



THE PEOPLE LIVING WITH HIV STIGMA INDEX 2.0

UKRAINE

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ABSTRACT

An important area of activity for HIV-service NGOs is combating stigma and discrimination based on HIV status and protecting the rights of PLHIV. A necessary prerequisite for this is the availability of a strong evidence base, namely clear indicators of the prevalence of various manifestations of stigma and discrimination in the PLHIV community. The international “PLHIV Stigma Index” methodology, which was developed in 2005 by a number of international organizations (GNP+, ICW, IPPF, UNAIDS) and finalized in 2018 under the auspices of the United Nations Population Fund (UNPFA) and the United States President’s Emergency Plan for AIDS Relief (PEPFAR), was aimed at collecting and documenting such data. Then, it was named “PLHIV Stigma Index 2.0”.

This study is the fourth stage of the “Stigma Index” in Ukraine (2010, 2013, 2016, and 2020), each of which was conducted jointly by the “All-Ukrainian Network of PLHIV” (CO “100% Life”) and AC “Socioconsulting.”

The study analyzed the prevalence of stigma and discrimination against PLHIV in various spheres of life: health care, social relations, employment, and occupation, as well as internal stigma and discrimination, the confidentiality and disclosure of the HIV status, the prevalence of human rights violations and readiness to protect them, etc.

Compared to previous stages of the “Stigma Index,” a feature of this survey was an attempt to implement a cross-sectional approach. In contrast to earlier waves of the study, which focused exclusively on the HIV-related stigma and discrimination, for the first time within the Stigma Index 2020, we studied

the experience of stigma and discrimination towards PLHIV based on their membership to key populations: drug users, sex workers, and MSM.

The study results show a gradual improvement in the situation regarding the observance of the rights of PLHIV in Ukraine. Still, the problem of HIV-related stigma and discrimination remains relevant. The internal stigma of PLHIV and double stigma of PLHIV who belong to KPs is exceptionally acute.

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The survey was ideological and methodological assisted by the Global Network of PLHIV (GNP+).

The People Living with HIV (PLHIV) Stigma Index is the joint initiative of the CO “100% Life”, the research organization AC “Socioconsulting,” under the management of Irina Demchenko, and the Joint United Nations Program on HIV/AIDS (UNAIDS).

On behalf of CO “100% Life” and the team of authors, we express our sincere gratitude to the regional coordinators of the study, who were able to select groups of responsible and concerned people, learn with them the methodology of the survey, as well as all interviewers who were able to collect essential and reliable empirical data on time, provide psychological and organizational assistance to their respondents. We would also like to thank the staff of CO “100% Life” Olga Petrash, Ayder Useinov, Stanislav Gaievskyi for supporting and promoting the implementation of the “PLHIV Stigma Index 2.0 in Ukraine” project.

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LIST OF ABBREVIATIONS

ARV therapy, ART	:	antiretroviral therapy
AIDS	:	acquired human immunodeficiency syndrome
AIDS Center	:	Center for AIDS Prevention and Control
CO	:	charitable organization
HCF	:	healthcare facility
HCT	:	HIV counseling and testing
HIV	:	human immunodeficiency virus
HIV -	:	HIV-negative status
HIV +	:	HIV-positive status
HTC	:	HIV testing and counseling
KPs	:	key populations
LGBT	:	lesbians, gays, bisexuals, and transgender people
MSM	:	men who have sex with men
NGO	:	non-governmental organization
PLHIV	:	people living with HIV
PrEP	:	pre-exposure prophylaxis
PWID	:	people who inject drugs
S&D	:	stigma and discrimination
STDs	:	sexually transmitted diseases
SWs	:	sex workers
VL	:	viral load
WSW	:	women who have sex with women

SUMMARY

● Introduction.

An essential area of HIV-service NGOs activity is to combat stigma and discrimination based on HIV status and protect the rights of PLHIV. A necessary prerequisite for this is the availability of a strong evidence base, namely clear indicators of the prevalence of various manifestations of stigma and discrimination in the PLHIV community. The international “PLHIV Stigma Index” methodology, which was developed in 2005 by a number of international organizations (GNP +, ICW, IPPF, UNAIDS) and finalized in 2018 under the auspices of the United Nations Population Fund (UNPFA) and the United States President’s Emergency Plan for AIDS Relief (PEPFAR), was aimed at collecting and documenting such data. Then, it was named “PLHIV Stigma Index 2.0”. This study is the fourth stage of the “Stigma Index” in Ukraine (2010, 2013, 2016, and 2020), each of which was conducted jointly by CO “100% Life” and AC “Socioconsulting.”

○ Method.

This study was conducted using quantitative and qualitative data collection methods. The survey’s quantitative component envisaged the collection of information using the method of structured face-to-face interviews with PLHIV using tablets. A total of 2201 interviews were conducted. A sample type is representative and proportional and includes quota by region, urban/rural population, the share of PLHIV who actively treat HIV and PLHIV who avoid HIV treatment, gender, age, and the percentages of key population representative. The quantitative data were supplemented by qualitative information obtained during in-depth interviews with PLHIV using the “life stories” method. A total of 26 in-depth interviews were conducted with PLHIV, who faced manifestations of S&D based on their HIV status in various spheres of life (“negative stories”) or experienced situations when the disclosure of HIV status led to positive consequences for them in different spheres of life, allowed them to feel the support and

care of members of the social environment (“positive stories”).

○ Results.

The analysis of data in the dynamics shows a tendency to reduce the incidence of S&D based on HIV status in many areas of PLHIV life.

- 1 **The situation regarding the confidentiality of information on HIV status is gradually improving.** This situation is evidenced by both the gradual decrease in the proportion of PLHIV who have at least once encountered confidentiality violations in each of the survey waves (from 37% in 2010 to 18% in this study) and significant differences in this indicator depending on the duration of life with HIV.
- 2 **The frequency of stigmatization and discrimination of PLHIV by the social environment is gradually declining** compared to previous waves, although the problem of S&D is still relevant in Ukrainian society. At least one in ten respondents (11%) reported stigma and discrimination in the past year. A comparison of data on two separate indicators, which have the highest unfavorable rating among respondents and were repeated in all four waves of the survey (gossip and verbal abuse/threats against PLHIV), shows a gradual decrease in people’s proportion suffering from these S&D manifestations. The proportion of respondents who faced gossip decreased from 30% in 2010 to 8% in the current survey. The ratio of PLHIV who reported verbal abuse/threats from others decreased from 18% to 5%.

- 3 The situation with stigma and discrimination in health care, including HIV diagnosis and treatment, is gradually improving. The **integral indicator of the restriction of PLHIV in access to health services is declining** in each of the survey waves compared to the previous one: from 22% in 2010 to 4% in 2020. At the same time, 17% of PLHIV faced any manifestations of stigma and discrimination from health professionals. The main indications of S&D in health care facilities are avoidance of physical contact with PLHIV (12% of patients of general HCFs and 5% of patients of HCFs specialized in HIV treatment faced such cases of S&D), slander, and gossip (9% and 7% respectively) and disclosure of HIV status without the consent of the respondent (9% and 5%).
- 4 **The situation with the observance of the rights of PLHIV to anonymity, confidentiality, and medical secrecy is improving.** Throughout the Stigma Index waves, there has been a decrease in the proportion of respondents who reported on disclosure of their HIV status by health workers without the respondent's consent: from 30% in 2010 to 6% in 2020. PLHIV's assessment of the confidentiality of medical records regarding HIV status is also improving. The proportion of respondents convinced of such documentation's confidentiality increased from 18% in 2010 to 51% in 2020.
- 5 The study results show a tendency to **increase the proportion of PLHIV who were tested for HIV voluntarily and consciously** - from 69% in 2010 to 77% in 2020. Simultaneously, the balance of PLHIV who were compulsorily tested continues to decrease from year to year (from 10% in 2010 to 2% in 2020).
- At the same time, there are some issues.
- 1 **Manifestations of self-stigmatization and self-discrimination of PLHIV remain quite common.** According to the current survey, 58% of respondents said that over the past year, they had had a negative impact of HIV status on at least one aspect of their lives (e.g., ability to build relationships with the social environment, desire to have children, psychological well-being, including self-confidence, stress resistance, self-esteem, personal and professional development, etc.). Almost two-thirds (63%) of respondents said about having at least one negative feeling about themselves (for example, shame, guilt, uselessness, or "dirtiness" regarding their HIV status). One in three respondents (30%) has made at least one self-discriminatory decision in the last 12 months (e.g., not having sex, isolating themselves from family or friends, avoiding medical or social assistance, not getting a job, etc.).
- 2 **The level of stigma and discrimination while receiving healthcare services, which are not related to HIV, exceeds the level of S&D in facilities specializing in HIV treatment.** Thus, half of the PLHIV interviewed (47%) stated that in the last 12 months, they had sought medical help for reasons not related to HIV infection (such as influenza, dental services, vaccination, injuries, etc.). At the same time, a fifth of them (21%) suffered from various forms of stigma and health staff discrimination.
- 3 **There are a few gaps in HIV treatment.** In particular:
 - two-thirds (68%) of respondents (excluding those born with HIV/infected with HIV in childhood) said they postponed the start of health care and HIV treatment after receiving a positive test result

b. almost half (47%) of respondents have ever interrupted HIV treatment

c. almost one-fifth (17%) had never received antiretroviral therapy

d. among those who started ART, a quarter of respondents (26%) did so after two years or longer after diagnosis

e. for 12 months before the survey, 28% of PLHIV who had ever started ART had problems with adherence to treatment (interrupted the therapy)

f. 16% of PLHIV stated that they were not currently under healthcare supervision or receiving HIV treatment

g. 14% of PLHIV involved in HIV treatment stated that they had experienced stigma and discrimination from the staff of healthcare facilities where they had received HIV treatment services in the last year.

INTRODUCTION

People living with HIV/AIDS often face prejudice (stigma) and specific actions by others that restrict the rights and freedoms of PLHIV (discrimination). Many PLHIV either do not know what their rights are and how to protect them, or they are desperate to defend them. This issue is challenging not only for Ukraine, as the HIV/AIDS epidemic has spread to all continents and in all countries. Wherever people do not clearly understand major modes of HIV transmission and how it is not transmitted, where a variety of myths about this disease is spread, there is a basis for stigma and discrimination against PLHIV.

According to the Political Declaration on HIV and AIDS: On the Fast Track to Accelerating the Fight against HIV and to Ending the AIDS Epidemic by 2030, adopted by the Seventieth session of the UN General Assembly, despite the reduction of S&D scale based on HIV status, the same issue is still relevant. Accordingly, overcoming stigma and discrimination, and preventing the violation of PLHIV rights remain one of the important tasks in the context of combating the HIV epidemic.

The tasks of non-governmental human rights organizations, particularly regional affiliates of the Network of people living with HIV, are to counter these phenomena and protect the rights of PLHIV. Such organizations have much evidence of stigma and discrimination against their clients, as well as examples of successful protection of their rights. To improve the situation at the national and international levels, it is important to have not only examples but also clear indicators that show the prevalence of these negative phenomena at the level of a PLHIV community. For this purpose, in 2010, 2013, and 2016, the CO "100% Life" (then the All-Ukrainian Network of PLHIV) conducted a study titled "The Indicator of Stigma Level of PLHIV – the Stigma Index."

This study was conducted based on an international methodology developed in 2005 at the initiative of credible international organizations, including the Global Network of People Living with HIV (GNP+), the International

Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federations (IPPF), and the Joint United Nations Program on HIV/AIDS (UNAIDS). At the moment, over 100 countries joined the study [<https://www.stigmaindex.org/about-the-stigma-index/what-is-the-people-living-with-hiv-stigma-index/>].

During the 2018 International AIDS Conference, held in Amsterdam, a process of reviewing and revising Stigma Index methods was initiated to take into account the current context in the global response to HIV. This process took place under the auspices of the United Nations Population Fund and the US President's Emergency Plan for AIDS Relief (PEPFAR) and resulted in creating a tool called the PLHIV Stigma Index 2.0 to be used for this study.

The study **aimed to** collect information on cases of stigma and discrimination, the realization of human rights in accordance with the experience of PLHIV in Ukraine.

To achieve this aim, the following **tasks** were solved:

Assess the prevalence of various forms of stigma and People living with HIV/AIDS often face prejudice (stigma) and specific actions by others that restrict the rights and freedoms of PLHIV (discrimination). Many PLHIV either do not know their rights and how to protect them, or they are desperate to defend them. This issue is challenging not only for Ukraine, as the HIV/AIDS epidemic has spread to all continents and in all countries. Wherever people do not clearly understand significant modes of HIV transmission and how it is not transmitted, where various myths about this disease are spread, there is a basis for stigma and discrimination against PLHIV.

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overcoming stigma and discrimination and preventing the violation of PLHIV rights remains one of the crucial tasks in combating the HIV epidemic.

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The study aimed to collect information on stigma and discrimination cases, the realization

of human rights under the experience of PLHIV in Ukraine.

To achieve this aim, the following **tasks** were solved:

- Assess the prevalence of various forms of stigma and discrimination against PLHIV based on HIV status;
- Investigate S&D against PLHIV based on their belonging to KPs;
- Improve the evidence base for influencing PLHIV policy, implementing programs to protect rights, and combating stigma and discrimination based on HIV status.
 - d discrimination against PLHIV based on HIV status;
 - Investigate S&D against PLHIV based on their belonging to KPs;
 - Improve the evidence base for influencing PLHIV policy, implementing programs aimed at protecting rights, and combating stigma and discrimination based on HIV status.

METHODS

THE TERRITORIAL COVERAGE OF THE STUDY

The study was conducted in the following regions: Chernihiv, Kyiv, Cherkasy, Dnipropetrovsk, Odesa, Kherson, Mykolaiv, Kirovohrad, Poltava, Zaporizhzhia, Donetsk, Lviv, Rivne, Kharkiv, and Sumy oblasts.

As in previous waves of the survey, an integral approach to empirical data collection was used to conduct an objective and comprehensive analysis of the current study's situation, which included a combination of quantitative and qualitative data collection methods.

1 **Quantitative component of the study**

This component provided for the collection of information through structured face-to-face interviews with PLHIV using tablets. This study method collects quantitative data on the prevalence of various manifestations of stigma and discrimination based on HIV status. Interviews were conducted using a questionnaire developed by international partners and adapted to Ukrainian realities.

A questionnaire developed by international partners and adapted to the Ukrainian context was used to conduct a quantitative component of the study.

The use of the standardized "People Living with HIV Stigma Index" questionnaires allows the following:

- Directly from PLHIV, collect the information on their experiences of stigma and discrimination;

- Trace changes that have taken place in comparison with the previous waves of the "Stigma Index" survey in Ukraine (according to repeated indicators);

- Provide facts and confirmations to initiate policy changes and implement programs to combat stigma and discrimination against PLHIV.

People, who have HIV-positive status and live openly with it, were interviewed.

There are the following advantages of this approach:

- Creating an atmosphere of trust between the interviewer and the respondent that does not distort the information;
- Learning new skills in conducting interviews (recruiting, interviewing, and documenting) by members of the PLHIV community;
- Forming perception and understanding of "data ownership, responsibility for results" in the PLHIV community, namely PLHIV become not the object of study, but the subject;
- The opportunity to provide adequate social support to respondents if they need it.

○ A sampling of the quantitative component of the study

The general population is people living with HIV who know about their status for at least one year, aged 18 and older, live in Ukraine (excluding the Autonomous Republic of Crimea, Sevastopol, and the temporarily occupied territories of Donetsk and Luhansk oblasts).

The sample population.

The total sample size is **2201** respondents.

The sample type is representative, proportional, based on regional quota, a settlement type, proportions of PLHIV who actively treat HIV and PLHIV who avoid HIV treatment, gender, age, and proportions of representatives of key populations.

Volumes of quotas (sub-samples) are determined in such a way as to provide opportunities for an acceptable statistical analysis (calculation of statistical significance of percentage and average differences, calculation of correlations) at the level of the total sample by the following categories:

- Gender and age,
- Regions,
- Urban/rural population,
- Belonging to key populations (PWUD/MSM/SW),
- Actively involved in HIV treatment/those who avoid HIV treatment.

Due to the need to ensure representativeness of the sample while its construction, quotas were set only for those KPs sufficiently represented in the structure of the general population of PLHIV, namely for drug users, sex workers, and MSM. Quotas for WSW,

bisexuals, and transgender people, which are insignificant among PLHIV, were not set to avoid bias in sampling. A particular, negligible number of representatives of these KPs were included in the sample by natural recruitment.

A total of **2201 structured interviews** were conducted with PLHIV, which belong to the target groups of the study (Table 1):

- 1 PLHIV who visit HCFs (who are registered for follow-up care in the AIDS Center and have received healthcare services for HIV treatment for the last 12 months: doctor's consultations, VL or CD4 tests, ART, etc.) - **1481 respondents or 67%** of the total sample.
- 2 PLHIV who do not attend HCFs (who knows their HIV-positive status, but are not registered at the AIDS Center, or they are registered for follow-up care but have not received healthcare services for HIV treatment in the last 12 months - **723 respondents or 33%** of the total sample size. This group also included:
 - PLHIV with low adherence to treatment (i.e., those who have interrupted therapy for more than one month in the last year);
 - PLHIV, who have long known their HIV status, have only started receiving ARV therapy within the previous six months.

Table 1. The sample interviewed, by regions

NAME OF REGIONS AND OBLASTS	SAMPLE, persons		PLHIV who visit HCFs		PLHIV who do NOT visit HCFs	
	Plan	Fact	Plan	Fact	Plan	Fact
The city of Kyiv	210	210	137	137	73	73
Kyiv oblast	100	100	65	65	35	35
Chernihiv oblast	90	89	59	59	31	30
Sumy oblast	75	75	49	49	26	26
Kirovohrad oblast	70	70	46	46	24	24
Poltava oblast	73	73	47	47	26	26
Cherkasy oblast	73	73	47	61*	26	12*
Kharkiv oblast	135	135	88	88	47	47
Donetsk oblast	200	200	130	150*	70	50*
Zaporizhzhia oblast	134	134	87	87	47	47
Dnipropetrovsk oblast	300	300	195	195	105	105
Rivne oblast	80	80	52	52	28	28
Lviv oblast	140	140	91	90	49	50
Mykolaiv oblast	170	170	110	110	60	60
Odesa oblast	250	250	162	162	88	88
Kherson oblast	100	105	65	83*	35	22*
TOTAL	2200	2204	1430	1481	770	723

The sample design was used for each category of PLHIV (including those receiving and not receiving HIV treatment services).

In particular, the selection of **PLHIV who do not treat HIV** was conducted randomly, and their distribution by socio-demographic characteristics was formed naturally. Instead, for **PLHIV who are being treated for HIV**, a quota system has been calculated based on aspects such as the type of settlement, gender, age, and belonging to key populations. Appropriate quotas were applied at the level of each of the study regions. These quotas were divided into two groups: the first group of quotas included a settlement and demographic characteristics, and the second group had the respondents belonging to key populations. Simultaneously, quotas were set only for KPs that were most represented in the people's structure, namely PWUD, SWs, and MSM. Quotas for other KPs (e.g., WSW, bisexual/transgender) were not set to provoke the bias in sampling.

○ Recruitment of respondents

To ensure maximum reach of different categories of respondents, three channels of respondent recruitment were used during the study:

- 1 Involvement of respondents through NGOs working in the field of HIV/AIDS prevention and control (CO "100% Life," Alliance for Public Health, etc.). Respondents were recruited among clients of projects on PLHIV care and support, harm reduction, etc.
- 2 Involvement of respondents through HCFs that provide services for PLHIV (AIDS Centers, consulting rooms, ART sites, etc.). Healthcare workers (primarily infectious disease doctors and, with the doctor's permission, nurses assisting the specialist) invited patients to participate in this study.

- 3 Using the “snowball” method, respondents who took part in the study were asked to invite their acquaintances who were HIV-positive and willing to participate in this study. The number of recruited by each respondent did not exceed three new respondents.

The proportion of respondents recruited using the “snowball” method was insignificant (according to coordinators, no more than 5%). The rest of the respondents were roughly equally divided between the other two recruitment channels, through HIV-service NGOs and HCFs.

Locations for interviews were chosen based on the following criteria: availability of conditions to ensure confidentiality, respondent “friendly” environment to provide the maximum level of psychological comfort, the minimum level of physical comfort for the respondent and interviewer, the convenience of the proposed location for the respondent.

Interviews were conducted in the following locations: separate premises at NGOs or AIDS Centers, interviews at the respondent’s place of residence, other locations convenient for the respondent (e.g., parks or squares near the respondent’s place of home or work, HCFs he/she visits, etc.).

2 **Qualitative component of the study**

The quantitative part of the research was supplemented by information obtained using a qualitative method - **in-depth interviews** with PLHIV **using the “life stories” method.**

In-depth interviews were conducted with respondents who were:

- a) Experienced the manifestations of HIV-based S&D in various spheres of life during the period limited from the last wave of the Stigma Index study (2016) to the period of the current research;
- 6) Experienced the situations when the disclosure of HIV status led to positive consequences for them in various spheres of life, allowed them to feel the support and care of the social environment (relatives, friends, employers, colleagues, health workers, etc.).

Therefore, if the interviewers found out while interviewing that the respondent had to face the manifestations of S&D, they asked the respondent to meet with the interviewer again and tell about this case in more detail.

The questions from the guide related to the following topics:

- Description of the case when the respondent was (felt to be) stigmatized and discriminated against because of his/her HIV status (or when the disclosure of his/her HIV status led to positive consequences);
- Respondent’s perception of the situation;
- Actions are taken by PLHIV to protect violated rights;
- Continuation of a current situation, consequences for PLHIV, his/her family (negative or positive).

The results of in-depth interviews allowed illustrating the data obtained during the quantitative component by the “living” experience of respondents, further exploring the nature of discriminatory actions against PLHIV and ways to counteract such actions or cases of support and positive attitude from others.

In each region, 1-3 in-depth interviews were conducted. The distribution of life stories by region mostly correlates with the distribution of the number of interviews within the study’s quantitative component.

A total of **26 in-depth interviews** were conducted (Table 2).

Table 2. The number of life stories, by regions

REGION	Number of life stories	
	Scheduled	Implemented
The city of Kyiv	1	1
Kyiv oblast	2	2
Chernihiv oblast	2	2
Sumy oblast	1	1
Kirovohrad oblast	1	1
Poltava oblast	1	1
Cherkasy oblast	1	1
Kharkiv oblast	2	2
Donetsk oblast	2	2
Zaporizhzhia oblast	2	2
Dnipropetrovsk oblast	3	3
Rivne oblast	1	1
Lviv oblast	2	2
Mykolaiv oblast	2	2
Odesa oblast	1	2
Kherson oblast	1	1
TOTAL	25	26

○ Data collection management

During the implementation of the study’s field phase, the research team in Kyiv provided constant consultative support for coordinators and interviewers, the monitoring and quality control of their work. Consultations were provided by phone, Skype, and e-mail. Representatives of regional teams most often asked about the implementation of the sample, selection of respondents, explanations of filling out individual blocks of questionnaires, various aspects of work on tablets, and the preparation of reporting documents.

All regional coordinators weekly provided interim reports on the survey’s progress and the implementation of the sample, including quotas by their regions. To ensure a more efficient flow of data collection, operational decisions were based on the analysis of these reports.

In parallel with the collection of primary data, 20%-quality control of interviewers in each region was conducted via phone.

DATA PROCESSING AND METHODS OF THEIR ANALYSIS

The data collected during the quantitative component of the study were analyzed using the SPSS software. The main methods of data analysis included:

- Calculation of descriptive statistics, namely one-dimensional and two-dimensional distributions of respondents' answers to the questionnaire. There are the main features, according to which the analysis of two-dimensional distributions will be carried out:
 - Demographic characteristics (sex, age, duration of life with HIV, type of settlement, etc.);
 - Experience of belonging to vulnerable groups: PWUD, SWs, MSM, and people who do not belong to any of them;
 - Involvement in HIV treatment (PLHIV who receive or avoid HIV treatment services). Moreover, the category of PLHIV not involved in the HIV treatment was selected by the strictest criterion: it included only those respondents who do not receive HIV treatment services (n = 347, 16% of the total sample).
- If possible, the analysis of data in the dynamics compares the results of the current survey with the data obtained in previous waves of the Stigma Index in Ukraine.
- Calculation and analysis of integral indicators related to stigma and discrimination in different spheres of life, their comparison in the dynamics by years (if possible), as well as by socio-demographic groups.
- Systematization and initial content analysis of transcripts of in-depth interviews and FGDs with regional coordinators.

- Systematization and content analysis of open answers in standardized interviews.

○ Study limitations

During the respondents' recruitment, there were some difficulties in recruiting the required number of PLHIV, which do not avoid visiting HCFs. The number of such PLHIV was limited in regions (it is connected with NGOs' diligent work to identify HIV-positive people and register them for follow-up care), the closed nature of these social groups, and their unwillingness to contact social workers, etc.

The data analysis's principal difficulties were related to the peculiarities of understanding (or misunderstanding) several terms (e.g., stigma, discrimination) by some respondents, their lack of legal literacy. As a result, respondents did not always adequately understand which statements/actions could be considered manifestations of stigma and discrimination, which was quite evident in some life stories. This led to a violation of logic in answering the questionnaire or interpreting some indicators with caution.

The low fill rate of some groups (for example, WSW, bisexuals, transgender people) hampered the conduct of statistically based data analysis. However, given the small number of these groups in the general population structure, if it is necessary to assess the manifestations of stigma concerning the representatives of these groups, a particular study should be conducted considering the relevant groups to be the object of this research. After all, the inclusion of WSW or transgender people sufficient for static analysis (formation of appropriate quotas) in the sample of the current study would bias the sample and result in the unrepresentativeness of the data obtained on the general population PLHIV.

Analysis of specific indicators in the dynamics in many cases was impossible due to the significant transformation of the tools used in this study, compared with previous Stigma Index waves.

○ **Ethical principles of the study**

The collection, storage, and analysis of empirical data of the study were based on the ethical standards and the protection of the right of these study participants to voluntariness, anonymity, and confidentiality. The questionnaire (and the data array) did not contain any personal data to identify the respondent. All employees involved in the project, including interviewers, coordinators, and controllers, signed confidentiality agreements. They undertook not to disclose and otherwise not to transfer to third parties any information about the respondents, which would become known to them in the performance of their professional duties.

PLHIV aged 18 and older were invited to participate in the study. Before the interview, each respondent was asked to review the contents of the information letter, which outlined the history and objectives of the study, peculiarities of its implementation and guarantees of anonymity and confidentiality for respondents, their right to voluntary participation in the research, and possibility to terminate the participation in any moment. In verbal consent to participate in the study, respondents filled out the form of informed consent in writing.

The development of study tools and the study's conduct was based on the principles of gender sensitivity.

MAIN RESULTS

1 Main characteristics of participants

The proportion of men and women among the respondents is approximately the same and is 51% and 49%. There were no respondents who identified themselves as transgender. Instead, two persons (0.1% of respondents) stated that they do not identify themselves as women, men, or transgender people. Another two respondents (0.1%) refused to answer questions about their gender identity.

Various age groups are sufficiently represented among the respondents, including young people and PLHIV aged 50 and older, although middle-aged people dominate (Fig. 1.1). The gender and age characteristics correspond to the gender and age distribution of the general population, which indicates the compliance with the set quotas during the recruitment of respondents and the representativeness of the data obtained.

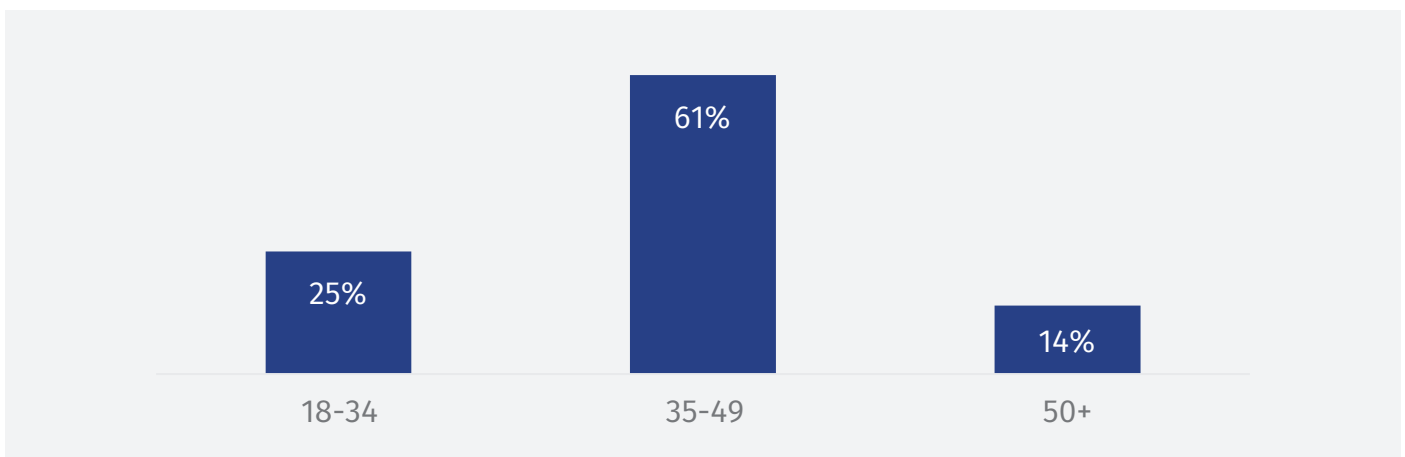


Fig. 1.1. The age of respondents, %

The respondents include people with a short duration of life with HIV, as well as those who were diagnosed more than 10 years ago (Fig. 1.2). In particular, the maximum duration of life with HIV is 28 years.

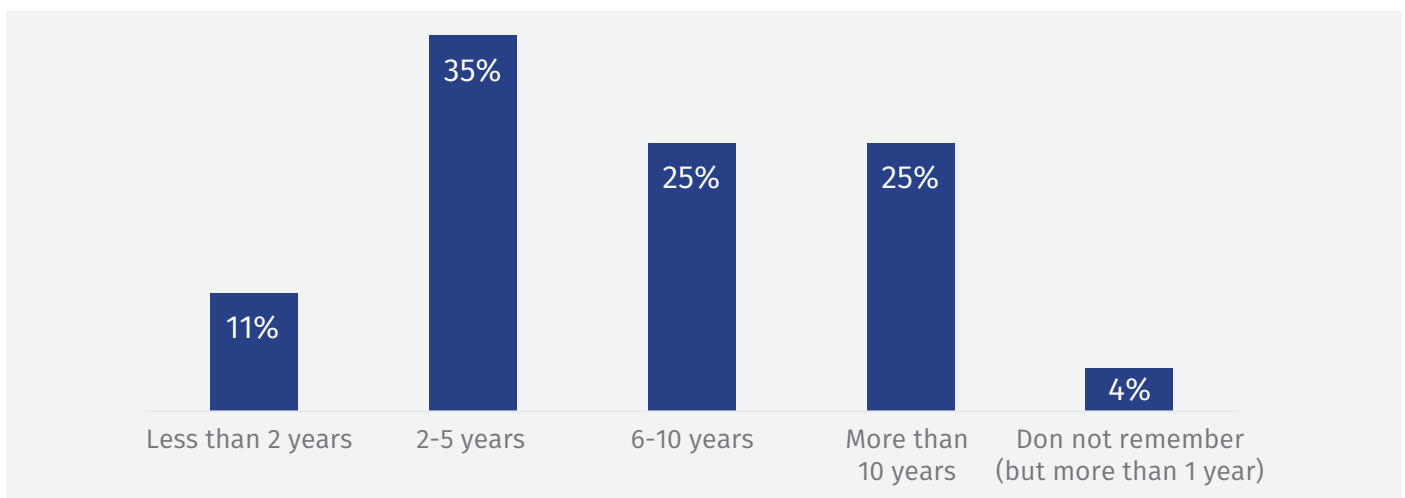


Fig. 1.2. The duration of life with HIV, %

More than half of the respondents are in close relationships, regardless of the official status of these relationships (registered marriage or not). At the same time, the proportions of those whose partners are HIV-positive and HIV-negative are approximately the same (Fig. 1.3).

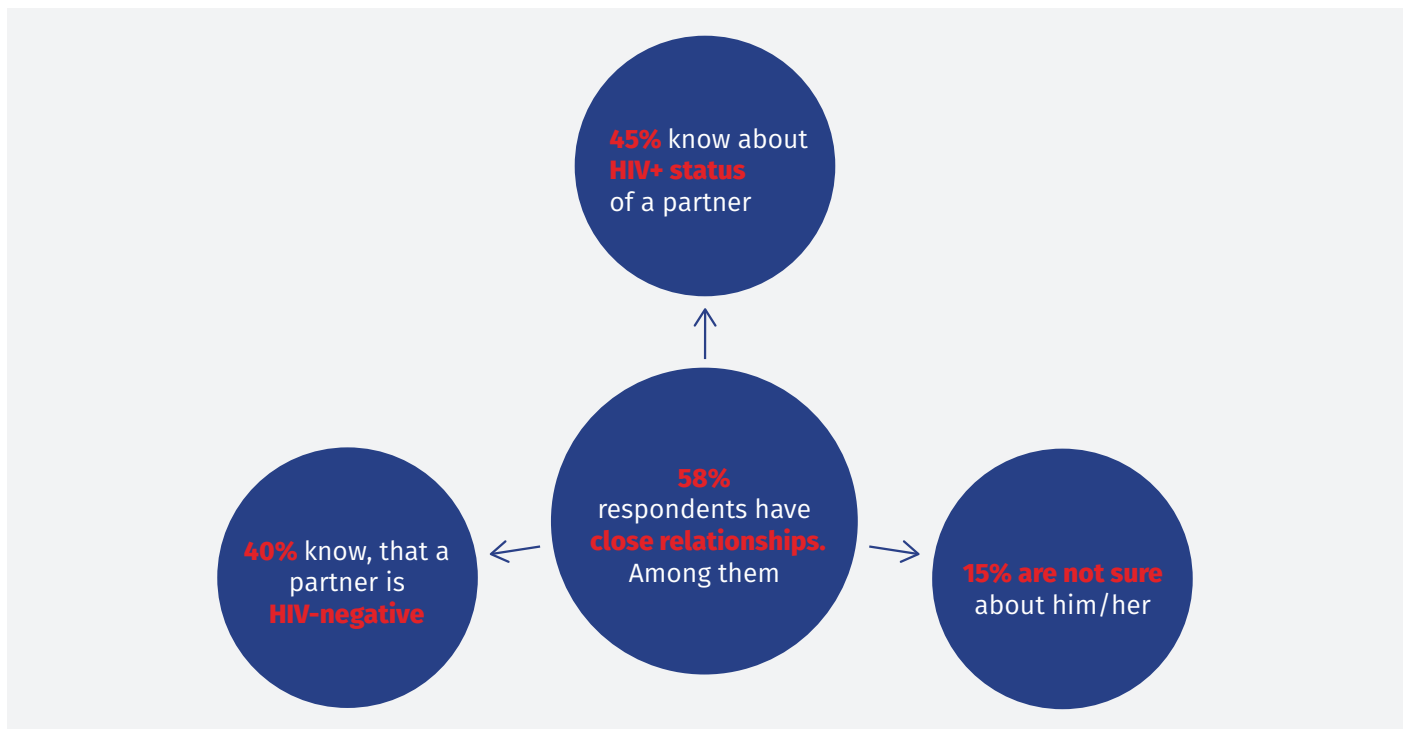


Fig. 1.3. Respondents' close relationships and HIV status of their partners, %

Two thirds (66%) of respondents stated that they do not have minor children they maintained. The remaining 34% of respondents have children. Most of them have 1 (22%) or 2 (9%) children. Three percent of respondents said that they had 3 or more children (the maximum number is 10). At the same time, respondents who stated that they did not have minor children more likely belonged to the 50+ age group (90%) than to young people under

35 years (59%) and middle-aged respondents (64%).

Three quarters (74%) of respondents have a general secondary or vocational secondary education (Fig. 1.4). Thus, the level of education of PLHIV as a whole remains slightly lower than the level of education of the general population.

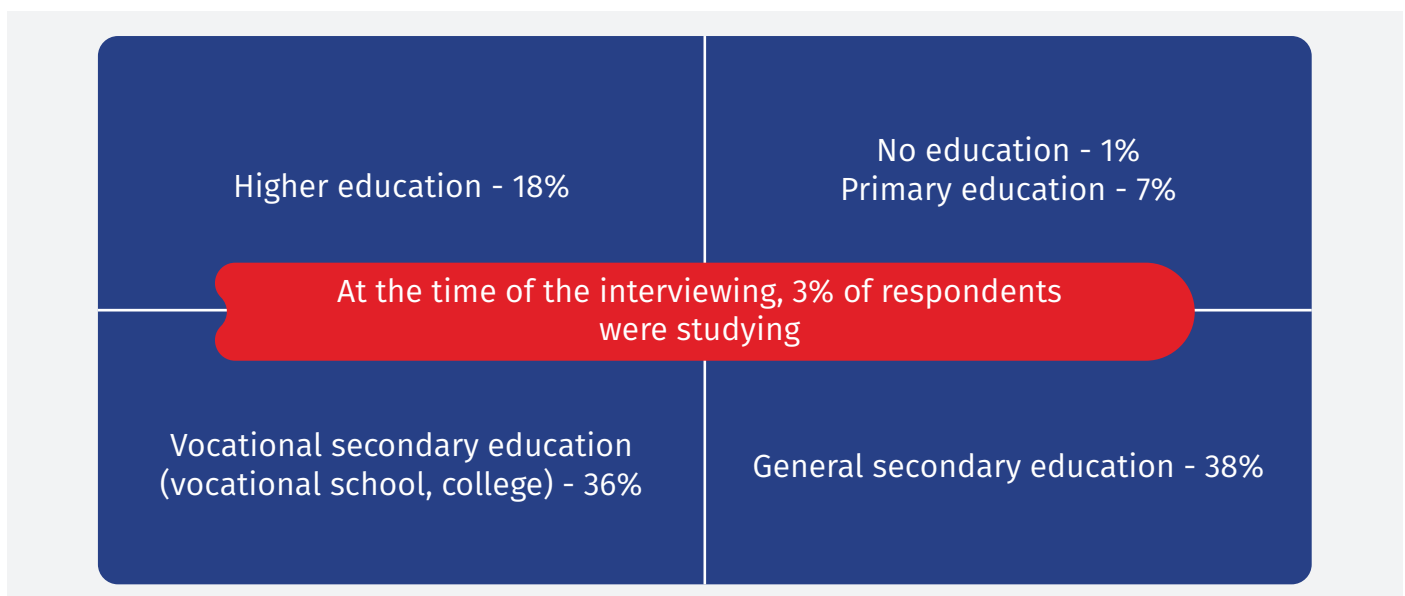


Fig. 1.4. The level of education of respondents, %

About 61% of respondents have some form of paid employment, the other 8% receive

pensions. Thus, almost a third (31%) of respondents have no personal income (Fig. 1.5).

