## National report

## Data for change

Sexual and reproductive health and rights of women living with HIV















NGO Re Generation is the first specialized organization dealing with policy, research, education and analysis of issues related to drugs in Serbia. You can find more information at www.regeneracija.org Re Generacija ©, 2022.

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The views expressed in this publication are exclusively the views of the persons who participated in the research, and all derived conclusions are the conclusions of NGO Re Generation as the author and may not reflect the views or opinions of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

The Global Fund to Fight AIDS, Tuberculosis and Malaria was not involved in agreeing and approving either the material itself or the possible conclusions from it.

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## **Executive summary**

#### **Organisation and purpose**

NGO Re Generation implemented a unique community-based research "Sexual and reproductive health and the rights of women living with HIV in the Republic of Serbia" based on Tool developed by EWNA<sup>1</sup>. The researchers aimed to find out the most important aspects of women's lives regarding sexual and reproductive health, gender equality and human rights, gender violence, as well as economic and political opportunities women living with HIV in Serbia.

#### **Format**

This type of research was conducted in Serbia for the first time, with women as the target group. The implementation of the community-based research is important because women living with HIV and the women service providers were directly involved as data collectors and participants. In parallel with the qualitative data survey, we conducted 2 focus groups with service providers, women who are activists, managers and employees of HIV service organizations and decision makers. Additionally, we collected 3 life stories of women who are living with HIV, to showcase the specifics of the situation of each one of them.

#### **Participants**

The survey involved 100 women who live with HIV, from all regions of Serbia with 100 filled questionnaires. A little over half of the participants who felt willing to share their experiences are not in the reproductive age (51%) are not in the reproductive age - over 50 and this is the largest share of respondents.

Other half (47%) is in the reproductive age between

26-49 years old, and only 2 respondents are younger than 26. Respondents represent different groups women living with HIV: have hepatitis C and history of active tuberculosis; have personal experience of drug use; have partners who used or are using drugs; have a disability; were in imprisoned or detained; have experience in sex work; or is in system of social support or invalid pension.

#### The results

The report presents the views of women living with HIV accessing healthcare, observance or violation of their rights, and recommendations for decision makers on improvements in service delivery where HIV and gender policy are combined. The cost of services for 83% of women and costs of travel to receive services is what makes access to services difficult. A correlation between HIV positive status and partner violence was recognized by one third of respondents (30%). The percentage of the respondents who fear possible violence since they have been diagnosed with HIV (26%) or believe that it is possible to be exposed to violence due to the diagnosis (26%) exists. 20% of respondents state they have experienced violence since they were diagnosed with HIV, and 24% believe that violence in health care was caused by their HIV positive diagnosis. The activist and service providers gave recommendations: to plan a more adequate referral system to other services (GBV, psychosocial support), and to design specific services for WUD who are not from key populations - as for them there are no designed services.

<sup>&</sup>lt;sup>1</sup> https://ewna.org/wp-content/uploads/2022/12/srhr\_ewna\_eng.pdf

## List of acronyms and abbreviations

AIDS – acquired immunodeficiency syndrome

ARV/ART - Antiretroviral therapy

GFATM – The Global Fund to Fight AIDS, Tuberculosis and Malaria

VCCT - Voluntary confidential counseling and testing

LGBTIQ+ - Lesbian, gay, bisexual, trans, intersexual, queer persons and others

MSM – Men who have sex with men

PWID - Persons who inject drugs

OST - Opioid substitution therapy

PMTCT – Prevention of Mother to Child Transmissions

RHIF - The Republic Health Insurance Fund

WHO - World Health Organization

SW - Sex workers

UNAIDS - The Joint United Nations Programme on HIV/AIDS

HIV - Human immunodeficiency virus

# Sexual and reproductive health and the rights of women living with HIV in the Republic of Serbia

## Introduction

NGO Re Generation is the first specialized civil society organization (hereinafter: the Organization) in the Republic of Serbia which is engaged in advocacy policies, scientific research, education and actions directed at reducing the use of psychoactive substances, as well as promoting the improvement of public health. Since its establishment, the Organization advocates for different, innovative programs, as well as change in attitudes related to drug policies in the Republic of Serbia, focusing on sustainable harm reduction programs, and acknowledging and respecting human rights of vulnerable and marginalized populations in Serbian society. Since its establishment, the Organization has actively participated in drug policy reform on the national and international levels, advocating for the improvement of public health and respect for human rights of the target population. The Organization directs its activities towards different vulnerable communities, as well as towards the improvement of their social status, focusing most on persons who use drugs (PWUD), the community of night club visitors and festival goers, at-risk youth, the LGBTIQ+ population, and other vulnerable social groups. In addition, the Organization's work is also directed at the general population, and in developing specific programs it has worked with specific groups such as kindergarten and school teachers, parents, health workers and police as well, although those activities are for the most part dependent on the available project funds.

Because of its research and advocacy experience, as well as the experiential knowledge of the Organization's members, Re Generation took the opportunity to, on the trail of the development of drug policies as well as women-oriented public health services – apply for the implementation of the research project "Data to change – Strengthening the advocacy response of women living with HIV", funded by the Eurasian Women's Network on AIDS<sup>2</sup> within the project "Women's empowerment in reducing HIV-related gender discrimination", which is in turn realized within the Regional project "Sustainability of services for key populations in the region of Eastern Europe and Central Asia" (SoS\_projekat 2.0), implemented by a consortium of civil society organizations led by the Alliance for Public Health in partnership with CO "100% life", with the financial support of the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM).

Project activities were conducted in accordance with the Research Protocol which was the result of the adaptation of the document "Tool for Monitoring Service Quality in Community Leadership on the Sexual and Reproductive Health of Women Living with HIV"<sup>3</sup>, developed by the Eurasian Women's Network on AIDS. The Protocol describes the basic principles for planning, preparing, implementing and dissemination of results of the research on sexual and reproductive health and rights of women living with HIV and it represents a comprehensive resource for women living with HIV but also professional and activist organizations which provide services to women living with HIV.

<sup>&</sup>lt;sup>2</sup> https://ewna.org/. Accessed 29/10/2022

<sup>&</sup>lt;sup>3</sup> https://ewna.org/wp-content/uploads/2022/12/srhr ewna eng.pdf. Accessed 02/07/2022

The implementation of this research in the Republic of Serbia is a pioneering endeavor, since research directed at monitoring and mapping the needs of women living with HIV in the Republic of Serbia had not been implemented in Serbia until now. Therefore, its importance in unquestionable, and its results should contribute to the development of better policies aimed at this population, as well as to the creation of new and gender-sensitive services for women living with HIV, and encourage them to join together for the purpose of a better advocacy approach in decision making processes.

## **Legal framework**

The right to health is one of basic human rights, rooted in the United Nations' Universal Declaration of Human Rights from 1948<sup>4</sup>, as well as the series of international documents that followed it. The right to health includes the rights to life, an adequate standard of living, access to health care and other basic determinants for achieving the highest level of health, which is much more than the absence of disease. The state of one's health is determined by a number of factors, some objective (the standard of living, the organization of the health system, the quality of medical services) and some subjective (the attitude towards one's health, the assessment of a healthy lifestyle, cultural characteristics, etc.). The World Health Organization (WHO) defines health as a state of physical, mental and social well-being.<sup>5</sup>

The right to health encompasses a series of freedoms and related rights, including the right to education and information on health issues, as well as reproductive health, which is recognized as one of the basic components necessary for the development of humanity and is, on the international level, treated as a priority area. According to the United Nations Guidelines on reproductive health, reproductive health is the state of physical, mental and social wellbeing in all areas related to the reproductive system, in all stages of life. Reproductive health stipulates that people are able to have a satisfactory and safe sex life and the ability to have offspring, as well as the freedom to decide if, when and how often to reproduce. An integral part of reproductive health is also the right of men and women to be informed, to have access to safe, effective, available and acceptable family planning methods of their choice, and the right to adequate health care services which enable a woman to have a safe pregnancy and childbirth.<sup>6</sup>

Sexual and reproductive health represents a universal concern for both men and women, but it is particularly important for women of reproductive age because it has a significant impact on their general health. Seeing as reproductive health is an important component of general health, it is also a prerequisite for social, economic and human development. The right to sexual and reproductive health is connected to other human rights, including the right to life, the right to freedom, the right to health, the right to privacy, the right to education and the prohibition of discrimination. The Committee on Economic, Social and Cultural rights and the Committee on the Elimination of Discrimination against Women (CEDAW) have clearly stated that women's right to health also includes sexual and reproductive health.

The laws of the Republic of Serbia that regulate this area are:

<sup>4</sup> https://www.un.org/en/about-us/universal-declaration-of-human-rights. Accessed 31/10/2022

<sup>&</sup>lt;sup>5</sup> https://cdn.who.int/media/docs/default-source/documents/almaata-declaration-en.pdf?sfvrsn=7b3c2167\_2. Accessed 18/10/2022

https://www.unfpa.org/resources/supporting-constellation-reproductive-rights. Accessed 31/10/2022

- Healthcare law<sup>7</sup>, which prescribes the principles that health care is based on so that every citizen has the right to exercise health care with adherence to the highest possible standard in human rights and values, that is, has the right to physical and psychological integrity and to personal security, as well as to respect for their moral, cultural, religious and philosophical convictions. The legal basis related to family planning and the protection of sexual and reproductive health and rights is defined by this law. It also stipulates that social care for health in the territory of the Republic of Serbia is achieved, among other things, by providing healthcare for women in connection with family planning and during pregnancy, childbirth and maternity up to 12 months after childbirth.
- Law on Health Insurance<sup>8</sup>, which recognizes women in relation to family planning and during pregnancy, childbirth and maternity up to 12 months after childbirth as a particularly sensitive category of insured persons which realizes rights from health insurance even in situations where it does not meet the prescribed conditions for acquiring the status of an insured person.
- Law on Patient Rights<sup>9</sup>, which regulates the right to equal access to health services, without discrimination in relation to financial possibilities, place of residence, type of illness, time of access to health services or in relation to any other form of diversity that may be the cause of discrimination; then the right to information; the right to preventive measures; right to notice; the right to free choice of recommended medical measures; the right to privacy and confidentiality; the patient's right to freely decide on everything concerning their life and health.
- Law on Prohibition of Dsicrimination<sup>10</sup>, which in Article 27 regulates issues related to the provision of health services and prescribes the prohibition of discrimination on any basis in the provision of health services.
- Law on Gender Equality<sup>11</sup> specifically emphasizes the prohibition of discrimination on the basis of gender and prescribes that every person of reproductive age has the right to health care and the provision of health services related to family planning, as well as that partners are equal in planning the number of children, access to information, education and resources which enable the use of these rights.

Specific regulations referring to women (and men) living with HIV are:

• Strategy for the Prevention and Control of HIV Infection and AIDS in the Republic of Serbia, 2018–2025<sup>12</sup>(hereinafter: the Strategy), the general goal of which is "to prevent HIV infection and other sexually transmitted infections, as well as provide treatment and support to all persons living with HIV". Within it, only Measure 1.8. is intended specifically for women, and it reads: Increased number of pregnant women counseled and tested for HIV with effective implementation of programs for the prevention of mother-to-child HIV transmissions. The

<sup>&</sup>lt;sup>7</sup> https://www.pravno-informacioni-sistem.rs/SIGlasnikPortal/eli/rep/sgrs/skupstina/zakon/2019/25/2/reg/. Accessed 29/10/2022

<sup>&</sup>lt;sup>8</sup> http://www.pravno-informacioni-sistem.rs/SIGlasnikPortal/eli/rep/sgrs/skupstina/zakon/2019/25/1/reg. Accessed 29/10/2022

<sup>&</sup>lt;sup>9</sup> https://www.paragraf.rs/propisi/zakon o pravima\_pacijenata.html- Accessed 18/10/2022

<sup>&</sup>lt;sup>10</sup> http://www.pravno-informacioni-sistem.rs/SIGlasnikPortal/eli/rep/sgrs/skupstina/zakon/2009/22/1/reg/. Accessed 21/10/2022

<sup>&</sup>lt;sup>11</sup> https://www.paragraf.rs/propisi/<u>zakon-o-rodnoj-ravnopravnosti.html</u>. Accessed 18/10/2022

<sup>&</sup>lt;sup>12</sup> http://www.pravno-informacioni-sistem.rs/SIGlasnikPortal/eli/rep/sgrs/vlada/strategija/2018/61/2/reg. Accessed 29/10/2022

Strategy states that recommended voluntary testing of pregnant women for HIV is still not a routine practice, so the number of tested pregnant women in the Republic of Serbia is at a low level (about 10% to 15% of all pregnant women annually). As some of the reasons for that, the following are cited: insufficient education and motivation of the medical staff, above all gynecologists in primary health care to offer testing to pregnant women; inadequate cooperation of gynecological services with institutes for health protection; insufficient supply of health protection institutes with tests (lack of material resources for testing pregnant women on referral, i.e. at the expense of RHIF); insufficient education and low motivation of pregnant women; insufficient media promotion. In order to achieve maximum effects in the area of prevention of vertical HIV transmission it is defined as necessary that the coverage of testing of pregnant women for HIV be greater than 95%, especially in environments where a higher rate of cases of HIV infection is registered, as well as that all other measures defined by the Prevention of Mother to Child Transmissions protocol (PMTCT protocol) be implemented.

The Strategy predicts that for the realization of measure 1.8. it is necessary to implement the following activities: (1) Routinely offer voluntary confidential counseling and testing (VCCT) to pregnant women at the primary level of health care (OPT-OUT model); (2) Counsel and test pregnant women particularly sensitive to HIV at the secondary and tertiary level of health care (OPT-OUT model); (3) Educate educators and healthcare workers in order to realize the routine offer of the VCCT service among pregnant women and prevent vertical transmission; (4) Provide/implement antiretroviral therapy (ART) in all pregnant women infected with HIV in accordance with the treatment protocol (lifelong treatment) and other measures defined by the PMTCT protocol; (5) Provide/implement early diagnostics of HIV infection in newborns and infants born of HIV-infected mothers and early treatment of all children diagnosed with HIV infection; (6) Include men in the program of prevention of vertical transmission through the infertility testing and treatment program.

The basic mechanism for coordinating the implementation of the Strategy is the Commission to Fight HIV/AIDS and Tuberculosis<sup>13</sup>, a multidisciplinary consultative body of the Government of the Republic of Serbia, which includes representatives of the relevant ministries, experts working in the field of prevention and control of HIV infection, representatives of civil society organizations, representatives of people living with HIV and other stakeholders. The Commission is appointed by the Government of the Republic of Serbia. The state secretary in the Ministry of Health, who is also the president of the commission, is responsible for the overall coordination of the commission's work and activities, while the vice president of the commission is a representative of the civil sector.

In the Strategy's introduction it is stated that its strategic approach is the realization of the principle of fairness in the health system, disease prevention and comprehensive information, education and raising the level of knowledge about HIV infection, and the basic principle is defined as equal availability of health and social care to people living with HIV and all sensitive categories of the population throughout the territory of the Republic of Serbia. In the indicators for monitoring the implementation of the Strategy, only key populations are insisted upon,

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<sup>&</sup>lt;sup>13</sup> Before this Commission (before 2018) The government established a Council to monitor the implementation of projects in the field of HIV/AIDS and tuberculosis, as foreseen by the requirements of the Global Fund to fight AIDS, tuberculosis and malaria.

while only indicators related to the percentage of children infected with HIV among exposed infants born in the last 12 months and the number of newly diagnosed children with HIV per 100,000 live births are aimed at women. It can be concluded that, within the Strategy, women themselves are not recognized as an important group with their own, more specific needs, aside from the context of pregnancy and childbirth, within PLHIV.

Along with the Strategy, the Action Plan for the period 2018-2021 was adopted, and it was planned that the Action Plan for the period 2022-2025 also be adopted in a timely manner, which, however, has not happened.

- The Criminal Code of the Republic of Serbia<sup>14</sup>, Article 250, which defines punishments for "transmission of HIV infection" and applies to both women and men:
  - (1) Whoever wittingly endangers another with infection by HIV virus, shall be punished by imprisonment up to two years.
  - (2) Whoever wittingly fails to observe regulations and measures relating to prevention of spreading of HIV infection to another person and thereby from negligence effectuates transmission of HIV infection to another person, shall be punished by imprisonment of one to five years.
  - (3) Whoever knowing that he/she is infected with HIV wittingly transmits the infection to another person, shall be punished by imprisonment of two to twelve years.
  - (4) If the offense specified in paragraph 3 of this Article results in death of the infected person, the offender shall be punished by imprisonment of three to fifteen years.
  - (5) If the offense specified in paragraphs 3 or 4 of this Article is committed from negligence, the offender shall be punished for the offense specified in paragraph 3 of this Article by imprisonment up to three years, and for the offense specified in paragraph 4 of this Article by imprisonment of six months to five years.

Regulations related to gender-based violence, which includes violence against women living with HIV:

• The Council of Europe Convention on Preventing and Combating Violence Against Women and Domestic Violence, that is, the Istanbul Convention, which was adopted in Istanbul on May 11, 2011, and which was signed by the Republic of Serbia on April 4, 2012 and ratified on October 31, 2013, so it entered into force on August 1, 2014<sup>15</sup>. Listed among the main goals of the Convention are protection of women from all forms of violence, contribution to the suppression of all forms of discrimination against women, as well as prevention, processing and elimination of violence against women and domestic violence. Although the signatory states of the Convention commit themselves to systematic action in the direction of achieving the mentioned goals and a certain number of measures (such as harmonization of the national legal framework with the Convention's propositions or establishment of the Coordinating Body for Gender Equality, the Sectora for Anti-discrimination Policy and the Promotion of Gender Equality and the Council for the Suppression of Domestic Violence) has formally already been implemented, a

<sup>&</sup>lt;sup>14</sup> https://www.paragraf.rs/propisi/krivicni-zakonik-2019.html. Accessed 31/10/2022

<sup>15</sup> http://www.parlament.gov.rs/upload/archive/files/cir/pdf/zakoni/2013/2246-13.pdf

situational analysis based on immediate field data shows that these efforts have not been made in a comprehensive and coordinated manner, and that they have various strategic and logistical shortcomings (The Istanbul Convention in Serbia – the Practice an Challenges of Gender Equality, The Committee of lawyers for human rights – YUCOM<sup>16</sup>).

- Law on Gender Equality<sup>17</sup>, which prohibits any discrimination on the basis of gender/sex when accessing health or social care services. The measures recognized by the Law for the promotion of gender equality include, among other things, creating equal opportunities for the participation and equal treatment of men and women in areas including social and health protection, as well as reproductive and sexual health. Although it does not deal directly with the subject of violence, Article 54 of the Law prescribes the category of General support services intended for victims of domestic and gender-based violence, and Article 55 defines specialized support services for women who are victims of violence.
- Law on Prevention of Domestic Violence<sup>18</sup> recognizes the physical, psychological, sexual and economic forms of violence. It also foresees the development of an individual protection and support plan for the victim, with the aim of the victim leaving the violent relationship. This law has no gender dimension, and it does not recognize women as additionally victimized, let alone women living with HIV.
- Strategy to Prevent and Combat Gender-based Violence Against Women and Domestic Violence for the period 2021 to 2025<sup>19</sup>, in which it is recognized that the legal system of the Republic of Serbia is not fully compliant with international standards when it comes to combating violence against women, and some of the mapped flaws are the lack of definitions of the terms "violence against women" and "gender-based violence against women" in the legal system. The Strategy has been supplemented compared to previous documents, so under the term of women from sensitive groups it also recognizes "women of a different sexual orientation and gender identity".

