HUMAN RIGHTS OF WOMEN LIVING WITH HIV IN UKRAINE:

FINDINGS OF COMMUNITY-BASED RESEARCH THROUGH THE LENS OF CEDAW
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In February-March of 2016, the charitable organization Positive Women conducted research on women and HIV, which generated information on stigma, discrimination, and the values and needs of women living with the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV and AIDS) in Ukraine. The researchers intended to explore important aspects of women's lives related to their sexual and reproductive health, gender equality and human rights, and gender-based violence, as well as their economic and political opportunities.

The research approach is based on the understanding that HIV prevention and treatment is not only a public health problem. The research focuses on the factors and the socio-economic context that lead to HIV infection, and the recognition that human rights violations, including gender inequality and gender-based violence, constitute major vulnerabilities to HIV infection. It also outlines major barriers to HIV treatment and provision of other health services in Ukraine.

**METHODOLOGY**

**RESEARCH METHODS:**
Surveys, focus group discussions, interviews, desk review of national HIV and AIDS policies and programs of Ukraine.

**RESPONDENTS:**
Women living with HIV in Ukraine over the age of 18, HIV service providers.

**HUMAN RIGHTS OF WOMEN LIVING WITH HIV IN UKRAINE:**
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The past decades of this epidemic have demonstrated that gender inequality is one of the driving forces behind the HIV epidemic; it increases infection rates and impacts the ability of women and girls to mitigate the consequences of the epidemic. Further, where women’s rights and agency are denied, their ability to protect themselves is severely limited.

Gender inequality and unequal power relations between women and men significantly influence the rate of HIV infection. Biological factors that make women and girls more vulnerable to HIV infection are exacerbated by socio-cultural and structural factors, such as poverty, harmful stereotypes, limited decision-making power, lack of control over financial resources, restricted mobility, violence, and lack of good quality sexual and reproductive health services.¹

Women living with HIV and organizations assisting them are often excluded from the decisions that guide policies and programmes on HIV. Their right to participate is not upheld, and their potential contributions of leadership and perspectives on how to manage the epidemic are lost. With women largely on the margins of decision-making, HIV plans and policies fall short in responding to the needs and rights of women and girls. This hinders the development of adequate programmes and budgets, which, in turn, hampers women from reaching prevention, treatment, care and support services.

A further challenge comes when national planning bodies lack the technical expertise and tools to conduct a gender analysis of HIV and prioritize gender dimensions. They need capacities to collect data disaggregated by sex and age, and to report on specific gender equality indicators to track and evaluate the effectiveness of HIV interventions.

Violence against women and girls is both a cause and a consequence of HIV infection. It is one of the key drivers behind the increasing number of women and girls living with HIV/AIDS. The subordinate position that many women and girls hold within their families, communities and societies restricts their access to information about sexual and reproductive health and their use of health care services. Fear of violence makes many reluctant to be tested or treated, and inhibits their capacity to negotiate safer sexual practices.

The study, “Sexual and reproductive health, gender equality and human rights, gender-based violence, and economic and political opportunities for women living with HIV in Ukraine” is unique, as it is the first time such research has been conducted in Ukraine by the women directly affected by the HIV epidemic.

This research provides both a qualitative and quantitative first-hand account of the experience of women living with HIV in Ukraine. It also provides the first such data-based evidence of the current situation of women living with HIV where there was none before. It provides evidence about the scale of discrimination faced by women living with HIV in Ukraine, and gives these women a platform where their voices can be heard.
HIV AND THE CONVENTION ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN (CEDAW)
CEDAW is one of the key global normative frameworks, along with the 2011 Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS, the Beijing Platform for Action, and the Sustainable Development Goals, that guide work on the prevention and response to HIV/AIDS. The CEDAW Convention and its General Recommendations, including General Recommendation No. 15\(^2\), contain important substantive provisions for advancing gender equality. They equip state parties with the tools to promote the full realization of women’s human rights, including developing gender-sensitive national responses to HIV/AIDS.