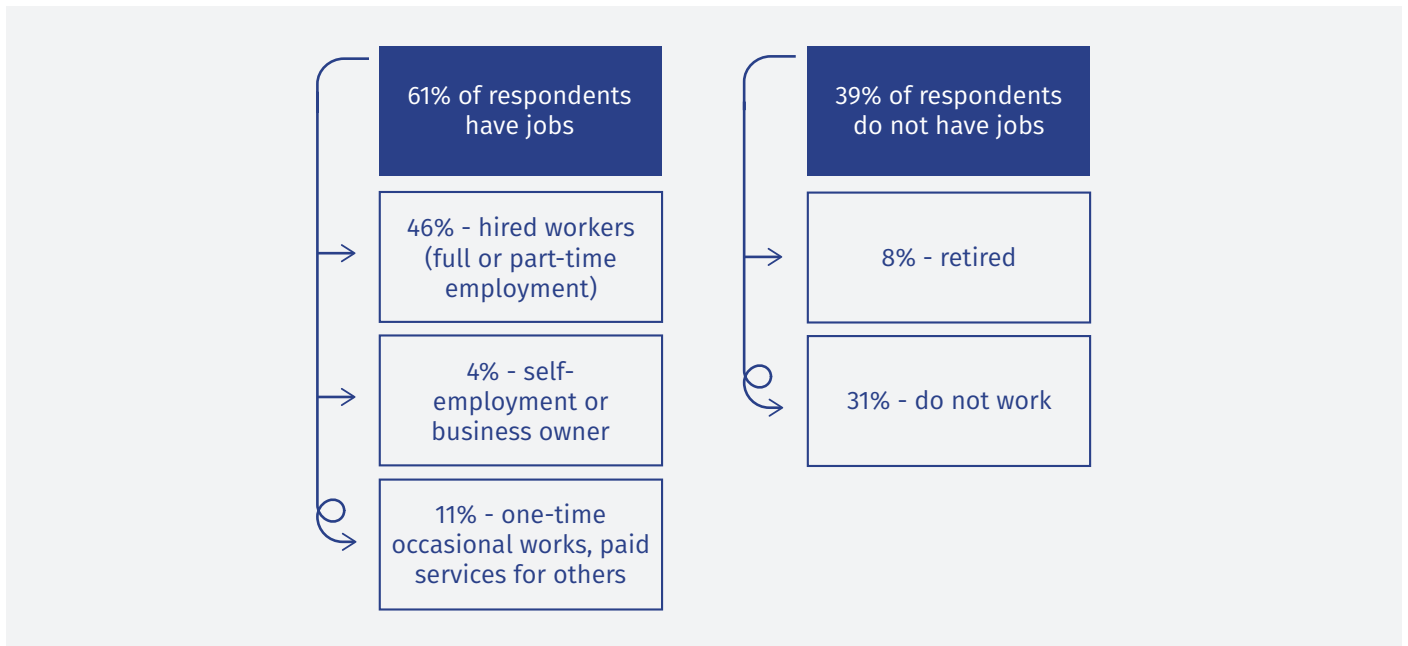


Fig. 1.5. The employment of respondents, %

Lack of income is one of the factors that a significant part of respondents is not able to meet basic needs (food, housing, and clothing). In particular, in the 12 months preceding the interviewing, 19% of respondents encountered such situations

systematically, other 43% of respondents faced it from time to time. At the same time, the proportion of those living below the poverty line (regularly unable to meet basic needs) reaches 29% among unemployed respondents (Fig. 1.6).

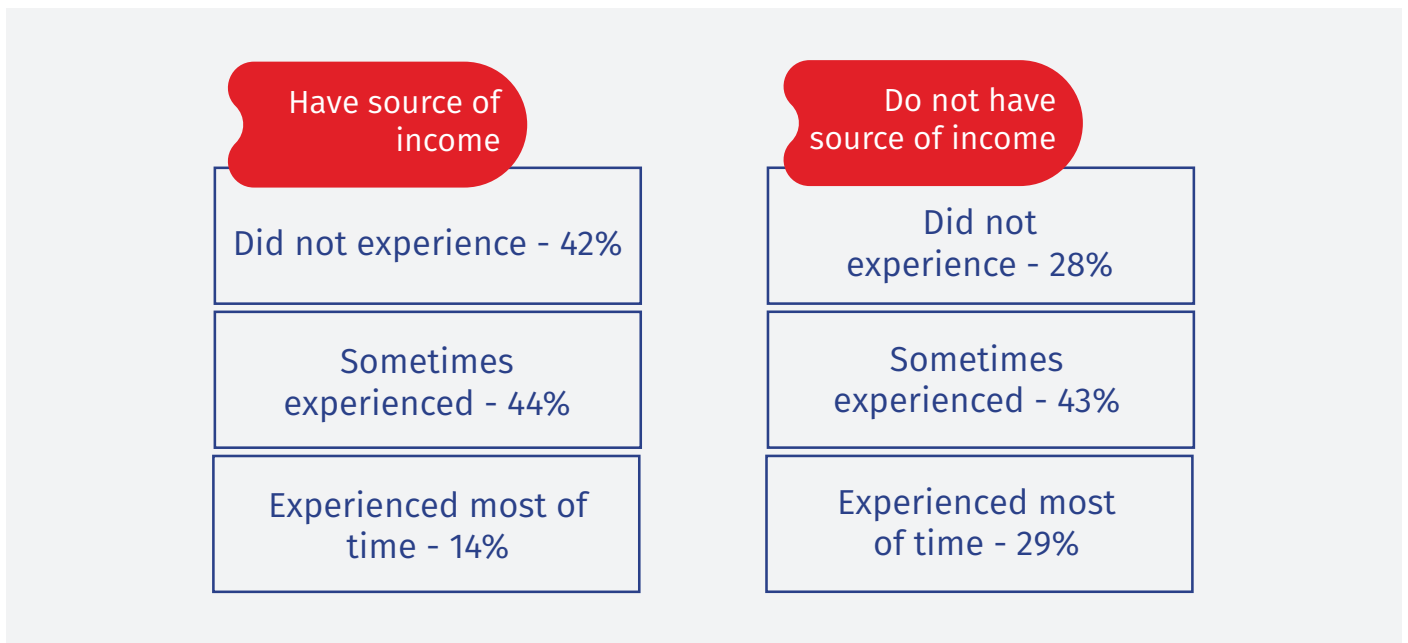


Fig. 1.6. The distribution of answers to the question: “How often during the last 12 months were you not able to meet your basic needs (e.g. food, housing, and clothing)”, % depending on the income (work/pension)

About 57% of respondents said that they did not belong to any of KPs, while 43% belonged to one or more such groups at the same time (Fig. 1.7). Most of the respondents are drug users, as well as sex workers and MSM. The proportion of respondents, according

to belonging to KPs, generally reflects the corresponding distribution in the general population (among people living with HIV in general) and indicates compliance with quotas during the selection of respondents and representativeness of the data received.

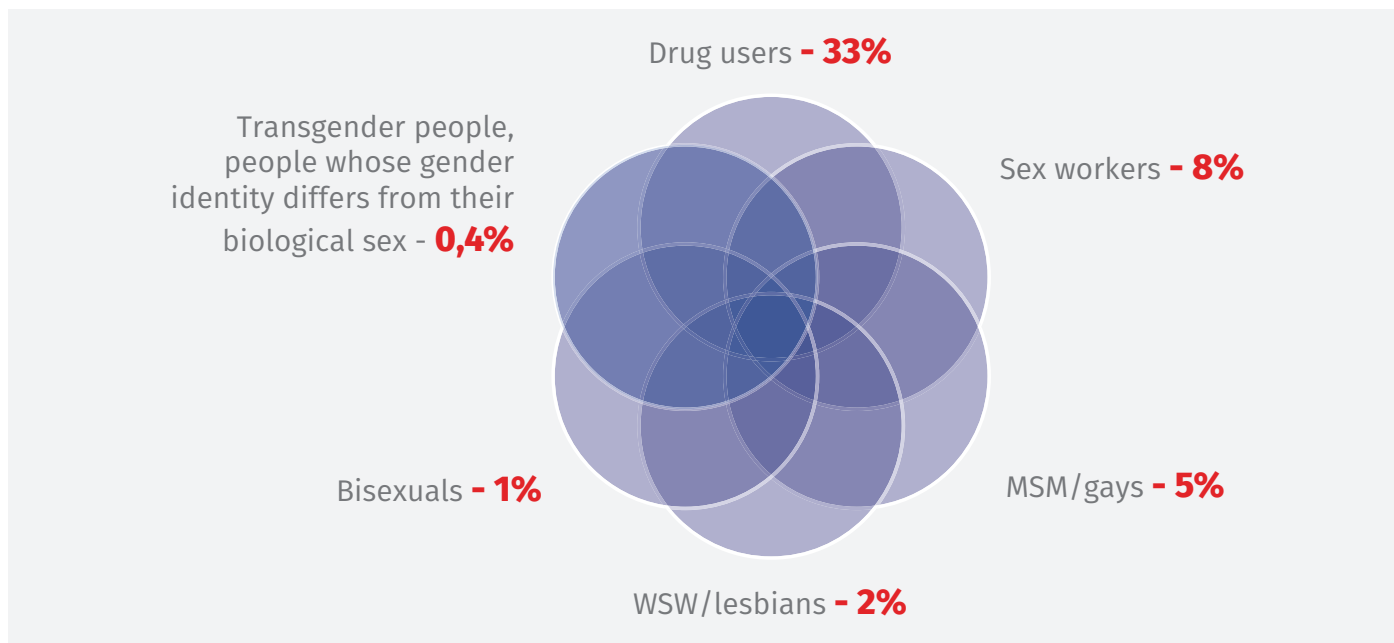


Fig. 1.7. Belonging of the respondents to key populations, %

A significant number of respondents also experienced in belonging to other socially vulnerable groups, including former prisoners, people with disabilities, ethnic minorities, IDPs (Fig. 1.8). The highest proportion is former prisoners, which is determined by peculiarities of the existing system of combating drug

use in Ukraine. In particular, due to the low maximum permissible amount of drugs for storage, the excess of which becomes a basis for criminal liability, a significant proportion of people who use drugs were imprisoned (45% compared to 11% among those who have no experience of drug use).

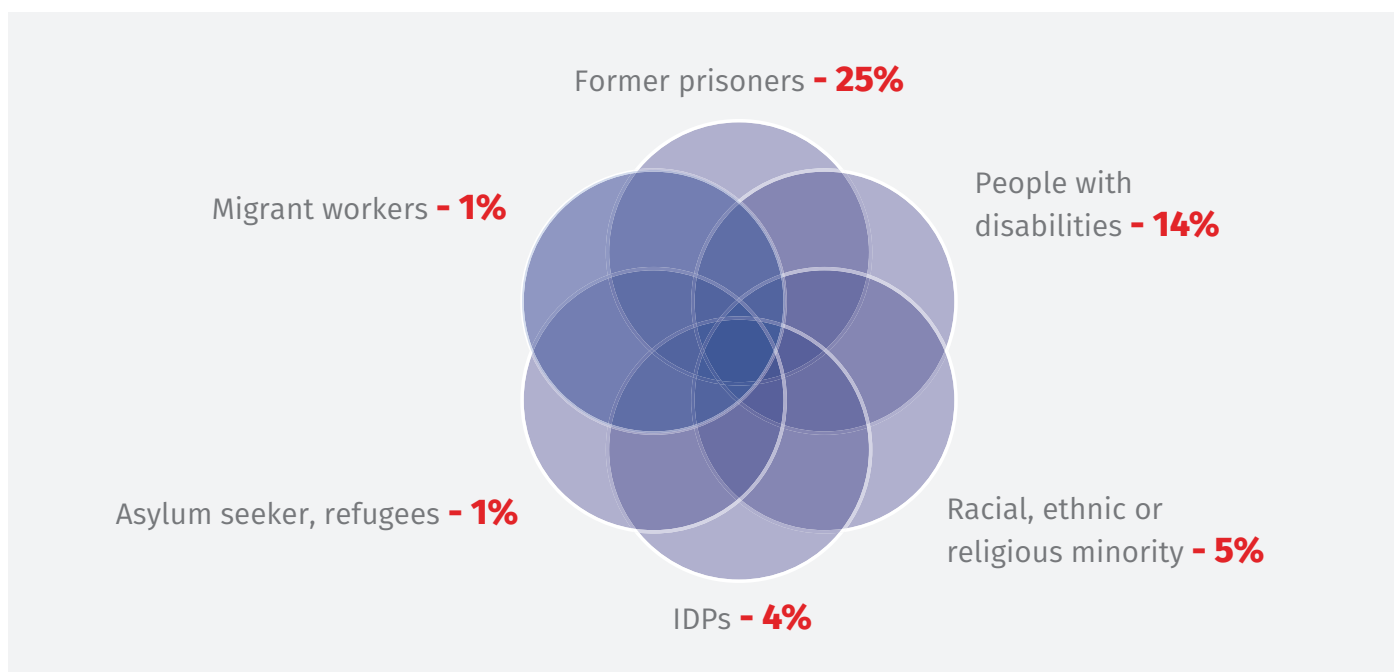


Fig. 1.8. Belonging of the respondents to other socially vulnerable groups, %

Thus, the socio-demographic characteristics of respondents, including gender and age distribution and distribution according to belonging to KPs, correspond to the

characteristics of the population, which indicates compliance with the set quotas during the selection of respondents and representativeness of the data received.

2 Disclosure of HIV status

Only 9% of respondents said that none of their social environment knew about their HIV status. Furthermore, among them, there are

both people living with HIV, whose diagnosis was determined recently, and those who live with HIV for 10 years and more (Fig. 2.1).



Fig. 2.1. Distribution of the respondents, whose HIV status is unknown to any of the representatives of their social environment, by the duration of life with HIV, %

Instead, the majority (91%) of respondents said that at least someone from their social environment knew about their diagnosis. They often talked about spouses/partners and other adult family members, as well as friends

and family doctors. Moreover, the respondents who had the experience of drug use often noted that drug use partners knew about their HIV status (Table. 2.1).

Table 2.1. The proportion of PLHIV whose HIV status has been disclosed to others, including without their consent, %

	Know about the HIV status of the respondent, %	Among them, learned about HIV status without the consent of the respondent, %	Frequency of unauthorized disclosure of HIV status among all respondents, %
ADULT FAMILY MEMBERS (EXCEPT SPOUSE/PARTNER)	60	12	7
SPOUSE/PARTNER	58	11	6
FAMILY DOCTOR	47	13	6
FRIENDS	46	12	6
INJECTING DRUG PARTNERS	25	10	3
CHILDREN	19	8	2
AUTHORITIES (POLICE, JUDGES, INVESTIGATORS, ETC.)	10	22	2
COLLEAGUES	7	8	0,5
EMPLOYER	6	5	0,3
NEIGHBORHOOD	4	34	1
LOCAL LEADERS (E.G., POLITICAL, RELIGIOUS LEADERS)	4	12	0,5
TEACHERS/ADMINISTRATION OF THE EDUCATIONAL INSTITUTION	1	57% (4 persons)	0,2
CLASSMATES/GROUPMATES	1	25% (4 persons)	0,2

*Green color in the table highlights the high values of the relevant indicators: the high proportion of respondents with disclosed HIV status and a high proportion of those whose HIV status was disclosed without their consent

Orange color in the table highlights the average values of the relevant indicators: the average proportion of respondents with disclosed HIV status and the average proportion of those whose HIV status was disclosed without their consent

Red color in the table highlights the low values of the relevant indicators: the small proportion of respondents with disclosed HIV status and the small proportion of those whose HIV status was disclosed without their consent

One in five respondents (20%) of PLHIV with disclosed HIV status or **18% in the whole** said they **faced at least once the unauthorized disclosure of HIV status** (Fig. 2.2).

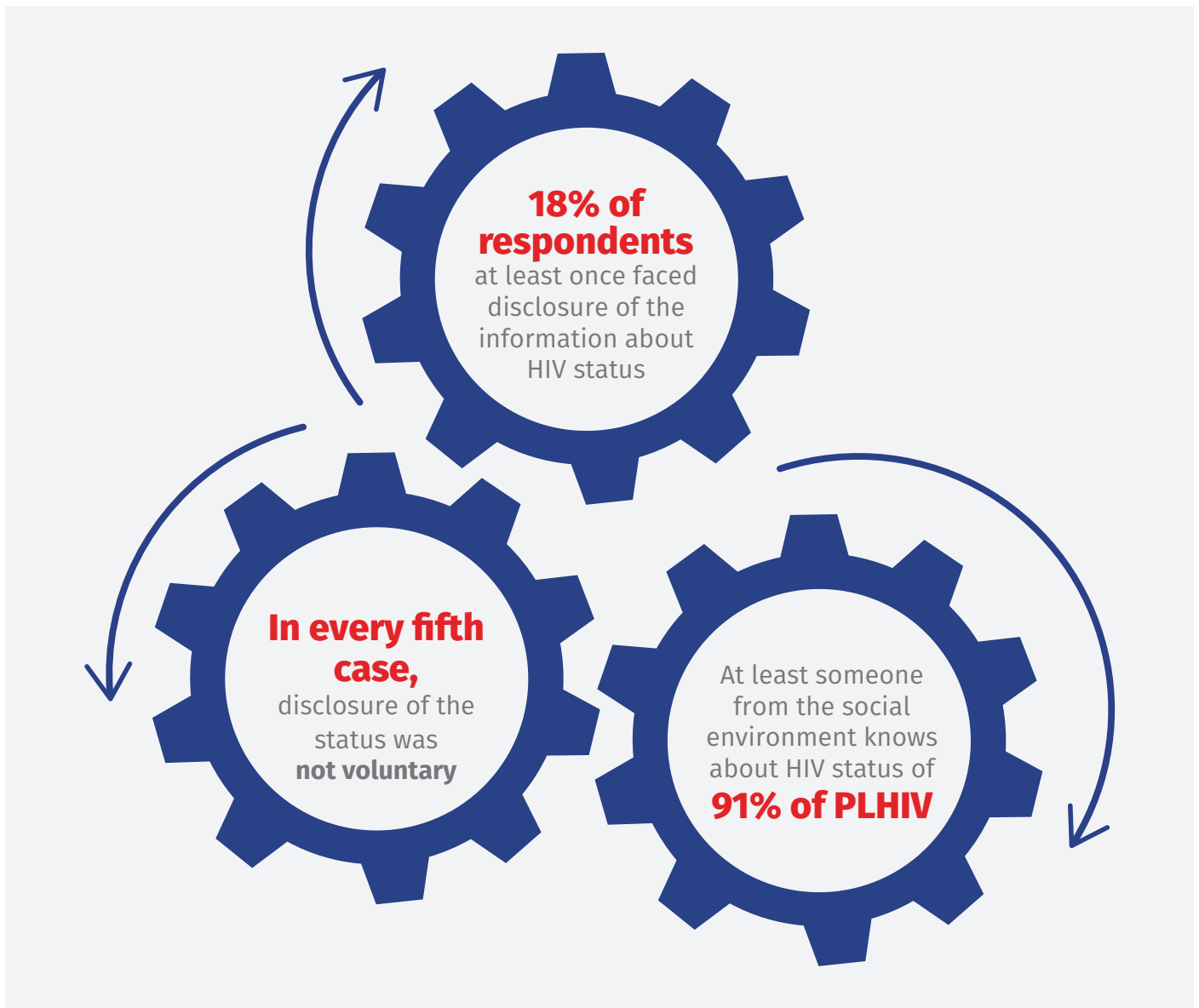


Fig. 2.2 The proportion of PLHIV whose HIV status has been disclosed to others, including without their consent, %

Unauthorized disclosure of HIV status to close people (relatives, friends, etc.) occurs relatively seldom in percentage terms (mostly, PLHIV disclose their status to the close social environment voluntarily), but the absolute number of such cases is significant. However, regarding neighbors, law enforcement officials (police, investigators, and judges), representatives of educational institutions (including both classmates/groupmates and teachers/management), and other people from whom information about HIV status is usually hidden, the proportion of unauthorized

disclosure of HIV status is significant in absolute terms, although such cases are rare (Table. 2.1).

It is quite predicted that the proportion of the respondents, who have at least once encountered unauthorized disclosure of HIV status (integral indicator), increases with the increase in the duration of life with HIV infection (Fig. 2.3).



Fig. 2.3. The integral indicator of HIV status disclosure depending on the duration of life with HIV, %

Other socio-demographic characteristics (e.g., gender, type of settlement, and even experience of belonging to KPs) do not affect this indicator. In particular, the integral indicator of HIV status disclosure for PLHIV who do not belong to KPs is 16% compared to 17% for members of KPs, including for PWUD - 18%, for SWs - 17%, for MSM - 12% (however, given the relatively low filling of this group, the differences are not significant).

As for the situation with unauthorized

disclosure of HIV status in the dynamics, according to the results of the third wave of the Stigma Index (2016), the proportion of PLHIV who indicated that they had at least once encountered unauthorized disclosure of HIV status was 20%. Differences in this indicator with the results of the current study (18%) are not significant (at $p = 0.05$), as well as differences in most of the individual components for which we can trace the dynamics (Table 2.2).

Table 2.2. The proportion of PLHIV who faced unauthorized disclosure of HIV status to members of the social environment, in the dynamics, %

	2010 (n=1500)	2013 (n=1500)	2016 (n=1500)	2020 (n=2201)
Husband/wife/partner	3	2	1	6
Other adult family members	10	6	5	7
Children in the respondent's family	2	1	1	2
Friends (including neighbors - for 2010 data)	13	6	2	5
Neighborhood	-	6	5	1
Colleagues	4	2	2	0,5
Employers or managers	2	1	1	0,3
Injecting drug partners	6	3	1	3
Religious leaders, community leaders	2	0	1	0,5
Employees of other healthcare facilities, except for the AIDS Center (for 2016). Family doctors (for 2020)	-	-	6	6
Teachers	1	0	0	0,2

* Differences are significant if they exceed 3%

Almost two-thirds of respondents (65%) agreed absolutely or in part that it was easier for them to disclose their HIV status over time. At the same time, there is a tendency that the disclosure of HIV status to loved ones was a

positive experience for most respondents, allowed feeling their support and help, while, in terms of strangers, such experience was positive in about one of the two cases (Fig. 2.4).

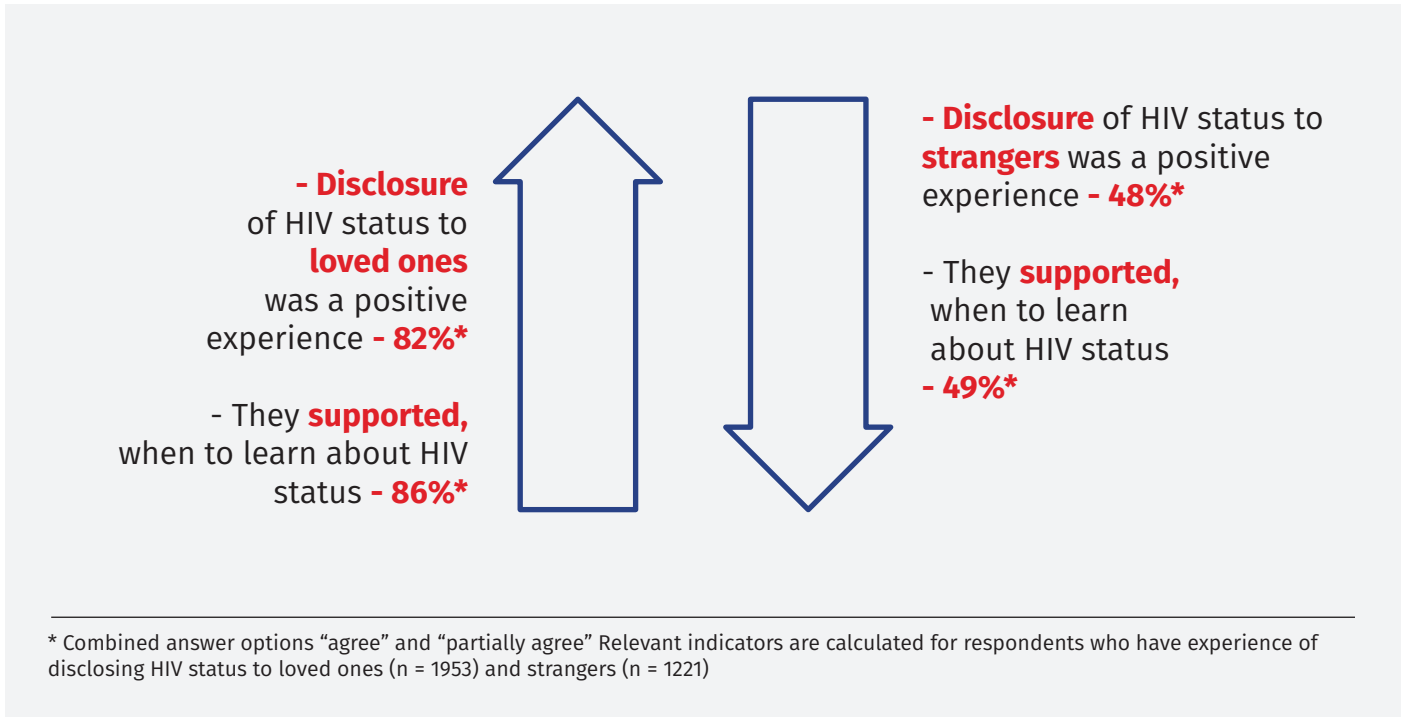


Fig. 2.4. The proportion of PLHIV who agreed with the relevant statements about the experience of HIV status disclosure, %

Thus, the situation with the confidentiality of information on HIV status is gradually improving. It is evident in both gradual decrease in the proportion of PLHIV who have

at least once faced confidentiality violations in each of the waves of the survey, and significant differences in this indicator depending on the duration of life with HIV.

3 **Stigma and discrimination from the social environment members**

Experience of stigmatization and discrimination for people living with HIV may be connected with situations of contacts, communication with various social agents – representatives of a close social circle (family members, relatives, partners, etc.), the inner circle (friends, neighbors, acquaintances, colleagues, etc.), as well as leadership, administration, staff members at places of employment or other institutional locations (hospitals, prisons, police, social services, etc.).

The results of the interviewing show that groups the respondents contact the most frequently are household members, a family, friends (only 5-6% of respondents indicated that these groups are not related to them), co-workers (11-15% answered that they were not related to these contacts) - Table. 3.1.

Table 3.1. The experience of stigmatization and discrimination due to HIV status from the social environment, %

Manifestations of S&D against PLHIV	Yes, for the last 12 months	Yes, earlier than 12 months ago	No	N/A
They were not allowed to participate in public events or activities (e.g., weddings, funerals, parties, and clubs)	1	2	91	6
They were not allowed to participate in religious events or visit prayer meetings	1	1	74	24
They were not allowed to participate in household chores (for example, cooking, eating together, sleeping in the same room, etc.)	1	5	89	5
Family members spoke negatively or gossiped about PLHIV	4	11	79	6
Other people (not family members) spoke negatively or gossiped	6	15	70	9
Verbal abuse and violence by other persons (e.g., screaming and quarrels)	5	11	80	4
Blackmail	2	4	90	4
Physical violence by other persons (e.g., punches, pushes, and blows)	1	2	93	4
Denial of employment, loss of job or earnings	1	5	83	11
Changes in job responsibilities, type of activity, or refusal of promotion	1	2	82	15
Discrimination against spouse partner or child/ children	2	3	77	18
Integral indicator*	11*	27*	–	–

* Integral indicators represent the proportion of PLHIV who stated that they had experienced at least one of these manifestations of S&D from the social environment during the 12 months before the interviewing or earlier

PLHIV most often indicate cases of insults, gossip from other people (not family members), as mentioned by 21% of respondents, including 6% have encountered such situations in the last 12 months. About 15% of respondents, including 4% of them during the last year, heard such negative statements from their family members. About 16% of respondents (including 5% in the last year) had the experience of verbal abuse (screaming, quarrels); 6% faced blackmail (including 2% during the last year); 3% survived cases of physical violence (punches, pushes, and blows), including 1% during the last year. About 5% said about situations of discrimination against a spouse/partner/child due to the HIV status of the respondent (18% said that this possibility did not apply to them).

Life stories consist of emotional descriptions of how difficult the person, who has learned about his diagnosis, perceives the rejection by a family and relatives, inability to find understanding and share his/her feelings:

“When I got to know (about my HIV status) at the hospital, somehow everyone abruptly kept away. My mother didn’t come to me, nobody came. [My brother] told me to get out of the house. He started collecting my things and throwing them away. I realized that I couldn’t live with these people in the same house”

(Life Story, Lviv).

Sometimes, the help of close and distant relatives or even acquaintances and classmates can save a person in quite extreme circumstances (being abroad, lack of money, housing, clothing, illness, etc.). PLHIV perceive this help as something special, exceptional in the face of stigmatization and discrimination from the majority of others:

"[My sister-in-law] knew about my status and tuberculosis. But she took that risk, well done; I would like to pay tribute to her. She met me at a station [after my release from a colony], took me to an apartment, and I spent the night there. She brought me things to change my clothes, a phone, everything I needed"

(Life Story, Kharkiv).

"They [a classmate's family] saved my life, honestly, because I was walking around the city with bags at night, and I didn't even know where to go. They helped me a lot, gave me money, and helped me find a job, an apartment"

(Life Story, Lviv).

In some cases, the more or less calm attitude of family members to a relative's HIV status changes for the worse. All such factors as deterioration of health due to HIV infection, other diseases, the inability to support the family financially, other family conflicts came on top of S&D based on HIV status, exacerbated them. This can manifest itself in psychological manipulation, deception, slander, other harassment of an HIV-positive person, and, as a result, lead to family breakdown, cause PLHIV to leave the place of joint residence, and so on.

"At first, it didn't show up and we lived normally. And then my wife began to 'go mad'. First of all, she decided to get a divorce to deprive me of my family. She got it. And then, the harassment of my ex-wife and children gradually began"

(Life Story, Zaporizhzhia).

People living with HIV status may face situations of rejection in **public spaces**, the inability to continue to communicate with acquaintances in the usual and acceptable for all forms. According to the quantitative interviewing, 3% of respondents (including 1% in the last year) experienced the prohibition against and undesirability of participation in public events (weddings, parties, etc.), 2% (including 1% in the last year) experienced unwelcome participation in religious events. We can find the confirmation of such situations in life stories:

"There are those who say directly: 'Don't hug me, I don't want to talk to you.' They say everything. Especially those, who knew me before, 'It's her fault she lived that way.' We cut off contacts with my girl-friend with whom we were once friends."

(Life Story, Lviv).

“I tried to get acquainted on the Internet, we just chatted. I immediately said what happened with me. A couple of times, and they stopped communicating with me. That’s why I don’t even try anymore.”

(Life Story, Lviv).

About 6% of respondents said about the experience of stigmatization and discrimination in the field of employment (e.g., denial of **employment**, loss of work, and earnings). About 3% of respondents faced cases of denial of promotion and change of job responsibilities. About 1% of respondents said that the relevant cases occurred within 12 months before the interviewing.

Cases from life stories show that managers and business administrators know what they are doing wrong by dismissing/not hiring a worker because of HIV status, but they do it obviously hoping that such people will not try to protect their rights. This is exactly the reaction of PLHIV that we see in in-depth interviews.

“I was putting on the staff. When they [the human resources department] took all my papers and saw [the information about HIV status], they started calling everywhere and immediately told me: “You do not fit us.”

(Life Story, Kryvyi Rih).

Having a “bitter experience”, people living with HIV may not say about their status the next time they are employed. But such a choice creates additional psychological tension and fear that this “secret” will be revealed. Instead, respondents who chose to

inform their employer about their HIV status emphasized that they benefited psychologically and socially from their decisions. Sometimes the truthfulness of a job seeker is perceived positively by employers:

“I think that the disclosure of my status was one of the reasons why my candidacy was approved in the company for a vacancy. They even emphasized later that I had won them with my openness”

(Life Story, Zaporizhzhia).

“When I start talking to someone or getting a job, I immediately say that I am HIV-positive so that there are no questions and problems later”

(Life Story, Kharkiv).

Cases of stigmatization can be found in organizations and institutions. The degree of negative attitude can range from physical and verbal violence, hostility, and fear of distancing and physical distancing.

“They [border guards] did not even touch it when they read a record. I turned over, and they took pictures. And then they looked at the photos, so at a distance”

(Life Story, Kharkiv).

Sometimes, the disclosure of HIV status gives PLHIV certain advantages. Life stories contain descriptions of cases how HIV status gave a respondent certain advantages while being in prison.

“When I was sent in prison, the correctional colony 74, in Odesa, I was released from all household chores, laid on the lower bed at once, given extra food, given a diet. Everything that the social workers brought, food, help, all things were given to me”

(Life Story, Kryvyi Rih).

According to the results of the survey, an integral indicator, the S&D index from the social environment, was calculated. It was calculated as the proportion of respondents who indicated at least one case of stigma and discrimination in the last 12 months (Table 2.1). According to the results of the current study, it is 11%.

During the last waves of the survey (2010, 2013, and 2016), the index of stigmatization by others was calculated similarly. However, due to the use of different lists of possible manifestations of S&D, while answering this question, a comparative analysis of indices of previous years with data as of 2020 is not correct. In general, we can say that integral indicators show a downward trend with each wave, i.e., the frequency of stigma cases against PLHIV by the social environment is gradually decreasing.

This conclusion is confirmed by comparing the data in the dynamics of separate indicators, which were used in all waves of the survey and gained a significant proportion of affirmative answers, namely, verbal abuse and other manifestations of verbal violence (Fig. 3.1).

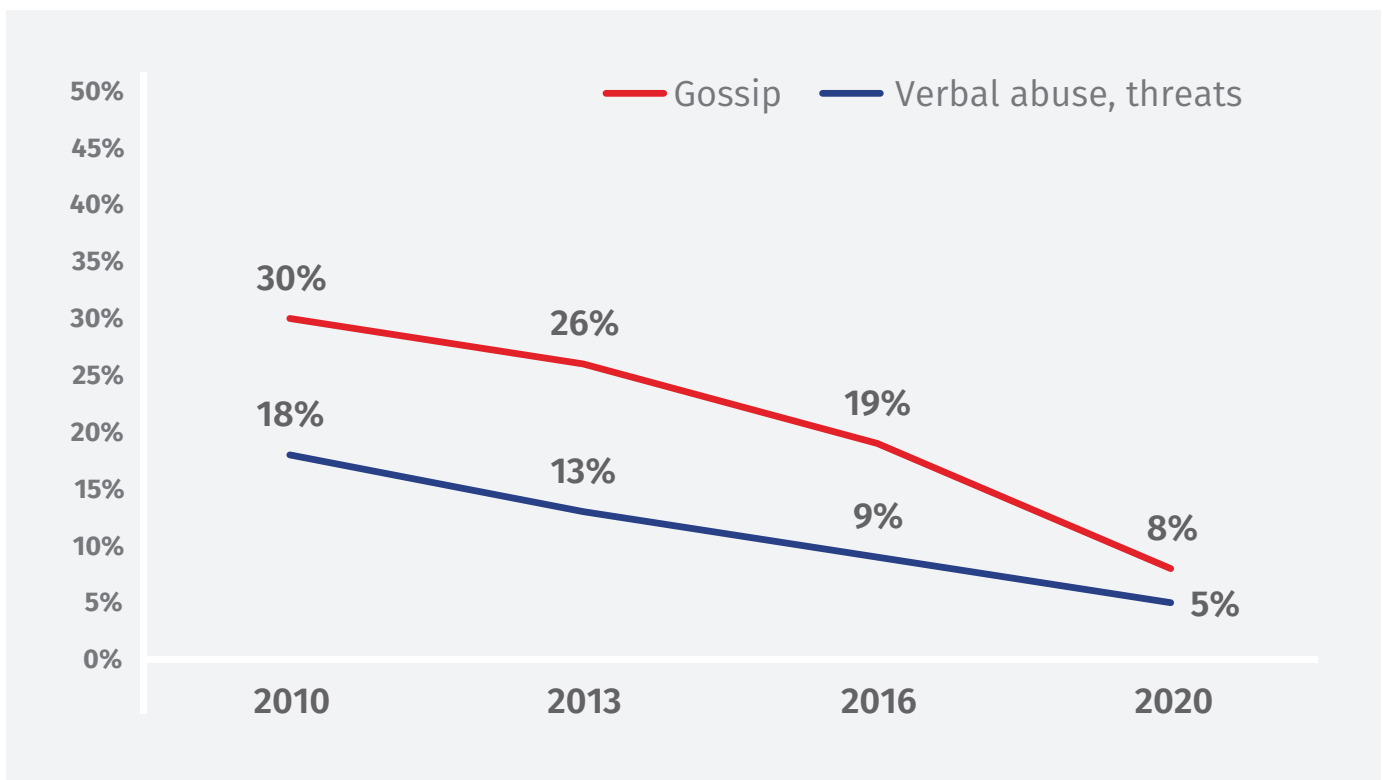


Fig. 3.1. Dynamics of separate S&D manifestations from the social environment, %

Integral indicators/indices can be used in the analysis in terms of individual groups of respondents. Thus, among PLHIV whose duration of life with HIV was less than two years, the stigma index (for the last year) is higher (14%) compared to the generalized indicator for the array (11%). The highest index of stigmatization is also among vulnerable categories: sex workers - 24%, MSM - 20%, drug users - 14% compared to those respondents who do not belong to vulnerable categories (8%).

According to the data of 2020, it was proposed such a new indicator as to the index of retrospective stigmatization, i.e., the indicator of respondents' recollection of cases of insults, violence, discrimination experienced earlier than in the last year (Table 3.1). This index shows that situations, when PLHIV faced the manifestations of S&D, are painful

for respondents and remain in the memory for a long time: for groups with more than 10 years of living with HIV, this index is 43%; 6 - 10 years, 25%; 2 - 5 years, 22%. Moreover, this indicator can be indirectly used to assess the development of the situation with S&D in the dynamics. The results of this assessment also indicate a gradual improvement in the situation regarding the stigmatization of PLHIV by the social environment.

Thus, the results of the interviewing show that the problem of stigmatization and discrimination against PLHIV by the social environment remains relevant in Ukrainian society, although the "degree" of tension is gradually decreasing compared to the survey in previous years.

4 Internal stigma and discrimination and resilience of PLHIV

Influence of the external environment (negative social and media communications about HIV and the PLHIV social group, interpersonal conflicts, prejudiced attitudes in facilities and organizations), lack of information, poor physical condition, these and other factors can contribute to the formation of internal stigma against people living with HIV. This can mean rejecting one's established in the past identity (one's materiality, sexuality, certain aspects of social and cultural identity) and constructing negative dimensions and definitions of identity (for example, "not like everyone else", "sick", "unhappy", "illness is your fault", "dangerous to others", etc.).

Constructing aspects of negative identity, manifestations of self-stigmatization are also associated with behavioral patterns: limiting contacts with relatives and acquaintances, changing places of residence, retiring from employment (as a result of an independent decision, not coercion by the employer or colleagues), etc., namely, they form self-discriminatory behavioral practices of adaptation to their own HIV status and further life with it.

During the survey, the respondents were asked to identify personal and socio-psychological changes that happened due to HIV status in their lives over the past year. Almost every third respondent mentioned problems with self-confidence (31%), inability to cope with tension, stress (28%), problems with self-esteem (21%) (Table 4.1).

A fairly high level of negative assessments can be observed regarding changes in the field of building friendship and trust relationships with the environment. Deterioration of the ability to build close and secure relationships with other people was mentioned by 31% of the respondents; 35% of respondents said about lowering the ability to enter into romantic relationships; 22% said about reduction/disappearance of desire to have children. About 15% of the respondents mentioned negative changes in personal and career development.

A certain, but non-significant part of the respondents (2-9%) mentioned the positive impact of HIV status on certain aspects of their psychological well-being and relationships with the social environment.

Most often, it was about positive changes in respect for other people (9%), the ability to build close relationships with others (8%), the ability to cope with stress (7%), and self-confidence (6%). A significant proportion of

respondents (48-83%) said that HIV status in no way affected (neither positively nor negatively) their psychological well-being and relationships with the social environment.