None of these documents recognize women living with HIV as a specific, particularly vulnerable category.

Regulations referring to specific groups within the category of women living with HIV (sex workers):

• Law on Public Order and Peace<sup>20</sup>,in Article 16, paragraph 1, defines "prostitution" and punishments for it: Whoever practices prostitution, uses prostitution services or lends premises to prostitution - will be punished with a fine from 50.000 to 150.000 RSD or prison sentense from 30 to 60 days.

<sup>&</sup>lt;sup>16</sup> https://www.yucom.org.rs/wp-content/uploads/2019/03/Istanbulska-konvencija-u-Srbiji-praksa-i-izazovi.pdf

<sup>&</sup>lt;sup>17</sup> https://www.paragraf.rs/propisi/zakon-o-rodnoj-ravnopravnosti.html- Accessed 18/10/2022

http://www.pravno-informacioni-sistem.rs/SIGlasnikPortal/eli/rep/sgrs/skupstina/zakon/2016/94/1/reg.
Accessed 18/10/2022

<sup>&</sup>lt;sup>19</sup> http://www.pravno-informacioni-sistem.rs/SIGlasnikPortal/eli/rep/sgrs/vlada/strategija/2021/47/1. Accessed 18/10/2022

<sup>&</sup>lt;sup>20</sup> https://www.paragraf.rs/propisi/zakon o javnom redu i miru.html. Accessed 21/10/2022

## **Current situation**

According to the available data from the surveillance over HIV infection and AIDS carried out and provided to us by the Institute for Public Health of Serbia "Dr Milan Jovanović Batut", at the end of 2021, 433 women knew they were infected with HIV (had a diagnosed HIV infection, and there is no information that they died as of December 31, 2021), which is 14% of the total number of the people living with HIV and AIDS who knew their HIV status at the end of 2021 in the Republic of Serbia (3.045 people).

According to the same research, in the population of sex workers in Belgrade (N=190) the seroprevalence of HIV infection was 0,5%, while in the population of women who inject drugs in Belgrade (N=87) the seroprevalence of HIV infection was 2,3%. The data further says that 14,7% of respondents from the population of sex workers in Belgrade stated that they had been exposed to physical violence because someone knew or assumed they do sex work, while 11,5% of female respondents from the population of persons who inject drugs in Belgrade stated that they had been exposed to physical violence in the last 12 months. Among the respondents from the population of persons who inject drugs in Belgrade, 67,8% used a sterile needle and syringe when they last injected drugs. Of the respondents who are members of the population of sex workers in Belgrade, 7% stated that they had been tested for sexually transmitted infections in the past three months. Also, 53% of respondents from the population of sex workers in Belgrade, and 8% of respondents from the population of Persons Who Inject Drugs (PWID) in Belgrade had been tested for HIV in the past 12 months and know that the result of their test was negative or know they are living with HIV.

According to the data from the Republic Health Insurance Fund (RHIF), in 2021 a total of 2.289 people with a diagnosed HIV infection used ART, 311 (14% of all people living with HIV and AIDS on ART) of which were women.

According to the last UNAIDS assessment from 2022, of a total of 3.600 people who were living with HIV at the end of 2021 (people with diagnosed and undiagnosed HIV infections) in the Republic of Serbia, it is estimated that there was a total of 520 women (14% of all people living with HIV and AIDS)<sup>21</sup>. Of the 172 people who were diagnosed with HIV infection in 2021, only 6 were women, while of a total of 49 people who were diagnosed with clinical AIDS in 2021 only one was a woman. Of the 14 people who died of AIDS in the Republic of Serbia in 2021, there was only one woman who was diagnosed with HIV infection, that is, AIDS.

Data from the aforementioned research shows that the coverage by the standardized preventive program defined by UNAIDS (at least two of the following services: distribution of sterile needles/syringes, counseling on condom use and safe sexual relations, distribution of condoms and lubricants) in the past three months among the respondents from the population of PWID in Belgrade was 14%, while the coverage by the standardized preventive program defined by UNAIDS (at least two of the following services: testing for a sexually transmitted infection, counseling on condom use and safe sexual relations, distribution of condoms and lubricants) in the past three months among respondents from the population of sex workers in Belgrade was 9%. From the population of sex workers in Belgrade, 97.5% of respondents stated that they had used a condom with their last client, while 25% of

<sup>&</sup>lt;sup>21</sup> https://www.unaids.org/en/regionscountries/countries/serbia. Accessed 21/10/2022

respondents from the population of persons who inject drugs in Belgrade stated that they used a condom during their last sexual encounter among those who had had sex in the past month.

Within the project "Support for Citizens' Associations' Activities in the Field of Prevention and Control of HIV Infection", co-financed with funds from the donation of The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and implemented by the Ministry of Health in cooperation with civil society organizations in 2021, 18% of sex workers (712 different from the total of 3900 sex workers (SW) in the Republic of Serbia) were reached by the preventive program in the community which was realized by three civil society organizations in Belgrade and Novi Sad, while 16% of PWID (3.123 different PWID from the total of 20.000 PWID in the Republic of Serbia) were reached that same year by the preventive program in the community which was realized by 4 civil society organizations in Belgrade and Novi Sad.

In general, the available information suggests that, annually, up to 5 women with a diagnosed HIV infection who are pregnant receive ARV therapy as one of the segments of the clinical protocol for the prevention of transmission of HIV infection from mother to child, that is, all pregnant women who are diagnosed with HIV are included in the program of prevention of the transmission of HIV from mother to child.

In the period from 2002 to 2021 in the Republic of Serbia, a total of 22 children were diagnosed with HIV infection, to whom the HIV infection was transmitted from mothers who did not know they were infected with HIV during the pregnancy, childbirth, or after childbirth, i.e. during breastfeeding.

Almost all of the women who transmitted their HIV infection to their children in the period between 2002 and 2021 reported that they belong to the category of heterosexuals, that is, that they were infected with HIV through sexual intercourse. The Institute for Public Health of Serbia "Milan Jovanović Batut" also states that they do not possess the information whether any of those women were sex workers.

The transmission of HIV infection from mother to child is extremely rare in the Republic of Serbia, that is, the number of newly diagnosed children with HIV (newly diagnosed cases of HIV infection with transmission from mother to child) is less than 5 per 100,000 live births. On the other hand, in the period from 2005 to 2021, more than 40 children were born who were not infected with HIV by mothers who had a diagnosed HIV infection and who were included in the program of prevention of the transmission of HIV from mother to child. Currently living with HIV in the Republic of Serbia are 14 children under 18 years of age, of which 5 are girls.

Activities realized within the response to HIV infection and AIDS are funded from different sources. Costs of blood screening among voluntary blood, tissue and organ donors, of routine surveillance over HIV and sexually transmitted infections, of certain preventive activities, as well as costs of VCCT in medical institutions, are covered by funds from the state budget. The Republic Fund for Health Insurance (RHIF) mostly covers costs related to treatment, therapy (ART, OST) and diagnostics on referral. Treatment and therapy, as well as diagnostics on a doctor's referral are available in the same way to men and women (the condition is to possess health insurance).

The first project to combat AIDS, tuberculosis and malaria, financed by funds from the donation of GFATM, was implemented in the period between 2003 and 2006. After that, the Republic of Serbia received two more projects from the same donation, where the first one, from the round 6 GFATM, in the value of 9 million EUR, was completed in 2012, after 5 years of implementation (2007-2012), and the

other, from round 8 GFATM, in the value of 12 million EUR, was completed in mid-2014 (realization period: 2009-2014).

Programs of prevention of HIV infection, as well as programs of support for people living with HIV were, until mid-2014, supported by funds from the donations of GFATM through a project led by the Unit for the implementation of the GFATM project at the Ministry of Health. After the completion of this project there was a reduction in activity among key populations at risk of HIV, as well as a shutdown of some programs. During 2018, the Ministry of Health implemented the process of application for the GFATM grant for co-financing programs of prevention of HIV infection in key populations (MSM, PWID, SW) and support programs for people living with HIV. This grant was approved and since October of 2019 the Ministry of Health has also started implementing this project entitled "Support to the activities of citizens' associations in the field of HIV infection prevention and control", co-financed by funds from the GFATM donation. Within this project, strategic activities of prevention of HIV infection among MSM, SW i PWID are supported, as well as activities of support to people living with HIV in the Republic of Serbia. The realization of this project started in October 2019, and it is envisaged that the financing of programs for the prevention of HIV infection and programs of support for people living with HIV is continuous, although the co-financing from the funds of GFATM donation lasted until June 30 2022, that is, according to the new GFATM grant, the listed activities for key populations at risk and people living with HIV and AIDS in the community, which are realized by civil society organizations under contract with the Ministry of Health, will be implemented in the period from July 1 2022 until the end of 2025.

During 2019, as well as during 2020 and 2021, the number of people covered by the service of HIV counseling and testing increased, but there were no programs (there still are no such programs) which are intended specifically for women who are not from the population of SW or PWID, which are considered key populations, so in that sense there are no programs or services specifically directed at them.

## Research goals and objectives

The goals of the research "Sexual and Reproductive Health and RIghts of Women Living with HIV in the Republic of Serbia" are:

- identifying key needs of women living with HIV in our country and problems they face, which are related to sexual and reproductive health, viewed through the prism of human rights,
- identifying priorities for the purpose of introducing measures to combat the HIV/AIDS epidemic into national strategies and action plans, as well as
- raising the capacity of women living with HIV and the capacity of civil society organizations that provide them with assistance, in order to increase women's participation in advocacy activities and thus improve their position.

#### Research objectives are:

- to form a social portrait of women living with HIV in the Republic of Serbia,
- to identify the influence of different life factors in women living with HIV, including violence, on their sexual and reproductive health,

- to study the experiences of women living with HIVwhen it comes to access to services in the area of sexual and reproductive health,
- to identify the degree of availability and use of services in the area of sexual and reproductive health by women living with HIV,
- to identify key factors affecting access and opportunities for obtaining different social services for women living with HIV,
- to identify obstacles in accessing health and social services, legal aid, government services, in women living with HIV in order to preserve and maintain sexual and reproductive health of women living with HIV,
- development of recommendations for preserving the rights and increasing access of women living with HIV in the area of sexual and reproductive health and other social services, as well as recommendations for combating the HIV/AIDS epidemic through gender-sensitive and gendertransformative national strategies,
- in the context of the Republic of Serbia, this research will also serve to further form communities of women living with HIV.

## **Research methodology**

The research was organized in two phases:

- 1) Conducting a survey among women living with HIV (including also the collection of life stories).
  - Personal surveying of women living with HIV, within the community and by the community, with the help of a standardized questionnaire, enabling the identification and defining of needs and challenges they encounter based on socio-demographic and other characteristics.
  - The questionnaire also contained open-ended questions, the purpose of which was to provide space for the respondents to describe their positive or negative experiences in areas related to the research topic. Life stories were recorded as responses to open-ended questions.
- 2) Discussions in focus groups with activists, providers of services for women living with HIV and representatives of institutions that provide services or have jurisdiction over service providers.
  - Focus group discussions were conducted in order to also get, aside from personal experiences of women living with HIV, expert opinions on the situation of HIV positive women, which enables a well-founded development of recommendations for improving the legal and normative framework and the quality of their access to services, as well as the formation of suggestions for the prevention of violence against HIV-positive women.

The sample was initially planned to be 100 respondents, although it was assumed that there was a risk that the sample could be smaller, because it is an extremely sensitive group, the members of which shy away from any public communication about their health status. Through a two-and-a-half-month-long outreach and data collection process, the initial number of 100 (100%) respondents was reached.

Before the start of the research, the National Reference Group for Research Implementation was established as an advisory body, which supported the research team in all phases of project

implementation and enabled the research to be carried out in a way that truly meets the needs and interests of women living with HIV. It included women living with HIV from different subgroups, thus respecting the principle of diversity and inclusiveness (women who use drugs, sex workers (SR), lesbian/bisexual/transgender women, young women or those living in discordant couples), as well as representatives of civil society organizations that provide services to women living with HIV in the Republic of Serbia.

For the purpose of the research and as per NGO Re Generation usual protocol, the Ethical opinion for the implementation was asked and received from the Serbian Ethnological and Anthropological Society, in order to advise and approve methodology of the research and safeguarding highest standards of the research implementation with the vulnerable communities we work with.

All respondents gave informed consent to participate in this project.

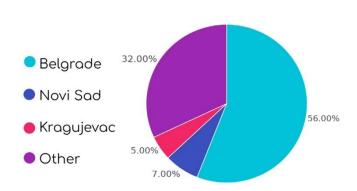


## **Survey analysis**

## **Demographics**

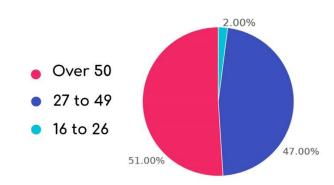
#### Place of residence

As is shown in the graph, the largest number of respondents were from Belgrade (56), and other two major cities were Novi Sad (7) and Kragujevac (5). Niš, which is also a major city with a University clinic, is not represented in the sample, because potential respondents did not want to participate in the research. Other towns are: Pančevo (2), Vršac, Sremska Mitrovica (2), Vrbas, Bačka Topola (3), Bačka Palanka (3), Subotica (4), Palić, Lazarevac,



Obrenovac (2), Šabac (2), Loznica, Čačak, Užice (2), Zlatibor, Raška, Bor, Negotin, Aleksinac, Leskovac. The largest number of the respondents outside the large centers are from Vojvodina, and the smallest from eastern and southern Serbia, which does not mean that there are really fewer women living with HIV in those areas, but rather that there are no civil society organizations that work with them, so they are either unrecognized or are not trusting enough to participate in the research.

#### Age

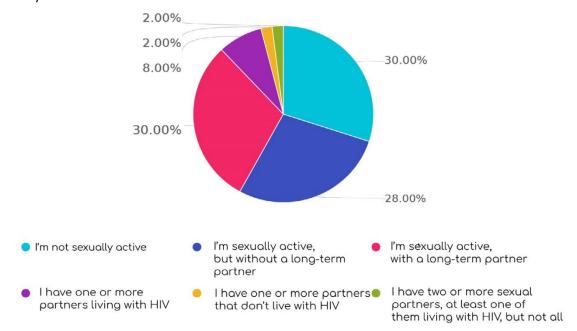


The sample contains very few young women (up to 26 years of age), and slightly more than a half of the women are older than 50 years. It can be assumed that older women, who, as a rule, have known their health status longer, are more willing to talk about the status and the consequences it has on their daily life, while younger women either do not know that they are HIV positive, or do not want to talk about it. This situation can also potentially be linked with the

fact that older women were covered by services in the previous phases of the implementation of the GFATM program, but that in the period of its termination and after 2014 there was no inclusion of women who had not been covered until then.

#### **Sexual activity**

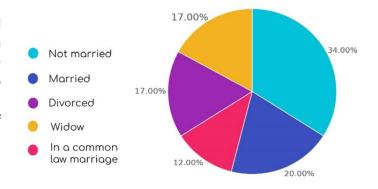
The responses to questions about sexual activity are almost equally distributed between sexually inactive (30%), sexually active with regular partners (30%) and sexually active without a regular partner (28%). The number of those who have one or more partner(s) (8%) and, particularly, those who have partners who are not living with HIV (2%) and those who have partners whose HIV status differs (2%) is significantly smaller.



The large number of sexually inactive women living with HIV can be interpreted as a consequence of stigmatization, due to which they are not ready to engage in sexual relations because that entails disclosing their HIV status. In consultations with service providers, this information was additionally explained as some of them having made the decision to abstain, whereas some have a lowered libido due to medicine side effects or other health issues.

#### **Marital status**

In this sense, the question about sexual activity overlaps with marital status to an extent: married women and those who are in a stable common law marriage make up 32% (20% and 12%) of respondents, widows and divorcees make up a total of 34% (17% and 17%), whereas 34% of them are unmarried.

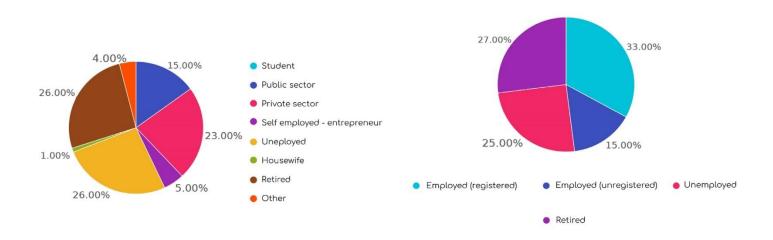


#### **Education**



The largest number of respondents completed a four- (35%) or three-year (22%) secondary school, which corresponds to the average education of the general population in the Republic of Serbia. There are significantly fewer respondents with completed elementary school (9%), and only one has stated that she is illiterate. On the other hand, about a third of the respondents have higher education (college 13%, undergraduate studies 16% and master studies 4%).

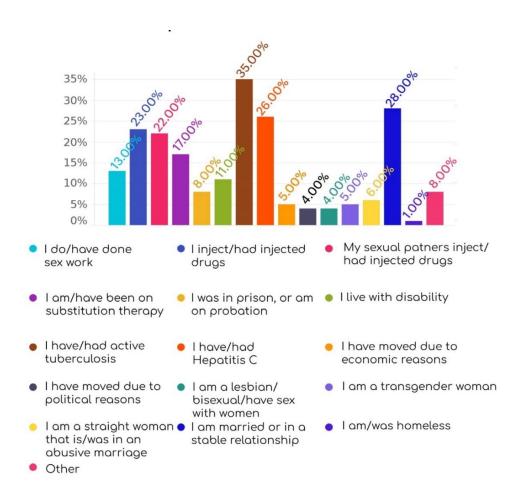
#### **Employment/occupation**



From the respondents' answers, we see that the issue of their economic status is very diverse, but also that they answer very similar questions differently. Housewives are, as a rule, unemployed, but some respondents, when asked about their occupation, opted for the category "Other": one as a recipient of public welfare, because she is unable to work, another one as a person receiving long-term disability benefits (although there is the category "retiree"), third as a sex worker and a fourth one as a high school student, which was really not foreseen in the questionnaire. In consultation with service

providers it was concluded that most women within the retiree category receive long-term disability benefits. It is significantly lower than old-age pension and additionally some of the respondents inherited their deceased parents' or partners' pensions. It is assumed that if "old-age pension" had existed as a response category, the percentage of those responses would have been very small.

#### Other information relevant to the respondent

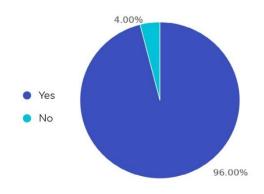


In order to try to get as clear a picture of our respondents completing the questionnaire as possible, the women were asked at the very beginning to mark any statements from the ones listed in the table above which refer to them. Based on the respondents' answers, the fact that a significant percentage of the respondents has comorbidities, that is, other diseases associated with HIV infection, comes to the fore. From the total number of respondents, 35% of them state that they have active tuberculosis or have at some point had tuberculosis, while 26% of respondents have or have at some point in their lives had hepatitis C. Just one of all the respondents stated, in the category "other", that she had hepatitis B.

Of the behaviors which are in public opinion, in addition to non-heterosexual relations, most often associated with HIV as possible ways of HIV transmission, the answers indicate that only 13% of the respondents do or have at some point done sex work, and that 23% of them inject or have injected drugs. Therefore, the results of this research do not confirm the assumption that only women who do sex work or inject drugs are at greater risk of HIV infection.

