

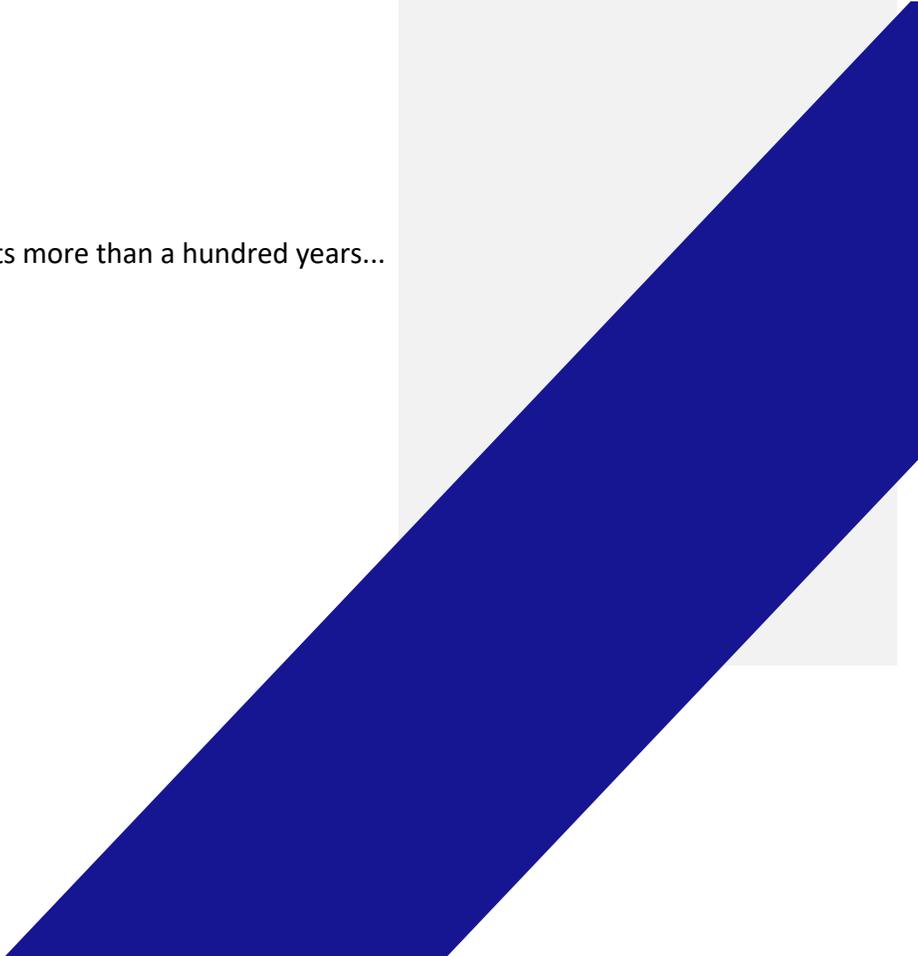
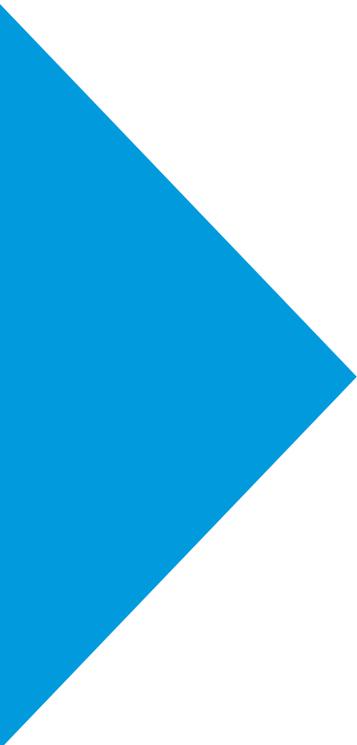
HEARING THE UNHEARD

SURVEY AMONG WOMEN LIVING WITH HIV

Survey of social and economic conditions of women living with HIV through the analysis of their unpaid housework

The day lasts more than a hundred years...

DUSHANBE, 2024



Survey among women living with HIV

The idea of this survey was initiated by the National (Republican) public organisation “Tajikistan Network of Women Living with HIV”. Over a span of fourteen years of work in interaction with women living with HIV, their usual response to the question of why they do not care about their health was “No time”. Therefore, it is clear there is a need to do research on women’s time use in everyday life and the existing barriers that could be eliminated so that women and their children have access to health and a better life.

It must be stated that this survey was carried out through the support from the UNAIDS office in Tajikistan and UNAIDS Regional Office for Eastern Europe and Central Asia. Public organisations working with people with multiple vulnerabilities, “Guli Surkh”, “SPIN Plus”, and “Marvorid” provided their great assistance.

Particular gratitude is expressed to the Asian Development Bank’s gender team and, personally, Ms. Gulnora Kholova for their technical assistance and shared standard questionnaire to assess women’s time use.

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ABBREVIATIONS

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
CCT	Criminal Code of Tajikistan
FGD	focus-group discussion
HCT	Health Code of Tajikistan
HH	household
HIV	human immunodeficiency virus
ICATUS	International Classification of Activities for Time Use Statistics
NGO	non-governmental organization
PLHIV	people living with HIV
RT	Republic of Tajikistan
SDG	Sustainable Development Goals
TDHS	Tajikistan's Demographic and Health Survey
TUSG	Time Use Survey in Georgia
WLH	women living with HIV
WTURT	Women's Time Use in Rural Tajikistan survey

SUMMARY

This assessment focuses on identifying the opportunities of women living with HIV as one of the most vulnerable populations in terms of receiving health services through their time use and decision-making practices regarding their own health and occupation. This is a holistic approach attempting to make a comprehensive review of the barriers faced by women living with HIV in exercising their rights.

Situation assessment took place from September through November 2024 and included the following activities:

- Interviews with 100 women living with HIV;
- Interviews with representatives of health system;
- Focus-group discussions with representatives of NGOs and women living with HIV.

The findings allowed making the following conclusions:

1. Just about all respondents (97%) hide their status from others. It is mostly because of fear of being outcast: *“My mother-in-law knew I got infected from her son. But she would interact with him while not taking a cup of tea from me. No one would talk to me.”*
2. Stigma and discrimination represent one of the most significant barriers for women living with HIV. Seeing a gynaecologist or a dentist for women living with HIV is not only and not so much of a financial barrier, because these medical specialists usually deny them services: *“Dentists refuse to see my daughters, whose status is women living with HIV, just like myself. When they complain about toothache, I want to end my life. I know that doctors won’t take them.”* Physicians usually refer to the fact that their medical appliances are used for the majority, and they cannot afford to put other patients’ health and lives at risk. The women living with HIV who do not have their own money and those living in rural areas are the most vulnerable.
3. Decree No. 600¹ about paid medical services does not have a clear and precise statement about the free-of-charge gynaecologist and dentist services to people living with HIV. However, Article 163 of the Health Code² states that people living with HIV are entitled to all types of free-of-charge healthcare including drug treatment. However, survey findings show that women living with HIV have to pay for both the services related to comorbidities and opportunistic diseases and for the dental, gynaecological, and surgical services. Another challenge faced by women living with HIV is to find specialists who agree to see them without a discriminating attitude.
4. The majority of women living with HIV (78%) are financially dependent on their family members as they are not considered employed: 65% are housekeepers, and 13% are unemployed. When it comes to making decisions about their health care, 55% of women living with HIV ask permission

¹ The procedure of delivery of healthcare services to the citizen of the Republic of Tajikistan by the health facilities of the public health system. Approved by Decree No. 600 of the Government of the Republic of Tajikistan, December 02, 2008 (as amended by the Government Decree dated 25.09.2018. No. 485, and 27.09.2023 No. 472).

https://www.adlia.tj/show_doc.fwx?Rgn=14173

² <https://goo.su/yS09>

from their relatives; it is mostly applicable to rural women (63% rural women vs. 49% urban ones). Meanwhile, the majority of respondents (80%) reported having other health conditions. Notably, **about a quarter (26%) of interviewees mentioned neuroses as comorbidity**. Compared to the urban population, rural women reported this disease more frequently, at 22% and 32%, respectively. Among those who make their decisions independently, 72% were widows or divorced.

5. One of the reasons for noncompliance with the schedule of health facility visits for general health care is financial constraints. This problem was reported by 55% of respondents. In addition, time constraints are a significant barrier: 23% of respondents said it was housework that impedes visits to healthcare facilities, and 20% reported they were preoccupied with their work. Overall, 92% of respondents did not have money for specialised services, including gynaecological, dental, and surgical. The majority in this group (18%) reported their need for gynaecology services. Surgical and dental care was required for 3% and 2% of respondents, respectively, and 2% needed all three services altogether. When asked where they sought the required care, the majority (65%) reported taking no action, mostly due to financial constraints and fear of being judged.
6. The effectiveness of antiretroviral therapy depends on regular collection of drugs and their intake. The major share of the surveyed women living with HIV (82%) reported they were to visit a healthcare facility every three months. Residents of rural areas are unable to adhere to the necessary schedule, in contrast to those in urban areas. As a rule, in rural areas, it is typical to live in extended families, where the major burden of housework falls on the daughter-in-law (wife of one of the sons). At the same time, if a woman does not have her own financial resources and is not engaged in decision-making, she cannot follow the schedule of visitation to a healthcare facility without prior consent of her husband or seniors in their household, despite the fact that women living with HIV are aware of the importance of regular ART.
7. Regular screening for cervical and breast cancer is a must for women living with HIV because of their higher risk of developing oncological conditions. The World Health Organization (WHO) recommends starting the screening for cervical cancer at the age of 25 years and repeating it every three years, and the screening for breast cancer is to be repeated every two years starting at the age of 40 years. These measures allow for early detection of illness when treatment is most effective and help prevent severe complications.³ Only 14% of respondents were screened for cervical or breast cancer (at least once in their life). The rest either did not know about the need to have the screening done or lacked the resources.
8. The proportion of women living with HIV who have no education is significantly higher than in the overall country's female population aged 18 years and older, making it 10% and 1%, respectively.

³ WHO. Cervical cancer: Fact sheet. Available at: <https://www.who.int/news-room/fact-sheets/detail/cervical-cancer>. Accessed on: November 17, 2023.

The findings of the survey allowed for drafting the following recommendations:

1. **To increase the access** of women living with HIV to comprehensive healthcare services by eliminating discriminatory laws and responding to the practice of denial of free-of-charge provision of healthcare services because of HIV status;
2. **Development of support service on a basis of organisations that provide support to women living with HIV**, helping to address the problems faced by them, including stigmatisation, discrimination, and mental health issues;
3. **Economic empowerment of women living with HIV**, i.e., implementation of projects and programmes aimed at building financial independence for women living with HIV (training in the in-demand jobs, implementation of small grants programmes for development of their own businesses, training of the target groups in financial literacy, etc.);
4. **To organise** programmes helping women to better manage their time, particularly finding a balance between the health-related activities, care, and occupation, including creating consumer services centres, support in child care, and work-at-home jobs, specifically in rural areas.
5. **To implement educational programmes** building awareness about HIV, modes of HIV transmission and prevention, aimed at both women and the wider public to reduce stigma.
6. **Advocacy and policy change** to protect the rights of women living with HIV, ensuring their equal access to resources and opportunities;
7. **Support of women's communities** by allocating funding to the projects of social support to women living with HIV, etc.;
8. **To arrange regular and widespread information campaigns** among the population, including healthcare workers.

INTRODUCTION

Following the ratification of the Convention on the Elimination of All Forms of Discrimination against Women in December 1993, the Government of Tajikistan, in its commitment to the principles of the Convention, pays significant attention to the issues of equal access to the labour market, education, healthcare services, and development of institutional mechanisms ensuring gender equality, including the most vulnerable populations. Based on 2023 data, Tajikistan improved its ranking in the field of health and life expectancy and ranked 69 out of 146 countries; however, overall, the country ranked 112 in the Gender Gap Index.⁴

The conducted surveys enable the identification of those problems and gaps and their resolution, which shall help eliminate them along the way towards gender equality. This assessment focuses on identifying the opportunities of women living with HIV as one of the most vulnerable populations in terms of receiving health services through their time use and decision-making practices regarding their own health and occupation. This is a holistic approach attempting to make a comprehensive review of the barriers faced by women living with HIV in exercising their rights.

The survey can throw light on complex and multilayered challenges faced by these women. Family care, which includes taking care of children, the elderly, patients, or persons with disabilities, as well as housework, creates a substantial invisible burden that is often overlooked when assessing the access of women, including women living with HIV, to health care and other services. Despite this, invisible work is recognised under [Sustainable Development Goal 5](#) (*hereinafter SDG 5*) related to the achievement of gender equality and women and girls' empowerment, the problem continues to remain urgent. Target 5.4 under SDG 5 calls for recognition and appreciation of invisible care and housework.