Table 4.1. The impact of HIV status on various aspects of respondents' lives, %

Aspects of life	Affected positively	Did not affect	Affected negatively	N/A
The ability to enter into a romantic relationship	4	50	35	11
Self-confidence	6	62	31	1
The ability to build close and secure relationships with other people	8	58	31	3
The ability to cope with stress/tension	7	64	28	1
Desire to have children	3	48	27	22
Self-esteem	5	73	21	1
Achieving personal and professional goals	4	72	15	9
Respect for others	9	83	7	1
The ability to participate in community life (cities, villages, etc., where you live)	3	69	5	23
The ability to practice your faith/religion as you wish (attend services and holy places, observe rites, etc.)	2	63	2	33
INDICES OF THE HIV STATUS INFLUENCE ON LIFE	19**		58*	

*The HIV negative impact index is calculated as the proportion of PLHIV who reported a negative impact on at least one aspect of their lives.

**The HIV positive impact index is calculated as the proportion of PLHIV who reported a positive impact on at least one aspect of their lives.

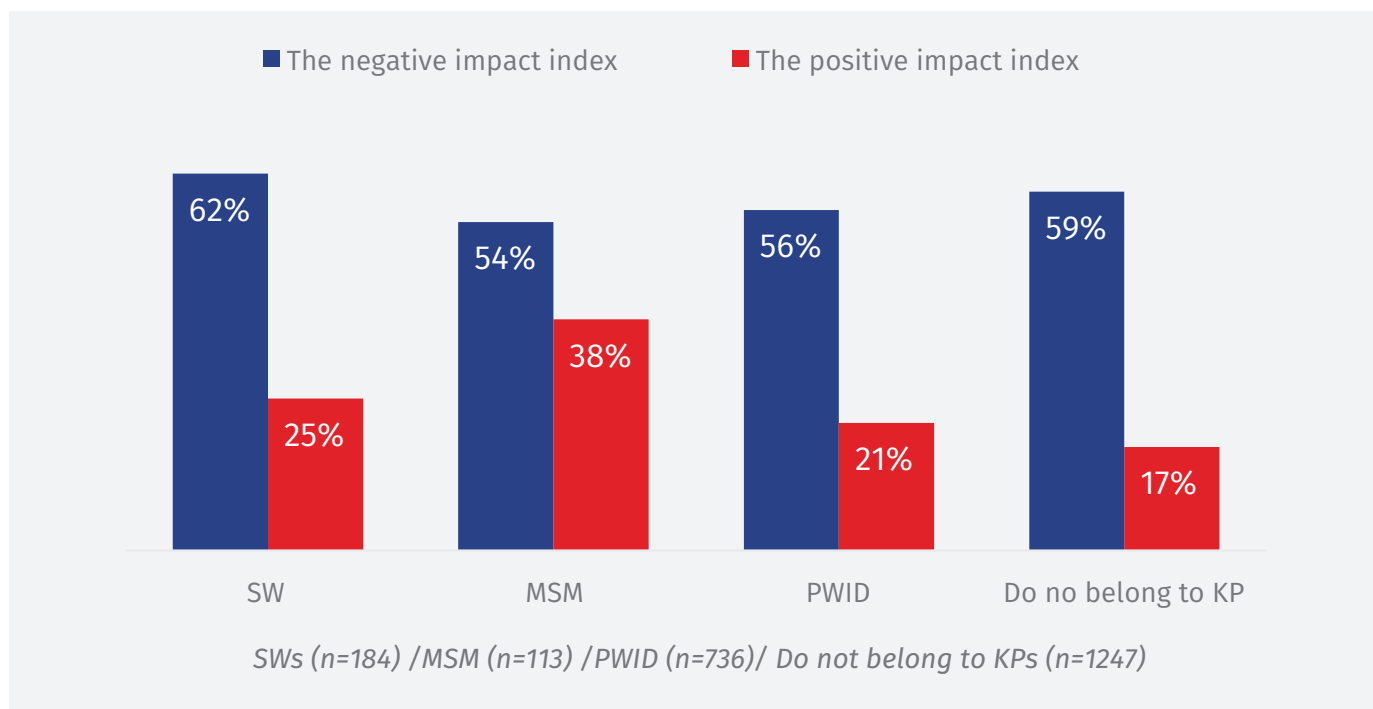
According to the results of the respondents' assessments, we built integral indicators - indices of the negative/positive impact of HIV status on the lives of PLHIV. In general, assessments of "no changes" prevail among respondents. At the same time, the use of these indices shows the ratio of those PLHIV who sharply perceive their condition as full of certain negative aspects (58%) and those who demonstrate the possibility of adaptation, finding positive manifestations in life with HIV status (19%).

The negative impact index is relatively higher among the respondents with a shorter duration of life with HIV status. In particular, for respondents with a duration of life with HIV for less than two years, this index is 65%, while for those diagnosed more than 10 years ago, it is 54%. This indicates that the first years after diagnosis, the beginning of social and socio-psychological adaptation to it is the most difficult for PLHIV.

The negative impact index among the age group of 18–34 years is 61% compared to 56% for the rest of the respondents. This indicates, in particular, that young people react more emotionally to their HIV-positive status. The proportion of respondents, who said about the negative impact of HIV status on various

aspects of their lives, is not significantly different among representatives of KPs and PLHIV who do not belong to such KPs. Instead, PLHIV, who do not belong to such KPs, rarer said about the positive impact and MSM said oftener about it (Fig. 4.1).

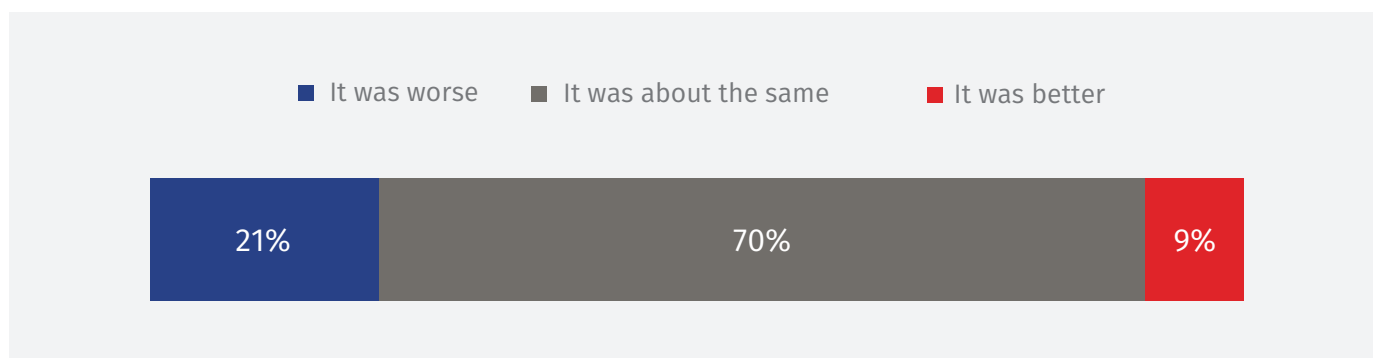
Fig. 4.1. The impact of HIV status on various aspects of respondents' lives, % based on belonging to KPs



The respondents also had the opportunity to assess the impact of HIV status on various aspects of their lives in an earlier period compared to the last year before the survey (Fig. 4.2). The majority chose the option “it was

about the same” – 70%, 21% of respondents indicated relative improvement (the option “it was worse before”), 9% of respondents said about relative deterioration (“it was better before”).

Fig. 4.2. The distribution of answers to the question: “How did your HIV status affect relevant aspects of your life earlier than 12 months ago?” %



The respondents were asked to agree/disagree with a number of statements that characterized their emotions, feelings, peculiarities of social communications in the context of HIV status. Thus, 86% of the respondents answered that they hide their

HIV status from other people and they had difficulties telling strangers about their diagnosis (Table 4.2). Almost every second respondent (45–48%) sensed guilt and shame. Occasionally, 27% of the respondents felt useless/worthless, and 23% felt “dirtiness”.

Table 4.2. Self-stigmatization of PLHIV, %

Manifestations of self-stigmatization	Agreed	Index-6	Index-4
It's hard for me to tell a stranger about my HIV infection	86	+	
I hide my HIV status from other people	86	+	
I feel guilty about my HIV infection	48	+	+
I feel the shame of being HIV-positive	45	+	+
Sometimes, I feel useless because I am HIV-positive	27	+	+
I feel dirtiness because of my HIV infection	23	+	+
SELF-STIGMATIZATION INDICES:		95*	63**

*The index of self-stigmatization-6 is calculated as the proportion of respondents who agreed with at least 1 of the 6 statements (marked with “+” in column 3 of the table).

**The index of self-stigmatization-4 is calculated as the proportion of respondents who agreed with at least 1 of the 4 statements (marked with “+” in column 4 of the table).

Life stories additionally show the specifics of the socio-psychological state of people living with HIV.

“I felt a misunderstanding, a kind of despair. I felt anger, irritation (why do they treat me like that?). I felt shame because people didn't understand me. It was hard to open u”

(Life Story, Kyiv).

“Despair, because I thought it was the end of the world, that it was the end of life... I protect myself from all this, I don't want to tell anyone or talk to anyone about it. I try not to disclose my status to anyone now because they all react sharply to it”

(Life Story, Lviv).

“The feeling is that I am abandoned and no one needs me at all”

(Life Story, Kryvyi Rih).

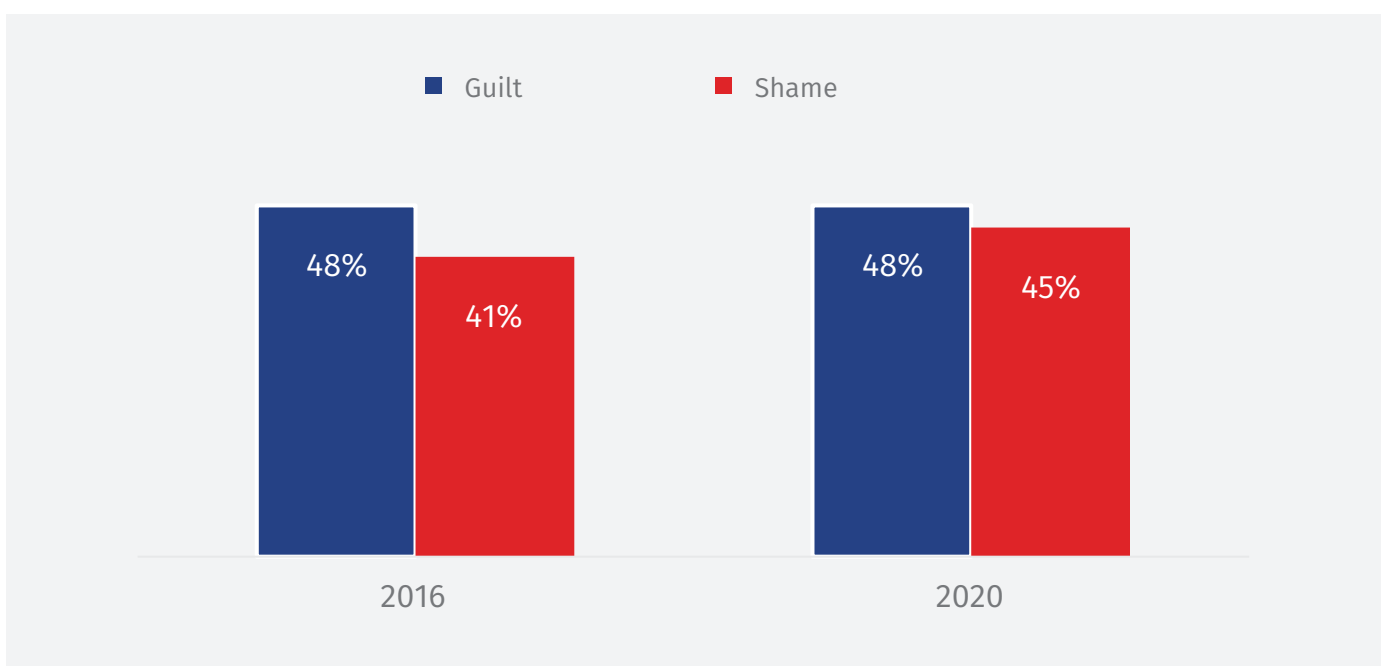
According to the results of the 2020 survey, we propose to use two integral indicators: self-stigmatization index-6 (calculated based on an agreement with at least one of six statements) and self-stigmatization index-4 (calculated based on an agreement with at least one of four statements). The first index is high (95%) due to the fact that a significant proportion of respondents chose options such as “it is difficult for me to tell a stranger about my HIV infection” and “I hide my HIV status from other people” (86% each). Nevertheless, it is informative and it indicates that certain manifestations of self-stigmatization are inherent in almost all interviewed PLHIV.

To analyze a more specific indicator of self-stigmatization, which relates to the respondents' feelings of shame, guilt, symbolic dirtiness, uselessness/worthlessness, an indicator of self-stigmatization was calculated according to these 4 statements. It is 63% and is higher among such KPs as MSM (67%) and sex workers (68%) compared to drug users (63%) and PLHIV who have no experience of belonging to key populations (62%).

Manifestations of self-stigmatization according to 4 indicators are more common among PLHIV with the duration of life with HIV up to 2 years (68%) and 2–5 years (64%) compared to those whose duration of life with HIV is more than 6 years (61%). There are gender differences: the self-stigmatization index-4 is relatively higher among women (65%) than among men (61%).

The question of the self-stigmatization manifestations used in previous waves of the survey was similar but not identical. Accordingly, the change of sociological tools does not allow making correct comparisons on the basis of integral indicators. Instead, a comparison of the individual components of self-stigmatization in the dynamics is possible. A comparison of two key emotional manifestations in the dynamics - guilt and shame for their HIV status - shows their stable reproduction for a significant proportion of respondents. During the 2016 and 2020 surveys, almost every second respondent experienced feelings of guilt and 41–45% of respondents felt shame (Fig. 4.3).

Fig. 4.3. Dynamics of individual self-stigma of PLHIV (feeling of guilt and shame), %



The emotions of shame and guilt in sociological literature consider basic features that signal the conformity/non-conformity between personal intentions, actions, and a certain system of morality learned in the process of socialization and connected with the current socio-cultural context. It is shame and guilt that are most inscribed in the mechanisms of social interaction. Their manifestations can support group morality and an individual's desire to maintain social relations with the group (family, friends, colleagues, etc.) by means of correction, justification, and so on.

"I tried to improve the relationship with my mother. She had a birthday. I called her, wanted to congratulate. She told me not to call because she had no daughter, but only a son"

(Life Story, Lviv).

Survey data confirm that internal self-stigmatization together with the pressure of the external environment (various forms of stigmatization and discrimination) lead a certain part of PLHIV to choose appropriate escapist tactics: avoiding intimate relations (19%), ignoring the need for medical care (12%), and isolating from family/friends (7%). Moreover, during the year preceding the survey, 5 - 6% of respondents decided to retire/not get a job, not to seek social assistance, not to attend public events (Tab. 4.3).

The help of representatives of the social environment (relatives, friends, social workers, etc.) plays an important role in preventing such developments. We see an example of such help in life stories.

"If my girlfriend did not stand up for me, not explain that it was impossible to infect others working with clothes, I would not [get a job] myself. I would come, ask for a job, tell about my status, they would say 'no' and that was it"

(Life Story, Lviv).

Another scenario is when guilt and shame contribute to interruptions of social relations, breaks in relations with group/groups based on the perception of individuals unworthy to be members of groups, or blaming a group for their troubles (offense, anger).

"When I learned about my status, I walked around and couldn't even talk to people. I was hurt"

(Life Story, Mykolayiv).

Table 4.3. Decisions related to HIV status made in the last year, %

Decision	No	Not applicable	Yes
You decided not to have sex	76	5	19
You decided not to seek medical help	87	1	12
You isolated yourself from your family and/or friends	91	2	7
You decided not to apply for social assistance	88	6	6
You decided to resign or not to get a job	82	12	6
You decided not to attend public events	89	6	5
Self-discrimination index			30*

*The self-discrimination index was calculated as the proportion of PLHIV who indicated that they had made at least one self-discrimination decision for the last 12 months

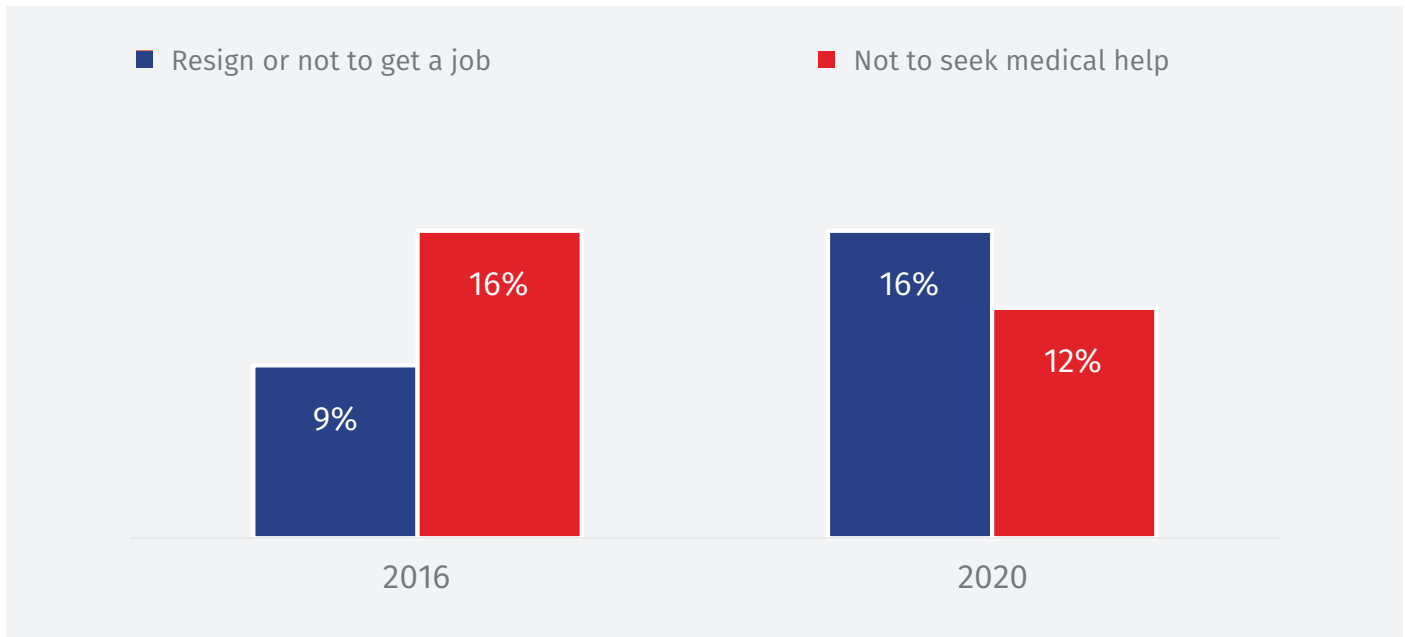
Because of the change of sociological tools (in the three previous waves of the survey, another list of alternatives was used), the correct comparison of the self-discrimination integral index in the dynamics is impossible. In 2020, this figure is 30% and is lower than the corresponding figure in previous waves of the survey, mainly due to the absence of such possible manifestations of self-discrimination as “not to have more children” and “not to be married”. The proportion of positive responses to these alternatives was 37 - 39% and 20 - 21%, respectively, as a result of which the integral indicator of self-discrimination was higher and amounted to 62% in 2010 and 2013, 56%, in 2013.

Instead, data on individual manifestations of self-discrimination in the 2016 and 2020 surveys are comparable. Thus, the

answer option “decided not to have sexual intercourse” (2016) is similar to the option “decided not to have sex” in 2020. The proportion of PLHIV who chose each of these response options is 18% and 19% respectively, which indicates the stability of the reproduction of this solution over time among the part of PLHIV.

There are signs of positive changes in such areas as employment and health care. According to 2020 data, slightly fewer respondents (6%) said about decisions to resign or not to get a job compared to 9% in 2016 (Fig. 4.4). About 16% of respondents in 2016 and 12% in 2020 mentioned the decision not to seek medical help.

Fig. 4.4. Dynamics of self-discrimination in the fields of employment and healthcare, %



The self-discrimination index is slightly higher among sex workers and MSM (33%) compared to drug users (29%) and PLHIV who do not belong to KPs (30%). This index is higher among those living with HIV relatively recently. In particular, among PLHIV with less than 5 years of living with HIV, the self-discrimination index reaches 35% compared to 26% among those living with HIV over 10 years.

At the same time, people living with HIV show signs of endurance, resilience, and a desire to maintain a normal lifestyle. Thus, in the last year 87-88% of respondents sought healthcare/ social assistance, 91% of them maintained contact with families and friends, 89% attended public events and 76% had intimate relations. As we saw above, almost one in five respondents said about an improvement in at least one aspect of their lives over the past year (index of the positive impact of HIV status on life), which relate to socio-psychological endurance, resistance to stress, relationships with loved ones, common social practices.

“Today I work and communicate with my friends, and it helps me. And I help people with the same status as mine”

(Life Story, Zaporizhzhia).

Life stories show that PLHIV, who take care of their health and receive ARV therapy, can adapt to their life situation, build new intimate and family relationships, and plan the birth of children. Such relationships exist with both HIV-positive and HIV-negative partners.

“Since we are both HIV-positive, we can talk about any topic, about the disease or therapy. He supports me, gives me flowers. I’m not alone, I’m awaited at home. We have been together for three years. We bought a car, got a cat and we live and enjoy life”

(Life Story, Mykolayiv).

*"If God gives children, we will give birth
" (Life Story, Sumy).*

Mutual assistance networks of PLHIV, communication with people who have the same problems, as well as the help of physicians and social workers play a significant role in adapting to the status and giving the life force.

"Social workers and psychologists also worked with us in (self-support) groups. And it helped me change my perception of life; I began to rejoice in a lot of positive moments in life (the beauty of nature). There appeared positive emotions, the confidence that I am not yet a lost soul and I can help society"

(Life Story, Mykolaiv).

"A doctor reassured me a little then that I had a chance to be treated. I didn't know what would happen next, but I thought it would be better"

(Life Story, Lviv).

Life challenges harden some respondents. They develop their own strategy of behavior in life, the leading idea of which is action and resistance to circumstances.

"The main thing is not to give up. If you give up, you lose. That's it. You have to move as long as you can move. While I try to do something, I live"

(Life Story, Kharkiv).

Thus, the manifestations of self-stigmatization and self-discrimination against PLHIV remain quite common: more than half of the respondents said that in the last year they had a negative impact of the HIV status at least on one aspect of their lives; almost two-thirds of respondents said about at least one negative feeling about themselves; every third respondent took at least one self-discriminating decision within the last 12 months.

5 Stigma and discrimination in healthcare facilities

5.1. Restrictions on access to health services and S&D due to HIV status in the healthcare facilities.

According to the international Stigma Index methodology, the questionnaire for PLHIV included questions that provided data on denials of health care (including dental care) and denials of sexual and reproductive health services (including services of family planning). To analyze the overall level of stigma and discrimination against PLHIV in the health sector and to compare the data of the 2020 survey with previous waves, an **integral indicator of restrictions on access to health services** was calculated. This is the proportion of respondents who have experienced denials of health care (including dental care) and sexual and reproductive health services (including services of family planning) over the past 12 months due to their HIV status. The integral indicator was calculated for the general sample of surveys.

The results of the survey continue to show a tendency to reduce the level of stigma and discrimination in the healthcare facilities. According to this survey ("PLHIV Index Stigma, 2.0", 2020), within the last 12 months, 4 % of respondents at least once faced restrictions on access to health care (including dental care and services in the field of sexual and reproductive health) for reasons related to HIV status. In 2016, this figure was 8%, in 2013 - 11%, and in 2010 - 22% (Fig. 5.1).

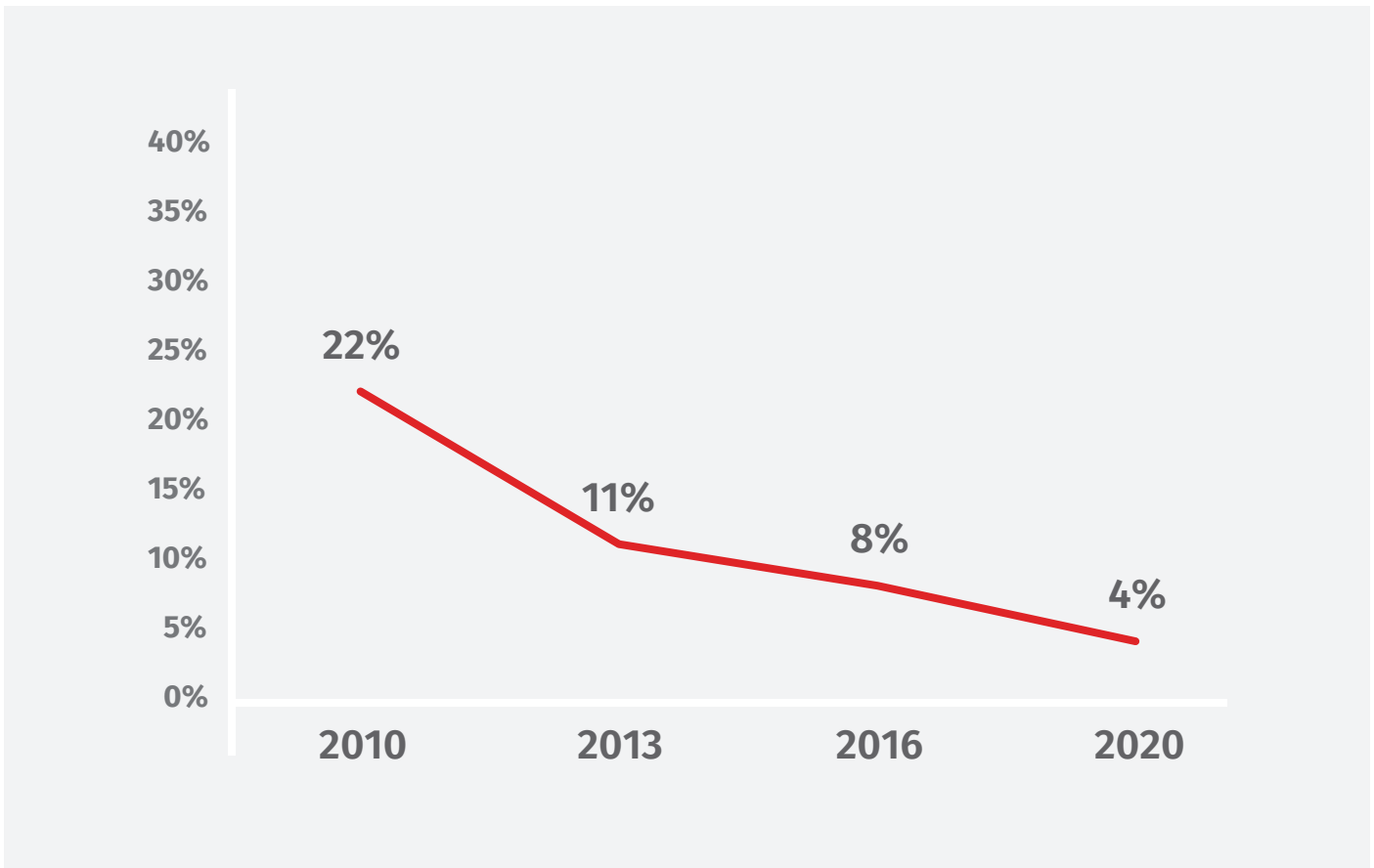


Fig. 5.1. Dynamics of the integral indicator of restrictions on access to healthcare services, %

For a generalized assessment of the level of stigma and discrimination in the healthcare facilities, the relevant integral indicator of S&D in the healthcare facilities was calculated. The indicator was calculated according to the UNAIDS Global AIDS Epidemic Monitoring 2020 guide [https://www.unaids.org/sites/default/files/media_asset/global-aids-monitoring_en.pdf] as a proportion of PLHIV who reported about their experiences in HIV-related discrimination in health care facilities in the following forms:

- Refusal to provide health care due to HIV-positive status.
- Recommendation not to have sex due to HIV-positive status.
- The respondent was rudely talked to or gossiped about because of the HIV-positive status.

- The respondent was exposed to verbal abuse due to the HIV-positive status.
- The respondent was subjected to harsh physical treatment due to the HIV-positive status.
- Physical contact with the respondent was avoided due to the HIV-positive status.
- The HIV-positive status of the respondent was reported to third persons without his/her consent.

In accordance with the results of the study, 17% of PLHIV faced discrimination due to HIV in healthcare facilities (Fig. 5.2).

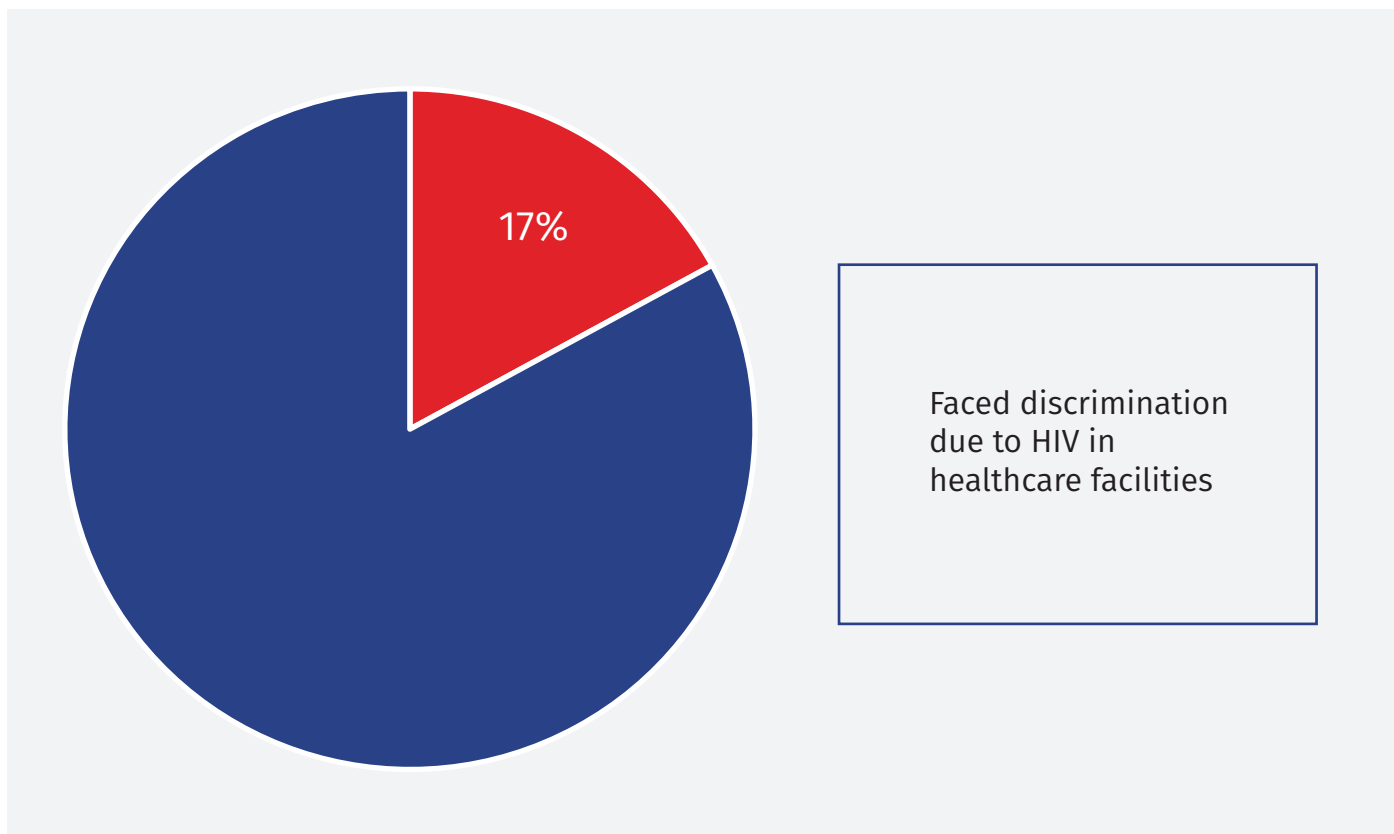


Fig. 5.2. The integral indicator of S&D in the healthcare facilities, %

According to the study, the main socio-demographic factors - gender, age, and type of settlement where the respondent lives – do not significantly affect the risk of discrimination in the healthcare facilities. However, PLHIV with a long duration of life with HIV (more than 10 years) slightly more often said about discrimination by healthcare workers than those who live with HIV less. This may be explained by the fact that, despite a notice in the questionnaire, the respondents mentioned the experience of S&D not during

the last year, but during the whole period of living with HIV. Representatives of key populations have also more experience of S&D in healthcare facilities. Involvement in HIV treatment also affects the level of discrimination by health professionals - those receiving HIV treatment more likely reported their experience of S&D (this may be explained by the fact that PLHIV who avoid treatment are more likely to hide their status when visiting healthcare facilities) (Table 5.1).

Table 5.1. The Integral indicator of S&D in the healthcare facilities, %

		They had the experience of S&D by healthcare workers
Age	18-34 years (n = 558)	19
	35-49 years (n = 1346)	17
	older than 50 years (n = 297)	17
Sex	Female (n = 1070)	19
	Male (n = 1131)	16
Type of settlement	City (n = 1986)	18
	Village (n = 215)	14
Life duration with HIV	0-2 years (n = 235)	16
	2-5 years (n = 764)	14
	6-10 years (n = 562)	17
	More than 10 years (n = 640)	22
Belonging to KPs	Do not belong to KPs (n=1247)	15
	Representatives of KPs (n=954)	20
	PWUD (n = 736)	20
	SWs (n = 184)	26
	MSM (n = 113)	19
Involvement in HIV treatment	Have treatment (n = 1854)	18
	Avoid treatment (n = 347)	14

In general, the analysis of life stories shows that the number of severe manifestations of S&D by healthcare workers is gradually decreasing. With each wave of the survey, we observe an increase in the number of patients who said about cases of positive attitude and support from healthcare staff who do not only work at specialized healthcare facilities (AIDS centers) but also at HCFs of other profiles. In their life stories, PLHIV gave examples of positive attitudes of medical staff towards patients with HIV status, including situations when it was the support of healthcare workers that allowed them to accept their diagnosis and start treatment.

«Three months ago I had a spine surgery... Before the surgery, I told the doctor that I had HIV status. He reacted absolutely adequately. He said, 'Thank you for saying that'. And there were no discriminatory actions against me»

(Life Story, Chernihiv).

«I visited a medical center to have gynecologic services. And the doctor suggested testing for HIV because she saw this as a possible cause of my gynecological problems. I said that I had known about the status for a long time, but did not want to do anything because everything was good for me. To my surprise, she seemed to worry more than I did. She began to convince me that if I did not take HIV therapy, then my problems in gynecology would not be solved either, that this was all connected that I should take care of my health. We talked with her for a long time. I visited her several times. In the end, she convinced me to go to the AIDS center. I was registered and started drinking therapy. I periodically come to her for an examination. She asks how I am doing, whether I am taking pills, how my health is, how I feel.»

(Life Story, Odesa).

5.2. HIV testing

For most respondents (85%), HIV testing was their own decision. At the same time, 77% decided to take the test consciously and voluntarily, and 8% did so under pressure from other people, although they decided themselves to take the test. One-tenth of respondents (12%) said that they were tested without their knowledge and they learned about it after taking the test. Other 2% of PLHIV were forced to take an HIV test without their consent (Fig. 5.3).

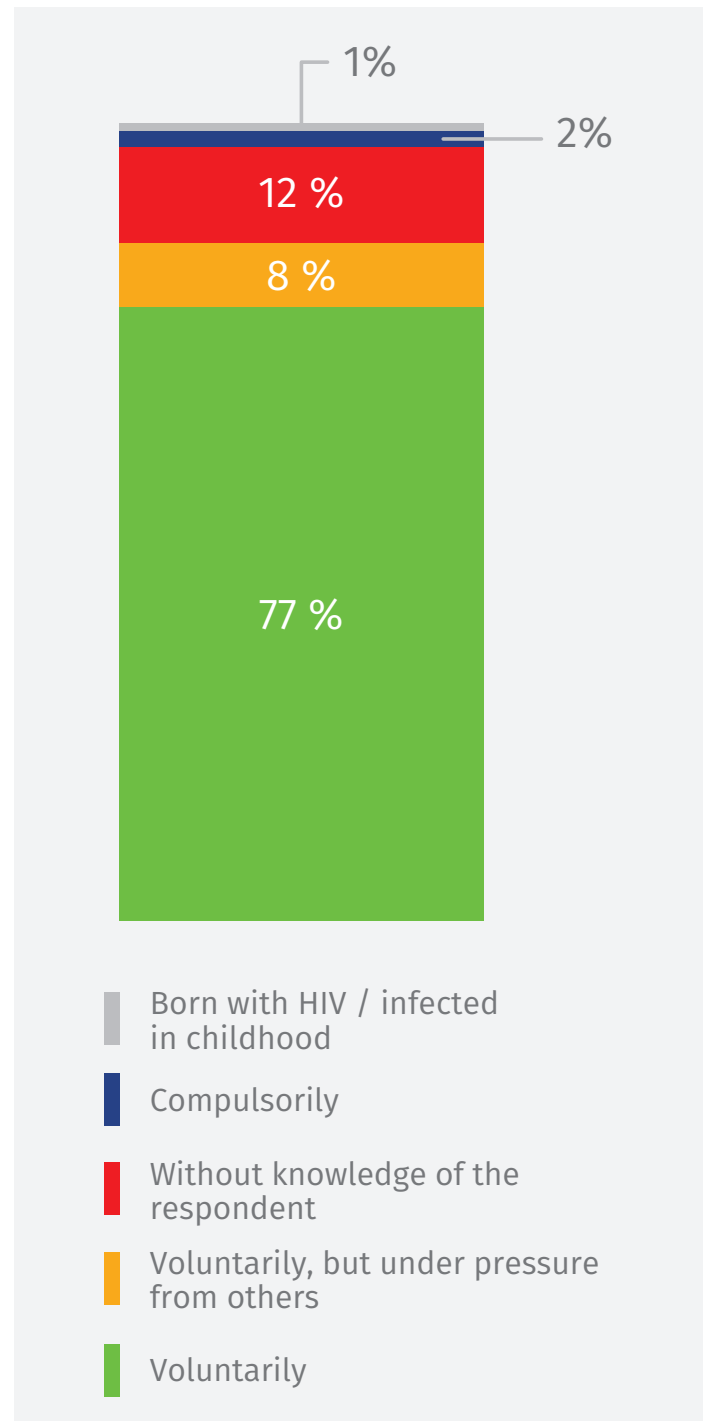
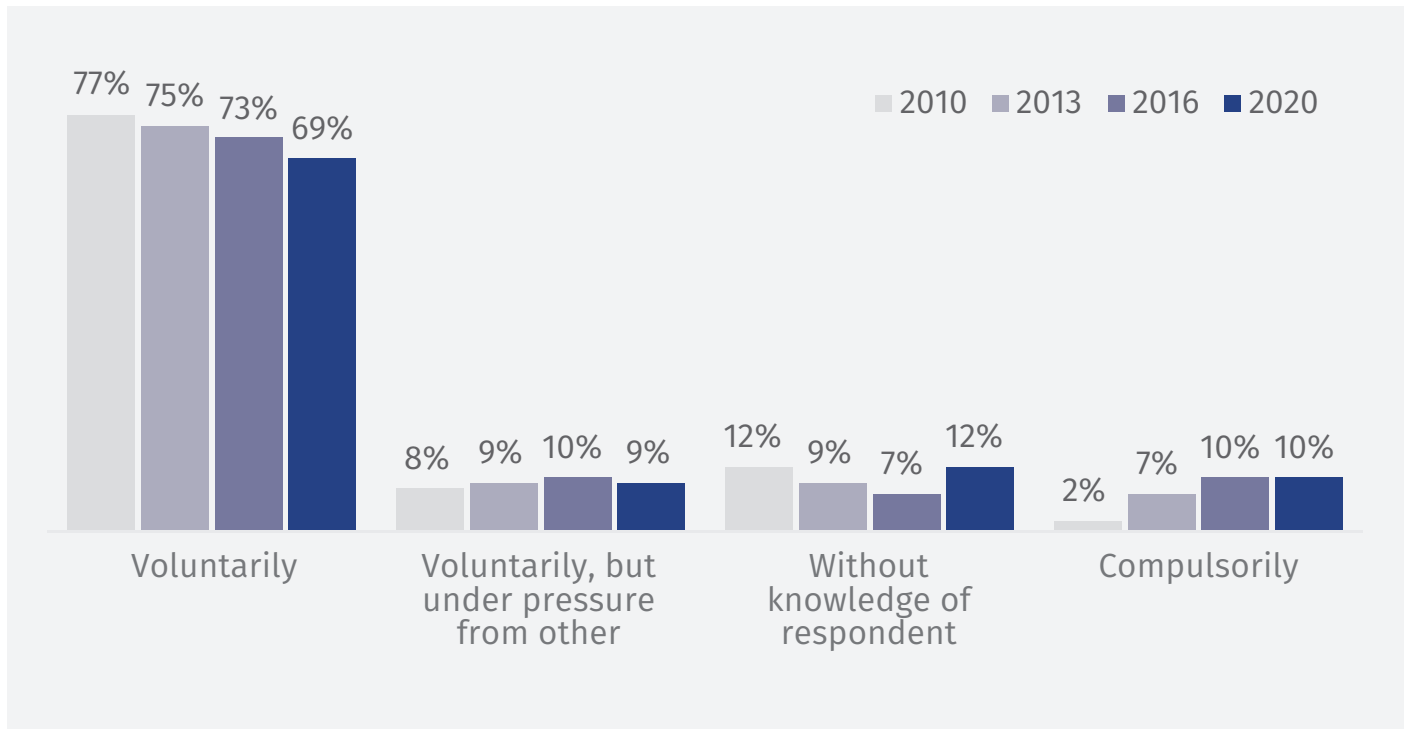


Fig. 5.3. The voluntary decision of the respondents to take HCT, %

Compared with the previous waves of the survey, we noticed a positive trend: the growth of those who tested voluntarily and reducing the proportion of those who were compulsorily tested for HIV (Fig. 5.4).