#### Children

In the examined sample, a total of seven (7) live children were born at a time when the mothers knew about their HIV status. Out of the seven, four have HIV. One of the children is HIV positive even though the mother states that she was not diagnosed with HIV when she gave birth to the child. When it comes to this child, it is unknown if they were born HIV positive or they were exposed to HIV infection after the pregnancy. One child died immediately after birth, and that mother learned that she was HIV positive then, during the childbirth itself.



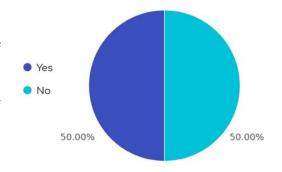
Only 4% of the women learned of their HIV positive status during pregnancy, which means that the rest of the women either already had the diagnosis of HIV before the pregnancy or they were diagnosed after the end of the pregnancy.

By analyzing the demographic data, we can conclude that there is no coherent community of women living with HIV that is proportionally developing, and that could provide support to younger women, but that those women who were once included in the programs and/or those who are currently included in harm reduction programs. More than half of the women who participated in the research do not belong to the "key populations" listed in the Strategy, and logically also in the partnership documents, and the question arises as to which services are available and accessible to them, since the strategy and donors set priorities according to the indicators according to key populations. More than half of the women are also older than 50 years, and there are only 2 of those from the youth category, which calls into question the perception of young women about the need for voluntary and confidential counseling and testing, as well as the coverage of the program in Serbia, and it should be more is being done in the future. Due to a irregular service provision and with the focus on key populations only where men are dominant gender in service provision, we have limitations in reaching out to other women living from HIV that are younger, or are belonging to other vulnerable groups of women

## Experience in gaining access to services in the area of sexual and reproductive health

#### **Disclosing their status**

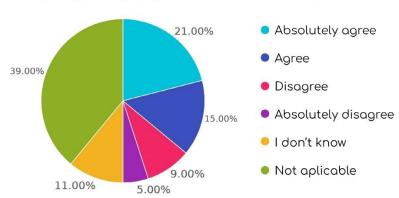
To the question if they reveal their HIV status to the specialist doctor or not, 50% of respondents gave an affirmative answer, and 50% a negative one. However, if one carefully looks at the additional information on the issue of revealing their HIV status in the health system, it can be seen that in actuality the largest number of respondents do not disclose their HIV status, except to gynecologists, while in other cases they keep silent about their HIV status. Those who are in a better financial



situation go to private practice doctors and, as a rule, do not disclose their positive HIV status to them.

Some of them have had bad experiences, although most agree that the situation is better now than it was some ten years ago.

A quarter of the women (25%) do not believe that, when they go to the doctor, they receive the same service as all other women, so that is probably one of the reasons why they hide their HIV positive status. Also, only 28% of the women believe that a doctor/gynecologist will not share their HIV positive status or other information about them without their consent, and only 39% believe that their doctors listen to them and give them appropriate advice and recommendations related to HIV status. This shows a very low level of trust in the health care system in the Republic of Serbia.



When I go to gynecologist, I get the same treatment as any other woman

Three quarters (75%) of the women consider that they are familiar with the therapies, information, services and products which exist in their country in the field of sexual and reproductive health (family planning, contraception, counseling and the like), but only 56% of the respondents state that they can access free and quality therapies, information and services at the gynecologist and other doctors. Of them, 60% believe that gynecologists are expert, friendly and supportive, 65% trust the advice and therapies they receive at the gynecologists and other specialist doctors, but only 45% believe that their gynecologists offer all services, including family planning options and the prevention, diagnostics and therapy of sexually transmitted infections (STI). Most (67%) have never felt any pressure to agree to a therapy, without the doctors having previously given them all the necessary information.

Also, only 35% of respondents think that, in the case of a violation of their rights, they would receive adequate legal protection, in accordance with the law, although 64% of them state that they know their rights and know how and where to file a complaint if those rights are violated. From individual personal experiences, it can be seen that this disproportion is not accidental, but a reflection of the real situation:

"A specialist of pulmology loudly commented on my HIV status. I didn't complain about that".

"I was lying in a hospital and they put my status in red letters on my chart, and I had asked them, because of my parents, who weren't aware of my illness, not to do it".

"Now that I got COVID (last year) they wouldn't admit me to the hospital, they sent me home even though I was very unwell. The female doctor said she didn't have a "special" place/room for me! I didn't have the strength to argue then, afterwards it had been 2 months and I didn't submit a lawsuit".

"A very bad experience in the dental office. The dentist said that because of my HIV status he wouldn't fix my tooth, and I was to go elsewhere".

"Since I live in a small town, everybody knows my HIV status, even those I didn't tell, so sometimes I feel uncomfortable at the doctor's".

However, although less often, there are also positive experiences:

"When I was very young I got HIV from my first partner. Through cooperation with the Institute of Vojvodina I reached the right medication, but they also helped me with my questions about the therapy, medication, as well as other health issues".

"I didn't have a negative experience at the "Narodni front" clinic. Other doctors don't know about my status".

It is a common attitude that the status is only told to the gynecologist, and only in centers which have specialized services, while for everything else the following rule applies:

"I didn't have issues because I didn't disclose my status".

To questions referring to the quality of the provided services, the largest percentage of the respondents answer that they are familiar with therapies, information, services and products which exist in their country in the field of sexual and reproductive health (family planning, contraception, counseling and the like), but that does not have to be a reflection of the real state of the quality of actual provided services, but rather of their perception of the services themselves.

#### How can one help promote and protect sexual and reproductive health and human rights?

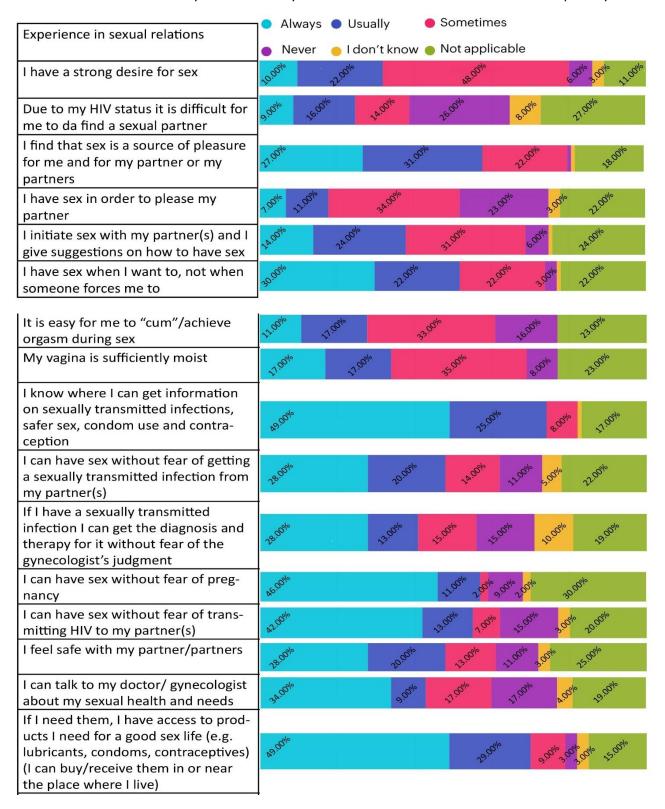
The women mostly answered this question (if they answered) by citing education, both of the general public and of medical workers in particular, especially in smaller communities. Some women insisted that HIV positive status should be categorized as a chronic disease. They also believe that cases of corruption and discrimination should be punished, although they themselves often did not report discrimination. One respondent summarized the fatalistic attitude towards the possibility of improving the situation by answering:

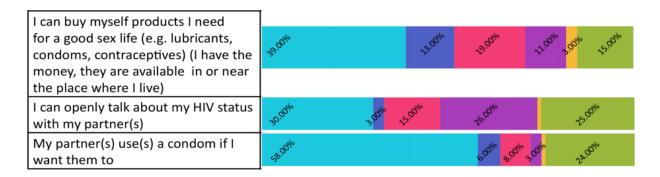
"What is there to promote? We have our ward (residents of Belgrade, at the Narodni front clinic). The rest of the women go to the community health center. Everyone's human rights are violated".

The results of this segment of the research are predominantly confusing and inconsistent and demonstrate that women living with HIV actually don't really understand their position and potential problems, as well as that they lack sufficient knowledge in the field of sexual and reproductive health. Seeing as only 50% of them disclose and admit their HIV status, they actually cannot really answer the question whether they receive a service like any other woman or not, because they access health services precisely as such. It should be noted that in practice and from the experience of service providers, infectologists send women to the Narodni Front clinic, to the specialized ward for guiding the pregnancies of women living with HIV, but that they do not go there except for those women who are planning a pregnancy and those undergoing a gynecological surgical procedure. The rest of them go to their community health centers and to private practices without disclosing their status or they do not go anywhere.

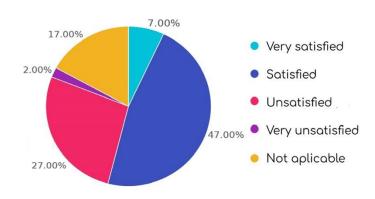
#### **Sexual practices**

The questionnaire foresaw that the questions regarding sexual relations and personal experiences connected to them would only be answered by women who had had sexual relations in the past 2 years.





Satisfaction with sexual relations in the last 2 years:



Respondents who are satisfied with their sex lives as a rule have a regular partner or do not share the information of their HIV status but always use protection. However, there are those who feel insecure even being on ARV therapy and knowing they cannot infect anyone with HIV. A large number of women hide their HIV status for fear of rejection, and almost a half of the respondents have neither regular nor occasional partners

and have actually completely given up on a sex life. Sex workers consider that precisely the clients are their greatest problem, but they do not disclose their status and they insist on using protection. As one of them states:

(The problem is) "the number of clients coming for a longer time period. The biggest problem is sometimes precisely the client. It bothers me that I am left to my own devices."

In a small number of respondents, it has also been noticed that some of them attempt to enter relations with partners who are also HIV positive, for example:

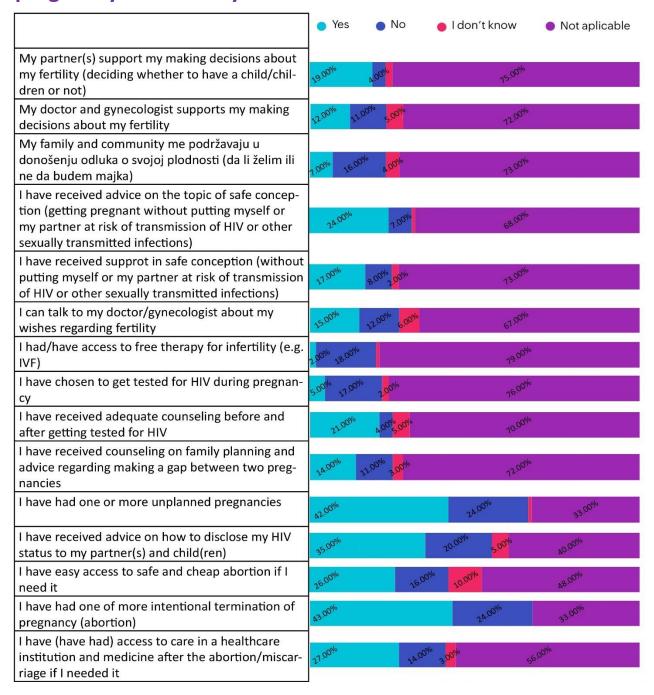
"As an HIV+ woman it is difficult for me to find a partner in my environment. I mostly look for HIV+ partners."

"I have managed to find a few sexual partners who are also HIV+, so I can mostly be satisfied with my sex life."

Women living with HIV should have the same rights and opportunities as all women to enjoy a healthy, safe and satisfying sex life, free from force, coercion, discrimination and violence. From the interviews with the women from the community who filled out the questionnaires with the interviewes, we received feedback that the women were mostly uncomfortable to answer these questions, and the conclusion is that they are not at all empowered to perceive their sexuality and sexual satisfaction as something that is important. This clearly confirms the patriarchal system of values that is a reality in Serbia, where they do not dare to prioritize satisfaction. Those women who are satisfied with their sexual life have partners. A large number of women hide their HIV status due to fear of rejection, and almost half of the respondents have neither permanent nor occasional partners, in fact they have

completely given up their sexual life, which is a clear influence of stigma and discrimination, especially women. from this population.

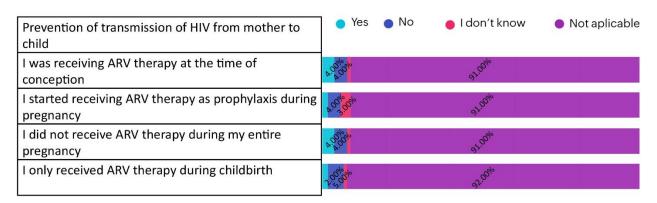
## Experiences of HIV positive women when it comes to pregnancy and fertility



I know that if I want to I can ask for advice on pregnancy/maternity from other women living with HIV	26.00%	16.00% S.00%	53,00%	
While I was pregnant and I knew that I was HIV positive I could decide where I want to give birth	5.00% 15.00% 2.00%		87.00%	
When I gave birth I received support in deciding how to feed my baby without fear of what people will say	5.00° 6.00° 00%	,	<sup>\$2</sup> 00%	
I can decide to have a/another child without fear of what people will say	5.00% 11.00% 2.00%	,	85'00%	
I can decide NOT to have a/another child without fear of what people will say	13.00% 5.00% 000	0	19.00%	
I know there are multiple kinds of family planning or contraception and they are available to me (I can buy them, I can go to counseling in my town and the like)	21 00%	10 00% \$ 00%	58.00%	
My partner has no influence on my decision what kind of contraception to use	28.00°/0	24.00% 2.00%	56.00%	
I have access to emergency contraception (the morning after pill) if I need it (I can buy or receive it)	25.00%	8'00ele 1'00ele	80 00%	
lmam pristup pravnom savetovanju o pitanjima usvajanja (u svom mestu ili okolini)	5.00% 15.00%	71.00%	63.00%	
I have access to pre exposure prophylaxis if my partner needs it (in or near my town)	19.00%	22.00%	47.00%	
I have access postexposure prophylaxis if I need it (in or near my town)	18.00%	23.00%	49.00%	
At least once in 2 years I go for an examination/do a PAP smear for early detection of cervical cancer	44.00°/0		24.00%	32,00%
At least once in 2 years I go for a breast examination (mammography or ultrasound)	8.00%		28.00°1°	23.00%

#### Prevention of the transmission of HIV from mother to child

The question referring to methods of prevention of HIV transmission from mother to child was answered by a total of 9 women who were pregnant while knowing their HIV status. The answers show that 8 women carried their pregnancy to term and gave birth to a child, while one of these women did not give birth. As the research was conducted with anonymity, we cannot know in which way the pregnancy was terminated, whether by spontaneous miscarriage or intentional termination.

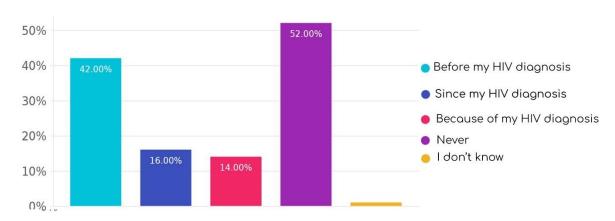




Women living with HIV have the same right as all women to make decisions about when and if they would like to have children, and to do so in a safe and supportive environment, knowing that they can have children without transmit HIV, and that they can receive support in their decision not to have children if they do not want them. Analyzing the answers of this segment, we learn that for those women who want children, it is clear where they can get support if they want it, but that the number of women who do not have support to make decisions about how and in what way they want to grow their family is smaller. The department of the People's Front where women living with HIV go to give birth is highly praised by both service providers and women who have been there. The limitation in providing services for women living with HIV who want to give birth safely is that they have to come to Belgrade and if they do not have that support, it is difficult for them to access the service.

#### **Violence**

Violence by sexual/intimate partner



Violence by a sexual/intimate partner was experienced by slightly less than half of the respondents: 52% say they have never experienced partner violence. A correlation between HIV positive status and partner violence, however, was recognized by only 30% of respondents (16% since they were diagnosed with HIV positive status, and 14% believe that the diagnosis is the cause of the abuse), even though as many as 42% stated that they had experienced partner abuse even before their positive HIV status was determined.

Most women believed that they have never experienced abuse by a family member or neighbor (68%) or within the community (74%). The percentage of those who state that they haven't experienced violence in a healthcare setting (55%) is slightly smaller, while 20% of respondents state they have experienced violence since they were diagnosed with HIV, and 24% believe that violence in health care was caused by their HIV positive diagnosis. They explicitly state:

"I was asked multiple times how I got HIV, whether I had been using drugs. They wrote it on my chart (the status) and talked inappropriately about it."

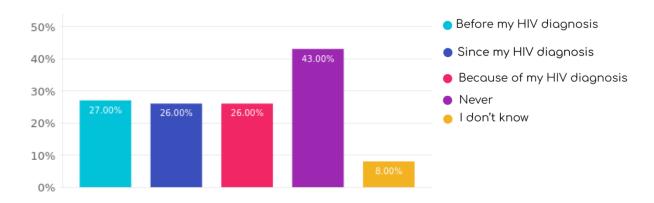
"At the community health center when I hadn't yet decided not to disclose my HIV status, I told them I was HIV, and they wrote in big red letters on the front page of my chart (that I was) HIV+. I went to the director and they erased it. Since then I don't tell my status, and I have changed community health care centers."

The large percentage (82%) of women who stated they had never experienced violence by police/army/prison or jail staff is a consequence of the fact that a small percentage of the respondents have actually been to prison (7%) or had closer contact with the police.

Although the percentage of the respondents who state that they have never experienced any form of violence is relatively high, there is still fear of possible violence among them to a significantly greater extent than could be assumed based on their real experiences. Particularly higher is the percentage of the respondents who fear possible violence since they have been diagnosed with HIV (26%) or believe that it is possible to be exposed to violence due to the diagnosis (26%). As one of them states:

"No one knows my status, but I fear someone would be violent if they learned."

I have experienced fear of any form of violence:



Most respondents who have experienced some form of violence did not even ask for any sort of help and/or support, because: "nobody protects those who are like me". The small number of those who did ask for help turned, as a rule, to non-governmental agencies for advice or psychological support:

"There used to be no non-governmental organizations that help people living with HIV and AIDS or persons who inject drugs. Now it's different, although the services aren't adapted specifically to women."

Only one respondent said she had turned to the Center for Social Work, where they helped her divorce and thus leave a violent relationship, but that was before she contracted HIV.

	• Very important	<ul><li>Less important</li></ul>
What do you think are the best ways to solve or prevent these forms of violence?	<ul><li>Not important</li></ul>	<ul> <li>Haven't tought about it</li> </ul>
Elimination of laws that criminalize sex work (prostitution)	83.00%	Check Bridge
Elimination of laws that criminalize drug possession	57.00%	16 age 51 age
Elimination of laws that criminalize exposure to HIV/transmission of HIV	63.18%	3.300° 500° 3.900°
Providing access to free rehabilitation and addiction treatment (alcohol, drugs)	84.10%	9.05% c.05%
Improving women's access to education and employment (professional training, tuitions, free courses, greater engagement of the National Employment Service)	op galo	And the second s
Providing increased social protection to women and children (social assistance, free baby formula, prescriptions for free medication, going to sanatoriums for therapies, especially for children with disabilities)	88 tg.	2000-000
An easier way to enroll a child in kindergarten (eliminate kindergarten waitlists)	82.90°/°	3,500% 25,00%
Improving access to harm reduction programs for women who use drugs and sex workers by providing services directed at women	8V.106/0	195° 0,95°
Focusing health workers' attention on the rights of women living with HIV (through training health workers for work with HIV+ women, introducing courses into medical schools/institutes/universities, conducting trainings in hospitals and polyclinics)	91.0glo	ç, ja <sup>n</sup> ı, ga <sup>n</sup> ı

When it comes to offered possibilities for reducing violence against women and improving their access to services, 24% of the respondents have never thought about recognizing and responding to the problem of marital or partner rape (analysis, building an evidence base, implementing educational campaigns) as one possibility, while 2% of them consider this to be completely irrelevant.