The CEDAW was ratified by Ukraine in 1981, and has been used since then to inform Ukrainian state policies and programmes regarding gender equality and the elimination of discrimination against women.\(^3\) It addresses women’s rights within political, social, economic, cultural, and family life. It calls on state parties to overcome the barriers of discrimination against women in legal rights, education, employment, health care, politics, and finance, and sets benchmarks.

CEDAW is particularly relevant to HIV/AIDS issues in Ukraine. The HIV epidemic in Ukraine magnifies violations of women’s human rights and heightens their vulnerability to HIV. Sexual and reproductive health rights are being inadequately protected. Measures addressing links between gender-based violence and HIV are missing. Legislation, or the lack thereof, biased legal practices, limited legal services, and a lack of awareness about women’s rights can all stand in the way of HIV-affected women seeking and accessing justice. Criminal laws may impede women from pursuing HIV prevention, treatment, and care. Therefore, it is critical to develop greater capacities for integrating the HIV issue into measures aimed at implementing the Convention on the Elimination of All Forms of Discrimination against Women in Ukraine, and to use the Convention when composing policy and legislation, implementing HIV/AIDS programmes, and conducting monitoring and evaluation for those programmes to ensure that special attention is given to the rights and needs of women and girls.

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\(^3\) UN Treaty Collection https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-8&chapter=4&clang=_en
Article 1

provides a definition of discrimination against women. Identifying and addressing gender-based discrimination is central to an effective HIV/AIDS response.

Article 5

of CEDAW calls on governments to take all appropriate measures to modify social and cultural patterns of conduct with a view to eliminating customs and other practices based on the idea of the inferiority or superiority of either sex or on stereotyped roles. The imbalance in power between women and men that favours men underlies women’s vulnerability to the infection.

Article 10

of CEDAW calls on governments to take all appropriate measures to eliminate discrimination against women in education, and Article 11 calls for measures to end discrimination in employment (including the right to work, employment opportunities, equal remuneration, and social security), which directly correlate with women’s future income and economic opportunities and their greater vulnerability to HIV.

Article 12

states the need to take appropriate measures to eliminate discrimination in health care in order to ensure women have the same access to health care services as men, including family planning access. Without access to adequate information, prevention resources, and treatment, women and girls continue to be at risk of HIV infection.

Article 14

highlights the unique problems that rural women face accessing health care and adequate living conditions, which are multiplied for women living with HIV in rural areas or small towns across Ukraine.

Article 18

requires parties to submit reports periodically to the Committee on the Elimination of Discrimination Against Women on measures they have taken to carry out the Convention, and the Optional Protocol introduces a crucial mechanism that allows individual women, or groups of women, to submit claims regarding violations of rights protected under the Convention directly to the CEDAW Committee.
The vast majority of those surveyed (87.4%) are within reproductive age: from 18 to 45 years old. Of those surveyed, 16.8% identified themselves as sexually active but without a partner, while 32.3% reported having one or more sexual partners living with HIV, and 29.9% reported having one or two partners without HIV. Almost half of the research participants (42.3%) learned about their HIV-positive status during pregnancy, and 54.7% gave birth to children after they learned about their HIV positive status, 15.9% of which have HIV positive children.

More than half of those surveyed (56.3%) are married or in stable relationships. More than one in three of the respondents (35.1%) has hepatitis C. One in three women use or have used drugs (32%), and 28.2% have partners who use or have used drugs. One in five (22.1%) is living with a disability. In addition, one in five has been in prison or in detention (9.2% and 12.4%, correspondingly), 7.3% have experience with sex work, 5% are internally displaced persons from Crimea or Donbas, and 8.6% of the HIV positive women surveyed have records of active TB in their medical history.
Survey Participants

- 16.8% sexually active but not having a partner
- 32.3% have one or more sexual partners living with HIV
- 29.9% have one or two sexual partners without HIV
- 56.3% are married or in stable relationships
- 35.1% has hepatitis C
- 8.6% has records of active TB in their medical history
- 22.1% is living with disability
- 32% have used drugs
- 42.3% almost one-half of the research participants learned about their HIV-positive status during pregnancy.
- 54.7% gave birth to children after they learned about their HIV positive status.
- 15.9% of them have HIV positive children.
- 5% are internally displaced persons from Crimea or Donbas.
Almost half of women living with HIV “do not know” (15.8%) or “do not believe” (33.3%) that health care providers do not disclose their HIV status or any other details without their consent.

