OBSTETRIC VIOLENCE AGAINST HIV-POSITIVE WOMEN IN UKRAINE



BACKGROUND INFORMATION

According to the WHO data, almost one in four women has <u>experienced violence during</u> <u>pregnancy</u>, <u>childbirth and the postpartum period in healthcare facilities</u> – the so-called obstetric violence, which can manifest itself in any actions taken against the will of the woman in labour.

SUCH ACTIONS CAN TAKE THE FORM OF:

- physical abuse (<u>Kristeller's procedure</u> or the fundal pressure technique, roughly spreading the legs, forcing a woman to a certain birthing position, etc.)
- humiliation, shouting, accusations and threats;
- moral pressure for the purpose of inducing labour (by rupturing the amniotic sac, applying synthetic prostaglandin gel to the cervix, etc.) for no justified reason;
- obstetric manipulations without prior written informed consent of the woman in labour and the presence of appropriate indications (introduction of epidural anaesthesia, episiotomy, amniotomy, caesarean section, etc.);
- 5 violation of privacy and confidentiality during the provision of medical care, etc.

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. Women living with HIV face multiple stigma due to their HIV-positive status.

Currently, there is no legislative regulation in Ukraine to prevent obstetric violence against women living with HIV, and the only legal acts regulating the provision of medical care to pregnant women living with HIV are the Order of the Ministry of Health of Ukraine, the Ministry of Education and Sciences of Ukraine, the Ministry of Family, Youth and Sports of Ukraine, the State Department of Ukraine for the Execution of Sentences, the Ministry of Labour and Social Policy of Ukraine dated November 23, 2007 No. 740/1030/4154/321/614a "On Measures to Organise Prevention of Mother to Child Transmission, Medical Care and Social Support of HIV-infected children and their families", as well as Evidence-based Clinical Guidelines on Prevention of Mother to Child Transmission and Standards of Medical Care "Prevention of Mother to Child Transmission", approved by Order No. 692 of the Ministry of Health of Ukraine dated April 26, 2022.

In order to advocate for reinforcing and making appropriate amendments to the regulatory and legal framework of Ukraine and guaranteeing the rights of women living with HIV to sexual and reproductive health, in May-June 2023, the CO "Positive women" conducted a survey among 104 women living with HIV in Ukraine regarding their experience of obstetric violence during the past 2-3 years. The survey findings formed the basis of this analysis, which was carried out with the support of the International Charitable Foundation "Alliance for Public Health" as part of the "STEP-UP Training Academy 2022/2023" project, funded by Gilead.

GOAL AND OBJECTIVES

THE GOAL OF THIS ANALYSIS IS:

to form an evidence base for advocating at the legislative level against obstetric violence against women living with HIV in Ukraine and ensuring their rights to sexual and reproductive health.

THE OBJECTIVES OF THIS ANALYSIS ARE:

- to identify the main forms (manifestations) of obstetric violence against women living with HIV in Ukraine;
- to study the existing national legislation and global best practices on overcoming obstetric violence against women living with HIV;
- to provide recommendations to CSOs and government agencies on preventing obstetric violence against women living with HIV in Ukraine.

METHODOLOGY

This policy brief is limited to the data received in response to the feedback questionnaire developed by CO "Positive women" and distributed among women living with HIV in Ukraine in May-June 2023.



FEEDBACK QUESTIONNAIRE

The questionnaire as a documentation tool contains 17 questions concerning:

1 information about the respondents (name, age, oblast and place of residence);

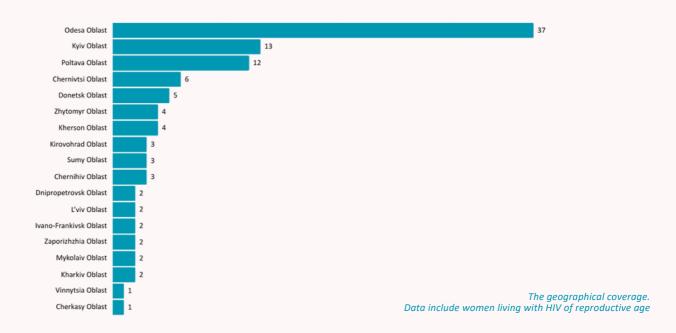
- cases of refusal to provide services in the field of obstetrics and gynaecology in a healthcare institution due to HIV-positive status (including demanding payment and
- **2** healthcare institution due to HIV-positive status (including demanding payment and blackmailing for the provision of free medical services);
 - cases of improper provision of services in the field of obstetrics and gynaecology in a healthcare institution due to HIV-positive status (for example: disclosure of HIV-
- **3** positive status both among the respondent's inner circle and among the medical staff, and its impact on further medical support; failure to give informed consent when placing on "D" account);
- consequences of refusal to provide or improper provision of medical services for the health of the respondent and/or her child;
- other disparaging, discriminatory or offensive situations that occurred during the provision of services in the field of obstetrics and gynaecology.