Ignoring the housework leads to ignoring the women's reality, particularly of those who combine two roles: paid job and unpaid housework. This double burden creates additional stress and tension, making it difficult to keep adequate balance between work and personal life. Moreover, although crucial, unpaid labour is still invisible, which contributes to gender disparity in the distribution of work and hinders the empowerment of women who bear the major burden.

The study of time use of women living with HIV is of particular importance in this context because these women face additional challenges related to their own health care and routine duties. As a rule, demand for the unpaid work is perceived as normal due to common gender stereotypes.

Another double burden that can create barriers for women living with HIV is gender-insensitive legislation and policies related to women living with HIV, stigma from others, especially those in the health system. It should be noted that in line with Article 163 of the Health Code of the Republic of Tajikistan, people living with HIV are entitled to receive all types of qualified and specialised health care free of charge, including drug care, at the public health organisations.

Thus, the survey will serve to shed light on the extent of the routine challenges faced by the women living with HIV and identify hidden aspects of their experiences, which will help address these factors in the development of policies and programmes aimed at supporting their health and well-being.

⁴ Global Gender Gap Report. World Economic Forum, June 2023. https://www3.weforum.org/docs/WEF_GGGR_2023.pdf

3. METHODOLOGY OF THE SURVEY

3.1. Goals and objectives of the survey

The goal of the survey is to identify opportunities and barriers for women living with HIV regarding their access to healthcare services through the analysis of their time use, decision-making practices regarding their health, occupation, and financial opportunities, as well as to identify their routine challenges and invisible burden affecting their well-being and economic independence.

Objectives of the survey:

- ⇒ **To study the time use** of women living with HIV related to care about their own health, housework, and caregiving to children and other dependents so that we see how this time use affects the access of women living with HIV to health services.
- ⇒ **To identify the decision-making practices** of women living with HIV regarding their own health, including the impact of financial opportunities and level of occupation on their access to health services.
- ⇒ **To assess the impact of invisible work** (housework and family care) on the overall stress and load of women living with HIV and on their capability to keep the balance between paid and unpaid work.
- ⇒ **To review the impact of legislative and policy factors** on the access of women living with HIV to health services, considering potential insensitivity of the health system's policy and practices towards their specific needs.
- ⇒ **To detect hidden aspects and problems** faced by women living with HIV and identify the additional barriers that prevent these women from accessing health and social care services.
- ⇒ **To recommend measures** for better access and support of women living with HIV, and based on the findings, to improve their well-being and economic independence.

3.2. Target groups

Target group 1 – women living with HIV, for objectives 1–3;

Target group 2 – health workers, for objectives 4–5;

Target group 3 – representatives of target non-governmental organizations (*hereinafter NGO*) working in the area of HIV/AIDS, and human rights activists, for objectives 4–6.

3.3. Survey design

The survey used desk review, as well as variable and attribute sampling:

Desk review

- ✓ Review of the available secondary data relevant to the research topic, including legislation, reports and publications

Variable

⇒ Survey, format “face to face” with women living with HIV. Total sampling size–100 respondents.

Attribute

- ⇒ Interview with women living with HIV, that best demonstrate the obstacles related to the subject matter–1 interview;
- ⇒ Interview with health workers–1 interview;
- ⇒ Focus group discussions with representatives of NGOs and women living with HIV–1 discussion.

3.4. Sampling methodology**Attribute sampling**

Sampling methodology was based on the population size of Dushanbe and the districts of Gissar, and Yavan. The total sampling size was 100 women living with HIV aged 18 years and older: 40 in Dushanbe, 30 in Gissar and 30 in Yavan. The women living with HIV to be surveyed were randomly selected from the villages, streets, and settlements, so-called primary sampling units (hereinafter PSU), target districts. It was planned to interview 10 women living with HIV from each PSU; thus, the total number of PSUs was 10. Table 1 lists the selected PSUs in each district.

Table 1. List of selected PSUs for survey among women living with HIV

City/District	Jamoat/District/City	Locality
Sino	Sino	Shamsi
Firdavsi	Firdavsi	Negmat Karabaev driveway 2
Shohmansur	Shohmansur	Dehlavi 1st avenue.
I.Somoni	I.Somoni	Faizullo Ansory
Gissar	Dehkonabad	Muminobod (Kulmunda)
Gissar	Nawabad	Mavlondjari Bolo
Gissar	Honai Kuhi	Kipchok
Yavan	Gulsara Jusufova (Nawkoram)	Kunchi
Yavan	Obimuki	Dashtabad
Yavan	Hayoti Nav	Komsomol

Sampling was made considering the population size of the target districts, because the higher the population size, the higher the probability of a larger number of women living with HIV. The following statistical information is used to calculate the population sizes in the target areas: “Population size of Tajikistan as of January 01, 2022”, the Statistics Agency under the President of the Republic of Tajikistan.

The sample of 100 respondents has a sampling error within $\pm 9.8\%$, and the results are reliable with a 95% CI.⁵ Multistage probability disproportionate random sampling was used for the sample design.

⁵ Sampling error was defined using online sampling calculator: <https://socioline.ru/rv.php>

The main steps of sampling process are given in Annex 1.

Variable-based sampling

Interview with health workers. For this interview, the most HIV/AIDS-sensitive health workers were selected based on the recommendation of targeted NGOs.

Focus group discussions with NGOs and representatives of women living with HIV. For this activity, representatives of the following organizations were invited:

- 1) Tajikistan Network of Women Living with HIV;
- 2) Your Choice;
- 3) SPIN Plus;
- 4) Marvorid;
- 5) Guli Surkh.

3.5. Tools of the survey

Attribute tools

To do this survey, a semi-structured questionnaire was used, consisting of open and closed ended questions. It included the following sections:

- ☐ A consent form;
- ☐ Household profile;
- ☐ Time use on a typical day;
- ☐ Time use on a non-typical day;
- ☐ Access and barriers.

Using this questionnaire, an interview lasted an average of thirty minutes. The complete questionnaire is provided in Annex 2.

Variable tools

The guide on interviews with women living with HIV included 5 sections:

1. General information
2. Health services
3. Community attitudes
4. Provided services
5. Gaps and recommendations

The complete guide is provided in Annex 3.

The interview collected not only respondents' views regarding the existing barriers but also recommendations for changing the situation. This allowed for the development of the propositions that were the outcome of the survey.

3.6. Data collection

Data collection for the survey continued from September 5 to September 23, 2024, and took 19 calendar days.

3.7. Data processing and analysis

Collected data were processed and visualised using SPSS and Microsoft Excel. Prior to analysis, the data were thoroughly cleaned to exclude various errors.

Methodology of determining bias in data

Analysis of outliers was carried out in order to ensure the validity of the analysis and to eliminate the impact of abnormal values in numerical variables that are representative of the target group of interest.

The outliers were identified using the interquartile range (IQR). This method is based on the calculation of quartiles Q1 (25th percentile) and Q3 (75th percentile) and the interquartile range ($IQR = Q3 - Q1$). The formulas for detection of outlier cut-off values:

- Lower cut-off: $Q1 - 1.5 \times IQR$
- Upper cut-off: $Q3 + 1.5 \times IQR$

Any value beyond these cut-off points is considered an outlier and is excluded from further analysis. The following are the steps taken to identify the outliers:

1. Detecting the values of the first (Q1) and third quartiles (Q3) that divide data into four equal parts.
2. Calculation of the interquartile range (IQR), which is equal to the difference between Q3 and Q1.
3. Setting the lower and upper cut-offs, with the values beyond them considered as outliers.
4. Exclusion of all values out of the set range.

This method was selected due to its computational efficiency, resistance to outliers, and ability to adjust to data distribution. It allows the effective detection of abnormal values without the need to make suggestions on a specific distribution type, which makes it a universal tool for data processing.

3.8. Limitations of the survey

1. Despite the reduced sampling error at the district level, it is still high (within $\pm 15.5\% - \pm 17.9\%$). Therefore, the results obtained at the district level should be interpreted with caution. And the conclusions and recommendations are developed on the basis of general data and not by separate target districts.
2. All attribute data as well as responses regarding the access to health services, stigma, decision-making, and other key indicators are based on information reported by the respondents. Thus, the data reflects the respondents' subjective views and may not fully and impartially present the real conditions.

4. SURVEY FINDINGS

What barriers do women living with HIV face in their access to health services? Which aspects of their everyday lives make it difficult for them to take care of their own health? Is the time use for keeping the household the main barrier, or are the most significant ones the financial barriers or stigma from people around? The answers to these and other questions aimed at identifying the major barriers for women living with HIV are given in this chapter and divided into the following sections:

1. Situation analysis based on the desk research, including the overall review of official statistics, legislation, and regulatory documents, as well as available studies.
2. Socio-demographic profile of households and respondents. This section provides information about the household size, i.e., the number of people living in it, which may hypothetically impact the women's time use for their unpaid domestic occupation. Also, the section includes information about the women living with HIV: their age, education level, occupation, and marital status.
3. Time use, care of health, and decision-making. The major question was whether the concerns about her health were part of the everyday life of women living with HIV, and responding to it consistently reviews potential barriers that prevent women living with HIV from taking care of their health.
4. Access to health services: finances, stigma, distance, time, transportation. This section describes the listed barriers impeding access of women living with HIV to health services.

4.1. Prevention of HIV-infection: situation overview

Tajikistan adopted the United Nations General Assembly Declaration of Commitment on HIV/AIDS (2011) and is one of the first countries in the world to develop the National Development Strategy that aligns HIV/AIDS response with the Millennium Development Goals: to stop the spread of HIV/AIDS and start the downward trend of incidence. The National Development Strategy until 2030 recognises the increasing burden of communicable diseases and identifies reducing the spread of HIV and AIDS as the main priority.

The National Strategy to Counter the HIV/AIDS Epidemic is expected to support Tajikistan's efforts to meet the Sustainable Development Goals. In particular, it aims to build a society free of HIV infection, where all people, regardless of their gender, age, and origin, will have access to treatment and care, enabling them to lead a fulfilling life. The National Strategy to Counter the HIV included the objectives aimed at achieving the following long-term goals by the end of 2017:

1. Reduce by 20% the number of new infections;
2. Reduce by 20% the AIDS-related mortality;
3. Reduce the socioeconomic effects of HIV in households and communities.⁶

⁶ Gender analysis of national policy for HIV/AIDS prevention in Tajikistan. The review was carried out by the association of legal entities, the "Central Asian Association of People living with HIV" and UN WOMEN in partnership with UNAIDS. https://ewna.org/wp-content/uploads/2022/10/gender-analysis-tajikistan_moroz.pdf

Survey among women living with HIV

It must be mentioned that every five years Tajikistan adopts national programmes to counter the HIV epidemic. Tajikistan's Government Resolution No. 566, dated December 30, 2021, approved the National programme for promoting healthy lifestyle in Tajikistan for 2022–2026, including a section on HIV infection.

The Health Code of Tajikistan prohibits discrimination associated with HIV infection (Articles 163, 165, and 166). In particular, in order to reduce the risk of HIV infection, the article guarantees the supply of breast milk substitutes to parents or legal caretakers of children born to HIV-infected mothers, from the moment of birth until the final diagnosis is confirmed.

Between 2012 and 2023 in Tajikistan, 13,190 new HIV infections were reported; the majority of these cases (8,117) were men, and 5,073 cases were women. Stated differently, men accounted for 62% of all newly reported cases, while women made up 38%.

The dynamics of new case registration differed from year to year: the lowest number of new cases was reported in 2013 (763 cases), while in 2018 the number was the highest (1,422 cases). In the years of 2022 and 2023, the number of new HIV infections remained at the level of the baseline period, which is based on 2012 data. Thus, in these years, 11 new HIV cases per 100,000 population were registered (see Table 2). It should be noted that the number of newly reported HIV cases has stabilised in recent years: about 1,000 new cases a year are reported in both sexes. At the same time, the proportion of women among new HIV cases tends to grow by an average of 6–7% over the past 10 years.⁷

⁷ Gender analysis of the national HIV response, Dushanbe, 2024.