One in three women living with HIV need better knowledge about their rights and the mechanisms to protect them. This group, 31.8% of women, do not know their rights and do not know where to file complaints against actions of health care workers if their rights are violated in medical institutions. One in five respondents (19.2%) believes that if, as a woman living with HIV, her rights are violated, she will not receive the necessary legal protection, and another 23.2% of women do not know whether they can rely on getting legal support.
Violence against women

Physical violence, the threat or fear of violence, and the fear of abandonment and destitution interact with other gender-based economic and social inequalities to significantly increase women’s vulnerability to HIV infection.⁴

Over one in three (35.3%) women living with HIV have experienced violence from their partner or spouse. This share is considerably higher than the average for Ukrainian women in general (19%). More than half (51.3%) of the women surveyed had no support whatsoever after experiencing violence.

Before their HIV positive status is diagnosed, women most often experience violence from their partners, yet the HIV diagnosis considerably increases the probability of being subjected to violence in all

⁵ UNFPA, Prevalence of violence against girls and women, Kyiv, 2014
spheres, and, to the greatest extent — by 15.5 times! — specifically in the healthcare settings, which women have to deal with in order to secure timely and proper care and treatment, and to lead a productive life.

Women living with HIV list having social protection among their highest priorities, along with the ability to secure care for their children and to independently earn their living, to have access to competent specialists (from medical doctors to lawyers), to be aware of the rights and problems of women living with HIV (and women from vulnerable groups), and to access support, through a hotline, support groups, and shelters. Most women do not see the criminalization of sex work, drug use or HIV transmission as institutional violence, and do not see how these laws are affecting access to services and the enjoyment of human rights.

VIOLENCE AGAINST WOMEN

**BEFORE HIV DIAGNOSIS**
- Partner: 22.5%
- Society: 10.3%
- Family members: 7.3%
- Police and other enforcement agencies officers: 3.2%
- Healthcare providers: 9.9%

**AFTER HIV DIAGNOSIS**
- Partner: 49.6%
- Society: 16.8%
- Family members: 9.3%
- Police and other enforcement agencies officers: 12.8%
- Healthcare providers: 25.8%
Healthy sexual life

For a long time, HIV-positive women were considered in the context of how to successfully prevent HIV vertical transmission, and sexual health issues for women living with HIV were not viewed as a priority, including by the women themselves.

One in five women with HIV has sex solely for the satisfaction of her partner, but never initiates sex herself, and 35.6% of the respondents always or usually have sex when her partner wants it. Of women living with HIV, 10.7% living with HIV consider their HIV positive status or fear of infecting their partner (8.9%) an obstacle to enjoying their sexual lives.

Only half of women living with HIV always feel safe with their partner, while 58.2% consider trusting relationships with their partners a prerequisite for a pleasurable sexual life. At the same time, only half of the women (54.8%) can discuss their sexual health and needs with their doctor. About half (59.1%) of the women are able to get diagnosed and treated for STDs without fear of being blamed by health care workers.

As for protection, 20.1% of women with HIV are not able to take their own decisions about using a (male) condom. Only one-third (29.1%) of women living with HIV can use female condoms when they choose, and one in three (33%) respondents can never use them.
Women living with HIV, both at the family-planning stage and during pregnancy, encounter numerous medical and psychosocial issues, such as taking into consideration the major risk factors of HIV transmission in conditions of expensive medical services and under pressure of stigmatization and social stereotypes. According to the research findings, a fairly significant share of HIV-positive women do not have proper support from their immediate environment or access to the consultations from medical professionals they need to take a decision about having children. Only 60.4% of those surveyed agreed that they had support from their partner in their choice to have or not to have children, and one in five said they did not have such support from their family and friends.

The respondents seem to have poor access to medical services related to the specific nature of reproductive health for HIV-positive women. Only 10.9% can or were able to use free infertility treatment or assisted reproductive technologies, and only one in five was given assistance conceiving safely. Only half of the surveyed women received consultations on childbearing issues.