As for the experience of violence, the largest number of women experienced violence from their partners, to a large extent even before learning about their diagnosis, while about a quarter of the respondents experienced forms of violence in the health and social welfare system. Only 8% of women experienced violence from police officers - which has something to do with the sample and the fact that a small number of women come from the position of key populations, and for that reason they did not have close contacts with the police and the army. In relation to experiences with violence, the percentage of experiencing violence is lower compared to the perception of the possibility of experiencing it, which shows a high degree of stigma and discrimination perceived by the respondents, which permeate as the most frequent factor in understanding the worldview and situation of women living with HIV- om to questions about violence and access to services. They see a possible solution in greater education of the health and social workers themselves in the system in which they access services, as well as the general population in this regard. Also, a large number of them see the need for

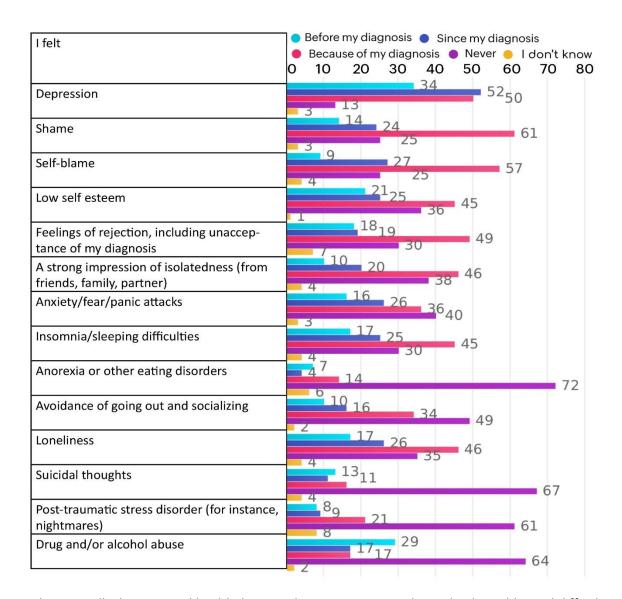
a better system of referrals to other services and SOS lines, improvement of access to safe houses as well as harm reduction program services and improvement of the capacity of the wounded in the same.

What do you think are the best ways to improve the access to quality support services for women who have experienced	<ul><li>Very important</li><li>Not important</li></ul>	<ul> <li>Less important</li> <li>Haven't tought about it</li> </ul>
violence (including sexual violence)	-	
Centers/shelters with the possibility of 24/7 accommodation, including for women with children	91.00%	30000
Centers/shelters with the possibility of 24/7 accommodation, including for women with children and for women who use drugs, sex workers and/or OST patients	97,00%	god*
SOS line available 24/7	97.00	, 00° 30° 00° 00° 00° 00° 00° 00° 00° 00°
Support groups	81/108/	, big, og,
Professional counseling (doctor, psychotherapist, lawyer, social worker)	93.00 <sup>6</sup>	3.00 000
Providing a minimum of free support after rape, including post-exposure prophylaxis, emergency contraception, testing for STI, social welfare and counseling	g, dd	1,55%
Providing legal protection from all forms of violence against women (free legal help, lawyers for women who use drugs and sex workers, mobile response teams, cooperation with the authorities with the aim of reducing police violence)	og and	° Zig <mark>k</mark> ah
Recognizing and responding to the issue of marital or partner rape (analysis, building an evidence base, implementing educational campaigns)	12.00°	Cook 24.00%
Providing efficient mechanisms for filing complaints and compensations in case of rights violations in health services (SOS phone line of the Ministry of Health/regional institute, surveillance over violations and reports of patient organizations to supervisory boards)	*chi	2 200 Lach
Other	1228 92.788	٥

#### **Mental health**

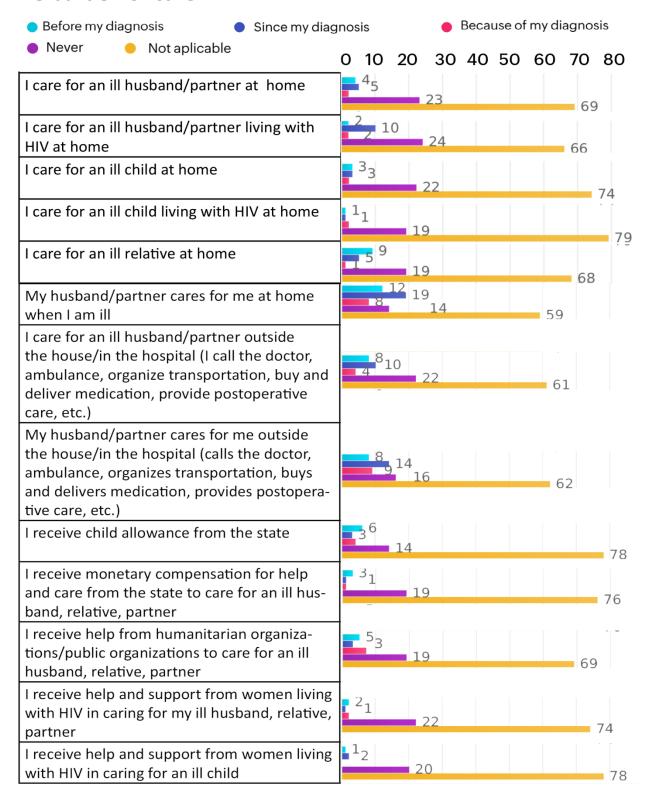
Most women stated that the health issues they experienced negatively influenced their sex lives, above all by reducing their interest in sexual relations, and as many as 6 stated that it influenced their decision not to have children (or not to have any more children). The lack of a desire for sex was a consequence of the general feeling lack of motivation and lack of confidence ("I feel like I am not a woman sometimes").

They all estimate that psychological help and support are the best contribution to the mental health of women living with HIV. Although most of them consider that medical help is necessary there (but less "medication", and more conversation), a part of them also believe in support provided by civil society organizations, i.e. they think that support groups are valuable help in the re-establishment of mental health. Because of that they think that psychosocial support and support groups have to be more available, but also that it is necessary to reduce stigmatization and achieve better understanding in society.



When we talk about mental health, living with HIV in some people can lead to additional difficulties with mental health, so an important contribution of this research is the understanding of the state of mental health of women living with HIV. All respondents stated that psychological and community support is an important service that they think they would need to improve their mental health. Since there is no psychological support as a service at the infectious disease clinic (in Belgrade, where the largest number of respondents come from), but only within the framework of civil society organizations and not all, this service adapted to the needs of women would be one of the most important improvements in the system of support for women who, due to their People with HIV status need psychological support. Support in the community, on the other hand, can contribute to strengthening the community, which could result in better representation of women and their needs among decision makers and stronger advocacy capacities.

#### The burden of care



#### Who performs the following activities in your household?

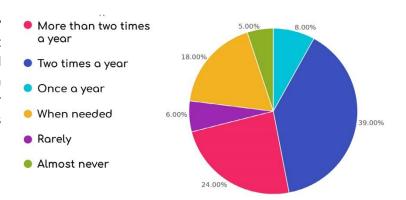
Who performs the	Only I	<ul><li>Only my partner</li></ul>	Together
following activities in your household?	<ul> <li>Sometimes partner, sometimes l</li> </ul>	Other household members	<ul><li>Not aplicable</li></ul>
Getting children ready for kindergarten/school in the morning	7300° 700°	ga.tugh	
Cooking	26:10° 2:00° 11:00°	god god god	
Cleaning the house	28,00%	Ar dela	
Laundry	33.10 <sup>616</sup>	gaso gaso gaso	lo .
Ironing	38 M3 10	" And " Green of the Charles	
Taking/bringing children home from kindergarten/school	gaste gaste aste	& del	9
Buying groceries/cleaning supplies	13.10°10	gath state	
Buying household appliances and other machines		Track, Track, 25'Tag,	0
Buying children's clothes	Trugge Tage	<sup>40</sup> Cg <sup>2</sup>	o
Paying utility bills	1261°	Jage Stage	\$
Organizing house parties		1 pp	o
Organizing parties outside the house (going to a cafe, theater and other)	**************************************	& of	ojo
Attending parent-teacher conferences/children's events	2200% 200% 200%	₽,¢	glo
Visiting the pediatrician/ Buying medication for children	Fig. Fig. Pag.	\$ <sup>6</sup>	Slo
Hospital visits/communi- cation with doctors/buying medication for adult family members	7	1 sego	
Caring for ill children at home	3.00% 1.00%	ęs <sup>5</sup>	is <sub>e</sub>
Caring for ill adult family members at home	Andelo Sacho Cacho	495	20 <sup>10</sup>

The questionnaire stipulates that this question should only be answered by women who lived in marriage or common law marriage with a partner during the past 2 years, so for this reason a large number of women did not answer this question.

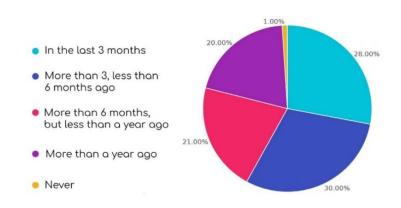
The distribution of household labor does not indicate any rules. A very small number of women have children that go to the kindergarten or the lower grades of elementary school, and from the data it cannot be concluded that the organization and distribution of household labor is a rule for one group of women in relation to another. It can only be concluded that each of them has organized her private life as best she could.

#### **Treatment**

To the question of how often they visit their infectologist, the largest number of respondents answered they do so two or more times a year, and only a small number controls their state "rarely", "as needed" or "never".



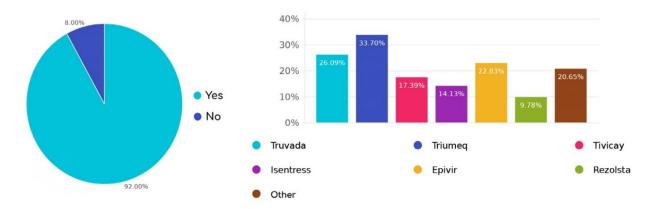
It is the same with the checking of blood CD4 level:



In the last 3 months, 28% (28) of the women had checked their blood CD4 level, for 30% (30) of the women it had been more than 3 but less than 6 months, 21% (21) of the women had checked it last more than 6 months but less than a year ago, 20% (20) of the women had checked it last more than a year ago, and just one 1% (1) never.

Of the total number of respondents, as many as 22 did not know their blood CD4 level, which corresponds approximately to the number of those who had last checked their CD4 level more than a year ago (20) or never (1).

An overwhelming majority of respondents take antiretroviral therapy. Of all respondents, only two did not know the name of the medication(s) they take. Others have different prescribed therapies which they receive at the expense of RFHI (the medication is received with a relatively low participation).



Those who stated they do not take ART offered the following explanations:

"They make me feel unwell, I don't need them."

"I don't believe it helps, and I feel unwell from it."

"I consider plant therapy to be much better."

"I forget to take the therapy, so I gave up."

"I think they don't help me."

"I don't need them."

"They bother me."

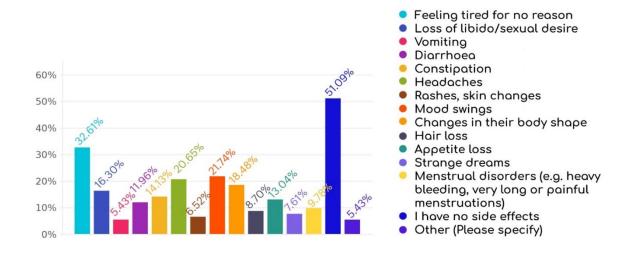
"I don't have a health card, it's not certified, and I don't have money for therapy, and I won't beq."

Although the issuance of a health card should be resolved by the Law on Health Insurance, specifically Article 228 and Article 16, paragraph 1<sup>22</sup>, in practice it is more difficult, according to the experiences of those working in CSOs that provide services to people living with HIV, because if people have debts on the basis of health insurance contributions, the first round of their ART is approved, but then the Fund insists that the debts be settled, and from practice they know no one whose debts were voided and card certified. When it comes to the Roma population, persons without citizenship, and displaced persons, by the Law on Health Protection (Sl.glasnik br.25/2019 Article 15) everybody has the right to health protection, but in practice it does not work like that. A person with temporary residence, without citizenship of the Republic of Serbia, bears the cost of treatment on their own, so for each category of the population there are regulations regarding how they realize health protection.

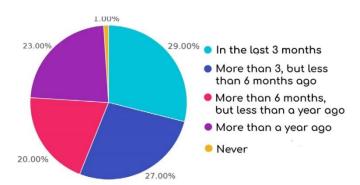
Regarding the side effects of some of the medications they take, the respondents gave different answers to questions about their general state of health. The question was answered by the 92 respondents who had previously responded that they take medication.

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<sup>&</sup>lt;sup>22</sup> Official gazette br 25/2019



### When was the last time you checked your viremia?



Virtually half of the respondents (42%) do not know or cannot remember what their viremia was last time they measured it, which indicates that either the data is not communicated as a figure, i.e. in numerical values, but rather only if it is good or not, or it is not a relevant piece of information for them which affects their everyday life.

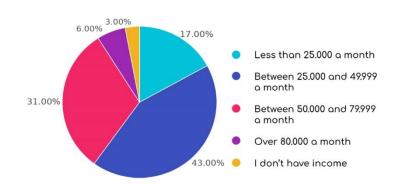
Regarding treatment and visits to the doctor, the vast majority of women go to the doctor regularly, and there are only a few who go rarely or never. This can be related to the time interval that is prescribed when they are given prescription drugs that allow them to take their therapy on time, which is supported by the RFZO. The number of women who do not go to the doctor regularly and do not take therapy generally have difficulties in accessing it, due to the price of the therapy or the inability to get it through insurance (they are not insured) or because of the severity and side effects of the therapy that they felt while taking it, and it is very possible that they did not discuss the consequences with their doctor in order to mitigate them.

Again, it is questionable how many women there are that we did not reach through this research in this short time, and who potentially have difficult access to both health services and access to voluntary confidential counseling and testing, which are narratively directed at the MSM population and not at young women who may (but not necessarily) come from key populations. It is necessary to work on improving the design of testing services for HIV, as well as other sexually transmitted infections, but also on innovations in access to the female population coming from key populations and risk groups in the way they need to feel that they are part of the community.

# Income and economic opportunities

#### **Income**

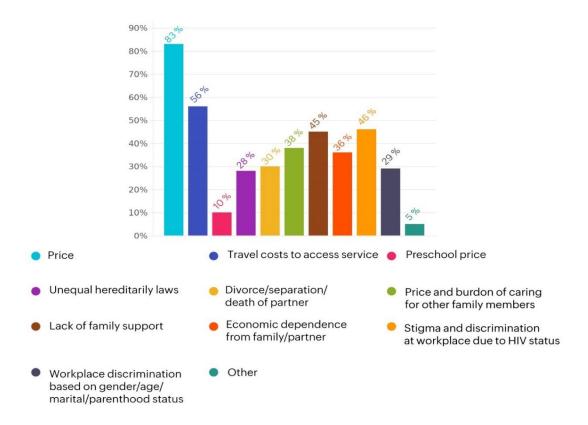
Almost half of the women who took part in this research have an income of between 25.000 and 49.999 RSD per month (43%). The percentage of those who have an income of less than 25.000 (17%) and those who have no income (3%) is significant as well, given the fact that they are at the bottom of the economic ladder, in a position of poverty, which makes their access to



medical, as well as all other potential services they should be able to access, significantly more difficult.

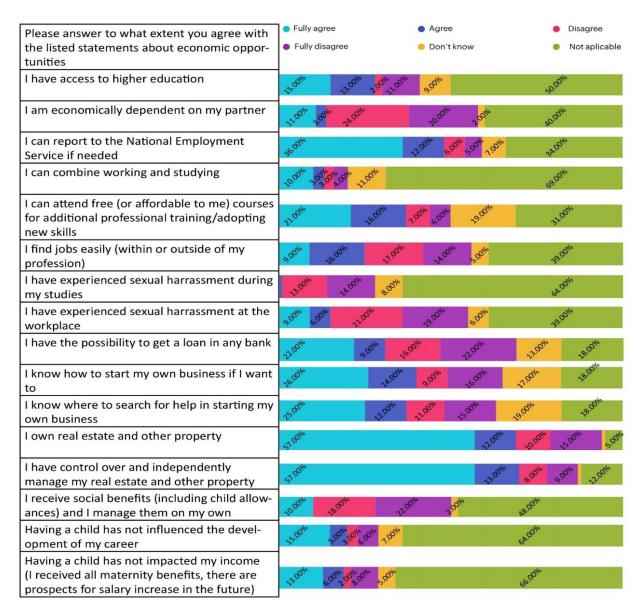
All of them, even those whose income is relatively high, think that they would need more money for a quality standard of life, but as a rule they estimate that that amount should be 50-100% higher than their current income.

### What makes the access of women living with HIV to quality health services more difficult?



The cost of services and costs of travel in order to access services are recognized by the respondents as the most important factors that make their access to services more difficult in a situation where declaratively there is free health protection on the whole territory of the state. This is the consequence of the fact that women most often visit doctors who have private practices, because that way they do not come into the situation of being stigmatized or discriminated against, or that they do not visit doctors in their own towns, but rather travel to another, as a rule bigger, town. The cases of pregnant women or women who are planning to have children are special, because services intended for them only exist in Belgrade (capital), so they are all forced to travel to Belgrade, which entails a significant increase in costs.

#### To what extent do you agree with the listed statements concerning economic opportunities



The respondents think that for the improvement of their position it would be important that there be a possibility for them to obtain better paid jobs, that active measures for hiring people living with HIV exist, and that HIV be declared a chronic illness, for that reduces discrimination in all situations, including obtaining employment. The respondents who are not socially insured (do not possess a health card) and members of the Roma national minority consider their status to need a special solution because currently no one is taking care of them.

# Qualitative analysis and focus groups

Within the second phase of the research two focus groups were conducted, one live and one online, which were preceded by a short questionnaire that served to assess priorities and attitudes on issues related to the lives of women living with HIV in the Republic of Serbia, based on their own attitudes, but also the attitudes and opinions of those who directly and indirectly provide services to women with HIV. After the completion of questionnaires, conversations in the form of semi-structured interviews followed. A total of 13 representatives of 8 different CSOs which operate in the field of HIV participated in focus groups, of which 3 CSOs primarily provide support to people living with HIV, 4 work primarily in the field of prevention and harm reduction, while one CSO is oriented towards work in the field of policy and advocacy.

The questionnaire was, aside from service providers, also completed by representatives from governmental institutions in the field of public health, 2 service providers and one representative from the Institute for Public Health of Serbia "Dr Milan Jovanović Batut".

The methodology for conducting the focus group discussions was adapted for the conditions in the Republic of Serbia; it was planned that focus groups be held with women living with HIV who are simultaneously service providers. Since in the Republic of Serbia there are only 5 people living with HIV who are service providers, that is the number of people who completed the questionnaire; of these 5 people, 3 are women.