Fig. 5.4. The voluntary decision of the respondents to take HCT, in the dynamics, %



There is a positive trend in increasing the proportion of respondents voluntarily and consciously tested for HIV depending on the duration of life with known HIV status: from 66% for those diagnosed more than 10 years ago to 85% for respondents with up to 2 years

of life (Table. 5.2). There is a similar trend in decreasing the percentage of those who were tested compulsorily or without consent - the shorter the duration of life with HIV, the less often respondents could face violations of their rights to voluntarily HIV testing.

Table 5.2. Voluntary counseling and testing, % by the duration of life with HIV

	0-2 years (n=235)	2-5 years (n=764)	6-10 years (n=562)	More than 10 years (n=640)
By themselves/voluntarily	85	82	78	66
By themselves, but under pressure from others	6	7	8	8
Without the knowledge of the respondent	9	9	11	19
Compulsorily	0	1	1	4
Born with HIV/infected with HIV in childhood	0	0	1	3

Representatives of key populations face violations of the right to voluntary HIV testing more often than those of PLHIV who do not belong to any KPs. Thus, among people living with HIV who belong to at least one of the key populations, 74% of the respondents decided to get tested and did it voluntarily (no pressure from others), while the proportion of those who do not belong to any of KPs is 79 %. At the same time, representatives of drug users and sex workers face discrimination to a greater extent when taking HIV tests (73% and 72%, respectively, were consciously and voluntarily tested); the proportion of MSM who tested

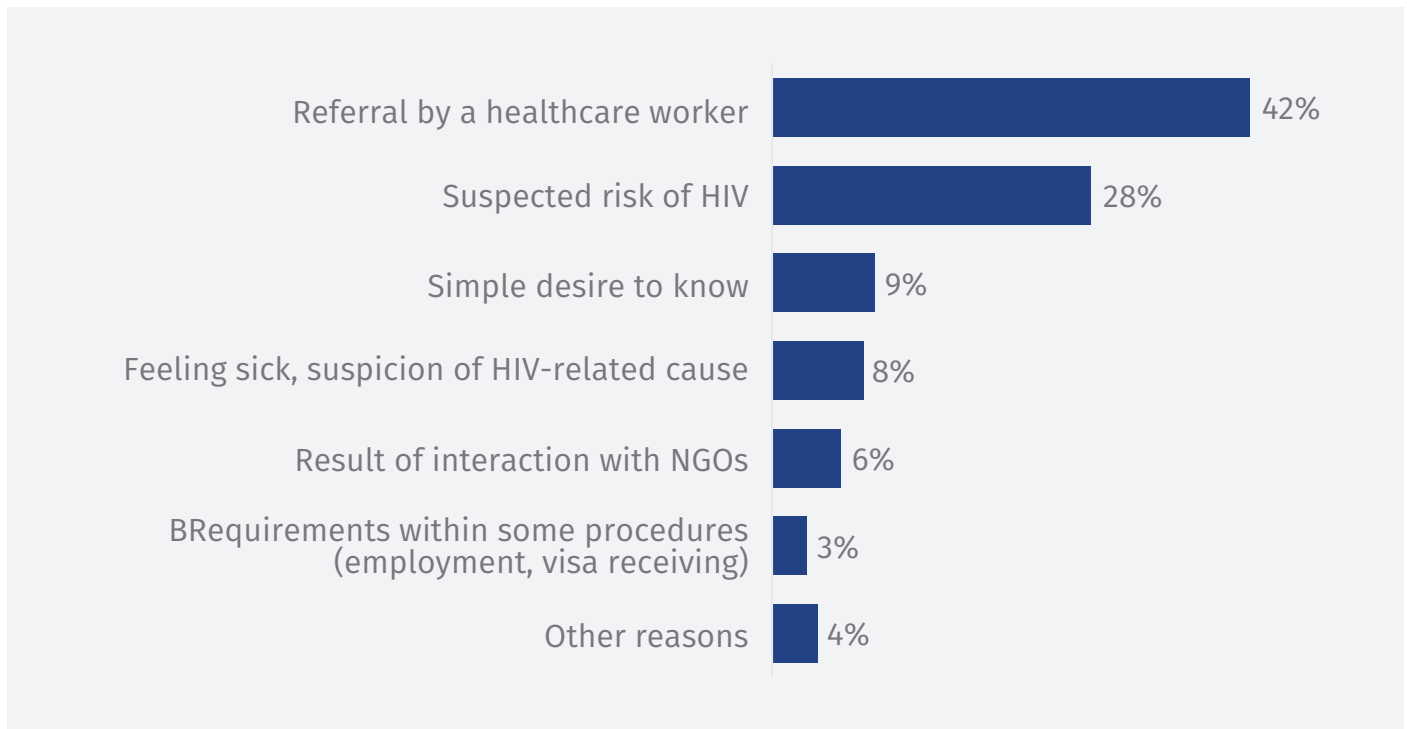
voluntarily and without compulsion is 89%. Among PLHIV, which is currently treated for HIV, there are more those who decided to test consciously and voluntarily (78% compared to 72% among respondents who avoid treatment). At the same time, among those who avoid treatment, there are more cases of testing without the knowledge of the respondents (17% compared to 12%) (Table. 5.3). This may indicate that violation of human rights to voluntary testing increases the risk that PLHIV will not be involved in HIV treatment in the future.

Table 5.3. Voluntary counseling and testing, % by involvement in HIV treatment

	Have HIV treatment (n=1854)	Avoid HIV treatment (n=347)
Consciously/voluntarily	78	72
Consciously, but under pressure from others	8	8
Without the knowledge of the respondent	12	17
Compulsorily	2	2
Born with HIV/infected with HIV in childhood	1	1

The respondents (those who decided to take the test themselves, including completely voluntarily or under pressure from others) mentioned that the main reason for taking HIV tests was the referral [to treatment] within the interaction with the health care system - 42% of respondents were tested following the advice of healthcare worker or as part of a specific medical procedure (e.g., antenatal care, medical male circumcision, STD screening/treatment,

pre-exposure prophylaxis). Another part of the respondents (6%) was tested in the framework of interaction with NGOs. The second main reason is testing due to the fact that the respondent suspects the risk of HIV infection; this reason was relevant for 28% of respondents. In addition, 8% had symptoms that, according to respondents, could indicate HIV. Approximately one-tenth of respondents (9%) were tested because they simply wanted to know their HIV status (Fig. 5.5).

Fig. 5.5. The reason for HIV testing, %

The reason “I just wanted to know” is more relevant for younger respondents (18-34 years) than for older age groups (13% compared to 6-8%). With increasing age, the relevance of

reasons for HIV testing due to symptoms that could indicate HIV infection increased from 5% to 15% (Table 5.4).

Table 5.4. The main reason for HIV testing, % by age

	18-34 years (n=467)	35-49 years (n=1148)	over 50 years (n=248)
The healthcare worker advised to take the test or the test was part of a medical procedure	40	42	41
Suspected risk of HIV	28	28	25
Just wanted to know	13	8	6
They felt sick, thought that it could be related to HIV	5	8	15
As a result of interaction with NGOs	6	7	7
This was a requirement (for example, for employment, visa receiving, etc.)	3	4	3
Other reasons	4	3	3

Women are tested for HIV following health workers' referrals more often than men (47% and 37%, respectively). At the same time, the reasons "Suspected risk of HIV" (30% compared to 25%) and "Just wanted to know" (10% compared to 7%) were more relevant for men than for women.

Residents of rural settlements were tested within health care procedures more often than urban residents - 51% of respondents from rural areas were tested for HIV by the doctor's referral, compared to 41%, from urban areas.

Among respondents with less duration of life with HIV, the proportion of those who took tests within the interactions with NGOs was greater (4% of those living with HIV for more than 10 years, 5% of those living with HIV from 6 to 10 years, 8%, 2-5 years, 9%, up to 2 years). Moreover, there is a trend in increasing the relevance of the reason "Just wanted to know" depending on the reduction of life duration with HIV from 7% to 12% (Table 5.5).

Table 5.5. The main reason for taking HIV tests, % by the duration of life with HIV

	0-2 years (n=214)	2-5 years (n=684)	6-10 years (n=487)	More than 10 years (n=478)
The healthcare worker advised to take the test or the test was part of a medical procedure	41	42	41	42
Suspected risk of HIV	23	26	31	28
Just wanted to know	12	10	7	7
They felt sick, thought that it could be related to HIV	10	7	8	10
As a result of interaction with NGOs	9	8	5	4
This was a requirement (for example, for employment, visa receiving, etc.)	3	2	4	4
Other reasons	2	4	3	4

Representatives of key populations take HIV tests following health workers' referrals less often than respondents who do not belong to them (33% compared to 48%). At the same time, for representatives of key populations, the reasons "Suspected risk of HIV" (33% compared to 23%) and "Interaction with NGOs" (10% compared to 4%) are more relevant. Among MSM, a significantly smaller proportion

of respondents (compared with other KPs and those who do not belong to them) took tests following referrals within the healthcare system (19% compared to 32-35%). For MSM, at the same time, curiosity is a more relevant reason for HIV testing (19% compared to 6-8%). Drug users less often take tests as a result of interaction with NGOs than other key populations - 8% compared to 15% (Table 5.6).

Table 5.6. The main reason for taking HIV tests, % by belonging to KPs

	Do not belong to KPs (n=1068)	Representatives of KPs (n=795)	PWUD (n=606)	SWs (n=151)	MSM (n=103)
The healthcare worker advised to take the test or the test was part of a medical procedure	48	33	35	32	19
Suspected risk of HIV	23	33	34	30	35
Just wanted to know	9	9	8	6	19
They felt sick, thought that it could be related to HIV	9	8	8	9	7
As a result of interaction with NGOs	4	10	8	15	15
This was a requirement	3	4	4	6	1
Other reasons	4	3	4	3	4

Most respondents (70%) were tested for HIV as soon as they thought they had to be tested. Other 15% of respondents took tests within six

months after it occurred to them to be tested. About 10% of PLHIV delayed the testing for 6 months or more (Fig. 5.6).

**Fig. 5.6.** The time interval between the moment when the respondents first thought about taking tests and the moment when they took them, %

When comparing the data of different waves of the survey, there is a steady tendency to reduce the time interval between the moment

when respondents first think about taking HIV tests and the moment when they directly take this procedure (Fig. 5.7).

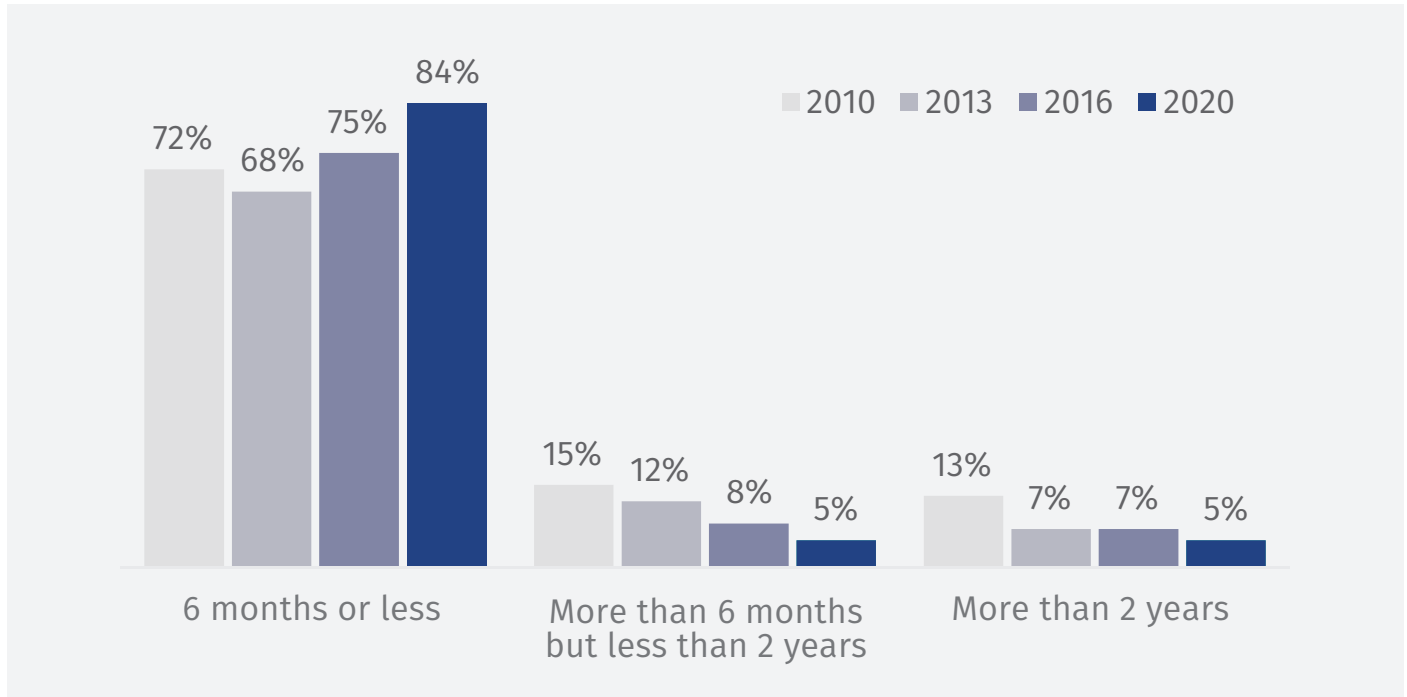


Fig. 5.7. The time interval between the moment when the respondents first thought about taking tests and the moment when they took them, in the dynamics, %

Among those living with HIV for more than 10 years, a significantly smaller proportion of respondents, compared to other respondents, took tests immediately, without thinking,

and at the same time, their number was significantly more among those who delayed the testing (Table. 5.7).

Table 5.7. The time interval between the moment when the respondents first thought about taking tests and the moment when they took them, % by the duration of life with HIV

	0-2 years (n=214)	2-5 years (n=684)	6-10 years (n=487)	More than 10 years (n=478)
I did not think, took the test immediately	73	70	72	65
6 months or less	14	16	12	13
More than 6 months, but less than 2 years	5	4	5	5
More than 2 years	2	4	5	9
I don't know/I don't remember	6	5	6	9

Representatives of key populations are more inclined to a long delay in taking tests compared to those respondents who do not belong to key populations (Table 5.8). Thus, among those who do not belong to any KPs, 74% of respondents were tested immediately,

while among representatives of KPs, the proportion of such respondents is 64%. It should be noted that for MSM representatives longer time intervals between the moment of first thought about the necessity of taking tests and the moment of taking are more typical.

Table 5.8. The time interval between the moment when the respondents first thought about taking tests and the moment when they took them, % by belonging to KPs

	Do not belong to KPs (n=1068)	Representatives of KPs (n=795)	PWUD (n=606)	SWs (n=151)	MSM (n=103)
I did not think, took the test immediately	74	64	65	64	53
6 months or less	12	16	15	19	25
More than 6 months, but less than 2 years	4	6	6	5	6
More than 2 years	4	6	6	5	11
I don't know/I don't remember	6	8	8	7	5

The fifth part of all respondents (21%) said they were afraid of reactions from other people (friends, family members, employers, or acquaintances) regarding possible positive HIV test results, which caused them to postpone testing. It should be noted that the proportion of those who were afraid and postponed tests, significantly higher among women than men (24% compared to 19%).

Thus, the results of the study show a tendency to increase the proportion of PLHIV who were tested for HIV voluntarily and consciously - from 69% in 2010 to 77% in 2020. At the same time, the percentage of those PLHIV who were compulsorily tested continues to decrease from year to year (from 10% in 2010 to 2% in 2020). Representatives of key populations, especially drug users and sex workers, more often face violations of the right to voluntarily HIV testing.

5.3. Experience in HIV treatment and adherence to ART

Among PLHIV interviewed (all but those born with HIV or infected with HIV in childhood), two-thirds (68%) reported delaying the start of health care and treatment for HIV¹. The proportion of PLHIV who delayed treatment is higher among women than among men (74% compared to 62%). Similarly, the proportion of those who delayed treatment is higher among representatives of key populations than among those who do not belong to them (70% compared to 65%). In the context of key populations, those who did not begin treatment immediately constituted most of the respondents (among them sex workers (73%), drug users (65%) and MSM (56%)).

For those respondents who had a time period between diagnosis of “HIV infection” and the HIV treatment, the main reason for the time delay is a fear that strangers can learn about

¹ It is calculated as the proportion of respondents who in the question “25. Has any of the following forced you to delay the start of medical care and treatment for HIV?” chose at least one reason for delaying treatment.

HIV status (relevant for 74% of respondents who delayed treatment) and unwillingness to do anything with HIV (68%) (Fig. 5.8). A significant number of respondents were also afraid of negative attitudes or discriminatory actions by health workers and were concerned

that family or friends would learn about their HIV status (62-61%, respectively). One-third of respondents delayed HIV treatment because of the previous negative experience of the interaction with health workers.

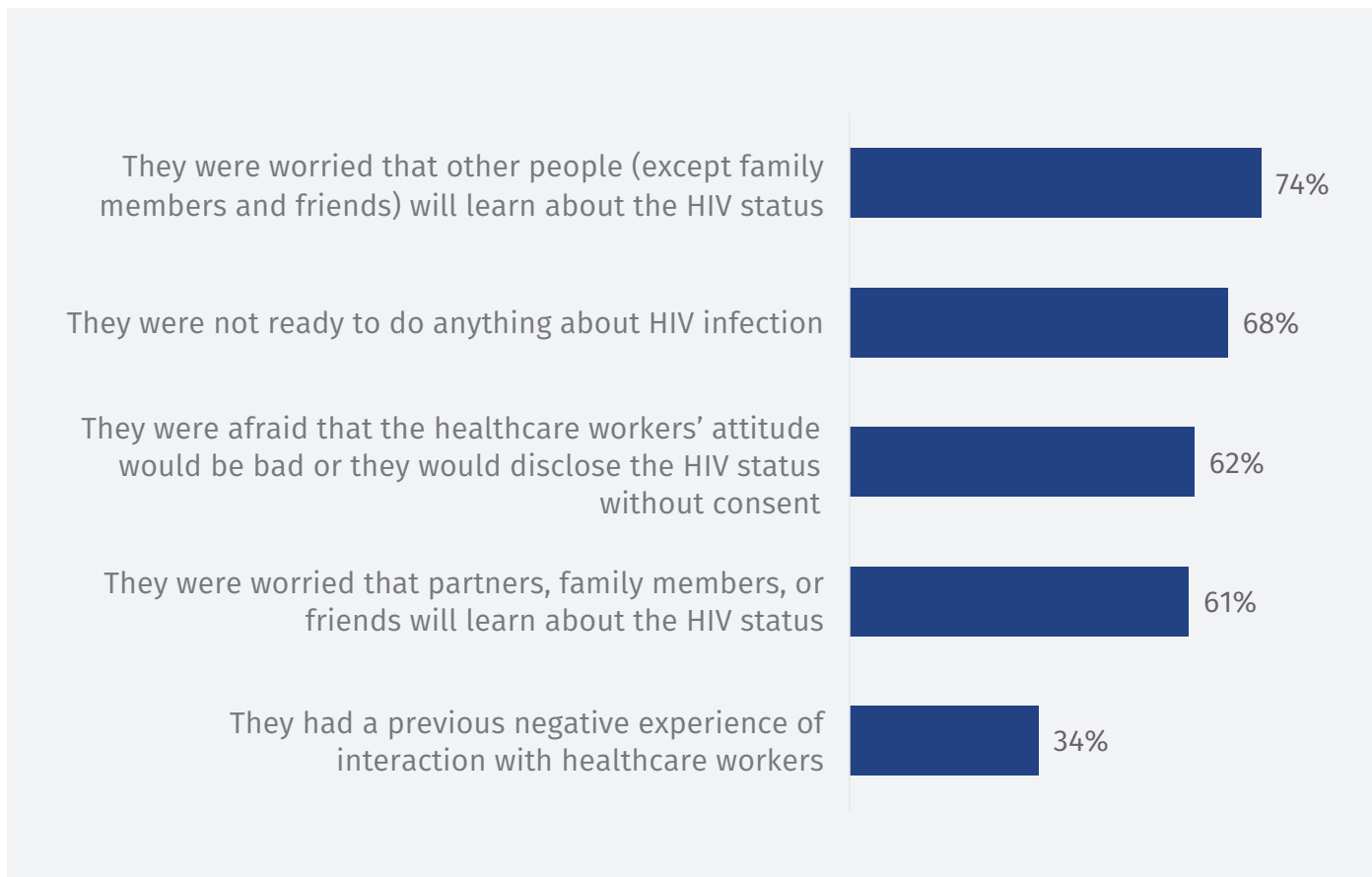


Fig. 5.8. Reasons for delaying health care and HIV treatment, % to those who delayed (n= 1471)

Almost half of the respondents (47%), among all except those born with HIV/infected with HIV in childhood, have ever interrupted HIV treatment². As was while delaying, interrupting HIV treatment, the main reasons for putting

off the retreatment for HIV were fear that strangers would learn about HIV status (43% of those who interrupted treatment) and unwillingness to do anything about HIV (42%) (Fig. 5.9).

² It is calculated as the percentage of respondents who in the question "26. If you have ever stopped HIV treatment, has any of the following forced you to delay the retreatment for HIV?" did not choose the option "a. You have never interrupted HIV treatment".

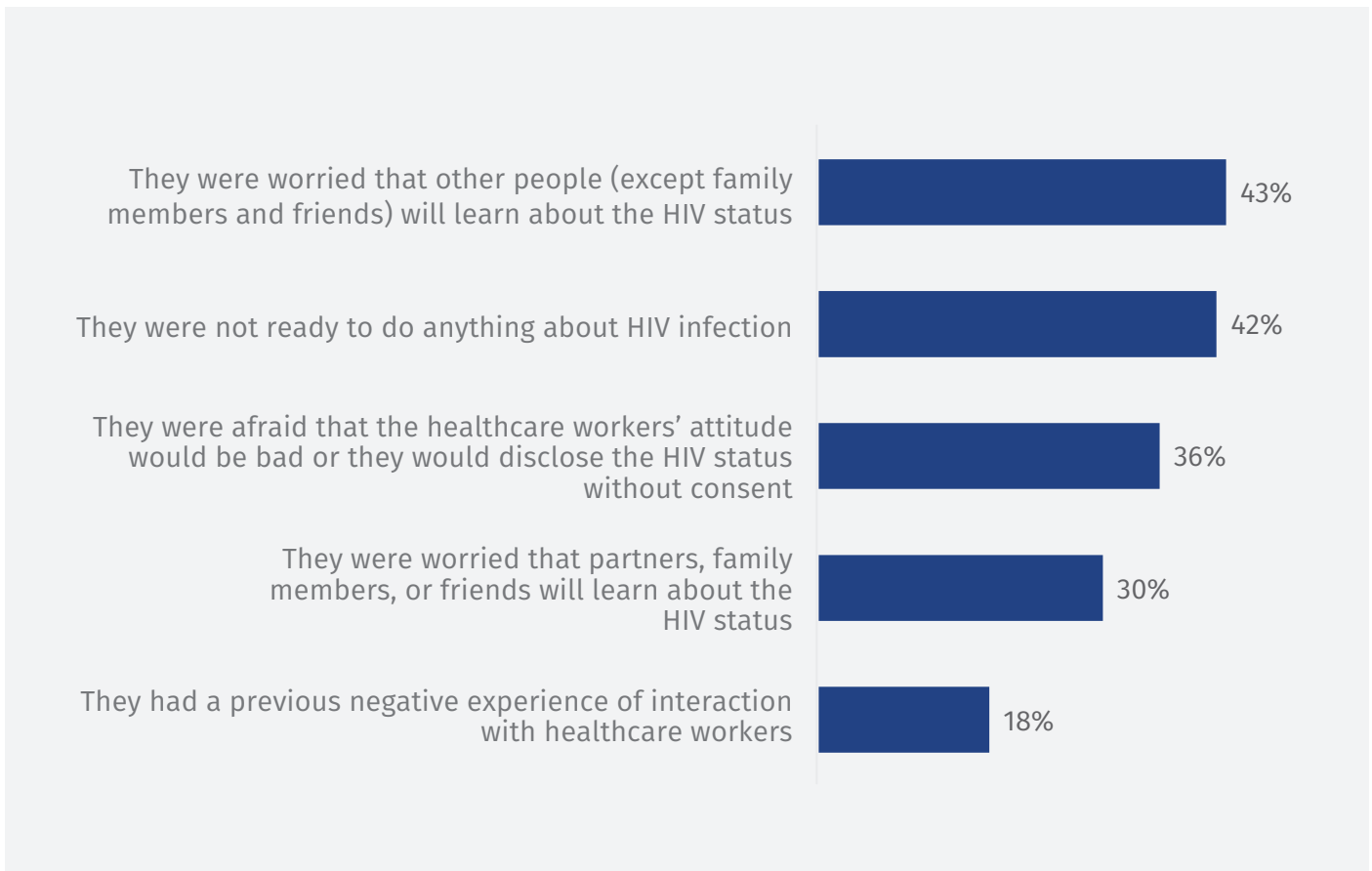


Fig. 5.9. Reasons for delaying the retreatment for HIV during interruption, % to those who delayed (n = 1015)

Among all respondents (except those born with HIV/infected with HIV in childhood), 17% had never received antiretroviral therapy (ART); accordingly, 83% have experienced with ART. Among those respondents who have ever been treated, 8% initiated ART soon after

diagnosis of "HIV infection"; nearly a third of respondents (30%) started ART within a month after diagnosis. A quarter of respondents initiated ART after 2 years of living with HIV (Fig. 5.10).

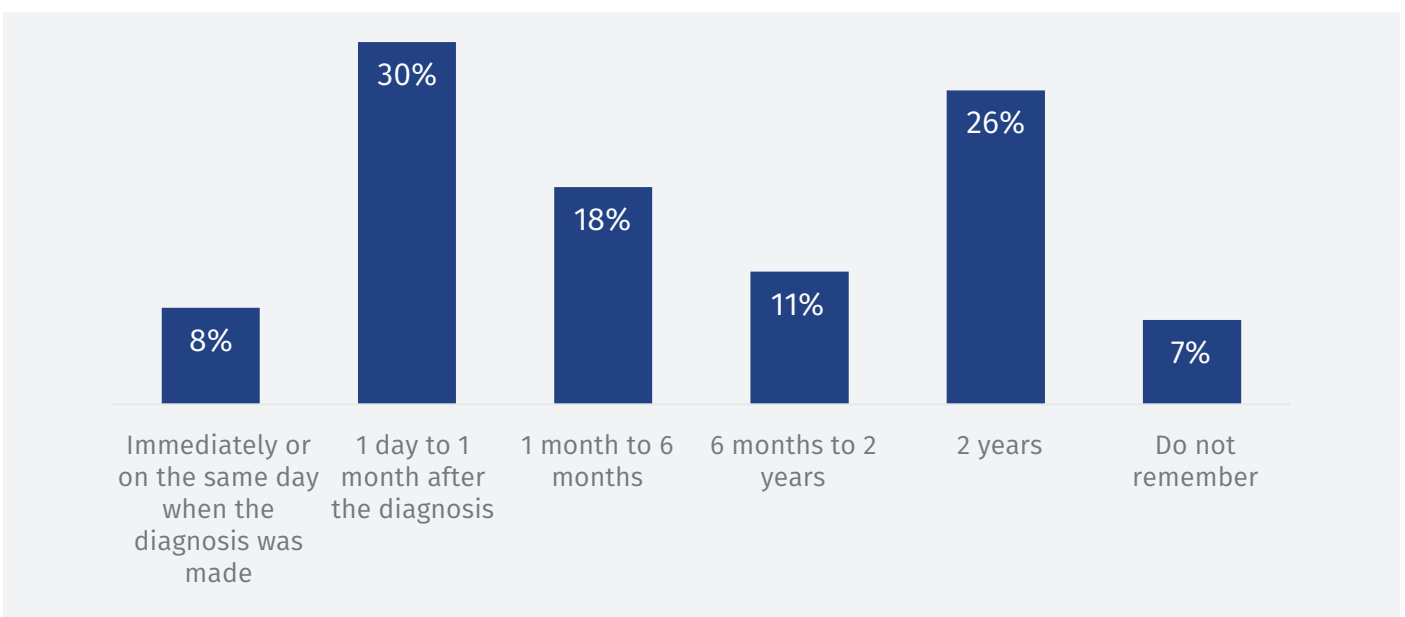


Fig. 5.10. Initiation of ART, %

There are no differences in the timing of ART initiation by sex. Instead, the trend in earlier initiation of ART is observed among younger PLHIV (Tab. 5.9). A similar trend is observed according to the duration of living with HIV: the longer respondents live with HIV, the later

they began receiving ART after the diagnosis (Tab. 5.10). The latter is obviously related to the change in HIV treatment protocols in accordance with international requirements for the earliest possible start of ART.

Table 5.9. Initiation of ART, % by age

	18-34 years (n=415)	35-49 years (n=1130)	Older than 50 years (n=259)
Immediately or on the same day when the diagnosis was made	14	5	6
> 1 day or to 1 month (30 days) after the diagnosis	38	26	32
> 1 month to 6 months after the diagnosis	19	18	15
> 6 months to 2 years after the diagnosis	10	12	9
> 2 years after the diagnosis	14	30	28

Table 5.10. Initiation of ART, % by the duration of living with HIV

	0-2 years (n=163)	2-5 years (n=606)	6-10 years (n=489)	More than 10 years (n=546)
Immediately or on the same day when the diagnosis was made	21	10	5	3
> 1 day or to 1 month (30 days) after the diagnosis	60	46	24	8
> 1 month to 6 months after the diagnosis	13	24	21	10
> 6 months to 2 years after the diagnosis	3	11	17	9
> 2 years after the diagnosis	1	7	25	55
I do not remember	2	2	8	14

A tendency to late initiation of ART is observed also among key populations: a significantly smaller proportion of representatives of KPs began to take ART immediately (5%) or within the first month after diagnosis (23%) compared

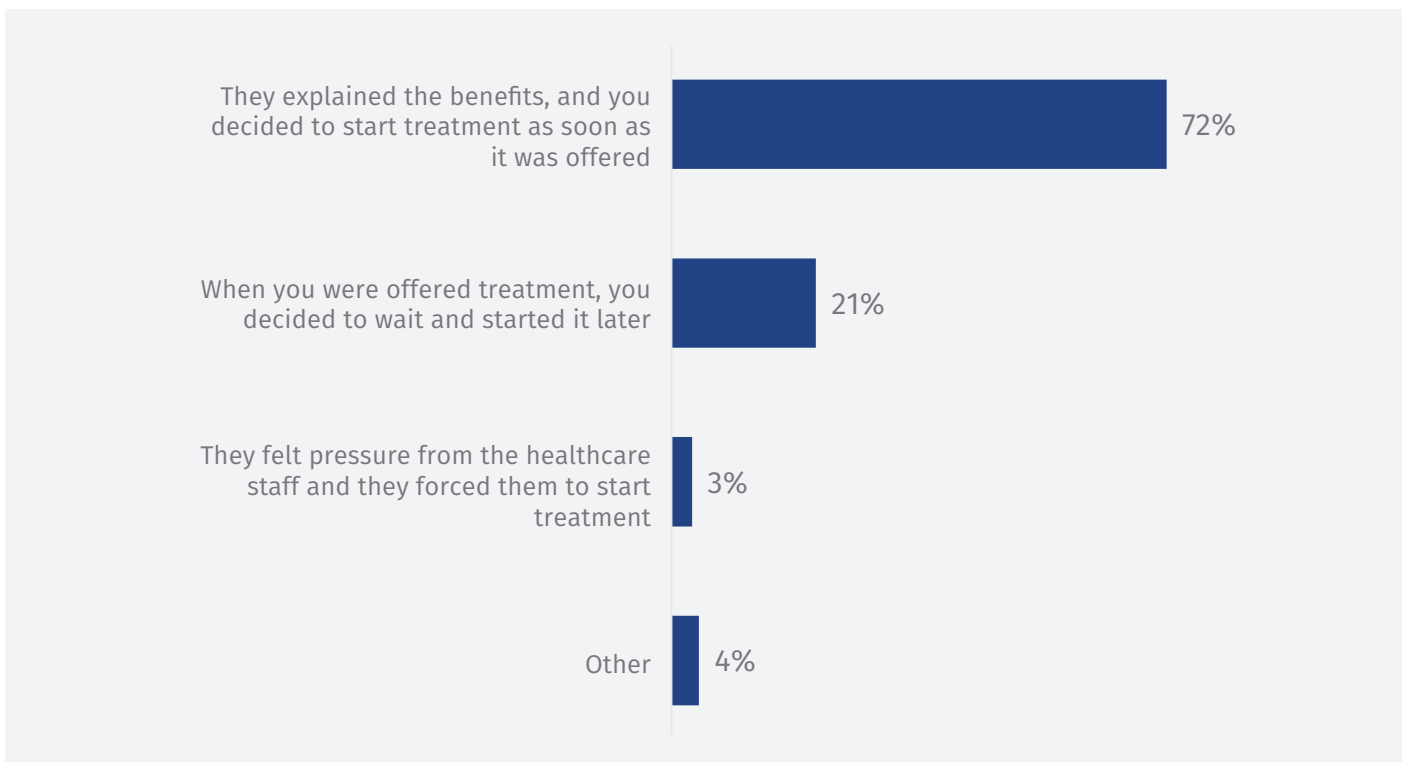
to those PLHIV who did not belong to KPs (9% and 35% respectively) (Table 5.11). Moreover, drug users initiate ART generally later than representatives of other KPs.

Table 5.11. Initiation of ART, % by belonging to KPs

	Do not belong to KPs (n=985)	Representatives of KPs (n=819)	PWUD (n=619)	SWs (n=158)	MSM (n=108)
Immediately or on the same day when the diagnosis was made	9	5	3	7	13
> 1 day or to 1 month (30 days) after the diagnosis	35	23	20	27	28
> 1 month to 6 months after the diagnosis	18	18	17	23	20
> 6 months to 2 years after the diagnosis	10	13	12	10	19
> 2 years after the diagnosis	20	34	39	30	19
I do not remember	8	7	9	4	2

For most of those who take (or have ever taken) ART, the decision to take the therapy was independent: at the beginning of taking therapy respondents were explained the advantages of it and they decided to start treatment as soon as it was offered to them

(72%). One-fifth part of respondents (21%) also made decisions on their own but decided to wait and start treatment later. Only 3% of PLHIV were forced to start treatment by healthcare staff (Fig. 5.11).

**Fig. 5.11.** Voluntary decision to initiate ART, %

At the same time, there is a dependence on the duration of life with HIV: among those whose diagnosis was made relatively recently,

there were more those who started treatment consciously and voluntarily (Table 5.12).

Table 5.12. Voluntary decision to initiate ART, % by the duration of life with HIV

	0-2 years (n=163)	2-5 years (n=606)	6-10 years (n=489)	More than 10 years (n=546)
They explained the benefits, and you decided to start treatment as soon as it was offered	85	78	67	66
When you were offered treatment, you decided to wait and started it later	13	16	25	25
They felt pressure from the healthcare staff and they forced them to start treatment	1	3	3	3
Other	1	3	4	6

Among those who have ever initiated ART, the vast majority (72%) have not interrupted ART in the last 12 months, respectively 28% interrupted ART in the last year³. Among older people, compared with younger PLHIV, there were fewer interruptions of ART in the last year: 80 % of representatives of the 50-year-and-older age group said that they did not interrupt ART, compared with 71% among people aged 35-49 and 69% among respondents aged 18-34 years. In addition,

among people living with HIV for less than 2 years, the proportion of those who have not interrupted ART in the last 12 months is higher (81% compared to 69-73% among those living with HIV for a longer period of time). Another factor influencing the interruption of ART was the belonging to key populations: representatives of KPs interrupted ART less often than those who did not belong to them (Table 5.13).

Table 5.13. Interruption of ART, % by belonging to KPs

	Do not belong to KPs (n=981)	Representatives of KPs (n=816)	PWUD (n=616)	SWs (n=158)	MSM (n=108)
Did not interrupt ART in the last 12 months	69	75	71	82	93

The respondents who had problems with taking ARV often mentioned stigma-related factors as reasons for discontinuation of ART. In particular, the most frequently mentioned was the unwillingness to do anything about their HIV status (44%), fear that someone would learn about the HIV status (23%), and fear that health workers would treat the respondent badly or disclose their HIV status

without their consents (9%). One percent reported being denied HIV treatment (ART) because they were using drugs at that time.

An assessment of responses about reasons for ART interruptions not related to stigma shows that among those respondents who have ever started ART, 55% have not interrupted ART; 19% of respondents interrupted, but earlier than

³ It is calculated as the proportion of respondents who in the question "29. If you have stopped taking ART for any period of time in the last 12 months, was it due to any of the following and stigma-related reasons?" chose any other option than "5. N/A - You have not stopped taking ART in the last 12 months."

the last 12 months. The proportion of those who previously took ART but currently do not take it is 15%⁴. The main reason not related to stigma why these respondents do not currently receive HIV treatment, according to them, is that they do not think that treatment

is necessary; this reason is relevant for almost half of respondents (45%). In addition, the fifth part of respondents (22%) cannot tolerate the side effects of drugs, and 13% cannot pick up drugs from clinics/drug stores (Fig. 5.12).