Nearly half of the survey participants (42.3%) learned about their HIV-positive status at a medical examination during pregnancy. Only 55.4% of the
A fairly significant share of the respondents were left alone to deal with the problem of their HIV status during their pregnancy.

Women got tested for HIV voluntarily, and only 61.8% received the necessary counselling; almost one in five did not receive consultations about how to feeding their infant (17.9%).

As for unintended pregnancies, 51.8% of the respondents had one or more. However, HIV-positive women on the whole have limited access to safe abortion and post-abortion assistance, including certain limitations on their access to emergency birth control.

“... When I came in to see my gynecologist in a women’s health clinic for a regular check-up, the doctor began shouting at me and accusing me for not telling her about my diagnosis. She told me that she would sue me, as I could have infected her, and added several derogatory terms, the most cultured of them was: “You junkie brought this on yourself!”... For a long time afterwards, I was afraid of going to doctors, I was afraid they would accuse me. It was even more humiliating to talk about my status.

That is why I did not seek medical assistance, even when I felt pain in my stomach, which was getting worse by the day. An ambulance took me to the gynecological ward unconscious and bleeding. As it turned out, I had a tubal pregnancy. They saved my life, but unfortunately, now I cannot have children. “

Maryna, 32, Poltava
Mental health and HIV

The issue of mental health for women living with HIV is still relevant, despite the expansion of HIV treatment and care programs in Ukraine. The respondents themselves emphasized the need for specialized assistance after being diagnosed, and considered consultations and peer-to-peer groups to be the best methods of protecting their psychological health.

In many cases, women’s psychological health issues emerge before they are diagnosed with HIV and are accompanied by risky behaviours, which is why making competent psychological support accessible to as many women in the highest-risk groups as possible is an important part of preventing the spread of HIV.

One in five respondents answered that she had abused drugs or alcohol before she was diagnosed with HIV; 15.5% of those surveyed had experienced a long-term depression before the HIV diagnosis.

A portion of the women (5-12%, who answered that they did not know whether they had experienced certain psychological issues) are unaware of their own psychological issues, and this complicates their identification and providing timely help.

HIV treatment and side effects

The survey findings demonstrated that women living with HIV have a generally responsible attitude toward the necessity of addressing health issues related to their diagnosis. The respondents regularly visit their HIV consultants and have their CD4 count checked.

The majority of the women surveyed are undergoing ARV treatment, and the key reason they refuse this treatment is the fear of side effects. Of those respondents taking ARV medications (predominantly – Aluvia, Tenvir, Virocomb), 87% experience side effects. Most often, these are fatigue, mood swings, headaches, and/or hair loss.
Burden of care

Issues related to the daily lives of women living with HIV are an important component in understanding the lifestyle and health of the women, who usually bear the burden of caring for their own health and running their household.

Elements of daily routines of women with a partner and children, such as, for example, getting children ready to go to school or kindergarten, fall entirely on the shoulders of 15.9% of women. More than one-third of the women cook (37.9%) and clean (36.5%) all by themselves, as well. As for laundry and ironing, 56.3% and 64.0%, respectively, receive no assistance with these tasks. About half of women (43.5%) are responsible for all the duties of representing the family at various institutions and agencies (visits to social services, state officials, the social security service, pension fund, migration service, etc.). Nearly one-third (29.9%) visit teacher-parent conferences at school, and 28.8% take their children to the doctor, by themselves.

Things that women do together with their partners include buying food (37.8%) and household appliances (55.9%), organizing holidays at home (52.5%), and outside it (51.0%). The task most listed as a “shared activity” with partners was taking decisions about the family budget (56.4%).

As most questions regarding household and lifestyle show, the way the burden of care is shared exposes entrenched gender stereotypes, as women perform the bulk of household chores by themselves, and men contribute when it is about money issues, big purchases, and the organization of leisure time.
Overall, the survey participants have a certain level of access to higher education. Almost half of the women (48.0%) depend on their partner to varying degrees, and somewhat less than a quarter (23.1%) are economically dependent on their partner always or usually. Under such circumstances, the women are vulnerable to economic and other forms of violence from their partner and are limited in their ability to take both financial and reproductive decisions.

