Analytical report

The People Living with HIV Stigma Index

Всеукраїнська
Мережа
ЛЖВ

All-Ukrainian
Network of
PLWH

Kyiv 2014

Analytical report

The People Living with HIV Stigma Index

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The report is illustrated with photographs of members and employees of the All-Ukrainian Network of PLWH
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Kyiv 2014

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LIST OF ABBREVIATIONS

AC – analytical centre
ACO – All-Ukrainian charity organization
AIDS – acquired immune deficiency syndrome
ARV-therapy (ART) – antiretroviral therapy
FSWs/SWs – female sex workers engaged in sexual activity for payment
HIV – human immunodeficiency virus
IDUs – injecting drug users / respondents having experience in injecting drug usage
LGBT – lesbian, gay, bisexual and transgender people
MOH – Ministry of Health of Ukraine
MSM – men who have sex with men
NGOs – non-governmental organizations
PLWH – people living with HIV/AIDS
STIs – sexually transmitted infections
SWs – sex workers
VCT – voluntary counselling and testing for HIV
VGs – vulnerable groups

ACKNOWLEDGEMENTS

The mission of the All-Ukrainian Network of PLWH is to create conditions for realization of rights to life, support and self-actualization of people affected by HIV/AIDS epidemic.

It is not easy to realize these rights, especially when one deals with disdain, imperceptions and rejection both from the society and representatives of some occupational groups.

Nevertheless, we believe that the world without stigma and discrimination is possible. We believe that **value of an individual**, not depending on his/her race, nationality, religion, social status and belonging to any group, may be a priority for any of us and the society as a whole.

With this edition we present the findings of the second national social research on stigma, discrimination and violation of human rights of people living with HIV.

On behalf of the All-Ukrainian Network of PLWH, I would like to express our sincere gratitude to regional coordinators of the research: Petro Ilchenko, Oleksandr Aleksandrov, Denys Troshyn, Tetiana Afanisiada, Mariia Vovchanetska, Svitlana Andrieieva, Yuliia Mekh, Kateryna Derhachova, Olena Baieva, Oleksandr Hryn, Dmytro Tyhach, Maryna Lebedieva and members of their teams who managed to collect the required data in a timely and quality manner and provide relevant assistance to the respondents of this survey. I also express our gratitude to the team of Analytical Centre "Socioconsulting" and workers of the Central Office of the Network for the analytical, organizational and methodical assistance in the process of conducting the research and writing the report.

Volodymyr Zhovtyak,
Head of the Coordination Council of the All-Ukrainian Network of PLWH

INTRODUCTION

According to the data of the Ukrainian Disease Control Centre of the MOH of Ukraine, taking into account all officially registered cases of HIV among Ukrainian citizens since the start of the epidemic, as of 01 Jul 2013 134,302 people (294.8 per 100 thousand people) were under dispensary observation, out of which 27,181 people with AIDS diagnosed (59.7 per 100 thousand people). However, it is a generally acknowledged fact that the official data do not reflect a real scale of the HIV/AIDS epidemic in Ukraine, in particular the actual number of HIV infected people. Updated HIV/AIDS assessments show that at the beginning of 2013 there were 219 thousand HIV infected people in Ukraine aged 15 and older which made up 0.57 % of the total population in this age group. These data differ from the official statistics re number of HIV people being under dispensary observation at specialized health care facilities (129.1 thousand) at the end of 2012. Difference between these indicators proves that every second person living with HIV has been tested for HIV antibodies presence and is aware of his/her HIV-positive status[1].

People living with HIV/AIDS often face prejudiced attitudes towards them (stigma) and specific actions by other people limiting rights and freedoms of PLWH (discrimination). Many PLWH either are not aware of what their rights are and how to protect them, or do not believe their rights can be upheld at all. This problem is vital not only for Ukraine, since the HIV/AIDS epidemic has spread over all continents and in all countries. The ground for PLWH stigma and discrimination exists anywhere, where the population does not understand clearly enough the major routes of HIV transmission and how it is not transmitted, where various myths about this disease are widespread.

Counteracting these phenomena and protecting the rights of PLWH is the duty of non-governmental human rights organizations, including associations of people living with HIV. Such organizations have a lot of evidence of stigma and discrimination against their clients, as well as examples of successful protection of their rights. However, to change the situation for the better at national and international levels it is important to have not only examples, but also clear indicators of the spread of these negative phenomena at the PLWH community level.

For this purpose, in 2005, several reputed international organizations – the Global Network of People Living with HIV/AIDS, the International Community of Women Living with HIV/AIDS, the International Planned Parenthood Federation, the Joint United Nations Programme on HIV/AIDS (UNAIDS) – initiated an international research entitled the People Living with HIV Stigma Index. As of today, over 50 countries all over the world[2] have joined the research, one of them is

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[1] According to "HIV-infection in Ukraine / Information bulletin» (No 40, 2013).

[2] Based on http://www.stigmaiNdex.org

Ukraine represented by the All-Ukrainian Network of PLWH. In 2010, the Network of PLWH initiated the PLWH Stigma Index sociological study in Ukraine. It was conducted in September-October 2010 by ACO The All-Ukrainian Network of People Living with HIV jointly with Analytical Centre "Socioconsulting".

The uniqueness of this research is that it was conducted by and for people living with HIV using a uniform methodology. Due to this, data captured in a certain country can be compared with data from countries that are located on different continents and have their own cultural and ethnic traditions. In addition to this, the research methodology provided an option of counselling and psychological support to survey respondents and, if necessary, their referral to human rights advocates, health care professionals or social workers able to render qualified assistance.

In 2013, the All-Ukrainian Network of People Living with HIV and Analytical Centre "Socioconsulting" in partnership implemented a repeated study in Ukraine using the same methodology. Its goal was to collect systematized, documented data on the level, spread and forms of stigma and discrimination based on a unified questionnaire as opposite to a common practice of documenting and using for advocacy only separate cases of stigma and discrimination, and human rights violation. Its implementation was aimed to create at the national level a bulk of reliable data (in terms of the cause) and to develop recommendations for further steps to overcome stigma and discrimination (changes in the legislation, programme interventions), to conduct analysis of dynamics if compared with the similar research conducted in 2010.

GOAL, OBJECTIVES AND METHODOLOGY OF THE RESEARCH

The goal of the research was to collect information and to identify the dynamics of stigma and discrimination, realization of human rights according to PLWH's experience if compared to the similar research of 2010.

To achieve the set goal, the following objectives were carried out:

- to study the spread of various forms of HIV-related stigma and discrimination against PLWH;
- to improve the evidence base for impact on the policy with respect to PLWH and for the implementation of programmes aimed at protecting their rights and combating HIV-related stigma and discrimination;
- to determine the dynamics of stigma and discrimination manifestations against PLWH compared with the similar research conducted in 2010.

ASSUMPTIONS OF THE RESEARCH

1. The level of stigma and discrimination against HIV-positive people from other people has decreased if compared to the similar research conducted in 2010.
2. HIV-related limitation in access to at least one of social or health care services has decreased if compared with the previous research.
3. A number of cases of discriminating attitude against PLWH has decreased if compared with the previous research.

RESEARCH METHODS

The same way as in 2010, to analyse the situation in an objective and comprehensive manner, an integrated approach to empirical data collection was applied: standardized interviews with PLWH were complemented with life stories told by some respondents.

QUANTITATIVE RESEARCH

The main data collection method was standardized interviews with PLWH using the methodology and the questionnaire developed by the International Planned Parenthood Federation (IPPF), the Global Network of People Living with HIV/AIDS, the International Community of Women Living with HIV (ICW) and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Application of the standardized People Living with HIV Stigma Index questionnaire allows to:

- collect information directly from PLWH regarding their experiences of stigma and discrimination;

- trace changes;
- provide facts, confirmation for initiating policy changes and implementing programmes to combat stigma and discrimination against PLWH. The Index also focuses on sexual and reproductive health and rights of people living with HIV.

The original questionnaire used in the research in 2010 was slightly revised to eliminate drawbacks identified in the course of the previous study. At that, questions related to major forms of stigma and discrimination remained unchanged to allow valid comparisons of stigma indicators in dynamics for the period of 2010-2013, and at national and international levels. Instead, social-demographic block questions (e.g. re respondent's marital status, education, type of employment, type of location where s/he lives, experience of belonging to vulnerable groups, etc.) and a list of answers to them were elaborated to adapt them to the national specifics which enabled to interpret the data obtained in a more adequate way. In addition, taking into account analysis of the 2010 research findings, the questionnaire was complemented with follow-up questions, for instance, regarding the circumstances under which a respondent had been discriminated at the labour market.

Standardized interviews were conducted in the form of a face-to-face conversation between two people having the same diagnosis of HIV infection: the interviewer and the interviewee.

Most interviewers were social workers or activists of regional branches of the All-Ukrainian Network of PLWH, specially trained by professionals from the AC Socioconsulting.

Advantages of such approach:

- creating an atmosphere of trust between the interviewer and the interviewee, not distorting the information;
- HIV community representatives gaining new skills in conducting interviews (recruiting, interviewing, documenting);
- formation in the PLWH community of feeling and understanding of "data ownership and liability for the results" – PLWH become not a research object, but rather a research subject.

Interviewees were people living with HIV. They include both members of the All-Ukrainian Network of PLWH and those who are not clients of this NGO. The latter were recruited at AIDS centres, TB medical facilities, drug users rehabilitation centres and other health care facilities (e.g. infectious diseases hospital, infectious diseases room). Respondents' age – 17 and older. In total 1500 respondents were interviewed.

QUALITATIVE RESEARCH

The results of the quantitative component of the research were complemented with the information obtained using qualitative methodology – in-depth interviews conducted using the method of "life stories" with PLWH who have been stigmatized. This enables to illustrate the data collected during the survey, to study in more depth the essence of discriminatory actions against PLWH and the ways to combat them. In-depth interviews were conducted and documented according a single guide, identical to the one used in the 2010 research.

The guide's questions were related to the following issues:

- description of the case when a respondent was subject to (experienced) stigma and discrimination because of his/her HIV status;
- respondent's feelings about the situation;
- actions of PLWH to protect their violated rights;
- further development of the situation, consequences for PLWH and their families.

Every interviewer selected among his/her respondents the most illustrative situation in which a respondent experienced discrimination in various areas of life due to his/her HIV status. With further respondent's consent, the interviewer then conducted an in-depth interview using the "life story" method. In total 58 interviews were conducted.

SAMPLING

The sampling covers all major socio-economic areas, each of them representing by several regions, therefore it is nationwide. According to epidemiological surveillance data, the absolute number of infected people and the rates of HIV spread are the highest in southern and eastern areas of Ukraine. Therefore the quotas for Odesa and Donetsk regions representing the said areas were increased (Table 1).

Table 1. **Sampling realization**

Area	**Structured interviews**		**Flexible interviews**	
	Planned	**Conducted**	**Planned**	**Conducted**
AR Crimea	100	100	4	4
Donetsk region	300	300	10	11
Ivano-Frankivsk region	100	100	4	4
Kyiv region	100	100	4	4
Kirovohrad region	100	100	4	4
Lviv region	100	100	4	4
Odesa region	200	200	8	8
Sumy region	100	100	4	4
Kharkiv region	100	100	4	4
Kherson region	100	100	4	3
Cherkasy region	100	100	4	4
Kyiv city	100	100	4	4
TOTAL	**1500**	**1500**	**58**	**58**

Another characteristic feature of the sampling is that it is focused on a particular target group – PLWH. This is not a representative sampling, since the exact data on the number of PLWH living in the country and exact parameters of the target group are unknown (due to specific epidemic trends, voluntary nature of testing and efforts of people themselves to conceal their HIV status). Available statistical data on PLWH reflect the main parameters of the totality of people registered with the dispensary at the Ukrainian AIDS Prevention and Control Centre. According to the expert data, this is only about one third of the total number of people living with HIV/AIDS in Ukraine.

At the same time, the sampling includes people of different age, sex, education level, employment and length of living with HIV/AIDS. Due to the large sampling size the data collected characterize precisely enough the situation concerning the observance of the rights of people living with HIV/AIDS in Ukraine.

IMPLEMENTATION OF THE FIELD PHASE OF THE RESEARCH: MAY – JULY 2013

EMPIRICAL DATA ANALYSIS METHODS

1. Calculation of descriptive statistics – univariate and bivariate distributions of interviewees' responses to the questionnaire questions. Key characteristics of bivariate distributions analysis:

- demographic (sex, age);
- length of living with HIV;
- belonging to key social groups (IDUs, SWs, LGBT, migrants, prisoners).

2. Comparative analysis of data of 2010 and 2013.

3. Calculation of integral indicators referring to stigma and discrimination against PLWH based on bulks of data of 2010 and 2013:

- PLWH stigma index in health care;
- PLWH stigma index in social area;
- PLWH stigma index from the social environment;
- PLWH self-stigmatization index;
- PLWH self-discrimination index;
- index of disclosure of HIV status.

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

5. Systematization and primary content analysis of in-depth interviews.

LIMITATIONS OF THE RESEARCH

The main data analysis difficulties are associated with peculiarities of understanding (or lack of understanding) by certain part of respondents of a number of terms (e.g. stigma, discrimination), and their insufficient legal literacy. As a result respondents did not always adequately assess which expressions/actions might be considered stigmatizing and discriminating, which, in particular, was quite vividly demonstrated in some life stories. This resulted in a lack of logic in answers to questions on the questionnaire or a necessity to interpret certain indicators with care.

Statistically valid data analysis was impeded by insufficient number of respondents in some groups (including, SWs, migrants, LGBT).

At the same time, an acceptable research methodology and a significant sampling size give grounds to regard the obtained stigma and discrimination indicators as reliable and trustworthy.

ETHICAL ISSUES

Collection, storage and analysis of empirical data of the research were based on the observance of ethical standards and protection of the research participants' right to voluntariness, anonymity and confidentiality. PLWH aged 17 and older were invited to participate in the research. Before the interview, each respondent was offered to read the information sheet which described the history and objectives of the research, and conditions of participation in the survey. In case of oral consent, respondents had to complete the informed consent form, receiving instead a filled in and signed by an interviewer Obligation of Confidentiality. The questionnaire did not include any data relating to respondents' names, addresses or other contact information.

MAJOR CHARACTERISTICS OF INTERVIEWED PLWH AND THEIR HOUSEHOLDS

1.

MAJOR CHARACTERISTICS OF INTERVIEWED PLWH AND THEIR HOUSEHOLDS

1500 respondents were interviewed in the survey, evenly divided by sex (50% – men, 50% – women).

Comparative analysis of the data obtained shows that people of reproductive and capable of work age (30-39 years old) prevail among interviewed PLWH as it was before. Nevertheless the respondents' group has "matured" somehow for the last three years, a portion of interviewed PLWH aged 25-29 remains large enough (18%) (Table 1.1). The smallest group of PLWH in the survey sampling is aged 15-19 (4 people in total, out of them 1 man and 3 women).

As before, the number of women is higher among relatively young respondents (aged 15-29), while there are significantly more men among 30+ interviewees. Such situation is most likely caused by the policy of VCT conducted by women's health clinics when registering pregnant women, most of which are aged under 30-35.

Table 1.1. **Age distribution of respondents depending on sex,** %, by years

Respondents' age	**2010**		**2013**		**TOTAL**	
	Men (N=822)	**Women** (N=677)	**Men** (N=724)	**Women** (N=746)	**2010** (N=1499)	**2013** (N=1470)
Aged 15-19	0,5	2	0,1	0,4	1	0,3
Aged 20-24	4,5	10	3	6	7	5
Aged 25-29	19	25	14	22	22	18
Aged 30-39	56	45	54	46	51	50
Aged 40-49	18	16	25	21	17	23
Aged 50 and over	2	2	4	4	2	4

Note. Differences are significant if exceed 4%.

The majority of respondents (66%) have been living with HIV diagnosis from 1 to 9 years (Fig. 1.1). No significant difference by sex was identified.

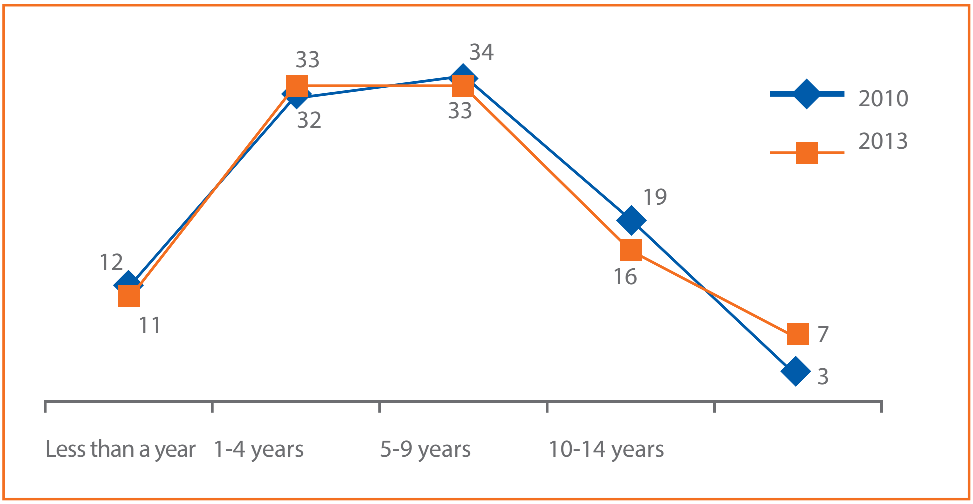


Fig. 1.1. **Respondents' length of living with HIV/AIDS,** %

In order to obtain more detailed information on certain aspects of PLWH life, respondents were offered to answer the questionnaire questions: "Do you currently belong or have you ever before belonged to any of the following groups?" (LGBT, SW, IDU, migrant, prisoner). At that, if in 2010 small portion of PLWH was interviewed in penitentiary institutions, in 2013 only former PLWH convicts took part in the survey.

According to the data obtained, injecting drug users (IDUs) (54%) and former prisoners (25%) remain the most vulnerable groups with regard to HIV-infecting among interviewees (Table 1.2). Men rather than women more often associated themselves with these groups of population. Shares of other HIV vulnerable groups are insignificant (1-5%).

At that it should be noted that among IDUs 42% conflicted with the law, for which have served a sentence in penitentiary institutions in the past. The majority of interviewed PLWH among former prisoners and SWs have experience of drug abuse (which was indicated by 90 and 64% respondents correspondingly).

In the current survey 39% of interviewed PLWH (versus 25% in 2010) did not associate themselves with any of the groups, most of these were women.

Table 1.2. **Self-identification of respondents with certain group of population,** %*

	2010	**2013**
Injecting Drug User	65	54
Prisoner	25	25
Gay, lesbian, bisexual, transgender/transsexual	7	5
Sex worker	5	2
Migrant	4	1
Refugee or individual seeking a shelter (from another country)**	0,3	-
Representative of native population **	8	-
Not belonging and not having belonged in the past to any of these groups	25	39

Note. Differences are significant if exceed 3%.

27% of interviewed PLWH have officially established disability, including 34% among vulnerable groups and 17% – among interviewees not belonging to these, most of them are representatives of HIV vulnerable groups (76% versus 24% among those not belonging to any of them). Most of PLWH with officially established disability are respondents aged from 30 to 45 (71%). Men significantly prevail among PLWH with disability (58%) over women (42%).

For the last three years the key tendencies with regard to marital status of PLWH remain stable (Table 1.3). As before, almost half of interviewed PLWH (45%) are in registered or common law marriage and live together, i.e. have a family (in 2010 this indicator was 39%).

A share of single people among PLWH (44%) remains high, including unmarried, and those without a partner, divorced or widowed. A tendency of correlation between interviewees' marital status and sex remains unchanged. In particular, women more often than men are in official or common law marriage. While there are more unmarried among men (Table 1.3).

Table 1.3. **Marital status of respondents,** %

	2010 (N=1498)	**2013** (N=1498)	**2013**	
			Men (N=745)	**Women** (N=753)
Married or cohabiting	39	45	38	52
Married but separated	7	5	5	5
In a relationship but not living together	8	6	7	5
Single (unmarried, with no partner)	28	27	36	18
Divorced	12	10	10	9
Widow/widower	6	7	4	11

Note. Differences are significant if exceed 4%.

* Sum exceeds 100% as respondents could choose several answer options.

** In 2013 such answer options were not envisaged.

The vast majority of interviewed PLWH (79%) are sexually active, as they indicated having sexual contacts for the last 12 months. At that no significant discrepancies by sex were identified (81% among men, 78% among women). Though, credibility of these data raises some doubts as, according to the interviewers' reports, not all respondents answered honestly to this question.

Over the last three years the tendencies with regard to the length of sexual relations of PLWH remain stable. As before, for 40% of interviewees, relations with a sexual partner last from 1 to 4 years (Fig. 1.2). A third of respondents have relationships lasting 5-9 years. At that no significant discrepancies by respondents' sex and age were observed. 17% respondents have long-term relationships (10 years and more) with a spouse or a partner, these are mostly PLWH aged over 30.

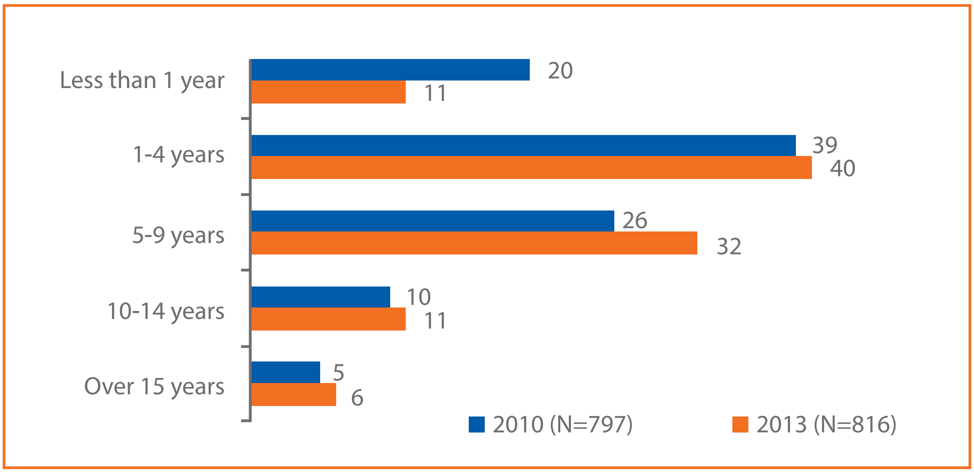


Fig. 1.2. **Distribution of respondents by the lengths of relations,** % to those in a marriage or having a constant partner

By education level, significant part of interviewed PLWH (41%) has secondary vocational education, 25% – complete secondary education, and 12% – complete higher education. At the same time, some part of interviewees (14%) does not have complete secondary education (out of them 11% of respondents completed 9 grades, and 3% – primary school only). A tendency of women having slightly higher level of education than men remains stable (Table 1.5).

Table 1.4. **Level of education of respondents in 2013, %**

	Men (N=746)	**Women** (N=754)	**TOTAL in a bulk** (N=1500)
Primary (below 8/9 grades)	3	2	3
Incomplete secondary (9 grades)	12	10	11
Complete secondary (11 grades)	24	26	25
Secondary vocational (vocational school, technical school)	44	38	41
Incomplete higher (bachelor)	9	8	8
Higher (specialist, master)	8	16	12

Note. Differences are significant if exceed 4%.

According to the data obtained, over the last three years a share of not working PLWH has raised from 39% in 2010 to 52% in 2013 (Fig. 1.3). At that no significant discrepancies by sex and belonging or non-belonging of PLWH to vulnerable groups were identified.

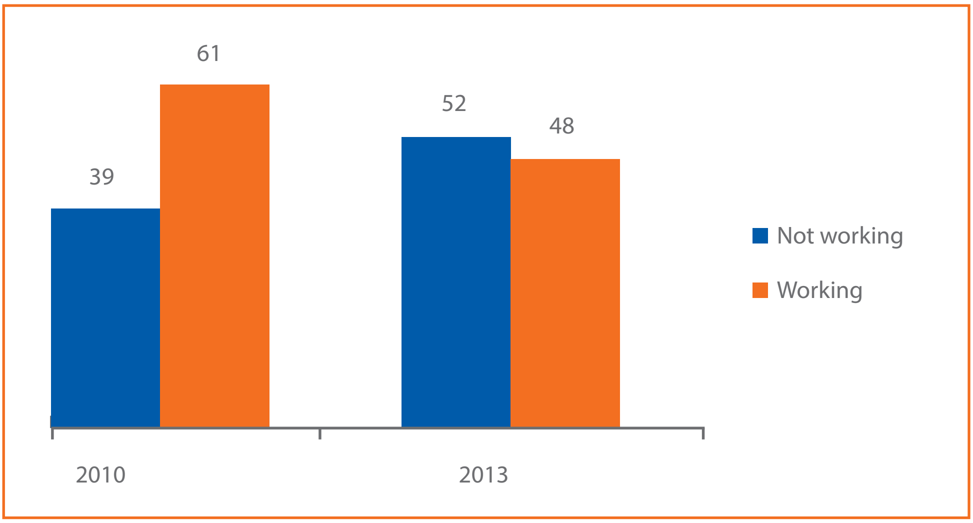


Fig. 1.3. **Distribution of respondents by employment, %**

Among employed, most respondents are employed as employees (including 52% of interviewees are fully or partially employed with official contracted labour relations with an employer, 42% are employed without official employment, and 7% are private entrepreneurs or self-employed).