The first conversation topic were policies and practice in the field of HIV which apply specifically to women and girls. When it comes to laws and regulations, the participants of the focus groups do not recognize documents that improve the access of women living with HIV to services connected to sexual and reproductive health and HIV. Through conversation in one of the focus groups, an example of good practice was identified when it comes to pregnancy managing in the Gynecological-obstetric clinic "Narodni front", but also identified was a lack of the implementation of such protocols in Niš, Novi Sad and Kragujevac.

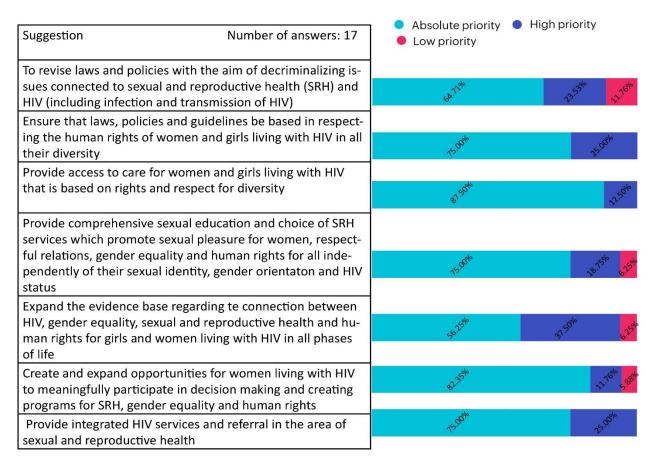
- FG2\_1: "I've never seen it, but I've heard that story from... from above all women who are, um... at te "Narodni front" clinic (were pregnant)... there is a special ward there for, let's say, te reproductive health of women living with HIV because of the special way of caring for te pregnancy."
- FG2\_3: "I don't know about Novi Sad, I know of some two cases where doctors were stupefied and expeditiously sent for Belgrade. Washed their hands of it all, said that it isn't smart to do that at all, to give birth to children, and that happened not so long ago and the women gave birth in Belgrade. But that shouldn't be the practice, for a simple reason, we can't all go to Belgrade."
- FG2\_2: "ere, let me add, yes, so from Niš pregnant women wo ave IV are referred to Belgrade, so, tat means, tere isn't a special gynecological ward ere in Niš, as far as I know, tat as so far had HIV mothers."

Wen it comes to laws and regulations which impede the access of women living wit HIV to services related to sexual and reproductive health and HIV, service providers have no specific objections to laws, but, except for Article 245 about negligent transmission of HIV infection, the overall attitude is that the laws that exist in our country are not followed, especially the Law on Prohibition of Discrimination.

FG2\_1: "...I don't think that there are aggravating, instead I think that existing laws aren't followed, so in that sense, if you have four centers and four Infectious Disease Clinics, so Belgrade, Novi Sad, Niš and Kragujevac, and if you have women, who don't have the possibility, who are living with HIV, to get a gynecological examination within either community health centers or clinical centers if we raise it to the higher, tertiary level, so then you have a violation of elementary laws, above all the one saying that health protection is available to all."

FG1\_2: "Well, there is only that law 245, paragraph 2, regarding unintentional HIV transmission, if you don't tell, let's say, your partner, you could go to prison for 12 years."

# **Policies and strategies**



Service providers stated that in the fields of policies and practice special attention should be paid to women who use drugs, people without a roof over their head, members of the LGBTIQ+ community, ethnic minorities, sex workers, and that the need for gender sensitive interventions in accordance with

evidence, for people living with HIV and AIDS as well as other sensitive population categories (in the area of public health), should be strategically defined.

The respondents do not know of any examples of good practice when it comes to successful integration of gender and HIV (gender sensitive service provision). Prevention services, voluntary testing and counseling, as well as treatment, are not gender-directed, but are planned and edited according to the needs of key populations which are defined, among other things, by the Strategy for Prevention and Control of HIV Infection and AIDS in the Republic of Serbia, 2018–2025, which are injecting drug users, men who also have sexual relations with men, sex workers and persons serving a prison sentense. In the provision of these services, if women appear in some of those CSOs, they will not be denied the services, but they will receive the same services which are provided to all, therefore they will not be gendersensitive. Precisely because of that, women approach CSOs dealing with HIV less, for they are aware that those spaces are not intended exclusively for them. They also consider the implementation of gendersensitive services to be dependent also on the management of CSOs, which in the Republic of Serbia mainly consists of men.

FG1\_4: "...a woman talks more easily to a woman than to a man, I would never go to <name of organization> and ask anything, I know <name of service provider> but it wouldn't cross my mind, I mean really, and with <name of person> I come here whenever I need, about everything, whatever is bothering me, I call her or come and we talk openly."

FG2\_6: "Well probably we have hardly heard of a humane approach, let alone a gender, um, sensitive"

FG2\_3: "About 3-4 women come to our organization. These others we know independently, we meet more at, say, coffees or when there's an issue "hello, can you do this, what do I do here or here"..."And that's it... I have women who simply... regardless of education, of all that, somehow have... an aversion to men when it comes to that, and now I am, I'm in contact with them, to create a social event, if there's five of us – there's five of us, we don't care. We have to start from so-from somewhere, because now that I have done all this (the is referring to the questionnaire), now that I've heard all that, it... the questionnaire itself takes 45 minutes at the very most, those are up to 3-hour-long conversations, meaning that women need conversation, they don't like to come to us but if I now manage to say that at that moment there will be women, some to whom I have talked accepted such a possibility. So let's just get out of here, let's move from this standstill... let them start coming even at first only when women are there, and later we'll see."

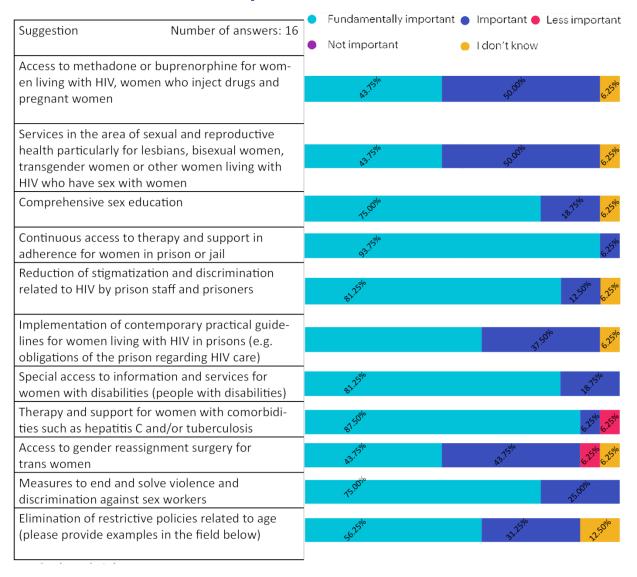
FG2\_1: "It is very difficult to unite women, they are otherwise marginalized and discriminated against in a much more specific way than men. And, there you also have one thing, if we are talking entirely openly, that, say, many of those older women have a... resistance, when she asks me "And who's going to be there? Are those young people?" And now she says, right, a certain word. Um... I mean, which describes their sexual orientation."

Another important fact is that donors' policies for the programs which are available in the Republic of Serbia also influence the availability of programs specifically for women:

FG2\_4: Yes, it is also a problem that donors very often, how do I put this, will not fund something where they cannot get a large number of users, that's also an issue in preventive services, why aren't women included, because the donor is looking for a population which is simply at that

moment proven to be at increased risk, and that's the MSM population. And you simply don't even have the option of applying for a program, project, which includes women. I mean simply, if we sent and said that is the number, that the support is for women and that there will be 10 women, simply no one would want to fund that. And that's the problem, I mean, we can only include them through already existing programs, e.g. psychological support for all.

# The factors that help women realize full access to services in the area of sexual and reproductive health:

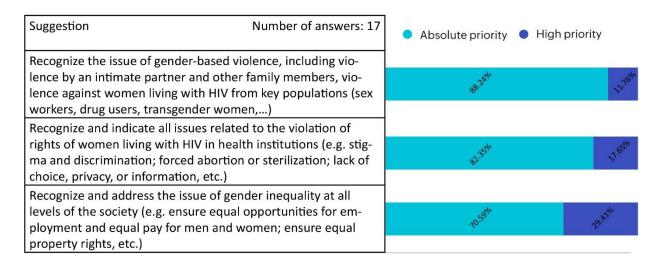


# **Gender-based violence**

When it comes to gender-based violence, the respondents were asked to share success stories of CSOs providing HIV services in the field of combating gender-based violence, as well as to map out governmental institutions in which they noticed institutionalized violence against women living with HIV. In this respect, all focus group respondents know of no civil society organizations or governmental

institutions which deal with the topic of gender-based violence specifically for women living with HIV. From the conversation about institutional discrimination, as well as from the data collected in this research, it is clear that discrimination in this area is very difficult to track because people do not disclose their HIV status:

FG2\_1: "When they ask "Is there discrimination?" Well there isn't because, I was just talking the other day to the commissioner, she says "There isn't". Well there isn't because people don't say they are HIV positive... Still, I can't really say "there would be if they said" either, because I don't know who will react in what way."



Other priorities related to gender policies and gender-based violence defined by the respondents refer to suggestions to tighten penal and legal regulations regarding violence, better implement laws governing this area, punish the media which inadequately report on cases of violence, implement pronounced legal measures, call to account the members of the Ministry of Internal Affairs, journalists, judiciary, prosecution, and the like. Additionally, they stated that, like when it comes to health services, an improvement within social protection (help and support of social services/public institutions) is needed, so as to, for instance, give space to the women who due to their HIV status fear for parenting and loss of parental rights, and therefore turn neither to the health protection system nor to the social protection system, some need material security, etc. It is necessary for services that are prescribed at the national level to be actually implemented at the national level, and not centralized only in Belgrade. As for parental rights, there is no data on how many, it any, such cases existed – except for one which reached the court in Strasbourg<sup>23</sup>; this is assumed to rather be a reflection of the lack of trust in the system and the fear of discrimination and stigma.

# Access to care and treatment

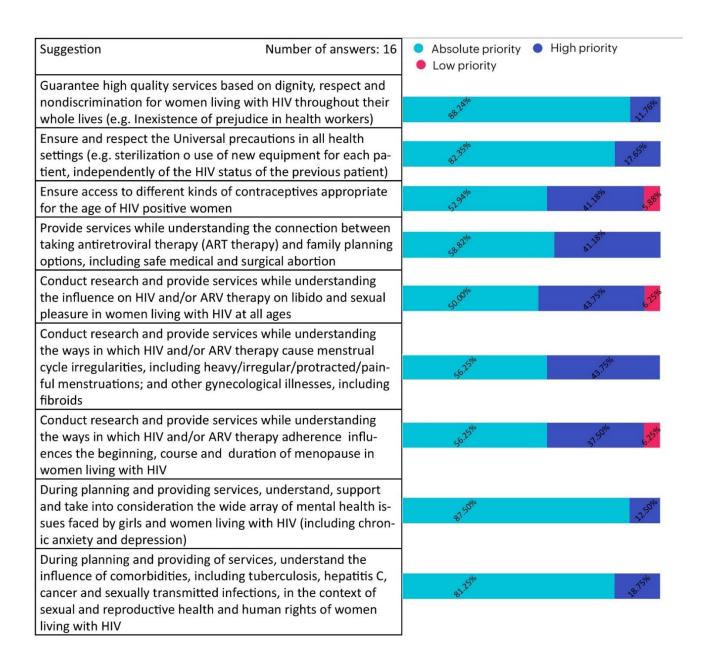
In the context of ARV therapy and support in treatment, the respondents do not have examples from practice when the improvement of compliance/adherence to ARV therapy had different approaches for men and for women. To the question if they are trained for different approaches in social support of

<sup>&</sup>lt;sup>23</sup> DF SPC Čovekoljublje (2012), Kako protiv diskriminacije osoba koje žive sa HIV/SIDOM u Srbiji?, Srbija

ARV therapy for women of different ages, from adolescents to women in menopause, and if they have applied these approaches in practice, their answer is the following:

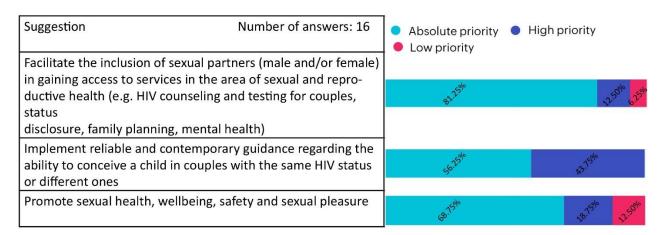
FG1\_3: "No. No. We didn't have, first no one ever told us that there is a difference in therapy dosage for children, adults, old men, old women, and the rest. So, it is only known that there are syrups for children, like, up to the age of 16, and already over 15-16 when they can swallow a tablet they start giving ordinary tablets, there is no more difference whatsoever."

GF1\_1: "And imagine female approaches, age, it doesn't matter at all, if she's 25 or 85. If it's menopause or menstruation or menstruation loss, or whatever, nothing, never. That we didn't, that wasn't so much as mentioned in education, here, say, never."



When asked how often, as service providers, they had counseled sexual partners (men and/or women) on issues of sexual and reproductive health in HIV positive women they stated the following:

- FG2\_1: "If we're talking about women now, so, in all these years I have only had 2 times, and only when the women decided to give birth."
- FG1\_3: "Worst of all is that women living with HIV have their partners much less, and much less often have regular partners, than MSM men or men living with HIV. Simply, they have partners much less often, dare to have a relationship much less often."
- FG1\_5:" It's unclear when it's harder (to disclose your status to your partner), at the beginning or later."



The respondents stated that preventive steps towards reducing the incidence of sexually transmitted infections are a special priority in the field of sexual relations, seeing as HIV is just one segment in the area of reproductive health. They also think awareness should be raised about the fact that proper application of ARV therapy reduces the possibility of HIV transmissions from mother to child, but also that the need for an increased access to IVF procedures for partners of different HIV status should be emphasized.

When it comes to assessments about the extent to which what the state offers in the field of care and support for the children of women living with HIV satisfies their needs, the respondents state that there is no systemic support in this area, and that even the support that existed until recently was provided on a voluntary basis. There is no psychological support for the MSM population either within the institutional system, so that is also the case with support for women and children.

- FG2\_3: "Well honestly I haven't even heard there is such a thing, unfortunately, I only know of cases where children learned in a very horrible way that their parents are positive, where in infirmaries they went so far as to write on their charts that their parents are positive, yes, so I don't know, maybe there really is some kind of help, I don't know of that. They can only have the opposite effect, as far as I can tell and as far as my experience goes, they can only do the opposite of helping."
- FG2\_4: "I wanted to say that, I mean, not just in that context but in general, within institutions there is no kind, I mean, everything is based on the treatment thing and that's it. I mean, we

don't have, here, [FG2\_1] has just said, so, the infectious disease clinic doesn't have psychological support, so there hasn't been a psychologist there, um, for a long time, I mean Jelena while she was working there she was volunteering, but for a long time now there hasn't been anyone there. So all of that, um, boils down to whether an organization has some kind of support within their activities or not, which again, so, it's just simply left, like, will the organization get a donation for those kinds of things or not. So I'm pretty sure it doesn't exist, I think."

FG2\_1"You know what, you have 2 cases there, or, unfortunately, according to statistical data, so, if the HIV positive status is not discovered in time in children that are so small, very soon they enter the terminal phase of the illness, the organism simply breaks down. If they were discovered in time, um, here, these children are already grown and they are taking therapy non-stop, they're okay. But, I see a lack of one continuous psychological support which should be provided to them from the start, and it should of course grow with time, completely develop and have, right, different aspects of what they need as a child, adolescent, later in sexual maturing and other things."

FG2\_1: "I encountered this girl some time ago, one of those girls, she is finishing undergraduate studies, her grandmother took care of her, it was the same case, parents were drug users and the were both deceased, um, and she is so completely alone now, I mean, really. And she would surely need some support from the system, but there is none. "

On the other hand, it was noticed that the level of stigma and discrimination by the general population towards children who are HIV positive is high, and that in some cases families were dissuaded from enrolling their children in kindergarten, or parents withdrew their children from a kindergarten if an HIV positive child was attending it. Since such situations are relatively few, they were reacted to on a case-to-case basis, without searching for a systemic solution:

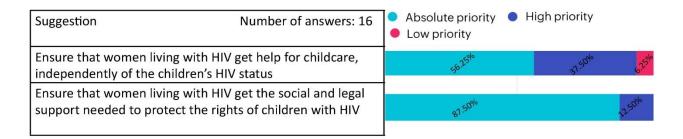
FG2\_1: "We don't do systemic solutions, we find an ad hoc solution there for the moment, and then the state says "oh awesome, here, we have solved the problem". I mean, we haven't solved anything, we only deepened the crisis."

FG2\_3: "Yes, we have. We have volunteer psychologists, who work with the children of our clients, the children are negative, but at some moment the time comes to find out that... normally they find out in a very ugly way, there we do what we can, I mean, the psychologist will do what they can."

All service providers admit that programs they have both for women and children do not form part of larger programs they implement, simply because the number of children they come in contact with is not large, and that programs financed by donors are not directed at women and children specifically, and consequently that in those cases they help and provide services *ad hoc*, without a specifically created program.

FG2\_4: "We actually have one or two cases, we don't have within the organization a program which provides support for children, we don't even have one for women...not official. Through projects we, what we have is actually directed at men, officially, but when cases like these happen we always, in cooperation with other organizations, try to help as much as we can, so all

those are some ad hoc (things) like that.. we don't have a program, a project, which deals exclusively with support for women and children."



Service providers additionally state that it is every woman's right to receive complete support and care in all areas of healthcare, not just at clinics for HIV/AIDS, which entails a continuous training of all health workers, regarding how to treat a person living with HIV, in order to avoid discrimination, which is unfortunately still present today to a large degree, although it has been more than 40 years since the first case of the AIDS disease. A law should be passed within the social protection system that children are not taken from women if they are living with HIV in the case of divorce, and more help should be provided to single mothers or families with children living with HIV or one parent living with HIV. HIV must also not be taken into consideration as an aggravating circumstance for a mother to be with her child in the case of divorce, and from now on it is also necessary to research possibilities for women living with HIV to be accepted, that is not to be rejected due to their HIV status during initiatives for adoption of children (in this area there have not been many initiatives in the past 20 years).

When it comes to the participation of women living with HIV in coordinating councils on HIV/AIDS, service providers cannot list examples of good practice for that participation, and do not view the bodies which coordinate this field as bodies which successfully perform that job in accordance with the needs of the target group, and according to what is written in strategic documents. What they definitely consider efficient is the period until 2014, when GFATM implementation was at a higher level, while they find that the obstruction of efficient and quality participation and representation of women's positions in these bodies is conditioned by discrimination and stigma. Also mentioned as a big obstacle to the participation of women in these bodies is a low degree of empowerment and knowledge acquisition in this area, as well as empowerment for activism and higher quality participation in policies and monitoring their implementation.

FG2\_1: "Well I don't know, because I think that unfortunately lately in coordinating bodies of the Republic Commission on HIV and that nothing is happening, and they put people there as decoration, I mean, because... And especially I lose it when they need to satisfy the form so they say "we'll have a person living with HIV sitting there", and this person has virtually no voting rights, nothing, no, they agree in advance and then come like that."

FG2\_1: "I think that at this moment we don't have a woman with HIV in the Republic Commission, it's a man, as far as I know."..."So, already in advance, aside from the fact that, if you are from the population of women living with HIV, then you have to also have a certain title or knowledge about that topic, so they look for a certain profile, so that's also very narrow, very, and of course you have to be completely out, you know, which is very difficult."