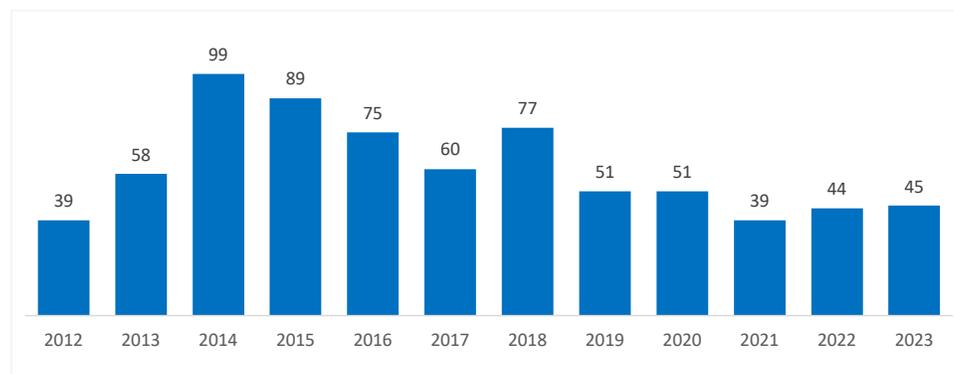
Survey among women living with HIV

Table 2. Number of newly registered HIV infections with confirmed diagnosis⁸

Sex	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	TOTAL
Male	539	453	579	683	624	737	882	773	911	578	663	695	8117
Female	289	310	429	463	416	470	540	547	486	344	374	405	5073
Total	828	763	1008	1146	1040	1207	1422	1320	1397	922	1037	1 100	13 190

The level of HIV infection among pregnant women is lower than in the overall female population of the country. In 2023 this indicator made 0.1% among all women and just 0.019% among pregnant women. The highest number of HIV-infected pregnant women was reported in 2014, and the lowest (39 cases) was in 2012 and 2022. Besides, according to the official statistics, in the last five years (2019–2023), the number of HIV infections in pregnant women shows a downward trend (see Figure 1). Along with this, the coverage of primary HIV testing has increased: in 2016 it was 76%, and in 2020 it reached 85%. In 2023, almost 99% of pregnant women in Tajikistan were covered with antenatal care. Out of this number, 93.4% were tested for HIV, and 93.2% of HIV-positive women received antiretroviral drugs (ARV) to reduce the risk of mother-to-child transmission of HIV. As a result, the level of mother-to-child transmission of HIV in Tajikistan reduced to 2.2%. The estimated share of children (0–14 years) who got HIV from their mothers is 0.4%.

Figure 1. Number of pregnant women with HIV in Tajikistan, 2012–2023⁹



The prevention of mother-to-child transmission of HIV is done in accordance with the “Clinical protocol to strengthen the measures of prevention of mother-to-child transmission of human immunodeficiency

⁸ Statistical yearbooks “Health in Tajikistan” for 2018, 2022 and 2024, the Statistics Agency under the President of the Republic of Tajikistan. Available at: 1) <https://www.stat.tj/wp-content/uploads/2024/07/sb-zdrav-vypusk-2017-2018.pdf> 2) <https://www.stat.tj/wp-content/uploads/2024/08/majmuai-omori-tandurusti-2022-varianti-ohir.pdf> 3) <https://www.stat.tj/wp-content/uploads/2024/09/tandurusti-dar-jumhurii-tojikiston-2024varianti-ohir.pdf>

⁹ See above

Survey among women living with HIV

virus in Tajikistan” approved by the Ministry of Health and Social Protection of Population of Tajikistan.¹⁰ The implementation of this protocol started in 2022 in all cities and regions of the country. In line with Article 163 of the Health Code of Tajikistan, mothers with HIV receive breast milk substitutes at the expense of the local budgets intended for HIV prevention in children.

The official statistics show the decrease in the number of new HIV infections in children over the last four years (2020–2023) as compared to the baseline period, which is 2012. If in 2012 the number of HIV infections per 100,000 population under 18 years old was 4, in 2020 it went down to 3, and in the period of 2021 through 2023—to 2.

In 2012–2023 in Tajikistan, 1,420 HIV infections were registered in children under 18 years old. The highest number of new cases was reported in 2019—187 cases, and the lowest number of 61 cases was reported in 2022. The share of boys in the total number of newly reported cases is 58%, and for girls, 42%, respectively.

Note that a possible reason of higher number of HIV cases in boys could be the tradition of *hatna* (circumcision), and since 2018 this procedure has been performed in healthcare settings and requires blood tests on the child¹¹ (see Table 3).

Table 3. Number of newly registered HIV infections in children (under 18 y.o.) with confirmed diagnosis¹²

Sex	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	TOTAL
Male	97	67	78	78	73	72	89	104	60	38	28	46	830
Female	39	42	55	62	51	58	57	83	42	32	33	36	590
Total	136	109	133	140	124	130	146	187	102	70	61	82	1420

¹⁰ Approved on September 30, 2021, Reg. No. 876

¹¹ The procedure of circumcision. Annex to the Order of the Ministry of Health and Social Protection of Population of Tajikistan, October 30, Reg. No. 994 http://portali-huquqi.tj/publicadliya/view_qonunhoviev.php?showdetail=&asosi_id=22360

¹² Statistical yearbooks “Health in Tajikistan” for 2018, 2022 and 2024, the Statistics Agency under the President of the Republic of Tajikistan. Available at: 1) <https://www.stat.tj/wp-content/uploads/2024/07/sb-zdrav-vypusk-2017-2018.pdf> 2) <https://www.stat.tj/wp-content/uploads/2024/08/majmuai-omori-tandurusti-2022-varianti-ohir.pdf> 3) <https://www.stat.tj/wp-content/uploads/2024/09/tandurusti-dar-jumhurii-tojikiston-2024varianti-ohir.pdf>

Survey among women living with HIV

The vulnerability of people living with HIV is exacerbated by the existence or misinterpretation of discriminatory norms in the legislation and virtual barriers. People living with HIV, particularly women, are frequently held criminally liable under Article 125 of the Criminal Code of Tajikistan (CCT). The legislation and courts do not take into consideration a partner's voluntary informed consent, use of condoms, and low viral load.

Such situations create risks of people living with HIV avoiding seeking healthcare and timely treatment, which can increase the mortality levels. In order to decriminalise people living with HIV, the Supreme Court of the Republic of Tajikistan passed a Resolution of Plenum No. 5 on December 26, 2023. This resolution strongly advised against convicting under Part 1 of Article 125 of the Criminal Code a person living with HIV who has a suppressed viral load and has taken all proper precautions. Besides, Part 1 of Article 125 (known exposure to HIV infection) was excluded in the draft amendments to the Criminal Code. It should be noted that Plenum No. 5 of 2023 was advisory in its nature.

After Plenum No. 5, 14 cases were reviewed in court. Out of them, eight cases were initiated against women.

One woman living with HIV was sentenced to five years in prison under Article 125, part 3 of the CCT. Two women living with HIV were found guilty under Article 78 of the CCT and given a suspended jail term.

Investigation of criminal cases under Article 125 of the CCT considering the recommendations of the Supreme Court Plenum's Resolution.

*Materials of the Roundtable
"Investigation of criminal cases under Article 125 of the CCT considering the recommendations of the Supreme Court Plenum's Resolution", September 24, 2024 <https://hrc.tj/archives/3694>*

4.2. Socio-demographic profile of households and respondents

Households. Over 70% of Tajikistan's population live in rural areas where it is typical to have extended, traditional families that comprise several generations and several families in one household; meanwhile, in urban settings, nuclear families consisting of parent(s) and children are more typical. Also, the patrilocal approach is traditional, when a wife moves to her husband's place. Such a family structure means that a significant share of a woman's time is devoted to serving the daily needs of the household. In this survey, more than two-thirds of households are categorised as extended (68%), and the category of nuclear families makes up 32%.

The survey findings show that on average a household has 6 members, which is in line with the data of the Statistics Agency¹³ (see Table 4).

Добавлено примечание ((П1)): The Figure below shows it the other way round: extended families 32% and nuclear families 68%. It has to be corrected appropriately either in the text or in the figure

¹³ Population of Republic of Tajikistan, 2022, the Statistics Agency under the President of the Republic of Tajikistan
URL: https://drive.google.com/file/d/1vJ0HgTGWKB2LISGQeHbRbuffgseJnjg/view?usp=drive_link

Survey among women living with HIV

Figure 2. Family types of households

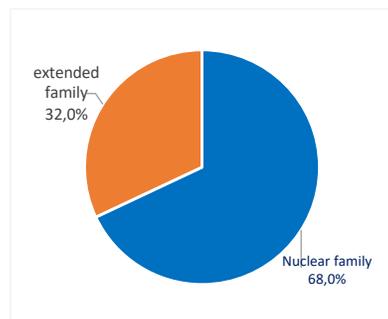


Table 4. Household size, by district

Districts	Average HH size	Total no. of HH members	Total HH
Gissar	6.1	204	30
Dushanbe	5.8	282	40
Yavan	5.7	171	30
TOTAL	5.9	657	100

Women make up 57% of household members, while men are 43%. In households, adults (aged 18 and older) are in the majority at 58%. The age distribution varies significantly by district (see Table 5).

Findings about the average household size, sex, and age breakdown are mainly in line with the official statistics on population size and census of the Republic of Tajikistan (hereinafter RT or Tajikistan) of the Statistics Agency under the President of RT.¹⁴

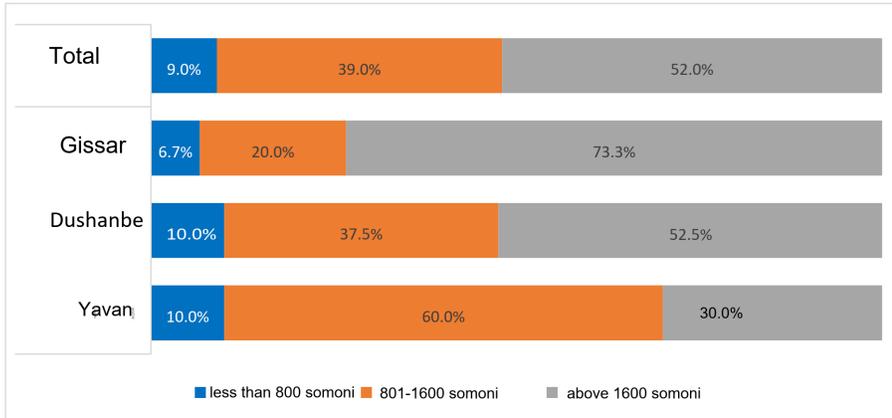
Table 5. Distribution of household members by sex and age

Districts	Sex		Age				Total, n
	Male	Female	0-6 years	7-14 years	15-17 years	18 years and older	
Gissar	44.6%	55.4%	16.2%	20.6%	7.4%	55.9%	204
Dushanbe	44.0%	56.0%	18.8%	14.9%	7.8%	58.5%	282
Yavan	40.9%	59.1%	11.1%	18.1%	9.9%	60.8%	171
Total	43.4%	56.6%	16.0%	17.5%	8.2%	58.3%	657

According to survey findings, the majority of households (52%) have a cumulative income of above 1600 TJS, and it makes an average of 267 TJS per one household member a month. In Gissar, the share of households with income above 1600 TJS is 73%, which is significantly higher than the same indicator for Dushanbe, where it is 53%. In Yavan households with this level of income are less represented, making up 30% (see Figure 3).

¹⁴ Population of Republic of Tajikistan, 2022, the Statistical Agency under the President of the Republic of Tajikistan
URL: https://drive.google.com/file/d/1vJ0HgTGWKB2LISGQeHbRbutfgseJnjg/view?usp=drive_link

Figure 3. Distribution of households by income level



Respondents. A total of 100 women living with HIV respondents participated in the survey: 40% in Dushanbe and 30% in both the Gissar and Yavan districts. Such distribution conforms with the planned distribution of the sample by target districts (see Picture 1).

Overall, 59% of respondents live in urban areas while 41% live in rural areas. In Gissar, the proportion of rural women was the greatest at 73%. (see Figure 4).

Picture 1. Distribution of respondents by districts, n = 100

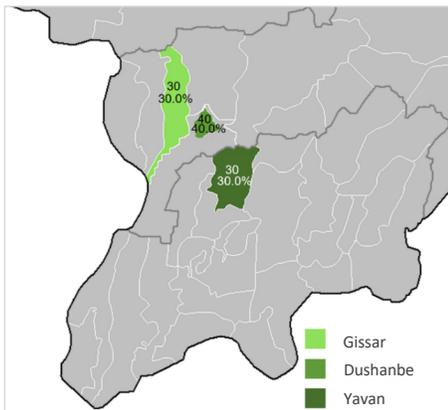
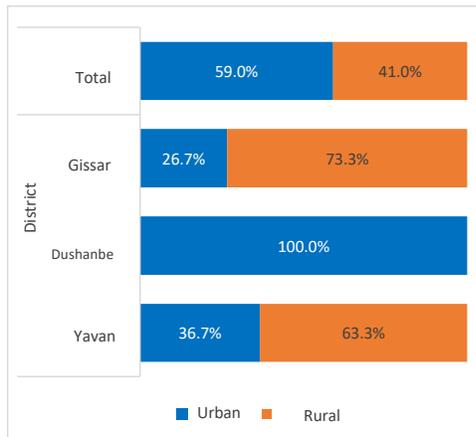


Figure 4. Type of location, n = 100



Survey among women living with HIV

The responders' average age was 41 years old. The youngest women living with HIV were found in Gissar, with an average respondent age of 38.

The majority of respondents (72%) have secondary education. The findings, taking into account a sampling error of $\pm 9.8\%$, correlate with the data of Tajikistan's Demographic and Health Survey (TDHS) for 2023, according to which 84% of women have secondary education¹⁵ (see Figures 5 and 6).

According to the survey, 10% of respondents do not have education. This indicator is in line with the survey findings of the People Living with HIV Stigma Index in Tajikistan, where a similar share of women living with HIV was found.¹⁶ It should be noted that the proportion of women living with HIV who have no education is significantly higher than in the overall country's female population aged 18 years and older, making it 10% and 1%, respectively.¹⁷ These results may indicate the existing problems women living with HIV encounter in accessing formal education.