The vast majority of interviewed PLWH live in regional centres and other large cities (73%), 17% of respondents live in small towns or urban-type settlements, and 10% live in rural areas.

The data obtained include the main features of households where

PLWH live. Minor children under 14 live in 43% of households. There is mostly one child (29%), less often, two children (11%), and in seldom cases, three children (3%). The second by size age group of household members is represented by senior and elderly people. Among all interviewees, about half (45%) of PLWH reside with people aged 50 and older. Over the last 3 years this indicator has hardly changed (in 2010 it made up 46%). In most cases, such households include middle-aged PLWH (both women and men) who live with their parents and/or senior relatives.

The key indicator of the socio-economic situation of households where PLWH live was determined as the average monthly income of the household in the last 12 months. According to the survey data, 12% of respondents stated that the average monthly income of their households made up less than 1000 UAH, which is less than the minimum wage which for the time of the survey totalled 1147 UAH in Ukraine[3]. Almost a third of interviewed PLWH (29%) received income from 1000 to 2000 UAH per month, 22% – from 2000 to 3000 UAH, which is less than the average salary, which for the time of the survey totalled from 3253 to 3429 UAH in Ukraine[4]. For almost a third of interviewees (31%) the household income made up over 3 thousand UAH per month (Fig. 1.4). The average monthly income of households for the totality of respondents was 2934 UAH.

Data of 2013 and 2010 were incomparable due to the change in the methodology of this indicator calculation. In 2010 respondents were asked to state an average monthly income per 1 member of the household which caused significant difficulties for many interviewees. In this connection, in the current survey the cumulative income of the household was used (the sum of all financial revenues of all members of the household per month).

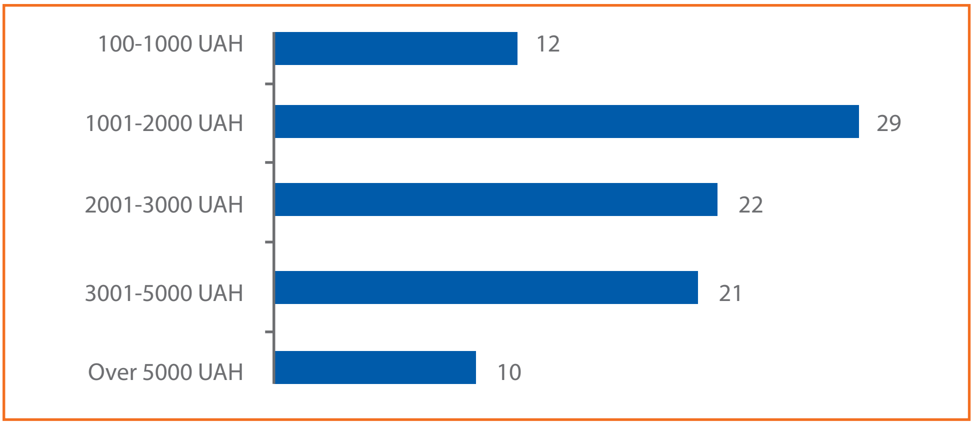


Fig. 1.4. **Average monthly income of the household in 2013, %**

[3] According to the Ministry of Finance of Ukraine data, the minimum wage for the period from 01.01.2013 till 30.11.13 totalled 1147 UAH. According to cl. 5 of art. 38 of the Budget Code of Ukraine the minimum wage is determined by the Law of Ukraine on the State Budget for the corresponding year. – Access mode: http://index.minfin.com.ua/index/salary/

[4] According to the State Statistics Service of Ukraine data, the average salary in Ukraine in 2013 made up: in June – 3253, in July – 3380, and in August – 3429 UAH. – Access mode: http://mojazarplata.com.ua/ru/main/news

At that, it should be taken into account, that in our country any respondents display high mistrust to questions about their incomes. Many people do not want to state their exact income at all or cannot do so. Therefore, answers obtained about the income level should be regarded as rather approximate with digression to reduction.

Analysis of the respondents' socio-economic situation also included the study of the food security of households. For this purpose, respondents were offered to answer a question about the number of days in the last month when members of their families had not enough food to eat. Most of interviewed PLWH (81%) deny the fact of the lack of food in the last month. This indicator remains unchanged (in 2010 it made up 83%). For 19% of respondents, the food problem is pressing, including 8% of interviewees who had not enough food for 1 to 5 days, 6% – for 6 to 10 days, and 3% – for about 2 weeks. Among interviewees there are people who regularly (every other day or even everyday) stint themselves on food or even face hunger – 2% or 22 persons among interviewed PLWH (Fig. 1.5). No significant discrepancies between answers of PLWH with regard to food security by respondents' sex, age, and their belonging to social groups were identified.

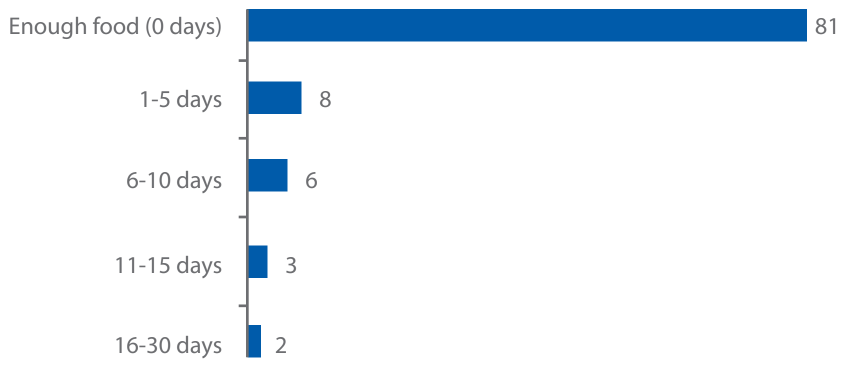


Fig. 1.5. **Number of days during which respondents felt lack of food, %**

The food problem is most common among the unemployed. Over a forth of respondents of this group (26%) felt lack of food during the last, before the survey, month. This problem is less common among working PLWH (12%).

Low-income households face food insecurity more frequently, and this tendency has not changed over the last 3 years. In particular, among those whose average monthly income makes up less than 1000 UAH, a third of PLWH (34%) felt lack of food for the last month before the survey, whereas among those with income of over 3000 UAH only

4% respondents faced this problem.

Therefore, the sex-age features of interviewed PLWH are characterized with their stability over the last 3 years. As a whole, as before, people of reproductive and capable of work age – aged 30-39 (49%) prevail among respondents. The majority of respondents (66%) have been living with HIV diagnosis from 1 to 9 years.

Injecting drug users (54%) and former prisoners (25%) remain the most vulnerable groups among interviewees. Among IDUs 42% have served a sentence in penitentiary institutions in the past. The majority of interviewed PLWH among former prisoners and SWs have experience of drug abuse (90 and 64% correspondingly).

Over the last three years a share of not working PLWH has raised (from 39% in 2010 to 52% in 2013). Among employed, 42% receive incomes as employees but are not officially employed.

The average monthly income of the household for 12% of respondents made up less than 1000 UAH, which is less than the minimum wage. For another 51% of interviewees it made up from 1000 to 3000 UAH, which is less than the average salary in Ukraine at the time of the survey.

19% of interviewed PLWH felt lack of food during the last month before the survey. Families with the income below 1000 UAH (34%) and the unemployed (26%) face food insecurity more often.

LEVEL OF STIGMA AND DISCRIMINATION

2.

LEVEL OF STIGMA AND DISCRIMINATION

2.1. STIGMA AND DISCRIMINATION FROM OTHER PEOPLE

After my HIV status became known the neighbours' attitude towards me has changed. The neighbour was crying loud in the street and humiliated me: "You, the AIDS carrier, do stand up and leave, you have no right to use anything which is public, and have no right to live. All of you, AIDS carriers, should be taken to the forest and buried» (life story, Odesa).

To analyse the general level of stigma and discrimination against PLWH from other people an integral indicator was calculated – a share of HIV-infected people who, in the last 12 months, have at least once experienced stigma or discrimination from the social environment for the reasons that include HIV status:

- were excluded from social gathering or activities;
- were excluded from family activities (cooking, joint meals, sleeping in one room);
- were excluded from religious activities or visits to places of religious service;
- were gossiped about;
- were verbally insulted, harassed, threatened;
- were physically harassed and/or threatened with action;
- were physically assaulted;
- experienced sexual rejection;
- were subjected to psychological pressure or manipulation by husband/wife/partner, when HIV positive status of a respondent was used against him/her;
- were discriminated against by other PLWH; and
- experienced discrimination against their wife/husband/partner or other household members.

Based on research findings, over the last 3 years, the integral index of PLWH stigma from the social environment has reduced in 11% (from 51% in 2010 to 40% in 2013). However, notwithstanding certain positive changes, the problem of stigma and discrimination against PLWH from other people remains rather pressing.

Representatives of HIV vulnerable groups (42%) experience stigma somehow more often than those who do not associate themselves with the former (35%), though taking into account discrepancy (+/-4%) these differences are not very significant. No significant differences depending on sex were reported.

The fact remains unchanged that experience of being stigmatized and discriminated by other people is directly influenced by the length of living with HIV. That is the longer the length of living with HIV, more often PLWH stated that, for the last year, they have experienced prejudiced attitude towards them by other people (43-44% among those who have been living with HIV for over 5 years, 38% – among those whole length of living with HIV is 1-4 years, and 24% – among those who have been living with HIV for less than a year).

This may be explained by better awareness of PLWH who have been living with HIV for a long time about their rights, due to which they more confidently identify cases of their violation, and also by the fact that most people perceive all time intervals subjectively enough and cannot always state with confidence which event took place a year ago, and which – a year and a half ago. Correspondingly, talking about experience of being stigmatized, in the last 12 months, respondents with a long-term length of living with HIV could attribute to it those cases of stigmatization that had taken place earlier.

Among forms of stigma against PLWH from other people, over the last 3 years, the most common remains gossips (Fig. 2.1). During the last year, over a forth of interviewed PLWH were gossiped about for the reasons that included HIV status (26%, whereas in 2010 this indicator was 30%).

> "After my neighbours became aware of my HIV status the attitude towards me has changed drastically. People were afraid of me and wanted to get me out of the village where I live with my husband and children. The neighbours wanted to put my house on fire; they prohibited their children to play with my kid. When my child comes up to their courtyard they would say: "Go away, your mum is an AIDS carrier". They would throw stones at him…" (life story, Donetsk).

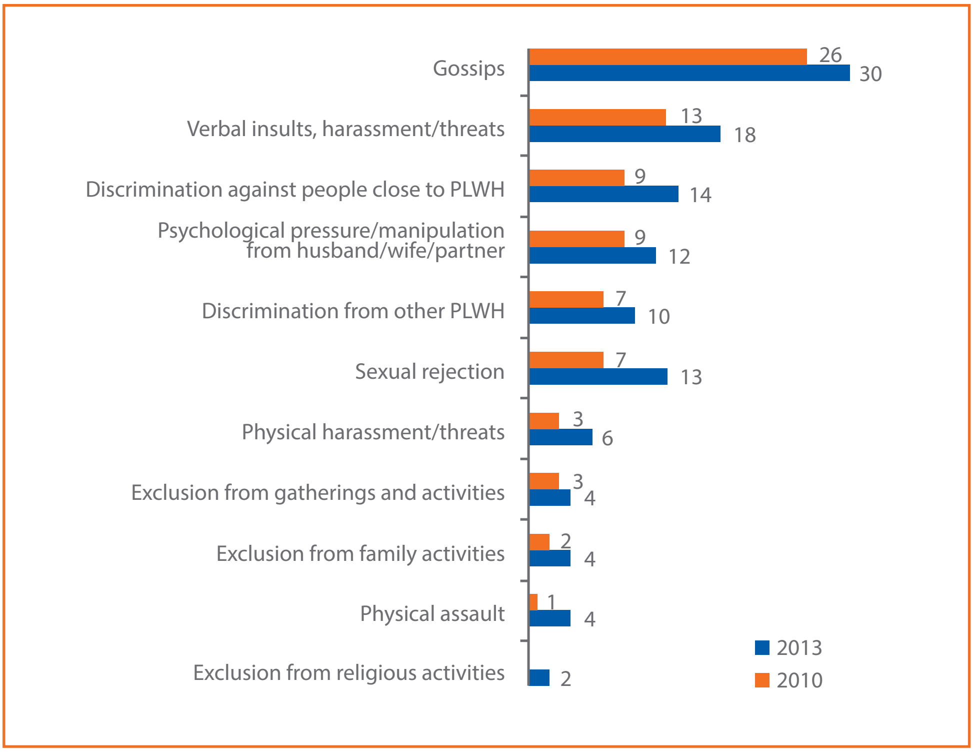


Fig. 2.1. **Percentage of respondents who experienced stigma and/or discrimination from the social environment for the reasons that included HIV status,** %, by years

The second common form of PLWH stigma/discrimination remains verbal insults, harassment and threats from other people. Over the last year, 13% of respondents versus 18% in 2010 faced such forms of stigma.

What concerns other forms of stigma and discrimination from other people differences are not very substantial, and sometimes – insignificant, though the tendency for decrease in stigma cases in 2013 if compared with the previous research remains.

Such forms of stigma and discrimination as verbal insults or threats are described in numerous life stories of PLWH.

Slightly less common remain such forms of stigma as psychological pressure on PLWH from a partner and discrimination against people close to PLWH (over the last year 9% of respondents faced each, which is 3-5% less than in 2010). No significant difference by sex was observed.

It should be noted that tolerant attitude of the environment is not always a reason of the absence of stigma. Over the last year, every sixth respondent, or 17% of the totality, has concealed his/her HIV status from other people, and perhaps because of that their family members (husband/wife/partner) have not been discriminated. In particular, among respondents who disclosed their HIV status to their friends and neighbours, 41% stated that their family members have experienced stigma or discrimination, whereas among those who kept their HIV status secret, there were only 5% of such.

In 2013, about 1% of interviewees were physically assaulted for the reasons that include HIV status, whereas in 2010 there were 4% of them. Although the most severe forms of PLWH discrimination, as physical harassment/threats or physical assault, occur comparatively rarely, their consequences are extremely heavy.

Analysis of life stories of PLWH shows that quite often due to physical harassments they are forced to change their place of residence in order to protect themselves and their children.

A tendency of who does physically assault PLWH remains unchanged. Among those who suffer from physical assault, most are acquainted with their offenders. At that, if compared with 2010 data, a share of PLWH suffering from physical assault from close people (husband/wife/partner or other family members) has increased (from 27% in 2010 to 43% in 2013). The same way as in previous years, women are more often physically assaulted by their husbands/partners (66%), and men – by people outside their households known to them (39%) or by unknown individuals (53%) (Table 2.1).

“Relatives have rejected us and don’t communicate with us. The younger kid suffered most. On his way to school and back he would be called by other children as an AIDS carrier, though he is not. They would throw stones at him and humiliated him. He would come home in tears. He didn’t want to go to school, wouldn’t go out or make friends. Neighbours turned their back on us, there was humiliation. Someone broke our windows at night. People created all the conditions and would tell us straight in the face to leave, as we were not needed here, as we presented danger. We had to sell our house and leave” (life story, Sumy).

«I’ve learned my HIV status when pregnant. My husband reacted harshly to the news: he wouldn’t let me cook, stay in our bedroom, made me wash dishes and floor with bleach” (life story, AR Crimea).

“At home separate dishes were set for me, and separate bed linen which was washed separately. If a drop of blood appeared on the linen this was an event that should be stayed away from. My relatives avoided me, they wouldn’t let me take my nephew in my hands, wouldn’t let me even come closer for me not to infect” (life story, Kirovohrad).

Table 2.1. Distribution of respondents' answers to the question: **"Who assaulted you physically?"**, % to those who experienced this

	2010			2013		
	Men (N=127)	**Women** (N=99)	**TOTAL** (N=226)	**Men** (N=51)	**Women** (N=61)	**TOTAL** (N=112)
Husband/wife/partner	2	42	20	2	66	37
Other family member	3	11	7	6	7	6
A person, not a family member, but known to the respondent	48	28	38	39	16	27
Unknown individual	47	19	35	53	11	30

Note. Differences are significant if exceed 14%.

"After diagnosis the head of the infection department informed my relatives about my HIV status and that 6 months were left for me to live. After that my relatives stopped communicating with me, they would prohibit me from talking to my child. They decided to protect my child from me, as I could infect him and all of them" (life story, Donetsk).

«My daughter wouldn't treat me as human, she would insult me, push me, refused to help me anyway (neither cook, nor go to chemist's to buy medicine). Then, she has decided to present me as mentally ill and forced me to the psychiatric clinic, having bribed doctors for them to make me legally incapable, to get the flat" (life story, Donetsk).

Other forms of stigma and discrimination related to HIV status remain less common (from 1 to 3% of interviewed PLWH reported of them) (Fig. 2.1). At that, many life stories of PLWH describe worsening of relationships with family members due to the respondent's HIV status. Wrong assumptions of PLWH family members regarding routes of HIV transmission have led to the situations with isolation at home, in particular, relatives would avoid using same dishes, bed linen, joint meals, etc. In some cases it would lead to the situation when family members tried many ways to get the respondent out of the house, deprive of accommodation or even take a child away from him/her.

Such situations urge PLWH to keep their HIV status secret, even from close relatives.

Results of the comparative analysis show that the major reason for stigma and discrimination against PLWH from other people, in interviewees' opinion, remains low awareness of the population about the major routes of HIV transmission which causes increased fear of HIV infection (Fig. 2.2). No significant difference in respondents' answers by social groups was observed.

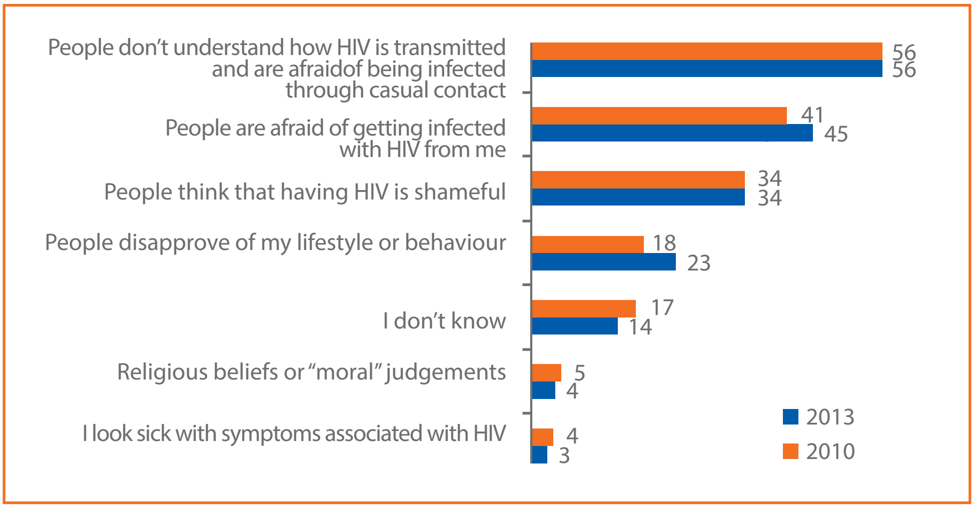


Fig. 2.2. **Reasons for stigma and discrimination from other people,** % of those who experienced any form of stigma and discrimination related to HIV status

At that, in many life stories PLWH stressed on low awareness about routes of HIV transmission both of the general population and health care workers.

The second most valid reason for stigmatizing and discriminating by the social environment is a desire to distance from HIV-positive people because of the belief that being HIV-infected is shameful (as indicated by 34% of interviewed PLWH).

Intolerance of certain lifestyles or behaviours of PLWH is on the third place among the reasons for stigma and discrimination from other people (18%).

For the last year, about half of interviewed PLWH (45%) have experienced stigma and discrimination from other people for the reasons not related to HIV status (in 2010 this indicator was 55%). The major reason for prejudiced attitude towards themselves from other people, most PLWH consider belonging to the group of injecting drug users (as indicated by 39% in 2010 and 36% in 2013). 9% of respondents stated that they had been stigmatized because of their belonging to the group of former prisoners, and 5% – because of their belonging to other HIV vulnerable groups.

Almost half of interviewees (48%) have chosen an answer option "other reasons". Among these the most common were personal dislike (52%) and problematic relationships with relatives, colleagues (36%). Alcohol abuse (10%), husband/wife/partner belonging to vulnerable groups (6%), and ethnicity, religion or race of a respondent (3%) were less frequently mentioned.

So, if compared to 2010, attitude towards PLWH from the

"My sister, though being a health care worker, would say that this disease had not been studied enough and routes of HIV transmission were unknown" (life story, Kirovohrad).

"My manager and foreman don't even know how HIV is transmitted, so they've decided I would present a threat to other employees and for themselves. They thought I could infect them" (life story, Ivano-Frankivsk).

"The level of the general population awareness, especially in small towns, is very low. For most people, both AIDS, HIV, TB are the same – infection. And such people should be isolated» (life story, Donetsk).

"After some time after resignation (of the respondent. – Author's note) the same happened to my father who had worked at the same company. Due to lack of understanding people were afraid that HIV could be transmitted to my father, and he would infect them. So both our families were left with no means of support" (life story, Ivano-Frankivsk).

social environment has significantly improved. Over the last three years, the general level of stigma and discrimination against PLWH due to HIV status from the social environment has reduced in 11% (from 51% in 2010 to 40% in 2013).

Among forms of stigma against PLWH from other people, over the last 3 years, the most common remain gossips, as well as verbal insults, harassment or threats. During the last year, over a forth of interviewed PLWH have been gossiped about for the reasons that included HIV status (26%, whereas in 2010 this indicator was 30%). The second common form of PLWH stigma/discrimination remains verbal insults, harassment and threats from other people. Over the last year, 13% of respondents versus 18% in 2010 faced such forms of stigma.

What concerns other forms of stigma and discrimination from other people differences by years are not very substantial, and sometimes – insignificant, though the tendency for decrease in stigma cases in 2013 if compared with the previous research remains.

Slightly less common remain such forms of stigma as psychological pressure on PLWH from a partner and discrimination against people close to PLWH (over the last year 9% of respondents faced each, which is 3-5% less than in 2010). The most severe forms of PLWH discrimination, as physical harassment/threats (3% in 2013 versus 6% in 2010) or physical assault (1% in 2013 versus 4% in 2010) for the reasons that include HIV status, occur comparatively rarely.

To conclude, in communication with the social environment, stigma manifests more not in physical assault, but in negative and emotional impact by other people (gossips, insults, negative expressions, etc.) which contributes to formation of relatively strong internal stigma of PLWH.

2.2. ACCESS TO WORK AND HEALTH AND EDUCATION SERVICES

Discrimination and social isolation of people living with HIV ruin all efforts in combating AIDS. Health care, education and employment are among key sectors which, under the absence of relevant approaches, present major sources of problems faced by PLWH in their everyday life and in many ways determine the extent of their social vulnerability.

EMPLOYMENT DISCRIMINATION

Questions about relationships with employers and the consequences thereof were asked to only those respondents who have been working over the last year, either through employment or through self-employment, including part-time jobs.

According to the data obtained, over the last 3 years a share of those not working among PLWH has raised from 39% in 2010 to 52% in 2013. No significant difference in respondents' answers by social-demographic features, as sex, age and belonging to vulnerable groups, was observed.

Among those who are not working, 36% of respondents are looking for a job, a third (30%) doesn't work due to health reasons, and almost another third (27%) are housekeepers or on a maternity leave.

What concerns working PLWH (48%), half of them (52%) are fully or partially employed in official employment, 42% are employed without official employment, and 7% (or 49 people of 714 those working) are private entrepreneurs or self-employed.

According to the survey data, in the last 12 months, 20% of respondents among those employed have lost their source of earned income for various reasons (including 9% of interviewees have lost their job more than once).