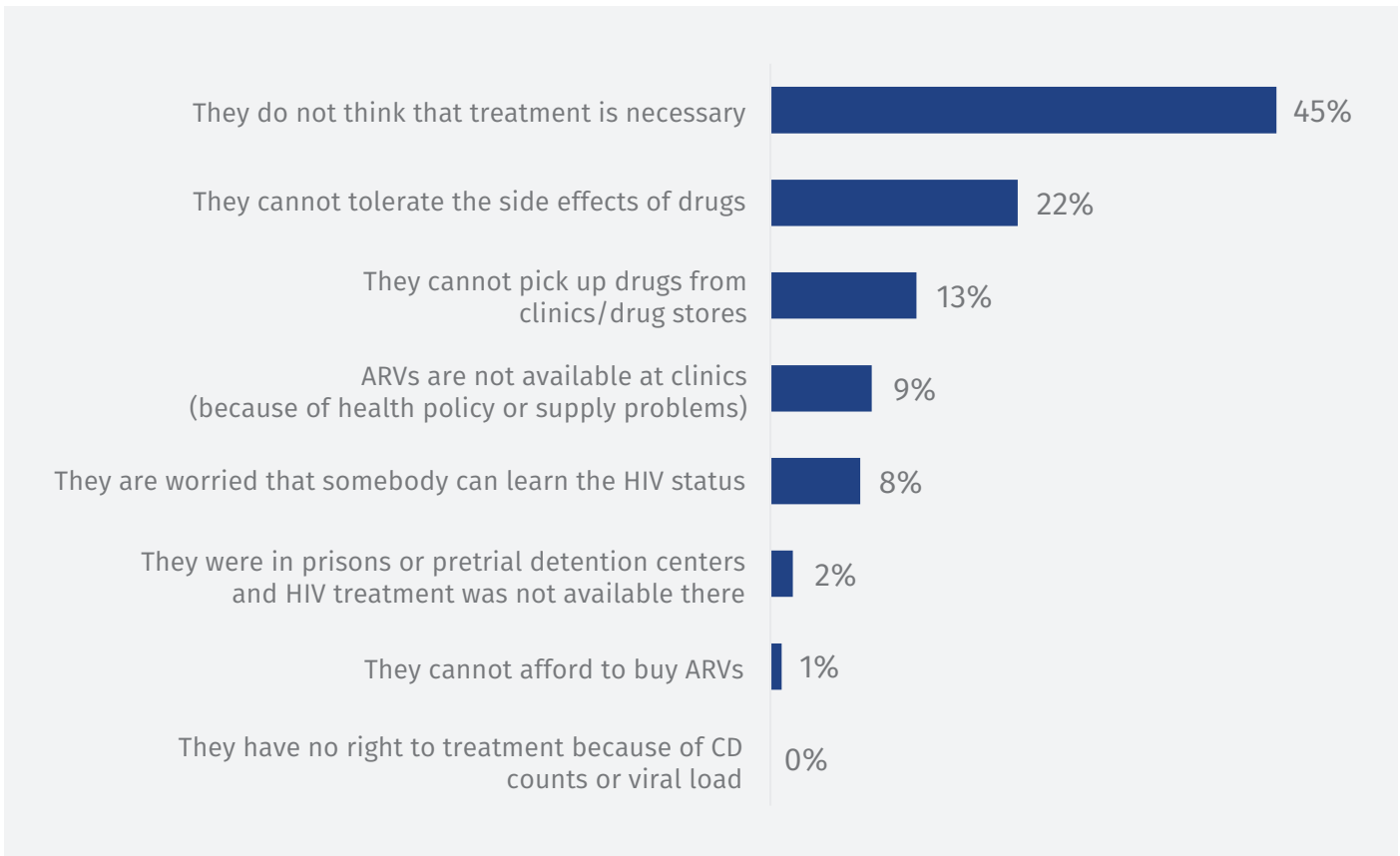


Fig. 5.12. Reasons for ART interruptions (not related to stigma), % to those who interrupted (n=339)

For a quarter (27%) of those who initiated ART but had an interruption in the last 12 months, the fear that someone might learn about their HIV status was the reason they skipped ARV.

Half of all PLHIV interviewed (51%) said that they had been informed about their undetected viral load in the last 12 months. Some respondents have not checked the viral load in the last 12 months, or they have checked, but have no results yet (21% and 10%, respectively). In 7% of respondents, the viral load is detected or the viral load is not suppressed. One-tenth of respondents (11%) said they did not know what viral load or viral suppression meant.

We traced the dependence of respondents' answers about their viral load level on their age and the duration of life with HIV. Thus, younger PLHIV (18-34 years) said less often, compared to other age groups, about undetected viral load - 47% compared to 52% among the 35-49 age group and 58% among PLHIV aged 50 and older (Table 5.14).

⁴ It is calculated as the percentage of respondents who in the question "30. What is the MAIN (non-stigma-related) reason why you are not currently receiving HIV treatment (ART)?" chose any of the reasons why they do not currently take ART.

Table 5.14. Undetected viral load, % by age

	18-34 years (n=558)	35-49 years (n=1346)	50 years and older (n=297)
Yes	47	52	58
No, VL has not been detected for the last 12 months	23	21	18
No, VL was detected and they are waiting for the results	10	9	10
No, VL is currently detecting or VL is not suppressed	8	8	4
They do not know what VL or viral suppression is	47	52	58

The smaller the duration of the respondent's life with HIV, the less proportion of those who said that they informed about viral suppression (undetected VL) - from 27% of PLHIV who have lived with HIV for less than 2 years to 58 % of those who have lived with HIV for more than 10 years. The majority of

respondents among PLHIV with the least duration of lives with HIV (less than 2 years), compared to other groups, did not check the viral load in the last 12 months (17% compared to 8-9%). In addition, PLHIV with a short duration of life with HIV has less information about what a "viral load" is (Table 5.15).

Table 5.15. Undetected VL, % by life duration with HIV

	0-2 years (n=235)	2-5 years (n=764)	6-10 years (n=562)	10 years and more (n=640)
Yes	27	49	57	58
No, VL has not been detected for the last 12 months	19	22	20	21
No, VL was detected and they are waiting for the results	17	9	9	8
No, VL is currently detecting or VL is not suppressed	10	8	7	6
They do not know what VL or viral suppression is	28	12	7	6

The representatives of key populations more often mentioned that they had been informed about the suppressed viral load in the last year (54% compared to 49%). Among key populations, MSM most often said about their undetected VL (Table. 5.16). Moreover,

among PLHIV who do not belong to any KPs, the proportion of respondents who do not even know what the viral load means is higher (12% compared to 8%). Among MSM, those respondents form the smallest proportion.

Table 5.16. Undetected VL, % by belonging to KPs

	Do not belong to KPs (n=1247)	Representatives of KPs (n=954)	PWUD (n=736)	SW (n=184)	MSM (n=113)
Yes	49	54	51	54	72
No, VL has not been detected for the last 12 months	21	20	22	18	8
No, VL was detected and they are waiting for the results	10	9	9	9	10
No, VL is currently detecting or VL is not suppressed	7	8	9	9	9
They do not know what VL or viral suppression is	12	8	9	11	2

It is also important to note that among residents of rural areas there is a higher proportion of respondents who have not detected viral load in the last year (27% compared to 20% among urban residents).

The majority of respondents (84%) said they had experience in receiving services related to health care and treatment of HIV. The

largest proportion of PLHIV (82%) receives HIV treatment services at public clinics or public healthcare facilities. However, 16% of respondents said that they were not currently provided with health care and HIV treatment (Fig. 5.13).

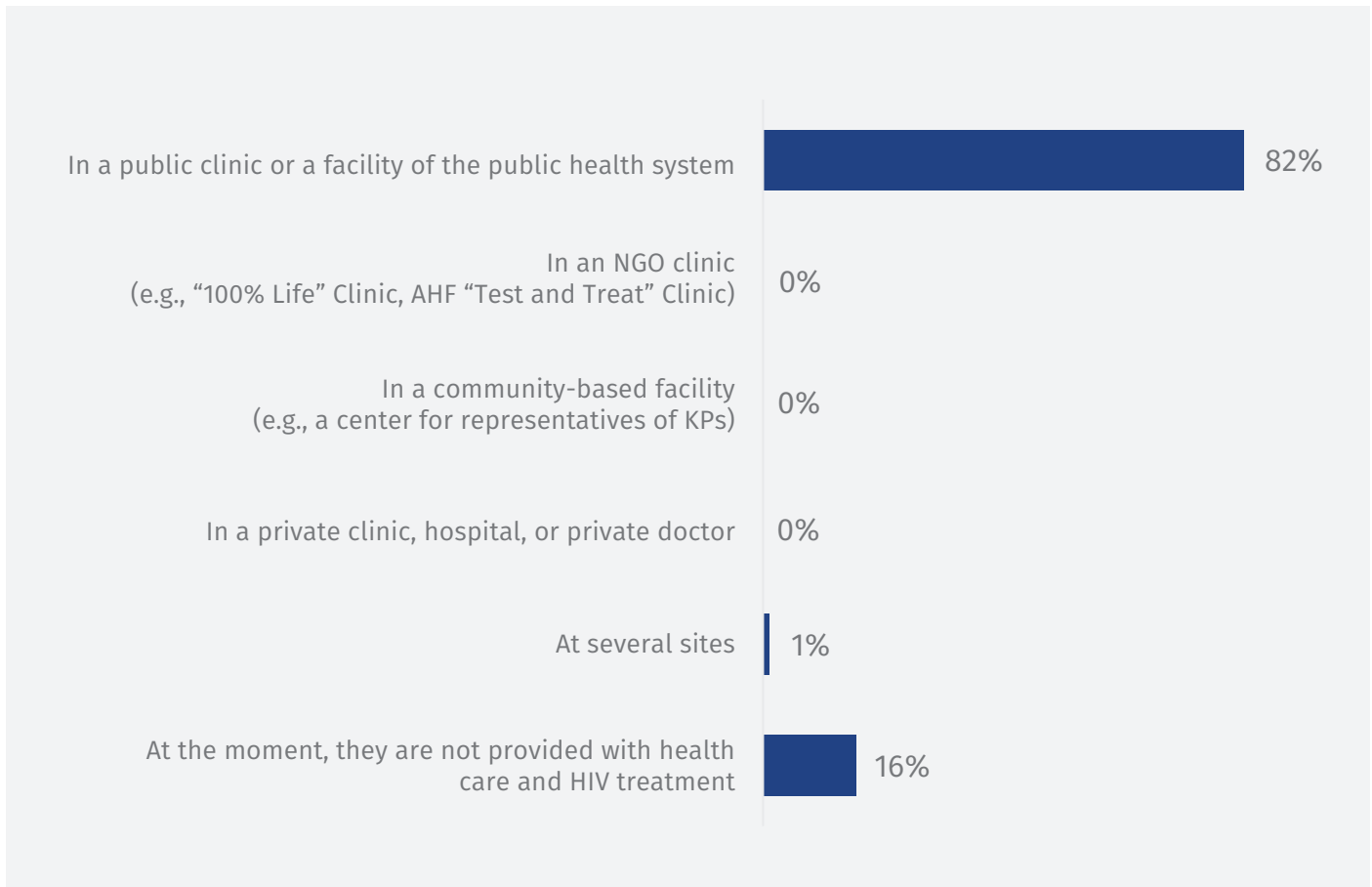


Fig. 5.13. Points of receiving services related to health care and HIV treatment, %

Comparing category profiles (distribution by socio-demographic characteristics) of respondents, according to their involvement in receiving services regarding health care and HIV treatment, the following tendencies are traced (Tab. 5.17):


- The age of respondents does not affect the level of their involvement in the HIV treatment system.
- Among PLHIV who avoid HIV treatment, the proportion of women is more than among those respondents who receive health care and HIV treatment services.

- Among the respondents who do not receive HIV treatment, the respondents from urban settlements form the highest proportion.
- PLHIV with less duration of life with HIV are more likely to avoid HIV-related services.
- Among those who do not receive HIV treatment services, the proportion of PLHIV who do not belong to KPs is higher than the respondents who are involved in HIV treatment. Members of the MSM community are less inclined to avoid HIV treatment.

Table 5.17. Profile of respondents who are involved and NOT involved in HIV treatment, %

		Receive HIV treatment (n=1854)	Avoid HIV treatment (n=347)
Age	18-34 years	25	29
	35-49 years	61	60
	50 years and older	14	11
Sex	Woman	47	55
	Man	53	45
Type of settlement	City	89	95
	Village	11	5
Duration of life with HIV	0-2 years	10	16
	2-5 years	33	44
	6-10 years	27	19
	More than 10 years	31	21
Belonging to KPs	Not representatives of KPs	56	63
	Representatives of KPs	44	37
	PWUD	34	31
	SW	9	7
	MSM	6	1

 *Significantly more important than among those who are involved in HIV treatment*

 *Significantly less important than among those who are involved in HIV treatment*

Among respondents involved in HIV treatment, 14% of them said that in the last 12 months they had experienced stigma and discrimination from the staff of healthcare facilities where they receive services related to health care and HIV treatment. The main manifestations of S&D by healthcare workers

of institutions providing HIV treatment were gossip (faced by 7% of those who received health care services) and avoiding physical contacts and disclosing HIV status by healthcare workers without the respondent's consent (faced by 5% of the respondents) (Fig. 5.14).

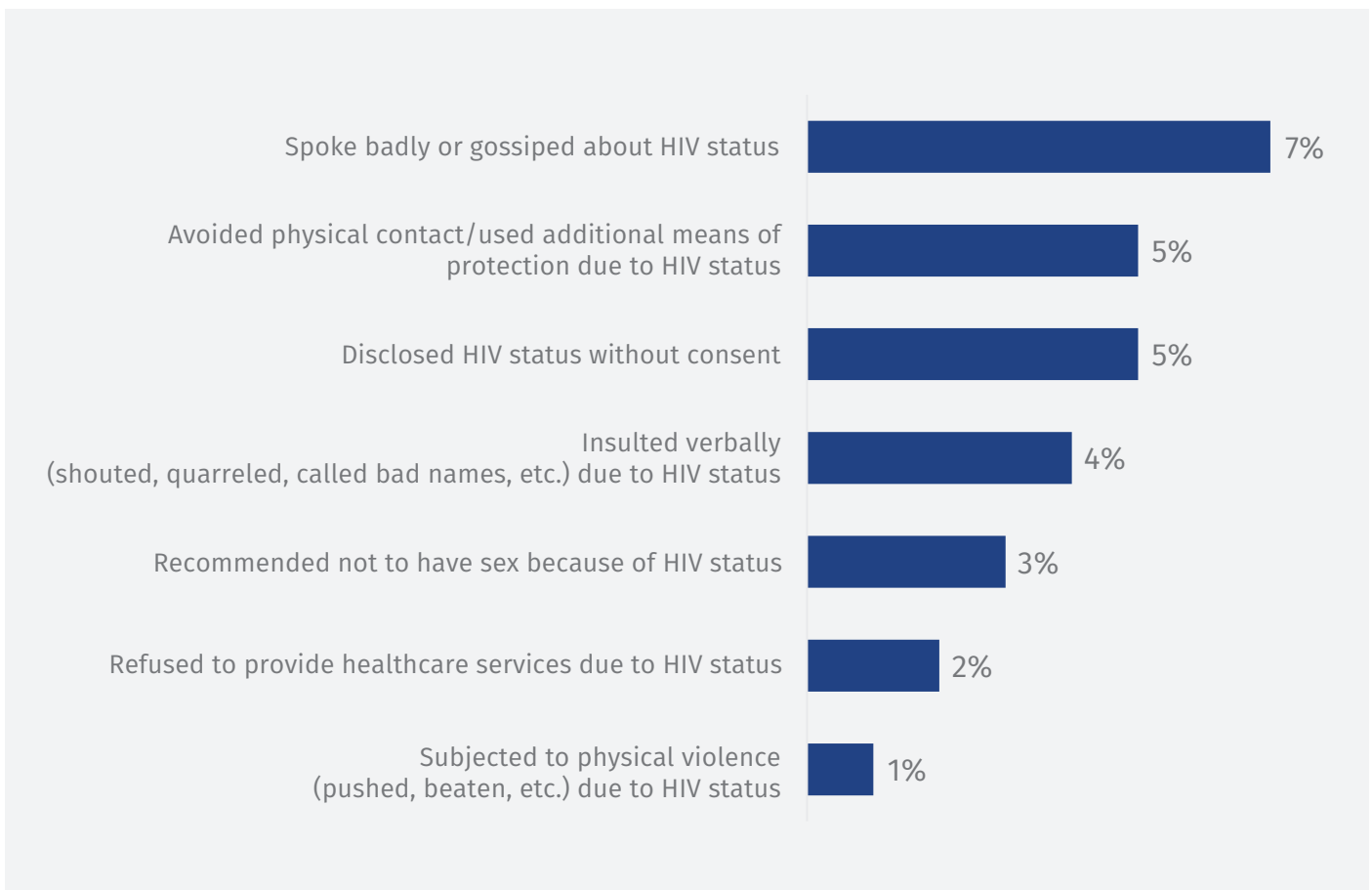


Fig. 5.14. Manifestations of stigma and discrimination by the staff of healthcare facilities that provide HIV treatment (in the last 12 months), %

The proportion of PLHIV who faced refusal to provide health care while receiving HIV treatment services has not changed compared to 2016 and is 2%.

It is important to note that the representatives of KPs more often faced stigma and discrimination of healthcare workers while receiving HIV treatment services - 16% of them said they had experienced negative actions by HCF staff, compared to 13% of those interviewed who do not belong to any KPs. In terms of separate KPs, there are no significant differences in the experience of S&D from healthcare workers of HCFs specializing in HIV treatment.

Among PLHIV who receive health care or HIV treatment services, a quarter of respondents (26%) are aware of the work of community-led clinics (NGOs) where they can receive

HIV treatment services. It should be noted that the proportion of those, who are aware of the opportunity to receive services in the community-based clinics, is higher among those whose duration of life with HIV is more than 10 years (31% compared to 21-25% of PLHIV with less duration of life with HIV). In addition, an awareness of such clinics is higher among members of KPs (29% compared to 23% of other respondents). The highest proportion of people who know about community-based clinics is among MSM - 38% compared to 30% among sex workers and 29% among drug users.

Those who know about community-based clinics demonstrate a fairly high level of knowledge about the specific services they can receive in such facilities - only 4% of the respondents could not name any service (Fig. 5.15).

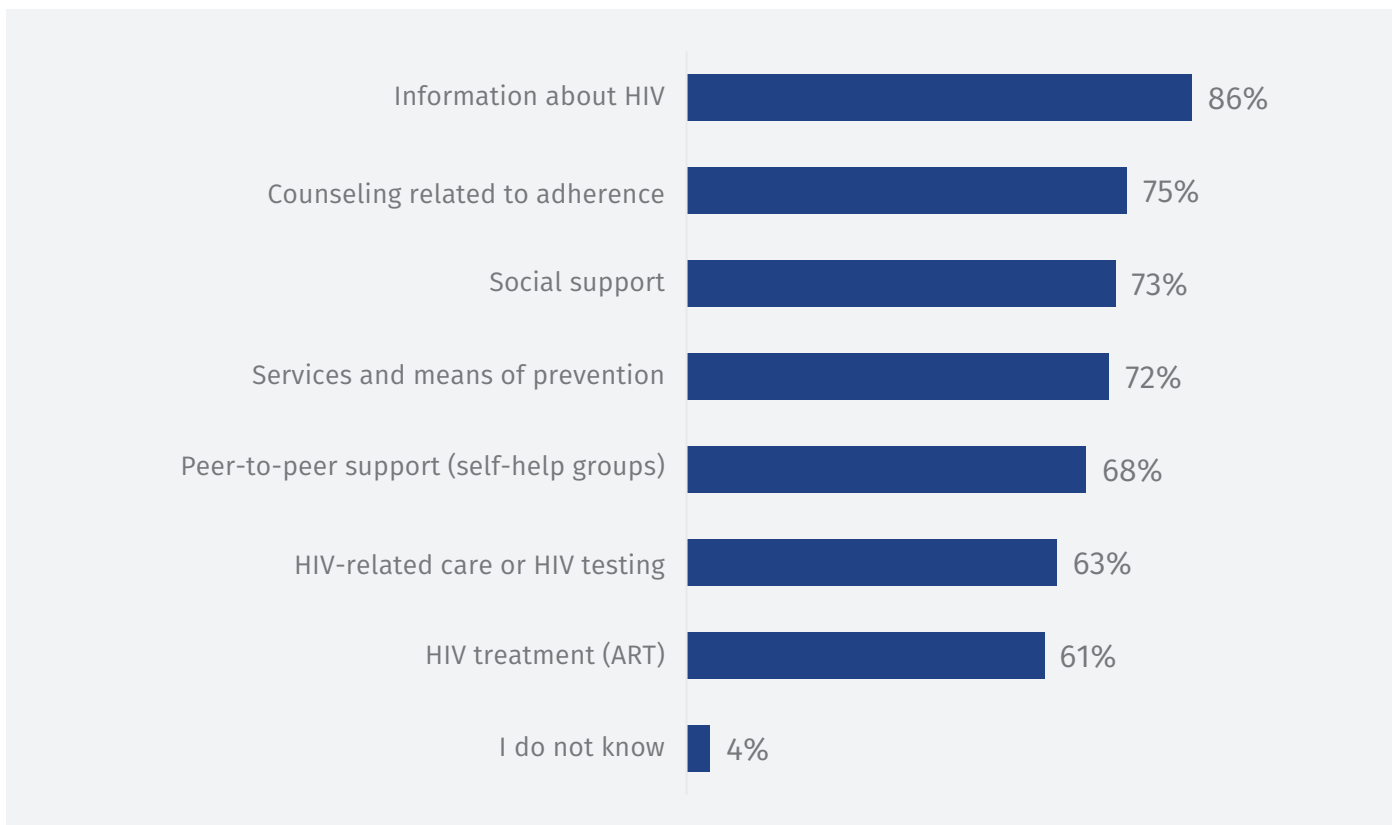


Fig. 5.15. Services available in community-based clinics, %

Thus, the problems of untimely initiation of HIV treatment and low adherence of PLHIV to ART remain relevant. In particular, two-thirds (68%) of PLHIV interviewed (excluding those who were born with HIV/infected with HIV in childhood) said that they delayed the start of health care and HIV treatment after receiving positive test results. Almost half of the respondents - 47% - have ever interrupted HIV treatment. Almost one-fifth - 17% - had never received antiretroviral therapy. In the last 12 months, among those who had ever initiated ART, 28% had problems with treatment (interrupted the therapy).

Among PLHIV involved in HIV treatment, 14% said that they had experienced stigma and discrimination from the staff of healthcare facilities where they received health care and HIV treatment services over the past year.

The main manifestations of S&D from health workers are gossip, avoidance of physical contact, and disclosure of HIV status without the consent of the respondent.

5.4. Sexual and reproductive health

About 2% of men and 6% of women interviewed said that for the last 12 months they had experienced at least one S&D manifestation in the sphere of sexual and reproductive health, including family planning, and S&D manifestations related to pregnancy, childbirth, and breastfeeding (Fig. 5.16).

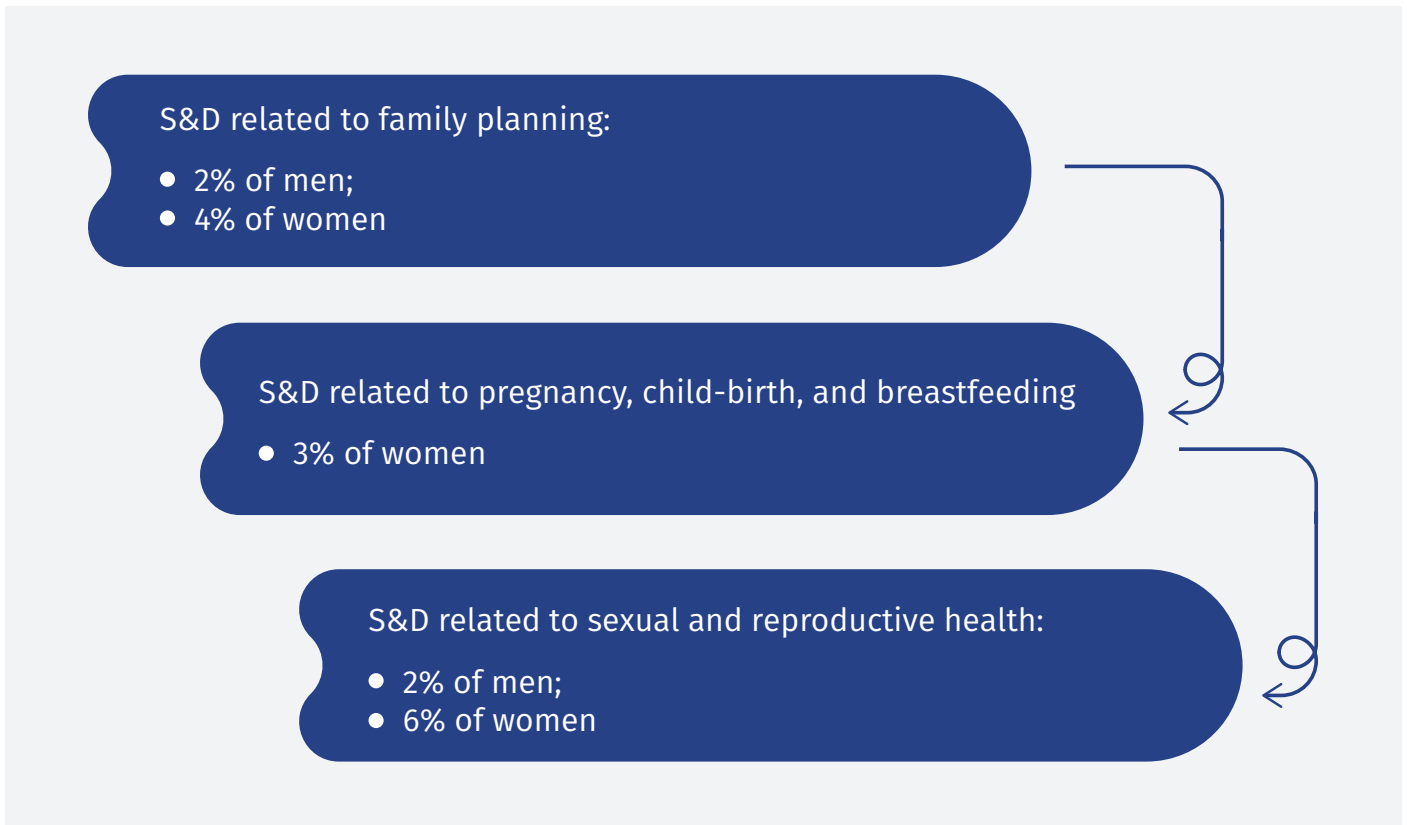


Fig. 5.16. The integral indicator of S&D in the field of sexual and reproductive health, % by sex

Specific manifestations of S&D in the field of family planning include advice not to have children, the pressure to undergo sterilization, denial of contraception or family planning services, etc., and S&D manifestations related

to pregnancy, childbirth, and breastfeeding, namely recommendations for abortion, the pressure to choose specific types of contraception, childbirth, breastfeeding, etc. (Table 5.18).

Table 5.18. Distribution of answers to the question: “During the last 12 months, did any of the healthcare workers do any of the following ONLY because of your HIV status?”, %

	Yes	No	N/A	I do not want to answer
S&D manifestations regarding family planning, % of all respondents				
They advised you not to become a mother/father	2	76	20	2
They pressured you or forced to undergo sterilization	1	72	26	1
They performed sterilization without your knowledge or your consent	1	73	25	1
They denied contraception or family planning services to you	0	76	23	1
You were told that you needed to use contraception, including any particular kind of it, to get HIV treatment (ART)	2	82	14	2

	Yes	No	N/A	I do not want to answer
S&D manifestations regarding pregnancy, childbirth, and breastfeeding, % of women (n = 1070)				
They advised you to terminate the pregnancy	1	50	48	1
They pressured you to use a specific type of contraception instead of advising different types of contraception and giving a choice	1	76	21	2
They pressured you to choose a specific method of delivery	1	44	53	2
They pressured you to choose a specific method of breastfeeding	1	42	56	1
They forced you to take ART to reduce the risk of HIV transmission, not offering it as an opportunity	1	78	19	2

Despite the fact that the question was related to the manifestations of S&D for the past 12 months, it can be assumed that in reality, the respondents mentioned situations that had happened to them for a longer period of time. This is confirmed by the fact that among women living with HIV less than 5 years, 4% of respondents reported the manifestations of S&D, while among those whose duration of life with HIV exceeds 5 years, there were 8% of them (differences are significant at $p = 0,01$).

Unfortunately, it is not possible to compare the data on S&D related to reproductive health in the dynamics, because in the previous waves of the survey it was about lifelong stigmatization experience from the moment of diagnosis, but not about the last 12 months.

5.5. Experience in receiving healthcare services for reasons not related to HIV

About 40% of PLHIV interviewed assess their health as good. Only one-tenth of respondents (9%) described their health state as poor. However, almost half of the respondents (45%) have been detected at least one comorbidities for the past 12 months. The most common are non-communicable diseases; about a fifth of the respondents (19%) had them, as well as viral hepatitis, 18% (Fig.5.17). Two-thirds of those PLHIV (67%) who had diseases had received appropriate treatment for the past 12 months.

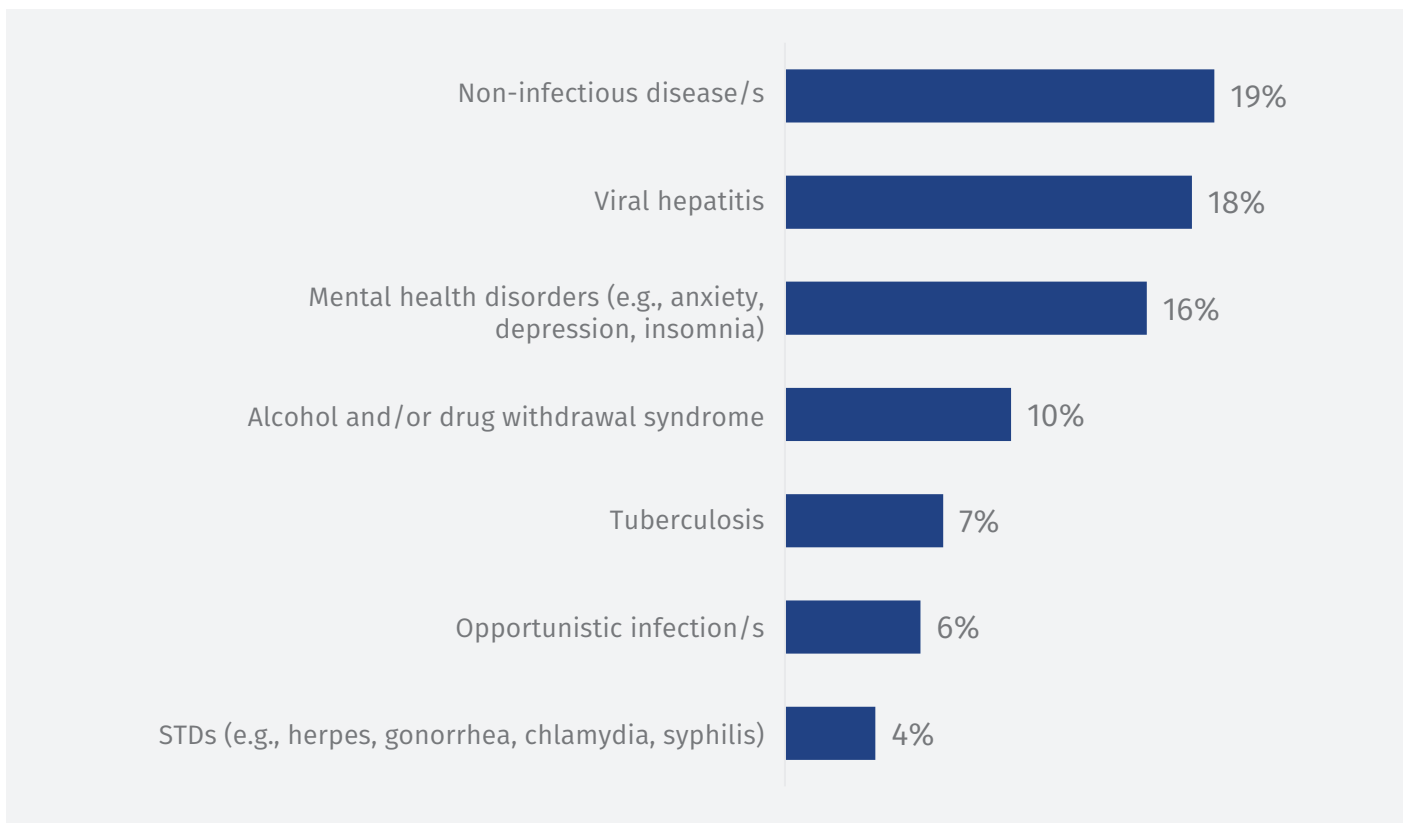


Fig.5.17. Diagnoses made in the last 12 months, %

Half of the PLHIV interviewed (47%) said that in the last 12 months they had sought medical help for reasons not related to HIV (such as influenza, dental services, vaccinations, injuries, etc.). Women more often sought health care than men (51% compared to 42%). There are no differences between respondents who belong to and do not belong to key populations. Instead, some of the key groups differ. Thus, 59% of MSM, 52% of sex workers, and 46% of drug users sought health care for reasons not related to HIV.

It is important to note that PLHIV who avoid HIV treatment significantly less often visit healthcare facilities seeking help not related to HIV than the respondents involved in HIV treatment (37% compared to 48%). This fact may be the reason, why among PLHIV who avoid HIV treatment, there is a smaller proportion of those who said about comorbidities (38% compared to 47% of those who are treated for HIV).

The level of stigma and discrimination in receiving health services for reasons not related to HIV exceeds the level of S&D in institutions specializing in HIV treatment. Thus, one-fifth (21%) of respondents, who had sought health care for reasons not related to HIV in the past year, said about at least one manifestation of S&D in healthcare facilities. It should be noted that belonging to key populations significantly increases the risk of stigmatization or discrimination by healthcare workers: representatives of KPs face S&D manifestations in healthcare facilities more often than other respondents (25% compared to 18%) (Table 5.19). Among key populations, drug users and sex workers suffer more from S&D by healthcare staff.

Table 5.19. The level of S&D from the staff of healthcare facilities which are NOT specialized in HIV treatment (in the last 12 months), % by belonging to KPs

	Do not belong to KPs (n=567)	Representatives of KPs (n=458)	PWUD (n=339)	SWs (n=95)	MSM (n=67)
They faced S&D from healthcare staff when seeking health care for reasons not related to HIV infection	18	25	25	28	16

The most frequent manifestations of stigma and discrimination from healthcare workers were avoidance of physical contact with PLHIV (faced by 12% of respondents who

visited general healthcare facilities), as well as gossip and disclosure of HIV status without the consent of the respondent (9% for each manifestation respectively) (Fig. 5.18).

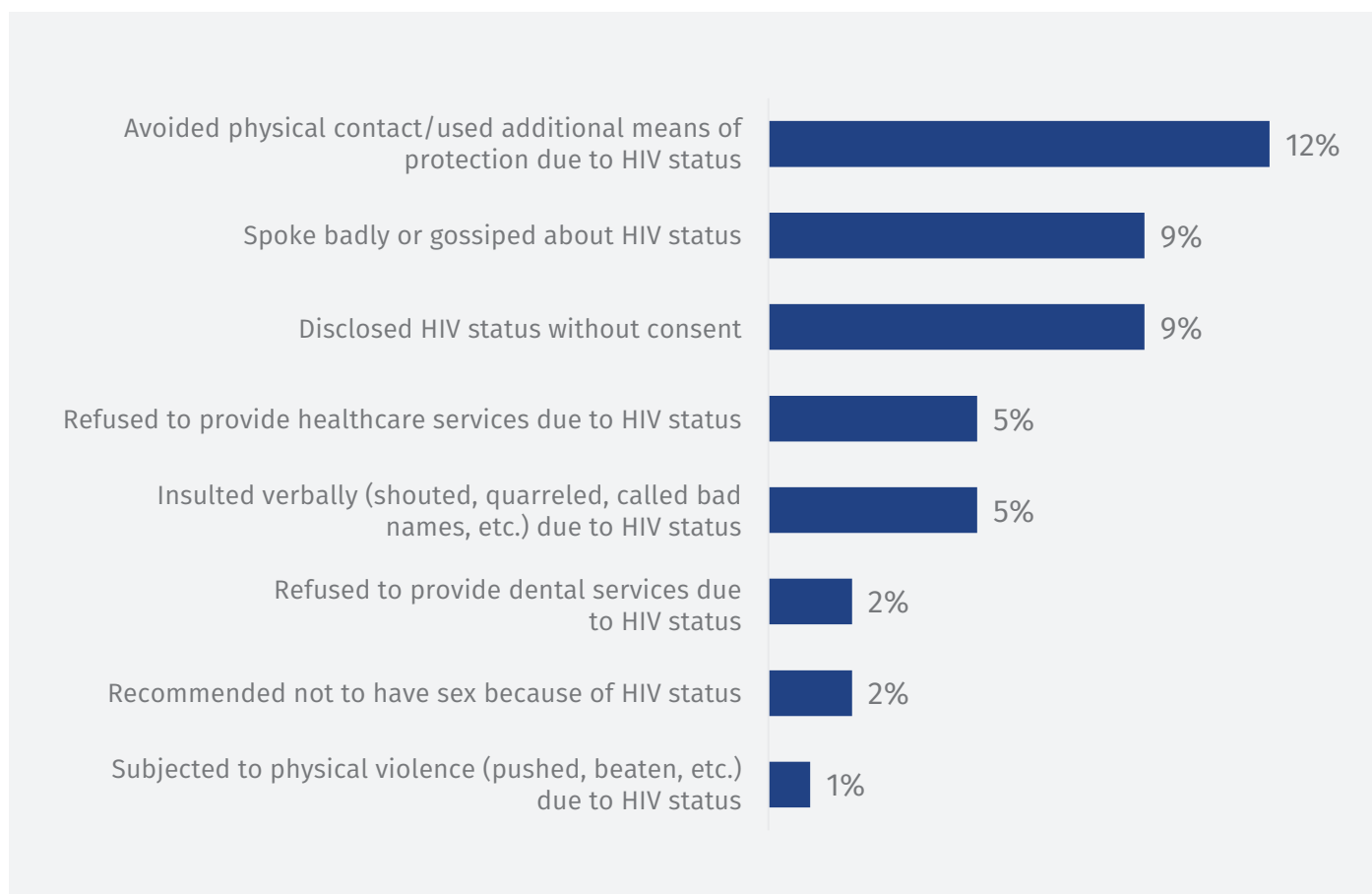


Fig. 5.18. Manifestations of stigma and discrimination by the staff of healthcare facilities which are not specialized in HIV treatment (in the last 12 months), %

Some life stories include vivid examples of direct or indirect discrimination against PLHIV in healthcare facilities if the patient's HIV status became known. Many respondents faced insulting remarks and disregard of them by the healthcare staff. Such situations often lead to patients refusing to inform doctors about their HIV status or avoiding healthcare facilities even if it is necessary.