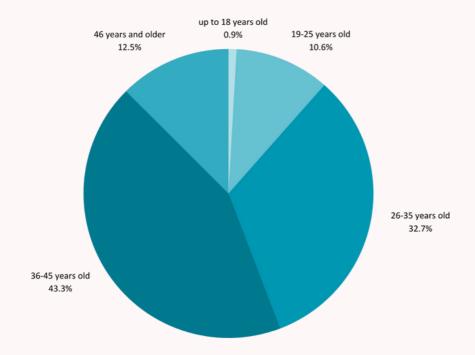
The survey was conducted by regional representatives of the CO "Positive women".



DATA LIMITATIONS

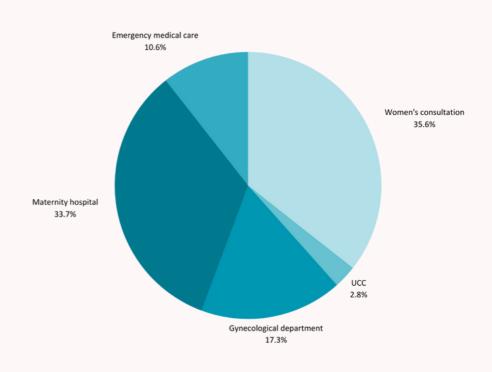
The data has limited geographic coverage (Vinnytsia Oblast, Zaporizhzhia Oblast, Dnipropetrovsk Oblast, Donetsk Oblast, Ivano-Frankivsk Oblast, Zhytomyr Oblast, Kyiv Oblast, Kirovohrad Oblast, L'viv Oblast, Mykolaiv Oblast, Odesa Oblast, Poltava Oblast, Sumy Oblast, Kharkiv Oblast, Kherson Oblast, Cherkasy Oblast, Chernivtsi Oblast, Chernihiv Oblast). Women living in the temporarily occupied Luhansk Oblast and Crimea did not participate in the survey. Half of the total number of respondents live in the Zaporizhzhia, Dnipropetrovsk and Oblasts. Most respondents live in oblast centres (70.2%).





Breakdown by the respondents' age

Violations of the rights of women living with HIV in the field of obstetrics and gynaecology were documented in such healthcare facilities as: women's consultation, gynaecology department, maternity hospital, emergency medical care and urgent care centre (UCC).



Breakdown by healthcare facility where cases of obstetric violence were documented

ANALYSIS OF CASES OF OBSTETRIC VIOLENCE AGAINST WOMEN LIVING WITH HIV IN UKRAINE

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). The actions of medical staff in relation to their patients may contain elements of a crime sufficient to bring to criminal responsibility.



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.)



"Many women experience disrespectful and abusive treatment during childbirth in facilities worldwide. Such treatment not only violates the rights of women to respectful care, but can also threaten their rights to life, health, bodily integrity, and freedom from discrimination... To achieve a high standard of respectful care during childbirth, health systems must be organized and managed in a manner that ensures respect for women's sexual and reproductive health and human rights"

WHO Statement, 2015

Until recently, the issue of obstetric violence was not given due attention. Only since 2015, when the World Health Organisation (WHO) published its <u>statement</u>, the problem of obstetric violence has gained global publicity.

In addition, the WHO has <u>identified</u> the specific vulnerability of women living with HIV to contemptuous and discriminatory treatment during pregnancy, during and after childbirth. For example, women living with HIV are 7-8 times more likely to die during childbirth and postpartum period than HIV-negative women; and networks of women living with HIV have documented many cases of stigmatising and discriminatory treatment (including forced sterilization) in about <u>40 countries</u>.

However, unfortunately, the issue of obstetric violence, especially with regard to women living with HIV, is still not on the agenda of Ukrainian decision-making bodies. Meanwhile, the consequences of obstetric violence are grave and long-lasting both for the woman herself and her child, as well as for the entire healthcare system, in particular, the experience of obstetric violence generally deters a woman from addressing to healthcare institutions both for obstetrics and gynaecology services, and for issues related to ensuring adherence to antiretroviral therapy.

Among the consecutive consequences of obstetric violence, the following can also be named:

- Increased risk of premature labour;
- Loss of productivity, as well as physical, emotional and psychological consequences for the patient;
- Loss of general trust in the healthcare system and distancing from any healthcare providers due to fear of being subjected to violence again;
- Reduction in the effectiveness of the program on prevention of mother to child transmission.