Among those who have lost their jobs in the last year, 15% (or 21 persons) associate this with reasons that include HIV status. In particular, almost half of them (9 people of 21) are sure they have lost a job as a result of discrimination on the part of their employer or co-workers. The same number of interviewees (9 people) considers their health condition as a reason for losing a job.

Over the last year, 3% of working PLWH faced refusal in employment due to their HIV status. At that, among working PLWH only 19% stated that their employer knew their diagnosis (including 18% had informed the employer of their HIV status themselves, and 1% – someone else had informed without PLWH consent). Most of working PLWH (63%) conceals their HIV status from their employer.

3% (or 23 persons) among working PLWH indicated such negative changes in the relations with the employer as demotion or referral to a less qualified job, reduction in salary, and deterioration of working conditions. But most of them do not associate such changes with HIV status.

At the same time, in their life stories PLWH quite often stressed on the fact that it was due to HIV status that employers and co-workers directly or indirectly forced them to resign.

So, what concerns forms of discriminations in the employment area, in the last 12 months, 20% of respondents among those working have lost their source of income, out of them 15% (or 21 people) associate this with the reasons that include HIV status.

Almost half of those who have lost their jobs due to HIV status (9 people of 21) are sure they have lost a job as a result of discrimination from their employer or co-workers.

Over the last year, the prevailing majority of PLWH (95%) have not experienced refusal in employment due to HIV status. This however

"When information on my status reached my manager he called me to his office, first told me that I was working badly, performing a small amount of work, and then asked me to file a resignation application as if voluntarily without any serious explanations" (life story, Ivano-Frankivsk).

"After I have disclosed my status to my employer such conditions were created for me that I had to leave my job. They've virtually eaten me" (life story, Ivano-Frankivsk).

"I couldn't prepare and warm up food jointly with others. I couldn't have a lunch when someone else was there, sit on the same sofa. Other employees would stand up and leave. If I took a towel they would immediately put it aside for laundry. If I took a cup then everything was told me in the face. As a result I resigned. I was simply forced to" (life story, Donetsk).

"When people at work learned about my HIV status I lost my job. My employer said that she didn't need HIV positive people, the company reputation was more important for her" (life story, Donetsk).

has likely happened not because of tolerant attitude of employers to PLWH but due to concealing their HIV status. As such, among working PLWH, 63% conceal their status from their employer.

"When I was hospitalized I informed a physician myself of my HIV status, for good reasons, to protect a physician. When a gynecologist learned about my disease she started acting inadequately, started calling me contagious and an AIDS carrier. She said that I was a drug addict and an AIDS carried and those, like me, had no right to be treated in hospital together with other people. All that I had to hear while being on a gynecological chair. Then she opened the door and started crying loud about my condition» (life story, AR Crimea).

"In hospital health care staff calls us disdainfully as "AIDS things". After these words I will never go to that department for treatment" (life story, Donetsk).

RESTRICTED ACCESS TO HEALTH CARE AND SOCIAL SERVICES

To analyse the general level of stigma and discrimination against PLWH in health care an integral indicator was calculated. It presents a portion of HIV-infected people who, for the last 12 months, have experienced refusals in medical care (including in dental care), family planning, sexual and reproductive health services for the reasons that include HIV status.

According to the survey data, in the last 12 months, 11% respondents at least once experienced limited access to health care services for the reasons related to HIV status. Decrease in this indicator over the last 3 years (in 2010 it was 22%) demonstrates relative improvement of PLWH access to health care services. Such limitations are more often experienced by PLWH who associated themselves with HIV vulnerable groups (14%) than those who do not belong to any of these (8%). No significant discrepancies by respondents' sex and age, and the length of living with HIV were observed.

As before, the most common form of discrimination against PLWH in health care remains refusal in medical care, including in dental care. Over the last year, 11% of interviewed PLWH experienced such problem due to HIV status (Fig. 2.3).

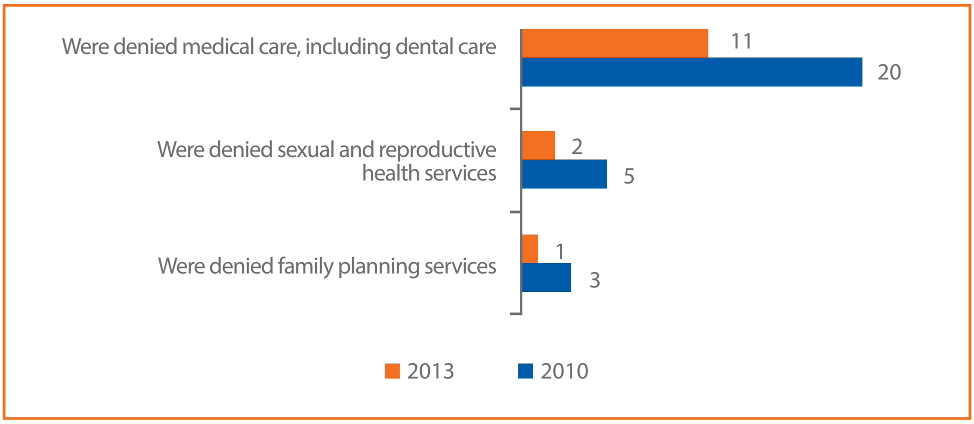


Fig. 2.3. **Percentage of respondents who experienced difficulties in access to health care services because of their HIV status,** %, за роками

Life stories vividly illustrate the survey data with examples of direct or indirect refusal of PLWH in medical care if HIV status of a patient was disclosed. Many of interviewees experienced offensive statements and disparaging attitude towards them on the part of health care workers. Such situations quite often become the reason for patients' refusal to inform physicians of their HIV status or even avoidance of visits to health care facilities even in case it is necessary.

HIV status became a comparatively less frequent reason for PLWH limitation in access to family planning services and sexual and reproductive health services (1-2%). It should be noted that all PLWH who applied for these services and got refusal had disclosed their HIV status to health care workers themselves.

To analyse the general level of stigma and discrimination against PLWH in social area an integral indicator was calculated. It presents a share of HIV-infected people who, in the last 12 months, for the reasons that included HIV status, had to change their place of residence or experienced difficulties in renting accommodation; experienced limitations in access to their education or education for their children.

According to the survey data, in the last 12 months, 2% of respondents experienced at least one form of stigma and discrimination in social area. This indicator remained almost unchanged over the last three years (in 2010 it made up 5%). No significant variances in respondents' answers by social-demographic features, as sex, age, marital status, the length of living with HIV, and belonging to vulnerable groups, were observed.

Among forms of stigma and discrimination in social area PLWH most frequently experienced limitation in access to housing. In particular, during the last year almost 2% of all interviewees had to move to another dwelling or faced difficulties with renting for the reasons related to HIV status one way or another. In 2010, 3% of respondents experienced such difficulties.

These forms of stigma and discrimination were described by PLWH in their life stories.

Only 1% of interviewed PLWH experienced the situation when their children had been dismissed, suspended or prevented from attending educational institutions. This indicator has remained unchanged over the last three years. None of 18 respondents currently studying reported obstacles in the process of their own education.

So, over the last year, 11% of interviewed PLWH experienced stigma and discrimination in health care. If compared to 2010 data this indicator decreased almost twice (in 2010 it was 22%). The most common form of stigma and discrimination against PLWH in health care remains refusal in medical care, including in dental care (11% in 2013 versus 20% in 2010). Instead, HIV status becomes a

"I was hospitalized via ambulance with a suspicion for appendicitis. At the reception I was put on a bed and covered with a blanket as I was shivering. After a doctor and a nurse learned from me about my HIV status they made big eyes, the doctor started crying and took a blanket away from me. She said I couldn't use common blankets. They have put strong moral pressure on me and though I wasn't refused in hospitalization directly they've prompted me to be treated at home. After a night spent in the hospital corridor I took prescribed medicine and went home for treatment" (life story, Donetsk).

"I try to avoid hospitals and outpatient clinics as far as possible and visit these only in case of utmost urgency. I warn about my hepatitis but say nothing of HIV, as people consider that disease (hepatitis) less dangerous. As people say, if you don't know – you'd do it without a qualm. I care for myself, not for doctors" (life story, Odesa).

"I was renting an apartment and having passed all tests kept all the documents (including those confirming my HIV status) at home. When I was away the landlady checked my belongings and found the documents. We had a conversation that night. She said she didn't want me to live there as I was ill and told me to vacate the apartment. I tried to explain to her that this was not dangerous but the landlady treated me with disdain and I had to leave" (life story, Odesa).

comparatively less frequent reason for PLWH limitation in access to family planning services and sexual and reproductive health services (1-2%).

In the last 12 months, 2% of respondents experienced stigma and discrimination in social area. This indicator has remained almost unchanged over the last three years (in 2010 – 5%). The most common form of stigma and discrimination against PLWH in social area remains limitation in access to housing, which was experienced by almost 2% of interviewees in 2013 versus 3% in 2010.

2.3. INTERNAL STIGMA

Self-stigmatization or "internal" stigma, contrary to "external" stigma first of all affects the feeling of one's own dignity. Stigma and discrimination associated with HIV/AIDS make a severe psychological impact on self-conscience of PLWH, in some cases inducing depression, low self-esteem and despair. This cuts up and exhausts PLWH forces, often making them blame themselves for having found themselves in such hard situation.

To analyse the general level of self-stigmatization of PLWH an integral indicator was calculated – percentage of HIV-positive people having any negative feelings about themselves due to HIV status in the last 12 months: felt shame, guilt, blamed themselves or others, had low self-esteem, felt a desire to be punished or to commit suicide.

As the obtained data show, over the last 3 years, the general level of self-stigmatization of PLWH remains high. As in the previous survey, the vast majority of interviewees (82%) stated they had experienced at least one of the negative feelings towards themselves due to HIV status at least once in the last 12 months. Women are apt to self-stigmatization slightly more often than men (85% versus 78% among men). As the length of living with HIV increases, the general level of self-stigmatization gradually decreases (from 86% among people living with HIV for less than 1 year to 70% among PLWH whose length of living with HIV exceeds 15 years). No significant variances by social-demographic features, as age, marital status, and belonging to vulnerable groups, were observed.

Over the last 3 years, self-accusation remains the most common form of internal PLWH stigma. More than a half of interviewees (58%) blame themselves for what has happened to them. At that, a share of those blaming themselves is slightly larger among representatives of HIV vulnerable groups (62% versus 52% among those not belonging to such groups) (Table 2.2).

Table 2.2. Distribution of respondents' answers to the question: **"In the last 12 months, have you experienced any of the following feelings because of your HIV status?"**, % of affirmative answers by social groups

	Vulnerable groups representatives N=906	**Not belonging to risk groups** N=594
Blamed themselves	**62**	52
Felt guilty	47	46
Had low self-esteem	46	47
Felt shame	**38**	**46**
Blamed others	**24**	**35**
Felt suicidal	15	20
Felt you should be punished	16	14

Note. Differences are significant if exceed 4%.

A feeling of guilt and low self-esteem remain rather common forms of internal stigma among PLWH. Over the last year, almost a half of interviewed PLWH (46%) felt these feelings due to their HIV status. A tendency remains unchanged of women feeling low self-esteem due to HIV status more often than men (52% versus 41% among men).

A feeling of shame remains rather common form of internal PLWH stigma. Over the last year, 41% of interviewed PLWH felt it. Those PLWH not belonging to vulnerable groups feel shame more often (46% versus 38% among representatives of risk groups) (Table 2.2).

According to the comparative analysis data, over the last year, a share of PLWH blaming other people for their HIV status has increased (from 20% in 2010 to 28% in 2013). As before, women are more apt to such feelings (32% versus 24% among men).

Major concern is caused by the fact that, if compared with the 2010 survey data, a share of PLWH willing to commit suicide due to internal stigma has increased twice (from 8% in 2010 to 16% in 2013) (Fig. 2.4). Young PLWH aged 20-29 are more apt to such moods (21% versus 15% among PLWH aged over 40).

"Even now I am afraid to shivers that my parents or relatives would learn about my problem. I am afraid of dying sooner than my mum or sister, because the certificate of death will show my diagnosis. I have no right to cause pain to my relatives. It's very difficult to live in a constant fear. It suppresses and wouldn't let live a normal life" (life story, Donetsk).

"After I was forced to resign I had a feeling as if I had just learned my diagnosis. Although I have been living with HIV for 10 years already. I felt offended, suppressed, confused. Tears were coming down, and I couldn't do anything with it. I can't bring myself together even now. Lack of confidence and fear appeared" (life story, Odesa).

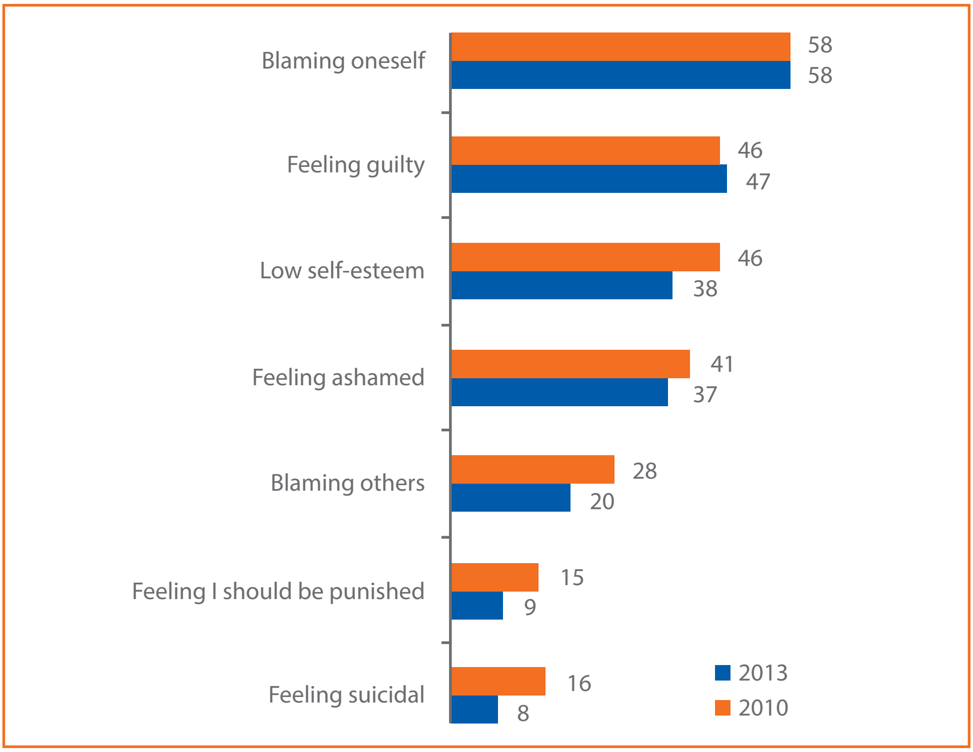


Fig. 2.4. **Respondents' feeling towards themselves due to HIV status,** % of affirmative answers by years

"I felt such pain, despair, I seemed to lose my ground, my family seemed to have no future. I felt greatly offended for myself, my children, who haven't done anything. There were also rage, and anger towards other people who stigmatized so easily. And there was a great fear! I was afraid of the future. I didn't go to a job. This case strongly affected my psychic condition. Now I am trying not to leave my home without a special reason. I withdrew into myself. The neighbours I used to be in good relations with don't drop in anymore" (life story, Sumy).

Analysis of life stories of PLWH shows that stigma and discrimination related to HIV status make a strong psychological impact on PLWH, that is why in most cases they feel fear, offence, pain and despair, which in turn leads to depression, lack of self-confidence, and finally results in social isolation.

This is confirmed with the PLWH survey data. To measure the general level of self-discrimination of PLWH an integral indicator was calculated – percentage of HIV-positive people who have taken/performed any self-discriminating decisions/actions due to HIV status in the last 12 months:

- decided not to attend gatherings;
- stop working;
- not to apply for a job/employment or promotion;
- not to get married;
- not to have sex;
- not to have children;
- isolated themselves from one's family or friends;
- rejected education/training or decided not to continue education/training;
- avoided visits to an outpatient clinic, even if there was a need in it;

- avoided hospitalization, even if there was a need in it.

According to the data obtained, over the last 3 years, the general level of self-discrimination of PLWH remains high. The same way as in the previous research, two thirds of respondents (62%) took at least one of auto-discriminating decisions in the last 12 months because of their HIV status. Belonging or non-belonging to HIV vulnerable groups, as well as sex of respondents do not have significant impact on self-discriminating decisions or actions by PLWH.

A peak of auto-discriminating decisions is in the first year after diagnosis. Further on, prevalence of such decisions taken by PLWH decreases slightly (from 66% among PLWH who have learned about their status less than a year ago to 55% among respondents who have been diagnosed 15 years ago).

Among self-discriminating decisions taken by PLWH, over the last 3 years, the most common remain decisions not to have children and not to get married (in 2013 these indicators are 39% and 21% correspondingly) (Fig. 2.5). At that, over the last year, a share of PLWH ready to give up sex has increased almost twice (from 10% in 2010 to 18% in 2013) and a share of PLWH willing to isolate themselves from their family and/or friends has increased almost to a third (from 12% in 2010 to 17% in 2013).

"In the outpatient clinic there was a case when the head doctor insulted me and called with bad words when I asked to refer me to a required doctor. She responded: "What should I do with all of you, "contagious"? No one wants to be in charge of you" – and refused to accept me. When I told I would complain to the department of health, she responded she didn't care" (life story, Lviv).

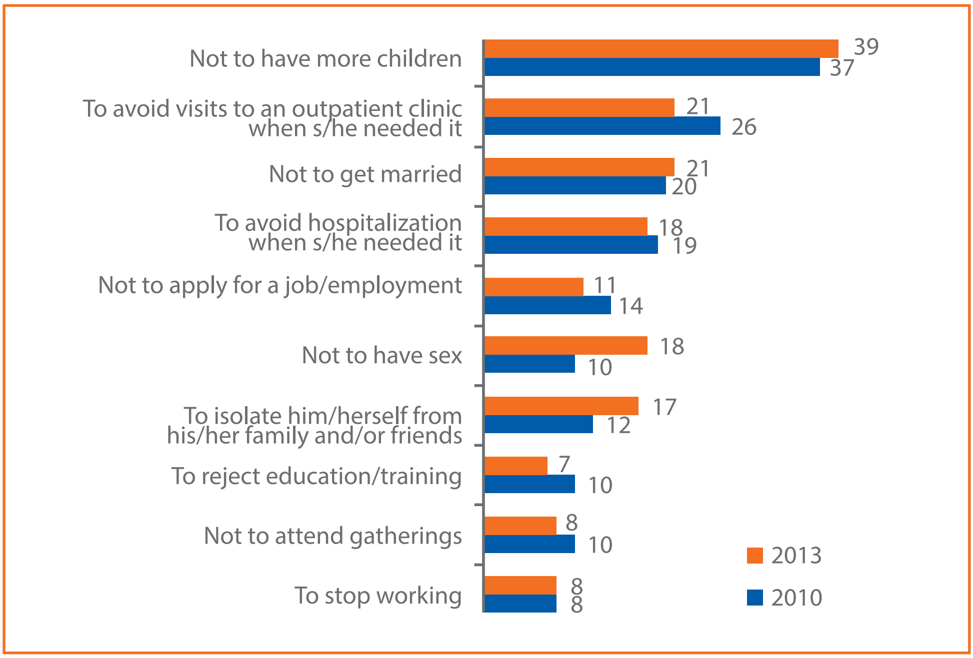


Fig. 2.5. **Decisions taken by respondents due to HIV status,** % of affirmative answers

"I feel complete indifference on the part of doctors. They refer me from one hospital to another, in circles. There was a case when I went to hospital and was referred to the head doctor. After a conversation with him I left his room for some time and when I came back and opened the door I heard a very unpleasant conversation of the head doctor with a physician about my HIV status. Talking about that they didn't want me there and things like that. I even heard cleaners in hospital talking about my HIV status, one of doctors should have told them» (life story, Lviv).

A practice of refusal from visiting health care facilities for the reasons related to HIV status remains rather common among PLWH. Over the last year, 21% of interviewed PLWH avoided visits to outpatient clinics, and 18% refused from hospitalization despite the necessity.

Analysis of life stories of PLWH shows that the major reasons for respondents' avoidance of visits to health care facilities are disclosure by medical workers of HIV status of interviewees and disdainful attitude towards them by doctors and other medical staff.

As before, PLWH are least likely to give up work, education/training, attending gatherings due to HIV status (7-11%).

Such auto-discriminating decisions as refusal from sexual contacts, self-isolation from family or friends, avoidance of visits to health care facilities are more often taken by PLWH not belonging to vulnerable groups (Table 2.3). Other decisions are not significantly impacted by the experience of belonging to risk groups.

Table 2.3. **Decisions taken by respondents due to HIV status in 2013,** by belonging to vulnerable groups, % of affirmative answers

	Vulnerable groups representatives N=906	**Not belonging to risk groups** N=594
Not to have more children	38	40
Not to get married	20	22
Avoid visits to an outpatient clinic when s/he needed it	**19**	**25**
Avoid hospitalization when s/he needed it	17	21
Not to have sex	**16**	**21**
Isolate him/herself from his/her family and/or friends	**15**	**21**
Not to apply for a job/employment or promotion	12	10
Reject education/training	8	7
Not to attend gatherings	8	8
Stop working	7	9

Note. Differences are significant if exceed 4%.

According to the survey data, such auto-discriminating decisions as refusal from sexual contacts, decision not to have more children, avoidance of visits to health care facilities (outpatient clinics/ hospitals) even if it is necessary are more often taken by women rather than men.

Almost three forth of respondents (70%; in 2010 this indicator was 72%) indicated various fears and anxieties due to HIV status. The most common fear remains a fear of being gossiped about due to HIV status. This indicator has been unchanged over the last 3 years and is 51-52% (Fig. 2.6). On the second place there is a fear of experiencing verbal insults or harassments (36%).

Over the last 3 years, a share of PLWH afraid that someone would not want to be sexually intimidated with them because of their HIV status has decreased 10% and is on the third position in the PLWH fears ranking (34%). As in previous years, these fears are of less concern for PLWH who have permanent partners (39%) than for those not having such (48%).

Over the last three years, a comparatively less common fear remains a fear of physical harassment and assault. One in five respondents is fearful of such forms of discrimination (20% and 18% correspondingly).

It should be noted that in practice less respondents experienced these or those forms of stigma and discrimination than are afraid of this.

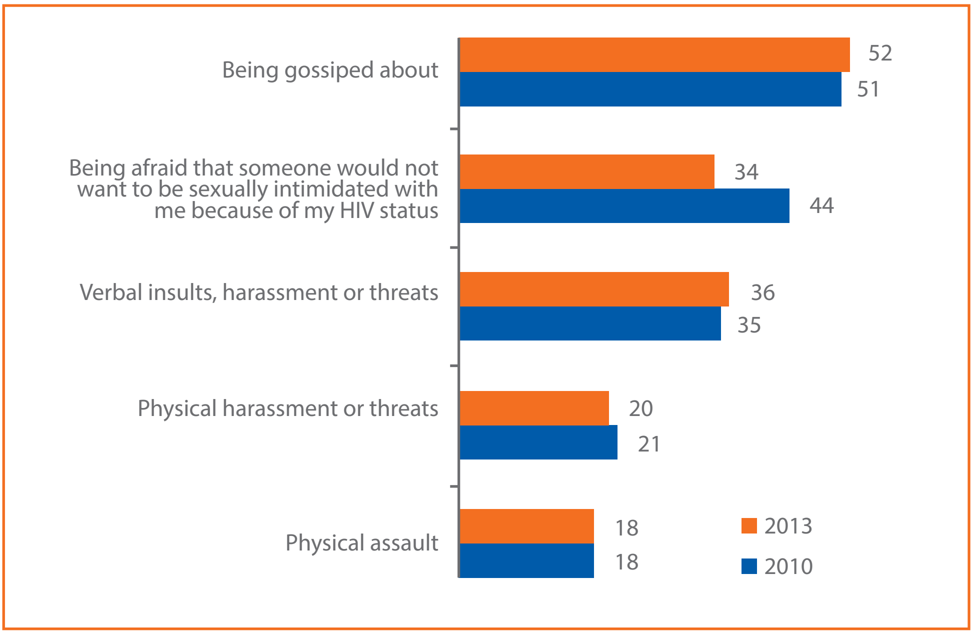


Fig. 2.6. **Fears and anxieties felt by PLWH for the reasons related to HIV status,** %

Almost all fears felt by PLWH, apart from a fear of sexual rejection, are of more concern for women than for men. Shares of respondents feeling various fears (apart from physical harassments and assaults) decrease with age. A similar tendency is observed depending on the length of living with HIV: as the length of living with HIV increases, a share of PLWH feeling various fears and anxieties goes down.