Significantly more than half of the women can always or almost always turn to employment centres. The question is still open, though, as to what work, for what pay, they will be offered at employment centres.

Over a quarter of the women (28.1%) answered that they could not combine education and work without losses. One-fifth (21.2%) answered that they always or usually could combine education and work without losses. This situation means that a significant portion of the women find it impossible to work and obtain education at the same time. In addition, almost half of the women surveyed have varying degrees of access to free or affordable courses, where they can get additional occupational and other new skills.

Two-thirds of the women surveyed do not have the knowledge and skills required to launch their own business. Only a quarter of the respondents know where to turn for assistance when launching their own business. Only half the women surveyed has varying degrees of access to loans in Ukrainian banks.

Two-thirds of the women do not own real estate or other property and only half of the women take decisions about their real estate or other property. The share of the women who manage social benefits and child support, is larger (by 15%), than the share managing their own real estate or other property.

Only one third of the women reported that having a child did not cause damage to their career, and for almost half of the women, having a child did not affect their finances or financial prospects.
To conduct surveys and discussions in 4 focus groups, 57 participants were engaged. These were women living with HIV, of whom

- 45.6% have been living with HIV for over 10 years, 35.1% – from 5 to 10 years,
- 34.4% have experience of activism from up to 5 years, 51.9% have been activists for 5 years or more;
- 28.3% have less than 5 years of experience of working in HIV services, 50.9% have more than 5 years of such experience.

Almost unanimously, the women set “absolute” or “high” priorities for addressing on the national level the following

Policies and strategies:
- Provide integrated HIV and sexual and reproductive health services and referrals – 98.2%;
• Expand the evidence base around the linkages between HIV and sexual and reproductive health and human rights for girls or women with HIV at all stages of our lives – 98.2%,

and issues related to **gender-based violence**:

• Acknowledge and address all health facility-based rights violations against women with HIV (for instance, stigma and discrimination; biases of medical workers; forced abortion or sterilization; lack of choice, privacy or information, etc.) – 98.2%,

• Acknowledge and address gender-based violence, including intimate partner violence, violence from other family members and violence against women with HIV who are from key affected populations (including sex workers, women who use drugs, women having sex with women, transgender women) – 98.2%,

• Acknowledge and address gender inequality in society at all levels (e.g. ensure equal employment opportunities and equal pay for men and women; ensure equal property and inheritance rights, etc.) – 98.2%.

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**One hundred percent of activists and service providers supported these recommendations:**

• In planning and providing services, to understand comorbidities, including tuberculosis, hepatitis C, cancer, and sexually transmitted infections, in the context of sexual and reproductive health and the rights of the women living with HIV.

• Promote accurate and up-to-date fertility and conception advice to couples with the same (seroconcordant) and couples with different (serodiscordant) HIV status.
How is this research used?
The research findings were included in the first ever shadow report specifically related to the situation of women who use drugs, women living with HIV, sex workers, and lesbian and bisexual women and transgender people in Ukraine.

It was prepared by several NGOs: Legalife-Ukraine, Insight, Positive Women, and Svitanok. The shadow report was presented at the 66th CEDAW Session in Geneva, Switzerland, on 14 February 2017.

The shadow report provided evidence and recommendations advocating for the better and non-discriminatory provision of services for women living with HIV, addressing sexual and the other types of violence, including police violence, reproductive and parental rights, and multiple stigmas.6

The CEDAW Committee reviewed the report and took into consideration some of the concerns raised by the civil society of Ukraine by integrating them in the Concluding Observations to Ukraine. The Committee emphasized that Ukraine should “intensify the implementation of strategies to combat HIV/AIDS, in particular preventive strategies, ensure access by women [survivors] of sexual violence to comprehensive medical treatment, including emergency contraception and anti-HIV/AIDS contamination, mental health care and psychological support provided by trained health care professionals, and provide effective access for women and girls to health care information and affordable services, in particular regarding reproductive health and contraceptive methods, collect disaggregated data and provide training to medical and health professionals, in particular in rural areas.” 7

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Focusing on the intersection between, sex, gender identity, HIV, as well as human rights and gender-related barriers and issues, including gender-based violence, it aims to inform future programme and policy HIV prevention efforts. Including findings from the research in measures for the implementation of CEDAW can affect policies to improve the quality of medical examination and observation, the provision of psychosocial, legal, and medical advice, medical care and medical support, social and legal protection, and the prevention of any form of discrimination in relation to HIV.