«My sinusitis worsened: my nose was blocked, headaches were very severe, and I had to blow it. I came to 'Krasnyi Khutor', explained the situation, including the status. By hook or by crook, they tried to send me to another place. 'Go to your hospital, we don't accept such people.' I explained that there, where I am being observed, they didn't have an otolaryngologist. Only when I started to raise hell that I would not go anywhere else, they did what I needed. It was done with such a facial expression as 'like with difficulty'. I felt humiliation and contempt, so I didn't want to go back there anymore. Then, I went to an ENT institute, there was a completely different attitude. I said about my status. A council of physicians gathered quickly and they all decided, prescribed me the right and normal treatment. They didn't even have (negative) facial expressions on their faces. They treated me like an ordinary person»

(Life Story, Kyiv)

«I was going home in June this year. At the tram stop, I felt sick, I lost consciousness. An ambulance arrived; I was taken to an emergency hospital. They started to do tests, ultrasound, asked about diseases. Not to infect others, I talked about my HIV and hepatitis. And immediately everyone, starting with a nanny who was riding me, began to pish at me. They gave an injection into a muscle. They called an ambulance for me and said: 'Take away'. The second ambulance took me to Makarov Hospital. It was the same there. They only heard about HIV status and immediately said: 'What are we going to do with him? We do not have wards for the homeless. Nobody will want to be with him.' They called the third ambulance: 'Where do you live, where were you treated?' I said where. They decide to take me to 'Dubky'. They brought me there, and only there they took me to the hospital»

(Life Story, Mykolayiv)

«This year, about six months ago, I went to have a tooth done. It was necessary to drill and fill it. Before he started, I called him and said, 'I'm sorry, I have HIV. I just don't know if it's written in the card or not.' He reacted strongly against this. He started looking through the medical record. He said: 'Now I'll go to write it down.' He went and was absent for a long time, and then he said: 'You have your own clinic where such treatment is provided. We do not work with HIV-infected people.' I did not rail against him, to sort out our relationship. I just said, 'Sorry, thank you!'»

(Life Story, Odesa)

Less than a quarter of all PLHIV interviewed (23%) said that they usually disclose their HIV status, receiving healthcare services of a general nature (not related to HIV) outside HIV clinic (in an outpatient clinic, at a private dentist's, etc.). Women less often than men inform healthcare workers about their HIV-positive status (19% compared to 26%). PLHIV

who avoid HIV treatment are also less open with healthcare workers, only 15% disclose their status, compared to 24% of PLHIV involved in HIV treatment. In addition, PLHIV with less duration of life with HIV tend to disclose their status less often in general health facilities (Table 5.20).

Table 5.20. Reported on HIV status in healthcare facilities, % by the duration of life with HIV

	0-2 years (n=235)	2-5 years (n=764)	6-10 years (n=562)	More than 10 years (n=640)
They disclose their HIV-positive status in general healthcare facilities	12	16	24	33

Representatives of key populations are generally more open with healthcare facilities staff not related to HIV treatment than those who do not belong to KPs. PLHIV of key populations twice as more likely to disclose

their HIV status than PLHIV from the general population (31% compared to 16%). However, representatives of MSM are an exception (Table 5.21).

Table 5.21. Reported on HIV status in healthcare facilities, % by belonging to KPs

	Do not belong to KPs (n=1247)	Representatives of KPs (n=954)	PWUD (n=736)	SW (n=184)	MSM (n=113)
Table 5.21. Reported on HIV status in healthcare facilities, % by belonging to KPs	16	31	34	25	19

Cases of S&D by healthcare staff lead to the fact that PLHIV quite often regret their decision to inform healthcare workers about their HIV status. Some PLHIV decide to turn only to "proved" physicians who are friendly to PLHIV (for example, those who work with HIV-service NGOs). But such a strategy is not always possible, especially in emergencies or when highly specialized care is needed.

«I tried to somehow warn the doctor so that he could protect himself. But in the end, I thought that it would be better if I did not tell. Although, my conscience does not allow me to do like that»

(Life Story, Odesa)

«I told myself (to the nurse in the manipulation room) because I expected that this person had been working for more than a year, and she faced it. But I realized that I generally need to hide my status from health workers. Because people are scared and then discriminate against me: they don't want to deal with it, they can't take tests»

(Life Story, Rivne)

«If there is such a need (to see a doctor), then I try, if possible, to use an organization to visit a friendly physician, who support HIV-positive people»

(Life Story, Kherson)

In general, the results of the study show an improvement in the situation regarding the observance of medical secrecy by healthcare workers. The results of each of the four waves of the Stigma Index survey in Ukraine show a gradual and noticeable decrease in the proportion of the respondents who reported

the disclosure of information about their HIV-positive status by healthcare workers without the respondent's consent (both in general healthcare facilities and healthcare institutions specializing in HIV treatment) - from 30% in 2010 to 6% in 2020⁵ [5] (Fig. 5.19).

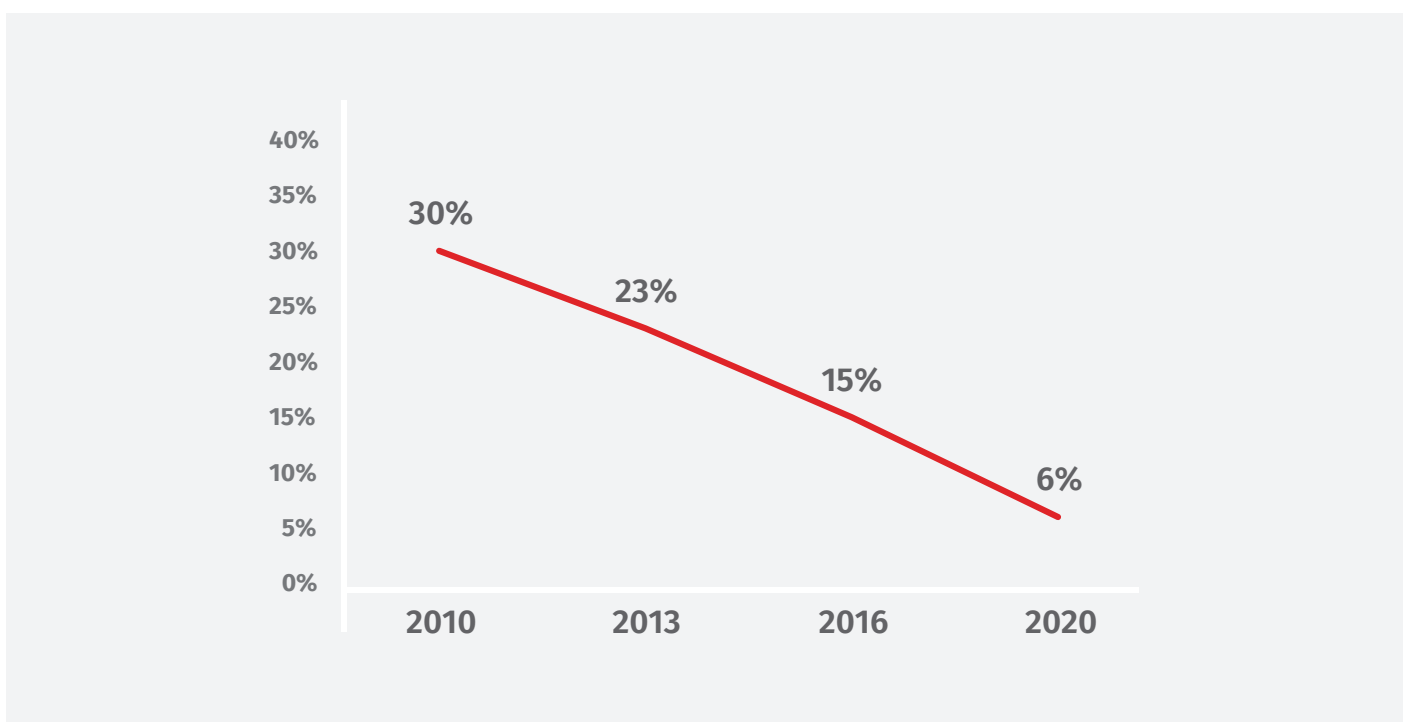


Fig. 5.19. The proportion of PLHIV who reported unauthorized disclosure of HIV status by healthcare workers, in the dynamics, %

⁵ Indicators are calculated for the total number of respondents. In 2010-2016, the indicator was calculated as the proportion of respondents who answered in the affirmative to the question "Did healthcare staff tell other people about your HIV status without your consent?" In 2020, the indicator is calculated as the proportion of respondents who in the questions "39. In the last 12 months, have you encountered any of the following from the staff of a healthcare facility where you receive services related to health care and treatment of HIV?" and "41. In the last 12 months, have you encountered the following from healthcare staff when seeking health care for reasons not related to HIV?" chose the answer "Disclose your HIV status without your consent."

The respondents continue to improve their assessment of the confidentiality level of medical records related to their HIV status. There is a tendency to increase the proportion of respondents convinced of the absolute

confidentiality of such documents - from 18% in 2010 to 51% in 2020 - and declining the proportion of those who have the opposite opinion - from 34% to 6% (Fig. 5.20).

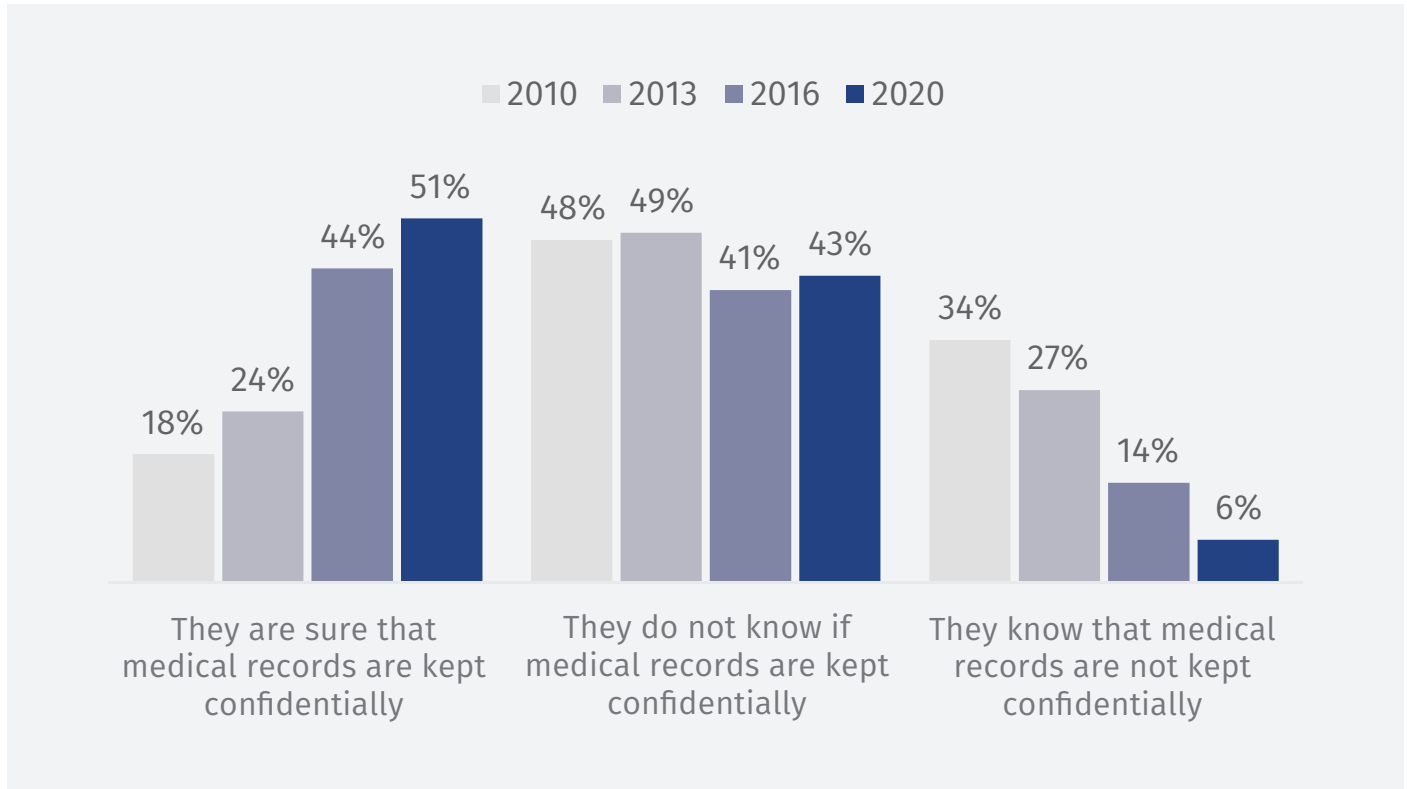


Fig. 5.20. Assessment of the confidentiality level of medical records related to HIV status, in the dynamics, %

Thus, the results of the study showed that the level of stigma and discrimination while receiving healthcare services for reasons not related to HIV exceeds the level of S&D in institutions specializing in HIV treatment. Thus,

a fifth part (21%) of the respondents who have sought non-HIV health care in the last year have suffered from various forms of stigma and discrimination from healthcare workers.

6 Human rights and changes

Ukraine has a legal framework aimed at protecting the rights of people living with HIV. First of all, it is the Law of Ukraine “On preventing AIDS and social protection of the population” as amended and supplemented (Vidomosti Verkhovnoi Rady (VVR) 1998, No. 35, p. 235).

At the same time, PLHIV’s knowledge about the law and, consequently, their readiness to protect their rights in case of violation remains insufficient. According to the survey, every second respondent answered that they were generally aware of laws that protected PLHIV from discrimination, and 41% of respondents did not know about such laws, the other 6% believed that there were no such laws (Fig. 6.1).

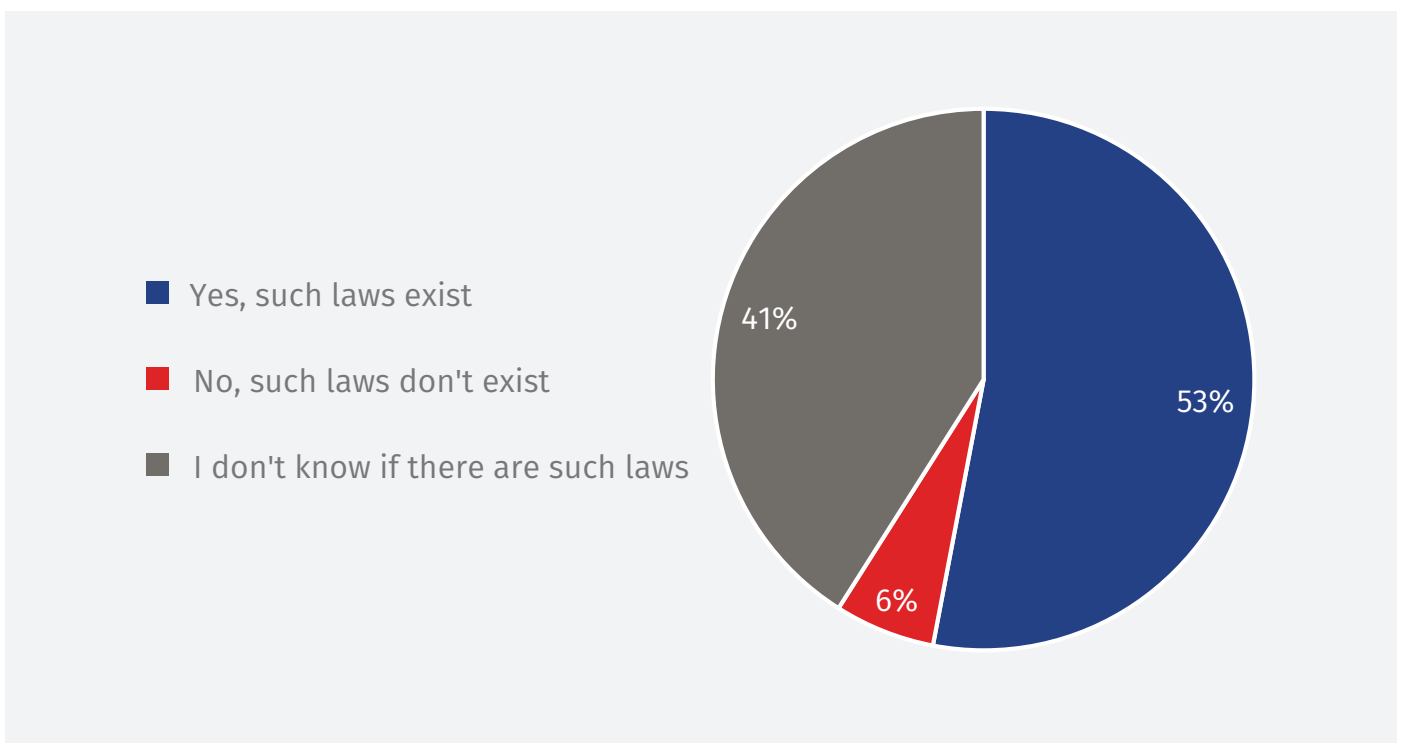


Fig. 6.1. Awareness of laws that protect PLHIV against discrimination, %

Awareness of the laws is higher among people with higher education (60%) compared to those with lower levels of education (51%), differences are significant at $p = 0.01$. Among KPs, MSM were most aware of (64%), while the level of knowledge of other KPs varies from 50% to 55%, and the level of knowledge among PLHIV who do not belong to KPs is 51%.

We can see the dependence of the level of knowledge about the legislation on the duration of life with HIV: the longer it is, the higher the proportion of those who are aware and can find legal protection in case of violation of PLHIV rights (Fig. 6.2).

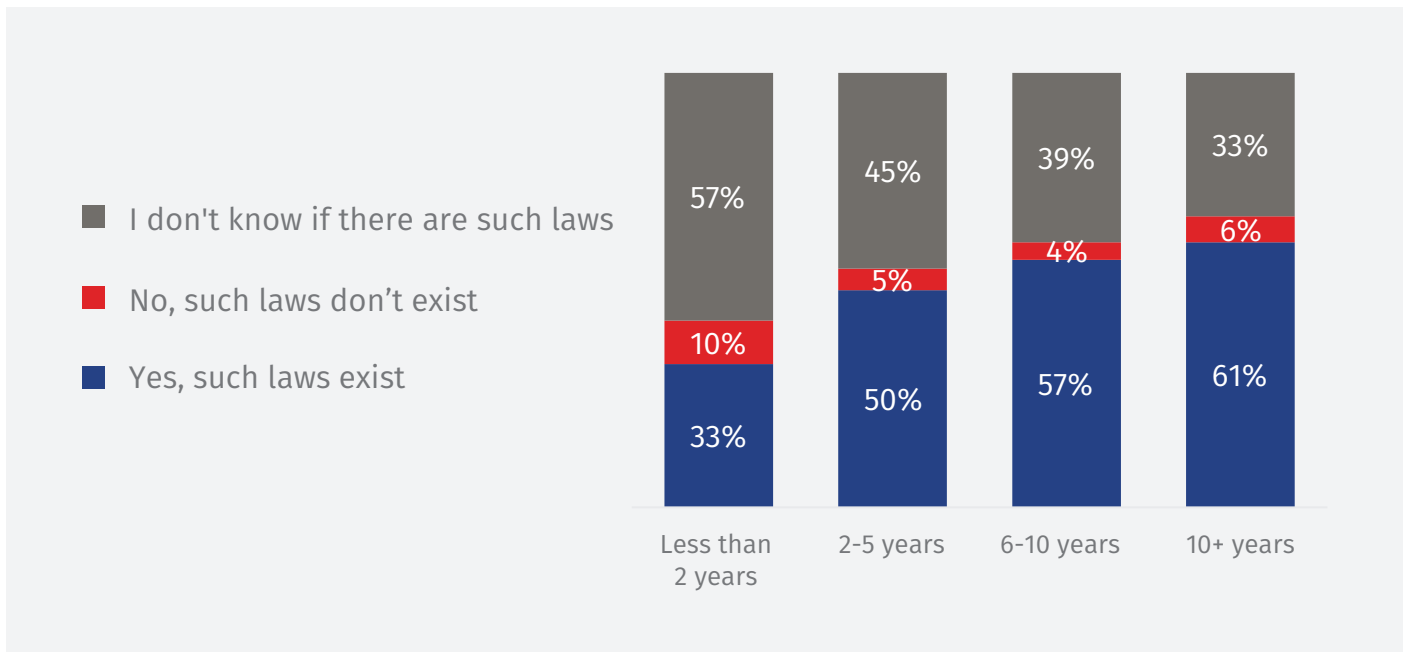


Fig. 6.2. Awareness of laws in Ukraine that protect PLHIV against discrimination, % by the duration of life with HIV

In-depth interviews show that lack of information on the legal mechanisms for protecting the rights creates additional tension in situations of discrimination against PLHIV by healthcare staff, business administrations, and so on.

«When I came to a hospital, I was told, 'What do you want? You are a drug addict. You have to understand that you are a threat to society.' They said that people like me should be put in a bag and drowned in a pond. I did not think that their actions were illegal, that law could protect me, and that it generally existed»

(Life Story, Donetsk)

take HIV tests/disclosure of HIV status (as a precondition for attending school, receiving a scholarship, employment, receiving a pension, receiving health insurance or healthcare services, obtaining a visa/applying for a residence permit or obtaining citizenship in the country).

Similarly, the vast majority of respondents were not detained/arrested or convicted for reasons related to HIV status; they were not denied a visa, entry, or stay in the country, obtaining a residence permit; they were not forced to disclose their status publicly/without consent; they did not face coercion to have sex.

The vast majority (95-98%) of women interviewed said that they did not face refusal to provide shelters for victims of domestic violence or obstacles created by their husbands/partners to receiving healthcare services (Table 6.1).

Respondents were asked what violations of their rights as PLHIV they had encountered in the past year or earlier. The results of the survey show that cases of rights violations are rare. The vast majority (96-98%) of respondents said that they had not encountered such violations of their rights as being forced to

Table 6.1. Violations of the rights of people living with HIV, %

Types of violations	In the last 12 months	Earlier than 12 months ago
Compulsory HIV test or HIV disclosure for...		
obtaining a visa, submitting documents for a residence permit/ citizenship in the country	1	1
employment	1	1
receiving a pension	1	1
attending school or receiving a scholarship	0	1
receiving healthcare services	1	2
obtaining health insurance	1	1
Other forms of violation of the PLHIV rights caused by HIV status		
The respondent was arrested or convicted for a reason related to HIV status	0	1
The respondent was detained or placed in a pre-trial detention center due to HIV status	0	1
The respondent was refused to obtain a visa or entry into the country due to HIV status	1	1
The respondent was refused to stay in the country or obtain a residence permit due to HIV status	1	1
The respondent was forced to disclose his/her HIV status publicly or the status was disclosed without his/her consent	1	3
The respondent was forced to have sex against the will (including physically forced)	1	3
INDEX OF VIOLATION THE RIGHTS OF PLHIV	4*	10**

*The index of violations of the PLHIV rights was calculated as the proportion of PLHIV who faced at least one of the violations of their rights during the last year

**Retrospective index of violations of the PLHIV rights was calculated as the proportion of PLHIV who faced at least one of the violations of their rights earlier than in the last year

The proportion of respondents who have encountered at least one of the above violations of their rights during the last year is 4%. In 2016, another list of possible violations of PLHIV rights was used. The integral indicator (the proportion of respondents who faced at least one of the violations) was then 3%. Some of the situations mentioned in both the current and previous waves of the survey are not common for the majority of the population of Ukraine, including PLHIV (for example, obtaining health insurance, obtaining documents for a residence permit or citizenship, etc.). During the first two waves of the survey (2010 and 2013), there

was an answer: “I had to agree to a medical procedure (including laboratory tests for HIV)”. This option received a significant number of positive responses from PLHIV (37-39%) and increased the integral indicator of violations to 41% in 2010 and 40% in 2013. Therefore, the comparison with the 2010 and 2013 surveys is not correct.

For a more detailed analysis based on 2020 data two integral indices were built: the index of violation of the PLHIV rights (the proportion of PLHIV who had at least one of the violations of their rights in the last year) and the retrospective index of violation of the

PLHIV rights (the proportion of PLHIV who had at least one of the violations of their rights earlier than in the last year). They are 4% and 10% respectively (Table 6.1).

Among vulnerable categories, sex workers most often complained of violations of their

rights as PLHIV: 24% is a retrospective index of violations of rights and 10% is an index of violations of rights in the last year. For PLHIV who do not belong to KPs, the relevant indicators are significantly lower: 8% and 3%, respectively (Fig. 6.3).

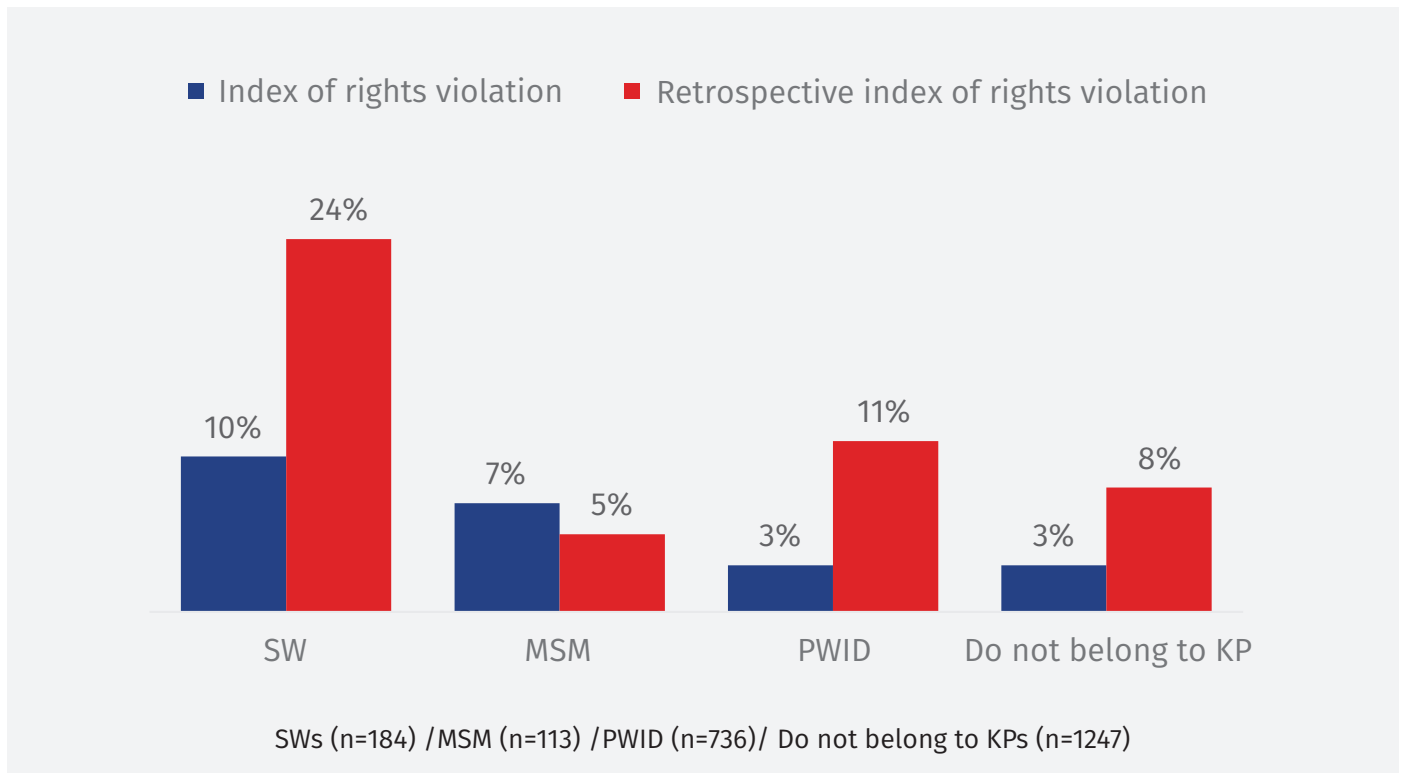


Fig. 6.3. Violation of the PLHIV rights, by belonging to KPs, %

There are gender differences: the retrospective index of the rights violations among women is 13%, among men - 8%. The values of these indices, especially retrospective ones, are increased with increasing the duration of lives with HIV. Thus, among persons with life duration up to 2 years, the retrospective index is 4%, for those, from 2 to 5 years - 8%, from 6 to 10 years - 12%, more than 10 years - 14%.

According to the survey, only 17% of respondents (15 people) who have faced violations of their rights in the past year, tried to defend them, did something to protect themselves. For this purpose, they did the following (possible actions are listed according to the rating):

- Sought help of an organization/network of people living with HIV, a self-help group, or a specific person with HIV status (10 people);
- Filed a complaint (4 persons);
- Consulted a lawyer (4 people);
- Voiced this problem in public (3 people).

None of the respondents chose the option of appealing to a government official or politician (in previous waves of the survey, such cases took place).

Regarding the results of these actions, a third of those who tried to protect their rights (5 out of 15) said that the problem was not solved; almost half (7 people out of 15) managed to achieve a positive result, i.e. they solved a problem; in 3 cases out of 15 the problem solving was still ongoing at the time of the survey. In 2016, respondents who sought legal assistance to protect their rights (67 people) were asked about whether their cases had been considered and not about the outcome of the consideration (whether the problem had been resolved). Accordingly, the comparison of data in the dynamics will be incorrect.

Some PLHIV who faced certain violations of their rights did not try to protect them (n = 67). Among the answers regarding the main reason that prevented them from trying to defend their rights, legal incompetence (they did not know where to go, what to do) and lack of confidence in a successful outcome was most frequently mentioned (19% each). Fears of attempting to protect their rights will lead to the disclosure of HIV status (15%) are in

third place; a fear of acting is in fourth place (13%); procedural difficulties is in fifth place (9%). Among the reasons for refusing to try to resume their violated rights, there is lack of financial resources (6%), lack of evidence of violations (3%), a fear of disclosure of the status for the MSM/transgender/sex worker/drug user (2%), and advice from other people do nothing (2%).

The 2016 survey used a different list of possible reasons that prevented those whose rights had been violated from seeking legal assistance (n = 103). This does not allow for a correct comparative analysis of data in the dynamics. Only two reasons that appeared in the 2016 and 2020 surveys are comparable. As we can see, fear remains an important reason that prevents PLHIV from actively defending their rights (Table 6.2).

Table 6.2. Reasons that prevented from defending violated rights, in the dynamics, % among those who have faced violations of their rights in the last 12 months, but not tried to defend them

In 2016 (n = 103)		In 2020 (n = 67)	
Lack of faith in a positive result	37	There was no confidence in a successful outcome	19
I felt too intimidated or depressed to take any actions	15	You were intimidated and afraid to act	13

Combating stigma and discrimination against people living with HIV include measures of various levels: public policy (laws, decrees, other regulations governing administrative actions in certain situations), education and advocacy campaigns (in the fields of media, education, medicine, psychological/social assistance, civil society), establishing direct contacts to share experiences in counteracting S&D, raising awareness among PLHIV, including in social networks.

The highest proportion of respondents is involved in contacts at the “grassroots” level of mutual help: over the past year, 15% of PLHIV provided emotional, financial, and other kinds of assistance to people living with HIV, other 14% of PLHIV provided similar support before, namely about 30% had experiences of participating in such actions (Table 6.3).

Table 6.3. Counteracting stigma and discrimination by PLHIV interviewed, %

Options for counteracting	Yes, for the last 12 months	Yes, but earlier than 12 months ago
They tried to convince or raise awareness of a person who manifested S&D against you	8	11
They tried to persuade or raise awareness of a person who manifested S&D against another person living with HIV	11	14
They provided emotional, financial, or other support to a person living with HIV to help him/her cope with S&D	15	14
They participated in the work of an organization or in an information campaign that counteracted S&D against PLHIV	5	5
They supported a community leader in action to address the problem of S&D against PLHIV	6	5
They supported politicians (deputies, officials) in actions aimed at solving the problem related to S&D against PLHIV	2	2
They talked in the media (gave interviews) about the problem of S&D against PLHIV	1	3
The index of combating stigma and discrimination	20*	27*

*The indicator is calculated as the proportion of respondents who have done at least any of the above in the last 12 months or earlier

A similar question was in the 2016 questionnaire, but in different and more specific wording: “Have you provided support to other people living with HIV in the last 12 months?” At that time, 57% of respondents answered in the affirmative, most of them provided emotional support (stories about their lives, counseling, etc.); 30–34% of them provided material support and information about specialized institutions/organizations.

Such actions cause moral satisfaction for the providers themselves.

“I like to help fellows and use my experience to tell that there is a law, that we can be protected, you just need to know where to go”

(Life Story, Donetsk)

Other work that PLHIV have to deal with on a regular basis is explaining and convincing of the wrongdoing of those who show stigmatizing and discriminatory actions against HIV-infected people (including against other PLHIV or directly against a respondent). In the last year or so, 19–25% of respondents have practiced such explanations.

About 10–11% of respondents informed about their involvement in organizational work, participation in information campaigns, and support for a community leader to counteract stigma and discrimination against PLHIV (they had such experience in the last year or earlier). The proportion of those who participated in such organized campaigns during the last year is 5–6%.

The lowest level of inclusion is counteracting at the media and political level. Only 4% of respondents said about such an experience. Over the last year, only 2% of respondents supported politicians (officials, deputies) in protecting PLHIV from discrimination, and 1% spoke with journalists about the problems of PLHIV stigmatization. On the other hand, such activities require special skills, free time, access to the media, established contacts among politicians, which is problematic for many ordinary citizens, and sometimes they are simply unachievable. At the same time, according to 2016 data, a certain proportion of respondents had guidelines on the *possibility of influencing* at the political level. Thus, 16% of respondents said that they felt that they could influence decisions related to such issues as the rights of PLHIV, local government policies, local PLHIV-related projects, central government policies, national programs, and international conventions on PLHIV.

To summarize the data on the involvement of respondents in defending their rights as PLHIV, two indices were built: *an index of combating stigma and discrimination* (relevant experience in the last year), which is 20%, and *a retrospective index of combating stigma and discrimination* (earlier than in the last year), the value of which is 27% (Table. 6.3).

Involvement in defending rights depends on the duration of life with HIV and the level of education. In particular, during the last year, 29% of respondents with more than 10 years of living with HIV tried to counteract HIV based on HIV status. While among those living with HIV for less than 2 years, the same figure is 14% (Fig. 6.4).

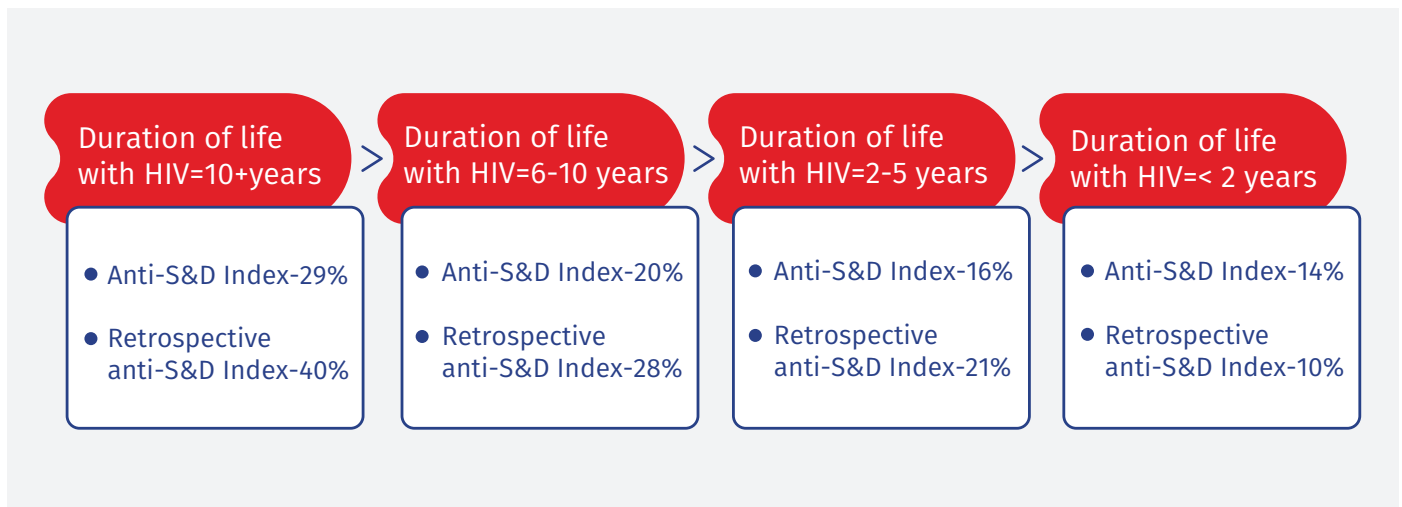


Fig. 6.4. Integral indicators of combating S&D by PLHIV interviewed, % by the duration of life with HIV

Higher education also correlates with active citizenship and involvement in various activities to combat S&D based on HIV status: among people with higher education, the index of combating S&D reaches 25%, the index for respondents with general secondary education is 18%, the index for respondents with lower than secondary education is 14%.

Representatives of KPs often said that they had experience in certain activities, aimed at combating S&D based on HIV status (against yourself or other PLHIV), providing support to people living with HIV (Fig. 6.5). It can be assumed that the double stigma and discrimination to which vulnerable categories of PLHIV are exposed is more actively resisted.

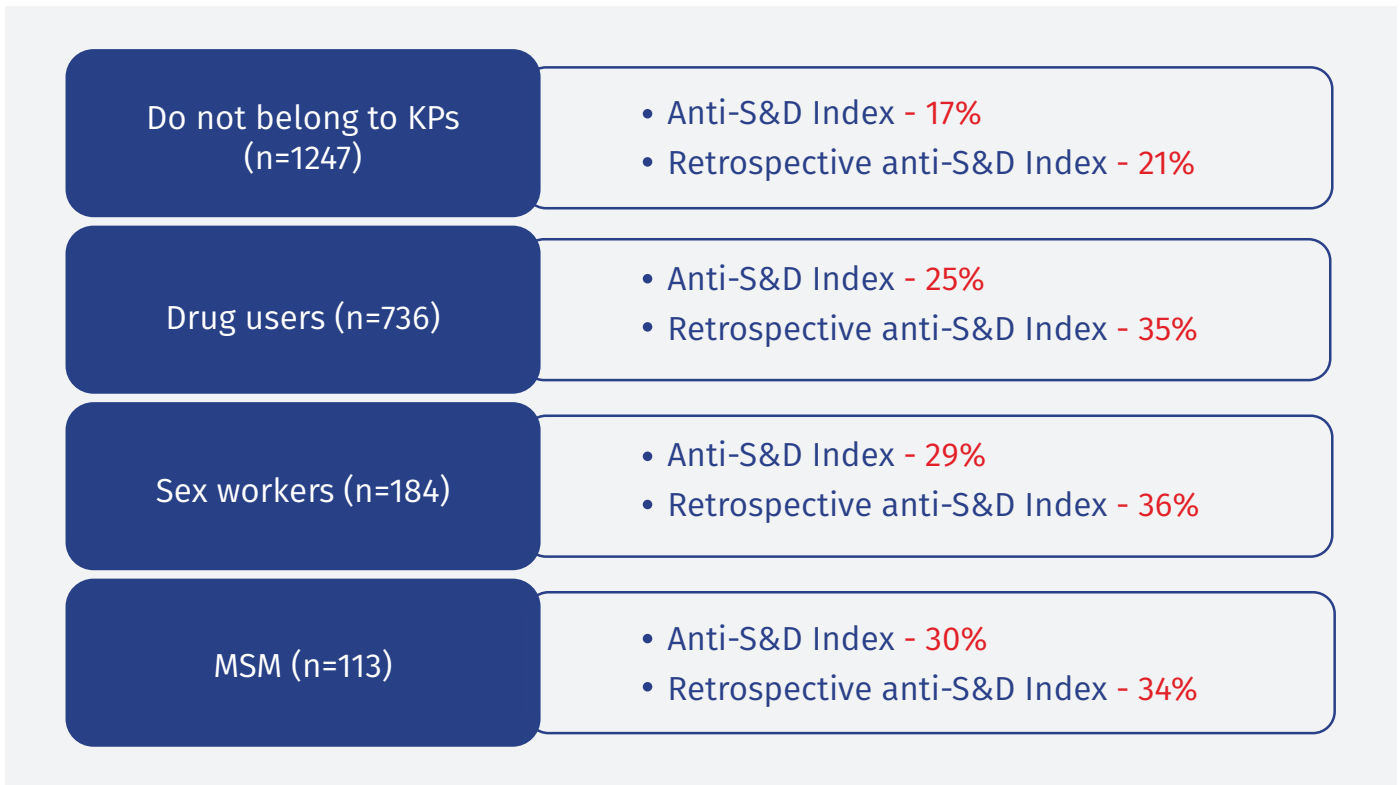


Fig. 6.5. Integral indicators of combating S&D of PLHIV interviewed, % by the experience of belonging to KPs

Life stories show that the experience of receiving social services at HIV-service NGOs, as well as the opportunity to work there and provide assistance to other PLHIV, can change the lives of people with HIV for the better:

"I know for sure that I will be able to stand for myself. I already read a lot, I know a lot about the laws. I began to study medical protocols. I have a job now. I am in the circle of communication, which I understand"

(Life Story, Donetsk)

Thus, cases of human rights violations against PLHIV (e.g., detention/arrest/imprisonment due to HIV status, coercion to disclose HIV status for realizing certain rights, including employment, health insurance, citizenship, etc.) are rare in Ukraine. About 4% of respondents

faced at least one of these violations in the 12 months preceding the survey.