As a whole, over the last year, a share of PLWH feeling various fears and anxieties (apart from a fear of being sexually rejected) has been significantly higher among respondents not belonging to any vulnerable group (Table 2.4).

Table 2.4. **Existing fears and anxieties felt by PLWH due to HIV status in 2013,** by belonging to vulnerable groups, % of affirmative answers

	Vulnerable groups representatives N=906	**Not belonging to risk groups** N=594
Being gossiped about	45	**61**
Being afraid that someone would not want to be sexually intimidated with me because of my HIV status	34	34
Verbal insults, harassment or threats	29	**45**
Physical harassment or threats	16	**26**
Physical assault	15	**23**

Note. Differences are significant if exceed 4%.

So, over the last 3 years, the general level of PLWH self-stigma due to their HIV status remains high (82%). Women (85%) are apt to self-stigmatization slightly more often than men (78%).

Over the last 3 years, the most common forms of internal PLWH stigma have remained as follows:

- self-accusation (58%, and this indicator has been unchanged since 2010);
- feeling of guilt (46% in 2013 versus 47% in 2010);
- low self-esteem (46% and 38% correspondingly);
- feeling of shame (41% and 37% correspondingly).

Over the last year, a share of PLWH blaming other people in their HIV status has increased (from 20% in 2010 to 28% in 2013), also a share of PLWH willing to commit suicide due to internal stigma increased twice (from 8% in 2010 to 16% in 2013). Young people aged 20-29 (21%) are more apt to such moods.

With age and increased length of living with HIV, a feeling of guilt and low self-esteem do not change comparatively, whereas other forms of self-stigmatization decrease.

Representatives of HIV vulnerable groups blame themselves for what has happened more often than others. PLWH not belonging to vulnerable groups more often feel shame and blame others for their HIV status.

Over the last 3 years, the indicator of self-discrimination of PLWH has remained high (62%). A peak of self-discriminating decisions is in the first year after diagnosis (66%), further on prevalence of such decisions taken by PLWH decreases slightly (55% for those who have been living with HIV for over 15 years).

Among self-discriminating decisions taken by PLWH, over the last 3 years, the most common remain as follows: decisions not to have children (39% in 2013 versus 37% in 2010), not to get married (21% and 20% correspondingly), and to avoid visits to health care facilities (including outpatient clinics – 21% and refusal from hospitalization – 18%).

LEGAL CULTURE OF PLWH AND RESPONSE TO DISCRIMINATION

3.

LEGAL CULTURE OF PLWH AND RESPONSE TO DISCRIMINATION

3.1. AWARENESS OF PLWH ABOUT THEIR RIGHTS

One of the factors having impact on the spread and display of discrimination and stigma is that significant part of HIV-positive people in Ukraine are not aware of their rights and/or cannot protect them in their everyday life.

So, 38% of interviewees have heard of the Declaration of Commitment on HIV/ AIDS (Fig. 3.1). A share of respondents who are aware of the Law of Ukraine On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and Social Protection of the Population is higher than in case of the Declaration and is 60% (Fig. 3.2).

It should be noted that percentage of respondents having heard of each of the mentioned documents has decreased if compared to 2010: for the Declaration from 61% to 38%, and for the Law – from 71% to 60%. In our opinion this year data better reflect the actual situation. As, according to the methodology applied in the previous research, interviewers could briefly inform respondents about the said legislative instruments during the interview. A considerable number of interviewees could have considered such step to be a discussion of the documents, which consequently could have resulted in an artificial increase in the level of respondents' legal awareness in the previous research.

At that, only 42% have read or discussed the Declaration, and half – the Law of Ukraine.

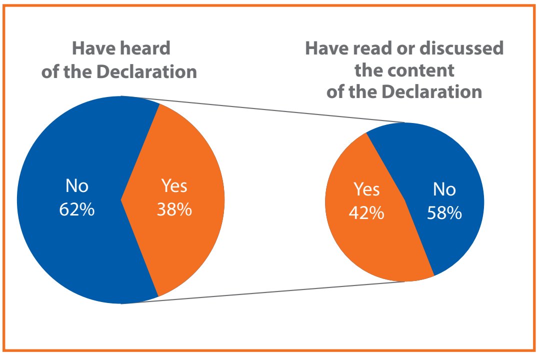


Fig. 3.1. **Respondents' awareness of the Declaration of Commitment on HIV/AIDS and the fact of discussing its content,** %

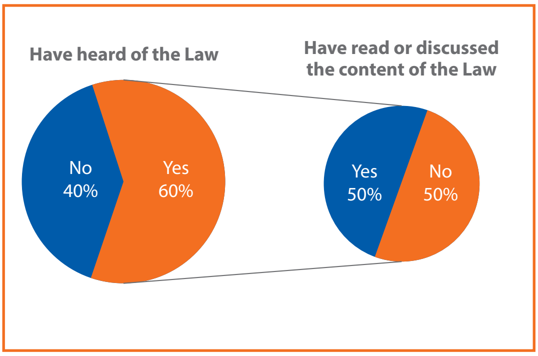


Fig. 3.2. **Respondents' awareness of the Law of Ukraine On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and Social Protection of the Population and the fact of discussing its content ,** %

No significant differences were observed in comparing respondents' answers by sex.

In Kirovohrad, Sumy, Cherkasy regions and AR Crimea percentage of respondents aware about the Declaration exceeded 50% (Fig. 3.3).

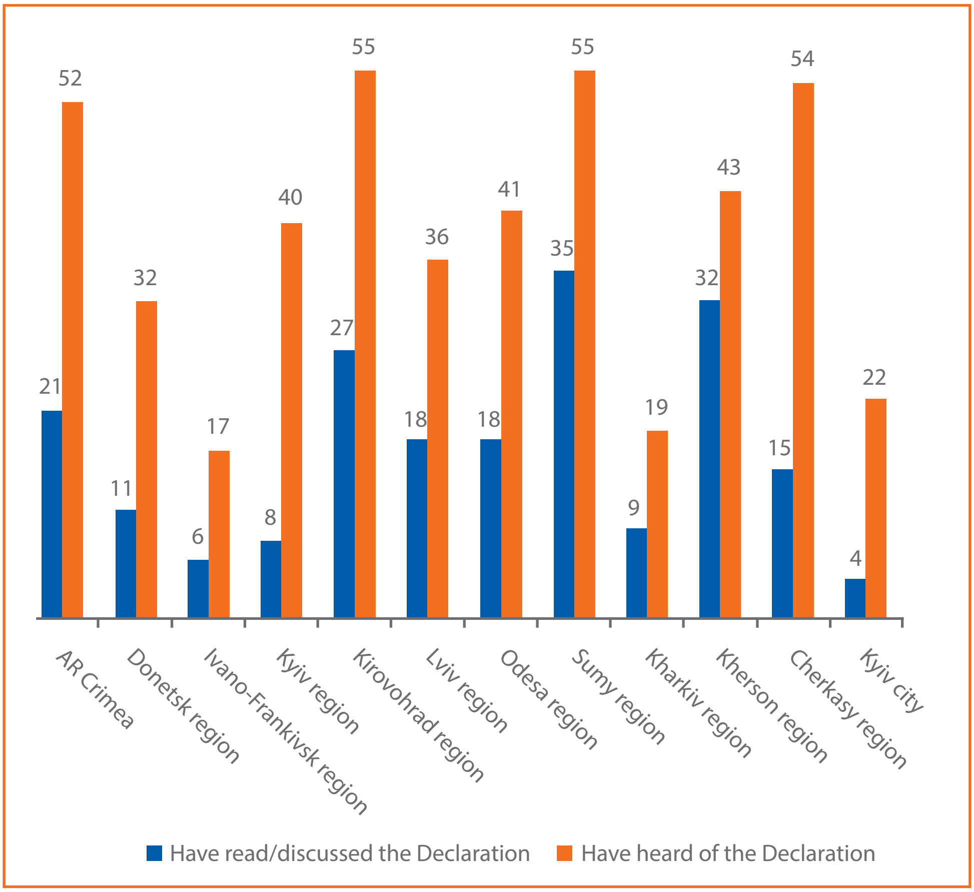


Fig. 3.3. **Respondents' awareness of the Declaration of Commitment on HIV/AIDS and experience of reading this document,** % by regions

In Cherkasy and Sumy regions there are more respondents aware of the Law of Ukraine On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and Social Protection of the Population. The latter region is also leading by the number of respondents who have read this document (Fig. 3.4).

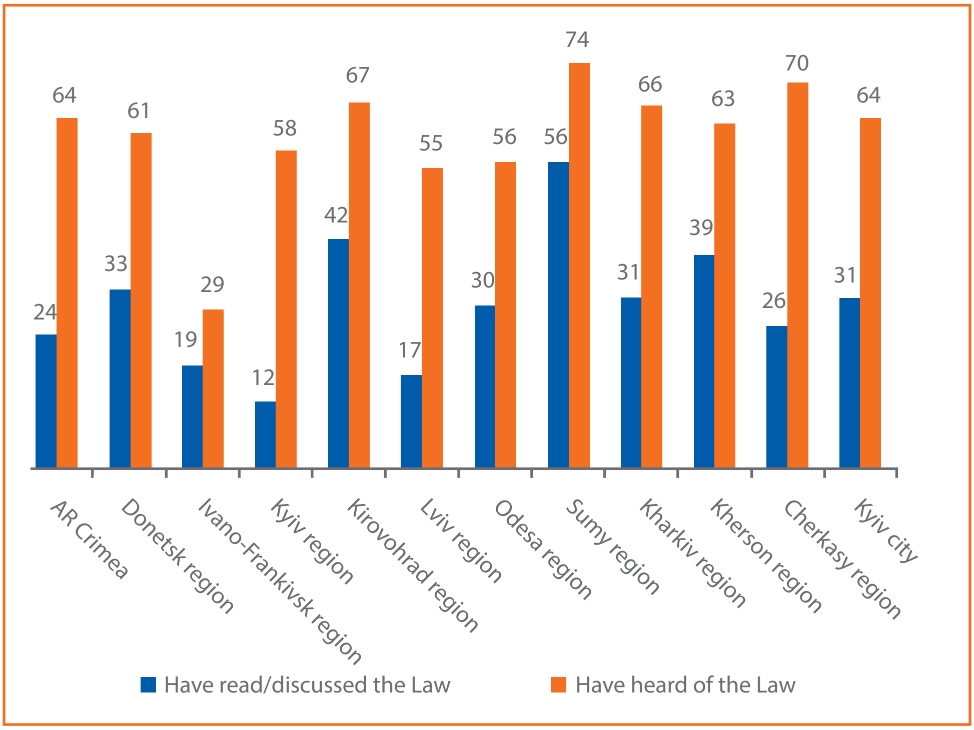


Fig. 3.4. **Respondents' awareness of the Law of Ukraine On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and Social Protection of the Population,** % by regions

20% of interviewees stated that, in the last 12 months, some of their human rights have been violated. If compared to the previous survey (22%) this indicator has not significantly changed. At that, 21% of respondents cannot state confidently whether their rights have been violated or not, and more than a half (59%) – state with confidence that in the last 12 months none of their rights were violated.

No significant differences regarding a share of those who indicated violation of their rights by sex, age and the length of living with HIV were observed. Representatives of HIV vulnerable groups slightly more often complained on violation of their rights (23%) than respondents not belonging to them (15%).

When respondents were given a list of actions in some way illustrating the violation of PLWH rights (Fig. 3.5), and offered to indicate whether any of such things happened to them in the last 12 months, then as much as 40% of interviewees (41% in 2010) stated that some of the listed or similar violations had taken place. This exceeds twice a share of respondents who gave an affirmative response to the question on whether their rights had been violated (20%). No significant differences in frequency of these or those events that have happened to respondents due to their HIV status, if compared to the previous research, are observed.

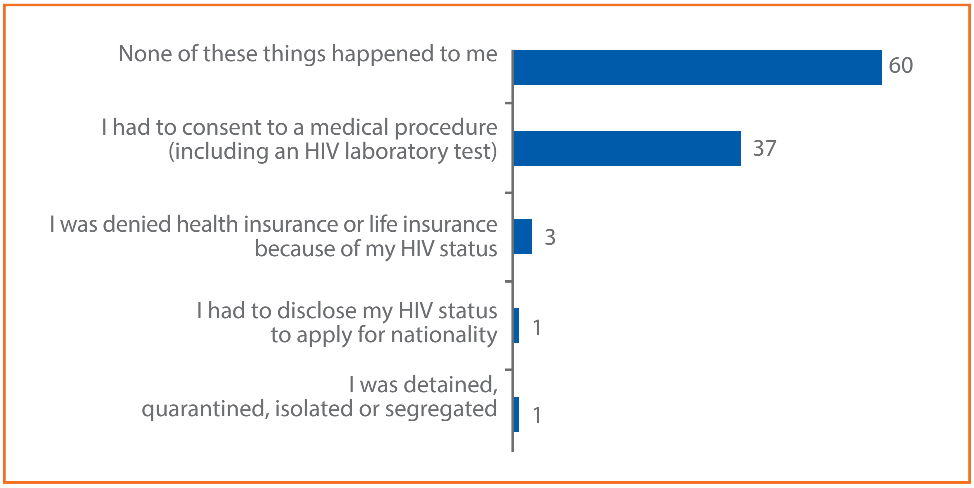


Fig. 3.5. **Events that happened to a respondent during the 12 months and were related to his/her HIV-positive status,** %

33% of interviewees (31% in 2010) among those whose rights were abused in the last 12 months tried to get legal redress (Fig. 3.6). It should be noted that a share of respondents, who after consultations have decided to proceed with specific actions and stand for their rights, has increased 10% if compared to 2010 (88% and 78% correspondingly).

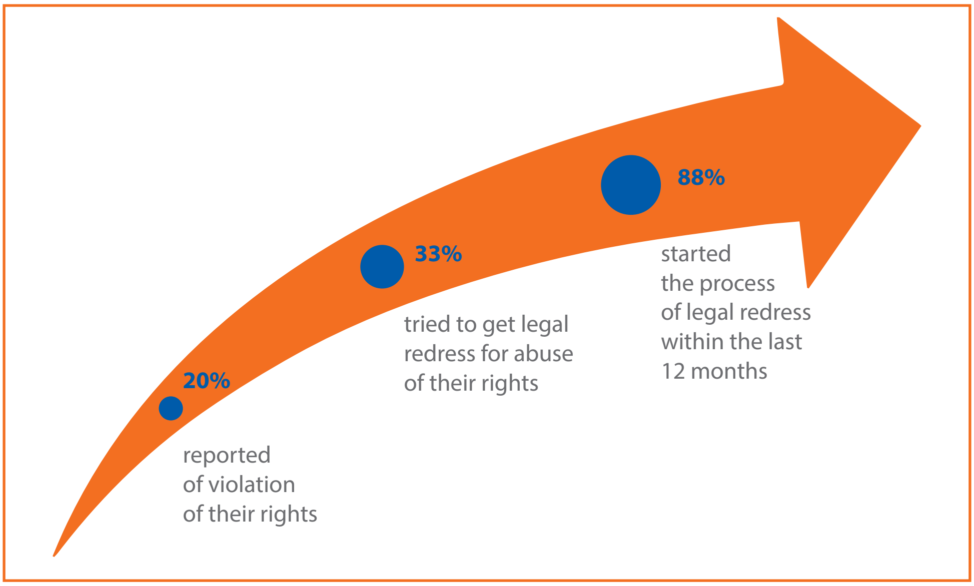


Fig. 3.6. **Violation of human rights and actions taken,** % among those who reported the fact of human rights violation (N=295)

Based on the survey results, efforts of a significant number of respondents made to uphold their rights have been unavailing: 40% (43% in 2010) of interviewees failed to achieve at least some positive result (Fig. 3.7).

As in the previous survey, 26% of interviewed PLWH tried to protect their rights with support of government employees. 94% of such respondents applied for their support in the last 12 months. Results of protecting one's rights with support of government employees are represented in Fig. 3.8. No significant differences if compared with the survey results of 2010 were observed.

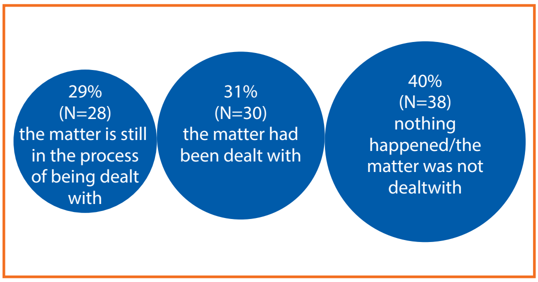


Fig. 3.7. **The outcome of seeking legal redress,** among those who sought legal redress (N=96), abs. val., %

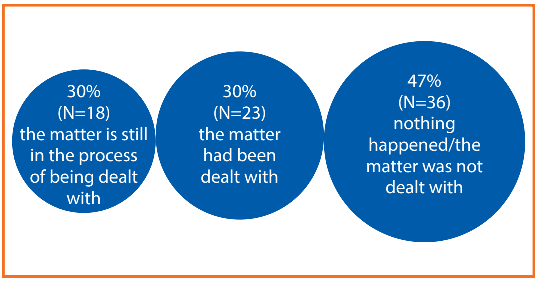


Fig. 3.8. **The outcome of seeking legal redress with support of government employees,** among those who sought legal redress and applied for support of government employees (N=77), abs. val., %

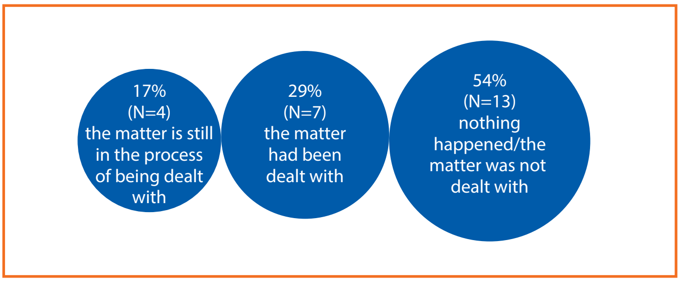


Fig. 3.9. **The outcome of seeking legal redress with support of politicians,** among those who sought legal redress and applied for support of politicians (N=24), abs. val., %

9% of respondents tried to protect their PLWH rights with support of politicians. 92% of them (N=24) – in the last 12 months. However, due to a small number in the PLWH group that applied to politicians it is not possible to make any grounded conclusions regarding results of such applications (Fig. 3.9).

Less than a half of respondents, namely 43%, which is 8% less than in the previous research, were not confident in positive solution of the situation involving the violation of their rights and have not tried to get legal redress (Fig. 3.10).

Bureaucratic process as a reason for not applying for legal redress has shifted, if compared with the previous survey, from the second to the third place: if in 2010 this reason was indicated by 23% of interviewees, then in the current research – 15%. Now the second valid reason for "not applying" by PLWH became insufficiency of financial resources to file a suit, which was indicated by 20% of interviewees in 2010 and 18% in 2013. 4% of interviewees (6% in the previous research) were influenced by surrounding people – their family members or friends advised them against taking any actions.

Fig. 3.10. **Reasons for which respondents did not seek legal redress,** among those who did not seek legal redress (N=119), %

Thus, despite the fact that most PLWH know their rights stipulated by the Law of Ukraine On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and Social Protection of the Population, only 33% of respondents try to protect them in case of violation. A large number of people not identifying actions towards them as illegal also raises concern. What should also be noted is the absence of dynamics in the structure of respondents' answers if compared with the previous research results, which in its turn demonstrates that the measures taken in the country to improve the legal condition of HIV-positive people have not resulted in significant changes over the last three years.

3.2. COMBATING STIGMA AND DISCRIMINATION

25% of interviewed PLWH, which is 12% than in the previous research, in the last 12 months, had to confront or inform someone who stigmatized or discriminated against them (Fig. 3.11).

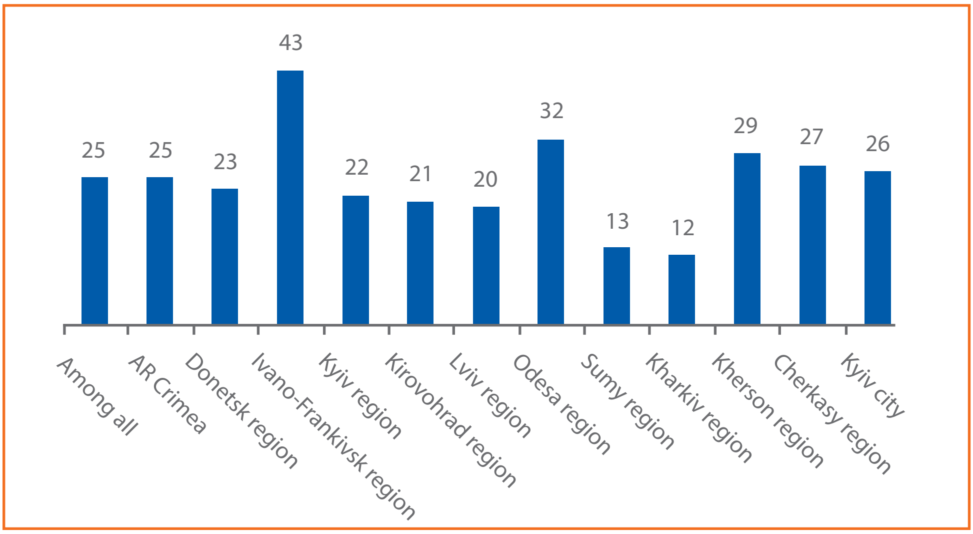


Fig. 3.11. **Respondents who faced, informed or confronted those who were stigmatizing or discriminating against them in the last 12 months,** % by regions

The majority of respondents (86%) are informed about organizations or groups from which one can seek help in case of experiencing stigma or discrimination against them. 32% of them did use such opportunity, which is 11% more than based on the previous research results. However a share of PLWH who do not possess necessary knowledge remains unchanged – 14%.

Most often, as in the previous research, respondents named such organizations known to them as the Network of People Living with HIV, PLWH support groups and other non-governmental organizations (Fig. 3.12).

It is rather common for PLWH to support other people living with HIV. Thus, 62% of respondents (75% in 2010) reported having done this. Most often (96%) such support was in the form of emotional participation in life of other PLWH (e.g., telling personal stories, sharing experience). 32% of interviewees supported PLWH providing material assistance (e.g. financial aid, food supplies), and 38% shared information on agencies where to apply. No significant differences by years with regard to types of mutual assistance between PLWH were observed.

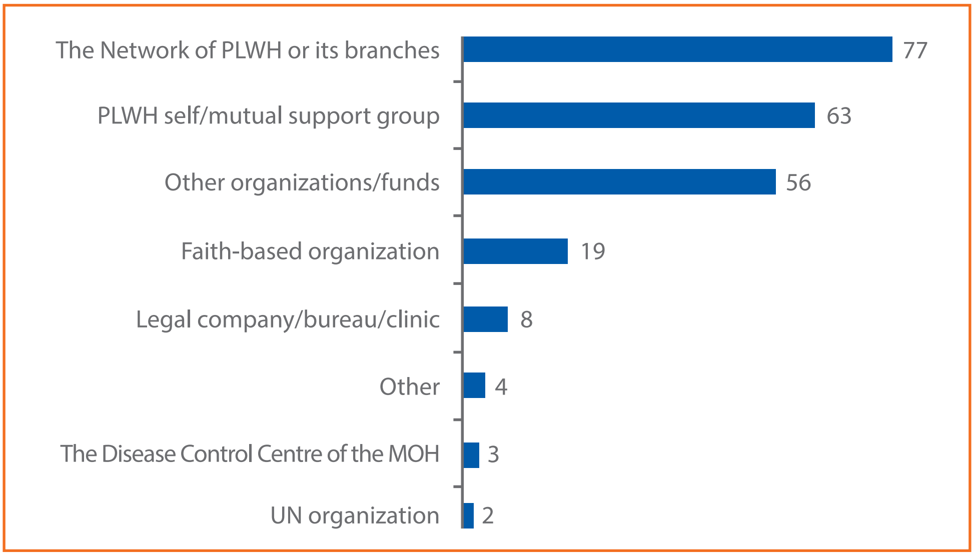


Fig. 3.12. **Distribution of respondents' answers to the question, "Which kinds of organizations or groups do you know about?",** % of those informed about NGOs to which they can apply in case of experiencing stigma or discrimination (N=1283)

A share of respondents who at the time of the research were members of PLWH support groups or the Network of PLWH has decreased if compared with the previous research – 23% and 35% correspondingly. A share of those who are members of PLWH support groups or the Network of PLWH rather increases with the increase in the length of living with HIV (Fig. 3.13).