The findings of the survey conducted by the CO "Positive women" among 104 women living with HIV in Ukraine regarding their experience of obstetric violence over the past 2-3 years indicate that women living with HIV were denied of or improperly provided with medical services, primarily due to their HIV-positive status.

In particular:



DENIAL TO PROVIDE OBSTETRICS AND GYNAECOLOGY SERVICES IN A HEALTHCARE INSTITUTION DUE TO HIV-POSITIVE STATUS

This section includes extracts from the respondents' citations, which were initially provided in Ukrainian or Russian. In this version of the Policy Brief, for the readers' convenience, they were translated into English



"The doctor read it on my B-20 medical referral and said to my mother that I had AIDS and they couldn't help me with anything"

"Refused to consult! They said that <u>people like me</u> <u>should be treated by our doctors!"</u>

"They insisted that I change the maternity ward and not give birth in their clinic. <u>So as not to spoil their statistics</u>"

"At first, they didn't want to do a caesarean section in the maternity ward, it took two days for the doctor who admitted me to do it. They constantly kept one in the box, gave injections and dragged out the time. When the staff learnt about my HIV status, they refused to give me injections, I gave them to myself"

28.8% of respondents (30 women) noted that they had been denied surgical intervention, including abortion, due to their HIV-positive status. **26.9**% of respondents (28 women) indicated that they had been denied giving birth due to their HIV-positive status.

31.7% of respondents (33 women) were denied counseling services during pregnancy, childbirth and/or the postpartum period, and **12.5%** of respondents (13 women) were denied laboratory diagnostic services due to their HIV-positive status.



The denial to provide obstetrics and gynaecology services was also predetermined by the demand to pay for such services, which according to the law should be provided free of charge.

44.4% of respondents (46 women) noted that they had been asked to pay for the provision of actually free medical services, referring to the patient's HIV-positive status, in particular, 47.8% of them (22 women) had been asked to pay for surgical intervention (including abortion), 23.9% of them (11 women) – for childbirth management, 17.4% of them (8 women) – for providing laboratory diagnostic services, and 10.9% of them (5 women) – for providing medical advice.



"The doctor gave a categorical recommendation to stay in a separate ward, for which she <u>demanded payment of funds not to the balance (account) of the hospital</u> and without specifying the purpose of payment"

"I was denied a free abortion referral and was sent to the gynaecological department, where I was offered an abortion for 4,500 hryvnias"



One of the respondents also noted that she had been forced to sign a consent to pay for additional medications and consumables without which she would not be admitted to the department, although all this is included in the package of services guaranteed by the state during childbirth (Area 28 "Medical assistance during childbirth" of the Medical Guarantees Program in 2023) and are free of charge (and have also been free of charge for the past 2-3 years). Accordingly, the National Health Service of Ukraine pays hospital for each delivery, and the patient does not have to pay any charitable or other contributions when admitted to the maternity ward.

Doctors often manipulate and increase the prices of medical procedures and interventions, learning about the patient's HIV-positive status and justifying this by the need to buy additional antiseptics and pay extra to the medical staff for the risk of working with HIV-positive women, or they "advise" to look for a clinic that will agree to work "with such patients".



DISCLOSURE OF HIV-POSITIVE STATUS AMONG THE RESPONDENT'S INNER CIRCLE AND ITS IMPACT ON FURTHER MEDICAL SUPPORT



"The partner told our other acquaintances and friends about my HIV status and <u>blackmailed me"</u>

"...get out of here and don't come back, <u>you are going to infect us"</u>

"My mother told my sister that I was HIV-positive when I was first diagnosed, she (mother) was frightened by this, and even gave me personal towels and set a schedule when one of us would take turns in the bathroom, not knowing the ways of transmission and nothing about HIV at all"

"The doctor simply told my parents that <u>I cannot give</u> <u>birth</u> as I have such a diagnosis, because the child will be sick and afterwards will die"

Thus, **70.2**% of all respondents (73 women living with HIV) reported the fact that medical personnel disclosed their HIV-positive status to their inner circle, namely:

24% of respondents (25 women living with HIV) noted that their HIV-positive status was disclosed to their partners; 12.5% of respondents (13 women living with HIV) — to their parents; 6.7% of respondents (7 women living with HIV) to their siblings, and 26.9% of respondents (28 women living with HIV) — to other relatives.

99

More than half of them (56.2%) noted that such disclosure had an impact on further medical support and provision of services related to pregnancy, childbirth or the postpartum period. Two women noted that HIV-positive status disclosure was carried out to force an abortion.