The findings of the research have been incorporated into Positive Women’s Advocacy Strategy for the Elimination of Discrimination Against Women Living with HIV for 2017-2018, which aims to work with partners in the government, development partners, and relevant civil society groups to influence legislative and healthcare policy affecting women living with HIV. The Ministry on Economic Development also took the research findings into consideration by integrating them into the 2017 National Baseline Report Sustainable Development Goals: Ukraine[^8] and in the localization of Sustainable Development Goals.

The research findings are important for the development and monitoring of national policies related to the protection of women living with HIV, such as the current National Targeted Social Program on HIV/AIDS Response (2014-2018), and the future State Program on Ensuring Equal Rights and Opportunities of Women and Men (2018-2022), as well as the Human Rights Action Plan (2015-2020).

A number of internationally approved norms and standards related to women and HIV/AIDS:

The Beijing Declaration and Platform for Action calls for the involvement of women in HIV/AIDS policies and programmes; the review and amendment of laws that contribute to women’s vulnerability to HIV/AIDS and the implementation of legislation, policies, and practices to protect women and girls from HIV/AIDS-related discrimination; and the strengthening of the national capacity to create and improve gender-sensitive policies and programmes on HIV/AIDS.

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and its General Recommendations contain important substantive provisions for advancing gender equality. They equip state parties with tools to promote the full realization of women’s human rights, including in developing gender-sensitive national responses to HIV/AIDS.

The 17 Sustainable Development Goals (SDGs) seek to end poverty by 2030 and promote social development, economic prosperity, and environmental protection for all. Goal 3 aims to ensure healthy lives and well-being, with a target to end AIDS by 2030. Goal 5 aims to achieve gender equality and empower all women and girls. These goals, along with all others, are critical roadmaps to address the cross-cutting gender inequalities in the HIV epidemic.

The 2001 UN General Assembly declaration of commitment on HIV/AIDS stressed that gender equality and women’s empowerment were fundamental elements in the reduction of the vulnerability of women and girls to HIV/AIDS. The 2006 Political
declaration on HIV/AIDS recognized that the promotion of gender equality and women’s empowerment, and the protection of the rights of female children must be key components of any comprehensive strategy to combat the epidemic.

In the 2011 Political declaration on HIV/AIDS: Intensifying our efforts to eliminate HIV/AIDS, UN Member States pledged to increase the capacity of women and adolescent girls to protect themselves from the risk of HIV infection, and to take all necessary measures to create an enabling environment for empowering women.

In the 2016 Political declaration on HIV and AIDS: On the fast-track to accelerate the fight against HIV and to end the AIDS epidemic by 2030, UN Member States made firm commitments to achieve gender equality and empower all women and girls as part of the efforts to end AIDS by 2030.

Human Rights Council resolutions on the protection of human rights in the context of HIV/AIDS include resolution 16/28. Adopted in 2011, it stresses ensuring the availability, accessibility and affordability of medicines and health care services for HIV-positive pregnant women. It also calls for establishing or expanding gender-sensitive national HIV/AIDS policies and programmes.

UN Security Council resolution 1983 from 2011 notes the disproportionate burden of HIV/AIDS on women. It urges Member States, UN entities, international financial institutions and other relevant stakeholders to support national health systems and civil society networks in assisting women living with or affected by HIV in conflict and post-conflict situations.

The UN Commission on the Status of Women has passed resolutions on women, female children, and HIV/AIDS, including resolution 60/2 in 2016. It has issued approved conclusions on the equal sharing of responsibilities between women and men, including caregiving in the context of HIV/AIDS in 2009, and on women, female children, and HIV/AIDS in 2001.
UN Women is the UN organization dedicated to gender equality and the empowerment of women. A global champion for women and girls, UN Women was established to accelerate progress on meeting their needs worldwide.

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