When students had to give blood for testing at school, my daughter said she could only give blood at the health centre. And the nurse answered her in front of everyone, "So, you have AIDS". After that, her classmates started laughing at her, and my daughter said she would never go back to school again.

From FGD findings

Figure 5. Average age of respondents, n = 100

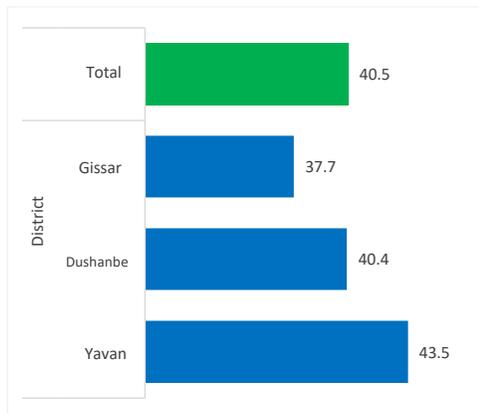
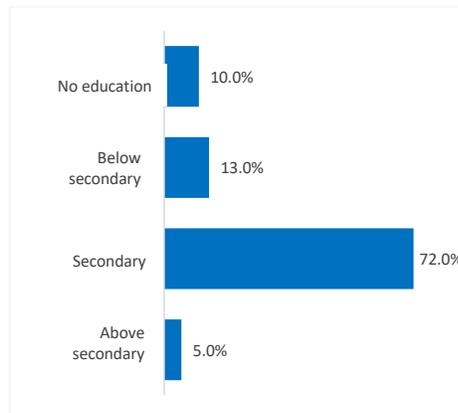


Figure 6. Educational level of respondents, n = 100



¹⁵ Demographic and health survey, 2023: Report on key indicators. – p. 12.

¹⁶ The People Living with HIV Stigma Index 2.0, Tajikistan, Analytical Report", Public Organization "SPIN Plus", 2021, p. 23.

¹⁷ Statistical yearbook "Population and housing census, 2020", Volume IV–Education level of the population of Tajikistan, the Statistical Agency under the President of Tajikistan, pp. 46–47

Survey among women living with HIV

Education is one of the drivers of individual empowerment. The higher the level of education, the higher the chances to be employed and thereby be financially independent to a certain extent. The total share of employed among women living with HIV is 22%. And the employed include those who have complete secondary education and higher (see Table 6). In other words, the rest 78% of women living with HIV are assumed to lack their own financial resources and are dependent.

I have participated in a number of surveys related to women living with HIV. In rural areas, women living with HIV mostly don't work because they fear that their status would be disclosed. For example, a situation happened in Gissar: a woman who worked as a cleaner got fired after they learnt about her HIV status. She was asked to not come and do any more work since she might spread the infection to other people.

Table 6. Educational level by respondents' occupation

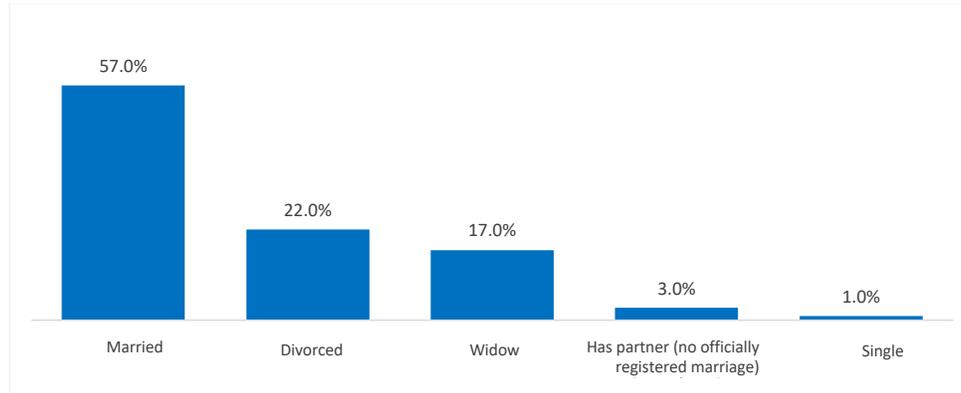
Employment status	No education n = 10	Below secondary n = 13	Secondary education n = 72	Above secondary n = 5
Paid work	—	—	26.4%	60.0%
Unemployed	30.0%	30.8%	8.3%	—
Housewife	70.0%	69.2%	65.3%	40.0%
TOTAL	100.0%	100.0%	100.0%	100.0%

According to survey findings, over half of respondents (57%) are married, 22% are divorced, and 17% are widows (see Figure 7). According to the official statistics for 2023,^{18 19} the percentage of divorces in the population is 13% of the total number of the officially registered marriages. The comparison enables the conclusion that the share of the divorced women living with HIV is comparatively higher than the same category in the general population, which is attributable to the HIV status of women.

¹⁸ <https://www.stat.tj/wp-content/uploads/2024/11/osnovnoj-regiony-2024-1.pdf>

¹⁹ <https://www.stat.tj/wp-content/uploads/2024/11/tadzhikistan-v-czifrah-2024-1.pdf>

Figure 7. Marital status of respondents, n = 100



The analysis of the demographic and social section leads to the following main conclusions that indicate how HIV status affects the following aspects of life:

1. The percentage of HIV-positive women without formal education is significantly greater than that of adult Tajikistani women (18 years of age and older)—10% and 1%, respectively;
2. The total share of employed women living with HIV is 22%, and this category includes women with complete secondary education and higher. In other words, the rest 78% of women living with HIV presumably lack their own financial resources and depend on others;
3. Share of the divorced among women living with HIV is 1.6 times higher than in the general population. This indicator is 13% in the general population, while among the women living with HIV, it is 22%.

4.3. Time use, taking care of health, and decision-making

Time use. One of the main ideas of the survey was that housework could be one of the barriers to women's access to health services. This section brings out the estimations of time women living with HIV use in everyday life. International Classification of Activities for Time Use Statistics (ICATUS) was taken as the basis for estimations. This methodology simplifies the classification of activities an individual spends time on during the day, and it serves as the basis for standardised evaluation of time use. Applying the ICATUS makes it possible to compare the findings of different surveys; consequently, it is now feasible to compare the results of this survey with the findings of the Women's Time Use in Rural Tajikistan survey²⁰ and the Time Use Survey in Georgia, 2020–2021.²¹

²⁰ Women's Time Use in Rural Tajikistan. Asian Development Bank, June 2020

²¹ Time Use Survey in Georgia 2020–2021. UN Women. Available at: <https://eca.unwomen.org/en/digitalibrary/publications/2022/12/time-use-survey-in-georgia-2020-2021-0>

For analytical purposes, all estimations are shown in the aggregate. Also, when presenting information on time use, sleep time (defined approximately as 8 hours) was deducted from 24 hours. The same approach was used for the Women's Time Use in Rural Tajikistan survey and the Georgia Time Use Survey.

According to survey findings, on average, the respondents spend most of their time (54%) on unpaid housework and family care, or 8 hours 42 minutes—which is twice as much compared to the results of the Time Use Survey in Georgia among all women (27%), and 1.2 times more than in Women's Time Use in Rural Tajikistan—44%.

Women living with HIV spend an average of 15% of their time on paid work (2 hours 18 minutes), which is slightly more than the 12% indicator found in the Georgia Time Use survey and more than in the Women's Time Use in Rural Tajikistan—10% (see Table 7). It should be noted that paid work includes such types of work as cleaning the premises, streets, and markets, as well as seasonal agricultural work.

Women spend less time on personal care and development:

– **Personal care including personal hygiene and care of their health**

Women's Time Use in Rural Tajikistan—11%, or 1 hour 48 minutes; women living with HIV—12% of their time, or 1 hour 56 minutes. These values are in fact twice as low as compared to the findings of the Time Use survey in Georgia, which stands at 23%, or 3 hours 36 minutes;

– **Rest and leisure time**

Women's Time Use in Rural Tajikistan—11%, or 1 hour 54 minutes, while this indicator for women living with HIV is 7%, or 1 hour 7 minutes; this indicator in the Time Use Survey in Georgia is 25%, or 3 hours 56 minutes;

– **Social and community interaction**

Women's Time Use in Rural Tajikistan—15%, or 2 hours 18 minutes; women living with HIV—5% of their time, or 0 hours 45 minutes, the Time Use Survey in Georgia—8%, or 1 hour 17 minutes;

– **Learning and self-development:** The Women's Time Use in Rural Tajikistan—0%, women living with HIV—2% or their time, or 0 hour 21 minutes; the Time Use Survey in Georgia—2%, or 0 hours 18 minutes.

The women living with HIV in rural areas earn money for living by sewing kurpacha (lightweight quilted mattress) or engaging in seasonal agricultural work—cotton and fruit picking. But these activities are short-term and only last for 3–4 months and do not provide stable income. Generally, most women stay at home without a permanent job.

Survey among women living with HIV

Table 7. Respondents' time use in comparison with the Georgia Time Use Survey and Women's Time Use in Rural Tajikistan

Type of activity	This survey		TUSG		WTURT	
	%	time	%	time	%	time
Unpaid housework and family care	54.4%	8 h. 42 m.	26.9%	4 h. 17 m.	43.6%	7 h. 00 m.
Paid work	14.4%	2 h. 18 m.	11.6%	1 h. 50 m.	10.4%	1 h. 42 m.
Self-care (personal hygiene and health)	12.1%	1 h. 56 m.	22.6%	3 h. 36 m.	11.1%	1 h. 48 m.
Rest and leisure	7.0%	1 h. 7 m.	24.6%	3 h. 56 m.	11.7%	1 h. 54 m.
Farming for own consumption	5.3%	0 h. 51 m.	4.4%	0 h. 41 m.	8.6%	1 h. 24 m.
Social and community interaction	4.7%	0 h. 45 m.	8.1%	1 h. 17 m.	14.6%	2 h. 18 m.
Learning and self-development	2.1%	0 h. 21 m.	2.0%	0 h. 18 m.	-	-
TOTAL	100%	16 h. 00 m	100%	16 h. 00 m	100%	16 h. 00 m.

Compared to nuclear families, people in traditional extended households devote less time to paid work. Besides, women living with HIV aged 30–44 allocate relatively more time for paid work compared to other age groups. In other words, while young people (20–29 y.o.) are almost fully occupied with the housework in their private spaces, the older a woman is, the more spare time she has, and consequently more opportunities to combine unpaid and paid work. It should be mentioned that paid work in this case is often categorised as informal, which implies unstable income, seasonality, and irregular hours.

As stated earlier, the major burden of housework and family care falls on the young daughters-in-law, and young respondents spend more time (70%) on these duties than older respondents (48%). Naturally, these tasks take longer in larger households. Therefore, the respondents from nuclear families are estimated to devote an average of 53% of their time to housework, whereas, in traditional extended families, these activities take 69% of their time. The difference is 16% or 2 hours 34 minutes.

It should be noted that findings of the women living with HIV survey agree with those of the Women's Time Use in Rural Tajikistan, according to which the older a woman gets, the more time she has for her rest and leisure. However, there is a negative correlation between the size of households and time allocation for rest and leisure; for traditional extended households, it is less typical. So, older respondents can afford more time (14%) on personal care (*see Table 8*).

Table 8. Respondents' daily time use by types of activity

Characteristics	Type of activity					
	paid work	Farming for own consumption	Unpaid housework and family care	Social and community interaction	Rest and leisure	Self-care (personal hygiene and health)
Type of location						
Urban	15.0%	2.7%	61.7%	4.6%	7.8%	8.1%
Rural	16.1%	10.7%	53.6%	5.4%	6.5%	7.7%

Survey among women living with HIV

Age group of respondents						
20–29 years	8.5%	3.3%	69.8%	4.2%	9.4%	4.7%
30–44 years	18.4%	3.9%	59.2%	4.3%	5.9%	8.2%
45–59 years	9.2%	11.6%	55.7%	8.4%	8.3%	6.7%
60 years +	15.6%	9.9%	47.2%	0.9%	13.7%	12.7%
HH type						
Nuclear	17.7%	6.8%	53.2%	5.0%	8.5%	8.8%
Extended	10.7%	4.4%	69.1%	5.0%	4.6%	6.2%
AVERAGE	14.4%	5.3%	54.4%	4.7%	7.0%	12.1%

Let's examine what activities constitute homework in more detail. According to survey findings, on average, the most time-consuming activities are:

- a) Cooking and setting up food takes up 55% of all housework time;
- b) Housekeeping and cleaning: 24% of time;
- c) Child care: 17% of time.

However, the analysis demonstrated that when calculating time costs, variables including the age of women living with HIV and the kind of household should be considered. As stated above, the younger a woman living with HIV is, the more time she spends on the unpaid domestic activities. The larger the household is, the more time will be spent on child care from the total time spent on housework, which is natural because there are several families in an extended household. Thus, young daughters-in-law from the traditional extended households have the least chance to be financially independent because they do not have time opportunities for paid work.