DISCLOSURE OF HIV-POSITIVE STATUS AMONG THE MEDICAL PERSONNEL AND ITS IMPACT ON FURTHER MEDICAL SUPPORT



"Arriving at the maternity hospital, I got to the department. <u>About an hour later, all the medical workers knew about my HIV status"</u>

"A nurse in the middle of the street shouted:"Where does a woman with AIDS live here?!"

"The medical staff insisted that I have an abortion, that I don't need a second child, that I won't be able to cope because I can neither hear nor speak. I refused to have an abortion. Then they told my partner, who does not live with us, to convince me to get rid of the pregnancy"

More than half of respondents, namely **54.8%** (57 women living with HIV), indicated that their HIV-positive status was disclosed to medical personnel without their consent that in case of **72%** of respondents negatively affected their further medical support.





FAILURE TO PROVIDE INFORMED CONSENT WHEN PLACING ON "D" ACCOUNT

It was recorded that **61.5**% of respondents (64 women living with HIV) had not been asked for informed consent when being placed on "D" account, had not been provided with additional explanations and/or the right to withdraw the given consent had not been stipulated.



According to the survey findings, the main manifestations (forms) of obstetric violence against women living with HIV in Ukraine are as follows (it is important that they are not mutually exclusive):



Physical abuse against women due to their HIV-positive status during the provision of obstetrics and gynaecology services

5.8% of respondents (6 women) stated that they had experienced physical abuse during pregnancy and/or childbirth due to their HIV-positive status.

Doctors, learning about the patient's HIV status, delayed the provision of emergency medical care, forced her to endure physical pain, refused hospitalization in the event of respective indications, beat patients, performed manipulations, causing intentional pain to both the HIV-positive patient ("get ready, we will conduct an examination with an iron mirror") and her child.



"When I didn't have the money to pay, the nurse who bandaged me and treated the wound <u>deliberately hurt</u> me and said she didn't want me to get AIDS"

"I was not transferred from the ward to the delivery room until the last minute, I went out myself and waited in the corridor, my water had already broken, an enema was given, but they were not transferred to the delivery room"

"When they gave the injections... they hurt a lot"

"The doctor hinted at an additional payment, since I am HIV positive and I reminded that childbirth is free, for which he took revenge on me and sewed me up so that the scars were very large and not aesthetic, they took a long time to heal and brought very strong discomfort, including during sexual intercourse act"



Cases of contemptuous, discriminatory and offensive treatment of women due to their HIV-positive status during the provision of services in the field of obstetrics and gynaecology

Hardly every woman living with HIV who took part in the survey had experienced psychological and emotional violence on the part of medical personnel because of her HIV-positive status. Thus, the following manifestations of violence were common: placement in a separate ward (isolator) with worse conditions and away from other women giving birth, often in a basement with posters about AIDS as a plague of the 20th century; forcing to visit the bathroom and shower separately from other women in labour; the use of several pairs of gloves by the doctor during the examination; labelling of containers with tests (inscription with diagnosis); HIV-positive patients were the last to be admitted for examinations; gossiping about the patient's status; avoiding and refraining from touching the patient and carrying out the necessary manipulations; refusing elementary requests during childbirth and the postpartum period; refusing to inform before carrying out any manipulations ("it is not in your position to ask questions. You must do what is said"); shaming and denying the right to give birth to "people like you" ("began to tell me that "in my situation, with a positive status, I should stop family planning, because children would suffer having such a parent and their future would not be stable").

3

Obstetric manipulations without obtaining the prior written informed consent of the woman in labour and the presence of appropriate indications



"She (paediatrician) started swearing that I didn't warn about my HIV status", and "she (paediatrician) "took the baby without gloves". I felt humiliated and unprotected all the time, starting at the perinatal centre, I had to tell the doctors that I was not contagious because I was on ART and had an undetermined viral load, that I was not a threat to the doctors during their work"

"Doctor, in front of my mother, said that with my status I need to go to some other place, and not to the ordinary women's consultation"

"All the nurses knew about my HIV status, and later they did not want to give me injections. During the delivery, the midwife, whose glove was damaged, discussed it with the nurse next to me, as if I were not there, that it was terrible and that she might get infected. I felt quilt and shame"

"It was terrible when you came with a child, and <u>they were</u> <u>looking at you like the plague of the 20th century</u>... This is a trauma, probably for the rest of my life"

"It was insulting that being a person like all others <u>I was</u> treated like some kind of animal"

"I felt <u>like I was in a zoo"</u>

Despite the fact that the respondents, above all, pointed to situations of contemptuous treatment in healthcare institutions in connection with their HIV-positive status, the cases of obstetric manipulations (in particular, taking histology) without patient's consent were also documented. Thus, one woman noted that "in the sixth month of pregnancy, I was forced to have an abortion", and after the surgical intervention, "I was forced to go to the ward on my own". Or the medical personnel blackmailed a woman with criminal charges if the latter refused to sign a consent for certain obstetric and gynaecological manipulation.