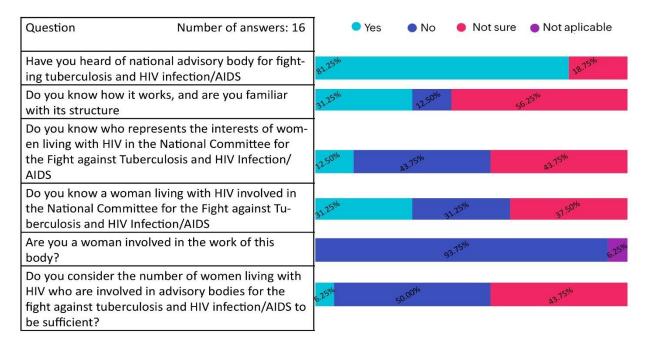
FG2\_5: "Well definitely multiple discrimination, regarding if they are drug users, sex workers, if they are, um, from, members of the LGBT population or the like, so all these other, um, things which accompany it and based on which they are discriminated against in these whole processes, so not just like..."

FG2\_1: "Another thing, if we had a person who satisfies the criteria, so that they have the knowledge, the title and they are ready to disclose their status, we should have a clearly defined policy what that is, in which direction to go, what women living with HIV really lack, let's say lack, is that a kind of service, what kind of support is it, are they some changes in legislature, what are the gaps, so, where are the holes, what do we fill them with, do the holes have to do with their children, will we deal more with this, is there a segment in treatment that's missing, whatever that is. So, I think that this thing you're doing now and when this is done, it could be a great basis for further things."

FG1\_5: "Yes, there is a barrier actually to including women from the community specifically in this case, well all in general, yes, I can't imagine someone who, a client, let's say, from any dropin, bring them to a meeting and ask them anything using that language, they don't know what you've asked them. No, how are you, how are you satisfied with the service? And he doesn't know that he's been provided a service, he doesn't perceive the drop-in center visits at all as him coming to obtain any kind of service."

FG1\_4"Women did participate and women were always seated there, I mean, but that's a small number, you know. I mean, I now remember some people who were sitting then and those organizations don't exist anymore, they're not at all... like, say, Q klub, and so on, so they're gone, they disappeared, meaning some organizations have disappeared from the scene because some things in terms of donations and support from the state, sector, especially from the sector af prevention, or support directly for HIV have completely disappeared."

The role of women living with HIV in national, regional and local advisory bodies:





Service providers have additionally, when it comes to local environments, mentioned that the protocols and procedures exist in those municipalities and local communities which signed the Paris declaration. The municipalities of Novi Sad and Šabac and service providers operating in these two municipalities highlight that through public tenders opened by these two municipalities they have received additional funds for the provision of their services.

There is the question of monitoring and evaluation of both tenders and provided services, seeing as no evaluation of either the strategy or the action plans was done at the national level, let alone at the local level.

FG2\_2: "Local governments are required to, so, to allocate budget lines for HIV, and now I say again it's a matter of evaluation, simply, if somebody is going to check if they are really doing that or not and there are other tasks as well, so, to form a commission for HIV, to, right, include HIV in local action plans, and so on, it's literally all worked out on their website, from the very start to, I don't know, what they expect from signed parties, however will that really happen, it would, like, be great if they fulfilled all that, but knowing how things are done in our country, I'm not very optimistic."

FG2\_6: "Signing of the declaration, in terms of Novi Sad, has contributed, um, I mean of course, Novi Sad participated in the signing of the declaration, and it has contributed, so, to announce a public tender, so, at the local level, so that you could then apply on that basis and this provided, let's say, additional funding."

# **DISCUSSION**

In order to form as comprehensive and targeted a set of recommendations as possible, it is necessary that we identify main research results, that is, the main insights we have reached based on the collected data. These insights enable a mapping out of fundamental directions in which measures should be taken to improve the access of women living with HIV to quality services in the area of sexual and reproductive health.

Primarily, it is necessary that we emphasize that the analysis of all data - both quantitative and qualitative - indicates the fact that women living with HIV, as a subgroup of the population of people living with HIV, have relatively low visibility, and their specific needs are underrecognized. Such a status within the community can be explained by a mix of impacts of different factors, from their relatively small number to the donor policies which focus on established groups recognized as key vulnerable populations. Unfortunately, the data also shows that this lack in recognition of women living with HIV and their specific needs has as a result, among other things, and absolute lack of services and programs directed specifically at this population. For this subgroup of the population of people living with HIV there are no strategic approaches when it comes to either prevention or support and therapy. State institutions resolve situations on the "case-to-case" basis, without formulating a systemic solution or protocols for similar cases, and the operating of CSOs is limited to broadening and/or adapting already available services and programs so as to include women, without financial and logistical capacities for developing services intended specifically for women living with HIV.

When it comes to types of services and programs which are needed, although when talking about HIV and AIDS the accent is often placed on programs related to the prevention of HIV transmission (needle exchange, VCCT) and therapy, or particularly complex situations (e.g. managing the pregnancy in women living with HIV), from the data we notice an extremely important lack of psychosocial support directed at women living with HIV, who are potentially forced to, for support and counseling, turn to staff which is specialized and sensitized for work with another population, e.g. the MSM population or the population of PWID. Many of the respondents do not belong to any of the populations which are identified as key because they are at increased risk and at which virtually all the available preventive, treatment and support programs are directed, and therefore their specific needs are in no way satisfied.

This research, as was previously stated, is the first research of this kind in Serbia. It is a good basis for further mapping of the needs of both the subgroups when it comes to women living with HIV. In the situation Serbia is in, and when women living with HIV for the most part do not belong to key populations singled out in the Strategy, preparing the ground and empowering communities should be the first and most important step, into which additional time and expertise should be invested, and additional focus should be placed on raising capacities of the community itself, in other for it to better understand the survey concept and questions, as well as to better conduct the process of surveying the community itself. This has been done within this project, but more time and a longer training plan would have given better results. After this implementation, this tool should be additionally improved so as to fit the context and cultural characteristics of Western Balkans, for better, higher quality results. Also, we believe that research on the topics of sexual and reproductive health, gender equality, and especially gender-based violence should be conducted as qualitative with all respondents, through semistructured interviews, in order to contribute to the understanding of their social positions, attitudes and issues.

# RECOMMENDATIONS

- In the new Strategy for Prevention and Control of HIV Infection and AIDS, include, above all, a
  gendered approach to service provision, as well as data collection according to gender and age
  structure, and consolidate the data and records for all key populations
- In the new Strategy for Prevention and Control of HIV Infection and AIDS, prescribe mandatory surveillance over services for persons living with HIV and AIDS, with the aim of increasing access to information as a prerequisite for creating services according to actual needs of people living with HIV and AIDS, focusing on women, and in accordance with other relevant documents related to gender equality
- Establish a continuous program of knowledge improvement for health workers who provide services to women living with HIV and AIDS, and for medical students themselves, with the aim of accessing new information and trends in the treatment of HIV and AIDS patients
- Establish a continuous program of knowledge improvement for psychologists and social workers who provide services to women living with HIV and AIDS, with the aim of accessing new information and trends in empowering and caring for HIV and AIDS patients. Such services would result in better access to these services of women living with HIV, and particularly in the context of social protection it would enable them to access safe houses so as to prevent gender-based violence.
- Provide funds for international exchange of professional knowledge between the Republic of Serbia and countries with more advanced programs for the prevention and control of HIV infection and AIDS, with the aim of increasing economically profitable and sustainable services of HIV prevention and support for people living with HIV and AIDS, and with special focus on women living with HIV/AIDS, both those from key populations and those who are not.
- Provide a sufficient number of medical and non-medical staff in the network of services intended for people living with HIV and AIDS, with the aim of increasing access to treatment and therapy and increasing individual motivation in regular application of therapy with particular focus on women living with HIV and AIDS.
- Provide funds for the creation of scientific publications in the field of prevention and control of HIV infection and AIDS in the Republic of Serbia, with the aim of increasing the visibility of actual needs of people living with HIV and AIDS.
- Provide funds for the creation and publication of manuals intended for people living with HIV and AIDS, with the aim of increasing the access to public health and legal information of public importance in order to improve the quality of life of people living with HIV and AIDS, with a particular focus on distribution in smaller environments, on different topics (e.g. menopause and pregnancy)[1]

- Improve the implementation of relevant laws, especially the law regarding prohibition of discrimination, with the aim of strengthening the support for women living with HIV or AIDS and their access to employment, Centers for social work, health and other services
- Improve the system of monitoring and evaluation of programs directed at people living with HIV, and the system of monitoring which would be conducted by the community, so as to ensure the quality of provided services in relation to their actual needs
- It is necessary to strengthen the capacities of the community of women living with HIV/AIDS in order to ensure not only their involvement in national, regional, town and local advisory organs which is key for ensuring quality services based on actual needs, but also their involvement in CSOs which provide services to the community, both of those coming from key populations and those who are not members of those populations. That would not only improve their involvement, but their familiarity with their rights, forms of reporting discrimination, etc. as well.
- It is also necessary to strengthen the capacities of state institutions which have jurisdiction over the protection of rights and the from discrimination, for instance Office of the Ombudsman/Commissioner, and strengthen cooperation and establishment of a system that will justly protect the rights of patients in that process.
- None of the documents closely regulating the area of HIV recognizes women living with HIV as specific, particularly vulnerable category, nor do they recognize women living with hepatitis B or C, who are more numerous than women living with HIV, so instead of placing them all under the same sensitive category of women, the recommendation for further advocacy could be to clearly separate them into subgroups.
- As one of the biggest focuses in the future, it is necessary to build better capacities of civil society organizations that deal with harm reduction and support for people living with HIV in the direction of recognizing and providing support to women who are victims of violence, as well as building a special protocol for improvement operation of safe houses and their capacities in order to better support women who are vulnerable on several grounds.

# **Annexes**

# **Anex 1 - Questionnaire**

### Sexual and reproductive health and rights of women living with HIV in Serbia

This research on the needs of HIV-positive women in Serbia is carried out by the NGO "Re Generacija", as an integral part of the research project "Data for change - Strengthening the advocacy response of women living with HIV", funded by the Eurasian Women's Network on AIDS.

The research consists of surveying women living with HIV/AIDS in Serbia through a questionnaire and consultations with representatives of institutions and/or organizations that provide services to women living with HIV/AIDS in Serbia through focus groups.

We are determined to discover the most important aspects of your lives in relation to sexual and reproductive health, gender equality and human rights, gender-based violence and economic opportunities.

Participation in this research is voluntary. All answers will be given anonymously, i.e. by assigning a security code, and stored in accordance with the General Regulation on the Protection of Personal Data and the Code of Professional Conduct and Ethics of the NGO Re Generacije.

The collected data will be analyzed as a group and used to write a National Report on the position of women living with HIV/AIDS in Serbia, and the most important conclusions will be contained in a protocol/guidelines that will be composed of both the needs of women and organizations that work with this key population. , and with the aim of familiarizing the representatives of state institutions and relevant ministries with the mapped problems and possibilities for overcoming them.

This research and the research protocol will be reviewed by the Research Ethics Committee of the Ethnological-Anthropological Society of Serbia.

If you have any questions about this research, please contact:

To the project coordinator: Vladana Stepanović vladana@regeneracija.com or 064/6109034

Principal researcher: Irena Molnar - irena@regeneracija.org 061/6951243

### Risks

This questionnaire includes a section asking respondents about their personal experiences of reproductive health and sexual violence. This section may be difficult for you or cause strong negative emotions for some of you. We are aware that filling out this questionnaire can revive difficult memories, if you feel uncomfortable, you can stop the research, and if you need a conversation with a psychotherapist, contact the person conducting the research with you.

#### Benefits for research participants

After completing this questionnaire, you will receive a value voucher from the person you completed the questionnaire with as compensation for the time and information you provided.

We are not asking for your name. Names listed in open responses will be removed. Any information that can identify you, such as other people's addresses or names, will be removed. This is necessary to ensure privacy.

Ι.	Thic	question	roquiros	an	answer
	11115	question	requires	un	unswer

1. I understand that filling in the survey, I give my consent for my responses to be used in publications. Please, highlight "I agree" to be able to continue

1	I agree	You continue the survey
2	I disagree	The survey is over

# Handwitten This question requires an answer.

2. I am a woman living with HIV. Please highlight "Yes" to be able to continue

	3	
1	Yes	You continue the survey
2	No	The survey is over

This question requires an answer	(entered by the person	collecting the data)
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Code: _		
	(acronym City-no of gift card-age)	

#### Part 1 - Personal Data

Please tell us about yourself.

1. Country where I am living now	2. City	3. Age

- 4. Relationship Status. Please highlight one answer:
  - 1. I am not sexually active
  - 2. I am sexually active, but do not have a partner
  - 3. I have one or more partner(s) living with HIV
  - 4. I have one or more partner(s) not living with HIV
  - 5. I have two or more sexual partners, one or more is living with HIV and one or more is not living with HIV
- 5. Special issues. Please highlight all that apply to you:
  - 1. I do or have done sex work
  - 2. I inject/use or have injected/used drugs
  - 3. My sexual partner(s) injects/uses or has injected/used drugs
  - 4. I am/have been a client of opioid substitution therapy programme
  - 5. I am/have been in prison
  - 6. I am/have been in a detention centre

	7. I am living with disability
	8. I have or have had active TB
	9. I have or have had Hepatitis C
	10. I migrated from one country to another for economic reasons
	11. I migrated from one country to another for political reasons
	12. I am lesbian, bisexual or have sex with women
	13. I am a trans woman
	14. I am a heterosexual woman
	15. I am married, or in a stable relationship
	16. I am an internally displaced person from Crimea or Donbas
	17. I am or have been homeless
	18. Other (optional)
	Total Contract (optional)
6. Ma	arital status
0	1. Single
	2. Married
	3. In a civil marriage/stabile relationship
	4. Divorced
	5. Widow
	5. WILLOW
8. I le 9. Wi educa 1. 2. 3. 4. 5. 6. 7. 8. 9.	I am illiterate (can't read and/or write) I did not finish all 8 grades of primary school Primary school High school for 3 years High school for 4 years Vocational studies (University for 3 years) Bachelor studies (duration of 4 years) Master studies
10. Occi	upation 1. Student
	2. Employed
	• •
	<ul><li>2.1 in the public sector (state-owned company)</li><li>2.2. entrepreneur</li></ul>
	2.3 in the private sector (company, corporation)
	3. Unemployed
	5. Housewife
	5. Retiree. The amount of the pension
	6. Other

- 11. I am \_\_\_\_\_ employed
  - 1. Officially
  - 2. Unofficially
  - 3. Unemployed
  - 4. Retiree

### Part 2 - Human Rights

12. When you go to a specialist doctor/gynecologist, do you disclose your HIV status? YES NO

If the answer is YES, continue filling in the questions, and if the answer is NO for the first four questions, put the answer not aplicable.

12. 1 Please share with us your experience of accessing sexual and reproductive health services as a woman living with HIV.

(Please choose one answer for each statement and mark it)

No	Statement	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
1	I experience the same service as any other women, when I go for sexual and reproductive health services	1	2	3	4	98
2	I am aware of sexual and reproductive health treatments, information, services and commodities that exist in my country	1	2	3	4	98
3	I can get free and quality sexual and reproductive health treatments, information, services or commodities, when I need them	1	2	3	4	98
4	I find the service providers well-trained and knowledgeable, friendly, and supportive	1	2	3	4	98
5	My experience of accessing sexual and reproductive health care has been good, and I have confidence in the advice and treatment I receive	1	2	3	4	98
6	I believe my service provider offers a full range of choices for sexual and reproductive health care, including family planning options and prevention, diagnosis and treatment of sexually transmitted infections (STIs)	1	2	3	4	98
7	I am given all the information I need to make a decision about proceeding with a service or treatment, without feeling any pressure from the service provider	1	2	3	4	98
8	I trust the service providers not to share my HIV status or any other details about me without my permission	1	2	3	4	98
9	My doctor listens to me, and gives advice based on my needs and realities as a women living with HIV	1	2	3	4	98

10	I know my rights, and if I experience a rights violation within the health service, I know where I can go to make a complaint	1	2	3	4	98
11	If my rights as a woman living with HIV are violated, I know that I will receive the necessary legal protection	1	2	3	4	98

13. Please feel free to give more information on your experience of accessing your sexual and reproductive health and human rights if you would like to

14.	What	would	you	like	to s	say t	o	decision	makers	and	policy	makers	in	Serbia	about	how	they	can	help	tc
pron	note ar	nd prot	ect y	our s	exu	al an	ıd ı	reproduc	tive hea	ılth aı	nd hum	nan right	s?	Please t	ry to b	e as s	pecifi	c as <sub>l</sub>	oossil	οle

15. What are the most important issues that you would like to see addressed in the legal and normative acts in order to make them the most useful tool? Please be as specific as possible

# Part 3 – Context and realities for women living with HIV

### 3.1.Healthy sex life

Women living with HIV have the same right and possibility as all women to enjoy a healthy, safe and satisfying sex life, free from force, coercion, discrimination or violence.

16. Please tell us about your sex experience (Please choose one answer for each statement and mark with an X)

No.	Statement	Always	Usually	Sometim es	Never	Don't know	Not applicable
1	I want to have sex often/have strong feelings of sexual desire	1	2	3	4	98	99
2	I find sex pleasurable for myself and for my partner(s)	1	2	3	4	98	99
3	I have sex to satisfy my partner	1	2	3	4	98	99
4	I initiate sex with my partner(s) and make suggestions about how we have sex	1	2	3	4	98	99
5	I have sex when I want to	1	2	3	4	98	99
6	I have sex when my partner(s) want(s) to	1	2	3	4	98	99

7	I find it easy to "come"/have an orgasm during sex	1	2	3	4	98	99
8	My body makes enough lubrication (how "wet" you feel when you want to have sex)	1	2	3	4	98	99
9	I know where I can get information on sexually transmitted infections, safer sex, condom use, and contraception	1	2	3	4	98	99
10	I am able to have sex without fear of getting any sexually transmitted infections (STIs) from my partner	1	2	3	4	98	99
11	If I have an STI I am able to get diagnosis and treatment for it without fear of judgement from the health provider	1	2	3	4	98	99
12	I am able to have sex without fear of getting pregnant	1	2	3	4	98	99
13	I am able to have sex without fear of passing on HIV to my partner(s)	1	2	3	4	98	99
14	I feel safe with my partner(s)	1	2	3	4	98	99
15	I am able to talk to my health care provider about my sexual health and needs	1	2	3	4	98	99
16	I am able to access the products I need to have a good sex life (e.g. lubricants, dental dams, female condoms, male condoms, contraceptives)	1	2	3	4	98	99
17	I can afford to buy the products I need to have a good sex life (see above)	1	2	3	4	98	99
18	I am able to discuss in a friendly manner my HIV status with my partner(s)	1	2	3	4	98	99
19	My partner is happy to use a male condom if I want him to	1	2	3	4	98	99
20	I am able to use a female condom if I want to	1	2	3	4	98	99

17. Please rate how satisfied you are with your sex life in the last 2 years (24 months). (circle the most correct answer)

Very satisfied	Satisfied	No satisfied	Not satisfied at all	Not applicable
1	2	3	4	99

<sup>18.</sup> As a woman living with HIV, what has helped you MOST to achieve a satisfying and enjoyable sex life? What has been the BIGGEST barrier to you enjoying a satisfying sex life, or what do you think most urgently needs to change?