Let us see in more detail the correlation between the types of housework, the age of women living with HIV and the type of household:

- **Age.** Young respondents (20–29 y.o.) spend the most of their time on cooking (33%) and childcare (28%). At the same time, for other age groups, the most time-consuming activities around the house are cooking and cleaning.
- **Household type.** For comparison purposes, those activities that consumed over 15% of time were taken. In the traditional extended household, three types of activities take up the most time: food cooking—51%, child care—21%, and cleaning—19%. In the nuclear household, two activities with time consumption over 15% were selected: food cooking—51% and cleaning of dwelling—21% (see Table 9).

Survey among women living with HIV

Table 9. Respondents' daily time use by type of unpaid housework

Characteristics	Type of Unpaid Housework					
	Food cooking and feeding arrangements	Cleaning and upkeep of dwelling	Child care	Family care (caregiving to the elderly, people with disabilities)	Shopping	Other household chores
Type of location:						
Urban	45.7%	19.6%	16.6%	4.4%	3.0%	10.8%
Rural	48.9%	20.7%	11.1%	5.4%	3.0%	10.9%
Age group of respondents:						
20-29 years	32.6%	17.4%	28.3%	3.6%	0.7%	17.4%
30-44 years	45.3%	20.5%	15.0%	4.3%	3.4%	11.5%
45-59 years	51.3%	19.6%	9.1%	7.5%	3.5%	8.9%
60 years +	65.8%	20.2%	8.8%	1.8%	0.9%	2.6%
household type:						
Nuclear	50.8%	20.7%	10.7%	5.4%	3.9%	8.5%
Extended	40.3%	18.9%	20.9%	3.7%	1.6%	14.7%
AVERAGE	54.9%	23.4%	16.8%	5.6%	3.5%	12.6%

The analysis of this section allowed for the following conclusions:

- Compared to the data of the Time Use Survey in Georgia, which covers time spent by women generally, for “Women living in rural Tajikistan” and women living with HIV, housework accounts for the largest portion of their time;
- Most of the respondents' time is spent on household chores, while only a minimum amount of time is provided for rest and social interactions;
- The respondents seldom ever dedicate any time to learning or personal development;
- Young women use two-thirds of their time for housework and less time for social interaction. Meanwhile, the larger the household size, the longer it takes to do housework;
- Personal care, which includes health care, takes relatively less time for young women;
- Cooking and organising meals, cleaning of house, and child care take most of the time of women living with HIV when they are doing the household chores;
- Child care takes more time for young respondents (20–29 years) and respondents from the traditional extended household.

4.4. Health and decision-making practices regarding health

This subsection consistently looks into health topics and focuses on respondents' understanding of the necessity of treatment and, consequently, of health facility visits. It has to be taken into account that a visit to a health facility suggests not only their awareness about treatment but also the opportunity for

Survey among women living with HIV

decision-making, which is described in the next part of this subsection. As found during the survey, decision making is closely linked with the stigma effect that is a serious barrier for women living with HIV.

Health. It is known that one of the most serious health threats for people living with HIV is so-called opportunistic infections. The majority of the respondents (80%) reported having other comorbidities in addition to HIV (see Figure 8). This could be the reason why 13% of respondents indicated they needed to visit a health facility once a month. 82% of women visit a health facility once every three months, 4% once every semester, and 1% once a year (see Figure 9).

Figure 8. Respondents' comorbidities

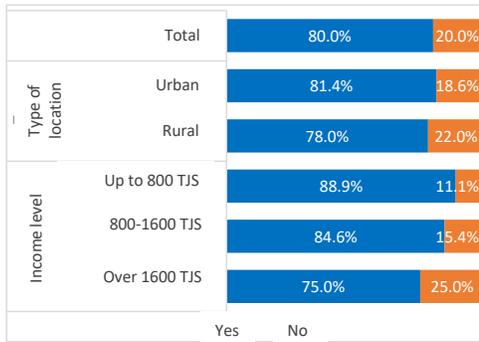
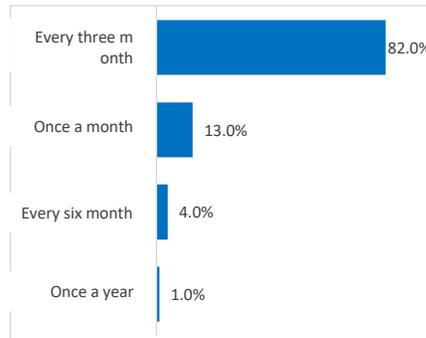


Figure 9. How often do you need to visit a health facility for HIV treatment?



Noteworthy, almost a quarter of the respondents (26%) mentioned neurosis as their comorbidity. Women in rural areas were more likely to mention it than those in urban areas (22% and 32%, respectively).

Other comorbidities listed in descending order were high blood pressure (18%), goitre (13%), STI (12%), reproductive health disorders (12%), and hepatitis (11%) (see Table 10).

Working with vulnerable populations, such as women living with HIV, raises important issues. When women of these populations are referred to a psychologist or psychotherapist, it is almost impossible to get qualified care because of the severe lack of such specialists, which eventually can lead to tragic consequences.

From FGD findings

Table 10. Types of other diseases in respondents

Type of disease	Total	Type of location	
		Urban, n = 59	Rural, n = 41
Neurosis	26.0%	22.0%	31.7%
High blood pressure	18.0%	20.3%	14.6%
Goitre	13.0%	13.6%	12.2%
STI and diseases of the reproductive system	12.0%	11.9%	12.2%
Hepatitis	11.0%	18.6%	–

Survey among women living with HIV

Gastritis	9.0%	6.8%	12.2%
Heart diseases	9.0%	10.2%	7.3%
Anaemia	9.0%	10.2%	7.3%
Tuberculosis	3.0%	3.4%	2.4%

Regular screening for cervical and breast cancer is a must for women living with HIV because of their higher risk of developing oncological conditions. WHO recommends starting the screening for cervical cancer at the age of 25 years and repeating it every three years, and the screening for breast cancer is to be repeated every two years starting at the age of 40 years. These measures allow early detection of illness when treatment is the most effective and helps to prevent severe complications.²²

According to the survey findings shown in **Figure 10**, only 14% of respondents were screened for cervical or breast cancer at least once in their life. The rest 86% who had not been screened, the vast majority (96%) reported they did not know it was obligatory. The other 4% knew it was necessary but did not have screening because of financial constraints (see *Figure 11*).

Figure 10. Screening for cervical and breast cancer, n = 100

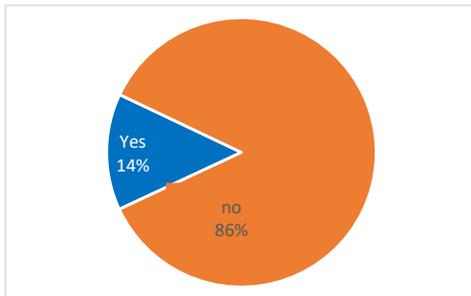
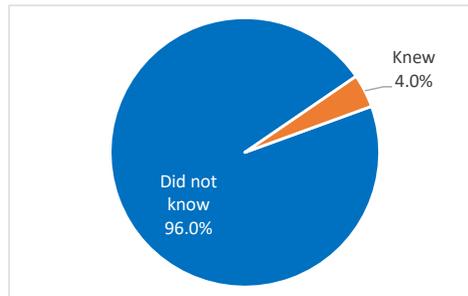


Figure 11. Respondents' awareness of obligatory screening, n = 86



So, why do women living with HIV not always visit health facilities even when they are aware of the need to do so? One of the crucial elements that is frequently assessed by Tajikistan's demographic and health surveys is the involvement of women in household decision-making. It includes three indicators: decision-making about large purchases, decision-making regarding their own health, and decision-making regarding the possibility of leaving home to visit her relatives or friends. According to the 2017 Tajikistan demographic and health survey, a total of 33% of married women participate in decision-making with regard of the three indicators either on their own or together with their husbands. Compared to the other two topics, the largest percentage of women (46%) participate in decision-making when it comes to their own health. However, 49% of women who are now married do not take part in any of the three decision-making processes.

²² WHO. Cervical cancer: Fact sheet. Available at: <https://www.who.int/news-room/fact-sheets/detail/cervical-cancer>. Accessed on: November 17, 2023.

Survey among women living with HIV

Men are the ones who make crucial decisions in most households (44%); joint decisions are taken in 20%; and the share of women making independent decisions regarding their own health is 31%. So, who are these women who can make independent decisions? As it was found, a total of 72% of those making decisions are widows or divorced (see Figures 12 and 13).

Figure 12. Sex of the major decision maker in household, n = 100

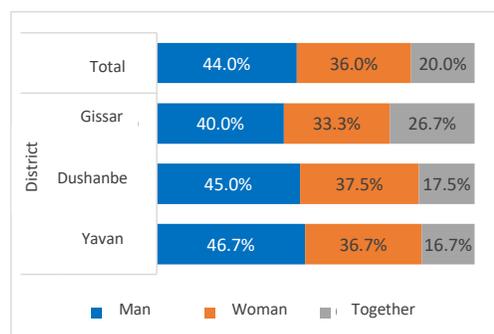
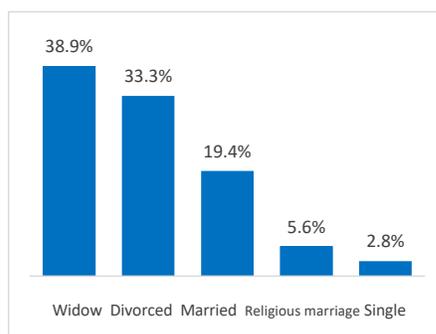
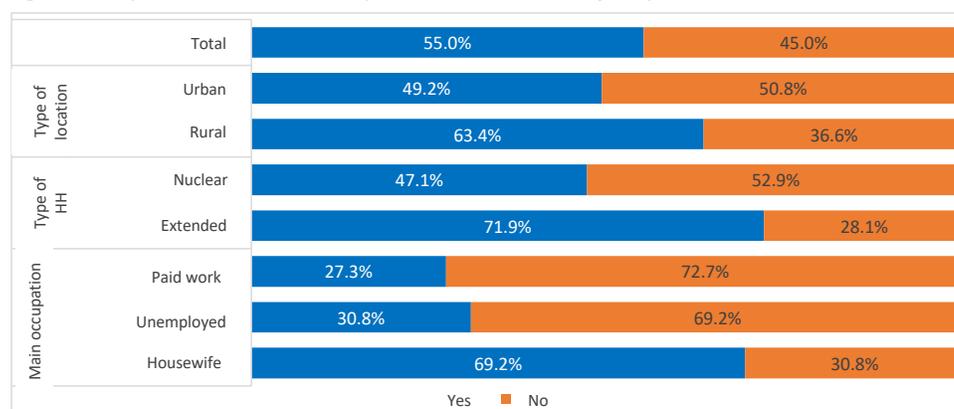


Figure 13. Marital status of women participating in decision making, n = 31



Women in rural areas are more likely to need to ask permission to leave the house (63%), housewives (69%), and those in traditional families (72%). They are more likely to be controlled and require permission from the household's seniors/husbands: *in villages women living with HIV are more strictly controlled, particularly by their mothers-in-law (see Figure 14).*

Figure 14. Do you need to ask someone's permission to visit a health facility?



Requesting permission does not always provide a favourable response, i.e., women living with HIV may face a refusal and may not be permitted to leave the house. This mainly occurs because women living with HIV do not disclose their status to their family. A possible reason is fear and internalised stigma

Survey among women living with HIV

As a rule, women don't tell anyone about their status—neither parents nor husband. Paradoxically, a woman infected by her husband may get a divorce. And she will be pilloried because HIV is viewed through the lens of morality.

And sometimes, it's easier for a woman to not go to the doctor than explain why and where she is going. And at this moment she may not know that she harms her own health.

From a conversation with an expert

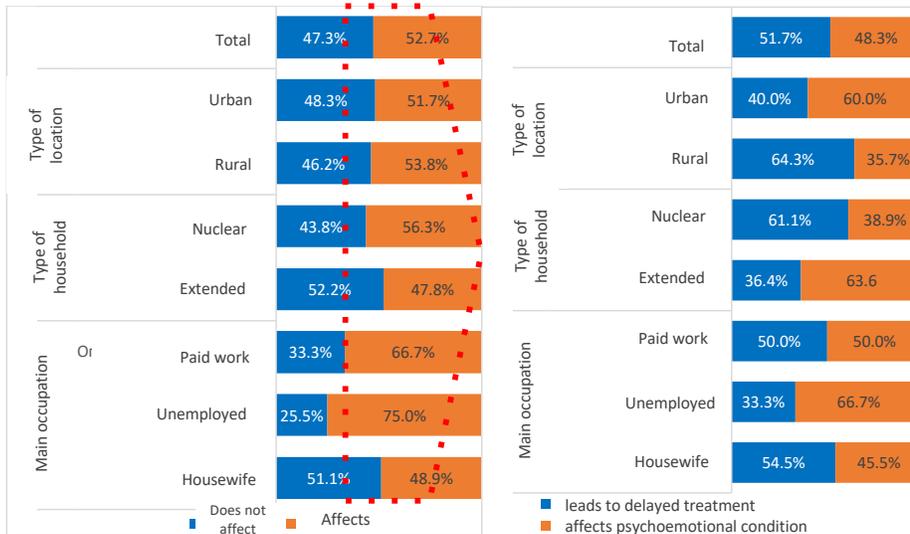
resulting from accepted social stereotypes, which leads to low self-esteem, higher isolation, and limited opportunities for social adaptation and maintaining psycho-emotional wellness.