It is worth noting that obstetric violence caused serious health consequences for 33.7% of respondents (35 women living with HIV) and/or their child. In particular, the following was mentioned: the death of a child; deterioration of health; untreated diseases; secondary infertility; psychological trauma; chronic pain; fear and delay in registering for subsequent pregnancies, family breakup, etc.



Some respondents noted that they stopped going to doctors, including gynaecologists, being ashamed of their status and fearing the repetition of stigmatizing attitudes and discriminatory treatment.



"The first examination by a gynaecologist in the maternity ward, during registration, ended with pain and short-term bleeding, because she (the gynaecologist) used a mirror that was too large, thereby injuring me, and I was pregnant... During the caesarean section, one of the doctors put a lot of pressure on my stomach (I still do not understand the reasons for this); fearing for the child and because I had nothing to breathe, I asked him not to do so; as a result, the child was born with congenital stridor"

- "I was literally driven into depression, and it was very difficult to get out of it"
- "I won't be able to get pregnant again"
- "My sick child remained in the hospital, and I was put on the street, the child died"
- "For a very long time I was depressed because of being sick. They told me that this is how the Lord was punishing me. As people started pointing fingers at me, I stopped going out at all, neighbours and relatives tried to avoid me. It took me a lot of time to come out of this state and I suffered a lot of damage moral, psychological, material, emotional, etc"
- "I had to pay 3 thousand hryvnias for the procedure. I had a feeling of being dirty and having no right to receive the same help as all other women in that institution"
- "I had a psychological breakdown, shame. I silently did what the doctors said, even what I disagreed with, because I was afraid that they would blame me for taking me with HIV"

REVIEW OF THE CURRENT LEGISLATION OF UKRAINE AND THE GLOBAL BEST PRACTICES ON OVERCOMING OBSTETRIC VIOLENCE AGAINST WOMEN LIVING WITH HIV

The current legislation of Ukraine does not contain a separate legal act aimed at the care and support of women living with HIV during pregnancy, childbirth and the postpartum period. This issue is regulated exclusively within the framework of the programme for the prevention of mother to child transmission of HIV, namely: Evidence-based Clinical Guidelines on Prevention of Mother to Child Transmission and Standards of Medical Care "Prevention of Mother to Child Transmission", approved by Order No. 692 of the Ministry of Health of Ukraine dated April 26, 2022. Thus, Standard 3 "Medical assistance to HIV-positive women during pregnancy, childbirth and the postpartum period" enshrines the right of HIV-positive pregnant women to "access to

high-quality prenatal medical care during pregnancy and to the use of effective medical technologies of PMTCT". All provisions of the Standard are written in such a way as to, first of all, minimize the risk of HIV transmission to the child (as well as the death of the mother and child from TB) during pregnancy, childbirth and in the postpartum period – through such measures as "adherence to ART by an HIV-positive woman after childbirth, assessment of the state of mental health of the woman and help in the case of postpartum depression, review of the plan of contraception in the postpartum period and psychosocial assistance to the woman". It is worth noting that according to the data of the Public Health Centre of Ukraine, in 2022, the frequency of mother to child transmission of HIV in Ukraine was 1.6% (21 children).



At the same time, the legal framework does not contain provisions for the protection of sexual and reproductive rights of women living with HIV, emphasis on respect for life, dignity and rights of a pregnant woman living with HIV, in particular the right to receive full and comprehensive information about the proposed manipulations, the right to refuse or agree to such manipulations, etc. On the other hand, the formal establishment of certain norms is not a guarantee that they will be followed in practice. For example, clause 2 of Standard 3.4 states that "medical workers are responsible for non-disclosure of information about the HIV-positive status of a pregnant woman, when performing functional duties in accordance with the requirements of current legislation". However, as evidenced by the survey findings, cases of disclosure of a woman's HIV-positive status occurred repeatedly (in 70.2% – disclosure to the patient's inner circle, in 54.8% – among medical personnel).

In 2023, important measures were taken in terms of combating obstetric violence against women living with HIV, namely, the updated Roadmap for the elimination of cases of mother to child transmission of HIV in Ukraine for 2023-2024 was approved. CO "Positive women" added the following measures to the Roadmap:

conducting training for obstetrician-gynaecologists of women's consultations, obstetrical health care institutions of all forms of ownership on the prevention of all forms of violence, stigma and discrimination, protection of the rights of women living with HIV and those vulnerable to HIV;

development and implementation of internal provisions on the ethical code of conduct between patients and medical personnel in the work practice of women's consultations and maternity health care facilities of all forms of ownership to protect women from all forms of violence, stigma and discrimination.

