric violence against women living with HIV in Eastern Europe and Central Asia”

as part of the regional campaign "No excuse for violence!"

1.Brief introduction of the survey

Community-led research “Obstetric Violence Against Women Living with HIV in Eastern Europe and Central Asia (EECA)” is an initiative of the Eurasian Women's Network on AIDS (EWNA) as part of the regional campaign "No excuse for violence!"

The survey aims to explorethe experiences of women livingwith HIV duringpregnancy, childbirth and the postpartum period, with a focus on obstetric violence. This will help EWNA to design and implement programmes that can better meet the reproductive health and rights needs of women living with HIV.

The survey questions are grouped into 5 categories, covering: filters (checking the selection criteria), socio-demographic characteristics, experience of receiving health services, experience of obstetric violence and discrimination, community support and additions/comments from respondents.

This is an online surveythat can be completed on a computeror mobile device(smartphone or tablet) with internet access.

Participationin the survey is voluntary and anonymous - respondents are not requiredto provide their names or any contact information.

2.Target audience and indicators

With this study, we aim to reach **women* living with HIV**, who have had a pregnancy and childbirth experience in the last 5 (five) years, and who are over the age of 18, from 13 countries in the EECA region: **Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Moldova, Tajikistan, Ukraine or Uzbekistan**.

*Women represent a diverse spectrum of experiences, identities, and socializations, shaped by the intersections of race, class, age, sexual orientation, gender identity, and other factors that influence self-perception and the right to self-identification.

Information on the plannednumber of respondents in each country:

№	Country	Number of Respondents
1	Azerbaijan	20
2	Armenia	20
3	Belarus	30
4	Georgia	20
5	Kazakhstan	20
6	Kyrgyzstan	15
7	Latvia	20
8	Moldova	20
10	Tajikistan	20
11	Uzbekistan	20
12	Ukraine	50
13	Estonia	15

3. Dissemination process

All coordinators will receivea link to the onlinequestionnaire in the language(s) relevantto the country. You will need to disseminate this link to recruit participants of the survey.

It might be usefulto make a dissemination plan, including:

(1) the channels you plan to use (some suggestions are provided below),
(2) list of organisations and social medialchannels to be contacted,
(3) actions.

The survey will run for 2 weeks,from **October 7 to October 20, 2024**. If there are not enough responses, it can be extended by one week.

4. Dissemination channels

There are a number of different channels that you can use to disseminate the survey. Here are a few examples:

- **Listservs** can be used to send information about the researchand a link to the survey directly to people from the target audience you work with.

  The survey can be promotedon your website.

- Information about the survey can be posted on social media, for example general **discussion forums or social media/messengers'** (Facebook, WhatsApp, Telegram, Viber, etc) **groups** where people from your target audience might be active. For example, a forum/group for women living with HIV.

- You can get in touch with other **organisations and groups**, working in the area of family planning (sexual and reproductive health), HIV response or other relevant areas that could support dissemination and ask them to share information on their social media.

- To ensure respondents diversity you can get in touch with the **network/organisation of marginalised communities** – women who use drugs, sex workers, LBT women, as well as youth and HIV service organisations.

- You can collaborate with country officesof **UN Agencies** (UNFPA, UNAIDS, UNDP, UN Women) in order disseminate survey through their channels.

- Another approach would be to **organise meetings, support group and discussions** with HIV-positive women to discuss pregnancy, childbirth and the postpartum period. At the end of the meeting, the participants will be asked to fill in the questionnaire and you can support them by providing clarifications, where necessary. When the meetingis face-to-face, make sure that all participants have access to electronic deviceswith internet connection and if needed, provide temporary access to such devices (tablets, smartphones, laptops, computers).

- It is also possible to disseminate the survey by contacting people **on the phone or face-to-face**. This might be helpful if you are concerned that people from your target group do not have access to internet, have limited computer literacy or may need support with understanding or filling the survey.