Getting denied permission to leave the house on the one hand and having to frequently ask for permission and provide explanations on the other hand altogether result in delayed treatment and/or worsened psycho-emotional condition. This is most likely the reason why 26% of respondents indicated neurosis as number one of their comorbidities. Delayed treatment was more often reported by

rural respondents and housewives.

By the type of employment, the situation is roughly consistent with the general picture where both problems are reported nearly equally. The unemployed women were an exception—67% of them reported poorer psycho-emotional health (see Figure 15).

Figure 15. Negative impact on the respondents' health by the requirement to ask permission to visit a health facility



Survey among women living with HIV

According to survey findings, almost all respondents (97%) hide their HIV status from others. It is mostly

If one has to profile an average person with HIV, I can say that they are about 30 years old. Whenever possible, they will move to cities because the city offers more opportunities: there are self-support groups there, which is very important; there are AIDS centres, where doctors will not point fingers at you and turn away.

A person who has HIV is afraid to tell the family and friends in person that she or he has HIV infection. This person is waiting for some kind of improvement in life, some miraculous recovery, new drugs invented by science and medicine that will completely cure this disease and restore their health.

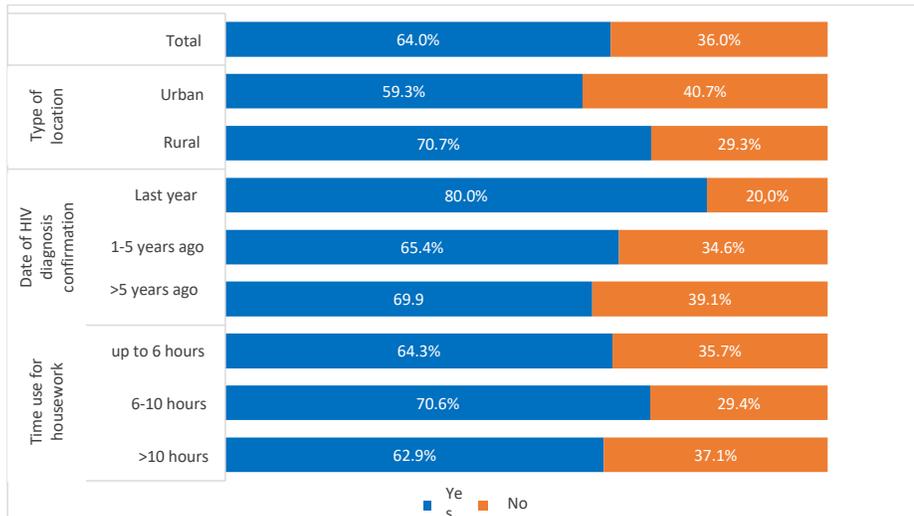
From an interview with the Head of the City AIDS Centre

because of the fear of being outcast: “My mother-in-law knew I got infected from her son. But she would interact with him while not taking a cup of tea from me. No one would talk to me”. Just about two-thirds of respondents (64%) reported stigma (social judgement) to be the barrier for them to visit health facilities for treatment of HIV and comorbidities. The rural women face this barrier more often compared to the urban women: 71% and 59%, respectively.

It should be mentioned that this barrier is more often indicated by female respondents (80%) who learned about their HIV status during the past year. To put this in perspective, 65% of the female

respondents who have been diagnosed one to five years ago still face this barrier against 61% of those who have been diagnosed for more than five years (see Figure 16).

Figure 16. Stigma as a barrier for access to health services



The analysis of this section allowed for the following conclusions:

- The need to ask permission to visit health facilities affects more than a half of respondents, especially in rural areas, among housewives and respondents from extended traditional families. This process impacts the health of more than half of the respondents, which is seen in delayed treatment and their poorer psycho-emotional condition;
- Only 14% of the total number of respondents were screened for cervical and breast cancer at least once. Meanwhile, almost all other respondents were aware of the necessity of this screening;
- One of the factors influencing the practice of women living with HIV visiting the health facilities is their participation in decision-making regarding their own health. According to the TDHS data, in the general population 46% of women make decisions about their own health, and according to this survey findings, among women living with HIV it is only 36%; besides, 20% of them take part in decision-making together with their husbands;
- Among women who make their own decisions, 72% belong to the category of widows or divorced;
- 26% of women living with HIV have neurosis, one of the most prevalent comorbidities; this may be due to the fact that nearly all women living with HIV conceal their HIV diagnosis from their family;
- Nearly all respondents (97%) conceal their status from family members;
- For 64% of women living with HIV, stigma and internalised stigma prevent them from visiting medical facilities for HIV and comorbidity treatment. This barrier is reported more often by the respondents who became aware of their HIV status during the past year.

4.5. Access to health services

This section presents the results of the analysis of the survey, in-depth interviews, and focus groups discussions regarding access to health services.

During the discussion of access to health services, the participants of the focus group discussion were offered to evaluate access using a 5-point scale, where 1 stands for absolutely free access, including appropriate attitude of healthcare workers, keeping confidentiality, and 5 would mean absolutely no access.

According to the participants of the focus group discussion that included representatives of relevant NGOs and women living with HIV, **access to health services can be scored as 4.4**. The main reason for such a score is the health workers' stereotypical thinking that perpetuates stigma and discrimination towards people living with HIV in general, as well as legislation: the participants often mentioned Article 125 of the CCT. According to the experts, the discriminatory attitude of health workers toward people living with HIV is a recognised issue, and there are several ways to address this multidimensional problem, such as reviewing curricula to determine whether HIV is covered, how many academic hours are dedicated to it, etc. *Discrimination grows on the ground of fear, which often stems from ignorance. Therefore, the first thing to start with should be the training curricula for physicians and other health professionals*, the director of the City AIDS Centre believes.

I haven't disclosed my status yet, and nobody knows that I have HIV. My two daughters also have HIV. My husband infected me, and I gave birth to girls with this disease. When they have toothache, I don't know what to do, because dentists don't accept them, saying, "Come tomorrow". When I go to the lab to get tested, I go through humiliation. Only 'our' doctors (from the AIDS centre) and my friends (people from NGOs working in the area of HIV and self-support groups) are the ones with whom I can freely talk about my problems, my pain.

From FGD findings

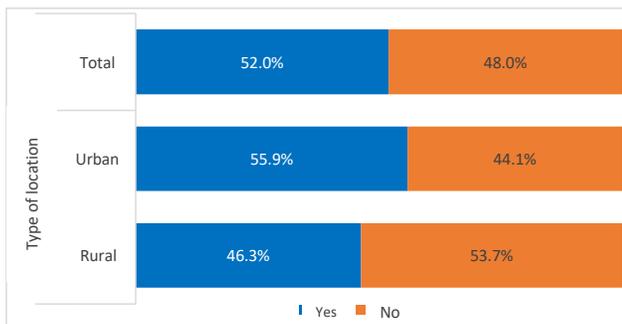
According to survey findings, 52% of women living with HIV comply with the required schedule of visits to health facilities for general health care,²³ while 48% do not follow it. It is mostly the respondents from rural areas (54%) who do not follow it, compared to those who live in urban settings (44%). It should be noted here that health services can be delivered in the specialised facilities such as AIDS Centres, as well as in the primary healthcare facilities. However, the experts say that AIDS Centres are more appropriate because of the tolerant attitude of the staff, which is crucial for women living with HIV.

²³ General healthcare includes regular check-ups and vaccinations, as well as consultations by medical specialists to improve the women's physical and mental condition.

Survey among women living with HIV

Finance. One of the reasons for noncompliance with the schedule of visits to health facilities for general health care is financial constraints. This problem was reported by 55% of respondents. In addition, time constraints are a significant barrier: 23% of respondents said housework was the biggest obstacle to

Figure 17. Do you follow the schedule of visits for general healthcare?



visiting healthcare facilities, and 20% indicated their jobs kept them busy. It should be mentioned that the paid work of the female respondents was mostly informal, which implied irregular and undefined working hours for cleaning and other house chores, while residents of rural areas were mostly working in the field. Financial constraints and a lack of time owing to work were reported both in nuclear

(77%) and traditional extended households (86%) (see Table 11).

Table 11. Reasons for noncompliance with the visits for general healthcare

Reason	Total	Type of households	
		Nuclear	Extended
Not enough money	55.1%	56.5%	52.2%
Not enough time because of household duties	23.2%	23.9%	21.7%
Not enough time because of work	20.3%	19.6%	21.7%
The health facility is too far	1.5%	—	4.3%
TOTAL	100%	100%	100%

According to the survey, the main type of costs related to treatment of HIV and other diseases includes travel costs as reported by 88% of respondents. Besides, almost half of the surveyed women mentioned the costs of dental care services (46%) and the purchase of drugs for comorbidities and opportunistic

Survey among women living with HIV

infections (42%). A quarter of respondents reported the costs for gynaecological services (25%). The costs for surgical services (19%), HIV-related tests (17%), cervical and breast cancer screening (14%), and medical consultations (11%) were less frequently mentioned.

Rural respondents reported a greater variety of costs than their urban counterparts. They mentioned more often the travel costs (98%), purchase of drugs for comorbidities and opportunistic diseases (27%), HIV-related tests (22%), and consultations (19%).

Similarly, the respondents with other diseases in addition to HIV overall reported a greater variety of costs as compared to those who did not have such health conditions. They mentioned more often the costs for dental care (48%), gynaecological (51%), and surgical (28%) services, as well as HIV-related examinations (19%) (see Table 12).

If I have a very bad toothache, I go to the dentist. I tell them I have HIV. And this dentist will force me to buy all the tools, which he will use to treat my tooth or remove it. It's about 800 or 900 TJS. Where do I or others like me get so much money? We have a lot of diseases because of the HIV.

I have a feeling that these medical workers, for example, surgeons and dentists, do not trust their sterilisations; they don't trust that they properly sterilised their instruments. Even if you go online and read about this, it says that this virus is not resistant, and minimal treatment kills it.

From FGD findings

Table 12. Types of HIV treatment-related costs

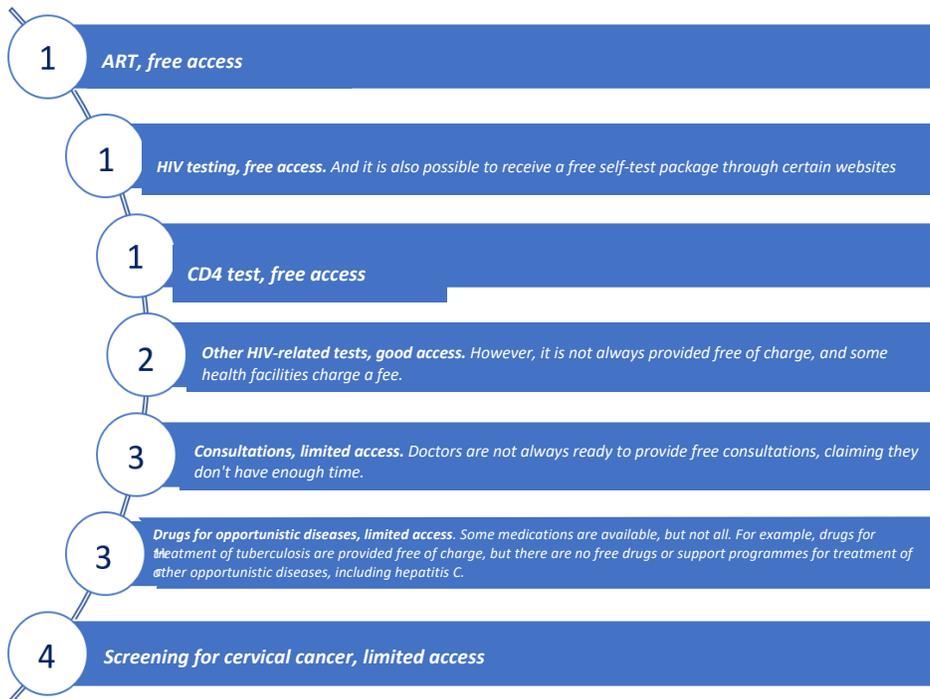
Type of costs	Total	Type of location		Other diseases	
		Urban	Rural	Yes	No
Transport	88.0%	81.4%	97.6%	86.3%	95.0%
Dental care services	46.0%	50.8%	39.0%	47.5%	40.0%
Gynaecology services	42.0%	40.7%	43.9%	51.3%	5.0%
Surgical services	25.0%	23.7%	26.8%	27.5%	15.0%
Medications for comorbidities and opportunistic diseases	19.0%	13.6%	26.8%	18.8%	20.0%
Other tests related to HIV	17.0%	13.6%	22.0%	18.8%	10.0%
Cervical and breast cancer screening	14.0%	11.9%	17.1%	16.3%	5.0%
Consultations	11.0%	5.1%	19.5%	10.0%	15.0%

During the interview, the director of the city AIDS centre was asked how he would rate the accessibility of various services for people living with HIV, using a 5-point scale where:

⇒ **1** – free access,

⇒ **5** – hindered access.