In addition, the Roadmap also contains other measures aimed at ensuring the human rights of women living with HIV, in particular in the context of "the implementation of policies to reduce stigma and discrimination in institutions that provide assistance to people living with HIV".

Global best practices for addressing obstetric violence against women living with HIV relate, first of all, to countering forced sterilization. Thus, in 2014, the International Community of Women Living with HIV (ICW), based on the appeal of the community of women living with HIV in the Republic of South Africa, developed and implemented an advocacy strategy against sterilization of women without their informed consent.



"They only told me that <u>they will sterilize me because I was</u>

<u>HIV positive</u>, and I was never supposed to get another child. I remember this because I was scared"

"I did not know which procedure was followed, that is, whether my tubes had been tightened or whether my womb was removed. They did not explain anything to me"



Information on the case of Securing justice for women living with HIV who were sterilized at State Hospitals in South Africa (2014) was provided by the International Community of Women Living with HIV

Despite the fairly progressive regulatory and legal framework of South Africa, even in the context of the prohibition of forced sterilization (The South African Sterilization Act 44 of 1998), in February 2020, the South African Commission for Gender Equality, based on a complaint filed by ICW and Her Rights Initiative in 2015, and following an investigation, confirmed that HIV-positive women were still being denied medical care if they refused to sign informed consent for sterilization procedures; they were provided with little information regarding those manipulations that related to their health during pregnancy and childbirth; women were misled into agreeing to sterilization procedures, women were told that due to their HIV-positive status

they could not refuse the sterilization procedure and, importantly, the <u>right to the highest</u> attainable standard of health was violated, including sexual and reproductive rights.

At the state level, an independent committee within the South African National Department of Health was formed to address issues of reparation for harm caused to women and to implement recommended changes to policies and regulations.

In particular, it related to:

- solving emotional and psychological disorders, physical injuries;
- holding medical personnel accountable for performing forced sterilization without informed consent;
- awarding compensation for women affected by this form of obstetric violence (financial support for training and shelter).

ICW's advocacy efforts have resulted in the implementation of clinical interventions and psychosocial treatment for women living in Gauteng who experienced violence.

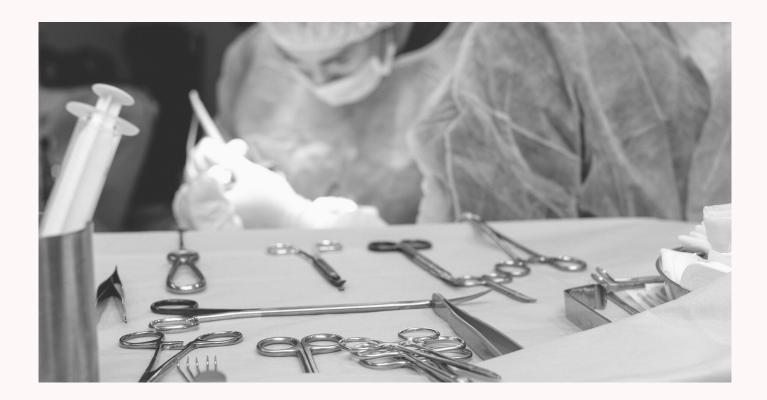
It is important that working toward combating obstetric violence, even one of its manifestations – forced sterilization, helped to:

- encourage women living with HIV to talk about their experiences of both forced sterilization and other forms of obstetric violence;
- prove that women living with HIV continue to face serious forms of discrimination in healthcare systems by healthcare providers;
- identify the need to develop and/or strengthen mechanisms for the restoration and compensation of violated rights, ensure access to justice;
- confirm the need for amendments to the regulatory framework and policies.

Among other successful advocacy activities, it is important to note the activity of 4M Mentor Mothers Network CIC, which, in particular, advocates for ensuring the right of a woman living with HIV to breastfeed her infant. Thus, in August 2020, the organisation together with the Salamander Trust published a position paper December 2020, ICW North America and The Well Project released an Expert Consensus Statement Calls to Advance Efforts Around Infant Feeding Among Women and Other Birthing Parents Living with HIV in the United States and Canada.

An intervention that deserves special attention and should also be supported in Ukraine is perinatal mentor mother peer support, which has been implemented since 2019 by 4M Mentor Mothers Network CIC in the UK and 4M+ in Kenya in accordance with the 2017 WHO Consolidated Guidelines on sexual and reproductive health and rights of women living with HIV.