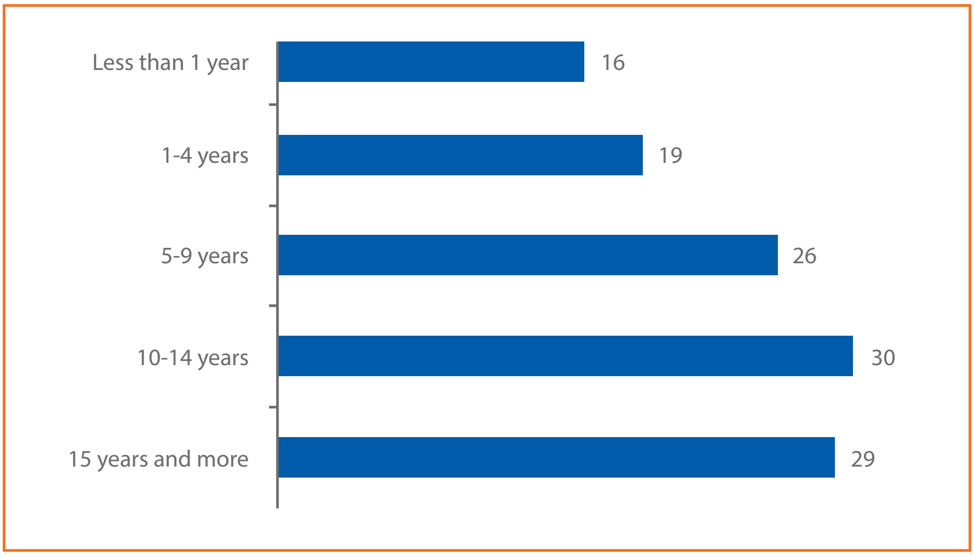
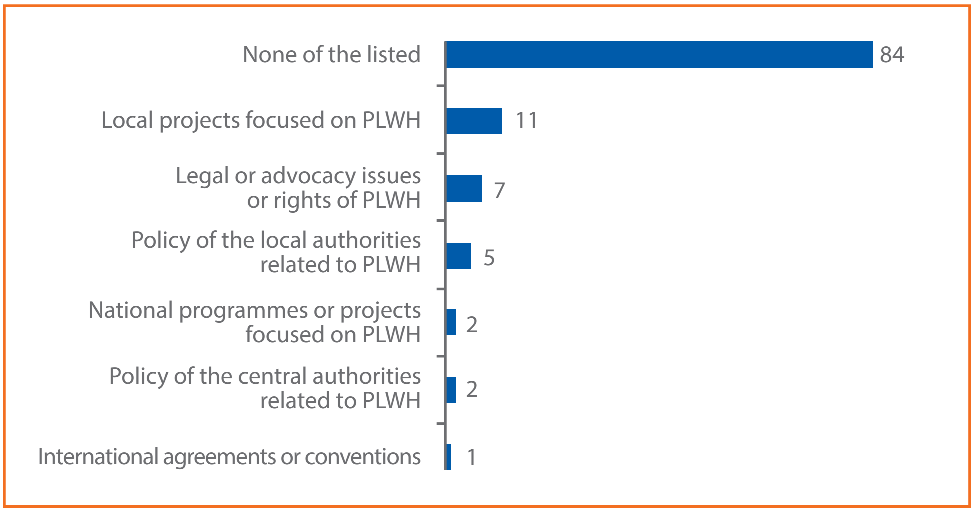


Fig. 3.13. **Respondents' membership with support groups and/or the Network of PLWH,** %, depending on the length of living with HIV

A share of respondents who, in the last 12 months, were engaged as volunteers or workers in some programme or project, whose mission was to provide assistance to PLWH, is even less and makes up 19% which is 12% less than in the previous research.

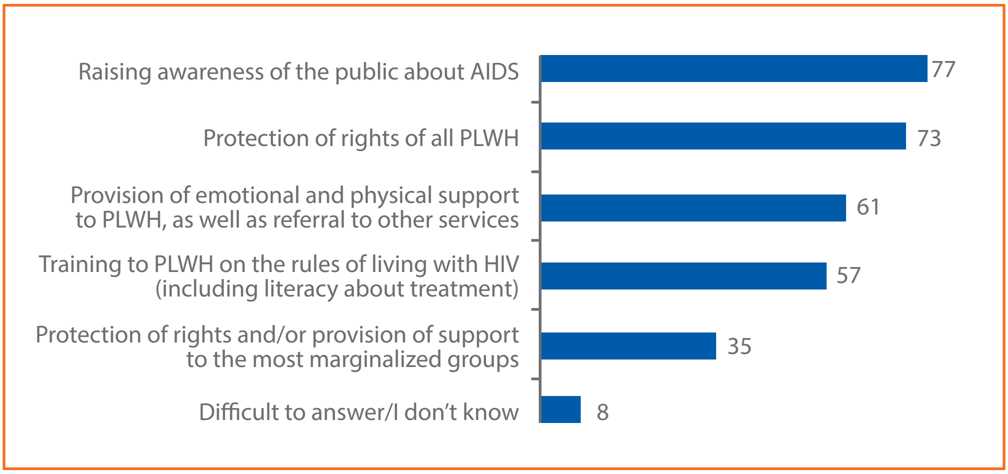
Most of interviewees (84% in 2013 and 71% in 2010) do not believe they have any power to influence any aspects of life of the PLWH community (Fig. 3.14). A share of interviewees who were able to make any influence on state and regional policy is actually even less. In the last 12 months, only 2% of interviewees (5% in 2010) were involved in the development of legislation, policies or guidelines related to HIV.



* Sum exceeds 100% as respondents could choose several answer options.

Fig. 3.14. **Respondents' feelings about being able to influence decision making regarding any of above issues,** %

In respondents' opinion, the most important thing which should be done to address stigma and discrimination against PLWH is raising awareness of the public about AIDS and advocating for the rights of all PLWH (Fig. 3.15). Comparison of data by years is complicated by the fact that in the 2010 questionnaire respondents were allowed to choose only one answer option, whereas in 2013 – all the relevant. However rating of measures is mostly the same: the first place in the previous survey was advocating for the rights of all PLWH (37%), the second – raising awareness of the public about HIV/AIDS (34%), and further on – in the same order as in the current survey.



Note. Sum exceeds 100% as respondents could choose several answer options.

Fig. 3.15. **Opinion as for areas on which organizations should focus their activities to address stigma and discrimination, %**

So, if compared with 2010, a share of people who applied to organizations able to help in solving problems related to stigma or discrimination has increased from 21% to 32%. It should be noted that a share of respondents living with HIV for less than 1 year and are members of support groups and other associations of PLWH has not significantly changed in the current survey (16%) if compared with 2010 (19%). These are most vulnerable people as they have rather limited experience of living with HIV and could be in need of constant emotional support.

Unchanged pessimistic perception by PLWH of their abilities to influence various areas of PLWH life is also alarming.

TESTING, DISCLOSURE, TREATMENT,HAVING CHILDREN

4.

TESTING, DISCLOSURE, TREATMENT, HAVING CHILDREN

4.1. TESTING & DIAGNOSIS

The data of the current survey demonstrate maintenance of the tendency in rating of reasons for taking HIV test. Top positions are as follows: desire to know one's status, referral by health care facilities due to existing symptoms that could be associated with HIV, and examination due to pregnancy. The same way as three years ago, HIV test is not popular when preparing for a marriage or sexual relationship (Fig. 4.1).

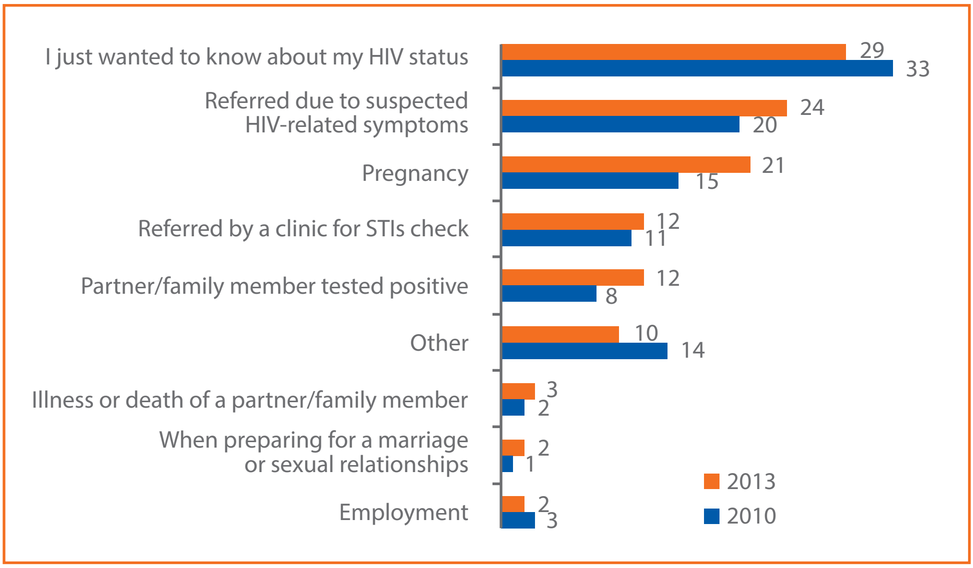


Fig. 4.1. **Reasons for taking an HIV test,** % by years

At the same time importance of factors caused by medical indications has largely increased this year, including pregnancy and suspicion for symptoms associated with HIV: at least one of the above reasons for VCT in 2013 was chosen by 44% of respondents, whereas in 2010 they were 9% less (35%)[5].

The situation generally remains unchanged with women learning their HIV status more often during planned examination due to

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[5] Statistical discrepancy is 3%.

pregnancy, and men – due to existing symptoms that may be associated with HIV, and also out of pure interest.

Much more interviewed female PLWH have taken VCT due to pregnancy in 2013 (41%) than in 2010 – 32% (Table 4.1). These data confirm a tendency of gradual actualization of the sexual route of HIV transmission and its spread out of the circle of HIV vulnerable groups. In addition, the data obtained may demonstrate increased volumes of HIV tests in pregnant women in health care facilities across the country.

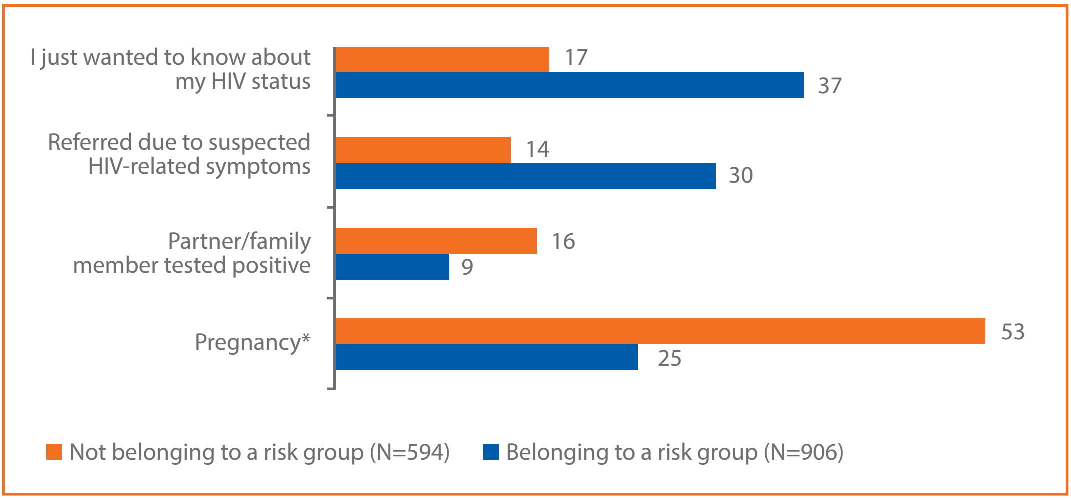
What concerns men, a share of those referred to VCT due to suspected HIV has increased if compared with 2010 (from 26% to 33%) and decreased for those whose major motive was pure interest. Also this year, contrary to 2010, men more often than women have taken VCT by doctor's referral to check for STIs (Table 4.1).

Table 4.1. **Reasons for taking an HIV test,** depending on sex, %

	Men		**Women**	
	2010 (N=822)	2013 (N=746)	2010 (N=677)	2013 (N=754)
Referred by a clinic for STIs check	12	**15**	10	**9**
Pregnancy	0	1	**32**	**41**
Referred due to suspected HIV-related symptoms	**26**	**33**	13	15
I just wanted to know about my HIV status	38	37	**28**	**22**

Note. Differences are significant if exceed 4%.

The fact remains unchanged that PLWH not belonging to any vulnerable group take a test due to pregnancy more often than others, as well as after their family member or partner has been tested positive, and much less frequent – just to satisfy their wanting to know or by referral due to suspected HIV-related symptoms (Fig. 4.2).



** The indicator is calculated for women not belonging to a risk group (N=443) and belonging to it (N=311)*
Note. Statistical discrepancy is +/–6% for the pregnancy indicator and +/–4% for other indicators

Fig. 4.2. **Reasons for taking an HIV test,** depending on respondent's belonging to vulnerable groups, %*

The last year tendency maintains of the increase with age of the share of those referred for testing due to HIV-related symptoms. It turned to be opposite for such factor as a desire to know one's status. If in 2010 a number of those willing to know their HIV status has decreased with age (from 54% in the group aged 15-19 to 36% – aged 50 and older), than in 2013 it has vice versa increased (from 25% to 35%) (Table 4.2).

Table 4.2. **Reasons for taking an HIV test,** depending on respondents' age, %

	Age, years			
	17-29 (N=337)	**30-35** (N=488)	**36-45** (N=515)	**46 and older** (N=130)
Pregnancy*	55	49	28	3
Referred due to HIV-related symptoms	14	21	29	35
I just wanted to know	25	28	32	35

Note. Differences are significant if exceed 8%.
** The indicator is calculated for women only.*

The length of living with HIV has no significant impact on the distribution of responses regarding reasons for testing.

The same way as a few years ago, the vast majority of respondents have decided to take a test independently and voluntarily. If compared with 2010, the reduction in the share of those who has taken VCT without personal consent is noticeable (taking into account the statistical discrepancy of 3%): from 12% to 7% in 2013 (Fig. 4.3).

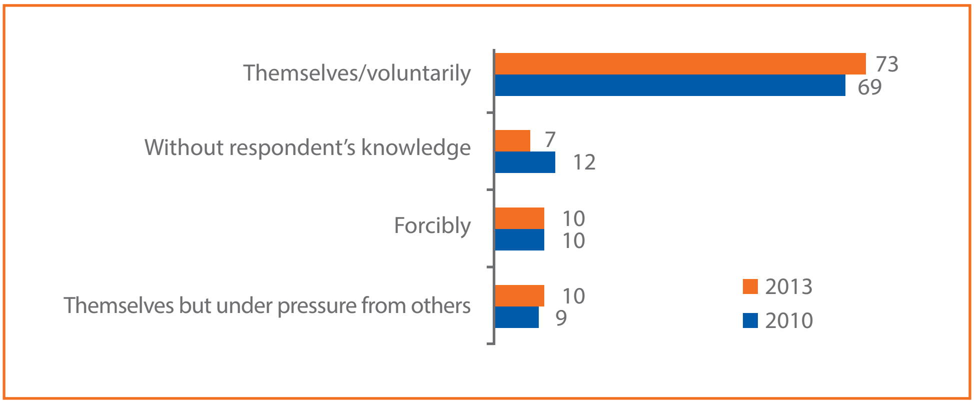


Fig. 4.3. **Voluntariness of respondents' decisions to undergo VCT,** % by years

A single criterion significantly impacting on the distribution of respondents' answers voluntariness of their decision to take VCT in 2013 was the length of living with HIV, as opposite to 2010, where respondents' answers also varied depending on a risk group and age.

As a whole, a tendency remains stable with a share of those having taking a test voluntarily decreasing the longer they have been living with HIV: from 80% for those who have been living with HIV for less than 1 year to 48% for respondents with the length of living with HIV for over 15 years (Table 4.3).

Table 4.3. **Voluntariness of a decision to undergo VCT,** depending on the length of living with HIV, %

	0-1 years (N=165)	**1-4 years** (N=498)	**5-9 years** (N=489)	**10-14 years** (N=241)	**Over 15 years** (N=100)
Themselves (voluntarily)	82	80	**73**	60	48
Themselves but under pressure from others	7	9	10	13	16
Forcibly	10	7	8	14	18
Without respondent's knowledge	2	4	8	13	18

Note. Data significantly exceeding the statistical discrepancy are marked in bold.

Positive changes have been observed in VCT quality. In 2013, 49% of interviewed PLWH received full (pre- and post-test) counselling as required by the Procedure for Voluntary HIV Counselling and Testing (Protocol), which is 6% (taking into account the statistical discrepancy of 3%) above the relevant indicator of 2010 (40%). Such increase was due to specifically the decrease (in 7%) of the share of those who have not received any pre- or post-test counselling during the HIV test (Fig. 4.4).

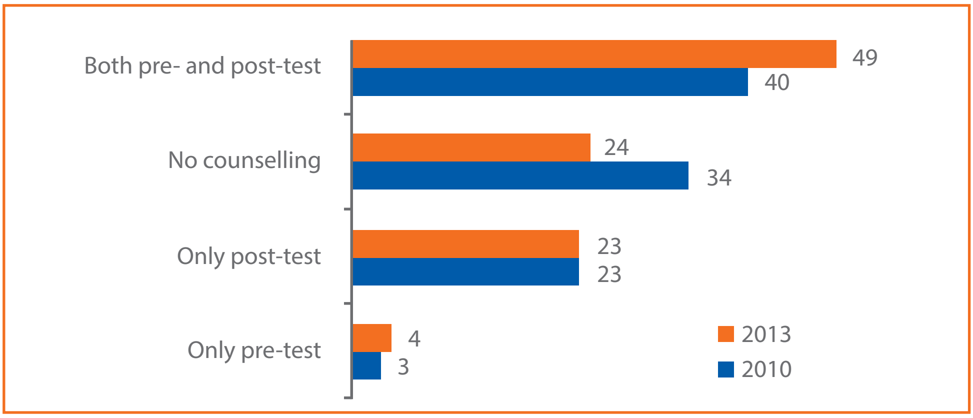


Fig. 4.4. Distribution of answers to the question: **"Did you receive counselling when you were tested for HIV?",** % by years

Improvement of VCT quality specifically for the last years is proved by maintenance of the tendency observed in 2010 for the decrease of the share of those having received full counselling with the increase of the length of living with HIV: from 62% for those who was HIV diagnosed not more than a year ago, to 28% for those who have been living with HIV for over 15 years (in 2010 – from 58% to 19% correspondingly) (Table 4.4).

Table 4.4.

Distribution of answers to the question: "Did you receive counselling when you were tested for HIV?", depending on the length of living with HIV, %

	0-1 year (N=163)	**1-4 years** (N=495)	**5-9 years** (N=487)	**10-14 years** (N=96)	**Over 15 years** (N=101)
Both pre- and post-test	**62**	**58**	**48**	31	**28**
Only pre-test	4	5	4	6	1
Only post-test	21	23	24	23	21
No counselling	**14**	**15**	**24**	40	**51**

Note. Differences are significant if exceed 10%.

Quality VCT is provided to PLWH not depending on their belonging to vulnerable groups. Thus, both PLWH with the experience of HIV risk practices and without such (49% each) similarly stated that they have received full (pre- and post-test) counselling when being tested for HIV. At the same time, PLWH who anytime belonged to vulnerable groups are more often left without any counselling, whereas for the rest of respondents VCT was more often limited to a post-test conversation (Fig. 4.5).

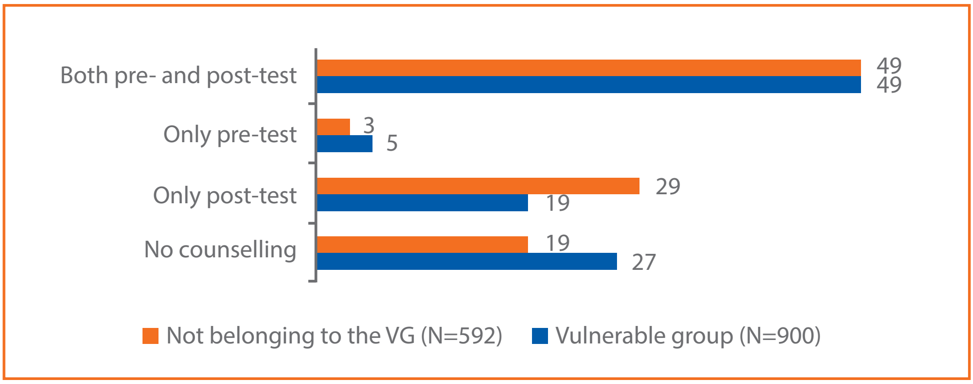


Fig. 4.5. Distribution of answers to the question: **"Did you receive counselling when you were tested for HIV?"**, depending on respondent's belonging to vulnerable groups, %

There are objective reasons for the prevalence of VG representatives among those who were left without any pre- or post-test counselling. In particular, IDUs more often than others are hospitalized in critical conditions requiring rapid decisions on the part of doctors, including as for the blood collection for an HIV test.

The vast majority of PLWH have undergone VCT within three months from the moment they had first thought of taking an HIV test (69%). If compared with 2010 this share has significantly increased (9%).

"I was in a subconscious state, and doctors wouldn't approach me as I was a drug addict... Afterwards they've taken some blood having explained that this was needed for some diagnosis, related to liver or something… My mum has told me that it was an HIV test, and that it was positive. Afterwards a head doctor came in and said that I had AIDS… This was a total shock. I haven't been prepared for such, no one has explained anything to me, I didn't know anything about this" (life story, Kyiv region).

Note. Statistical discrepancy is 3%.

Fig. 4.6. **Time gap between the moment when respondents first thought of testing and the moment they underwent it, %**

The time gap between the decision and the HIV test is shorter for women (76% have been tested within three months, versus 62% of men), and PLWH not belonging to vulnerable groups (82% versus 60% for those who had experience of risk practices). This is mostly caused by a planned test for HIV for women during pregnancy.

Apart from objective reasons the time gap between the moment of deciding to take a test and the moment of testing may be also prolonged by respondents' fears of negative social consequences should the test be positive. Similarly to the previous research data, more than a half (55% in 2013 versus 58% in 2010) of interviewees has admitted they were afraid of the possible reaction from the social environment (family members, friends, and co-workers) before they took an HIV test.

This was more often referred to by women (61%) than men (49%); by respondents without risk practices experience (61%) than those with such experience (51%). Such fear is rather more typical for young people aged 17-29 (60%) rather than respondents above 46 (44%) (Fig. 4.5).

Fig. 4.7. **Percentage of those who feared to take a test due to a possible reaction from other people should the HIV test be positive,** % to those who answered this question (N=1366)

As a whole only a third (30%) of interviewed PLWH stated that they had no fears related to a possible positive HIV test. A leader among all fears mentioned by interviewed PLWH is the fear of being abandoned by their friends and families in case of an HIV-positive test. However if compared with 2010 this share has slightly decreased: from 58% to 53% (statistical discrepancy is 3%). A share of those being doubtful about whether PLWH can get married has also decreased (from 27% to 19%). On the other hand, a fear of interviewed PLWH as for disclosure of information about their extramarital sexual relations or belonging to MSM, SW or IDU groups has become more acute: from 10% to 18% (Table 4.5).

Table 4.5. Distribution of answers to the question: **"Have you been afraid that any of the following things would happen if you were tested positive?", %***

	2010	**2013**
No fears* **	-	**30**
My friends and family will stay away from me	**58**	**53**
I will not be able to get married	**27**	**19**
My partner will abandon me	19	17
People may think that I am sexually promiscuous; that I am a MSM, a SW or an IDU	17	18
I will be forced to terminate pregnancy	17**	16**
I will lose my job or be expelled from education	16	18
I will be subjected to psychological violence from other family members	16	20
My children will be mistreated within our family, community or at school	13	16
I will be subjected to psychological violence from my partner	11	13
People may get to know that I have had extramarital sexual relationships or have them now; that I am a MSM, a SW or an IDU	**10**	**18**
I will be forced to leave my home or move to another place	8	10
My children will be taken away from me	7	9
Police or other law enforcement bodies may try to initiate criminal proceedings against me	6	6
I will be subjected to psychological violence from the members of my community	4	6
Other fears	**30**	5

**Sum exceeds 100% as respondents could choose several answer options.*

***The indicator is calculated for women only.*

****The questionnaire used in the survey in 2010 did not contain an answer option "No fears".*

PLWH not belonging to VGs are usually more afraid of possible consequences of a positive HIV test than other respondents: 25% and 33% of respondents correspondingly have chosen the option “No fears”. The former, more often than VG representatives, are afraid of their families and friends staying away from them (58% and 49% correspondingly), of losing a job or being expelled from education (22% and 14%), of their children being mistreated by other people (22% and 11%), of being forced to terminate pregnancy (19% versus 11%), and of being deprived of parental rights (14% and 6%). Whereas PLWH having experience of HIV/AIDS risk practices are more afraid of disclosure of their belonging to the IDU, SW, LGBT group or accusation in extramarital sexual relations (15% versus 7% for those not belonging to VGs) (Table 4.6).