5. How to spark interest to a Survey

Some suggestions on how to present the information and generate interestonline:

- Use simple messagesand visually appealingimages
- Create posts that will appeal to you audience.
- Create some posts a few days before the start of the survey to create interest: "*A new study on obstetric violence experienced by women living with HIV is launching soon. Stay tuned for more details or visit our website for further information".*

- You might want to stress on the potential benefits from the survey, for example, improved access to reproductive health services for women living with HIV.
- EWNA Communication Officer will propose some options that you can use for survey dissemination.

6. Supporting participants with completing the questionnaire

Some people may need support with filling in the questionnaire, for example due to issuesrelated to access to internet, computer literacy, accessibility of information or other. You can support them in different ways, including:

- providing a devicewith internet connection for them to complete the questionnaire,
- assisting them in filling in the online version – by explaining and clarifying the questions, if needed, or marking their answers online for them.
- providing a paper version of the questionnaire for them to complete,
- assisting with completing the paper version.

Since this is an online survey, if there are any paper copies of the questionnaire completed, you will need to transfer the information in the online survey.

Please, note that the paper version is only to address any access issues.Where possible, the questionnaire should be completed directly online.

7. Monitoring of the sample

During the data collection (fieldwork) period, we will contact you every 2-3 days to inform/update the response rates in each country.

If you have questions, feel stuck or need help, feel free to contact ***Medea Khmelidze*** medeakhmelidze@gmail.com and ***Lyubov Vorontsova*** vorontsova.kz13@gmail.com

Annex 2. Invitation to participate in the Survey

INVITATION

We invite you to participate in the community-led research “Obstetric Violence Against Women Living with HIV in Eastern Europe and Central Asia (EECA)”. This study aims to understand the experiences of women living with HIV during pregnancy, childbirth, and postnatal care, with a focus on obstetric violence.

The survey contains various questions in which you are asked to share your experience of receiving medical services during pregnancy, childbirth and the postpartum period as a woman living with HIV.

Your answers will help us to design and implement programmes that can better meet the reproductive health and rights needs of women living with HIV.

The study is organised by the Eurasian Women’s Network on AIDS (EWNA) as the part of women-led regional campaign "No excuse for violence!"

Filling in the questionnaire takes about 15 minutes. Your participation in this survey is anonymous and voluntary. You can stop the survey at any time.

More information about this research, how we process the collected data and how we protect your privacy can be found below in the Information Letter for participants in the study.

If you have questions on the study, please contact the researcher at the following e-mail address: medeakhmelidze@gmail.com.

To participate in this survey:

- You need to be 18 years or older
- You need to be a Woman Living with HIV and aware of your HIV-positive status before or during your most recent pregnancy
- You need to have childbirth experience within the past 5 (five) years
- You need to reside in the following EECA countries at the time of your last childbirth: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Moldova, [redacted] Tajikistan, Ukraine or Uzbekistan.

* Women represent a diverse spectrum of experiences, identities, and socializations, shaped by the intersections of race, class, age, sexual orientation, gender identity, and other factors that influence self-perception and the right to self-identification.

We thank you in advance for your time and participation.

Annex 3. Information letter for participants in the Study

INFORMATION LETTER FOR PARTICIPANTS IN THE STUDY

Below you can find more information about the study “Obstetric Violence Against Women Living with HIV in Eastern Europe and Central Asia”. Should you have any questions after reading this document, the researchers are happy to answer any of your questions. You can also download this document to read the information again.

Why do we study obstetric violence against women living with HIV?

The results of this study will therefore contribute to the development of recommendations for strengthening health systems and community services in support to inclusive and non-discriminatory sexual and reproductive health policies and programmes.

Who is conducting this research?

The study is organised by the Eurasian Women's Network on AIDS (EWNA, https://ewna.org/about-us/). EWNA research team is Data Controller and Data Processor, collects the online responses submitted through smartphones, tablets or computers, analyses and reports on the data.

Am I obligated to participate?