19.	What would improve your sexual health, safety, well-being and pleasure? (These could be psychological,
phy	sical, sexual, spiritual financial, legal and/or institutional support – or something else. It's entirely up to you.)
Plea	se try to be as specific as possible.

### 3.2. Pregnancy and fertility

As women living with HIV, we have the same right as all women to make choices about when and whether we would like to have children, and to do this in a safe, informed and supportive environment, knowing that we can be healthy mothers to healthy children - or can be supported in our choice not to have children if we don't want to.

20. Please tell us about your experiences of pregnancy and fertility as an HIV-positive woman (Please choose one answer for each statement and mark with an X)

No.	Statement	Yes	No	Don't know	Not applicable
1	I have been supported by my partner(s) to make choices about my fertility (to decide whether or not to have a child/children)	1	2	98	99
2	I have been supported my by health provider to make choices about my fertility	1	2	98	99
3	I have been supported by my family and community to make choices about my fertility	1	2	98	99
4	I have been given advice about safe conception (getting pregnant without putting myself or my partner at risk of transmission of HIV or other sexually transmitted infections)	1	2	98	99
5	I have been given support with safe conception (without putting myself or my partner at risk of transmission of HIV or other sexually transmitted infections)	1	2	98	99
6	I can talk to my doctor/service provider about my fertility desires	1	2	98	99
7	I have been/am able to access free infertility treatment, assisted reproductive technology if I need it (e.g. I.V.F.)	1	2	98	99
8	I have chosen to test for HIV during pregnancy	1	2	98	99
9	I was given adequate counselling before and after the test for HIV	1	2	98	99
10	I have been given counselling on family planning and advice on child spacing	1	2	98	99
11	I have had one or more unplanned pregnancy	1	2	98	99

12	I have been given advice on how to disclose my HIV status to my partner(s) and my children	1	2	98	99
13	I have access to safe and free or affordable abortion, if I need it	1	2	98	99
14	I have access to post-abortion/-miscarriage care, if I need it	1	2	98	99
15	I know I can speak to other women living with HIV who will give me advice on healthy motherhood if I want to	1	2	98	99
16	I have been able to make choices about where I want to deliver my baby	1	2	98	99
17	I have been supported to make decisions about how to feed my baby without fear of what people will say	1	2	98	99
18	I can decide to have a(nother) child without fear of what people will say	1	2	98	99
19	I can decide NOT to have a(nother) child without fear of what people will say	1	2	98	99
20	I can access the family planning/contraception that I prefer	1	2	98	99
21	I am able to use the family planning/contraception that I prefer without resistance from my partner(s)	1	2	98	99
22	I have access to emergency contraception (the morning-after pill) if I need it	1	2	98	99
23	I can access legal counselling on adoption choices	1	2	98	99
24	I can access pre-exposure prophylaxis, if my partner needs it	1	2	98	99
25	I can access post-exposure prophylaxis, if I need it	1	2	98	99
26	I have regular check-ups/Pap smears for early detection of cervical cancer	1	2	98	99
27	I do regular breast screening	1	2	98	99

## 21. Prevention of mother-to-child transmission of HIV

! (Only women who were pregnant while they knew they were HIV positive should answer)

No	Statement	Yes	No	Don't know	Not applicable
1	I took ARV at the time of conception	1	2	98	99
2	I started taking ARV as a prophylaxis during pregnancy	1	2	98	99
3	I did not take ARV throughout my pregnancy	1	2	98	99
4	I took ARV only in childbirth	1	2	98	99
5	My child took syrup in the first days of his/her life	1	2	98	99

6	My baby had a PCR before he/she was 2 months old	1	2	98	99			
	22. Describe the BEST experience you have had to support your decisions and desires about having children — or not having children.							
23. \	What has been the BIGGEST barrier for you to make choices abou	ıt your fer	tility desi	res?				
	What would improve your reproductive health and human rigl cial, legal and/or institutional support – or something else). Pleas		_		· ·			

#### 3.3. Violence against women

Violence against women: Any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.<sup>24</sup> Violence against women includes child sexual abuse, rape, intimate partner violence, sexual violence and harassment, trafficking in human beings and harmful traditional practices, including female genital mutilation.

Intimate partner violence: Actual or threatened physical or sexual violence or psychological and emotional abuse directed towards a spouse, ex-spouse, current or former boyfriend or girlfriend, or current or former dating partner<sup>25</sup>. Intimate partner violence includes slapping, kicking, burning, strangulation (physical); coerced sex through force, threats, intimidation, etc. (sexual); isolation, verbal aggression, humiliation, stalking, economic violence, controlling victim's access to health care or employment (psychological).

Violence against women living with HIV: Any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV<sup>26</sup> Violence against HIV-positive women is described in more detail below.

A: Violence from a sexual partner or spouse could include: hitting, kicking, punching; threats of physical or emotional violence (for example threatening to leave you); making you have sex when you don't want to; making you have sex without a condom; blame, name-calling; making you feel stupid; stopping you from seeing friends; working; leaving the house; seeking medical care for you or your children.

#### 25. I have experienced violence from a sexual partner or spouse (please mark all the answers that apply)

diagnosis diagnosis
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<sup>&</sup>lt;sup>24</sup> General assembly UN 48/104

<sup>&</sup>lt;sup>25</sup> Saltzman et al, 1999

<sup>&</sup>lt;sup>26</sup> Fiona Hale and MariJo Vazquez, 2011

1 2	3 4	98
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B: Violence from a member of my family/neighbours could include: refusing to share food/utensils; name-calling; blame; rejection; abandonment; physical violence like hitting, kicking, or pulling hair; a member of the family or neighbour touching, kissing or making you have sex when you don't want to.

26. I have experienced violence from a member of my family/neighbours (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

C: Violence in the community could include: gossip, bad words, rejection, avoidance, children being stigmatized or avoided; being attacked or beaten by a stranger; being touched or made to have sex with someone who is not your partner when you don't want to; being raped because of your sexual orientation or gender identity ("corrective rape"); hate-motivated violence against trans women; any form of violence against sex workers by clients or strangers.

27. I have experienced violence in the community (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

D: Violence in a health setting could include: rude or judgmental service providers; denial of medical care; being asked how you came to be HIV-positive; disclosing your status without your consent; making you take an HIV test without telling you or without asking for your consent; refusing to give you all the information about available services; forced/coerced abortion or sterilization; making you wait until other clients have been seen; being refused a certain type of contraceptive, even when it is available; placing in separate or isolated rooms.

28. I have experienced violence in health settings (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

E: Violence from the police/military/prison or detention services could include: police harassment; arrest without giving a reason, or because you are carrying condoms, lubricant or clean injection equipment; threat of or actual sexual violence or rape by police, prison/detention guards, military personnel; denial of health care in prison or detention; disclosure of HIV status; refusal to provide services.

29. I have experienced violence from the police/military/prison or detention services (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

30. I have experienced fear of any form of violence (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

31.	Please te	II us abou	t any of t	hese experi	iences of vio	olence in	more detail.
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32. If you have experienced any of these forms of violence, were you able to access support services, and did the help you to deal with the situation/experience?

33. What do you think are the most important ways to address or prevent these forms of violence? (Please choose one answer for each statement and mark with an X)

No.	Statement	Critical	Important	Less important	Don't know
1	Remove laws which criminalise sex work		2	3	98
2	Remove laws which criminalise drug possession		2	3	98
3	Remove laws which criminalize HIV exposure/transmission	1	2	3	98
4	Ensure access to free rehabilitation and addiction treatment (alcohol, drugs)	1	2	3	98
5	Increase access to education and employment for women (entrepreneurship education, vocational training, scholarships, free courses, interaction with employment centres)	1	2	3	98
6	Provide for enhanced social protection for women and children (social benefits, free infant formula, prescriptions for free medicines, health resorts, especially for children with disabilities)	1	2	3	98
7	Ensure the availability of pre-school education (eliminate turns in kindergartens)	1	2	3	98

8	Increase access to harm reduction programmes <sup>[4]</sup> for women who use drugs and sex workers by providing women-centred services	1	2	3	98
9	Focus the attention of healthcare workers on the rights of women living with HIV (through training of healthcare workers on working with HIV+ women, introduction of courses in medical schools/institutes/universities, conducting trainings in hospitals and polyclinics)	1	2	3	98
10	Increase access to quality support services for women survivors	of violend	ce (includin	g sexual vio	lence):
10.1	Centres/shelters with the possibility of round-the-clock accommodation, including with children	1	2	3	98
10.2	Centres/shelters with the possibility of round-the-clock accommodation, including with children and for women who use drugs, sex workers and/or OST patients	1	2	3	98
10.3	24/7 hotline	1	2	3	98
10.4	Support groups	1	2	3	98
10.5	Professional counselling (doctor, psychotherapist, lawyer, social worker)	1	2	3	98
11	Provide a minimum free support after rape including post- exposure prophylaxis, emergency contraception, STI screening, social assistance and counselling	1	2	3	98
12	Provide legal protection against all forms of violence against women (free attorneys to handle litigations, street lawyers for women who use drugs and sex workers, mobile response teams, engagement with law enforcement to reduce police violence)	1	2	3	98
13	Recognize and address the issue of marital and date rape (analyze, build evidence, conduct education campaigns)	1	2	3	98
14	Provide effective mechanisms for filing complaints and redress in case of violation of rights in the healthcare service (hotline of the Ministry of Health of Serbia or the oblast department of health, monitoring of violations and reports of public/patient organisations to coordination/supervisory boards)	1	2	3	98
15	Other (please specify)	1	2	3	98

### 3.4. Mental health and HIV

Many women living with HIV experience mental health problems, and this can impact on our ability to have a healthy sex life and about ability to make choices about our fertility desires and to claim our human rights.

Please think about whether you have experienced any of the following for extended periods of time – i.e. more

than the usual "ups and downs" of life.

## 34. I have experienced extended periods of: (choose the answer for each issue)

No.	Statement	Before my HIV diagnosis	Since I have HIV diagnosis	Because of my HIV diagnosis	Never	Don' know
1	Depression	1	2	3	4	98
2	Shame	1	2	3	4	98
3	Self blame	1	2	3	4	98
4	Low self esteem	1	2	3	4	98
5	Feelings of rejection, including to accept one's diagnosis	1	2	3	4	98
6	A strong sense of isolation (from friends, family, partners)	1	2	3	4	98
7	Anxiety/fear/panic attacks	1	2	3	4	98
8	Insomnia/difficulty sleeping	1	2	3	4	98
9	Anorexia/difficulty eating	1	2	3	4	98
10	Difficulty going out and socializing	1	2	3	4	98
11	Loneliness	1	2	3	4	98
12	Suicidal feelings	1	2	3	4	98
13	Post traumatic stress disorder (for example, nightmares)	1	2	3	4	98
14	Drug and/or alcohol abuse	1	2	3	4	98

35. Please tell us more about the impact of these experiences on your sexual and reproductive health	and numar
rights.	

36.	What do you think is the best way of supporting women living with HIV to deal with mental health issues?

### 3.5.Burden of care

36. The burden of care for other family members often falls on the shoulders of women living with HIV. Mark each line with an X only once.

	only once.	Never	Seldom	Sometimes	Often	Not
No	Statement					applicable
1	I take care of a sick husband/partner at home	1	2	3	4	99
2	I take care of a sick husband/partner living with HIV at home	1	2	3	4	99
3	I take care of a sick child at home	1	2	3	4	99
4	I take care of a sick child living with HIV at home	1	2	3	4	99
5	I take care of sick relatives at home	1	2	3	4	99
6	My husband/partner takes care of me at home when I am sick	1	2	3	4	99
7	I take care of a sick husband/partner outside the home/in the hospital (I call a doctor, an ambulance, arrange transportation, collect medical tests, buy and deliver medicines, assist with medication, provide post- operative care, etc.)	1	2	3	4	99
8	My husband/partner takes care of me outside the home/in the hospital (calls a doctor, an ambulance, arranges transportation, collects medical tests, buys and delivers medicines, assists with medication, provides post- operative care, etc.)	1	2	3	4	99
9	I receive child care financial assistance (government help)	1	2	3	4	99
10	I receive child care non-state support (charitable/public organisations)	1	2	3	4	99
11	I receive support from the government to care for a sick husband/relative	1	2	3	4	99
12	I receive support from charitable/public organisations to care for a sick husband/ relative	1	2	3	4	99
13	I receive help and support from women living with HIV to care for a sick husband/relative	1	2	3	4	99
14	I receive help and support from women living with HIV to care for a sick child	1	2	3	4	99

<sup>37. !</sup> This question is to be answered only by those of you who has a partner and has been living with him in the same territory for the last 3 months (mark each line with an X only once)

No.	Activity	Only me	Only my partner	Together	Someti mes he, sometim es me	Other family members	Not applicable
1	Getting children ready to kindergarten/ school in the morning	1	2	3	4	5	99
2	Cooking	1	2	3	4	5	99
3	Housecleaning	1	2	3	4	5	99
4	Laundry	1	2	3	4	5	99
5	Ironing	1	2	3	4	5	99
6	Taking children from kindergarten/ school in the evening	1	2	3	4	5	99
7	Purchase of foodstuffs/ household chemical goods	1	2	3	4	5	99
8	Purchase of household appliances	1	2	3	4	5	99
9	Children's clothing shopping	1	2	3	4	5	99
10	Payment of utility bills	1	2	3	4	5	99
11	Organisation of house parties	1	2	3	4	5	99
12	Organisation of parties outside the home	1	2	3	4	5	99
13	Attending parent-teacher conferences/children's events	1	2	3	4	5	99
14	Visiting a paediatrician/ purchasing medicines for children	1	2	3	4	5	99
15	Visits to the hospital/communication with doctors/purchasing medicines for adult family members	1	2	3	4	5	99
16	Taking care of sick children at home	1	2	3	4	5	99
17	Taking care of sick adult family members at home	1	2	3	4	5	99
18	Visiting social services, officials, social security, pension fund, migration service, etc.	1	2	3	4	5	99
19	Family budget income distribution (who should spend and for what)	1	2	3	4	5	99

#### 3.6.HIV treatment and side-effects

Our sexual and reproductive health and human rights can also be affected by our experience of accessing antiretroviral medicine (ARVs). If we have access to ARVs when we need them, and are able to take them regularly with food (in case of such prescriptions), we can stay well.

In this section, we ask you to reflect on some of these issues in relation to ARVs and our sexual and reproductive health and human rights.

89.	When was your last check on CD4 count? (please highlight one answer)
	1. Within the last 3 months
	2. 3-6 months ago
	3. 6 months – 1 year ago
	4. More than 1 year ago
	5. Never
0.	What is your CD4 count? (if you don't know, just write it so)
<b>l</b> 1.	Are you taking antiretrovirals (ARVs)? YES NO
12.	If yes, what is the name of your medication?
13.	If no, please explain why.
	Do you regularly experience any of the following? (Please highlight as many as apply
	Do you regularly experience any of the following? (Please highlight as many as apply 1. Fatigue/tiredness
	Do you regularly experience any of the following? (Please highlight as many as apply
	Do you regularly experience any of the following? (Please highlight as many as apply  1. Fatigue/tiredness
	Do you regularly experience any of the following? (Please highlight as many as apply 1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea
	Do you regularly experience any of the following? (Please highlight as many as apply)  1. Fatigue/tiredness  2. Loss of libido/sexual desire  3. Vomiting  4. Diarrhoea  5. Constipation
	Do you regularly experience any of the following? (Please highlight as many as apply 1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea 5. Constipation 6. Headaches
	Do you regularly experience any of the following? (Please highlight as many as apply)  1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea 5. Constipation 6. Headaches 7. Rashes
	Do you regularly experience any of the following? (Please highlight as many as apply)  1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea 5. Constipation 6. Headaches 7. Rashes 8. Mood swings
	Do you regularly experience any of the following? (Please highlight as many as apply 1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea 5. Constipation 6. Headaches 7. Rashes 8. Mood swings 9. Changes of body shape
	Do you regularly experience any of the following? (Please highlight as many as apply 1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea 5. Constipation 6. Headaches 7. Rashes 8. Mood swings 9. Changes of body shape 10. Hair loss
	Do you regularly experience any of the following? (Please highlight as many as apply)  1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea 5. Constipation 6. Headaches 7. Rashes 8. Mood swings 9. Changes of body shape 10. Hair loss 11. Loss of appetite
	Do you regularly experience any of the following? (Please highlight as many as apply)  1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea 5. Constipation 6. Headaches 7. Rashes 8. Mood swings 9. Changes of body shape 10. Hair loss 11. Loss of appetite 12. Strange dreams
	Do you regularly experience any of the following? (Please highlight as many as apply)  1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea 5. Constipation 6. Headaches 7. Rashes 8. Mood swings 9. Changes of body shape 10. Hair loss 11. Loss of appetite 12. Strange dreams 13. Menstrual disorders (e.g.) heavy bleeding, very long or painful periods)
	Do you regularly experience any of the following? (Please highlight as many as apply)  1. Fatigue/tiredness 2. Loss of libido/sexual desire 3. Vomiting 4. Diarrhoea 5. Constipation 6. Headaches 7. Rashes 8. Mood swings 9. Changes of body shape 10. Hair loss 11. Loss of appetite 12. Strange dreams

- 1. Within the last 3 months
- 2. 3-6 months ago
- 3. 6 months 1 year ago
- 4. More than 1 year ago

5. Never
46. What is your latest viral load? (if you don't know, just write it so)
47. Are there any problems with having an undetectable viral load? If so, please explain in your own words.
7. Income and economic opportunities
48. Income. Please indicate your personal monthly income (including salaries, pension, child allowances, financial assistance to IDPs, etc.) RSD
49. Number of members of your family living in the same household (area) people
50. Indicate the monthly income of your family RSD
51. Indicate the desired level of average monthly income (how much you need for a prosperous life, including to take care of your own health) RSD
<ul> <li>52. Access to services. Which of these issues has the biggest impact on you or other women living with HIV in your community to access quality sexual and reproductive health care and well-being? (please highlight all that apply)</li> <li>1. Cost of services at point of delivery</li> <li>2. Cost of travel to access services</li> <li>3. The cost of preschool education, carers for children, the queue for kindergarten</li> </ul>
<ol> <li>Unequal inheritance and property rights</li> <li>Divorce, widowhood, separation</li> <li>Cost and burden of care for other family members</li> </ol>
<ul> <li>7. Lack of family support</li> <li>8. Economic dependence on partner(s), family members</li> <li>9. HIV-related stigma and discrimination in the workplace</li> </ul>
10. Discrimination in the workplace based on gender, age or presence/lack of children

## 53. Economic opportunities. Please choose one answer for each statement and mark with an X

No.	Statement	Always	Usually	Sometimes	Never	Don' t know	Not applicable
1	I have access to higher education	1	2	3	4	98	99
2	I am economically dependent on my partner	1	2	3	4	98	99
3	I can apply to the employment centre if necessary	1	2	3	4	98	99

4	I have the opportunity to combine study and work (distance learning) without financial losses in wages (for example, losses — unpaid leave during the session)	1	2	3	4	98	99
5	I can take free (or at a price that I can afford) courses for additional specialty/to acquire new skills	1	2	3	4	98	99
6	I easily find a job (within my specialty or not)	1	2	3	4	98	99
7	I experienced sexual harassment during my studies	1	2	3	4	98	99
8	I experienced sexual harassment in the workplace	1	2	3	4	98	99
9	I have access to lending services in any bank in Serbia	1	2	3	4	98	99
10	I know how to start my own business if I want to	1	2	3	4	98	99
11	I know where to ask for help to start my own business	1	2	3	4	98	99
12	I own real estate and other property	1	2	3	4	98	99
13	I have autonomy over my real estate or other property	1	2	3	4	98	99
14	I receive social benefits (including child allowances) and manage them independently/ freely/without coercion	1	2	3	4	98	99
15	Having a child has not affected my career path	1	2	3	4	98	99
16	Having a child has not affected my income (I have received all maternity benefits, there are prospects for salary increase in the future)	1	2	3	4	98	99

J4.	What are the profity changes in policy and practice that would help address these illiancial issues:

Thank you for your answers!