Table 4.6. Distribution of answers to the question: **“Have you been afraid that any of the following things would happen if you were tested positive?”,** depending on respondents’ belonging to vulnerable groups, %

	Belong to VG (N=906)	**Do not belong to VG** (N=594)
No fears	33	25
My friends and family will stay away from me	49	58
I will be forced to terminate pregnancy	11*	19*
I will lose my job or be expelled from education	14	22
My children will be mistreated within our family, community or at school	11	22
People may get to know that I have had extramarital sexual relationships or have them now; that I am a MSM, a SW or an IDU	15	7
My children will be taken away from me	6	14

Note. Differences are significant if exceed 5%.
**The indicator is calculated for women.*

As a whole women are more afraid than men of stigma and discrimination as possible consequences of HIV diagnosis. This is proved by a much lower share of women who stated that they had no fears before VCT: 23% versus 37% among men. The same with much higher indicators for separate criteria. Thus, apart from family and friends staying away and psychological violence in case of a positive HIV test, women are twice more afraid of negative attitude of other people to their children (23% and 8%), possible deprival of parental rights (13% and 6%), and of course forced termination of pregnancy (16%).

Significance of any fears reduces with age. Absence of fears was stated by 39% respondents aged over 46, whereas in the youngest group (aged 17-29) there were far less of such (27%). The following indicators for the oldest age group were slightly lower than those for other age groups: as for fears related to family members staying away (42% and 54% for those aged 17-29), impossibility to get married (12% and 25% correspondingly), termination of pregnancy (0% and 13%), and possible ruining of family relations (5% and 21%). Age differences for other indicators are statistically insignificant and do not exceed discrepancy of 10%.

So, if compared with 2010, in the rating of reasons for taking VCT there was the increase in significance of factors caused by medical indications, including pregnancy and suspected HIV-related symptoms: at least one of the above reasons for VCT in 2013 was chosen by 44% of respondents, whereas in 2010 they were 9% less (35%)[6]. This demonstrates the general increase of volumes of HIV tests in pregnant women in health care facilities across the country.

The indicator of voluntariness of HIV testing has slightly improved, in particular a share of those who underwent a test without their personal consent has decreased (from 12% to 7% in 2013).

Quality of pre- or post-test counselling has improved which is proved by the increase from 40% in 2010 to 49% of the share of those who received full counselling as required by the Procedure for Voluntary HIV Counselling and Testing (Protocol).

The tendency of the increase in tests in first three months after a relevant decision has been taken is positive: from 60% to 69%.

A third (30%) of interviewed PLWH stated that they had no fears related to a possible positive HIV test. A leader among all fears mentioned by interviewed PLWH is a fear of being abandoned by their friends and families in case of an HIV-positive test. However if compared with 2010 this share has slightly decreased – from 58% to 53%.

4.2. DISCLOSURE AND CONFIDENTIALITY

Over the last three years the situation with observance of PLWH rights to anonymity, confidentiality and medical secrecy guaranteed by the Ukrainian legislation[7]. This is proved by the significant decrease of the HIV status disclosure indicator[8]: from 37% in 2010 to 24% in 2013. In particular, there is a decrease in a share of respondents who reported about unauthorized disclosure of HIV status by health care professionals (8% versus 13% in 2010). The data for such representatives of the social environment as friends and neighbours is not subject to comparison by years as in the previous research they were united in one group, whereas in the current research they are separated. This was made based on respondents' comments that "friends and neighbours" are totally different things" (Table 4.7).

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[6] Statistical discrepancy is 3%.

[7] Article 8 of the Law of Ukraine On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and Social Protection of the Population # 1972-XII dated 12 December 1991.

[8] A share of respondents who at least once experienced the situation when the information on their HIV-positive status was disclosed to other people without their consent.

Table 4.7. **Ways of informing people about the respondent's HIV status, %***

	I told them		Someone else told them, WITH my consent		Someone else told them, **WITHOUT my consent**		They don't know my HIV status		Not applicable	
	2010	2013	2010	2013	2010	2013	2010	2013	2010	2013
Your husband/wife/partner	68	69	2	1	3	2	6	8	22	20
Other adult family members	64	64	4	3	10	6	18	19	7	8
Children in your family	13	12	1	0	2	1	**36**	**41**	48	46
Your friends (including neighbours for 2010 data)	**33**	**49**	3	1	**13**	**6**	**48**	**37**	8	7
Your neighbours	-	3	-	0	-	6	-	72	-	19
Other PLWH	**82**	**70**	5	4	7	3	**8**	**18**	4	5
Your co-workers	**21**	**11**	2	0	4	2	39	41	37	46
Your employers or managers	**19**	**10**	3	0	2	1	37	39	41	50
Your clients	**14**	**5**	2	0	2	0	25	27	59	68
Injecting drug partners	**41**	**29**	2	0	6	3	13	9	44	59
Religious leaders	18	14	1	0	1	0	15	11	66	75
Community leaders	**15**	**10**	1	1	1	0	**15**	**10**	69	79
Health care professionals	63	64	6	8	**13**	**8**	12	14	8	6
Social workers or counsellors	83	85	5	6	3	2	5	3	7	4
Teachers	2	0	0	0	1	0	13	10	85	90
Government officials	4	2	1	0	1	0	**18**	**10**	77	88
Mass media	4	2	1	0	0	0	**18**	**9**	77	89

Note. Differences are significant if exceed 3%.

** Sum in a line exceeds 100% as respondents could choose several answer options.*

"My child attends a specialized boarding school. When I brought my child at the beginning of 2012 school year the school nurse came up to me and asked me to disclose my child's status to the teacher and director… She was afraid that if

Respondents living with HIV for over 10 years (32%) more often experienced their HIV status disclosure than those living with HIV for less than 10 years (21%). No significant differences depending on sex and respondents' belonging to VGs were observed.

If compared with 2010 a share of PLWH who at least once experienced pressure on the part of other PLWH or PLWH groups/networks regarding disclosure of their HIV status has decreased almost twice (from 13% to 7%). Also, respondents less frequently reported about pressure on the part of people not having HIV diagnosis, though differences by years do not exceed 1% taking into account 3% discrepancy (Table 4.8).

this information became known from any other sources she would have problems. I was afraid as there is only one boarding school in the city… though I know that the nurse attended the lectures on HIV/AIDS and knew all aspects» (life story, Kyiv)

Table 4.8. **Distribution of answers to the question: "How often did you feel pressure to disclose your HIV status?",** by years, %

	2010	**2013**
From PLWH, PLWH groups/networks		
Often	2	1
Several times	8	4
Once	3	2
Never	87	93
From people not living with HIV		
Often	3	2
Several times	10	8
Once	3	2
Never	84	88

Note. Differences are significant if exceed 3%.

What concerns pressure from other PLWH, groups/networks of PLWH, it was more often experienced by respondents whose length of living with HIV exceeds 15 years (18%), and less frequently by those whose status has been established within the last year (5%). Age, sex, belonging to vulnerable groups, and a type of location where a respondent resides have no statistically significant impact on the distribution of answers.

In one of the life stories a respondent described the situation when pressure regarding disclosure of HIV status was made by a nurse of the boarding school who insisted on notifying the teacher and the headmaster of the school about the respondent's child's diagnosis.

The data obtained show improvement of the situation with observance of medical secrecy by health care professionals. As in 2013 there was a 4% decrease (taking into account statistical error of 3%) in a share of respondents who reported about the facts of disclosure by doctors of the respondent's HIV status without his/her consent (Fig. 4.6).

"As our town is small, the health care staff learned my HIV status, then it went further. The health care worker lives in the same street, she told the people next door, and they told their friends. My co-workers learned… The landlady learned and forced my daughter to vacate the rented apartment. All the conditions were created for my daughter in her educational institution and they "pushed" her out from there. She had to leave" (life story, Sumy).

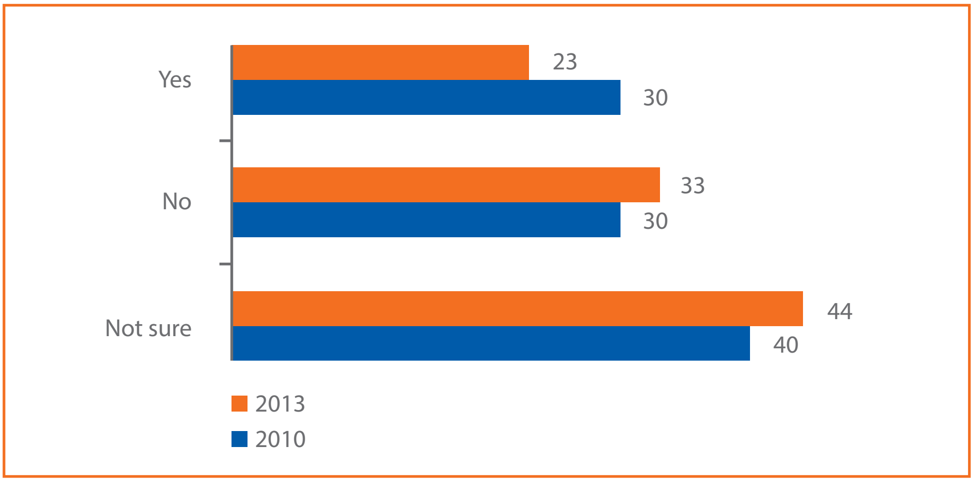

Fig. 4.8. Distribution of answers to the question: **"Have health care professionals (e.g. a doctor, a nurse, a counsellor, a laboratory assistant) told other people about your HIV status without your consent?",** by years, %

"I had been trying for a while to prove to the kindergarten manager that my child was healthy. I would say that I could present a medical certificate but she wouldn't hear me. She yielded that no medical certificate was needed as «all the hospital» knew what my husband had died of, and that I was «the same» (life story, Sumy).

A share of those who experienced cases of disclosure of their HIV status by health care workers significantly increases with the length of living with HIV: from 9% for those living with HIV for less than a year to 35% for those whose experience varies within 10-14 years (under discrepancy of 10%). However for the group of respondents living with HIV for 15 years and more the relevant indicator largely decreases – up to 22% (Fig. 4.7).

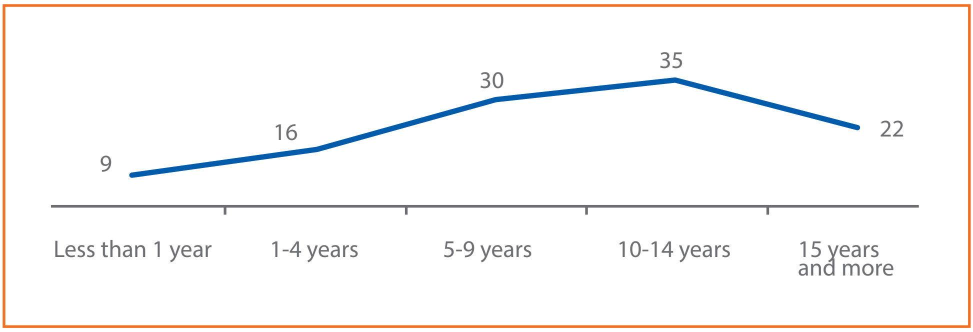

Fig. 4.9. **Percentage of respondents who reported about the facts of disclosure of their HIV status by health care professionals without their consent,** depending on the length of living with HIV, %

Women more often experienced disclosure of their HIV status by health care workers (28% and 19% for men). Whereas the fact of HIV/AIDS risk practices has no significant impact in this case.

Despite some improvement in the situation with observance of medical secrecy PLWH keep experiencing "unauthorized" disclosure of HIV status by health care professionals, mostly at general profile health care institutions (more often by nurses). Life stories vividly illustrate consequences of health care workers' neglect of ethical norms with regard to HIV patients touching not only PLWH, but also their families, children, and social environment.

PLWH's assessments of the level of HIV medical records confidentiality have also improved. Thus, if compared with 2010 a share of respondent confident in absolute confidentiality of such documentation has increased (from 18% to 24%), and a share of those having an opposite opinion has decreased (from 34% to 27%) (Fig. 4.7).

"The stock manager of the shop where I work once told me about two women having come to the shop asking whether I worked there, and then said: "The matter is that we know her (my) husband very well, this woman has AIDS, so if you don't dismiss her, you won't have normal customers"… The kindergarten my child attended was just across the street from where I lived. Every morning I took backways to take my daughter to the kindergarten. I couldn't go for a walk with my kid. I had to go for a walk with her to another park or forest not to meet other people… I hated myself, and everybody. Such a feeling as if everybody knew, as if everybody perked a finger in me, I didn't want anything…" (life story, Kyiv).

"The head of the hospital department informed my relatives about my HIV status and said that I had 6 months to live. I believe she had no right to talk to my relatives of this. After that my relatives stopped communicating with me… They decided to protect my child from me... The social service for children's rights protection filed a suit. We were successful in action. Then there was a second suit – and again we were successful. Our child stayed with us" (life story, Kirovohrad).

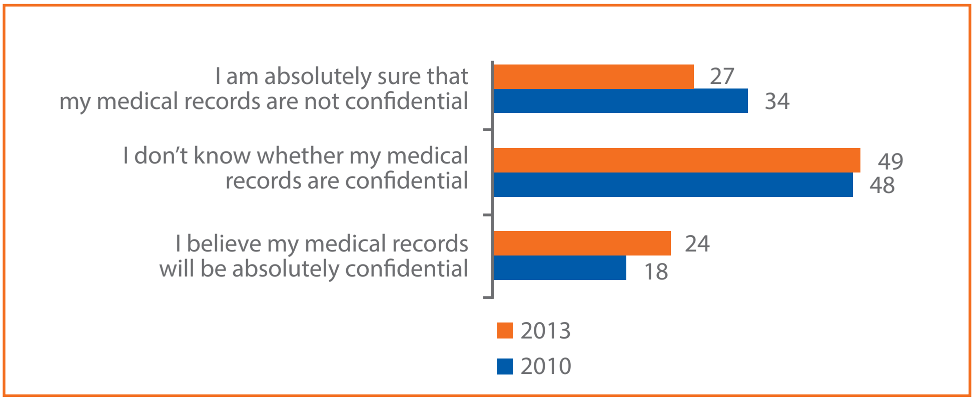

Fig. 4.10. Distribution of respondents' answers to the question: **"In your opinion, to what extend the medical records related to your HIV status are confidential?", %**

At that PLWH not belonging to VGs complained more often on the absence of proper conditions for ensuring confidentiality of PLWH medical records: 32% and 20% for those who have experience of HIV/AIDS risk practices (statistical discrepancy is 4%).

Impact of the age criterion is more significant than the length of living with HIV. With age the share of those confident in lack of confidentiality of medical records reduces: from 33% for young people under 29 to 12% for PLWH aged over 45.

Men more often than women tend to believe that these records are not kept confidential. Though these differences are insignificant as they exceed discrepancy (of 4%) for 2% only.

What has not changed since 2010 is the character of the reaction of the social environment to disclosure of HIV status by PLWH: in most cases relatives and friends do not change their attitudes to PLWH after the latter's status is disclosed or prove to be supportive. The highest level of support is generally provided by social workers and counsellors, as well as by other PLWH. Whereas the lowest level is displayed by health care professionals (Table 4.9).

At the same time, if compared with the previous research, the attitude of health care workers has improved. In particular, a share of PLWH who experienced discriminating attitude from representatives of this social group towards them has decreased (from 24% to 18%), with the increase in a share of those who indicated their reaction as "attitude has not changed" or even "supportive" (Table 4.9).

Statistically significant decrease in a share of those who indicated the absence of any changes in the attitude towards themselves from co-workers, employers and other more distant social groups is also observed (Table 4.9).

Table 4.9. **Reaction of other people when they first knew about the respondent's HIV status, %**

	Very discriminatory		**Discriminatory**		**No different**		**Supportive**		**Very supportive**		**Not applicable**	
	2010	2013	2010	2013	2010	2013	2010	2013	2010	2013	2010	2013
Your husband/wife/partner	3	2	5	4	24	20	25	28	16	19	27	27
Other adult family members	3	2	7	5	22	20	29	31	17	17	22	25
Children in your family	0	0	1	0	7	5	6	6	4	3	82	86
Your friends (including neighbours for 2010 data)	1	0	8	3	27	27	14	23	3	4	47	43
Your neighbours	-	1	-	5	-	3	-	1	-	0	-	90
Other PLWH	0	0	0	1	**29**	**22**	47	43	13	11	**11**	**23**
Your co-workers	0	0	2	1	**13**	**7**	9	5	3	1	**73**	**86**
Your employers or managers	1	0	2	1	**11**	**5**	7	4	2	1	**77**	**89**
Your clients	0	0	1	0	**12**	**3**	3	2	1	1	**83**	**94**
Injecting drug partners	0	0	3	1	**36**	**27**	4	5	1	0	**56**	**67**
Religious leaders	0	0	1	1	7	4	10	7	3	3	**79**	**85**
Community leaders	0	0	1	0	5	2	10	7	2	2	**82**	**89**
Health care professionals	4	3	**24**	**18**	**34**	**39**	**16**	**20**	3	3	19	17
Social workers or counsellors	0	0	0	0	19	16	54	56	15	20	12	8
Teachers	0	0	1	0	2	0	1	1	0	0	96	99
Government officials	1	0	2	2	2	1	1	0	0	0	94	97
Mass media	0	0	1	0	3	1	1	1	0	0	95	98

Note. Differences are significant if exceed 3%.

Life stories illustrate both positive and negative changes in the health care worker's attitude after the patient's HIV-positive status is disclosed.

The distribution of PLWH assessments has not changed since 2010 what concerns the impact disclosure of HIV status made on solution of their personal problems. It helped a half of interviewees (53%), whereas a third (34%) experienced only negative consequences of informing other people about their HIV status. Another 13% stated their status remained undisclosed. Though the data obtained should be treated with care. As according to the respondents' comments they quite often thought that this question was about the impact of a HIV-positive individual being aware of his/her diagnosis himself/herself rather than consequences of disclosure of HIV status to other people. Thus, answers as presented below were quite typical: "Of course, disclosure of my status helped me as I started to take care of my health / to receive medical care / have changed my life style."

The longer PLWH have been living with HIV the larger is a share of those whom disclosure of their status helped to solve their personal problems: from 43% for those whose experience is not more than a year to 58% for those with experience of over 15 years.

So, over the last three years, the situation with observance of PLWH rights to anonymity, confidentiality and medical secrecy as guaranteed by the Ukrainian legislation has improved. This year less respondents stated about disclosure of their HIV status[9]: 24% versus 37% in 2010. In particular, there is a decrease in a share of respondents who reported about unauthorized disclosure of HIV status by health care professionals (8% versus 13% in 2010).

If compared with 2010 (13%) a share of PLWH who at least once experienced pressure on the part of other PLWH or PLWH groups/networks regarding disclosure of their HIV status (7%) has decreased almost twice. What concerns non-PLWH no significant changes took place.

The situation with observance of medical secrecy by health care workers has improved slightly: 23% of respondents experienced disclosure of their HIV status by doctors without a relevant consent, whereas in 2010 there were 30% of them.

This year PLWH gave more positive assessment to the level of observance of confidentiality of medical records related to HIV status. Thus, if compared with 2010 a share of respondents confident in absolute confidentiality of such documentation has increased (from 18% to 24%), and a share of those having an opposite opinion has decreased (from 34% to 27%).

If compared with the previous research, the attitude of health care workers towards PLWH has also improved. This year 18% of interviewed PLWH experienced discriminating attitude from health care professionals (24% in 2010).

"The doctor asked for a specific amount of money for the surgery, and having learned my status he doubled it. At the end a doctor from the AIDS centre was called. He said the surgery was not needed otherwise I could simply die" (life story, Kharkiv).

"I told him about HIV. He said: "Ok, I am not afraid of it, hepatitis C is more frightening." I said to him that I would bring face masks, some protection, whatever needed! He said: "It's not fearful. I will do the surgery with no problem»... He did that surgery» (life story, Donetsk).

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[9] A share of respondents who at least once experienced the situation when their HIV-positive status was disclosed to other people without their consent.

4.3. TREATMENT

In 2013, most of interviewees consider their health to be rather good: only about a quarter (27%) of respondents described it as poor, others – as good or fair. Practically the same distribution of respondents' answers to the relevant question was reported in 2010 (Fig. 4.8).

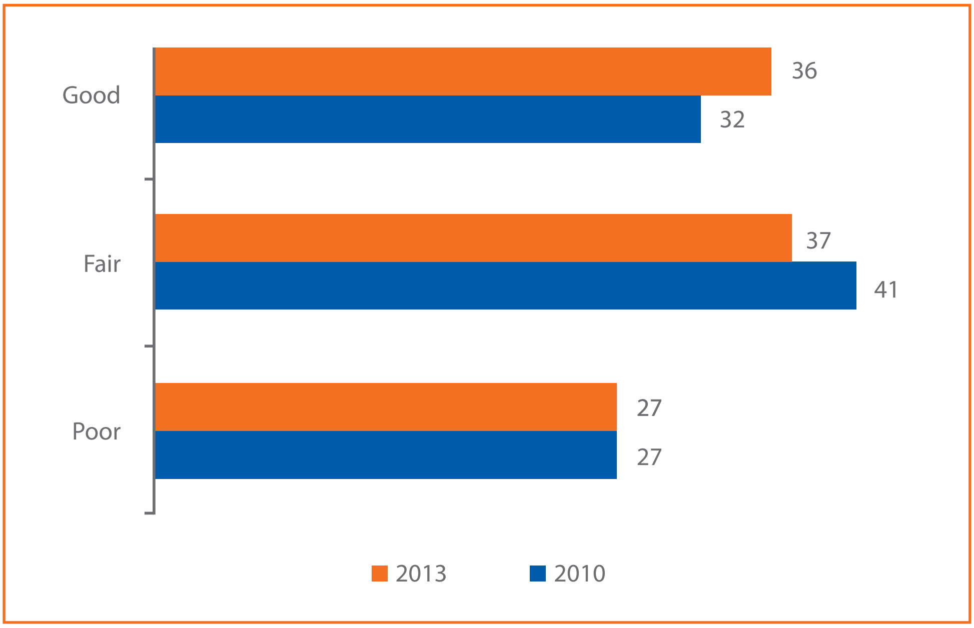

Fig. 4.11. **Respondents' assessment of their health**, % by years

The same way as in 2010, women gave slightly higher assessments of their health than men. A share of those describing their health as good or very good reached 37% for women and 26% for men.

The older the interviewees are and the longer they have been living with HIV their health predictably worsens, with more significant differences observed between the age groups (Table 4.10).

Table 4.10. **Self-assessment of health,** depending on respondents' age, %

	Aged 17-29 (N=337)	**Aged 30-35** (N=488)	**Aged 36-45** (N=515)	**Aged 46-64** (N=130)
Good	43	36	24	20
Fair	41	41	43	33
Poor	16	23	33	47

Note. Differences are significant if exceed 8%.

Respondents not belonging to any vulnerable group show much better health (46% assessed it as good or very good) than those having experience of HIV risk practices (22%).

The legislation of Ukraine guarantees for PLWH the free of charge provision of medications necessary to treat any of their diseases. Comparison of the research results of 2010 and 2013 demonstrates improvement of PLWH access to antiretroviral therapy, whereas access to medications for opportunistic infections has remained at the same level. At the time of the survey in 2013 60% of respondents (versus 41% in 2010) were receiving ART, and 28% of respondents (31% in 2010) were receiving medications for prevention or treatment of opportunistic infections. In 2013, 91% of interviewees versus 81% in 2010 considered ARV drugs as accessible, and 54% of interviewed in 2013 versus 55% in 2010 expressed confidence that if needed they would be able to get treatment of opportunistic infections (Table 4.11).

Table 4.11. **Respondents' assessment of access to ARV therapy or medications for opportunistic infections,** % by years

	2010	2013
Do you have access to ARV therapy even if you do not receive it currently?		
Yes	81	91
No	6	2
I don't know	13	7
Do you have access to medications for opportunistic infections even if you do not receive them currently?		
Yes	55	54
No	20	18
I don't know	25	28

Note. Differences are significant if exceed 3%.