The organisation works closely with doctors, HIV-service organisations, and organisations dealing with housing, immigration, mental health, domestic violence, and other issues that affect the lives and health of women living with HIV.



The issue of obstetric violence should be raised not only at the level of individual states, but also at regional and global platforms. Submission of alternative reports to the UN treaty bodies is one of the possible tools. For example, in 2012, the Indonesian Positive Women's Network Ikatan Perempuan Positif Indonesia (IPPI) submitted an alternative report to the UN Committee on the Elimination of Discrimination against Women (CEDAW), alleging cases of forced sterilization and violence against women living with HIV. For the purposes of the report, a community-based survey of 122 women living with HIV in Indonesia about their experiences of obstetric violence was conducted, as well as a <u>survey</u> of 757 pregnant women living with HIV in six Asian countries about their experiences of verbal and physical abuse by medical personnel before, during and after childbirth.

KEY FINDINGS

In Ukraine, there is a problem with the implementation of the rights of women living with HIV to sexual and reproductive health, in particular in the context of pregnancy, childbirth and postpartum care. The conservatism of medical practices, the power imbalance in the relationship between doctors and patients, as well as the low awareness of both the general population about HIV and the women living with HIV themselves about the rights and freedoms they are entitled to, as well as the lack of knowledge about their own physiology, provoke the increase in the incidence of obstetric violence. The current legal and regulatory framework of Ukraine is intended, first of all, to prevent the mother to child transmission. However, it is not aimed at ensuring such a system of maternity care in Ukraine, where the needs of a woman living with HIV are adequately met and where there is no place for such manifestations of obstetric violence, as, for example, interventions without prior written informed consent, interventions despite the woman's refusal, violation of obstetric and gynaecological care protocols, misinformation, psychological pressure and intimidation, verbal aggression, insults, humiliation, notations, criticism, sarcasm, painful examination and other types of physical abuse.

According to the findings of the survey conducted by the CO "Positive women" among 104 women living with HIV in Ukraine regarding their experience of obstetric violence over the past 2-3 years:

- all respondents were denied certain obstetrics and gynaecology service in a healthcare institution due to their HIV-positive status, namely **26.9%** of the respondents were denied giving birth due to their HIV-positive status.
- **44.4**% of respondents were asked to pay for free medical services because of their HIV-positive status.
- **70.2**% of respondents reported that their HIV-positive status was disclosed to their inner circle, which in **56.2**% of cases affected further medical support.
- the HIV-positive status of **54.8**% of respondents was disclosed to the medical staff, which in the case of **72**% of respondents had a negative impact on further medical support.
- **61.5**% of respondents were not asked for giving an informed consent when being placed on "D" account.
- **5.8%** of respondents stated that they had experienced physical abuse during pregnancy and/or childbirth due to their HIV-positive status.

- all respondents experienced psychological and emotional violence due to their HIV-positive status on the part of the medical staff.
- **33.7**% of respondents faced various serious consequences for their health or the life and health of their child as a result of obstetric violence.

These are not all documented cases. There are many that women choose not to mention, fearing future consequences from doctors for themselves or their child, or when women did not realize that such actions or inaction actually constitute obstetric violence. In isolated cases, women try to hold doctors responsible for the damage caused to their health and the health and life of their child, but on this way, they face violence, attempts to intimidate and bribe. More stories of women who have suffered from obstetric and gynaecological violence can be found on Facebook using the hashtags #StopObstetricViolence and #rogimobyatu.

KEY RECOMMENDATIONS

Take measures to overcome stigma and discrimination against women living with HIV in institutions providing medical, particularly obstetric and gynaecological, care in Ukraine.

Regularly conduct training for doctors, medical and other personnel of maternity hospitals, as well as other institutions providing obstetric and gynaecological care, on basic knowledge of HIV, human rights, gender equality, including the right to informed consent for obstetric and gynaecological manipulations, etc. It is important to ensure a holistic, gender-sensitive.

- 1.1 and gynaecological manipulations, etc. It is important to ensure a holistic, gender-sensitive, non-discriminatory and patient-centred approach, and that relevant staff have the necessary behavioural, communication and other skills to work with women living with HIV, respect women's right to make decisions about their own bodies, including in the context of abortions, in accordance with the current legislation of Ukraine.
- Clearly enshrine in PMTCT programmes and services the ability of women living with HIV to make voluntary, fully informed and autonomous decisions about whether and when to receive the necessary help and examination in connection with pregnancy and childbirth.

Attract women living with HIV who have received the necessary qualifications as a doula to provide information, household and emotional support to women at various stages of preparation for childbirth, during childbirth and in the postpartum period, as well as as a

1.3 prenatal psychologist and breastfeeding consultant. For example, this can be implemented through clause 3.8 of Standard 3 "Medical assistance to HIV-positive women during pregnancy, childbirth and the postpartum period", which ensures involving "volunteer or social support in the framework of partner childbirth with the consent of the woman" (desirequality criteria).