The assertiveness of PLHIV (i.e., the willingness to actively defend their own rights and the rights of PLHIV in general, counteract S&D based on HIV status, provide support to other HIV-positive people) also remains low.

7 Stigma and discrimination for reasons not related to the HIV status

According to the results of previous studies, a significant number of PLHIV perceive not only the stigma related to HIV-positive status but manifestations of stigma and discrimination related to their belonging to key populations: drug users, sex workers, and representatives of the LGBT-community. This section describes data on the stigma against PLHIV related to their belonging to risk groups.

7.1. Drug users

About 40% of respondents said that they have experience injecting drugs use or regular

using such drugs as heroin, cocaine, and methamphetamine. At the same time, some of these respondents do not identify themselves as drug users (Fig. 7.1). Thus, the proportion of PLHIV who identified themselves as drug users (and answered the relevant block of questions) in the total sample reaches 33%. This KP is most represented in the sample and in the general population as a whole. This is due to the history of the HIV epidemic in Ukraine, during which HIV transmission related to injecting drug use has long dominated.

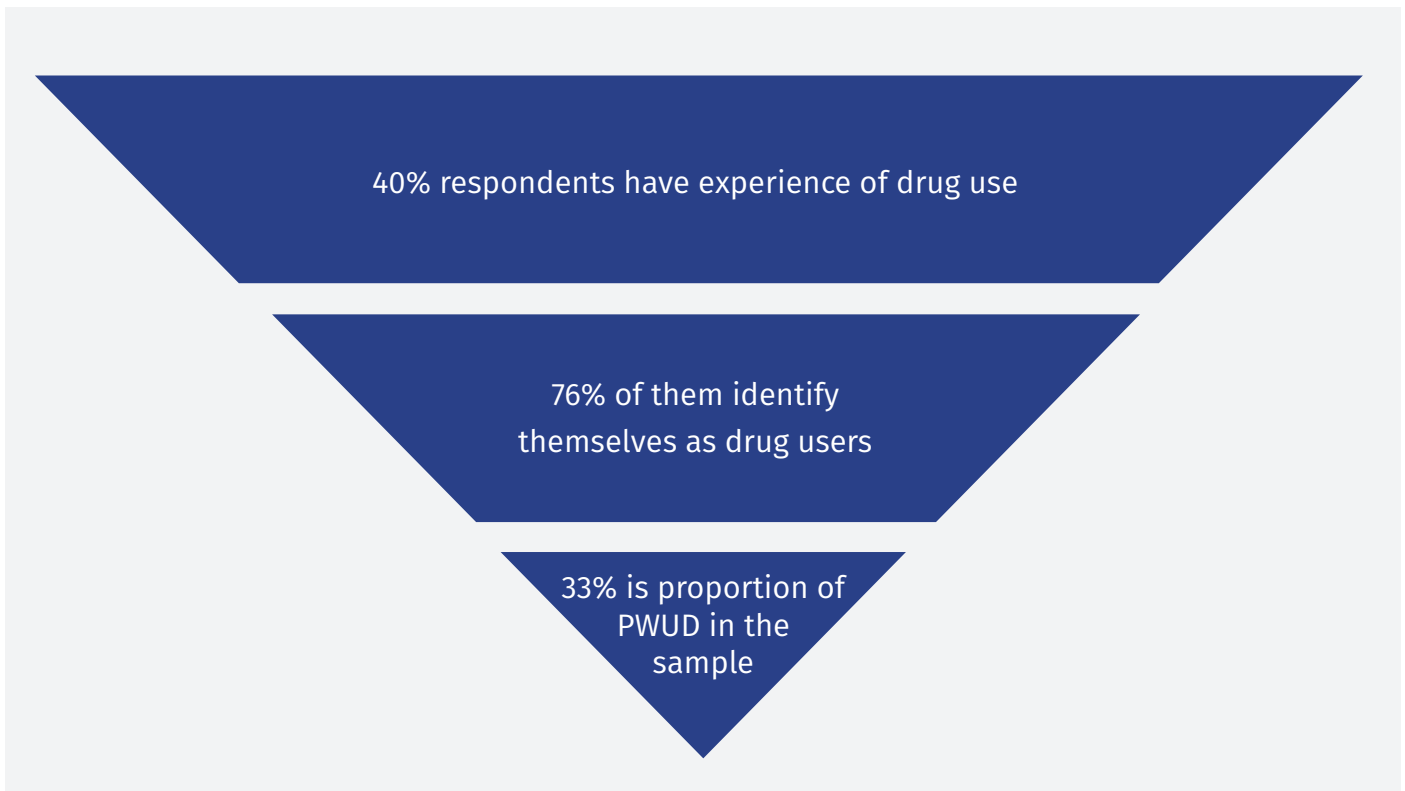
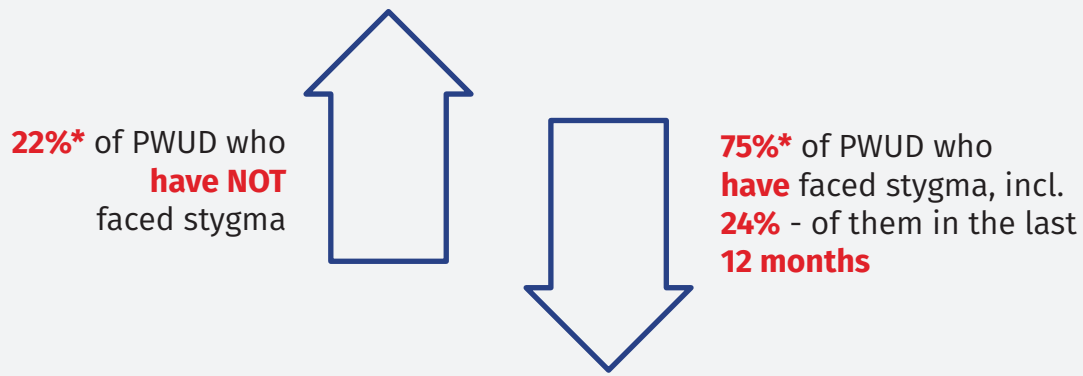


Fig. 7.1. Representation of drug users in the sample, %

Only 1 out of 5 PWUD interviewed (22%) said that they had never encountered stigmatization or self-stigmatization due to their belonging to this social group. Instead,

three quarters (75%) of respondents have such experience, including 24% of respondents have faced at least one of the S&D manifestations in the 12 months preceding the survey (Fig. 7.2).



*The sum of indicators is less than 100%, as a certain proportion of respondents refused to answer these questions

Fig. 7.2. Integral indicators of stigmatization of drug users, % to PWUD (n = 736)

The most common manifestations of S&D are verbal insults and discriminatory remarks related to PWUD, including from family members. The fear of seeking medical help,

including refusal of necessary medical services, also is commonly associated with self-stigmatization. Other forms of S&D are relatively rare (Table 7.1).

Table 7.1. Prevalence of S&D towards drug users, % to PWUD (n = 736)

	No	Yes		I do not want to answer
		Within the last 12 months	Earlier than 12 months	
Someone tried to harass you verbally	38	17	42	3
Family members made discriminatory remarks against you or gossiped about you	44	13	40	3
You have been afraid to seek medical help because someone may find out about your experience of drug use	61	9	27	3
You avoided medical care because you were afraid that other people would find out about your experience of drug use	64	7	26	3
You were not allowed to participate in family events	72	4	21	3
Someone influenced/harassed you physically or hurt you physically	75	4	18	3
Someone blackmailed you	83	4	11	2

Almost all PWUD interviewed (99%) said that members of the social environment know about their belonging to this group. Other

PWUD, family members, and friends are most often informed about this (Fig. 7.3).

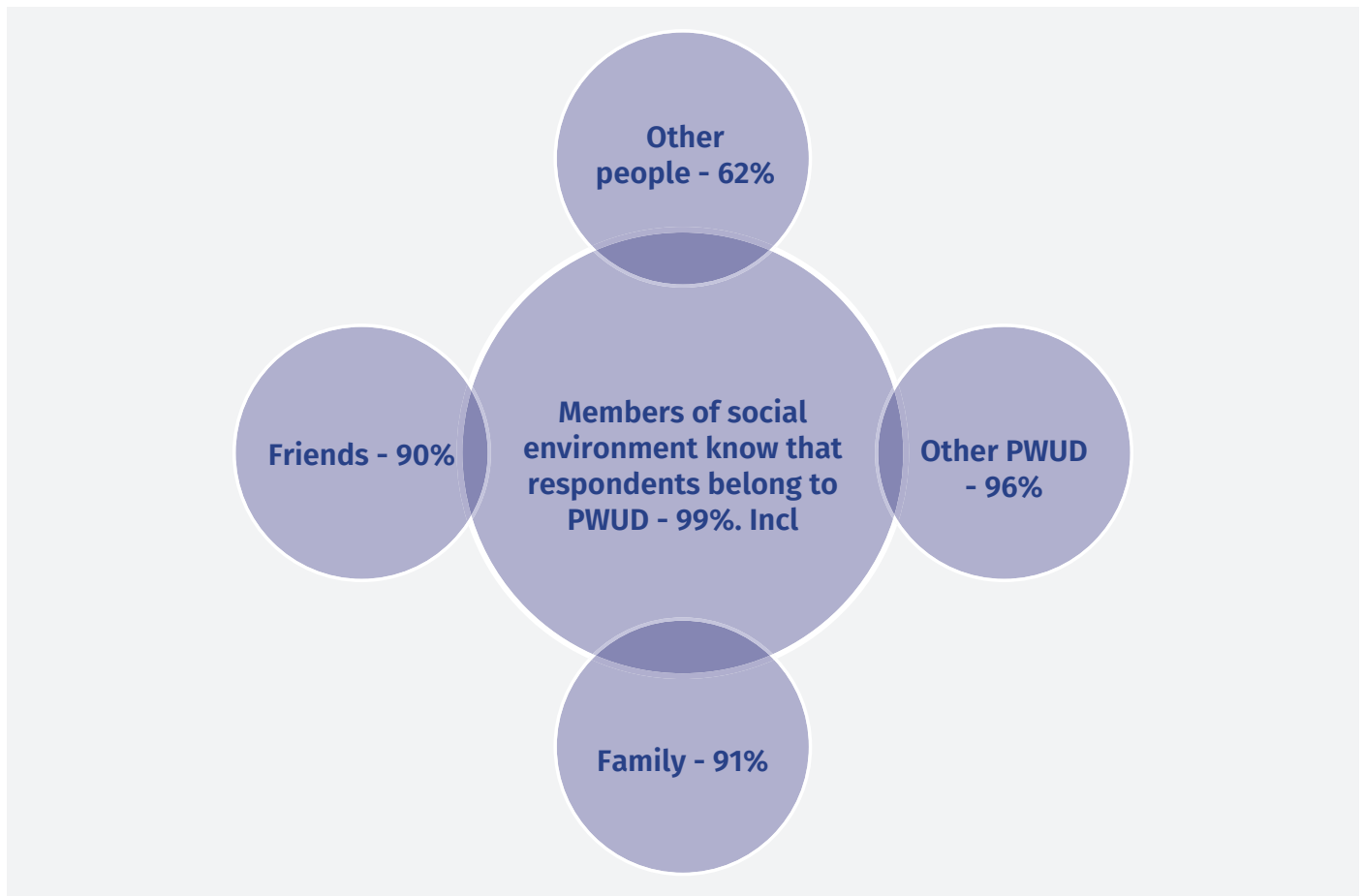


Fig. 7.3. Awareness of the social environment about the belonging of respondents to the group of drug users, % to PWUD (n = 736)

About 10% of respondents said that they belonged to a network or group/association/

organization/informal group of drug users.

7.2. Sex workers

About 8% of respondents said they had ever had sex in exchange for money or other benefits, including 14% of women and 2.5% of men. At the same time, a significant number of such respondents do not identify themselves as sex workers. Instead, some respondents stated that they considered themselves sex workers, although they declined to answer questions about the experience of sexual

contact for a fee. Thus, the proportion of PLHIV related to the group of sex workers based on affirmative answers to at least one of these questions reaches 8% in the total sample (Fig. 7.4). Most of them (83%) are women, 15% (28 persons) are men and 2% (3 people) refused to answer questions about their gender identity.

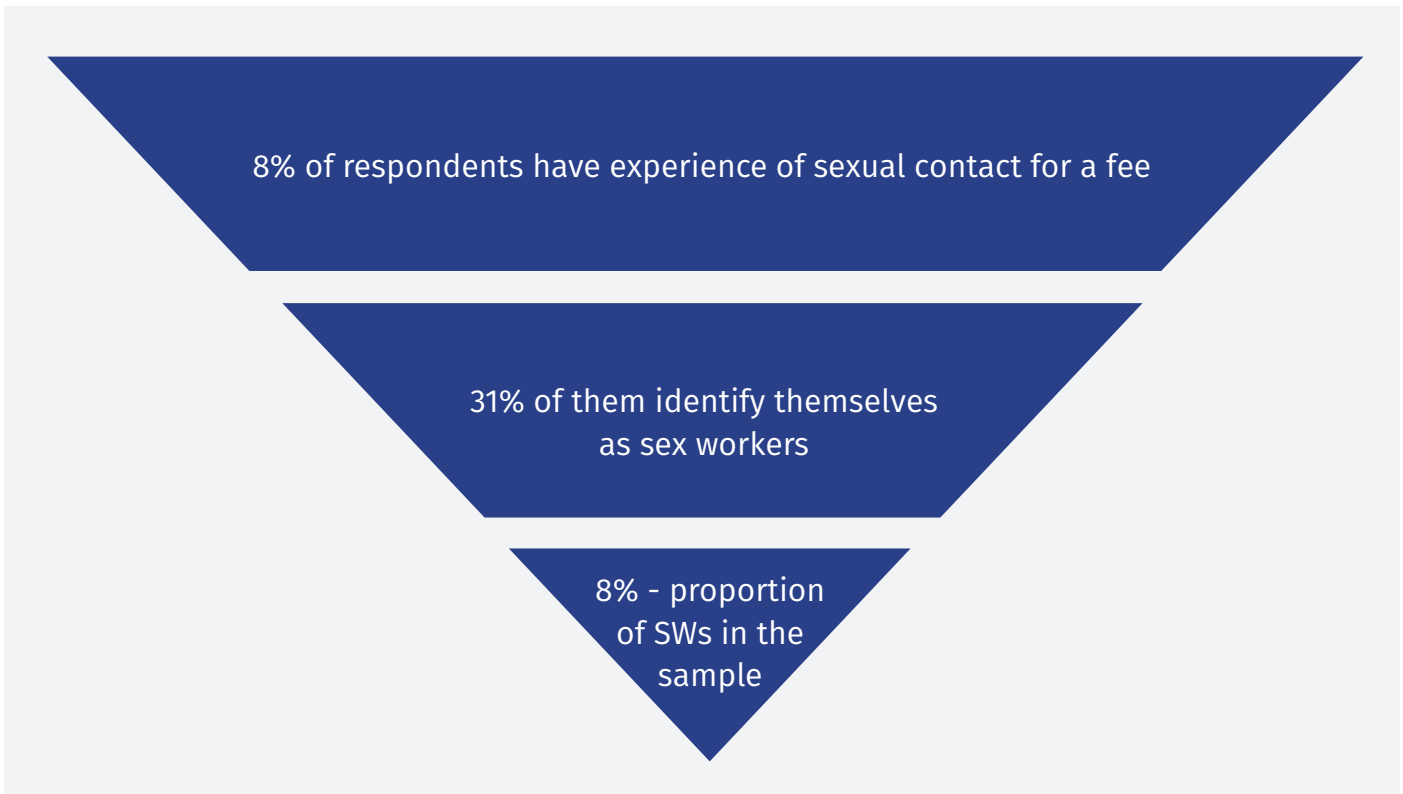


Fig. 7.4. Representation of sex workers in the sample, %

Slightly more than a third of sex workers interviewed (36%) said that they had never encountered stigma or self-stigma because of their belonging to this social group. Instead,

56% of respondents have such experience, including 15% of them have faced at least one S&D manifestation for 12 months preceding the survey (Fig. 7.5).

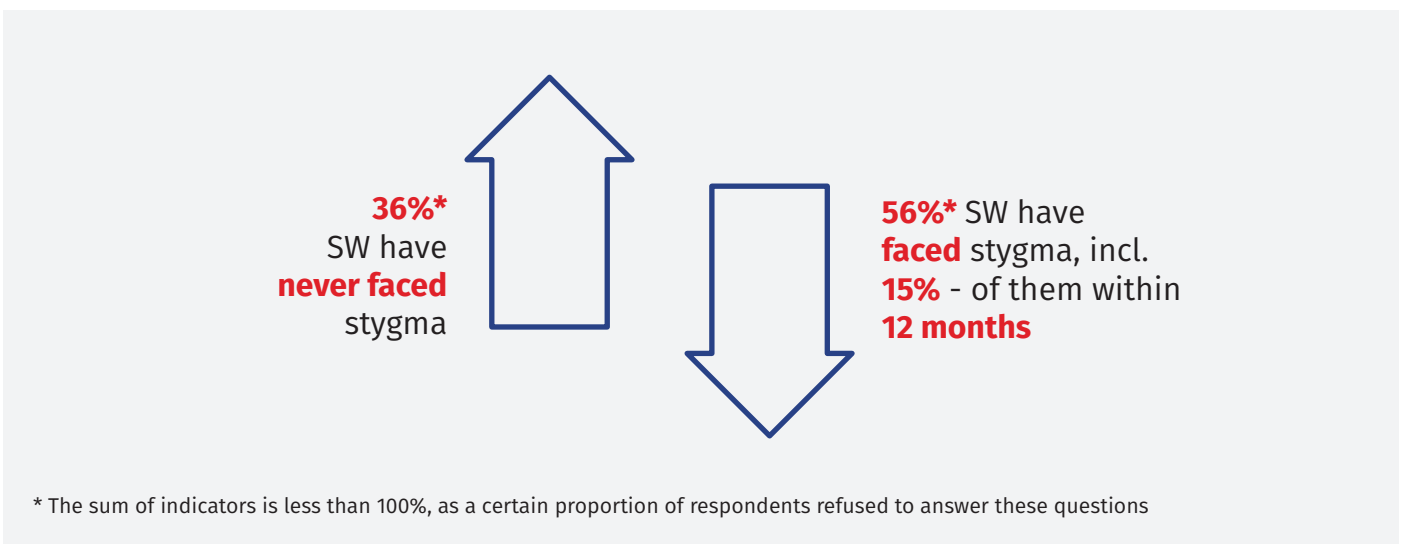


Fig. 7.5. Integral indicators of sex workers stigmatization, % to SWs (n = 184)

The most common manifestations of S&D are verbal abuse and blackmail. Discriminatory remarks by family members and physical

harassment/violence against SWs are also quite common (Table 7.2).

Table 7.2. Prevalence of S&D towards sex workers, % to SWs (n = 184)

	No	Yes		I do not want to answer
		Within the last 12 months	Earlier than 12 months	
Someone tried to harass you verbally	58	9	27	6
Someone blackmailed you	60	5	27	8
Family members made discriminatory remarks against you or gossiped about you	70	3	22	5
You have been afraid to seek medical help because someone may find out that you are a sex worker or provide sex services for a fee	70	5	17	8
Someone influenced/harassed you physically or hurt you physically	73	2	18	7
You avoided health care because you were afraid that other people would find out that you are a sex worker or provide sex services for a fee	76	5	14	5
You were not allowed to participate in family events	81	0	14	5

However, the ability of respondents to objectively assess the reasons for the stigmatization against themselves by members of the social environment, in some cases, is questionable. For example, a third of sex workers (18 out of 52 or 35%), who complained of ill-treatment by family members due to their experience in providing sex services, responding to another question, said that family members did not know about their belonging to the SW group.

Almost two thirds (63%) of sex workers interviewed said that at least one of their social environment members knew about their belonging to this group. Most of them are other sex workers; family members and friends were mentioned much less often (Fig. 7.6).

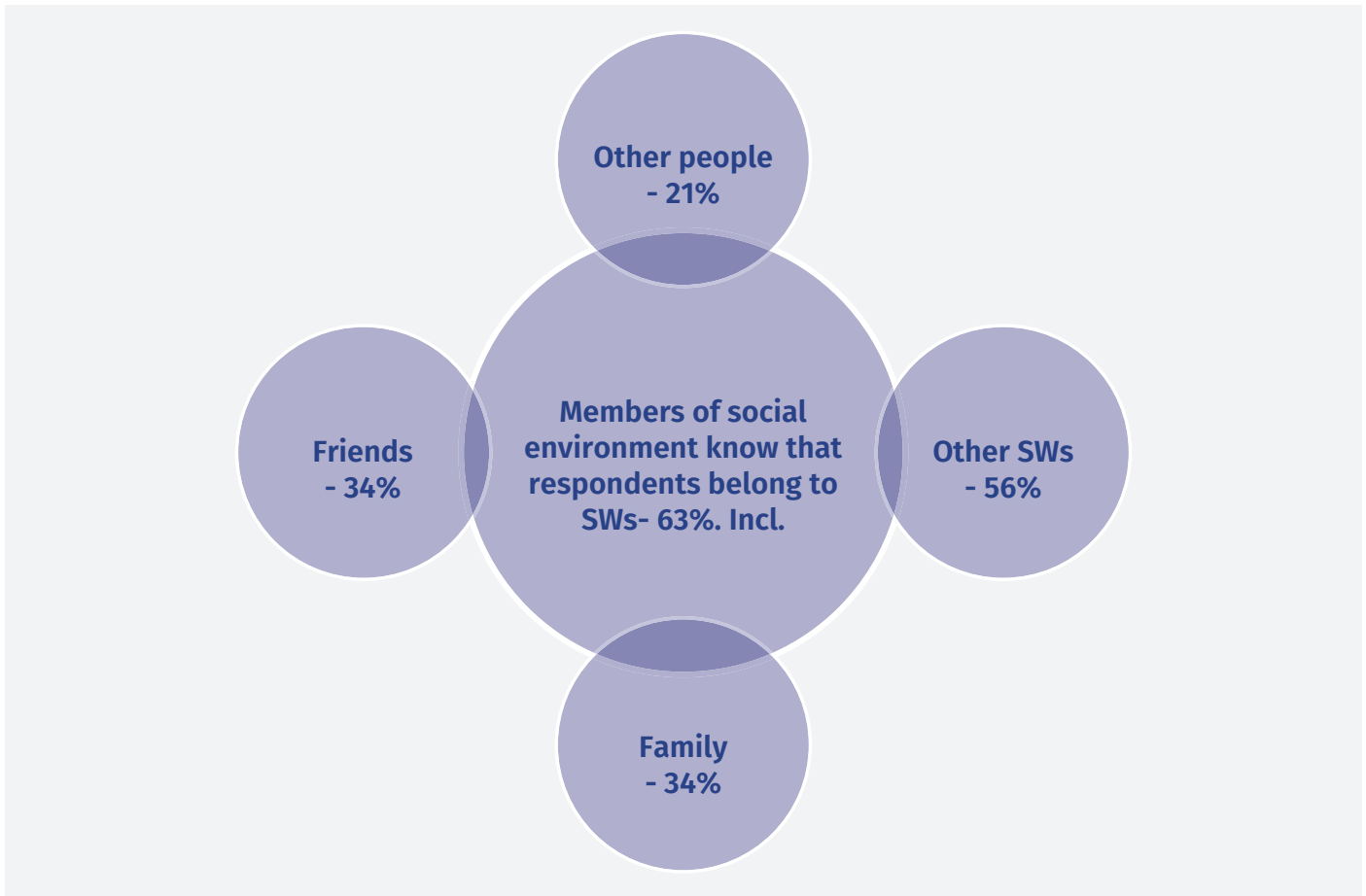


Fig. 7.6. Awareness of the social environment about the belonging of respondents to the group of sex workers, % to SW (n = 184)

About 7% of respondents said about their belonging to a network or support group for sex workers.

7.3. Representatives of the LGBT community MSM/gays

About 9% of men interviewed said that they identified themselves as MSM or gays. Respondents who stated that they did not belong to these groups were asked a clarifying question about the experience of sexual

contact with men. Five more people answered in the affirmative (1% of respondents who do not consider themselves MSM/gays). As a result, the proportion of respondents related to MSM/gays based on affirmative answers to at least one of these questions reaches 10% among men and 5% among the whole array of respondents (Fig. 7.7).

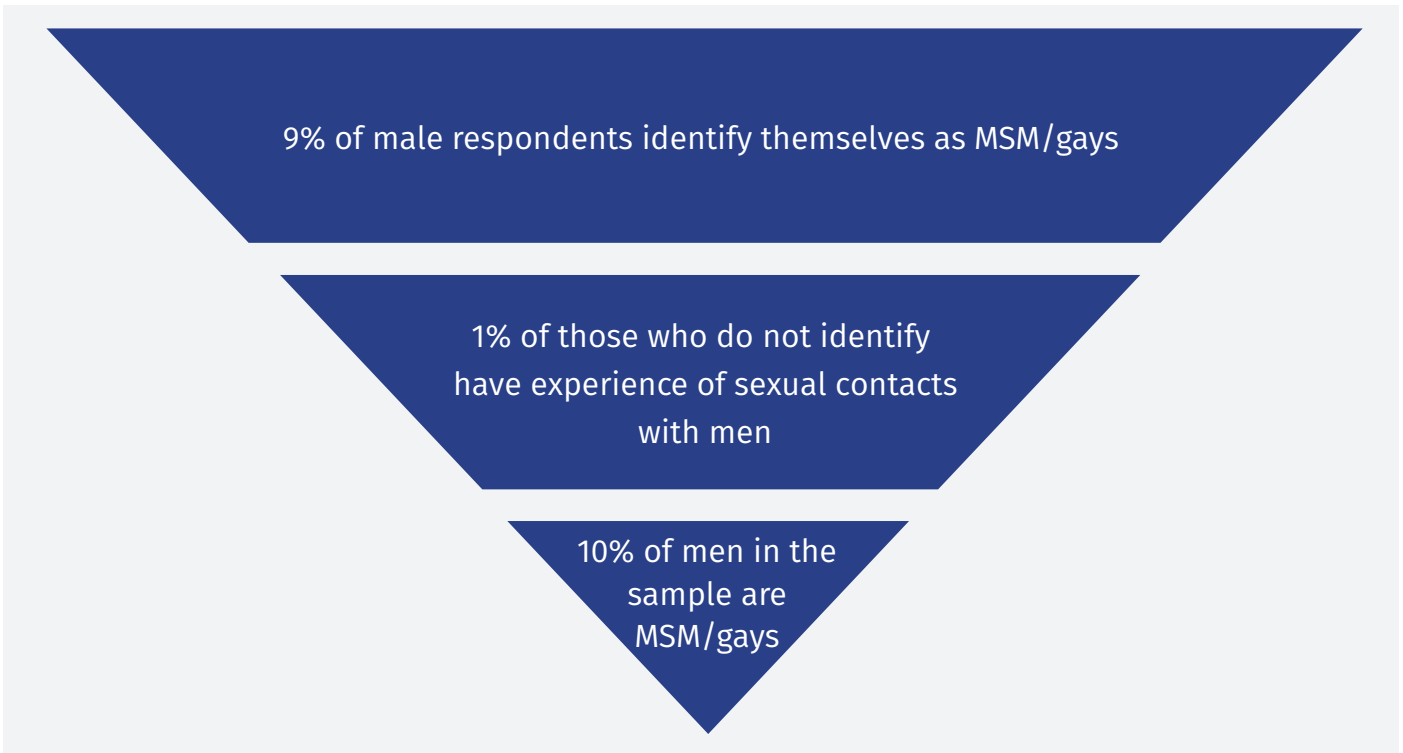


Fig. 7.7. Representation of the MSM/gay group in the sample, % to men (n = 1128)

Almost a quarter of MSM/gays interviewed (22%) stated that they had never faced manifestations of S&D (including self-stigma) because of their belonging to this social group. Instead, 64% of respondents have

such experience, including 26% of them have encountered at least one of the manifestations of stigma in the 12 months preceding the survey (Fig. 7.8).

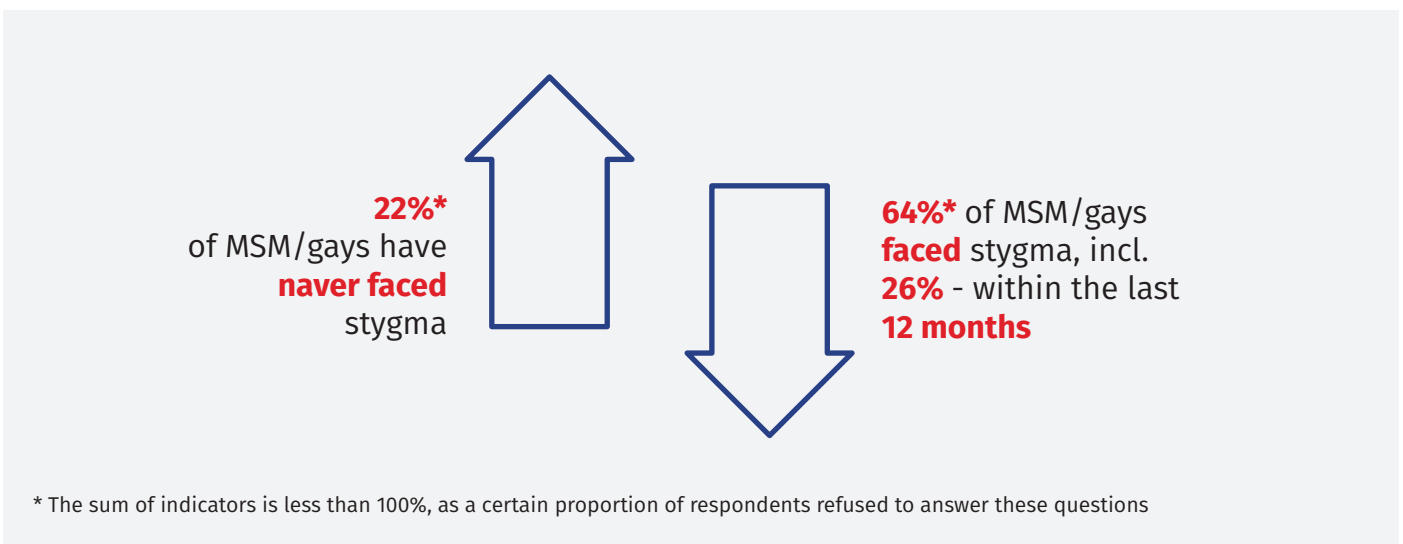


Fig. 7.8. Integral indicators of MSM/gay stigmatization, % to this group (n = 113)

The most common manifestations of S&D are verbal insults and discriminatory remarks, made also by family members. A quite common feeling is the fear to seek medical

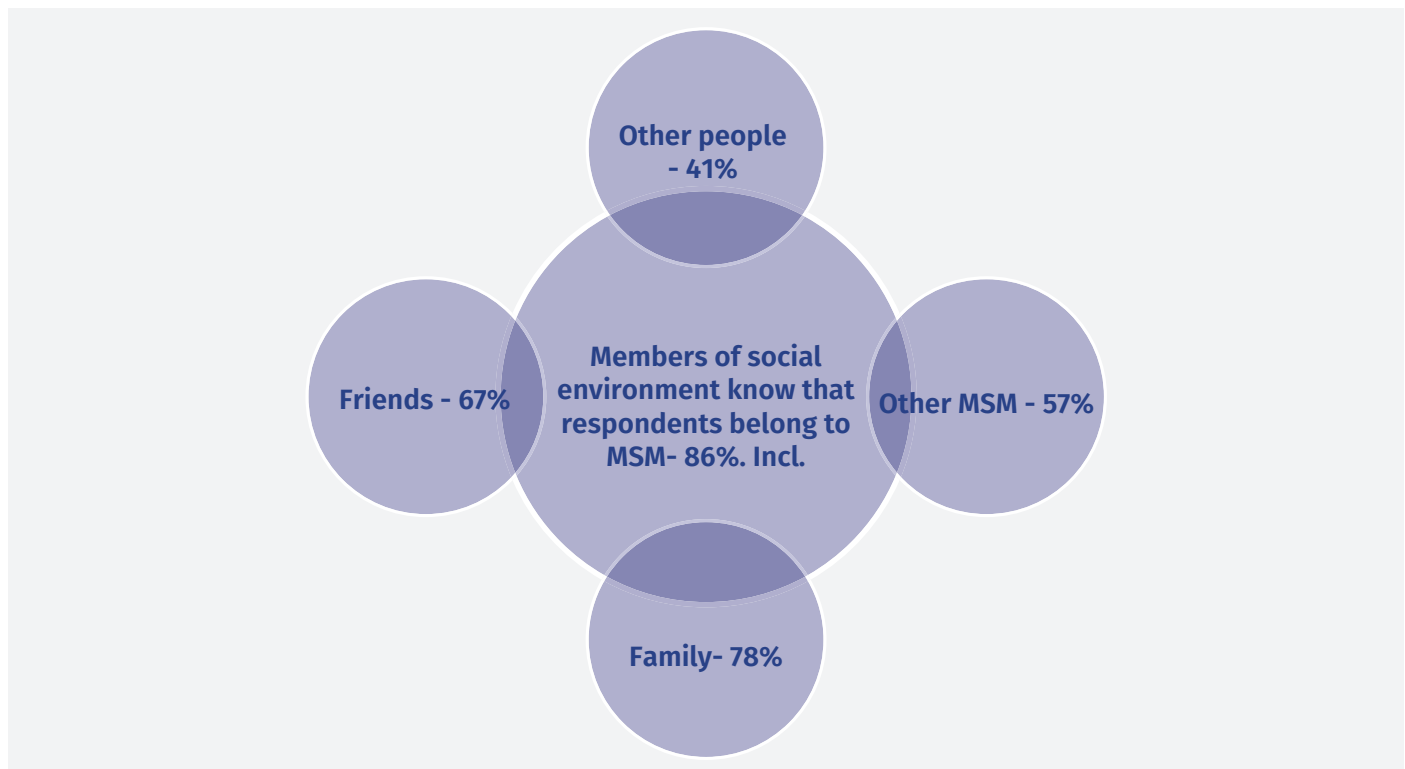
help due to expected stigma, discrimination, blackmail, and physical harassment/violence against MSM (Table 7.3).

Table 7.3. Prevalence of S&D towards MSM/gays, % to this group (n = 113)

	No	Yes		I do not want to answer
		Within the last 12 months	Earlier than 12 months	
Someone tried to abuse you verbally	47	15	24	14
Family members made discriminatory remarks against you or gossiped about you	54	7	26	13
You were afraid to seek medical help because someone might find out you were gay/had sex with men	60	9	19	12
Someone blackmailed you	64	8	17	11
Someone influenced/harassed you physically or hurt you physically	68	4	16	12
You avoided health care because you were afraid that other people would find out that you were gay/had sex with men	73	4	12	11
You were not allowed to participate in family events	75	3	11	11

The vast majority (86%) of MSM respondents said that at least someone from their social environment members knew about their belonging to this group. They are mostly family

members and friends; other MSM and other members of the social environment were mentioned relatively rarely (Fig. 7.9).

**Fig. 7.9.** Awareness of the social environment about the belonging of respondents to the group of MSM/gays, % to this group (n = 113)

About 29% of MSM respondents stated that they belong to a network or group/association/organization/informal group of gays/men who have sex with men, which is the highest rate compared to representatives of other social groups.

WSW/lesbians

A little more than 1% of women interviewed said that they identified themselves as members of the WSW or lesbian group. Respondents who stated that they did not

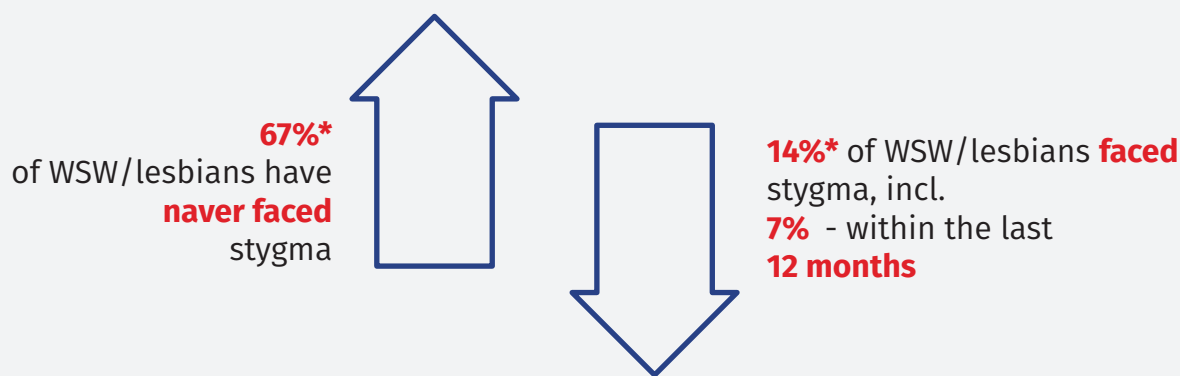
belong to these groups were asked a clarifying question about their experience of sexual contact with women. Other 2% of respondents who do not consider themselves WSW/lesbians were answered in the affirmative. As a result, the proportion of respondents related to the WSW/lesbians group based on the affirmative answers to at least one of these questions reaches 4% (43 people) among women or about 2% among the total number of respondents (Fig. 7.10).



Fig. 7.10. Representation of the WSW/lesbians group in the sample, % to women (n = 1069)

Two-thirds of WSW/lesbians interviewed (67% or 29 out of 43) said they had never experienced stigma or discrimination (including self-stigmatization and self-discrimination) because of their social group.

Instead, 14% of respondents (6 of 43 people) said about their experience of S&D, including 7% (3 of 43 people) who stated that they faced at least one S&D manifestation in the 12 months preceding the survey (Fig. 7.11).