Your participation in this survey is entirely voluntary. The non-participation will not cause any harm to you. You can withdraw your consent at any time.

What will happen with my data?

The research data will only be used for scientific, educational or statistical purposes, and to produce recommendations for strengthening health systems and community services in support to inclusive and non-discriminatory policies and programmes on sexual and reproductive health of women living with HIV in the Eastern Europe and Central Asia region. All answers will be processed into documents, reports or publications (in scientific journals or conferences) about the study, in which no individual answers can be identified. Your participation in this survey is entirely confidential. Ensuring confidentiality, however, implies that it will not be possible to change, look at or delete your data afterwards.

How is my personal data protected?

EWNA adheres to the United Nations “Personal Data Protection and Privacy Principles” adopted by the UN High-Level Committee on Management (HLCM) on October 11, 2018. Your participation in this survey is entirely confidential. The researchers do not know your name, nor your address details. The researchers adhere to the provisions of the legislation on data.

Will I be compensated for my participation in this research?

We do not pay money for your participation in the survey.

Where can I go with questions about the research?

Should you have questions, remarks or complaints about the survey, you can get in contact with the researcher Medea Khmelidze at the following e-mail address: medeakhmelidze@gmail.com.

Annex 4. Informed consent

INFORMED CONSENT

I herewith declare that, as participant of the women-led research “Obstetric Violence Against Women Living with HIV in Eastern Europe and Central Asia”:

1. I have read and understood the information letter for participants. I have been informed about the nature, duration and purpose of the research and about what is expected of me.
2. I was offered the opportunity to obtain additional information.
3. I understand that participation in the research is voluntary. I know I can withdraw my participation at any time without having to justify this.
4. I authorize the researchers to store my answers in a confidential way so that these data can be reused for future research and education.
5. I authorize the researchers to process and report my results in a confidential way.
6. I am aware that I can contact the EWNA employee for more information about the protection of my data.
7. Since completing the questionnaire is completely confidential, I do not have the possibility to change, review or delete my data afterwards.

By ticking this box, I agree with the above mentioned, give my consent and wish to participate in the study:

Yes

Annex 5. Survey questionnaire

Questions	Answers
0. Selection	
0.1. Which of the following countries di you live in while you received medical services related to your last pregnancy, childbirth, and postnatal care?	1. Azerbaijan 2. Armenia 3. Belarus 4. Georgia 5. Kazakhstan 6. Kyrgyzstan 7. Latvia 8. Moldova 10. Tajikistan 11. Uzbekistan 12. Ukraine 13. Estonia 14. Other. End survey. Unfortunately, the survey is only for those residents in the above-mentioned countries. Thank you for your interest.
0.2. How old are you?	1. Under 18: End survey. Unfortunately, this survey is only for adults aged 18 or above. 2. 18-24 3. 25-34 4. 35-44 5. 45 and over
0.3. Your experience of living with HIV	1. I am a woman living with HIV 2. I do not know my HIV status. End survey. Unfortunately, this survey is only for women living with HIV. Thank you for your interest. 3. I am an HIV-negative woman. End survey. Unfortunately, this survey is only for women living with HIV. Thank you for your interest.
0.4. Your childbirth experience	1. I have given birth to a child(ren) in the last 5 (five) years 2. I have NOT given birth to a child(ren) in the last 5 (five) years. End survey. Thank you for your interest.
0.5 Knowledge of HIV status before or during the last pregnancy	1. I knew I was HIV positive before my last pregnancy 2. I learned I was HIV positive during my last pregnancy or birth 3. I did NOT know I was HIV positive before or during my last pregnancy or childbirth. End survey. Thank you for your interest.
1. Socio-demographics	
1.1. What is your highest degree of education?	1. No formal education 2. Primary education 3. Secondary or secondary technical education 4. Higher (or incomplete higher) education
1.2. How would you describe your employment? Select all that apply.	1. Unemployed 2. Self-employed 3. Employed in the private sector 4. Employed in the public sector 5. Employed in the non-governmental sector 6. On maternity leave 7. Student