- 2 Involve women living with HIV in the processes of developing and implementing programmes and policies related to sexual and reproductive health in Ukraine.
- Increase the awareness of women living with HIV about their rights in the field of sexual and reproductive health, in particular in the context of pregnancy, childbirth and the postpartum period, in order to expand their opportunities and knowledge in communication with doctors and staff of institutions providing medical care, including obstetric and gynaecological care in Ukraine. In this way, to form a base of equal consultants (doulas, prenatal psychologists and breastfeeding consultants).
- 4 Provide support to networks of women living with HIV in documenting cases of obstetric violence in Ukraine.
- Ensure access of women living with HIV, who experienced obstetric violence, to justice, restoration of violated rights and/or compensation for harm caused.
- **5.1** Provide financial support for professional legal assistance for women living with HIV, who experienced obstetric violence.
- **5.2** Develop a network of peer women paralegals with expertise in obstetric violence.
- Develop and support alternative grievance mechanisms in partnership with women living with HIV to hold health professionals accountable and ensure women's access to reporting violations of their rights without fear of consequences for themselves, their health and wellbeing of their children.
- 5.4 Include the issue of obstetric violence in alternative reports to UN treaty bodies in order to draw attention to this problem at the state and global levels.
 - Support research and surveys on the experience of obstetric violence against women living with HIV in Ukraine, the causes of higher maternal mortality (compared to HIV-negative women), etc. with the aim of forming an evidence base for overcoming negative factors for maternal health, including stigma and discrimination, and attracting donor funding.
- 6.1 Ensure that such studies and surveys are regularly conducted in order to monitor the dynamics of the situation with obstetric violence in Ukraine.
- Testablish at the level of normative and legal acts, in particular criminal legislation, the responsibility of doctors, medical and other personnel of institutions providing medical, in particular obstetric and gynaecological, assistance for obstetric and gynaecological violence against women living with HIV.

- Harmonize the national legislation of Ukraine in the context of SRHR of women living with HIV, during perinatal care and throughout the lifespan of women and girls living with HIV, in accordance with the norms and standards of international law, in particular the 2017 WHO Consolidated Guidelines on sexual and reproductive health and rights of women living with HIV.
- Introduce the position of national women monitors on issues of obstetric violence in order to monitor compliance with the rights of women living with HIV to sexual and reproductive health and document cases of obstetric violence.



The document was prepared by Nataliia Gerasymchuk, Human Rights Expert, Consultant of the CO "Positive women".

The author expresses her gratitude to Olena Stryzhak, Head of the Board of the CO "Positive women" for her continuous support in the process of developing the policy brief, the regional representatives of the CO "Positive women" for their assistance in data collection, Sophie Brion, Director of Global Programmes of the International Community of Women Living with HIV, for sharing their experience in combating obstetric violence against women living with HIV at the global level, and Yuliia Kucherova for helping with the editing and layout of the policy brief.

The opinions, findings, and recommendations expressed in this document are those of the author and do not purport to reflect the views of the European AIDS Treatment Group, International Charitable Foundation "Alliance for Public Health" and Gilead, which provided financial assistance.

ANNEX 1

FEEDBACK QUESTIONNAIRE

- Name.
- 2 Age.
- Oblast.
- 4 Locality.
- Health care institution.
- 6 Which service were you denied due to your HIV-positive status?
- Were you asked to pay for the provision of free medical services referring to your HIV-positive status?
- 8 Was your HIV-positive status disclosed to your relatives or partner without your consent?
- 9 If the disclosure took place, please describe under what circumstances it was done.
- Was your HIV-positive status disclosed to the medical staff without your consent?
- If your answer to question 10 was "Yes", please describe under what circumstances it was done.
- Did the notification of your HIV-positive status or its disclosure affect further medical support and receiving services?
- 13 If your answer to question 12 was "Yes", please indicate what has changed.
- Did you sign the informed consent when being placed on "D" account without additional explanations and the right to withdraw it?
- Describe a situation that, in your opinion, was humiliating, discriminatory or offensive to you.
- Did the refusal to provide you with a medical service or its improper provision have consequences, or did any damage to your health or the health of your child occur?
- If your answer to question 16 was "Yes", please describe the damage that was caused.

In accordance with the Law of Ukraine dated June 01, 2010 No. 2297-VI "On Protection of Personal Data" as amended of December 21, 2019, I give my consent to the CO "Positive women" to process, store and use my personal data in compliance with data protection requirements.