Picture 2. Assessment of service accessibility on a 5-point scale



Thus, it is clear from the interview results that HIV treatment and testing, and also other tests related to HIV, were scored as having a high accessibility level. Meanwhile, testing and treatment of comorbidities was scored low, which is explained by the lack of appropriate support programmes and noncompliance with the principle of free-of-charge access in health facilities.

Generally, only 8% of respondents reported having financial resources for all specialised services, including gynaecologist, dentist, and surgeon.

The rest 92% of respondents did not have money for specialised services, including gynaecological, dental, and surgical care. The majority in this group (18%) reported their need for gynaecology services. Surgical and dental care was required for 3% and 2% of respondents, respectively, and 2% of respondents needed all three services (see Figures 18 and 19).

Figure 18. All specialised services were received

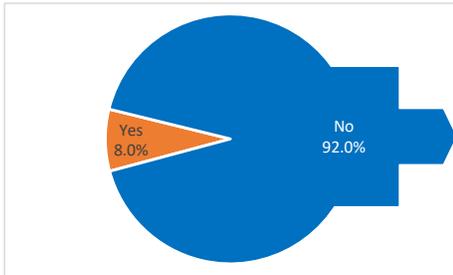
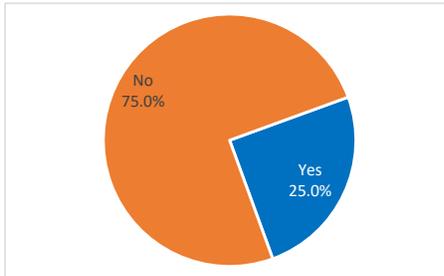


Figure 19. Did you need these services?



When asked where they sought the required care, the majority (65%) reported taking no action, mostly due to financial constraints and fear of being judged. Among those who sought care (35%), the majority reported going to the AIDS centres (88%), and the rest of them went to other public primary health care facilities (12%) (see Figures 20 and 21).

Figure 20. Did you seek the required specialised care?

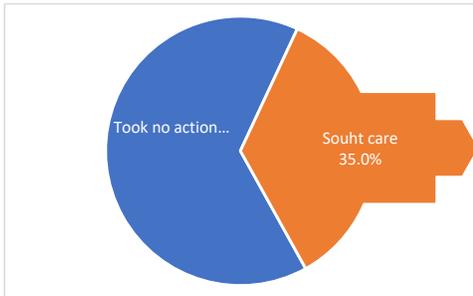
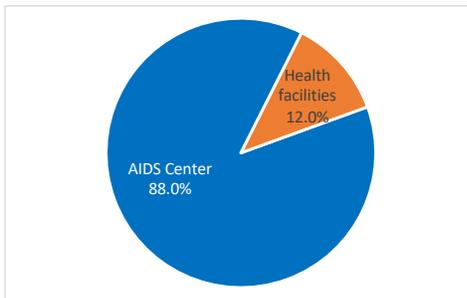


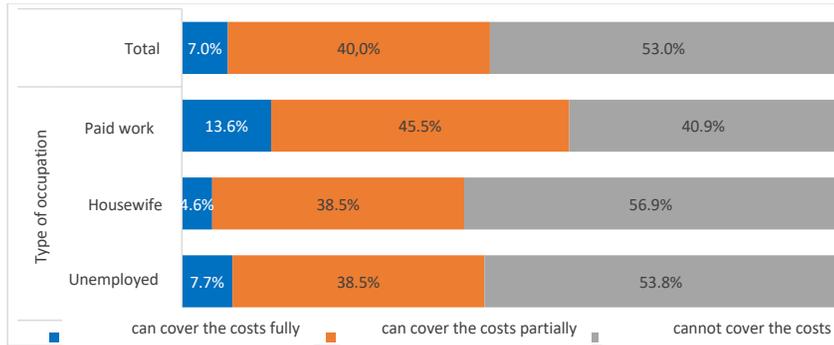
Figure 21. Where did you go for care?



Survey findings show that generally only 7% of respondents may fully cover the costs of the examination and treatment of HIV, 40% can cover them partly, and the other 53% cannot afford it. This highlights a significant financial vulnerability of respondents in accessing health care services related to HIV.

The ability to cover the costs of HIV testing and treatment depends on the respondents' employment status. Employed respondents are more likely to be able to fully cover the costs of HIV testing and treatment (see Figure 22).

Figure 22. Respondents' ability to cover costs for HIV testing and treatment



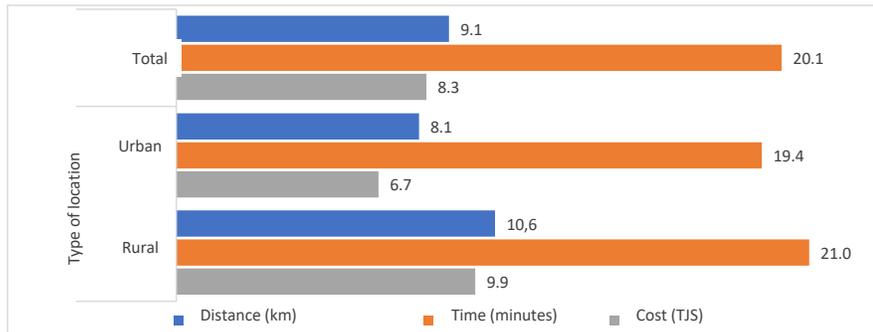
Distance to health facility. The average distance to a health facility is about nine kilometres, which takes about 20 minutes, on average, to reach it, and it takes about 8 TJS.

Respondents from rural areas typically travel farther and spend more time and money in order to receive healthcare services than respondents from urban areas (see Figure 23).

There are instances when women living with HIV in rural areas cannot afford even 5–10 TJS to come to the AIDS centre to get their ARV drugs.

From FGD findings

Figure 23. Average distance, time, and travel costs to get to health facility for HIV treatment



The analysis of this section allowed for the following conclusions:

- According to the focus-group participants, access to healthcare services can be scored as 4.4. The main reason for the reduced score was the discriminatory attitude faced by the people living with HIV in general;

Survey among women living with HIV

- Financial constraints are among the causes of failing to stick to the schedule of visits to healthcare facilities to maintain general health. 78% of respondents reported this problem;
- Lack of time is also a significant obstacle: 31% of respondents mentioned that household chores impede their visits to health facility, and 29% of respondents indicated being too busy at work;
- Generally, only 8% of respondents reported financial expenditures on all specialised services, including gynaecologist, dentist and surgeon. 25% of them stated they needed these services. However, it was noted that it was difficult to find those physicians who would be willing to see women living with HIV;
- The average distance to health facilities is about 9 kilometres. Respondents from rural areas typically travel farther and spend more time and money in order to receive healthcare services and HIV treatment than respondents from urban areas.
- Self-care and mutual assistance services are very important for women living with HIV. But they are available only in those cities where relevant NGOs are active: Dushanbe, Gissar, Vahdat, Rudaki, Kulyab, and Khujand. In other words, these services are only available in the capital city, the regional capital of the Soghd Region, one city in the Khatlon Region, and three cities in the Districts of Republican Subordination.

CONCLUSIONS AND RECOMMENDATIONS

1. The number of newly diagnosed and registered HIV cases continues to rise. At the same time, there is a declining trend in the number of HIV infections in pregnant women and children. In addition, the coverage of primary HIV testing is rising nationwide, rising from 76% in 2016 to 85% in 2020.
2. In recent years, the number of newly diagnosed HIV cases in children has significantly dropped. Among the detected cases, there is a comparatively higher number of reported cases in boys than in girls. A possible reason for the higher number of HIV cases in boys could be the tradition of *hatna* (circumcision), and since 2018, this procedure has been performed in healthcare settings and requires blood tests on the child.
3. The proportion of women living with HIV who have no education is significantly higher than in the overall adult female population in Tajikistan aged 18 years and older, making it 10% and 1%, respectively,²⁴ and this is a serious fact requiring attention;
4. Women living with HIV face serious financial challenges. They are seriously lacking in education (10% with no education among women living with HIV against 1% among all adult women in Tajikistan), low occupation rate (only 22% is employed, mostly those with secondary education), and high proportion of divorced (22% against 13% in the general population), which highlights their financial vulnerability.
5. Respondents spend most of their time doing the housework, especially in the large households, where housework takes two-thirds of their time. Meanwhile, the minimum amount of time is allocated for rest, social interactions, studying, and self-development. Personal care, including care of their health, also takes significantly less time, which can have a negative impact on their physical and psycho-emotional condition.
6. Furthermore, there are significant barriers to accessing healthcare services. More than half of respondents have to get permission from other family members to visit a health facility, especially in rural areas and in large households, which causes a delayed treatment and worsened psycho-emotional condition. Financial constraints also pose a serious problem for respondents: for this reason, 78% of them cannot afford regular checkups with a doctor, and only 7% of them can fully cover the costs of testing and treatment of HIV. Additionally, stigma and discrimination are barriers for most of the respondents (64%), preventing their access to medical services.
7. Discriminatory legislation and practical restrictions exacerbate the vulnerability of people living with HIV, particularly women, who are often held criminally responsible under Article 125 of the Criminal Code of Tajikistan. In order to decriminalise people living with HIV, the Supreme Court of the Republic of Tajikistan passed a Resolution of Plenum No. 5 on December 26, 2023. This resolution strongly advised against convicting under Part 1 of Article 125 of the Criminal Code a person living with HIV who has a suppressed viral load and has taken all proper precautions. However, the said resolution of the plenum is merely advisory.

²⁴ Statistics book "Population and housing census, 2020", Volume IV – Educational level of population of Tajikistan, the Statistics Agency under the President of Tajikistan, pp. 46-47.

The findings of the survey enabled drafting the following recommendations:

1. **Increasing the access** of women living with HIV to comprehensive healthcare services, including:
 - a) Uninterrupted access to antiretroviral therapy, regular check-ups for comorbidities and opportunistic diseases and their treatment if detected, mental health care;
 - b) Development of programmes specifically aimed at meeting the reproductive health needs of women living with HIV, including family planning, maternal health care, and screening for cervical and breast cancer;
 - c) Conducting information and educational activities to reduce stigma and discrimination in healthcare settings to ensure non-discriminatory services for women living with HIV and their families.
2. **The development of a support service on a basis of organisations led by women living with HIV:** develop and promote groups of self- and mutual assistance and counselling services, which help address the problems encountered by women living with HIV, including stigma, discrimination, and mental health issues. Create professional psychological support programmes for women living with HIV in order to prevent neurosis.
3. **Economic empowerment of women living with HIV:** provide training and resources for economic empowerment, including education, skills development, and employment assistance to help women achieve financial independence.
4. **Organizing personal time and support:** offer programmes helping women to better manage their time, particularly finding a balance between the health-related activities, caregiving, and employment, as well as creating community service centres, child care facilities, and work-at-home jobs. The expansion of consumer services will help address the issues of employment and provision of expanded services to all groups of women, irrespective of their HIV status, especially in rural areas.
5. **Education and awareness:** Implement educational programmes to promote awareness about HIV, modes of HIV transmission and prevention, aimed at both women and the general public to reduce stigma.
6. **Advocacy and policy change:** development of policies protecting the rights of women living with HIV, ensuring their equal access to resources and opportunities:
 - a) **Using the evidence-based approach, introduce into the new National HIV/AIDS Programme and other future documents** the aspects of needs and problems of women living with HIV and appropriate response measures.
 - b) **Promote universal implementation and strict enforcement** of the Resolution of Plenum No. 5 of the Supreme Court of the Republic of Tajikistan dated December 26, 2023, through information and educational activities with representatives of law enforcement agencies and the judicial system in order to prevent unjustified prosecution under article 125 of the Criminal Code.

2. **Work with communities:** focus community engagement efforts on creating an enabling environment for women living with HIV, to reduce stigma burden and provide emotional and practical support.
3. **Arranging regular and widespread information campaigns** about the “Undetectable = Untransmittable” principle and the importance of a tolerant attitude to people living with HIV. It is recommended to run information campaigns about the U = U principle and the importance of a tolerant attitude toward people living with HIV among the general population, including health workers.