ART therapy is administered to 64% of women and 55% of men which is likely explained by the fact that part of women started to receive ART during pregnancy. What concerns medications for opportunistic infections, no differences were observed.

The older interviewees are, the more significant is the increase in a share of those receiving ART. What concerns medications for prevention and treatment of opportunistic infections a similar tendency is also observed, however it is less apparent which may evidence the efficiency of ARV therapy (Table 4.12).

Table 4.12. **Percentage of respondents taking ART and medications for opportunistic infections,** by the length of living with HIV, %

Length of living with HIV	Receiving ART	Receiving medications for opportunistic infections
Less than 1 year (N=165)	29	26
1-4 years (N=498)	52	23
5-9 years (N=490)	66	27
10-14 years (N=241)	77	37
15 years and more (N=101)	78	39

Note. Differences are significant if exceed 10%.

Representatives of different sex-age groups assess accessibility of ARV therapy and medications for opportunistic infections in a similar way: differences do not go beyond statistical discrepancy. Whereas respondents who have been diagnosed less than 1 year ago assess accessibility to ART at a rather lower level (82% consider it accessible for them) than other interviewees (88-97%). This may be explained not as much by real differences in access to medications but by lesser awareness of "freshmen" about the mechanism of ART prescription and its being free of charge. What concerns medications for opportunistic infections, no such differences were observed.

High accessibility of ART for vulnerable groups' representatives should also be noted. In particular, a share of those receiving ARV drugs reaches 59% among representatives of vulnerable groups and 61% among respondents not belonging to them, which does not go beyond statistical discrepancy.

Analysis of life stories also confirmed that although receipt of ARV therapy is not completely unproblematic for representatives of the target group, still there are considerably less difficulties in this area than in receipt of medical care at any other health care institutions apart from AIDS centres.

There was only one out of 58 life stories fully dedicated to problems related with access to ART. To receive medications the respondent had to undergo an examination conducted by the medical commission at the local outpatient clinic. However this process was highly complicated due to neglectful attitude of the local outpatient clinic's infectiologist to her job duties.

The respondent attempted to solve the problem through application to the head doctor but was rejected. The situation has changed only after involvement of the NGO lawyer.

> "For a long time I couldn't make a visit to her: she was either absent or busy or having other duties. The office hours start at 9a.m. but she would start accepting patients at 11a.m. … A month passed before I was accepted… After I underwent the medical examination and came to the infectiologist for a scheduled visit she was absent again… A nurse would repeat "tomorrow": please come tomorrow or a day after tomorrow. This has taken about a week. Then I've realized that the test results would expire soon and I would have to undergo them again. Finally I got to know that she (the doctor) had gone to Kyiv for a training course and would be back after the 1st of January" (life story, Cherkasy).

However, having solved the problem of ART receipt the respondent faced similar difficulties when trying to get medications for opportunistic infections from the same doctor.

Another respondent described in her life story a conflicting situation with the AIDS centre doctor regarding a choice of the specific scheme of treatment, but this problem has been solved quite easily.

Stories dedicated to problems in relations with AIDS centres' doctors are exception rather than a rule. More often respondents stated that among all health care professionals only AIDS centres' workers showed good attitude towards PLWH and did not allow for violation of their rights. This is confirmed with the results of other sociological surveys[10].

Several life stories described positive examples when health care professionals respondents had to communicate with had been friendly and indeed supportive.

What concerns medications for opportunistic infections, representatives of vulnerable groups receive them rather more often (32%) than respondents not belonging to them (22%). Discrepancy is +/–4%.

What concerns assessment of accessibility of ART and medications for opportunistic infections, no significant differences between representatives of vulnerable groups and respondents not belonging to them were observed.

The distribution of answers to the question on the accessibility of ART and treatment for opportunistic infections depending on whether a respondent is taking relevant medications seems to be rather interesting. Among those taking treatment for opportunistic infections at the time of the survey, 76% of interviewees considered them accessible, 15% responded negatively, and 9% found it hard to answer this question. Such distribution of answers seems to be quite logical taking into account a rather common practice of patients buying themselves medications to treat opportunistic infections. Among 894 PLWH who were receiving ART at the time of the survey, about 1% of interviewees (8 persons) assessed it as inaccessible or it was difficult for them to answer, which may be explained by disruptions in supplies of ARV drugs or insufficient treatment adherence of the patients.

Quality of the counselling aspect of the medical care provided to PLWH has rather deteriorated if compared with 2010. A share of respondents who stated that in the last year they had a constructive discussion with a health care professional over the HIV treatment schemes has maintained practically the same in 2013, making up 70% versus 65% in 2010. Discrepancy is +/–3%. At that, among those receiving ARV drugs, 80% of interviewees have received guidance as for treatment versus 56% among those not receiving ARV drugs.

"Together with the lawyer, we filed a complaint to the Department of Health, where we were advised to take this complain to the head doctor. I did so… When I said that I would take this complain further, and someone would be punished, they quickly did everything and asked me not to file the complaint anywhere further… The head doctor signed all the documents I needed to receive ART, although this should have been done by the infectiologist (his daughter). He signed for her, fixed a seal and called the AIDS centre to arrange a visit for me" (life story, Cherkasy).

"At the AIDS centre my doctor in charge, although I warned her about my plans to have children, wanted to prescribe me a scheme including Efcur (women taking this medicine are recommended to avoid pregnancy). We had quite an unpleasant conversation. I went to the head doctor and filed an application for a doctor's replacement. A doctor has been replaced, and I have got a good ART scheme prescribed" (life story, Odesa).

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[10] For example, results of the operating research "Determinating the degree of "friendliness" to clients of services provided to PLWH in various social and health care institutions" conducted by AC Socioconsulting contracted by ACO The All-Ukrainian Network of PLWH in 2011-2012.

As for discussing other issues (e.g., sexual and reproductive health, sexual relationships, emotional well-being, drug use, etc.) with health care workers, the percentage has slightly decreased in 2013 making up 49% versus 56% in 2010.

With age a share of respondents receiving guidance regarding HIV treatment slightly increases (from 64% for the youngest respondents to 77% for the oldest), whereas a share of counselled for aspects like sexual and reproductive health, emotional well-being, drug abuse, etc. decreases (from 52% to 40%). However, taking into account discrepancy, which in this case equals 8%, these differences are insignificant.

No differences in quality of counselling between representatives of different social groups were observed.

Among those interviewed in 2013, a share of those who started receiving medical care related to HIV within the first three months after HIV-positive status had been established is significantly higher if compared with 2010. What concerns other answer options, differences are not statistically significant but also confirm the tendency for more timely application for medical care by PLWH interviewed in 2013 (Fig. 4.9).

"I was hospitalized to the 22nd Infectious Diseases Hospital. I was in the room with a girl with open tuberculosis. Hennadiy Lvovych (a doctor from the AIDS centre) visited me and was shocked… After the ICU I was transferred to a single-patient room. Hennadiy Lvovych arranged that... He also visited me in the ICU» (life story, Kharkiv).

"When I told my infectiologist about the situation that had happened to me (disclosure of the respondent's HIV status by the nurse let to employment rejection) he said he would take measures. Later I learned that measures had been taken indeed. That person was identified and punished, and I was employed as a social worker in a hospital. Now I am fine there" (life story, Cherkasy).

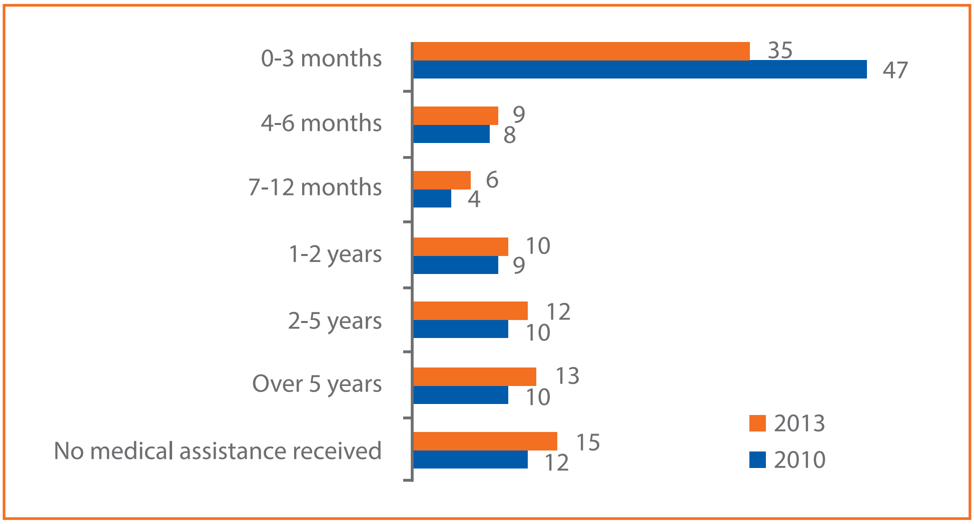

Fig. 4.12. **Time gap between the HIV diagnosis being established and the start of receiving medical treatment,** % by years

Among respondents who have not received any medical care yet there are people with varying length of living with HIV, starting from those whose diagnosis has been established less than a year ago (23%) and to respondents having been living with HIV for over 5 years (37%). At that these respondents do not show better health if compared with other interviewees: distribution of answers to the question on self-assessment of health for this group of respondents differs from answers of other interviewees within statistical discrepancy.

Respondents who took their time before receiving medical assistance for over three months since having HIV-positive status established were asked about the reasons for such behaviour. As respondents' answers demonstrate, apart from objective life circumstances (like staying in prison) various fears also play their role (e.g. disclosure of HIV status or stigma or discrimination from health care staff). What concerns the research results for 2010 and 2013, despite statistically significant differences (marked in bold in the table below) by specific reasons, their rating is largely the same (Table 4.13).

It should be noted that some part of respondents understand a notion of "taking time before receiving medical assistance" in a rather specific way. In particular, in 2013, when the question on the reasons for untimely application for medical care included the answer option "No time gaps", 11% of interviewees who had applied to doctors more than three months after having been diagnosed did chose this option. In 2010, when there was no such answer option respondents would write it down under "other".

Interpreting answers to the question about the time gap between being tested HIV-positive and the start of receiving medical assistance it should be taken into account that a part of respondents, even despite a special notice in the questionnaire, interpreted the term of "receiving medical assistance" as the start of taking ARV drugs. In particular, this is confirmed by the analysis of respondents' answers to the question on the reasons of taking time before receiving medical assistance under "Other". More than in half of the cases (50 people out of 83 who chose the alternative "Other") responses were like "there was no need in medical assistance as CD4 count was sufficient", and also about delayed supplies of ARV drugs or impossibility to receive ART for other reasons.

A share of those who started receiving medical assistance within three months after being diagnosed is much higher for women (55%) than for men (38%). These differences were mostly provided by that part of female respondents whose HIV-positive status had been established during pregnancy. As prevention of vertical transmission is identified as a priority direction in the provision of medical care to PLWH at the national level, pregnant women are the first to be

Table 4.13. **Reasons for time gaps between the moment of being tested HIV-positive and the start of receiving medical treatment,** by years, % to those who has taken time before receiving medical assistance for over three months*

	2010 (N=972)	**2013** (N=799)
I was not prepared to do anything with respect to my HIV infection	**39**	**46**
Other	**24**	**10**
I was afraid I could meet any of my acquaintances there	18	16
I was afraid health care workers would mistreat me	16	19
I was afraid health care workers would disclose my status without my consent	**14**	**21**
I did not get a referral or did not know where I should go for HIV-related assistance	14	15
I stayed in prison and had no access to HIV treatment	15	14
A clinic or a hospital was hard to reach	10	7
I had previous negative experience of communicating with health care staff	10	11
I was afraid to be treated as if I was sexually promiscuous; a MSM, a SW or an IDU	8	12
I could not afford medical treatment	7	8
I would have to tell my husband/wife/partner if I started receiving medical treatment	2	2
I could not receive medical treatment during working hours without disclosing my HIV status to my employer	2	4
I have an illegal status or documents	1	1
No time gaps		11

Note. Differences are significant if exceed 4%.

** Sum exceeds 100% as respondents could choose several answer options.*

provided with ART. Correspondingly, a share of those who started receiving medical assistance within three months reaches 69% among women who had undergone VCT for HIV due to pregnancy versus 45% among other female respondents.

The variances in a share of those who had applied for medical assistance within three months after being diagnosed between representatives of vulnerable groups (36%) and those not belonging to them (63%) is also explained by a different share of women in these groups who had undergone VCT due to pregnancy. Among respondents having no experience of belonging to vulnerable groups, a share of women whose HIV-positive status has been established during pregnancy makes up 40% versus 9% among representatives of vulnerable groups.

Women much more often than men stated about various fears and prejudices as a reason for taking time before receiving medical assistance. Whereas men more often stated about such life situation as staying in prison (Table 4.14). What concerns other factors that may prevent from applying for medical care (e.g. absence of information on where to apply to treat HIV, complicated access to health care institutions, etc.) as well as psychological non-readiness to do anything due to one's illness, no differences between man and women were observed.

Table 4.14. **Separate reasons for time gaps between the moment of being tested HIV-positive and the start of receiving medical treatment,** depending on sex, % to those who has taken time before receiving medical assistance for over three months

	Men (N=460)	**Women** (N=339)
I stayed in prison and had no access to HIV treatment	18	8
I was afraid I could meet any of my acquaintances there	11	22
I was afraid health care workers would mistreat me	13	27
I was afraid health care workers would disclose my status without my consent	17	27
I was afraid to be treated as if I was sexually promiscuous; a MSM, a SW or an IDU	9	16

Note. Differences are significant if exceed 5%.

With the increase in the length of living with HIV a share of those who has not applied for medical care due to their disease yet quite predictably decreases. At that, a share of those who have started receiving medical assistance within the first three months after being diagnosed also significantly decreases (Table 4.15). This presents another evidence that receipt of medical assistance was understood by respondents mostly as the start of receiving ART which accessibility has been improving in time.

Table 4.15. **Time gap between the moment of being tested HIV-positive and the start of receiving medical assistance,** depending on the length of living with HIV, %

	0-1 year (N=165)	**1-4 years** (N=498)	**5-9 years** (N=490)	**10-14 years** (N=241)	**Over 15 years** (N=101)
0-3 months	66	**52**	**45**	**336**	**27**
4-6 months	7	9	9	5	5
7-12 months	2	6	5	3	1
1-2 years	0	12	9	11	4
2-5 years	1	6	14	16	7
Over 5 years	0	1	9	23	52
No medical assistance received	**24**	**14**	**9**	**6**	**4**

Note. Differences are significant if exceed 10%.

What concerns objective obstacles for timely application for medical assistance (e.g. have not received a referral or did not know where to apply, difficult to get to a clinic or hospital, etc., apart from staying in prison) no differences between representatives of vulnerable groups and other respondents were observed. Whereas PLWH having no experience of belonging to vulnerable groups rather more often than representatives of the latter indicated various fears as obstacles (fear of disclosure of their HIV status by heath care workers, fear of meeting any of their acquaintances in a health care institution). However, taking into account discrepancy these differences are insignificant and do not exceed 3%. Their presence is evidently explained by the fact that among vulnerable groups, there were twice less women (33%) for which various fears are more characteristic than among other respondents (67%).

Thus, comparison of the research results of 2010 and 2013 demonstrates improvement of PLWH access to antiretroviral therapy, whereas access to medications for opportunistic infections has remained at the same level. At the time of the survey in 2013 60% of respondents (versus 41% in 2010) were receiving ART, and 91% of respondents (versus 81% in 2010) considered it accessible. In 2013, 28% (in 2010 – 31%) of respondents were receiving medications for prevention or treatment of opportunistic infections, and 54% (in 2010 – 55%) of respondents considered them accessible.

The results of the current research (the same way as the research of 2010) proved the absence of significant problems with access to ARV therapy for representatives of vulnerable groups. Shares of those receiving ARV drugs among representative of risk groups (59%) and those not belonging to them (61%) do not significantly vary. Assessment of accessibility of ARV drugs by representatives of different social groups is also similar.

Quality of the counselling aspect of medical care provided to PLWH has rather deteriorated if compared with 2010. A share of respondents who stated that in the last year they had a constructive discussion with a health care professional over the HIV treatment schemes has maintained practically the same in 2013, making up 70% versus 65% in 2010. As for discussing other issues (e.g., sexual and reproductive health, sexual relationships, emotional well-being, drug use, etc.) with health care workers, the percentage has slightly decreased in 2013 making up 49% versus 56% in 2010.

4.4. HAVING CHILDREN

Half (51%) of those interviewed in 2013 have children (in 2010, there were 53% of these), including 38% of men and 64% of women. As the 2013 questionnaire was about minor children, the majority of respondents having them are young and middle-aged people. In the 17-35 age group 57% of respondents have children, and among respondents aged 36-45 – 50%. Whereas among respondents aged over 45 this share is 15%, with discrepancy of age groups comparison making up to 8%.

66% interviewees who do not belong to vulnerable groups have children versus 41% for representatives of risk groups. The mentioned differences are connected with the fact that a vast part of respondents with no experience of belonging to vulnerable groups is made up of women whose HIV status has been established during pregnancy (40% versus 9% among representatives of risk groups).

Among 15% of those who have children at least 1 child is HIV-positive (7% of the totalality). In 2010, HIV status was reported by 11% of respondents who have children (6% of the total number). However, this figure cannot be interpreted appropriately due to the lack of information about which respondents having children gave birth to them after such respondents' diagnosis had been established.

More than a third of respondents (38%) received counselling about having children after being diagnosed as HIV-positive. There were 46% of such in 2010. Among those who have not received such counselling, two thirds have not done this as they do not plan to have children, whereas a third plans having children (Fig. 4.10).

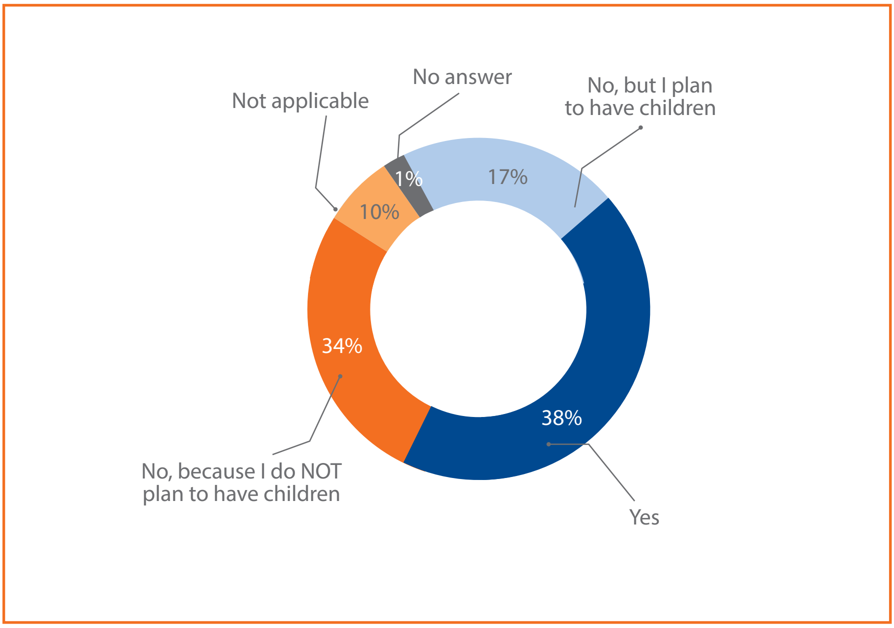

Fig. 4.13. Distribution of answers to the question: **"Since being diagnosed as HIV-positive, have you obtained counselling regarding a possibility to have children?", %**

A share of those planning to have children is approximately the same for men and women, while women seek advice on this issue more often than men (Fig. 4.11). Discrepancy in this case equals 4%.

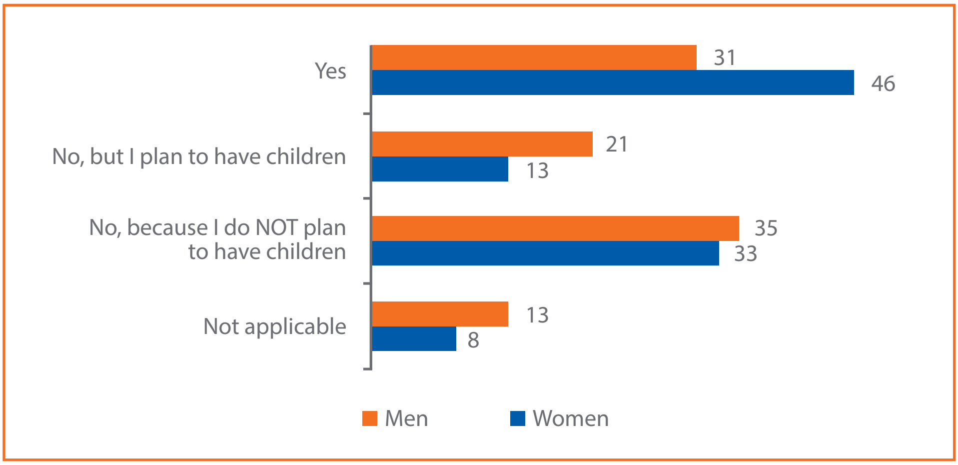

Fig. 4.14. Distribution of answers to the question: **"Since being diagnosed as HIV-positive, have you obtained counselling regarding a possibility to have children?", % depending on sex**

> "There are doctors who having learned about HIV may cause harm just to do dirt. My gynecologist terminated my pregnancy during swabbing. I had all signs of pregnancy whereas after the gynecological examination the problems occurred. I think she has done something on purpose for me not to give birth" (life story, Odesa).

Young people receive counselling about their reproductive options more often (45% for respondents aged 17-35) than representatives of older age groups (34% – for the 36-45 age group and 10% – for respondents aged 46-64). Respondents having a constant partner, not depending on whether their relationships are officially registered, receive counselling about having children more often (47%) than those not having such a partner (29%), whereas PLWH not belonging to vulnerable groups – more often (47%) than those belonging to them (33%).

15% of respondents were at least once advised by health care providers not to have children versus 18% in 2010. In 2013, 4% of respondents versus 3% in 2010 stated that they had experienced situations of being forced to undergo sterilization. Thus, as we can see, taking into account discrepancy (3%) no differences by years regarding the above discriminating practices in the reproductive area were observed.

However, when interpreting the results obtained, it should be taken into account that the issue of having children is very sensitive to the majority of respondents, especially women, therefore in some cases they tend to treat health care professionals with some prejudice, interpreting any ambiguous situations as forms of discrimination on their part. For example, one respondent in her life story described a case when a gynecologist had allegedly terminated her pregnancy due her HIV status. However the respondent had no objective evidence that she had indeed been pregnant or that medical error had taken place and had been caused specifically by HIV status.

The same way as in 2010, in the current survey women more often than men experienced violation of their rights in the area of having children (Table 4.16).

Table 4.16. **Discriminating practices in the area of having children,** % depending on sex

	Men (N=746)	**Women** (N=754)
Have any of health care professionals advised you not to have children after HIV+ status being established?		
Yes	7	24
No	79	69
I don't know	14	7
Have any of health care professionals forced you to undergo sterilization after HIV+ status being established?		
Yes	1	8
No	81	85
I don't know	18	7

Note. Differences are significant if exceed 4%.

Respondents aged under 45 more often complained about violation of their rights in the area of having children than PLWH of older age. 15-18% of representatives of younger age groups were advised to refuse from having children versus 6% of respondents aged over 45. A similar tendency is observed for a share of those being advised to undergo sterilization, however taking into account discrepancy (8%) these differences appeared to be insignificant. The said differences are apparently explained by the fact that young people and middle-aged PLWH seek counselling about having children more often than older respondents who have already given birth to, in their opinion, a sufficient number of children.

A share of respondents being advised not to have children also increases the longer respondents have been living with HIV: from 4% for those diagnosed less than a year ago to 25% for respondents having been living with HIV for over 10 years. A similar tendency is observed for a share of those being advised to undergo sterilization, however as such respondents were in a comparatively low number, the differences between the groups appeared to be insignificant.

Differences in a share of those advised not to have children between PLWH not having experience of HIV risk practices (21%), on the one hand, and representatives of vulnerable groups (12%), on the other hand, are apparently explained by a different share of women in these groups. In particular, women make up 75% of those not belonging to risk groups, and 34% among respondents belonging to risk groups.

Similarly to 2010, the question whether an opportunity to receive ART depended on the birth control methods used by respondents was misunderstood by most respondents and caused anxiety. This year, 2% of interviewees gave affirmative answer to this question, and in 2010 – 1%, however credibility of these data raise significant doubts.