	8. Retired due to health reasons 9. Other (please specify) _____
1.3. What best describes your relationship status? Select all that apply.	1. I am not in a relationship. Go to question 1.5. 2. Currently in a relationship but we do not live together 3. Currently in a relationship and live together 4. Widowed 5. Divorced or separated 6. Other (please specify) _____
1.4. If you are in a relationship, what is the status of your relationship?	1. Legally or formally married 2. Living with in a consensual union/partnership without official registration
1.5. How would you describe your economic situation?	1. Not at all well-off 2. Not very well-off 3. Moderately well-off 4. Quite well-off 5. Very well-off
1.6. How many children do you have?	1. No children 2. 1 child 3. 2 children 4. 3 children 5. 4 or more children
1.7. Were you able to make your own decisions whether to have children, and if so, when to have them?	1. Yes, I could 2. No, I couldn't
1.8. Which intersectional characteristics apply to you? Select all that apply.	1. I had/have an experience of drug use 2. I was/am a sex worker 3. My sexual partner injects/uses or has injected/used drugs 4. I am a client of opioid substitution therapy programme 5. I have been in a prison 6. I have been in a pre-trial detention centre or temporary detention facility 7. I live with a disability 8. I have or have had active tuberculosis 9. I have or have had hepatitis C 10. I am/was exposed to domestic violence 11. My child has special needs (lives with disability) 12. I migrated from one country to another for economic reasons 13. I migrated from one country to another for political reasons 14. I am lesbian, bisexual or queer 15. I am an internally displaced person 16. I was/am homeless 17. None of the above
2. Experience of receiving health services	
2.1. How often did you visit a healthcare facility during your last pregnancy?	1. Never / Contacted a medical facility already in labour 2. Once or twice 3. Three or four times 4. Five or more times
2.2. Where did you give birth to your last child or receive pregnancy-related services?	1. Public hospital 2. Private hospital 3. I gave birth at home 4. Other (please specify) _____

2.3. Who paid for medical services related to pregnancy and childbirth?	1. Myself (from my own or family budget) 2. Covered by the state/state insurance 3. Covered by private insurance 4. NGO support/fundraising 5. Covered from various sources
2.4. How satisfied were you in general with the medical services you received in connection with pregnancy and childbirth?	1. Very satisfied 2. Satisfied 3. Neutral 4. Dissatisfied 5. Extremely dissatisfied
3. Experiences of obstetric violence and discrimination Please recall whether you experienced the following types of violence from healthcare workers during your last pregnancy and/or childbirth and/or postpartum period?	
3.1. Verbal abuse (as part of psychological abuse). Select all that apply.	1. Shouting 2. Insults 3. Humiliation 4. Accusations 5. Threats 6. Other (please specify) _____ 7. None of the above
3.2. Psychological abuse. Select all that apply.	1. Intimidation 2. Requiring to do cleaning of a hospital room or place of stay yourself 3. Pressure to perform any procedure without justified reason 4. Ignoring requests for help 5. Isolation 6. Other (please specify) _____ 7. None of the above
3.3. Physical abuse. Select all that apply.	1. Slapping in the face 2. Hitting or slapping parts of the body 3. Rough handling 4. Pushing the fetus out during contraction (fundus pressure technique) 5. Roughly spreading the legs 6. Forcing to take a certain position for childbirth 7. Other (please specify) _____ 8. None of the above
3.4. Unconsensual medical procedures (procedures for which you did NOT give verbal or written consent). The exception is emergency situations when the life of a woman and/or fetus is at risk and the woman is unconscious. Select all that apply.	1. Perineotomy/Episiotomy (cutting the area between the vaginal opening and the anus (back passage)) 2. Application of obstetric forceps to extract the fetus 3. Caesarean section (cutting the abdomen and uterus to remove the baby) 4. Amniotomy (forced rupture of the amniotic sac) 5. Application of prostaglandin gel to the cervix to induce labour 6. Using injections or vaginal tablets to induce labour 7. Surgical sterilization (medical procedure that prevents a person from having children in the future) 8. Insertion of an intrauterine contraceptive device 9. Other (please specify) _____ 10. None of the above
3.5. Breach of confidentiality/disclosure of HIV status/transfer of information about my health to third parties without my consent.	1. Family member(s) 2. Other healthcare provider 3. Sexual partner 4. Insurance agent 5. Other (please specify) _____