5. ANNEXES

Annex 1. Sampling methodology for survey

To make a sample, a multistage probabilistic disproportionate random sampling was used. The main steps of the sampling process are given below:

Step 1: Stratification—sample distribution by target districts

The first step was to stratify the target districts; for this, a sample (100 people) was proportionally distributed by each of them, according to the size of the population (*see Table 13*).

Table 13. Distribution of the sample proportion

Target districts/cities	Population, N	Interviews, N	Fraction, %	Sampling error, ±%
Dushanbe	1 201 800	70	67.5%	11.7
Gissar	331 400	20	18.6%	21.9
Yavan	248 100	10	13.9%	31.0
Total	1 781 300	100	100.0%	9.8

It is important that the findings are analysed not only cumulatively, but also by target districts. However, with proportional distribution high sampling errors were found in Gissar city and Yavan district: ±21.9% and ±31,0% respectively (*see Table 12*). To minimise sampling errors in this case, the optimal solution is to increase sampling in these districts by reducing the sample size in Dushanbe city. After these procedures, it was possible to minimize sampling errors from ±15.5 to ±17.9% in all districts (*see Table 14*). The disproportionality of the sample in the analysis of findings is then smoothed out by applying the statistical weighting procedure.

It is worth pointing out that that the district-level values are still high even with the decreased sampling error. That's why the results at district level should be interpreted with caution. In addition, the conclusions and recommendation should be developed based on the overall data, avoiding drafting them as target district specific.

Table 14. Disproportional sampling

Target districts/cities	Population, N	Interviews N	Fraction %	Sampling error, ±%
Dushanbe	1 201 800	40	40.0%	15.5
Gissar	331 400	30	30.0%	17.9
Yavan	248 100	30	30.0%	17.9
Total	1 781 300	100	100.0%	9.8

To determine the quantity of primary sampling units (PSU) in each target district, a number of interviews in each PSU was set. In this research, PSUs represent localities from target districts: villages, towns, streets, and mahalla [*neighbourhood or smaller settlement*]. It was decided to do 10 surveys in each PSU. The decision to conduct 10 surveys was found to be optimal based on time and financial resources. Besides that, increasing the number of interviews will cause a reduction in the number of locations, and this will have a negative impact on data quality due to a smaller geographical coverage. And reducing the number of interviews will lead to an increase in transportation and time costs. The distribution of the number of PSUs in each target district is shown in Table 15.

Table 15 Distribution of PSUs by target districts

Target districts/cities	PSU
Dushanbe	4
Gissar	3
Yavan	3
Total	10

Step 2: Selection of PSU in target districts

In Dushanbe, 4 locations for the survey were randomly selected. In Gissar and Yavan, also a random selection of 3 locations in each district was done. The list of selected locations is given in Annex 4.

Step 3: Selection of households

The households for the survey are those who have women living with HIV and are located in the selected PSUs.

Step 4: Selection of respondents

The respondents are women living with HIV aged 18 years old and older, living in the selected PSUs.

Annex 2. Survey questionnaire



-

Annex 3. Guide on focus-group discussion with target NGOs and women living with HIV

Hi! My name is _____. Thank you for your willingness to meet and for your time. The topic of our discussion touches upon a number of questions about HIV, for example, what the current situation in overall legislation regarding this topic is, whether any barriers exist to receiving health or social care services, and what you think can be done to change the situation.

Our discussion will take about xxxx of your time; it will be confidential in the sense that no names will be disclosed, and the results will be summarised.

To be able to analyse the data, we need to keep an audio record.

Do you agree with it?

MODERATOR, I shall read out the Ethics Agreement, and the participants shall sign it.

Venue	
Date of the event	
Focus-group discussion start time	_____ hour _____ minutes
Focus-group discussion end time	_____ hour _____ minutes
Number of participants	
Focus-group discussion language	Russian _____ Tajik _____
Participants reaction on the questions during the focus-group discussion	
Check list for the moderator	Guide Ethics Agreement Audio record Focus-group discussion report

Section 1. Getting to know NGO

First of all, I suggest that we talk about what your activities are in the field of HIV. And now our discussion will look more like an interview than a general conversation. This section will take about 10–15 minutes.

1. Tell us please about your NGO's main activities.

- What is the primary activity of your NGO?
- How long has your NGO dealt with HIV issues?
- Have you personally taken any training on HIV issues? What kind of training?
- Have your employees taken training on HIV issues?
- Please, name your main partners for HIV-related projects.
- Who are your main donors for HIV-related projects?

2. In your opinion, what is the biggest achievement of your NGO regarding HIV during your work in this field?

Section 2. Women’s access to services

In this section, we will talk about women’s access to services, primarily to healthcare.

3. When we talk about access of women living with HIV to healthcare services, what comes to your mind first?

- Please provide reasons for your answers.
- What are the legislative provisions regarding the access of women living with HIV to healthcare services?

4. I suggest we do the following exercise. We will try to characterise the current legislation, using a scale from 1 to 5, where the score of 1 is “legislation sensitive to women living with HIV” and score of 5 is “legislation insensitive to women living with HIV”.

1				5
legislation sensitive to women living with HIV				legislation insensitive to women living with HIV

Why was it rated that way?

- 5. Would you like to change anything in the current law about accessibility to healthcare services for women living with HIV? What changes, you think, are needed and why?
- 6. In your opinion, which needs of women living with HIV are currently not taken into account by the legislation?

Section 3. Barriers and problems

Now we will move on to the topic of barriers and problems that women living with HIV face.

7. Based on your experience, can you state problems the women living with HIV face when receiving healthcare services?

MODERATOR, document all the problems listed by the participants.

Considering that women living with HIV are different people, some live in a city, some live in a rural area, some are employed, and some are not. We will try to distribute these issues by different categories:

Urban	Rural	Employed	Unemployed
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8. Please tell whether all challenges have been stated. Are there any that we don’t know about?

- How easily can women living with HIV obtain information about accessing healthcare services, particularly if they reside in a rural area?
- If they don't receive the service, do they know where they can go?
- What source of information do they usually use?

9. What challenges arise when working with women living with HIV or receiving information from them? And what is a barrier to receiving information?

- Disapproval from the family
- Fear of further discrimination/stigma

10. What actions/measures were undertaken by NGOs in case of a stigma against a woman living with HIV?

- Financial support
- Rehabilitation programme
- Consultations

Section 4. Recommendations for improvement

11. Each of you has worked in this field for a long time. Can you name those projects or activities that were implemented by you or another organisation that were the most effective in relieving the burden of the women?

- Why exactly were these measures effective?
- In your opinion, can these measures be implemented on a system level so that they are undertaken not only by NGOs but also by the government? If not, why? If yes, what needs to be done: changes in law, politics?

12. What recommendations would you like to give to the government to improve the situation of women living with HIV regarding their access to healthcare and social services?

- Does it need changes in legislation/policies?
- What else?

13. Has it ever happened that you made recommendations to the government, but they were not accepted? Have you got an official response because of refusal? Why do you think they were not accepted?

14. What else would you like to add in terms of barriers? Any suggestions?

THANK YOU FOR PARTICIPATING IN SUCH A SIGNIFICANT EVENT!

Annex 4. Guide on interviewing health workers

Read this text to the respondent:

Hi! My name is _____. As you already know, presently we are conducting research to understand the situation of people living with HIV, existing barriers, what can be done, and what is being done to allow them to receive healthcare services. The data we receive will be confidential; that means your name will not be mentioned anywhere. There will be a number of such interviews. We will also have conversations with non-governmental organisations and women living with HIV. These findings will enable better understanding of the existing problems. Thank you for your willingness to participate!

Our conversation will take about an hour. Please feel free to share your opinion about the issues we will be discussing. There are no right or wrong answers here, and your views are important for understanding the situation. All conclusions and information will be shown in a generalised and anonymous form.

If you feel uncomfortable at any stage of the conversation, please feel free to ask for a pause or stop the interview.

INFORMED CONSENT

General data

Please, introduce yourself _____	
Type of respondent	
Respondent's ID	
Date	____ (dd) / ____ (mm) / _____ (yyyy)
Time of starting and ending the interview	
Name of region/district	
Name of city/village	
Modality of informed consent	____ oral ____ written
Respondent's age	
Fill out this form after completing the interview	
Questions from the participant	
Participant's reactions to the interview	
A brief description of the interview setting	
Check upon completion	Data collection form ____ Informed consent form ____ Audiofile ____ Interview summary ____

Section 1. General information

The interview will begin with questions about you.

- 1.1. Please tell us about yourself: your education, where you work, and what your position is there.

Section 2. Healthcare services

- 2.1. If you try to draw a portrait of your typical client who comes to you for a service, please describe what this person is like.

Probing questions:

- ✓ Age
- ✓ Occupation
- ✓ Do your clients face any difficulties when seeking health services? If they do, what kind of difficulties?

- 2.2. About 30 years ago, almost all services (here we talk about healthcare services) were free of charge. However, times have changed, and along with the services provided free of charge, there are paid ones.

You can list them now?

- 2.3. Now let’s talk about the clients/patients...

- 2.4. What kind of healthcare services do you generally need? Can you name them?

Write down all services listed by the respondent and check with the following list:

- ✓ CD4 and VL tests
- ✓ Other tests related to HIV
- ✓ Consultations
- ✓ HIV drugs (ART)
- ✓ Drugs for opportunistic diseases
- ✓ Surgical services
- ✓ Dental services
- ✓ Reproductive health services
- ✓ Cervical and breast cancer screening

Now let’s try to rate accessibility for each of them using a scale from 1 to 5.

1				5
<i>Absolutely free access, any time that it is needed, I can get necessary service.</i>				<i>Absolutely no access. I can't get the service I need.</i>

Discuss with the respondent the reasons behind the scores assigned to each service.

- 2.5. Do you know who to contact in case of obstacles?

Probing questions:

- ✓ Who do you usually go to?
- ✓ What usually happens in this case?
- ✓ Who supports you in general? How does it work?

Section 3. Public attitudes toward the topic

- 2.6. Can you describe how the general public views this issue?
Probing questions:
✓ What is people's attitude to the issue of HIV and people living with HIV?
- 2.7. What are the most common stereotypes?
Probing questions:
✓ Are there differences in socio-demographic groups in discussing this topic or existing stereotypes?
- 3.1. Which words, terms, and phrases are used when discussing HIV?
- 3.2. In your opinion, do these words and terms contribute to stigma?
Probing questions:
✓ What do you think the use of words/terms depends on? I mean, why are these words/terms used? When did it start, and can it be changed?
✓ In your opinion, what feelings/reactions do people generally have about language/terms used in connection with HIV?
✓ How do people living with HIV feel or react to the phrases and language used?
- 3.3. If other words/terms were used, could that change the stigma? If so, how?

Section 4. Services provided

- 4.1. Which kind of HIV services exist in our country? Who provides these services?
- 4.2. Who is using them?
Probing questions:
✓ How do people learn about these services?
✓ How do people seek healthcare services?
- 4.3. Are there any shortcomings in the services provided?
- 4.4. In your opinion, are there any people who have chosen not to seek support even when they need it?

Section 5. Gaps and recommendations

- 5.1. What shortcomings are evident in the current perception of HIV among the general public and professionals?
- 5.2. How do these shortcomings affect:
– Patient care;
– Readiness to address and discuss HIV problems?
- 5.3. What can be done to reduce HIV-related prejudice/stigma among the general public?
- 5.4. (*also, if not covered: ...*)
- 5.5. What message should be communicated to the public in order to lessen stigma? What information should people learn about HIV to eliminate stigma?
- 5.6. What channels/platforms are preferable for sharing this message/information?

Thank you very much for your time and ideas. Your input is invaluable for our project, and it will help us shape our future strategy.

Annex 5. Grouping of independent variables

Education. The educational level of women living with HIV was determined based on the highest level of formal education attained. In the report, women living with HIV were categorised for analytical purposes into the following groups based on their educational level:

1. **No education.** Women living with HIV who did not even complete 1st grade or did not attend school at all.
2. **Elementary education.** Women living with HIV who have primary education, i.e., those who completed 1, 2, 3, or 4 grades.
3. **Secondary education.** Includes all types of secondary education—basic secondary education (5–9 grades), secondary general education (10–11 grades), and secondary professional/vocational education (colleges).
4. **Higher education.** Includes women living with HIV who received higher education, both under the old system (specialist degree) and the new (bachelor’s degree, master’s degree). This level includes those who have postgraduate education (PhD and higher degrees), yet none of the respondents had such education.

Size of household. Households were divided into two types according to their size:

1. **Extended.** Includes several generations and married couples.
2. **Nuclear.** Consists of two parents with children or one parent and children.

Main occupation. To learn about the main occupation of women living with HIV, the questionnaire included the following response options:

1. Full-time job;
2. Part-time job;
3. Unemployed;
4. Retired (welfare recipient);
5. Housewife;
6. Student;
7. Other (specify).

Based on the responses, women living with HIV indicated that they were primarily employed as full-time or part-time employees or were unemployed or housekeepers. The other options were not checked off. In the report, for analytical purposes, options 1 and 2 (full-time and part-time work) were combined into the group “paid work (occupation)”.