# **Annex 2 - Questionnaire**

# Questionnaire on policies, practices and services that exist for women living with HIV in Serbia

Questionnaire for representatives of institutions/organizations that provide assistance to women living with HIV, and for women living with HIV.

The NGO Re Generation conducts research on the sexual and reproductive health and rights of women living with HIV, as an integral part of the research project "Data for change - Strengthening the advocacy response of women living with HIV", funded by the Eurasian Women's Network on AIDS.

The research consists of a survey of women living with HIV in Serbia and consultations in the form of a focus group with representatives of institutions and organizations that provide services to women living with HIV/AIDS in Serbia, as well as consultations with women living with HIV.

We are determined to discover the most important aspects of the lives of women living with HIV/AIDS in Serbia, in relation to sexual and reproductive health, gender equality and human rights, gender-based violence, as well as economic and political opportunities.

Before you is a questionnaire for assessing priorities and attitudes on issues concerning the lives of women living with HIV in Serbia, based on their personal attitudes, as well as the attitudes and opinions of direct and indirect providers of services to women with HIV.

Your participation in the research by filling out this questionnaire is completely fine, and the data is collected anonymously.

**Potential risks** - inconvenience and the right to abstain from participation. Participation is voluntary, and you can choose not to answer some questions or stop the questionnaire at any time.

**Expected benefit** - Your answers will help us to see all the difficulties and challenges faced by women living with HIV/AIDS in Serbia, as well as the main challenges faced by your organizations/institutions in order to provide assistance. The collected data will be analyzed as a group and used to write a National Report on women living with HIV/AIDS in Serbia, the most important conclusions of which will be contained in the protocol/guidelines with the conclusions and needs of both women and organizations/institutions, with the aim of getting to know the representatives. state institutions and ministries with mapped problems.

Information about researchers - If you have questions or doubts about your rights as a research participant, you can contact the Principal Researcher Irena Molnar at phone number 061-695-1243 or Project Manager Vladana Stepanović at phone number 064-610-90-34.

- I confirm that I have read and shared the written notification above about the
  goals and purpose of the research focus, "Sexual and reproductive health and
  rights of women living with HIV in Serbia."
- I understand that the data collected during my participation in this questionnaire
   Yes
   No
   will be entered into a database, analyzed without personal data, and used
   exclusively for scientific and advocacy purposes.

## Questionnaire for focus group discussion

	1.	Personal data
1.	Wha	at gender do you identify with?
		Male
	2)	Woman
	3)	A trans man
	4)	Trans woman
		Other
	6)	I'm don't want to answer
2.	Insti	tution / Organization you come from (If applicable)
3.	I cor	me from:
	1)	Civil society organizations
	2)	Government institutions
4. A	re vo	ou living with HIV?
	1)	Yes
	2)	No

- 5. I know my HIV status for:
  - 1) 0-2 years
  - 2) 3-5 years
  - 3) 5-10 years
  - 4) Over 10 years
  - 5) Not applicable
- 6. Has experience in activism:
  - 1) 0-2 years
  - 2) 3-5 years
  - 3) 5-10 years
  - 4) Over 10 years
  - 5) I don't have experience in activism
- 7. I have experience in providing services to people living with HIV:
  - 1) 0-2 years
  - 2) 3-5 years
  - 3) 5-10 years
  - 4) Over 10 years
  - 5) I don't have experience in activism

### 2. Policies and strategies

9. Below is a series of statements related to policies and strategies that relate to women and girls living with HIV in Serbia.

Please answer which of the statements below do you consider to be a high priority to address at the national

level? (Please choose one answer for each question)

No.	Issue	Absolutely	High priority	Low priority
1	Amend laws and policies with regard to decriminalisation of issues related to sexual and reproductive health (SRH) and HIV (including infection and transmission of HIV)	1	2	3
2	Ensure laws, policies and guidelines are based on respect for the human rights of women and girls living with HIV in all our diversity	1	2	3
3	Ensure rights-based approach to care for women and girls living with HIV in all our diversity	1	2	3
4	Provide comprehensive sexuality education and a choice of SRH services that promote sexual pleasure for women, respectful relationships, gender equality and human rights for all regardless of sexual identity, gender orientation and HIV status	1	2	3
5	Expand the evidence base on the relationship between HIV, gender equality, sexual and reproductive health and human rights for girls and women living with HIV at all stages of life	1	2	3
6	Create and expand opportunities for women living with HIV to participate meaningfully in decision-making and programming on SRH, gender equality and human rights	1	2	3
7	Provide integrated HIV and sexual and reproductive health services and referrals	1	2	3

11. Other priorities (if you wish to m	tion)
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# 12. Gender Based violence

Below is a series of statements related to gender-based violence.

Please answer which of the statements below do you consider to be a high priority to address at the national level? (Please choose one answer for each question)

No.	Issue	Absolutely	High priority	Low priority
1	Recognize and address the issue of gender-based violence, including intimate partner violence, violence by other family members and violence against women living with HIV from key populations (sex workers, drug users, women who have sex with women, transgender women)	1	2	3

2	Recognize and address all issues related to violations of the rights of women with HIV in healthcare facilities (e.g., stigma and discrimination; bias in the workplace; forced abortion or sterilization; lack of choice, privacy, or information, etc.)	1	2	3
3	Recognize and address the issue of gender inequality in society at all levels (e.g. ensure equal employment opportunities and equal pay for men and women; ensure equal property rights, etc.)			

13	. Oth	er pric	orities	(if '	you	wish	to	menti	ion)	
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## 14. Access to clinical care, treatment and support

Below is a series of statements regarding access to services for women living with HIV in Serbia. Please answer which of the statements below do you consider to be a high priority to address at the national level? (Please choose one answer for each question)

No	Issue	Absolutely	High priority	Low priority
1	Guarantee high-quality services based on dignity, respect and non-discrimination for girls and women living with HIV throughout their lives (e.g. no bias from healthcare workers, which can be a barrier to accessing services)	1	2	3
2	Ensure Universal Precautions in all healthcare settings (e.g. sterilisation or use of new equipment for each patient, regardless of previous patient's HIV status)	1	2	3
3	Ensure access to a full range of age-appropriate contraceptives for HIV-positive women	1	2	3
4	Provide services with an understanding of the relationship between taking antiretroviral therapy (ART) and family planning options, including safe medical and surgical abortion	1	2	3
5	Research and provide services with an understanding of the impact of HIV and/or ART on the libido and sexual pleasure of women living with HIV at all stages of their life	1	2	3
6	Research and provide services with an understanding of how HIV and/or ART cause menstrual irregularities, including heavy/irregular/long/painful periods; and other gynaecological diseases, including fibroids	1	2	3
7	Research and provide services with an understanding of how HIV and/or adherence to ART affects the onset, course and duration of menopause in women living with HIV	1	2	3

8	In planning and delivering services, understand, support and address the wide range of mental health issues faced by girls and women living with HIV (including chronic anxiety and depression)	1	2	3
9	In planning and delivering services, understand the impact of comorbidities, including tuberculosis, hepatitis C, cancer and sexually transmitted infections, in the context of the sexual and reproductive health and human rights of women living with HIV	1	2	3

5. Other priorities (if you wish to mention)	

### 16. Sexual relationshps

Below is a series of statements regarding sexual relations. Please answer which of the statements below do you consider to be a high priority to address at the national level? (Please choose one answer for each question)

No	Issue	Absolutely	High priority	Low priority
1	Facilitate the participation of sexual partners (male and/or female) in accessing sexual and reproductive health services for HIV-positive women (e.g. HIV counseling and testing for couples, status disclosure, family planning, mental health)	1	2	3
2	Implement reliable and up-to-date guidance on the ability to conceive a child in couples with the same or different HIV status	1	2	3
3	Promote sexual health, well-being, safety and sexual satisfaction	1	2	3

3	Promote sexual health, well-being, safety and sexual satisfaction	1	2	3				
17.	17. Other priorities (if you wish to mention)							

## 18. Care and support for children of women living with HIV

Before you is a series of statements related to care and support for children of women living with HIV. Please answer which of the statements below do you consider to be a high priority to address at the national level? (Please choose one answer for each questions)

No	Issue	Absolutely	High priority	Low priority
1	Ensure that women with HIV receive childcare support, regardless of the children's HIV status	1	2	3
2	Ensure that women with HIV receive the necessary social and legal support to protect the rights of children with HIV	1	2	3

19. (	Other priorities (if you wish to mention)					
Asse	Sexual and reproductive health, gender equality an ess the factors that help women from different good human rights? (Please choose one answer for each	roups to h	nave full acc	_		-
No.	Issue	Critical	Important	Less important	Not important	Don't know
1	Access to methadone or buprenorphine for women living with HIV, women who inject drugs and pregnant women	1	2	3	4	98
2	Sexual and reproductive health services specifically for lesbian, bisexual, transgender women or other women living with HIV who have sex with women	1	2	3	4	98
3	Comprehensive sexuality education	1	2	3	4	98
4	Continued access to treatment and adherence support for women in prison or in detention	1	2	3	4	98
5	Addressing HIV-related stigma and discrimination from prison staff and inmates	1	2	3	4	98
6	Implementation of modern practical guidelines for women living with HIV in prisons (e.g. obligations of prisons and colonies in terms of HIV care)	1	2	3	4	98
7	Special access to information and services for women with disabilities (people with disabilities)	1	2	3	4	98
8	Treatment and support for women with comorbidities such as hepatitis C and/or tuberculosis	1	2	3	4	98

10	Measures to end and address violence and discrimination against sex workers	1	2	3	4	98
11	Eliminate age-related restrictive policies (please provide examples in the box below)	1	2	3	4	98
21. (	Other factors (if you wish to mention)					

Access to gender reassignment surgery for

trans women

22. Participation of women living with HIV in coordination councils to fight tuberculosis and HIV-infection/AIDS

No.	Question	Yes	No	Not sure	Not Aplicable
1	Have you heard of the National Council on Tuberculosis and HIV/AIDS?	1	2	3	99
2	Do you know how it works, and are you familiar with its structure	1	2	3	99
3	Do you know who represents the interests of women living with HIV at the National Council on Tuberculosis and HIV/AIDS?	1	2	3	99
4	Do you know a woman living with HIV involved in the National Council on Tuberculosis and HIV/AIDS?	1	2	3	99
5	Are you a woman involved in the work of this body?	1	2	3	99
6	Do you think that enough women living with HIV are involved in the National Council on Tuberculosis and HIV/AIDS?	1	2	3	99

23. If you answered Yes to any of the questions above, please indicate the number of women you know are involved and/or the names of organizations/institutions involved in the work of the National Council to Fight Tuberculosis and HIV Infection/AIDS

24. Please indicate whether you agree with the following statements made regarding the participation of women living with HIV in TB and HIV/AIDS Coordinating Councils (select only one answer per question)

No.	Question	Yes	No	Not sure	Not Aplicable
1	Have you heard of I have heard of the Regional/City/Municipal Council to Fight Tuberculosis and HIV Infection/AIDS	1	2	3	99
2	Do you know how it works, and are you familiar with its structure	1	2	3	99
3	Do you know who represents the interests of women living with HIV at the Regional/ City/Municipal Council on Tuberculosis and HIV/AIDS?	1	2	3	99
4	Do you know a woman living with HIV involved in the Regional/City/Municipal Council on Tuberculosis and HIV/AIDS?	1	2	3	99
5	Are you a woman involved in the work of this body?	1	2	3	99
6	Do you think that enough women living with HIV are involved in the Regional/City/Municipal Council on Tuberculosis and HIV/AIDS?	1	2	3	99

25. If you ans	wered	Yes to	any	of the	questions	above,	please	indic	ate t	he n	umbe	r of	f women	you	know	are
involved and/	or the	names	of	organiza	ations/inst	itutions	involve	d in	the	work	oft	he	Regional/	'City/	Munic	ipal
Council to Figh	t Tuber	culosis	and	HIV Infe	ection/AID	S										

26. Please indicate whether you agree with the following statements made regarding the participation of women living with HIV in TB and HIV/AIDS coordinating councils (you can choose only one answer)

No	Tema	Yes	No	Don't know
1	Have you participated/collaborated with local self-government and other institutions/ organizations in the fight against HIV and support for people living with HIV?	1	2	3
2	Do you think that city/municipal councils should be established to fight tuberculosis and HIV/AIDS and/ or its subgroups	1	2	3
3	Are issues related to HIV and PLHIV support, as well as sexual and reproductive health protection part of a local action plan or other document in the local community?	1	2	3
4	Do you know where you can request or read the TB and HIV/AIDS Council protocol and protocol decisions	1	2	3

27. If you answered "Yes" to any of the previous questions, how much did the local community deal with these issues? Please also indicate which local community you are talking about

If you have been involved in the work of the National or any Regional/City/Municipal Council for the fight against tuberculosis and HIV/AIDS in the last two years, tell us whether the following matters were discussed and decided at the meetings (If you were not involved in the work of the National or the Regional/City/

Municipal Council for the Fight against Tuberculosis and HIV Infection/AIDS skip this question)

Br.	Tema	Yes	No	Don't know
1	Sexual and reproductive health of women living with HIV (e.g. access to condoms, contraception, I.V.F., prevention of mother-to-child HIV transmission, access to prenatal and postnatal care)	1	2	3
2	Gender-based violence (e.g. police violence, domestic violence statistics, stigma and discrimination in maternity hospitals)	1	2	3

3	Provision of specific services for women who use drugs, women in prisons and sex workers, their access to harm reduction services, OST and rehabilitation, legal support	1	2	3
4	Home and community care (support group establishment, non-medical home care, day centres/rooms for children, drug delivery, child nutrition)	1	2	3
5	Developing the capacity of women living with HIV to effectively participate in political processes (for example, development of regional programmes and strategies, monitoring of social budgets, implementation of social orders, gender budgeting)	1	2	3

# **Aneks 3. Focus Group**

#### Issues for discussion

#### 1. Policies and practice

Based on your experience, please tell us:

- 1.1 What laws and regulations improve the access of women living with HIV to services related to sexual and reproductive health (SRH) and HIV
- 1.2. What laws and regulations impede the access of women living with HIV to services related to sexual and reproductive health (SRH) and HIV
- 1.3. Examples of successful integration of Gender and HIV (gender-sensitive service delivery)

#### 2. Gender-based violence

- 2.1. Name success stories of HIV-service NGOs in the field of combating gender-based violence
- 2.2.Name government organizations where you observe institutionalized violence against women living with HIV

#### 3. ARV treatment and support

- 3.1.Could you please provide examples when developing adherence to ARV therapy had different approaches for men and women
- 3.2. Have you been trained in different approaches in social support of ART for women of different ages, from adolescent girls to menopausal women, and have you put these approaches into practice? Describe these approaches

#### 4. Sexual partners

4.1. How often have you counseled sexual partners (male and/or female) on sexual and reproductive health issues for HIV+ women. Describe your experience

#### 5. Children of women living with HIVBased on your experience:

- 5.1.Please assess the extent to which what the state offers in the field of care and support for children of women living with HIV meets their needs
- 5.2. Describe what HIV-service NGOs offer for the children of women living with HIV

#### 6. Participation of women living with HIV in coordination councils on HIV/AIDS

- 6.1. Provide examples of effective participation of women living with HIV in HIV/AIDS coordination councils
- 6.2. Provide examples of effective participation of women living with HIV in other coordination and/or advisory and/or monitoring structures
- 6.3. What increases and what hinders effective participation

# 7. Participation of women living with HIV in the development, review or evaluation of HIV/AIDS programmes

7.1.Describe the successes and challenges of the participation of women living with HIV in the development, review or evaluation of a national and/or local target social programme on combating HIV/AIDS for 2014-2018

#### 8. Armed conflict and the annexation of Crimea

- 8.1. Describe the range of services for HIV+ women, internally displaced women who arrived from Crimea or Donbas, both provided by the state and NGOs
- 8.2. How war affects the health and well-being of women living with HIV

# **Annex 4. Ethical opinion**

Etnološko-antropološko društvo Srbije U Beogradu, 15.07.2022.

Mišljenje Etnološko-antropološkog društva Srbije o etičnosti predloga studije u vezi sa seksualnim i reproduktivnim zdravljem i pravima žena koje žive sa HIV-om u Srbiji, a koja se sprovodi NVO Re Generacija u okviru projekta "Podacima do promene - Osnaživanje zagovaračkog odgovora žena koje žive sa HIV-om" finansiranom od strane Evroazijske ženske mreže za AIDS.

Na osnovu molbe dostavljenom dana 13.07.2022. godine od strane nevladine organizacije Re Generacija, uvidom u dostavljeni istraživački protokol za istraživanje "Seksualno i reproduktivno zdravlje i prava žena koje žive sa HIV-om u Srbiji", te uvidom u detaljni upitnik za istraživanje, upitnik za fokus grupe, teme za diskusiju u fokus grupama i obimnu propratnu dokumentaciju, za projekat čiji je glavni istraživač Irena Molnar iz NVO Re Generacije, izražavam pozitivno mišljenje o etičnosti predloženog istraživanja.

Studija doprinosi istraživanju teme koja nije u velikoj meri istražena u Republici Srbiji, a pristup obuhvata istraživanje stavova i iskustva samih žena koje žive sa HIV-om/AIDS, ali i pružaoca usluga u organizacijama civilnog društva i relevantnim institucijama koje su namenjene ženama sa HIV-om. Pristup temi iz dva ugla omogućava dobijanje jasnih i sveobuhvatnih podataka o problemima i izazovima sa kojima se suočava istraživana ciljna grupa, a rezultati ove studije mogu biti korišćeni u naučno-istraživačke svrhe, ali i predstavljati osnovu za promene zvaničnih dokumenata Republike Srbije, a tiču se prava i pristupa uslugama za ženama koje žive sa HIV-om.

U dokumentaciji se jasno i na nedvosmislen način primenjuju načela etičnosti relevantna za istraživače u području etnologije-antropologije i društveno-humanističkih nauka uopšte, u sprovođenju svih faza istraživanja.

Provera ispunjenosti standarda izvršena je kroz priloženi obrazac koji propisuje i neophodnu propratnu dokumentaciju. Stoga, odobravamo protokol za period do 31. Decembra 2022. godine uz obavezu se da su sve osobe koje će sprovoditi istraživanje pravilno informisane o uvedenim promenama u odnosu na prvobitno dostavljenu verziju, ukoliko do izmena dođe, kao i da će svi primiti kopiju odobrenog protokola.

Utvrđujući poštovanje etičkih standarda, kao i dobru praksu etnografskog istraživanja koju propisuje EADS, a na osnovu metodoloških smernica, globalno prihvaćenih u etnologiji i sociokulturnoj antropologiji, Etnološko-antropološko društvo Srbije daje pozitivno mišljenje za sprovođenje ovog istraživanja.

Prof. dr Miloš Milenković,

Filozofski fakultet Univerziteta u Beogradu

Izvršni odbor Etnološko-antropološkog društva Srbije

profesor Metodologije etnologije i antropologije