*The sum of indicators is less than 100%, as a certain proportion of respondents refused to answer these questions

Fig. 7.11. Integral indicators of WSW/lesbians stigmatization, % to this group (n = 43)

Mostly 1-2 respondents said about their experience of each of the S&D manifestations mentioned in the questionnaire (Table 7.4).

Table 7.4. Prevalence of S&D towards WSW/lesbians, persons among this group (n = 43)

	No	Yes		I do not want to answer
		Within the last 12 months	Earlier than 12 months	
Someone tried to abuse you verbally	31	2	2	8
Family members made discriminatory remarks against you or gossiped about you	31	1	3	8
Someone blackmailed you	33	1	1	8
Someone influenced/harassed you physically or hurt you physically	34	1	0	8
You were afraid to seek medical help because someone might find out you were WSW/had sex with women	34	0	1	8
You were not allowed to participate in family events	34	0	1	8
You avoided health care because you were afraid that other people would find out that you were WSW/had sex with women.	35	0	0	8

Perhaps the relatively smaller number of S&D against WSW/lesbians indicates that in many cases others are not aware of their belonging to this group. In particular, less than half of

the respondents (44% or 19 people out of 43) stated that at least one of the representatives of their social environment knew about their sexual preferences (Fig. 7.12).

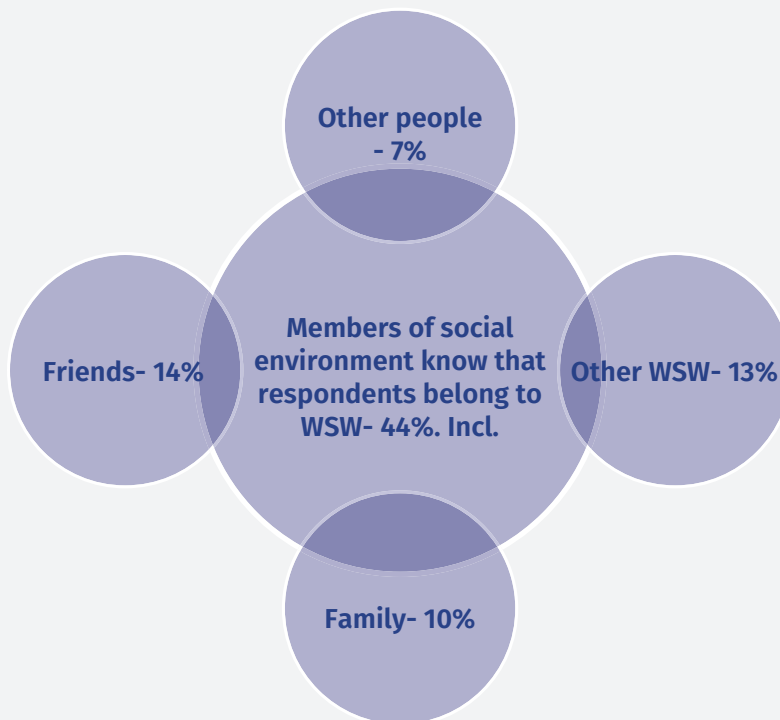


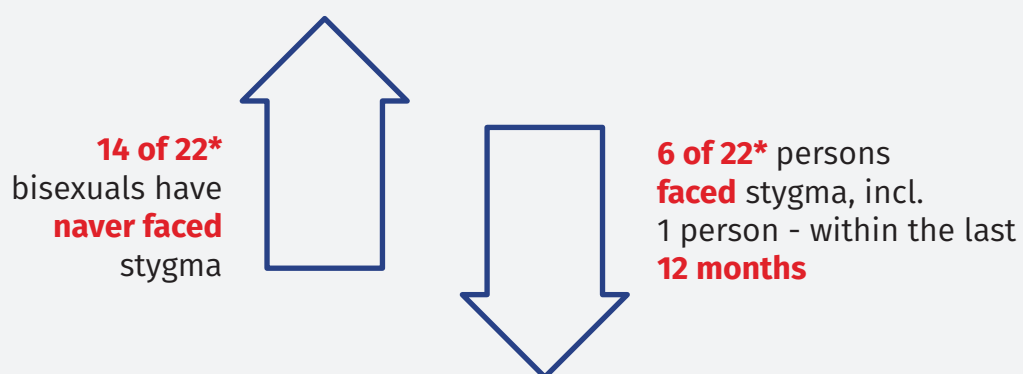
Fig. 7.12. Awareness of the social environment about the belonging of respondents to the group of WSW/lesbians, % to this group (n = 43)

About 7% of WSW interviewed (3 out of 43 persons) stated that they belonged to a network or a group/association/organization/informal group of lesbians/women who had sex with women.

Bisexuals

Twenty-two persons, representing 1% of the total number of respondents, identified themselves as bisexuals, including 13 women and 9 men.

Two-thirds of bisexuals interviewed (64% or 14 out of 22 persons) stated that they had never experienced S&D, including self-stigma, because of their belonging to this social group. Six respondents (27%) said about the experience of stigmatization, although only one case (5%) happened within the 12 months preceding the survey. Other cases of S&D were earlier (Fig. 7.13).



*The sum of indicators is less than n = 22 as a certain proportion of respondents refused to answer these questions

Fig. 7.13. Integral indicators of bisexuals stigmatization, persons among this group (n = 22)

No more than 2-3 respondents said about the experience of each of the S&D manifestations indicated in the questionnaire (Table 7.5).

Table 7.5. Prevalence of S&D towards bisexuals, people among this group (n = 22)

	No	Yes		I do not want to answer
		Within the last 12 months	Earlier than 12 months	
You were afraid to seek medical help because someone might find out you were bisexual/had sex with men and women	17	0	3	2
Someone tried to abuse you verbally	18	1	2	1
Someone blackmailed you	18	0	3	1
Someone influenced/harassed you physically or hurt you physically	19	0	2	1
Family members made discriminatory remarks against you or gossiped about you	19	0	1	2
You avoided health care because you were afraid that other people would find out that you were bisexual/had sex with men and women.	20	0	1	1
You were not allowed to participate in family events	21	0	0	1

Eighteen out of 22 respondents (82%) said that at least one member of their social environment knew about their sexual

preferences. Most often, they are other bisexual people and/or friends (Fig. 7.14).

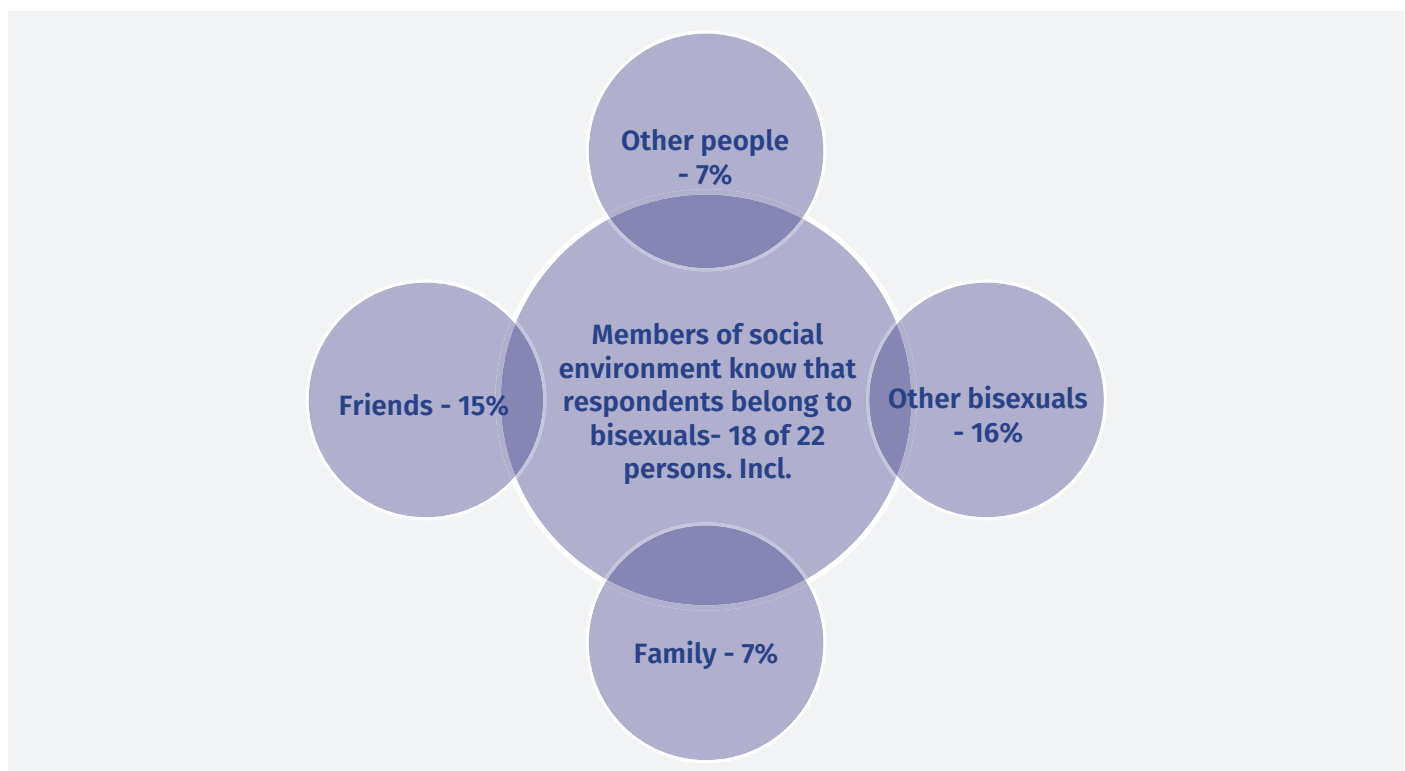


Fig. 7.14. Awareness of the social environment about the belonging of respondents to the group of bisexuals, persons among this group (n = 22)

One respondent (about 5%) said about belonging to a network or a group/association/organization/informal group of bisexuals.

Transgender people

Nine respondents (0.4% of the total number of respondents) were identified as transgender people. None of them identified themselves as transgender people, but 7 stated that their gender self-identification was different from the gender indicated on the birth certificate, and 2 refused to answer questions about their genders.

None of the respondents from the transgender group said about the experience of stigma and discrimination (including self-stigma) due to their gender identity.

Four out of 5 respondents who answered the relevant question stated that at least one of the representatives of their social environment knew about their gender identity (Fig. 7.15).

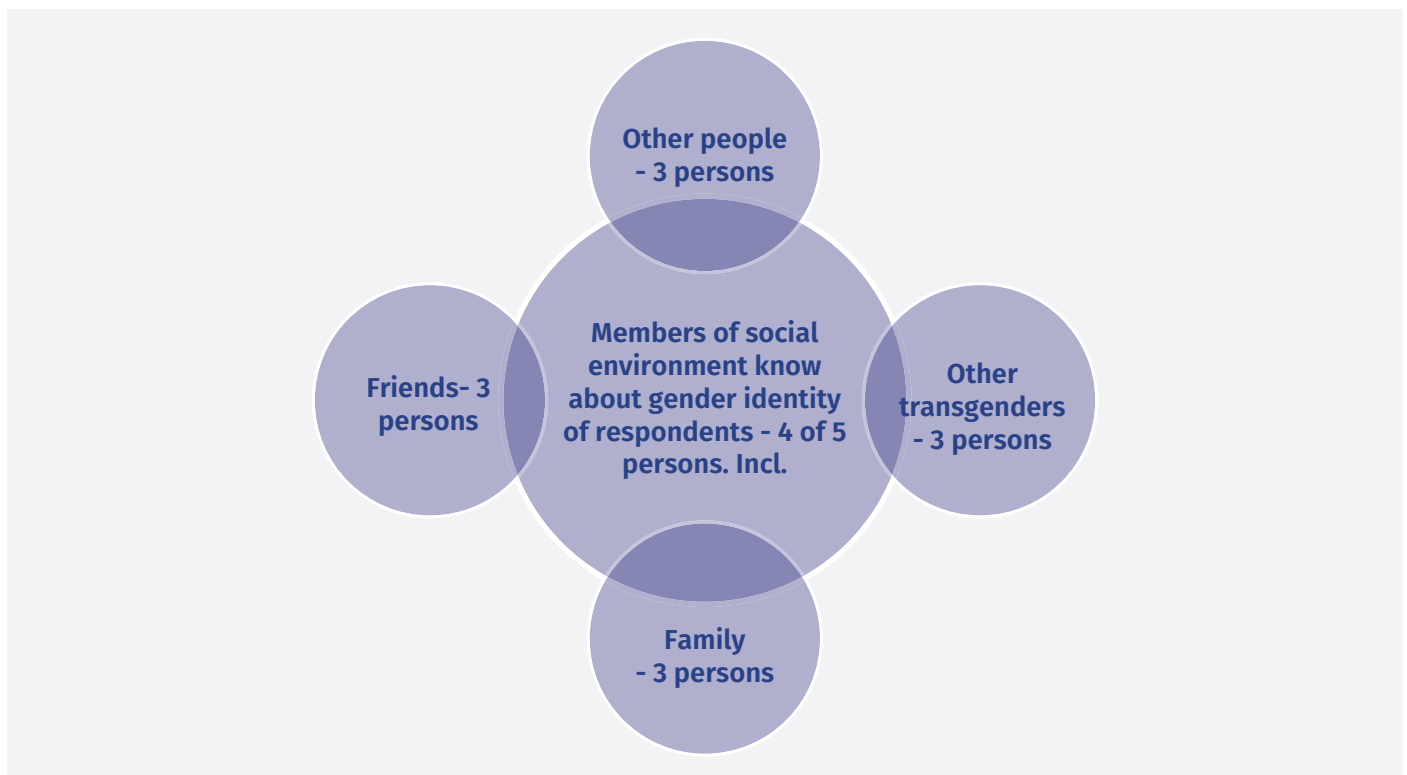


Fig. 7.15. Awareness of the social environment about the belonging of respondents to the group of transgender people, persons among those who answered this question (n = 5)

None of the respondents indicated that they belonged to a network or group/association/organization/informal group of transgender people or people whose gender differed from the gender indicated at birth.

Thus, the study results show that PLHIV, who belong to KPs, in many cases bear a double S&D burden because stigma based on HIV status combined with the stigma associated with belonging to socially condemned groups such as drug users, sex workers, and members

of the LGBT community. The results of the comparative analysis show that drug users often complained about manifestations of stigma and discrimination due to their belonging to the relevant social group; sex workers complain less often. At the same time, the frequency of S&D manifestations mentioned by the respondents correlates with the level of awareness of the social environment about the belonging of respondents to the relevant social group.

8 Awareness of HIV infection and sources of information

The level of awareness of respondents about HIV leaves much to be desired. The proportion of respondents who correctly answered some questions about various aspects of HIV prevention and treatment varies from 87% to

40%. The respondents are the least informed about HIV prevention using PrEP and post-contact prophylaxis, and they are the most aware of the need to use condoms during each sexual intercourse (Fig. 8.1).

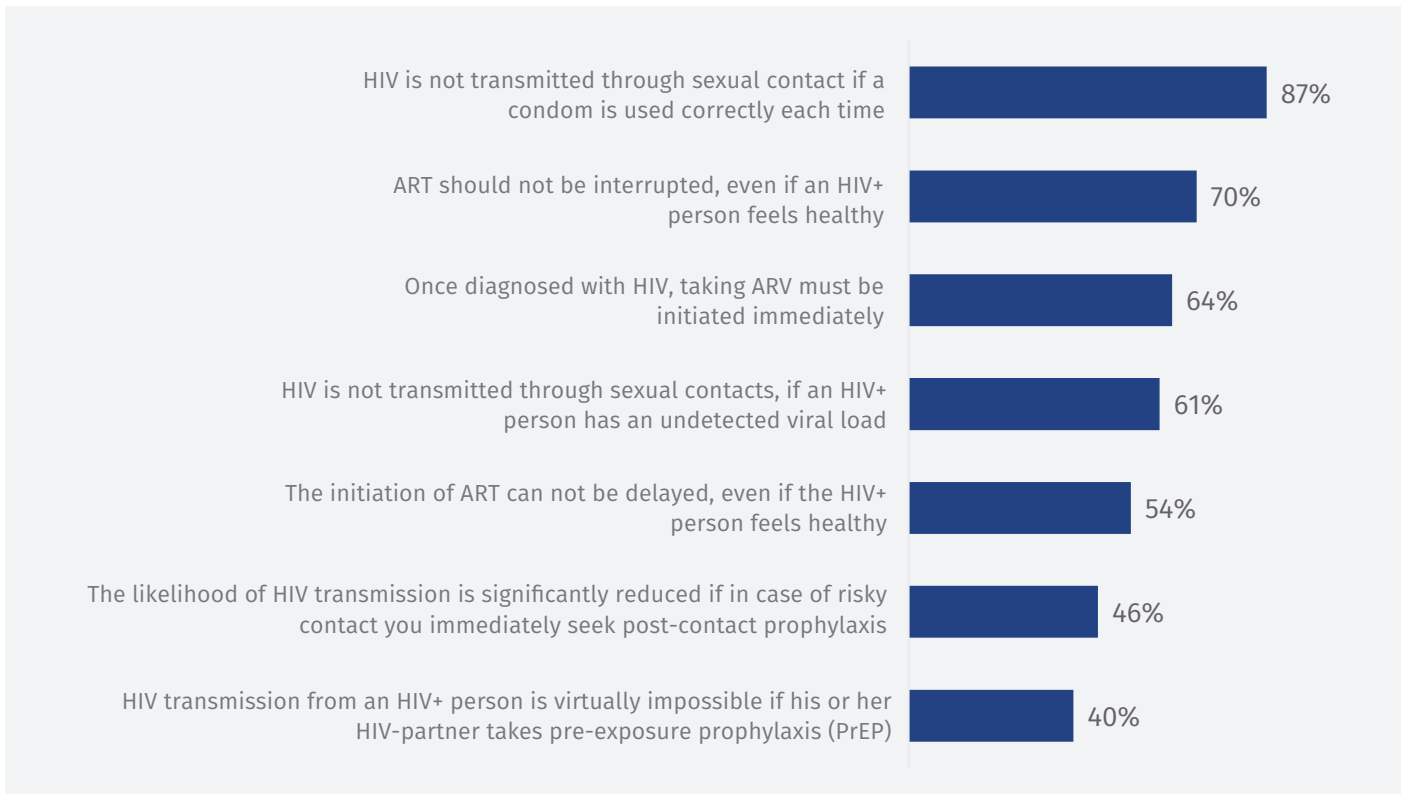


Fig. 8.1. Awareness of respondents about some aspects of HIV prevention and treatment, %

The proportion of respondents who answered all the questions correctly is 18% (Fig. 8.2).

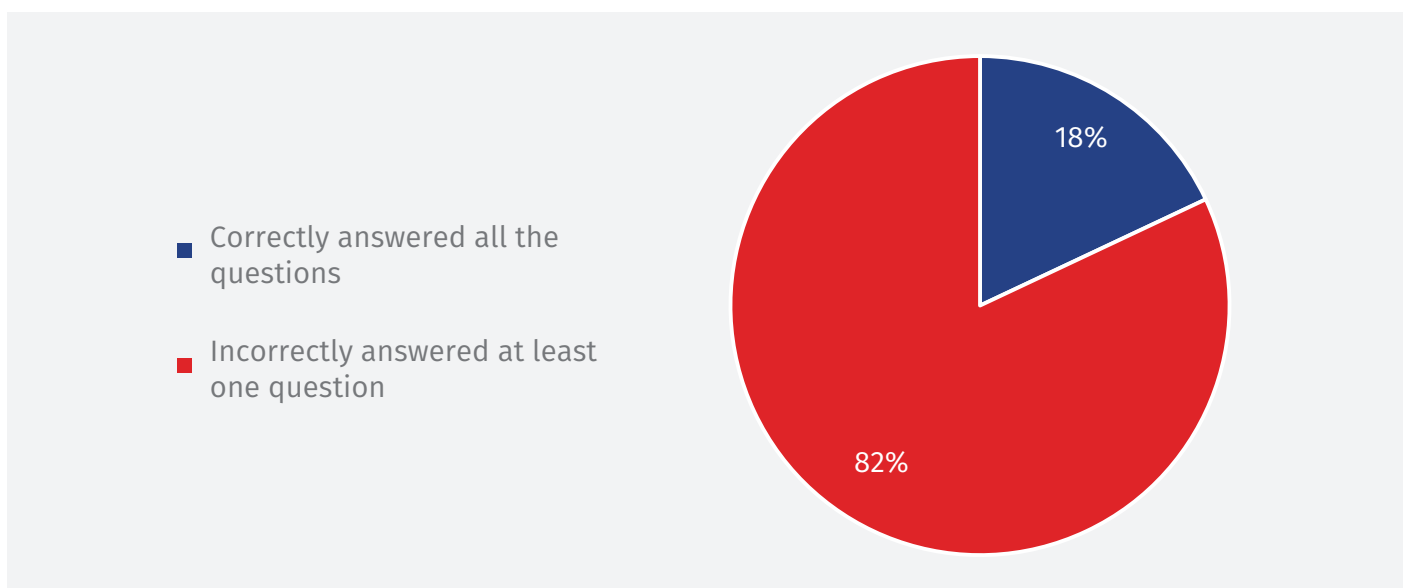


Fig. 8.2. The integral indicator of respondents' awareness of various aspects of HIV prevention and treatment, %

To some extent, the respondent's duration of life with HIV influences the level of knowledge. Thus, the integral indicator of awareness varies from 14% for respondents living with HIV for less than 2 years to 20% for PLHIV whose duration of lives with HIV exceeds 10 years. The latter are better informed about

the inadmissibility of ART interruption, as well as about the fact that HIV is not transmitted during sexual intercourse under the condition that the level of viral load is undetectable, as well as about post-contact prophylaxis and PrEP (Fig. 8.3).

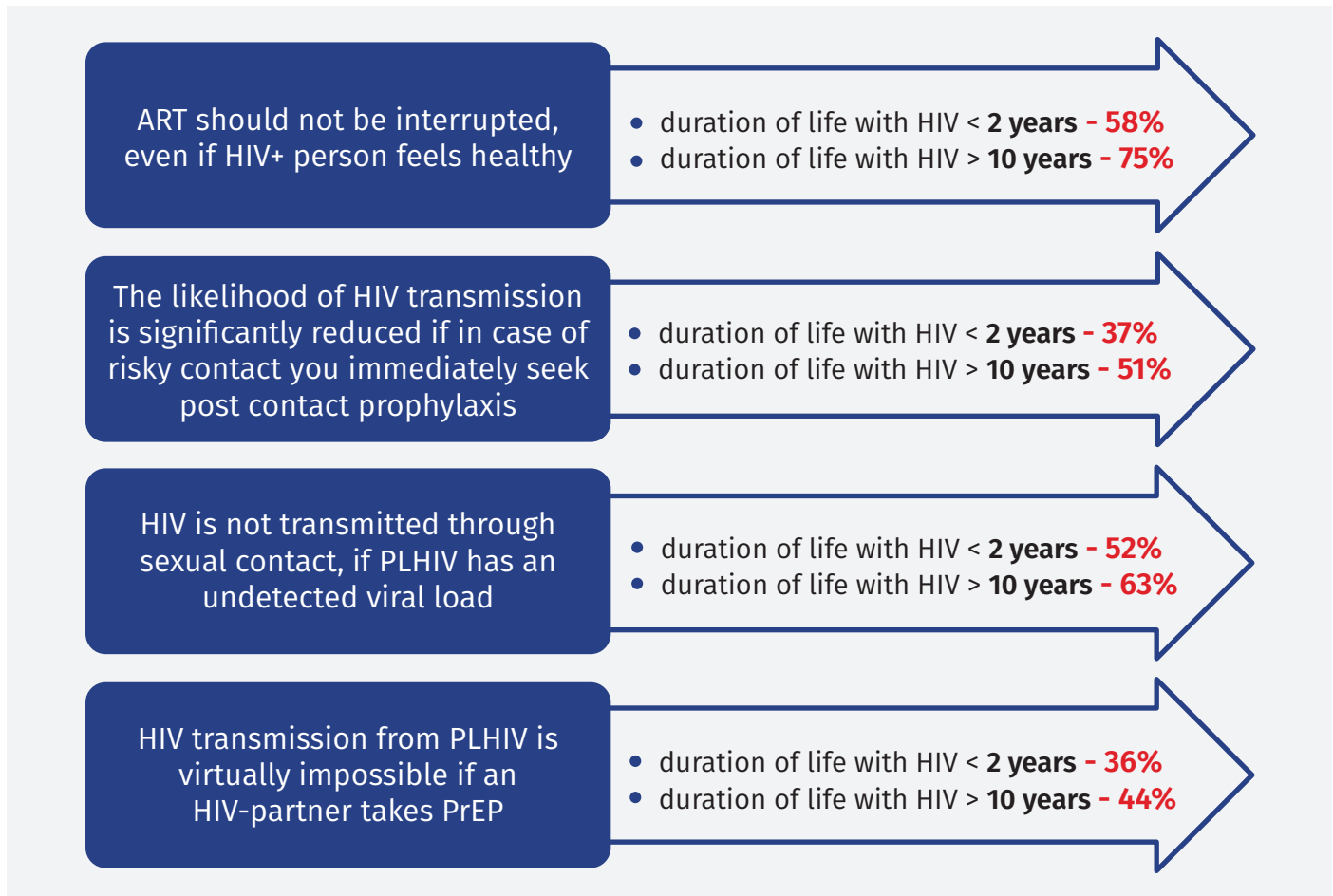


Fig. 8.3. Awareness of PLHIV about certain aspects of HIV prevention and treatment, by the duration of life with HIV

According to the popularity among respondents, sources of information on HIV can be divided into three groups.

1) The most popular are healthcare and social workers, from whom more than 90% of respondents receive or are ready to receive information.

2) The second group includes NGOs, government health agencies, family members, and other representatives of the social environment (friends, acquaintances, colleagues), as well as all types of media, ranging from the press and television to social networks and messengers. The proportion of respondents who use/are

ready to use these sources of information varies from 61% to 79%.

3) The least popular are such sources of information as religious leaders/organizations and scientific/educational institutions, to which about 40% of respondents are ready to consult.

It should be noted that the respondents are quite critical of various sources of information about HIV. In particular, despite the fact that a significant proportion of respondents receive information from the media, the level of trust in it is low and varies from 1.9 to 2.2 points on a five-point scale (Table 8.1).

Table 8.1. “Popularity” and the level of trust of respondents in various sources of information about HIV

Sources	Proportion of users, %*	Confidence level, average score **
HEALTHCARE WORKERS	96	4,4
SOCIAL WORKERS	92	4,5
PUBLIC ORGANIZATIONS, CHARITABLE FOUNDATIONS	79	4,1
TV	74	2,2
FAMILY, CLOSE ENVIRONMENT	71	2,9
STATE AGENCIES IN THE FIELD OF HEALTH CARE (MOH, NHSU, PHC)	69	3,7
NEWS OR ENTERTAINMENT SITES ON THE INTERNET	69	1,9
PRESS	68	2,1
SOCIAL NETWORKS	68	2,2
YOUTUBE VIDEO SERVICE	66	2,2
Radio (including Internet radio)	62	1,9
MESSENGERS	62	1,9
FRIENDS, ACQUAINTANCES, NEIGHBORS, COLLEAGUES	61	2,0
RELIGIOUS AND SPIRITUAL LEADERS AND ORGANIZATIONS	46	2,2
SCIENTIFIC AND EDUCATIONAL INSTITUTIONS, INDIVIDUALS	42	2,9

*Green color in the table highlights the high values of the relevant indicators: the high proportion of those who use a certain source of information and have a high level of trust in it

Orange color in the table highlights the average values of the relevant indicators: the average proportion of those who use a certain source of information and have an average level of trust in it

Red color in the table highlights the low values of the relevant indicators: the small proportion of those who use a certain source of information and have a low level of trust in it

**The average score was calculated as the arithmetic mean weighted on a 5-point scale, where 1 is not a reliable source of information, and 5 is a very reliable

Thus, the level of knowledge of the respondents about various aspects of HIV treatment and prevention of HIV transmission from PLHIV to HIV-negative partners is insufficient. The proportion of respondents

who gave correct answers to separate questions varies from 40% to 87%, while the integral indicator (the proportion of those who answered all questions correctly) is 18%.

DISCUSSION

The main characteristics of the respondents, including the distribution of respondents by gender, age, and key populations, corresponding to the features of the general population, which indicates the compliance with the set quotas during the recruitment of respondents and the representativeness of the data obtained for PLHIV aged 18 and older, who are residents of the government-controlled areas of Ukraine.

The data obtained also indicate several factors that increase the social vulnerability of PLHIV and may be overlapped with S&D based on HIV status and exacerbate it. Specifically, 43% of respondents belong to one or even a few KPs simultaneously, including 33% of them are drug users, 8% are sex workers, and 5% are MSM/gays. This can lead to double or multiple stigmas. The level of education of PLHIV interviewed is slightly lower than the general population (the proportion of respondents with higher education in the current survey was 18%, while among the general population, such people are usually about a third). Almost a third (31%) of respondents do not have any personal income (including some form of employment or social benefits). This situation leads to the problem of poverty, which is relevant for almost two-thirds of respondents. In particular, in the 12 months preceding the survey, 19% of respondents systematically encountered situations where they could not meet their basic needs (food, clothing, housing). Other 43% of PLHIV found themselves in such cases from time to time.

The current study was conducted using tools revised by international experts («PLHIV Stigma Index 2.0»), which has undergone significant changes compared to the instrument used in the survey's previous three waves. This significantly complicated the comparison of data in the dynamics. According to 4 waves of the study, correct comparison

of integral indicators was turned out to be impossible in many cases.

Analysis of data in the dynamics (where possible) shows a tendency to reduce the incidence of S&D based on HIV status in many areas of the PLHIV life.

The situation regarding the confidentiality of information on HIV status is gradually improving. This is reflected in both the gradual decrease in the proportion of PLHIV, who have at least once faced confidentiality violations in each of the survey (from 37% in 2010 to 18% in the current study) and significant differences in this indicator depending on the duration of life with HIV. In particular, at least one case of unauthorized disclosure of HIV status was reported by 22% of the respondents living with HIV for more than ten years, compared to 6% of PLHIV diagnosed less than two years ago. We can assume that a considerable part of the situations, which the respondents with a long duration of life with HIV talked about, occurred a relatively long time ago.

The frequency of stigmatization and discrimination manifestations against PLHIV by the social environment is gradually declining compared to previous surveys. However, the problem of S&D from the social environment is still relevant in Ukrainian society. At least one in ten respondents (11%) said about the experience of stigma and discrimination in the past year. In the retrospective experience of people living with HIV, S&D incidence of S&D from the social environment is even higher (27%). A data comparison according to two separate indicators, which have the highest unfavorable rating among respondents and were repeated in all four waves of the survey (gossip and verbal abuse/threats regarding PLHIV), shows a gradual decrease in the proportion of people suffering from these S&D manifestations. The

ratio of respondents who experienced gossip decreased from 30% in 2010 to 8% in the current survey. The proportion of PLHIV, who said about verbal abuse/threats from others, changed from 18% to 5%.

Manifestations of self-stigmatization and self-discrimination of PLHIV remain quite common. According to the current survey, 58% of respondents said that they had had a negative impact of HIV status at least on one aspect of their lives over the past year (e.g., ability to build relationships with the social environment, desire to have children, psychological well-being, including confidence, stress resistance, self-esteem, personal and professional development, etc.). Almost two-thirds (63%) of respondents mentioned at least one negative feeling about themselves (for example, senses of shame, guilt, uselessness, or «dirtiness» because of their HIV status). Inability to cope with negative emotions and manifestations of internal stigma are dangerous because they contribute to the choice of tactics of self-isolation, interpersonal distancing, closed nature, experiencing their problems alone. This creates a vicious circle effect for PLHIV and hampers adaptation to their life situation, inclusion in ordinary social practices, and strengthening resilience. One in three respondents (30%) has made at least one self-discriminatory decision in the last 12 months (e.g., not having sex, isolating themselves from family or friends, avoiding healthcare or social assistance, not getting jobs, etc.).

Although it is impossible to compare integral indicators in the dynamics, the analysis of individual indicators of self-stigmatization and self-discrimination, repeated in different waves of the survey, shows that the positive changes in this area are not significant. The situation with stigma and discrimination in health care, including HIV diagnosis and treatment, is gradually improving.

In particular, the **integral indicator of the PLHIV restriction in access to health services is declining** in each of the survey waves

compared to the previous one: from 22% in 2010 to 4% in 2020. At the same time, 17% of PLHIV faced any manifestations of stigma and discrimination from healthcare workers. The main S&D indications in healthcare facilities are avoidance of physical contact with PLHIV (12% of patients faced it in general HCFs and 5% of patients, in HCFs specialized in HIV treatment), slander and gossip (9% and 7% respectively), and disclosure HIV status without the respondent's consent (9% and 5%).

The situation with the observance of the PLHIV rights to anonymity, confidentiality, and medical secrecy is improving. Throughout all Stigma Index waves, there has been a decrease in the proportion of patients who stated that healthcare workers disclosed their HIV status without the respondent's consent: from 30% in 2010 to 6% in 2020. PLHIV's assessment of the confidentiality of medical records regarding HIV status is also improving. The proportion of respondents convinced of such records' confidentiality increased from 18% in 2010 to 51% in 2020; at the same time, the proportion of those who believe that these records are not confidential is reduced from 34% to 6%.

The study results show a tendency to **increase the proportion of PLHIV who were tested for HIV voluntarily and consciously** - from 69% in 2010 to 77% in 2020. Simultaneously, the balance of PLHIV, who were compulsorily tested, continues to decrease from year to year (from 10% in 2010 to 2% in 2020). It is important to note that the observance of the right of PLHIV to voluntary testing has an impact on further involvement in the HIV treatment system. Thus, among PLHIV who are currently being treated for HIV, there is a higher proportion of those who have decided to get tested for HIV on their own and voluntarily (78% compared to 72% among those who avoid treatment). Simultaneously, among those who avoid treatment, more those people were tested without their knowledge (17% compared to 12%).

In particular, drug users and sex workers, representatives of key populations face

violations of their rights to voluntary HIV testing more often than the respondents who do not belong to any of the key people. The proportion of the respondents who tested voluntarily and consciously is 73% among PWUD and 72% among SWs compared to 79% among PLHIV who do not belong to any KPs.

At the same time, the results of the study indicate **several gaps in HIV treatment**. In particular:

- Two-thirds (68%) of the respondents (excluding those born with HIV/infected with HIV in childhood) said they delayed the start of health care and HIV treatment after receiving a positive test result. The main reason for this was anxiety that other people would learn about the HIV status of the respondents (74% of the respondents who delayed treatment stated this) and their unwillingness to do anything about HIV (68%);
- Almost half (47%) of the respondents have ever interrupted HIV treatment. The main reasons why respondents delayed the retreatment were a fear that their HIV status would become known to other people (43% of those who interrupt treatment) and unwillingness to do anything about HIV (42%);
- Almost one-fifth (17%) of respondents had never received antiretroviral therapy;
- Among those who initiated ART, a quarter of the respondents (26%) did so more than two years after diagnosis;
- For 12 months before the survey, 28% of PLHIV, who had ever initiated ART, had problems with treatment adherence (interrupted therapy). The main reasons for interruptions (related to stigma) were unwillingness to do anything about their HIV status (44%), anxiety that someone would learn about HIV status (23%);

- 16% of PLHIV stated that they were not currently provided by health care and HIV treatment services;

- 14% of PLHIV involved in HIV treatment said that they had experienced stigma and discrimination from the staff of healthcare facilities where they received HIV treatment services in the last year. The main S&D manifestations from healthcare workers were gossip (7%), avoidance of physical contact (5%), and disclosure of HIV status by healthcare workers without the respondent's consent (5%).

Two percent of men and six percent of women interviewed said that in the past 12 months they had experienced at least one S&D manifestation in the sphere of **sexual and reproductive health**, including advice not to have children, the pressure to undergo sterilization, denial of contraception or family planning services, as well as recommendations for abortion, pressure related to choices of specific contraceptives, childbirth, breastfeeding, etc.

The study results showed that the **level of stigma and discrimination while receiving healthcare services for reasons not related to HIV exceeds the level of S&D in facilities specializing in HIV treatment**. Thus, half of the PLHIV interviewed (47%) stated that in the last 12 months, they had sought healthcare help for reasons not related to HIV infection (such as influenza, dental services, vaccination, injuries, etc.). At the same time, a fifth of them (21%) suffered from various forms of stigma and healthcare workers' discrimination. The most frequent manifestations of stigma and discrimination by healthcare workers were the avoidance of physical contact with PLHIV (12%) and gossip and disclosure of HIV status without the respondent's consent (9% each). At the same time, the representatives of key populations, mostly drug users (25%) and sex workers (28%), face S&D manifestations in healthcare facilities more often than respondents who do not belong to KPs (18%).

Cases of human rights violations against PLHIV (e.g., detention/arrest/imprisonment due to HIV status, coercion to disclose HIV status for the exercise of individual rights, employment, health insurance, citizenship, etc.) are rare in Ukraine. Four percent of respondents faced at least one of these violations in the 12 months preceding the survey.

The assertiveness of PLHIV (i.e., the willingness to actively defend their rights and the rights of PLHIV in general, to counteract S&D based on HIV status, provide support to other HIV-positive people) also remains low. In particular, only 1 in 6 respondents whose rights had been violated during the last year (15 out of 90 persons) tried to defend them. The proportion of respondents who stated that in the previous year they participated in specific activities aimed at overcoming S&D based on HIV status and/or providing support to PLHIV is 20%, including 17% of PLHIV who do not belong to key populations and 25-30% of representatives who belong to some KPs.

The survey results show that **PLHIV who belong to KPs in many cases bear a double burden of S&D** because of HIV-related stigma combined with the stigma related to belonging to socially condemned groups such as drug users, sex workers, representatives of the LGBT community. Representation in the sample of such social groups as WSW, bisexuals, and transgender people was insufficient to conduct a statistically correct analysis of the frequency of S&D manifestations against members of these groups. This is due to the small number of these groups in the structure of the general population. Accordingly, the issue of multiple stigmas against these social groups may be the subject of further research using a target sample.

Instead, the representation of drug users, sex workers, and MSM in the sample allows for a statistically valid analysis. The latter's results show that drug users most often than sex workers complained of stigma and discrimination due to their belonging to the relevant social group. Simultaneously, the

frequency of mentions of S&D manifestations, which the respondents had to face, correlates with the awareness of the social environment about the fact that respondents belong to the relevant social group. In other words, a more "tolerant" attitude towards sex workers depends on the fact that others do not consider them sex workers and therefore do not allow negative behaviors towards them.

The respondents' level of knowledge about various aspects of HIV treatment and prevention of HIV transmission from PLHIV to HIV-negative partners is insufficient. The proportion of respondents who gave the correct answers to some questions varies between 40% and 87%, while the integral indicator (the proportion of those who answered all the questions correctly) is 18%. In other words, 4 out of 5 respondents either share certain prejudices that may negatively affect their adherence to treatment (for example, believe that if they are feeling healthy, ART can be interrupted) or do not have the necessary knowledge to prevent HIV transmission to a partner (for example, they do not know about the existence of PrEP, not to mention the fact that they can persuade their partner to take it). Moreover, the insufficient level of knowledge is typical not only for PLHIV, whose diagnosis was made relatively recently, but also for the respondents who have been living with HIV for ten years or more.

**DISCLAIMER:**

The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination. In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower People living with HIV on human rights related to HIV. Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research participants interviewees have a right to anonymity and to confidentiality regarding their responses. In addition to the empowerment function, appropriate uses of the data are for advocacy and in order to inform stigma/discrimination reduction programming and policy responses in the national response to HIV.