Select all that apply.	6. None of the above
3.6. Have you ever been denied certain medical procedures and/or services? Select all that apply.	1. Abortion (medical (pills), surgical) 2. Coagulation of the cervix (using heat to treat the outer surface of the cervix) 3. Pain relief/management 4. Postnatal depression assessment and support 5. Breastfeeding support (i.e., discouraging breastfeeding rather than making informed choices) 6. Pelvic floor health (helps strengthen muscles weakened by pregnancy and childbirth, reducing the risk of urinary incontinence) 7. Contraception (protection against unwanted pregnancy) 8. Postnatal complications management 9. Other (please specify) _____ 10. None of the above.
3.7. If you have experienced any form of violence (listed above), who did it (was the abuser)? Select all that apply.	1. Chief physician/Head of department 2. Physician 3. Nurse/midwife 4. Orderly (nursing assistant) 5. Administrative staff 6. Technical staff 7. Social worker 8. Other (specify) _____ 9. I have not been subjected to obstetric violence
3.8. In your opinion, on what basis was discrimination carried out in the medical institution? Select all that apply.	1. HIV status 2. Age 3. Ethnicity 4. Socioeconomic status 5. Sexual orientation 6. Gender identity 7. Experience with drug use 8. Experience with sex work 9. Presence of diseases/co-infections (e.g., viral hepatitis C, tuberculosis) 10. Migration status 11. Belonging to the rural population 12. Place of residence/registration/no registration 13. Other (specify) _____ 14. I find it difficult to answer. Go to question 4.1 15. I have not been discriminated. Go to question 4.1
3.9. Please explain your answer to question 3.8. In what ways did you experience discrimination?	
3.10. If you have experienced any form of obstetric violence and/or discrimination, have you reported it to anyone?	1. Yes 2. No. Go to question 3.13
3.11. If yes, whom did you report it to?	1. Hospital/clinic management 2. Family member(s) or friend 3. Police officer, lawyer, advocate 4. Representative of a public or human rights organisation 5. Other (specify) _____
3.12. Were any actions taken as a result of your report?	1. Yes 2. No

	3. Not sure / I don't know
3.13. Has violence/discrimination caused harm to your health or foetus?	1. Yes 2. No 3. Not sure / I don't know
3.14. How has violence/ discrimination affected your mental and emotional well-being?	1. No effect 2. Mild effect (e.g., stress, anxiety) 3. Moderate effect (e.g., depression, loss of confidence) 4. Severe effect (e.g., trauma, severe depression) 5. Other (please specify) _____
3.15. How has violence/ discrimination influenced your decision to seek sexual, reproductive and maternal health services in the future?	1. No effect 2. I hesitate to seek medical care 3. I avoid certain healthcare providers or facilities 4. I have completely stopped seeking sexual, reproductive, and maternal healthcare 5. Other (please specify) _____
4. Community support and feedback/additions	
4.1. Have you received any support related to pregnancy and/or childbirth from the community/organisations of women living with HIV in your country?	1. Never 2. Sometimes 3. Always 4. I don't know about a community/organisation of women living with HIV in my country
4.2. Would you like to share any additional comments or experiences related to obstetric violence as a woman living with HIV?	
Thank you for participating in this survey. Your answers will contribute to understanding and solving the problem of obstetric violence in EECA countries. In solidarity, Eurasian Women's Network on AIDS	

Eurasian Women's Network on AIDS

www.ewna.org