Respondents who stated about being pregnant in the last 12 months (129 persons) were asked about violation of their rights by health care providers. At that the 2010 questionnaire did not contain a filter question with regard to pregnancy which complicates comparison of the results by years. Thus, in the research of 2010 it had been supposed that women not being pregnant would chose the answer option “indicator not applicable” whereas it turned out that part of them had chosen the answer option “no” (“I haven’t felt pressure as I wasn’t pregnant”). Thus, a share of those having experienced violation of their rights, according to the results of the 2010 research, turned to be rather underrated which should be taken into account when comparing the results of 2010 and 2013 (Table 4.17).

Table 4.17. Distribution of answers to the question: **"Have you experienced pressure/coercion due to HIV status from health care professionals regarding…?",** by years, %

	2010 (N=277)	**2013 (N=116)**
Termination of pregnancy (abortion)		
Yes	12	20
No	88	80
Method of giving birth		
Yes	15	24
No	85	76
Infant feeding practices		
Yes	14	19
No	86	81

Note. Differences are significant if exceed 9%.

According to respondents' answers, in the current year, access of HIV-positive pregnant women to ARV therapy has slightly increased. In 2013, ART was received by 94% of HIV-positive women being pregnant in the last 12 months, whereas in 2010 this figure was 81% (Fig. 4.12). Discrepancy in this case equals 9%. In the current survey, no women reported about refusal in this treatment, while in 2010, 2 respondents had reported this.

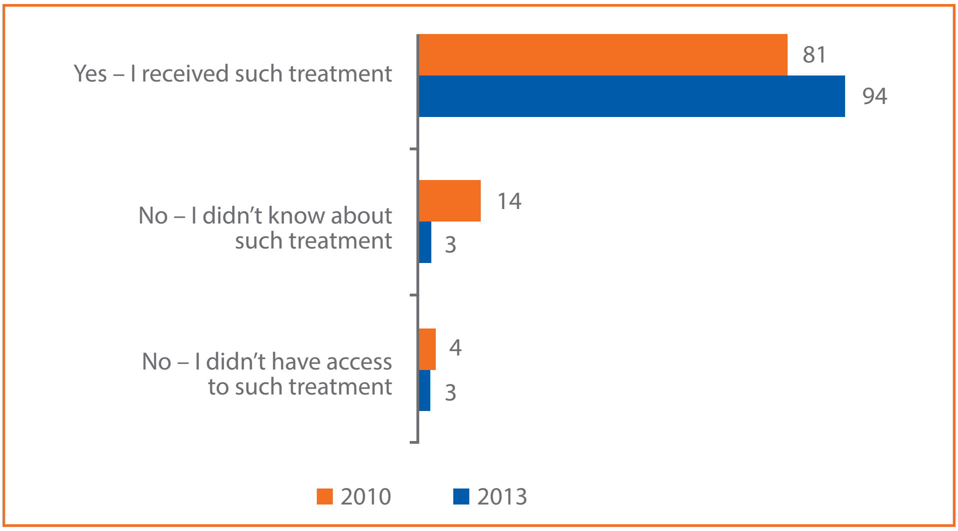

Fig. 4.15. Distribution of answers to the question: **"Have you received ARV therapy during pregnancy for the prevention of mother-to-child HIV transmission?",** by years, % of HIV-positive women being pregnant in the last 12 months

Practically all respondents having received ART during pregnancy (98%) were provided information on healthy pregnancy and maternity in the context of the prevention of mother-to-child HIV transmission. In 2010, such information was received by 91% of women having received ART for the prevention of vertical transmission. However, taking into account discrepancy the said differences are insignificant.

Thus, no significant differences by years regarding discriminating practices in the area of having children were observed. So, in 2013, 15% of respondents were at least once advised by health care providers not to have children versus 18% in 2010. In 2013, 4% of respondents versus 3% in 2010 stated that they had experienced situations of being forced to undergo sterilization. At that, women more often than men experienced violation of their rights in the reproductive area. In particular, 7% of men and 24% of women were at least once advised not to have children.

According to female respondents' answers, in the current year, access of HIV-positive pregnant women to ARV therapy for the prevention of vertical transmission has slightly increased. In 2013, ART was received by 94% of HIV-positive women being pregnant in the last 12 months, whereas in 2010 this figure was 81%. Practically all respondents having received ART during pregnancy (98%) were provided information on healthy pregnancy and maternity in the context of the prevention of mother-to-child HIV transmission. In 2010, such information was provided to 91% of women; however, taking into account discrepancy the said differences are insignificant.

CONCLUSIONS

The comparative analysis of the findings of the PLWH surveys conducted in 2010 and 2013 using a single methodology and the same tools enables to come to the following conclusions.

Over the last 3 years, sex-age features of interviewed PLWH are characterized with their stability. As a whole, as before, people of reproductive and capable of work age – aged 30-39 (49%) prevail among respondents. The majority of respondents (66%) have been living with HIV diagnosis from 1 to 9 years.

Injecting drug users (54%) and former prisoners (25%) remain the most vulnerable groups among interviewees. At that, for a considerable part of interviewees a double problem is distinctive – combination of drug addiction and experience of staying in prison. There were 42% of such among IDUs. Experience of drug abuse is characteristic for the vast majority of interviewed PLWH – former prisoners and SWs: 90 and 64% correspondingly.

Over the last three years a share of not working PLWH has increased: from 39% in 2010 to 52% in 2013. Among employed, 42% receive incomes as employees but are not officially employed. This results in a mostly low standard of living of respondents.

The average monthly income of the household for 12% of interviewed PLWH did not exceed 1000 UAH, which is less than the minimum wage. For another 51% of interviewees it made up from 1000 to 3000 UAH, which is less than the average salary in Ukraine for the time of the survey. 19% of interviewed PLWH felt lack of food during the last month before the survey. Families with the income below 1000 UAH (34%) and the unemployed (26%) face food insecurity more often.

If compared with 2010, attitude towards PLWH from the social environment has significantly improved. Over the last three years, the general level of PLWH stigma and discrimination due to HIV status from the social environment has 11% decreased: from 51% in 2010 to 40% in 2013.

Among forms of PLWH stigma from other people the most common remain gossips, verbal insults, harassment or threats. During the last year, over a forth of interviewed PLWH have been gossiped about for the reasons that included HIV status (26%), whereas in 2010 this indicator was 30%. The second common form of PLWH stigma/discrimination remains verbal insults, harassment and threats from other people. For the last year, 13% of respondents versus 18% in 2010 faced such forms of stigma.

What concerns other forms of stigma and discrimination from other people differences by years are not very substantial, and sometimes – insignificant. At the same time, the tendency for decrease in stigma cases in 2013 if compared to the previous research remains.

Slightly less common remain such forms of stigma as psychological pressure on PLWH from a partner and discrimination against people close to PLWH: for the last year 9% of respondents faced this, which is 3-5% less than in 2010. The most severe forms of PLWH discrimination, as physical harassment/threats (3% in 2013 versus 6% in 2010) or physical assault (1% in 2013 versus 4% in 2010) for the reasons that include HIV status, occur comparatively rarely.

To conclude, in communication with the social environment, stigma manifests more not in physical assault, but in negative and emotional impact by other people (gossips, insults, negative expressions, etc.) which contributes to formation of relatively strong internal stigma of PLWH.

Over the last 3 years, the general level of PLWH self-stigma due to their HIV status remains high (82%). Women (85%) are apt to self-stigmatization slightly more often than men (78%).

Over the last 3 years, the most common forms of internal PLWH stigma have remained as follows:

- self-accusation (58%, and this indicator has been unchanged since 2010);
- feeling of guilt (46% in 2013 versus 47% in 2010);
- low self-esteem (46% and 38% correspondingly);
- feeling of shame (41% and 37% correspondingly).

Over the last year, a share of PLWH blaming other people in their HIV status has increased (from 20% in 2010 to 28% in 2013), also a share of PLWH willing to commit suicide due to internal stigma increased twice (from 8% in 2010 to 16% in 2013). Young people aged 20-29 (21%) are more apt to such moods.

With age and increased length of living with HIV, a feeling of guilt and low self-esteem do not change comparatively, whereas other forms of self-stigmatization decrease.

Representatives of HIV vulnerable groups blame themselves for what has happened more often than others. PLWH not belonging to vulnerable groups more often feel shame and blame others for their HIV status.

Over the last 3 years, the indicator of self-discrimination of PLWH remains high (62%). A peak of self-discriminating decisions is in the first year after diagnosis (66%), further on prevalence of such decisions taken by PLWH decreases slightly (55% for those who have been living with HIV for over 15 years).

Among self-discriminating decisions taken by PLWH, over the last 3 years, the most common remain as follows: a decision not to have children (39% in 2013 versus 37% in 2010), not to get married (21% and 20% correspondingly), and to avoid visits to health care facilities (including outpatient clinics – 21% and refusal from hospitalization – 18%).

What concerns forms of discriminations in the employment area, in the last 12 months, 20% of respondents among those working have lost their source of income, out of them 15% (or 21 people) associate this with the reasons that include HIV status. Almost half of those who have lost their jobs due to HIV status (9 people of 21) are sure they have lost a job as a result of discrimination from their employer or co-workers.

For the last year, a prevailing majority of working PLWH (95%) have not experienced refusal in employment due to HIV status. This however has likely happened not because of tolerant attitude of employers to PLWH but due to concealing their HIV status. As such, among working PLWH, 63% conceal their status from their employer.

For the last year, 11% of interviewed PLWH experienced stigma and discrimination in health care. If compared to the 2010 data, when this indicator was 22%, it has decreased almost twice. The most common form of stigma and discrimination against PLWH in health care remains refusal in medical care, including in dental care (11% in 2013 versus 20% in 2010). HIV status becomes a comparatively less frequent reason for PLWH limitation in access to family planning services and sexual and reproductive health services (1-2%).

For the last 12 months, 2% of respondents experienced stigma and discrimination in the social area. This indicator has remained almost unchanged over the last three years (in 2010 – 5%). The most common form of stigma and discrimination against PLWH in the social area remains limitation in access to housing (almost 2% of interviewees in 2013 versus 3% in 2010).

So, the data obtained partially confirmed the assumption about reduction of limitations in PLWH access to social or health care services: decrease in the rates of stigma and discrimination due to HIV status in health care over the last year has been proven.

Comparative analysis of data also demonstrates other important tendencies in PLWH access to medical care. If compared with 2010, in the rating of reasons for taking VCT there was the increase in significance of factors caused by medical indications, including pregnancy and suspected HIV-related symptoms. At least one of the above reasons for VCT was chosen by 44% of respondents in 2013, whereas in 2010 they were 9% less (35%).

The indicator of voluntariness of HIV testing has slightly increased, in particular a share of those who underwent a test without their personal consent has decreased (from 12% in 2010 to 7% in 2013). Quality of pre- or post-test counselling has improved which is proved by the increase from 40% in 2010 to 49% of the share of those who received full counselling as required by the Procedure for Voluntary HIV Counselling and Testing (Protocol). The tendency of the increase in tests in first three months after a relevant decision has been taken is positive: from 60% to 69%.

A third (30%) of interviewed PLWH stated that they had no fears related to a possible positive HIV test. A leader among all fears mentioned by interviewed PLWH is a fear of being abandoned by their friends and families in case of an HIV-positive test. However if compared with 2010 this share has slightly decreased: from 58% to 53%.

Over the last three years, the situation with observance of PLWH rights to anonymity, confidentiality and medical secrecy as guaranteed by the Ukrainian legislation. This year less respondents stated about disclosure of their HIV status: 24% versus 37% in 2010. In particular, there is a decrease in a share of respondents who reported about unauthorized disclosure of HIV status by health care professionals (8% versus 13% in 2010).

If compared with 2010 (13%) a share of PLWH who at least once experienced pressure on the part of other PLWH or PLWH groups/networks regarding disclosure of their HIV status (7%) has decreased almost twice. What concerns non-PLWH no significant changes took place.

The situation with observance of medical secrecy by health care workers has improved slightly: 23% of respondents experienced disclosure of patient HIV status by doctors without a relevant consent, whereas in 2010 there were 30% of them.

This year PLWH gave more positive assessment to the level of observance of confidentiality of medical records related to HIV status. Thus, if compared with 2010 a share of respondents confident in absolute confidentiality of such documentation has increased (from 18% to 24%), and a share of those objecting it has decreased (from 34% to 27%).

If compared with the previous research, the attitude of health care workers towards PLWH has also improved. This year 18% of interviewed PLWH experienced discriminating attitude from health care professionals (24% in 2010).

Improvement of PLWH assessments regarding accessibility of antiretroviral therapy is observed, whereas, in respondents' opinion, accessibility of medications for opportunistic infections has remained at the same level. At the time of the survey in 2013 60% of respondents (versus 41% in 2010) were receiving ART, and 91% of respondents (versus 81% in 2010) considered it accessible. In 2013, 28% (in 2010 – 31%) of respondents were receiving medications for prevention or treatment of opportunistic infections, and 54% (in 2010 – 55%) of respondents considered them accessible.

The results of the current research (the same way as the research of 2010) proved the absence of significant problems with access to ARV therapy for representatives of vulnerable groups. A share of those receiving ARV drugs among representatives of risk groups (59%) and those not belonging to them (61%) do not significantly vary. Assessment of accessibility of ARV drugs by representatives of different social groups is also similar.

Quality of the counselling aspect of medical care provided to PLWH has rather deteriorated if compared with 2010. A share of respondents who stated that in the last year they had a constructive discussion with a health care professional over the HIV treatment schemes has maintained practically the same in 2013, making up 70% versus 65% in 2010. As for discussing other issues (e.g., sexual and reproductive health, sexual relationships, emotional well-being, drug use, etc.) with health care workers, the percentage has slightly decreased in 2013 making up 49% versus 56% in 2010.

No significant differences by years regarding discriminating practices in the area of having children were observed. So, in 2013, 15% of respondents were at least once advised by health care providers not to have children versus 18% in 2010. In 2013, 4% of respondents versus 3% in 2010 stated that they had experienced situations of being forced to undergo sterilization. At that, women more often than men experienced violation of their rights in the reproductive area. In particular, 7% of men and 24% of women were at least once advised not to have children.

According to female respondents' answers, in the current year, access of HIV-positive pregnant women to ARV therapy for the prevention of vertical transmission has slightly increased. In 2013, ART was received by 94% of HIV-positive women being pregnant in the last 12 months, whereas in 2010 this figure was 81%. Practically all respondents having received ART during pregnancy (98%) were provided information on healthy pregnancy and maternity in the context of the prevention of mother-to-child HIV transmission. In 2010, such information was provided to 91% of women; however, taking into account discrepancy the said differences are insignificant.

Thus, the assumption regarding the decrease in a number of cases of discriminating attitude against PLWH over the period of observations may be generally considered as confirmed. If compared with the research of 2010, a share of respondents having experienced these or those forms of discrimination in various areas of life has decreased or remains at the same level.

Despite the fact that most PLWH know their rights stipulated by the Law of Ukraine On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and Social Protection of the Population (60% of interviewees have heard about this law, and 50% have read or discussed its content), only 33% of respondents try to protect them in case of violation.

A large number of people not identifying actions taken towards them as illegal also raises concern. In particular, 20% of interviewees gave affirmative answer to the question whether, in the last 12 months, any of their human rights have been violated. But when respondents were given a list of actions in some way illustrating the violation of human rights and offered to indicate whether any of such things happened to them in the last 12 months, then 40% of interviewees gave affirmative answers.

What should also be noted is the absence of dynamics in the structure of respondents' answers regarding PLWH awareness about their rights and experience of standing up for them, if compared with the previous research results. This demonstrates that the measures taken in the country to improve the legal condition of HIV-positive people have not resulted in significant changes in PLWH mentality and conduct over the last three years.

If compared with 2010, a share of people who applied to organizations able to help in solving problems related to stigma or discrimination has increased from 21% to 32%. It should be noted that a share of respondents living with HIV for less than 1 year and are members of support groups and other associations of PLWH has not significantly changed in the current survey (16%) if compared with 2010 (19%). These people are the most vulnerable as after being notified of the positive test result they for some time are experiencing a psychological shock and are in need of constant emotional support.

Unchanged pessimistic perception by PLWH of their abilities to influence various areas of PLWH life is also alarming. 84% of interviewees versus 71% in 2010 stated that they had no power to influence any aspects of life of the PLWH community.

ANNEX 1

INTEGRAL INDICATORS OF STIGMA AND DISCRIMINATION: CALCULATION METHODOLOGY AND RESULTS

PLWH STIGMA INDEX IN HEALTH CARE No 1 – a share of HIV infected people who were refused in health care services provision due to HIV status in the last 12 month.

METHOD OF INDEX CALCULATION

Numerator: in the last 12 months, a number of interviewed PLWH who, for the reasons that include HIV status:

- experienced refusals in medical care, including in dental care;
- experienced refusals in family planning services;
- experienced refusals in sexual and reproductive health services.

Denominator: A total number of interviewed PLWH.

Index value

According **to 2010** data	**22%**
According **to 2013** data	**11%**

* Discrepancy is +/–3%.

Differences by years are significant (Fig. 1).

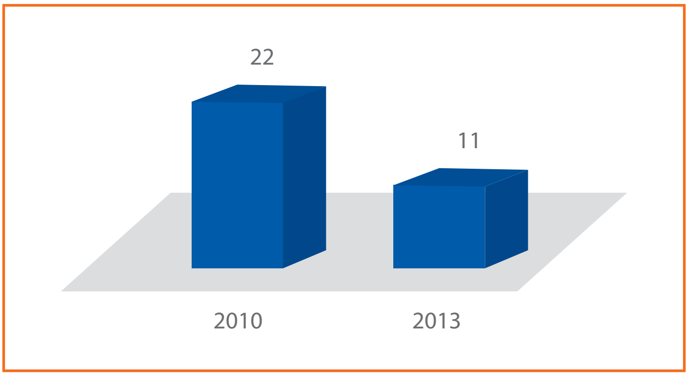

Fig. 1. **PLWH stigma index in health care, %**

PLWH STIGMA INDEX IN SOCIAL №2 – a share of HIV infected people who experienced limitations in access to social services due to HIV status in the last 12 month.

METHOD OF INDEX CALCULATION

Numerator: in the last 12 months, a number of interviewed PLWH who, for the reasons that include HIV status:

- had to change their place of residence or experienced difficulties in renting accommodation;
- were dismissed, suspended or prevented from attending an educational institution;
- experienced the situation when their children were dismissed, suspended or prevented from attending an educational institution.

Denominator: A total number of interviewed PLWH.

Index value

According **to 2010** data	**5%**
According **to 2013** data	**2%**

* Discrepancy is +/–3%.

Differences by years are insignificant.

PLWH STIGMA INDEX FROM THE SOCIAL ENVIRONMENT №3 – a share of HIV infected people who experienced stigma and discrimination from the social environment due to HIV status in the last 12 months.

METHOD OF INDEX CALCULATION

Numerator: in the last 12 months, a number of interviewed PLWH who, for the reasons that include HIV status:

- were excluded from social gathering or activities (e.g. wedding, funeral, parties, club visits);
- were excluded from religious activities or visits to places of religious service;
- were excluded from family activities (e.g. cooking, joint meals, sleeping in one room);
- found out being gossiped about;
- were verbally insulted, harassed, threatened;
- were physically harassed and/or threatened with action;
- were physically assaulted;
- were subjected to psychological pressure or manipulation by husband/wife/partner, when HIV positive status of a respondent was

used against him/her;

- experienced sexual rejection;
- were discriminated against by other PLWH;
- experienced discrimination against their wife/husband/partner or other household members.

Denominator: A total number of interviewed PLWH.

Index value

According **to 2010** data	**51%**
According **to 2013** data	**39%**

* Discrepancy is +/–3%.

Differences by years are significant (Fig. 2).

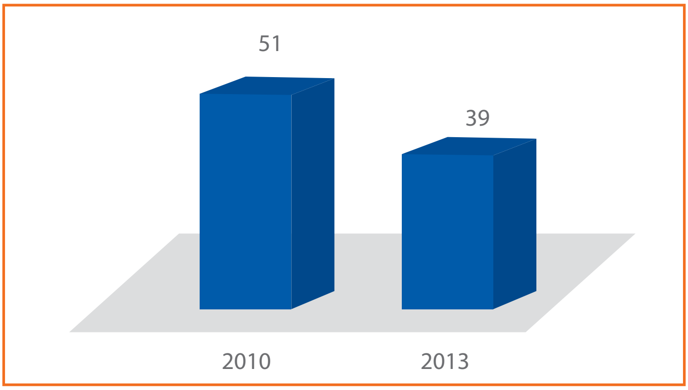

Fig. 2. **PLWH stigma index from the social environment, %**

PLWH SELF-STIGMA INDEX №4 –a share of HIV infected people having any negative feelings about themselves due to HIV status in the last 12 months.

METHOD OF INDEX CALCULATION

Numerator: in the last 12 months, a number of interviewed PLWH who, for the reasons that include HIV status:

- felt shame;
- felt guilty;
- blamed themselves;
- blamed others;
- had low self-esteem;
- felt they should be punished;

- felt suicidal.

Denominator: A total number of interviewed PLWH.

Index value

According **to 2010** data	**82%**
According **to 2013** data	**82%**

* Discrepancy is +/–3%.

Differences by years are insignificant.

PLWH SELF-DISCRIMINATION INDEX №5 – a share of HIV infected people who have taken/performed any self-discriminating decisions/actions due to HIV status in the last 12 months.

METHOD OF INDEX CALCULATION

Numerator: in the last 12 months, a number of interviewed PLWH who, for the reasons that include HIV status:

- decided not to attend gatherings;
- isolated themselves from one's family or friends;
- decided to stop working;
- decided not to apply for a job/employment or promotion;
- rejected education/training or decided not to continue education/training;
- decided not to get married;
- decided not to have sex;
- decided not to have children (anymore);
- avoided visits to an outpatient clinic, even if there was a need in it;
- avoided hospitalization, even if there was a need in it.

Denominator: A total number of interviewed PLWH.

Index value

According **to 2010** data	**62%**
According **to 2013** data	**62%**

* Discrepancy is +/–3%.

Differences by years are insignificant.

INDEX OF DISCLOSURE OF HIV STATUS №6 – a share of HIV infected people who experienced unauthorized disclosure of their HIV status.

METHOD OF INDEX CALCULATION

Numerator: a number of interviewed PLWH who at least once experienced disclosure of their HIV status by representatives of their social environment without their consent.

Denominator: A total number of interviewed PLWH.

Index value

According **to 2010** data	**37%**
According **to 2013** data	**24%**

* Discrepancy is +/–3%.

Differences by years are significant (Fig. 3).

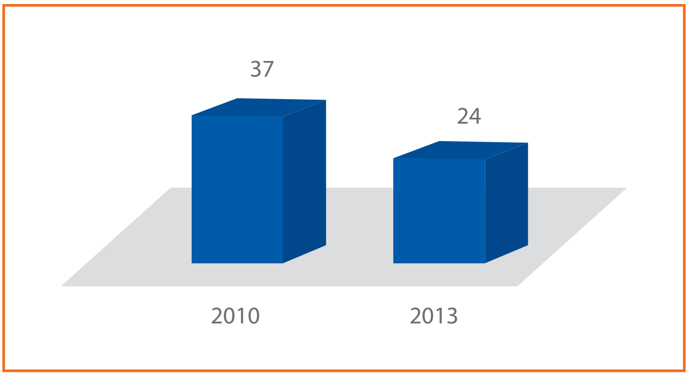

Fig. 3. **Index of disclosure of HIV status, %**

ANNEX 2

INTEGRAL INDICATORS IN 2013, BY AREAS, %

Area	Index description					
	Stigma in health care	Stigma in social area	Stigma from other people	Self-stigma	Self-discrimination	Disclosure of HIV status
AR Crimea	6	0	22	74	53	17
Donetsk region	12	2	41	80	60	20
Ivano-Frankivsk region	17	6	72	96	77	40
Kyiv region	18	0	44	93	66	24
Kirovohrad region	12	5	31	78	57	27
Lviv region	18	4	40	84	70	15
Odesa region	14	3	48	83	67	20
Sumy region	8	4	23	65	54	9
Kharkiv region	7	3	29	81	60	40
Kherson region	3	2	42	83	69	26
Cherkasy region	5	1	33	79	52	39
Kyiv city	15	1	38	86	54	19
Total in a bulk	**11**	**2**	**39**	**82**	**62**	**24**

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Network of
PLWH

The analytical report was published under financial support of the All-Ukrainian Network of PLWH in the framework of the project "Building a sustainable system of comprehensive services on HIV/AIDS prevention, treatment, care and support for MARPs and PLWH" supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria.