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# Access to Rights and Services

of People Living with HIV in Ukraine:  
Social Research Results

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Legislation and its implementation as a whole is an extraordinarily problematic issue in the field of HIV/AIDS in Ukraine, primarily because it is unclear whether the legislation actually works for the good of people directly affected by HIV/AIDS. Only the united work of local and international organizations, in particular in assessing the real situation at different governmental levels — from Oblast HIV/AIDS Coordinating Councils to the Verkhovna Rada of Ukraine — has made it possible to attract government and popular attention to the need to strengthen protection of the rights of people living with HIV/AIDS (PLHA). But creating and improving a system of PLHA rights protection is only a small part of larger work consisting of many components and directions of activity.

Unfortunately, until recently there were no legal precedents of documented PLHA rights violation. Thus the unfortunate situation has arisen that, as a rule, people whose rights have been violated do not try to protect them or strive for a legitimate solution, thereby giving anyone the opportunity to violate their rights again and again. A kind of vicious circle has come into existence, and breaking it appears to be vital.

The following investigation into the facts of breach of PLHA rights is the first of its kind and on such a scale in Ukraine. While collecting information for the investigation, different aspects of life with HIV were taken into consideration: rights and privileges guaranteed to HIV-positive people by the government, PLHA familiarity with them, availability of medical and social services for PLHA, availability and familiarity with antiretroviral therapy, experience of discrimination and intolerance towards PLHA. Importantly, fourteen regions of Ukraine (of a total of 27) were involved in the research.

Thus the All-Ukrainian Network of PLWH together with the International HIV/AIDS Alliance in Ukraine has made an attempt to assess the situation throughout the whole country, and we hope that the facts and outcomes from this investigation will provide essential support for activities directed towards protection of the rights of PLHA and provision of social and medical services guaranteed by the state for HIV-positive people in our country.

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## SURVEY GOALS AND OBJECTIVES

This survey of people living with HIV/AIDS (PLHA) was carried out by the All-Ukrainian Network of People Living with HIV with the support of the International HIV/AIDS Alliance within the Global Fund to Fight AIDS, TB and Malaria program 'Overcoming HIV/AIDS Epidemics in Ukraine'. The survey had the following key goals: 1) to evaluate the accessibility of prevention and treatment of opportunistic infections, social and psychological support and counseling for PLHA; 2) to accumulate quantitative information about PLHA awareness of their rights and benefits; 3) to identify violations of the rights of people with HIV; and 4) to study how PLHA perceive attitudes of different social groups towards them.

Achievement of these survey goals included the implementation of the following objectives:

- 1) To compare data collected in regions with different levels of HIV prevalence;
- 2) To study the influence of membership of PLHA organizations on awareness of PLHA rights and services and on their assessment of the quality of services studied;
- 3) To compare the answers of respondents with a history of injecting drug use with the answers of the rest of respondents.

## SURVEY METHODOLOGY

The survey was carried out in July-August 2004 in 16 Ukrainian cities: Kyiv, Zhitomyr, Chernihiv, Odessa, Mykolayiv, Kherson, Simferopol, Donetsk, Kharkiv, Poltava, Kirovograd, Znamenka, Kryviy Rih, Pavlograd, Cherkassy and Chernivtsi.

The method of information collection was based on questioning performed by members of the PLHA Network. The questionnaire included blocks of questions on health care, testing and counseling, human rights, social attitudes towards PLHA and general questions. The survey report is divided into sections corresponding to the blocks of questions included in the questionnaire.

Questioning was performed by quota sampling. Taking into account the poor accuracy of existing statistical information on the total number of HIV-positive people in the surveyed cities, as well as limited demographic data on registered PLHA, sampling was designed in the following manner. Survey cities were subdivided into three groups by HIV prevalence on the basis of existing information: 1) cities with less than 500 officially registered HIV-positive people (Znamenka, Kirovograd, Kherson, Zhitomyr, Chernivtsi); 2) cities with 500 to 2,000 registered HIV-positive people (Cherkassy, Chernihiv, Kharkiv, Pavlograd, Poltava); 3) cities with more than 2,000 registered HIV-positive people (Donetsk, Kryviy Rih, Simferopol, Odessa, Mykolayiv, Kyiv). The total number of HIV-positive people questioned in each city was determined separately for each group of

cities: 30 people in each city with less than 500 HIV-positive people (with the exception of Znamenka where 20 people were questioned); 50 respondents in each of the second group of cities (500-2,000 registered PLHA); and, finally, 70 respondents in cities with over 2,000 PLHA<sup>1</sup>. Quotas for the selection of respondents in the cities were calculated on the basis of official data on registered HIV-positive people, their sex distribution and general share of injecting drug users (IDU) among PLHA in Ukraine (the number of IDUs was evaluated as 70%). A separate quota was based on expert evaluation of the number of men and women among IDUs.

The planned sample size was 810 HIV-positive people. During the survey 692 respondents were interviewed.

In order to implement the sampling, two methods to reach the respondents were used: interviewing clients of AIDS-service organizations and the snowball method. When both methods were applied, the respondents were selected on the basis of the quota task.

## GENERAL SAMPLING CHARACTERISTICS

The number of interviews in 16 cities is shown in table 1 below.

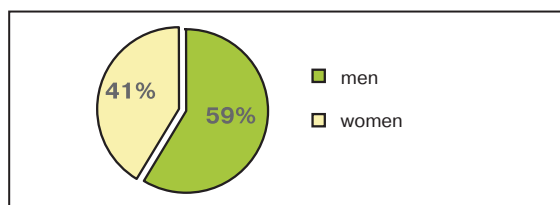
Table 1  
Number of interviews in 16 cities of Ukraine

| City         | Number of interviews | %          |
|--------------|----------------------|------------|
| Cherkassy    | 52                   | 7.5        |
| Chernihiv    | 23                   | 3.3        |
| Chernivtsi   | 40                   | 5.8        |
| Donetsk      | 38                   | 5.5        |
| Kharkiv      | 52                   | 7.5        |
| Kherson      | 35                   | 5.1        |
| Kirovograd   | 13                   | 1.9        |
| Kryviy Rih   | 50                   | 7.2        |
| Kyiv         | 82                   | 11.8       |
| Mykolayiv    | 65                   | 9.4        |
| Odessa       | 60                   | 8.7        |
| Pavlograd    | 30                   | 4.3        |
| Poltava      | 48                   | 6.9        |
| Simferopol   | 70                   | 10.1       |
| Zhitomyr     | 21                   | 3.0        |
| Znamenka     | 13                   | 1.9        |
| <b>TOTAL</b> | <b>692</b>           | <b>100</b> |

<sup>1</sup>Therefore the sampling structure is not proportional to the shares of separate regions, or to the shares of the selected cities in the total number of registered HIV-positive people in the surveyed cities. The non-proportional sampling was due to the lack of complete and accurate data on PLHA in the surveyed cities.

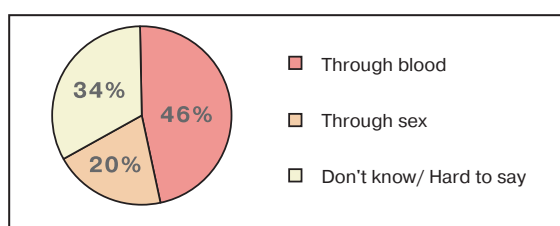
A total of 692 respondents took part in the survey. They included 404 men (58.6%) and 285 women (41.4%); three respondents did not specify their sex. Medium age of the respondents is 29.7 years (the youngest respondent in the sample was 17, and the oldest 55 years old).

*Diagram 1*  
Sex distribution of respondents



Two thirds of respondents know how they got HIV, while 33.5% could not answer or do not know how exactly they were infected. 46.4% of respondents said that their infection was blood-borne and 20.1% were infected sexually.

*Diagram 2*  
HIV transmission routes



More than two thirds (68.5%) of interviewed HIV-positive people had experience of regular or occasional injecting drug use in the last 10 years. The rest (31.5%) said they did not use drugs.

More than half of respondents who used drugs in the last 10 years also used injecting drugs in the last six months. Therefore over one third of the total number of respondents can be considered active injecting drug users.

Those respondents who had regularly used injecting drugs mostly said their HIV infection was blood-borne (63.7% of answers), while non-users indicated sexual transmission in more than half of cases (55.1% of answers).

Respondents described the length of time they were aware of their HIV positive status as follows: 20.3% learnt of their status during the last 12 months; 25.7% learnt about it 1-2 years ago; 22.2% of respondents learnt that they were HIV-positive 3-4 years ago; 13.0% and 18.8% have been aware of their status for 5-6 and more than six years respectively.

682 respondents answered the question 'What is your main occupation?' Of them, 28.9% have permanent jobs; 17.9% are occasionally employed (they work from time to time in different places); almost every tenth person (9.7%) is involved in small-scale household farming; 29.2% do not work; 12.9% are unemployed and searching for work; only 1.5% are students (at schools or universities).

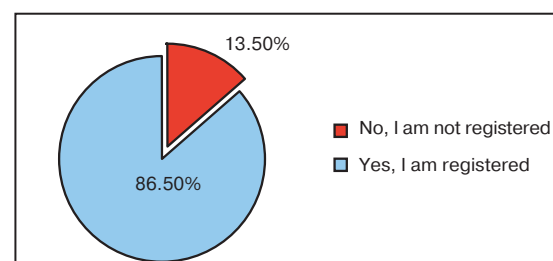
One third (33.4%) of HIV-positive people with full time or temporary jobs work in AIDS-service organ-

izations. The overall share of PLHA working in AIDS-service organizations from the total number of questioned PLHA is 15.6%.

Almost half (49.5%) interviewed PLHA said their HIV status did not influence their employment; every one in ten respondents (10.2%) said they had lost a paid job because of HIV; 8.7% of respondents had to change jobs; 6.6% of respondents found a paid job at an AIDS-service organization. 15.6% of respondents could not answer. The majority of answers of respondents who chose the option 'Other' (9.4%), were: 'I did not work before and now it is difficult to find a job', 'I do not work due to disability', 'I am involved in volunteer activities', 'I want to change my job and work in AIDS service', 'I changed (or lost) my job due to poor health'.

A positive answer to the question 'Are you registered at an AIDS Center?' was given by 86.5% of respondents. That is, 13.5% of HIV-positive people are not registered at an AIDS Center.

*Diagram 3*  
Answers to the question  
'Are you registered at an AIDS Center?'



29.3% of respondents are members of a PLHA organization, i.e., 198 out of 676 respondents who answered the question 'Are you a member of a PLHA organization?' Over two thirds of respondents (70.7%) answered 'No' to this question.

More than half (54.1%) of those who are members of a PLHA organization joined less than a year ago. These respondents constitute 15.2% of the total. Almost one third of PLHA organization members (33%, or 9.2% of the total number of respondents) have 1-2 years membership in the organization. 12.4% have been members of PLHA organizations for 3-4 or more years, which is 3.5% of all respondents. Only one respondent had a record of over six years at a PLHA organization.

One fourth (25.6%) of HIV-positive people interviewed during the survey need antiretroviral (ARV) treatment according to health indicators. An approximately similar share (27.9%) said they do not need ARV therapy. Many PLHA (35% of the total number of respondents) do not know whether they need treatment because they have not had the necessary medical examination. This share is even larger (43.2%) among those who learnt of their HIV status during the last 12 months. 10.8% of respondents said they do not know anything about antiretroviral treatment.

The data demonstrate that the share of respondents who know they need ARV treatment is growing, while the share of those who believe they do not need such treatment decreases with the term



of living with HIV (or knowing about their HIV status). We can compare the following: among those who found out about their HIV positive status during the last 12 months, 12.2% say they need ARV treatment and 30.2% believe they do not need to take ARVs, while among people who have known about their status for more than six years the distribution of affirmative and negative answers is 43.1% and 13.1% respectively.

6.4% of 692 interviewed said they are receiving ARV therapy. The share of these respondents is 24.1% of those who need ARV therapy according to health indicators. Slightly more than half of those receiving ARV therapy are members of a PLHA organization (53.5%).

## MEDICAL SERVICES, AVAILABILITY OF TREAT- MENT AND DIAGNOSTICS

The most prevalent medical conditions among respondents include hepatitis (40.8% of respondents are in need of treatment), candidiasis (34.7% respondents need treatment) and herpes (32.4% are in need of treatment).

19.7% of respondents need treatment for tuberculosis. 7.4% of respondents require treatment for pneumocystic pneumonia. 2.6% and 2.2% are in need of treatment for toxoplasmosis and cytomegalovirus respectively. 7.2% of respondents need treatment for other opportunistic infections.

It should be noted that the level of respondents' awareness of the need for treatment of various diseases is rather low. This may be either because of the lack of diagnostics, or the general poor culture of health among respondents.

Respondents are least of all aware of whether they have cytomegalovirus or toxoplasmosis: 44.2% and 43.8% of respondents respectively do not know whether they need to treat these diseases.

31.9% of respondents do not know whether they

need to treat pneumocystic pneumonia; 26.3% candidiasis, and 22.7% herpes. 17.2% of PLHA interviewed in the survey do not know whether they need treatment for hepatitis.

Regarding other opportunistic infections, 29% of respondents do not know whether they need treatment and another 41.3% could not answer this question.

Respondents are relatively well aware of whether they have TB. The share of people who do not know whether they need treatment for TB is only 14.5% of the total number of respondents.

It should be noted that these data indicate that the need to treat hepatitis and candidiasis obviously increases with the term of living with HIV (the more years people have known their HIV positive status, the higher is the number of affirmative answers, while the share of 'Don't know' answers remains virtually unchanged). At the same time, the longer people live with HIV, the better they understand the need to treat herpes, and the data show that the growth of affirmative answers occurs at the expense of the decreasing share of 'Don't know' answers, while the percentage of negative answers remains almost unchanged.

HIV-positive respondents give different estimates of the availability of treatment and diagnostics in their cities.

The questionnaire included TB, herpes, toxoplasmosis, cytomegalovirus, pneumocystic pneumonia, candidiasis, hepatitis and other opportunistic infections.

According to the respondents, diagnostics and treatment of TB and candidiasis are the most available, while that of toxoplasmosis and cytomegalovirus are the least available.

We can conclude, first of all, that people who urgently need such services are most aware of the availability of diagnostics and treatment of certain diseases. Secondly, the general level of awareness of access to diagnostics and treatment of the above diseases is low. TB is an exception as most people know about its diagnosis and treatment opportunities.

**Diagram 4**  
Answers to the question  
'Do you need treatment for the following diseases?'

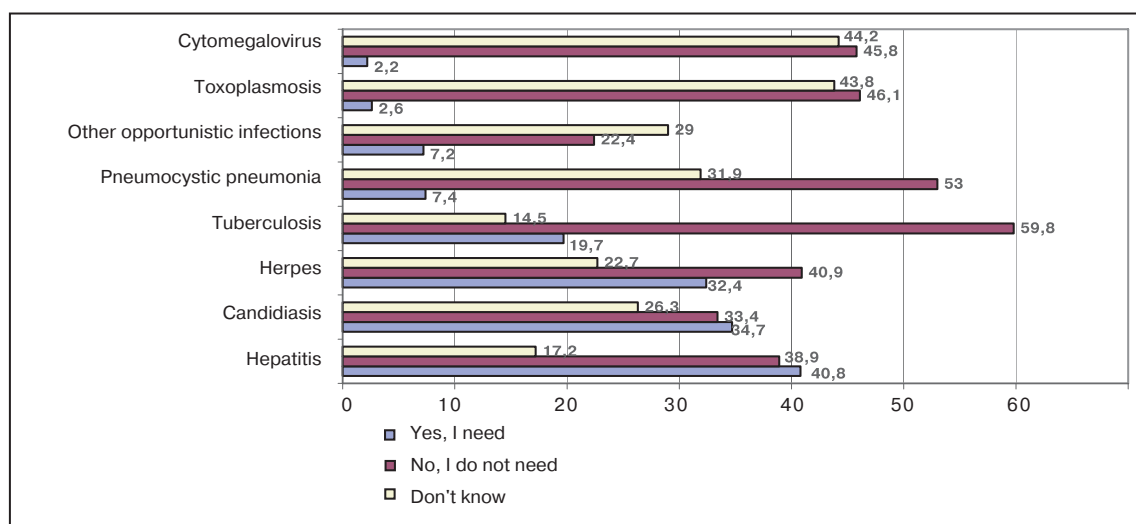


Table 2

Answers to the question

'Please, evaluate how available for HIV-positive people are diagnostics and treatment of these diseases in your city' (N=692)

| Disease                        | DIAGNOSTICS                 |                       |                |                            | TREATMENT                   |                       |                |                            |
|--------------------------------|-----------------------------|-----------------------|----------------|----------------------------|-----------------------------|-----------------------|----------------|----------------------------|
|                                | Available free of charge, % | Available but paid, % | Unavailable, % | Hard to say/ Don't know, % | Available free of charge, % | Available but paid, % | Unavailable, % | Hard to say/ Don't know, % |
| Tuberculosis                   | 62.7                        | 16.0                  | 1.7            | 16.8                       | 46.4                        | 22.1                  | 1.9            | 21.4                       |
| Herpes                         | 16.8                        | 28.8                  | 3.0            | 39.2                       | 12.4                        | 41.2                  | 2.6            | 33.8                       |
| Toxoplasmosis                  | 5.9                         | 17.2                  | 5.3            | 64.2                       | 2.2                         | 19.2                  | 4.3            | 62.0                       |
| Cytomegalovirus                | 5.8                         | 16.2                  | 5.3            | 64.9                       | 1.7                         | 17.1                  | 4.5            | 64.0                       |
| Pneumocystic pneumonia         | 16.0                        | 20.8                  | 3.8            | 52.7                       | 7.1                         | 29.5                  | 3.0            | 47.8                       |
| Candidiasis                    | 34.8                        | 20.2                  | 2.7            | 37.3                       | 12.4                        | 39.0                  | 2.9            | 34.4                       |
| Other opportunistic infections | 4.6                         | 7.7                   | 1.9            | 42.5                       | 2.5                         | 9.4                   | 2.2            | 40.0                       |
| Hepatitis                      | 36.3                        | 34.7                  | 1.7            | 20.2                       | 9.2                         | 54.5                  | 2.5            | 20.4                       |

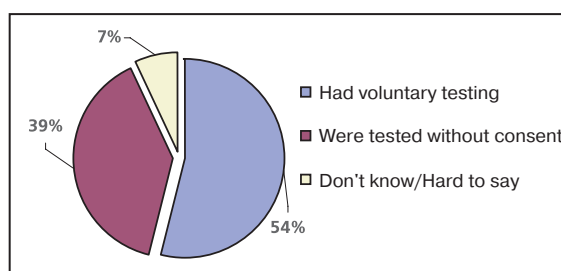
## TESTING AND COUNSELING

During the survey 54% of respondents said they had learned about their HIV positive status after voluntary testing. More than one third (39%) were tested without their consent. Part of respondents (7.1%) could not give a definite answer to this question.

Diagram 5

Answers to the question

'How did you go through testing, the results of which let you know your HIV status?'



Distribution of answers to the question whether respondents went through voluntary HIV testing depending on the time when they were tested helps to see the trend for growth of voluntary testing. Among those HIV-positive people who were tested more than six years ago, slightly more than one third (36.2%) had voluntary testing, and more than half (53.8%) were tested without their consent. In comparison, among those who were tested for HIV less than 12 months ago these shares were 67.9% and 27.9% respectively.

Thus 420 of all interviewed PLHA were tested either on a voluntary basis or could not definitely say they were tested without their consent. Less than one third of them, i.e. 29.7%, received pre- and post-test counseling. Almost the same share of respon-

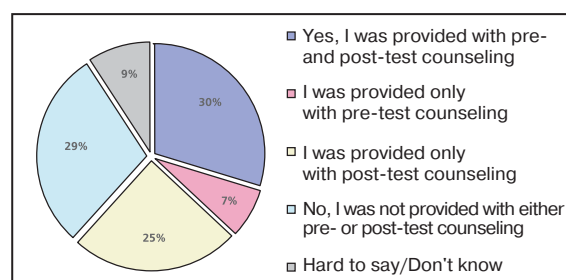
dents — 29.3% — did not receive either pre-test or post-test counseling. Less than one fourth (24.7%) of 420 respondents received only post-test counseling. 7.2% respondents got only pre-test counseling.

In total, post-test counseling was provided to 227 people out of 692, which constitutes 32.8% of sampling, i.e., one third. At the same time, 154 people of 692 received pre-test counseling, that is, 22.1% of sampling, or less than one fourth of respondents.

Diagram 6

Answers to the question

'Did you receive pre- and post-test counseling?'

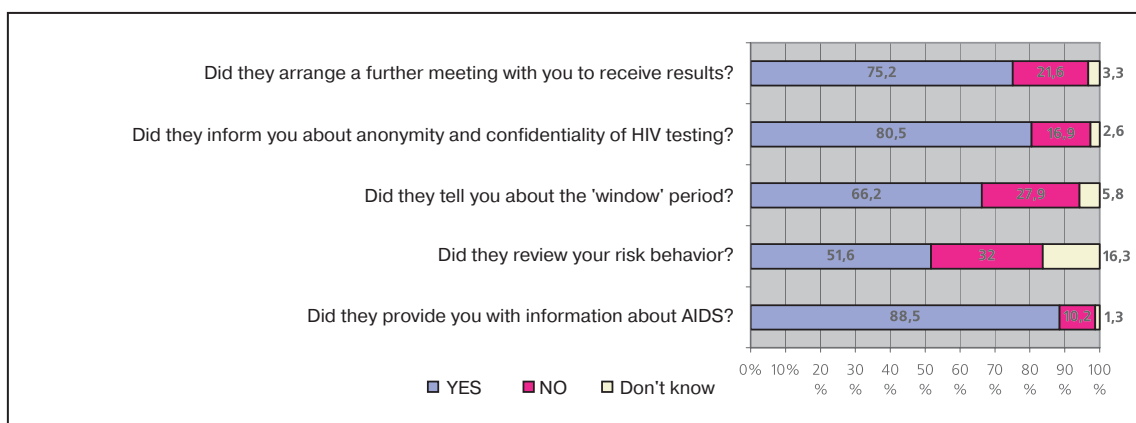


Respondents who received pre-test counseling answered the following questions about its content: were they provided with information about AIDS during counseling; was a review of risk behavior performed; were they told about the 'window' period in HIV testing; and were they provided with information about anonymity and confidentiality of HIV testing.

According to their answers, most respondents who were provided with pre-test counseling received information about AIDS (88.5% of 154). 10.2% did not receive this information, and 1.3% of respondents did not know whether this information was provided to them.

Counselors discussed risk behaviors with most people (51.6%); they did not do so during less than

**Diagram 7**  
Information content at pre-testing counseling



one third of pre-test counseling sessions (32.0%), and 16.3% of respondents who received pre-test counseling do not know whether their risk behaviors were reviewed.

Slightly less than two thirds (66.2%) of respondents who received pre-test counseling were informed about the 'window' period. More than one fourth (27.9%) were not informed about it, and another 5.8% of respondents said they did not know whether they were told about it.

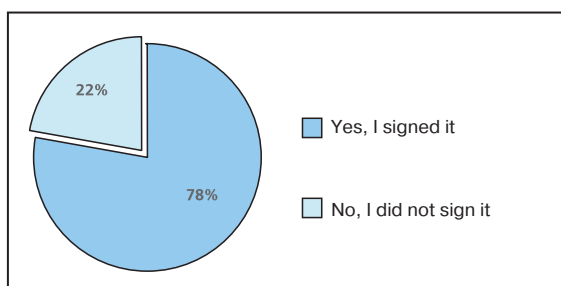
Answering the question 'Were you provided with information about anonymity and confidentiality of HIV testing?', a rather significant portion (80.5% of 154 respondents) gave affirmative answers; 16.9% answered negatively and the rest (2.6%) answered 'I don't know'.

Counselors arranged a further meeting to receive the test results in three out of four cases (75.2%) of pre-test counseling, according to respondents; in 21.6% cases such meetings were not arranged. The rest of respondents (3.3% of 154) do not know whether such meetings were arranged.

Answers to the question whether counseling helped to reduce stress had the following distribution: 63.1% respondents of 154 who received pre-test counseling gave affirmative answers, and 36.9% said counseling had not helped them to overcome stress connected to knowing their positive test result.

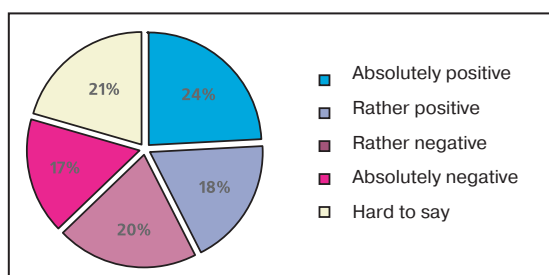
When they received test results, two thirds of respondents (77.8%) signed a form on criminal responsibility for intentional HIV infection ('Warning to HIV infected person'), while one third (22.8%) did not sign such a paper.

**Diagram 8**  
Answers to the question 'Did you sign the 'form' on criminal responsibility for intentional HIV infection when you received your test result?'



Answers to the question 'What is your attitude to the requirement to sign the 'form' on criminal responsibility for intentional HIV infection ('Warning to a HIV infected person') when you get your test result?' were distributed as follows: 'Absolutely positive' 24.3% and 'Rather positive' 18.1%; 'Rather negative' 20.2% and 'Absolutely negative' 16.6%. 20.5% of respondents could not answer. Thus, it cannot be said that there is a unanimous attitude towards signing this 'Warning', because supporters and opponents of this procedure are divided into almost equal parts — 42.5% for and 39.9% against.

**Diagram 9**  
Answers to the question  
'What is your attitude to the requirement to sign the 'form' on criminal responsibility for intentional HIV infection?'



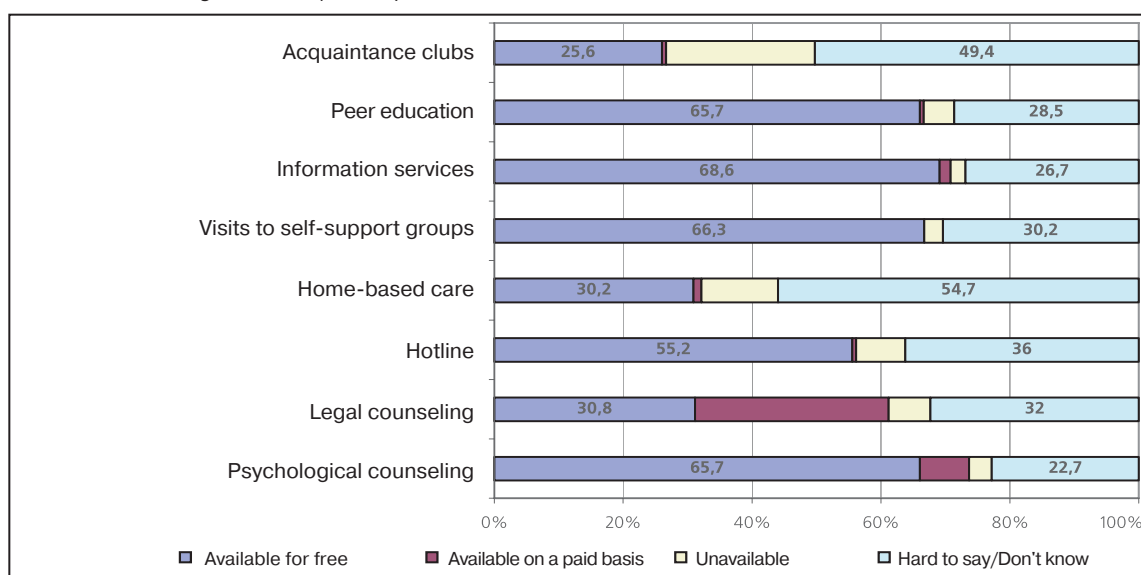
## SOCIAL AND PSYCHOLOGICAL SUPPORT AND NON-MEDICAL CARE

In order to obtain an estimate of the accessibility of social and psychological support and non-medical care to PLHA, the questionnaire included the following list of services: psychological counseling, legal counseling, hotline, home-based care, self-help groups, information services, peer education, acquaintance clubs. Respondents were asked to estimate the availability of each service in their cities using the following scale: available free of charge, available on a paid basis, unavailable.



**Diagram 10**

Evaluation of availability of services for PLHA who are not members of PLHA organizations or employees of AIDS-service organizations (N=198)



Survey results demonstrate that social and psychological support is not equally available for all respondents. The same can be said about the awareness of availability of these services. There is a relation between the level of awareness and evaluation of availability of social and psychological services, and employment of the respondents in AIDS-service or PLHA network organizations.

Respondents who work in AIDS service and members of PLHA organizations give much higher estimates of the availability of free social and psychological services compared to respondents who do not belong to either of these groups.

Respondents of all three groups similarly evaluate the availability of paid services.

The difference in the evaluation of availability of social and psychological services by different groups of respondents can be explained by the fact that membership in PLHA organizations or employment in AIDS-service organizations provides better access to these services and contributes to access to information about free services.

Diagrams 10-12 demonstrate the evaluation of access to social and psychological services made by different groups of respondents.

Representatives of the group that includes all who do not work in AIDS-service organizations or belong to PLHA organizations constitute 28.6% of all respondents.

On the basis of the list of social and psychological services, the respondents named information services for HIV-positive people the most accessible (68.6% of answers 'Available free of charge'). Free visits to self-help groups were named by 66.3% of respondents of this group. Psychological counseling and peer education are available for free to 65.7% of respondents. A hotline is considered available for HIV-positive people by 55.2% of respondents from this group. Less than one third (30.8%) of respondents of this group pointed out free legal counseling, another 32.0% said that these services are available on a paid basis; 30.2% named free home-based care. Slightly more than one fourth — 25.6% — of respondents said that free acquaintance clubs are available for HIV-positive people.

Members of PLHA organizations demonstrate a much higher awareness of the availability of social and psychological services. A much larger portion of respondents of this group evaluate social and psychological services as available for free.

**Diagram 11**

Evaluation of availability of services for PLHA who are members of PLHA organizations (N=172)

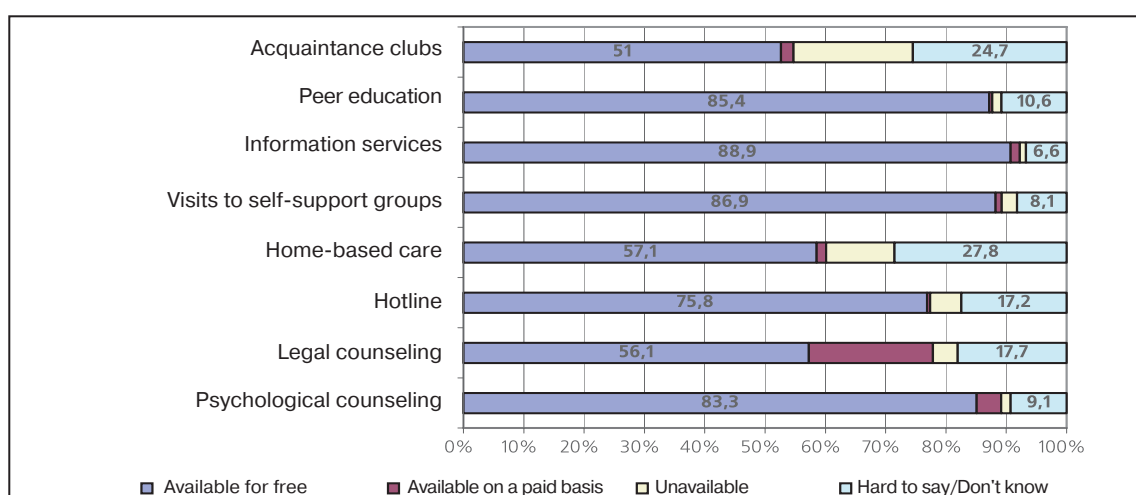
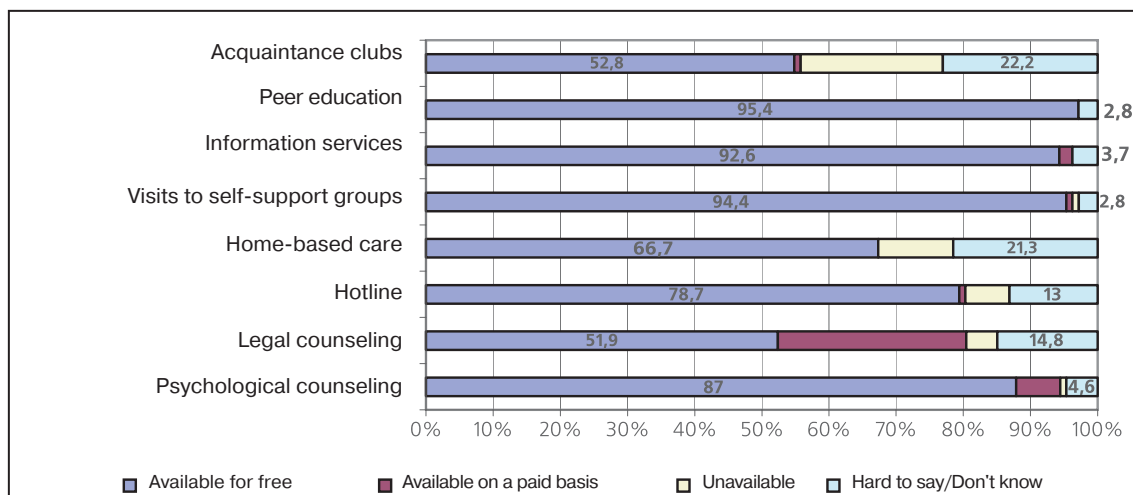


Diagram 12

Evaluation of availability of services for PLHA who are employees of AIDS-service organizations (N=108)



Employees of AIDS-service organizations, as can be seen from the diagrams, are the most informed about available social and psychological services (both free and paid); they are also more inclined to evaluate these services as freely available for HIV-positive people.

Possibly, some of these services are available only for employees of AIDS-service organizations or for members of PLHA organizations. Under these conditions, the evaluation of availability of services by each group most probably reflects the real situation in the sphere of social services for different groups of HIV-positive people.

In general, according to the evaluation of all respondents, information services, self-help groups, peer counseling and psychological counseling are most available for HIV-positive people, while hotlines, home-based care, legal counseling and acquaintance clubs are less widely available.

## HUMAN RIGHTS OF PEOPLE LIVING WITH HIV

According to the survey results, interviewed PLHA do not know much about the content of the Law On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and on Social Protection of the Population. In answer to the question 'Do you know about the Law of Ukraine On Prevention of

Acquired Immune Deficiency Syndrome (AIDS) and on Social Protection of the Population?', only 7.3% of 686 respondents selected the answer 'I know well almost all provisions of this law'. 28.9% of all respondents know some provisions of this law, 37.3% have heard about the law but do not know its content; and 20.1%, i.e., one fifth of 686 respondents, have never heard of the law. 6.4% of respondents could not find an answer. Answers to this question do not depend on the HIV prevalence in the city.

The level of awareness of the law among people who are members of PLHA organizations and those who do not belong to them differs. Members of PLHA organizations demonstrate a much higher awareness of the law and its content.

A total of 248 (35.8%) respondents selected the first and second answers, i.e. they are to some extent aware of this law. Most of them (56.3%) have a positive attitude to the law, while the rest (43.7%) think of it negatively or rather negatively.

Respondents who selected the 'Other' option pointed out that the law does not work properly as there is no mechanism to enforce it and control its implementation.

Only an insignificant portion of respondents enjoys the benefits envisaged by this law. This is the case, on one hand, because of low awareness of the existence of such benefits, and on the other hand due to the unavailability of such benefits.

Diagram 13

Answers to the question 'Do you know about the Law of Ukraine On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and on Social Protection of the Population?'

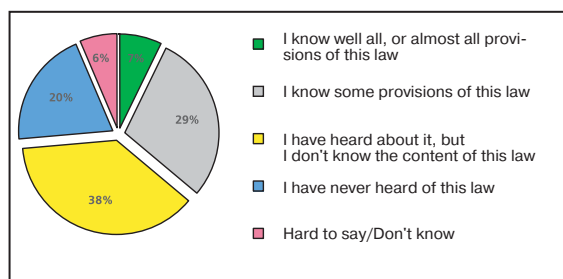
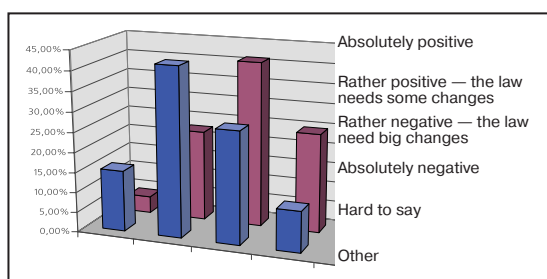


Diagram 14

Answers to the question 'What is your attitude to this law?'



Most often people use the right to free medicine to treat existing diseases, and individual means of prevention and social-psychological support. Respondents who indicated that they use this benefit made up 22.3% of the total number of respondents; 11.6% of respondents have used these benefits in the past.

More than one third (36.6%) of respondents are unaware of the benefit to receive free medicine. This benefit is unavailable for 23.4% of the total number of respondents; 23.3% of respondents do not need to use it.

The right to a separate room is used only by 2.7% of respondents, while in the past this figure was even smaller — 1% of all questioned HIV-positive people. Most respondents do not know about this right; they constitute almost half (47.3%) of all questioned. Over one fourth of respondents (26.4%) do not use this benefit due its unavailability, and 7.8% said they do not need this benefit.

Free transportation to and from a place for treatment at the expense of the health care facility issuing a referral is used by only 2% of interviewed people, while earlier it was used by a slightly larger number (2.6%) of people. 43.8% of the interviewed do not know about this benefit. 26.2% need such a benefit but cannot use it because it is not available. 10.8% know about it but do not use it as they do not need it.

Only two people (0.3% respondents) confirmed that at the moment they are using the right to compensation of losses related to the limitation of their rights

occurring due to disclosure of information about their HIV status. Two other people used this right in the past as well. More than one third, i.e., 36.6% of respondents do not know that they have such a right, and 23.4% cannot enforce it. Another 23.3% of respondents have not experienced any violations of their rights in terms of disclosure of their HIV status.

Comparing the level of awareness of rights and freedoms among people who are members of PLHA organizations and among the rest of respondents, one can see that PLHA organization members have a higher awareness of their rights as HIV-positive people.

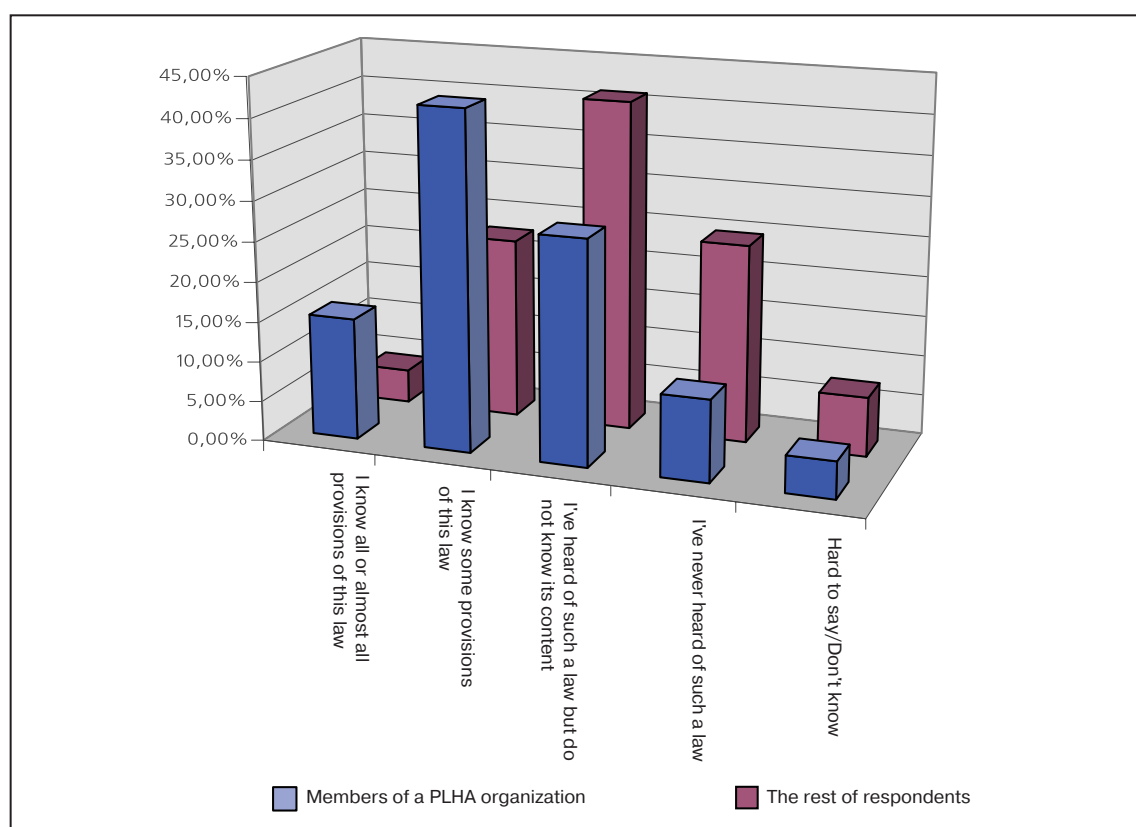
Compared to the rest of respondents, more members of PLHA organizations indicated that they do not need compensation of losses relating to the limitation of their rights due to the disclosure of information about their HIV status. Such distribution of answers shows that members of PLHA organizations are more protected than the rest of respondents.

Another essential difference between the aforementioned groups is that more respondents (31.6%) who are members of PLHA organizations use free medicines, individual prevention means and social-psychological support than people who are not members of such organizations (18.7%).

Concerning other benefits, the difference in answers depending on the membership or non-membership of PLHA organizations are related mostly to the level of awareness of the right to obtain such benefits.

**Diagram 15**

*Correlation of awareness of the Law of Ukraine On Prevention of Acquired Immune Deficiency Syndrome (AIDS) and on Social Protection of the Population and membership in a PLHA organization*



**Table 3**

*Do you use now, or have you used in the past, the following benefits envisaged by the law for HIV-positive people?*

| Benefits   | I use them now | I have used them in the past | I don't know about such a benefit | I know about such a benefit but never used it as it is not available for me | I know about such a benefit but never used it as there was no need | Hard to say/ Don't know |
|--|----------------|------------------------------|-----------------------------------|---|--|-------------------------|
| Compensation of losses related to the limitation of rights that occurred due to the disclosure of your HIV status                            | 0.3            | 0.3                          | 36.6                              | 23.4  | 23.3   | 15.2                    |
| Free provision of medicines needed to treat any existing disease; provision of products for individual prevention; and psycho-social support | 22.3           | 11.6                         | 23.0                              | 24.6  | 8.7  | 9.2                     |
| Free transportation to the place of treatment and back at the expense of the health care facility that issued the treatment referral         | 2.0            | 2.6                          | 43.8                              | 26.2  | 10.8   | 13.2                    |
| Use of a separate living room  | 2.7            | 1.0                          | 47.3                              | 26.4  | 7.8  | 13.2                    |

A small portion of respondents gave an affirmative answer to the question 'Are you a mother/father of an HIV-positive child?' Only 11.6% of all HIV-positive respondents are parents of HIV-positive children (79 people). This number is insufficient for a statistical analysis of the distribution of answers to the next question related to benefits provided by law for HIV-positive children.

These benefits include:

1) joint stay in in-patient clinics with children up to 14 years of age, with paid sick leave;

2) preservation of uninterrupted work record and payment of unemployment benefit to a mother/father who has to quit their job to care for an HIV-positive child up to 16 years of age, provided that the parent finds a job when the child reaches the age of 16 years;

3) payment of a monthly benefit in the amount of UAH 34 to HIV-positive children till they reach the age of 16 years.

However, the distribution of answers in table 4 given in absolute units provides a picture of the scale of use of these benefits.

Nine people, i.e., each ninth respondent who has a child with HIV, use the right to stay with children up to 14 years of age at in-patient clinics with paid sick leave. Almost every one in 20 respondents used this benefit in the past, while approximately every one in three respondents is unaware of this right. Every seventh respondent does not have access to this benefit.

Concerning the right to preserve an uninterrupted work record and receive unemployment benefit for a mother or father who has to quit their job to care for an HIV-positive child until it reaches 16, the picture is even worse. Only five people in 79 use this benefit now. No respondent used it in the past, and each third person does not know about it. Almost every one in eight respondents who have HIV-posi-

**Table 4**

*Do you use now, or have you used in the past, the following benefits envisaged by the law for parents of HIV-positive children (number of people)? N=72*

| Kinds of benefits   | I use it now | I used it in the past | I do not know about such a benefit | I know about such a benefit but never used it because it is inaccessible for me | I know about such a benefit but never used it because there was no need | Hard to say/ Don't know |
|---|--------------|-----------------------|------------------------------------|---|---|-------------------------|
| Joint stay in in-patient clinics with children up to 14 years of age, with paid sick leave  | 9            | 4                     | 23                                 | 12  | 17  | 7                       |
| Preservation of an uninterrupted work record and payment of unemployment benefit to a mother/father who had to quit their job to care for an HIV-positive child up to 16 years of age, provided that the mother/father finds a job when the child reaches the age of 16 | 5            | 0                     | 28                                 | 10  | 18  | 9                       |
| Payment of a monthly benefit in the amount of UAH 34 to HIV-positive children till they reach the age of 16   | 49           | 4                     | 8                                  | 7   | 7   | 5                       |

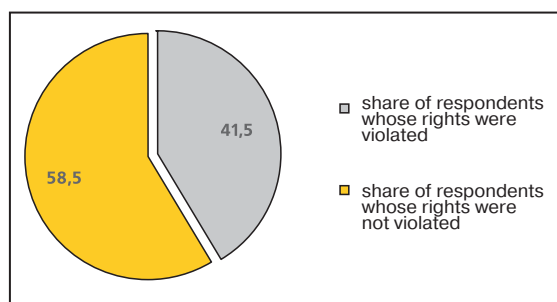
tive children know about this benefit but cannot use it.

More than half of parents receive a monthly payment for their HIV-positive children under 16. This is the benefit known and used by most respondents (49 people). Four respondents (every twentieth) used it in the past, and every tenth does not know about its existence. Approximately the same number would like to use it, but do not have access to it.

The survey data allows us to conclude that violations of the rights of HIV-positive people are widespread in Ukrainian society. Thus, in answer to the question 'Were your rights violated due to your HIV status?', 41.5% of respondents said 'Yes'. At the same time, the HIV prevalence level in the surveyed city did not influence the number of respondents who said their rights had been violated.

**Diagram 16**

Answers to the question 'Were your rights violated due to your HIV status?'



Taking into account the low level of awareness of respondents of their rights, the data about such violations may be understated, because respondents could not always see that their rights were violated.

Every third case of human rights violations of HIV-positive people, as demonstrated in table 5, is violation of the right to employment or education. More than two thirds of respondents who faced or now face violations of their rights have experienced violation of their right to health care. Slightly more respondents (69.9%) said their right to confidentiality of diagnosis had been violated — more than two out of three respondents whose rights were violated against their will experienced disclosure of their HIV status.

**Table 5**

Answers to the question 'Exactly which rights have been violated during the time that you have been living with HIV?'

|   |       |
|---|-------|
| The right to employment/education         | 33.3% |
| The right to health care                  | 68.8% |
| The right to confidentiality of diagnosis | 69.9% |

Despite such poor protection of the rights of HIV-positive people, only 6.7% of respondents have documented evidence of such violations.

That is, only 19 of 692 respondents in the survey have such documents. At the same time, only half of them (10 out of 19) would like to protect their rights in court.

Answers to an open-ended question relating to legal issues of interest to respondents confirm the low level of legal literacy of the questioned PLHA. Since HIV-positive people do not know their rights, there were a lot of questions about the list of PLHA rights and benefits.

HIV-positive people participating in the survey are most concerned about the mechanism to obtain disability status and pension, as well as about the conditions and access to free legal, medical, social and psychological services and to other payments provided by the state. When speaking about legal services, respondents most often mean protection of their rights and compensation of moral and material losses.

One of the most popular legal issues is the possibility to realize the right to a separate room, which is perceived by many respondents as the right to a separate apartment.

Certain aspects of labor legislation on HIV-positive people are also important to respondents.

The issue of confidentiality also concerns respondents as it is closely related to the sphere of labor relations and health care. People want to know about the legal aspects of relationships with health care personnel; in particular, which medical staff have the right to know the HIV status of the patient, under which conditions they can be refused medical care, whether health care specialists have the right to do an HIV test without the patient's consent or disclose his/her diagnosis after the death of the latter, etc.

A comparatively small number of respondents are interested in aspects of criminal legislation relating to HIV-positive people, in particular, whether HIV is considered an attenuating circumstance, what are the conditions of detention of HIV-positive people, etc.

Other problems faced by respondents due to their HIV status most frequently include psychological discomfort, complication of relationships with their social circles; and most often they described situations that can be classified as discrimination (refusal to provide health care due to HIV status, dismissal from work, disclosure of diagnosis, etc.). Health problems, lack of job opportunities and financial problems were also mentioned rather frequently as the consequences of HIV positive status.

Respondents mentioned complicated interpersonal relations with family and sexual partners, lack of communication, and the negative attitude of society as the biggest problems occurring due to their HIV status.

Another large group of problems is related to negative attitudes and discriminatory behavior towards HIV-positive people on the part of health care specialists, employers and others.

Financial problems mentioned by the respondents are related to the inaccessibility of free medicines, which are otherwise very expensive,



and to the lack of access of some respondents to free health care. Taking into account the fact that one third of respondents are active injecting drug users, the financial problems of some may be conditioned by the need to regularly buy drugs.

Discomforting psychological feelings include difficulty in informing relatives and friends about an HIV diagnosis, as well as deep emotions after receiving this diagnosis.

## ATTITUDES OF SOCIETY TOWARDS PEOPLE LIVING WITH HIV

Disclosure of HIV status is a considerable problem for people living with HIV because, as described above, the rights of HIV-positive people are often violated, while concealment of HIV status makes it impossible for PLHA to use their legal rights and privileges.

As a rule, HIV-positive people are not inclined to inform others of their positive HIV status. Each tenth respondent, when asked 'Have you informed anyone about your HIV positive status?', answered 'I have not informed anyone about my status'. About a third of those surveyed (34.2%) have informed their relatives only. One quarter of respondents feel able to disclose their status to people other than relatives or close friends depending on the situation. Only 17.8% of those polled inform medical workers about their HIV status if necessary. 11.8% of HIV-positive people do not conceal their status.

The circle of people who know about a person's HIV status increases with the number of years that a person has lived with HIV. Of the number of respondents who learned about their positive HIV status during the last 12 months, 21.6% have not told anyone about their status, 39.6% have informed only members of their families and close friends. Only 5.8% out of this PLHA category are ready to discuss their status in public. At the same time among respondents who learned about their positive HIV status over six years ago, only 3.9% have not informed anyone about it. 20.2% of respondents have informed their relatives, while 21.7% do not hide their status and are ready to talk about it openly.

It is indicative that among people ready to openly discuss their positive HIV status, the share of PLHA organization members is 52.5%, while

among respondents living with HIV for over six years this index reaches 67.9%.

The majority of respondents (59.2% of the total) evaluates the attitudes of Ukrainian society towards them as negative. Each fifth respondent believes that Ukrainian society is indifferent to HIV-positive people. Only 6.4% of respondents consider the attitude of society towards PLHA to be sympathetic.

The evaluation of social attitudes towards HIV-positive people differs somewhat between men and women. Unlike women, men are inclined to consider Ukrainian society indifferent towards people living with HIV. Such a belief in the indifference of the Ukrainian population is shared by more than 25% of men participating in the survey, while among women this percentage is twice lower — only 12.7% of polled women share this opinion.

The survey results demonstrate that no level of an HIV-positive person's social surroundings, regardless of the closeness of relations, is absolutely free from intolerance.

In addition, there is a link between the level of informing others about positive HIV status and the frequency of negative or changed attitudes. The larger the number of respondents who state that people around them do not know about their positive HIV status, the lower the percentage of statements of negative or changed attitudes from social circles.

Respondents believe another regular tendency to be that the more distant a social circle is from a person, the less tolerant are representatives of this circle towards HIV-positive people.

It is necessary to mention medical personnel as a social circle. On one hand this circle is best informed about respondents' HIV status; on the other hand, medical personnel are the least tolerant towards PLHA.

The level of awareness of status is distributed as follows (according to the table): the most informed are medical workers; the least informed are neighbors.

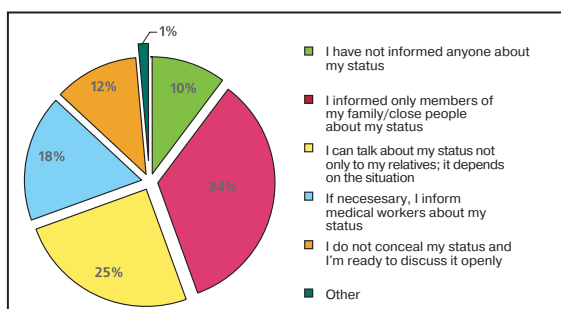
Friends and relatives occupy second place in terms of awareness of respondents' HIV status. At the same time they demonstrate the highest level of tolerance towards people with HIV.

Sexual partners are not aware of the HIV status of respondents in more than 20% of cases and also demonstrate a comparatively high level of tolerance towards HIV-positive people.

In the majority of cases colleagues do not know about the status of HIV-positive people who work

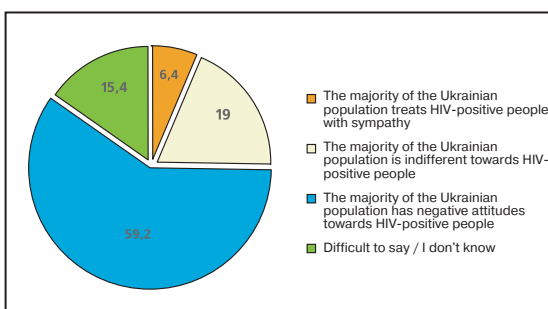
**Diagram 17**

Answers to the question 'Have you informed anyone about your positive HIV status?'



**Diagram 18**

Answers to the question 'How would you evaluate Ukrainian social attitudes towards HIV-positive people?'



with them. Exceptions are respondents' colleagues who work in AIDS-service organizations. These are more informed about respondents' status and thus a higher percentage of respondents working in AIDS-service organizations report manifestations of negative or changed attitudes because of their HIV positive status.

Officials are one of the least informed and at the same time least tolerant groups towards respondents.

Somewhat different are results among polled men and women. Women more often report manifestations of changed attitudes because of their positive HIV status; they more rarely report that surrounding people do not know of their HIV status. In other words, HIV-positive women are more open and suffer more because of changed attitudes.

An exception to this trend is the attitude of colleagues towards HIV-positive men and their knowledge of the status of HIV-positive men; as well as the frequency of negative manifestations towards men from their sexual partners. Colleagues and sexual partners of HIV-positive men more often demonstrate negative attitudes in comparison with women.

In addition to the more open status of HIV-positive women, a factor which leads to women's more frequent complaints concerning negative behavior, is in some cases women's greater sensitivity to surrounding behavior.

The other two variables that influence distribution of answers concerning social attitudes towards respondents is experience of injecting drug use during the last 10 years and use of injecting drugs during the last six months.

IDUs in continuous remission, as compared to those who do not use injecting drugs, face more negative treatment from friends and relatives. In all other cases there are no considerable differences between these two groups.

Active IDUs generally report negative attitudes more often from various circles because of their positive HIV status.

Such data allow us to assume that drug dependent people are inclined to link changed or negative attitudes with their positive HIV status, while in real-

ity negative attitudes are caused by intolerance of IDUs in society.

More than half of respondents (381 people) answered the question 'What government actions towards PLHA would be the most essential?' Respondents answered this question on the basis of their personal needs and problems (with rare exceptions). Respondents' statements generally indicate a passive position concerning resolution of HIV-related issues.

The most frequent suggestion is to introduce free access to various social and medical services (treatment, diagnostics, expert counseling, employment, recreation, etc.), as well as free access to ARV treatment and other medicines. Respondents talk not only about the declaration of rights for free access to listed services, but real realization of HIV-positive people's rights. That is why, along with the suggestion to ensure free access to the aforementioned services, they propose increase of payments, introduction of HIV pension, material support for people with HIV, and financing and provision of humanitarian assistance as important government actions concerning HIV.

Similarly popular is the idea of government information work both among HIV-positive citizens (information on rights and benefits, treatment, etc.) and among the general population. The main point of statements concerning the necessity of information distribution among the public is that such a campaign might promote de-stigmatization of HIV-positive people.

Some respondents believe that battling intolerant behavior is of major importance. Respondents note lack of sympathy, support and understanding from both the state and fellow citizens. There is a widespread opinion that the state needs to ensure protection of PLHA rights, and, by punishing violators of such rights, promote tolerant attitudes towards people with HIV. This statement has something in common with the proposal to establish law enforcement mechanisms concerning PLHA and HIV issues.

Less popular but no less important is the idea that the government should ensure access to resources for HIV activists to fight this problem on their own.

*Table 6*  
Answers to the question 'Have you personally felt during your life with HIV (if yes — how frequently) manifestations of negative or changed attitudes to yourself as an HIV-positive person?'

|                         | Always | Often | Sometimes | Never | These people are not aware of my HIV status |
|-------------------------|--------|-------|-----------|-------|---|
| From sexual partners    | 5.2    | 8.8   | 21.1      | 35.7  | 22.5  |
| From relatives, friends | 2.6    | 6.5   | 30.8      | 41.6  | 14.7  |
| From colleagues         | 1.7    | 2.6   | 7.9       | 21.2  | 59.1  |
| From neighbors          | 2.6    | 2.9   | 5.9       | 10.3  | 72.1  |
| From officials          | 3.0    | 5.9   | 8.2       | 10.7  | 64.3  |
| From medical workers    | 8.1    | 24.3  | 35.7      | 16.8  | 11.1  |

## CONCLUSIONS

Data received from the public opinion survey among people living with HIV in 16 Ukrainian cities allow us to draw the following conclusions concerning survey goals:

- The general awareness of polled PLHA concerning access to diagnostics and treatment of opportunistic infections and hepatitis is low. Participants are somewhat better informed about accessibility of diagnostics and treatment of candidiasis and herpes; somewhat worse about accessibility of diagnostics and treatment for toxoplasmosis and cytomegalovirus infection. According to surveyed PLHA, most accessible is diagnostics and treatment of tuberculosis: diagnosis of this disease (according to the majority of respondents) is free in their city, while its treatment was evaluated as accessible and free by 46.4% of respondents; accessible and paid by 22.1%. Those PLHA who desperately need appropriate services are generally more informed about access to diagnostics and treatment of opportunistic infections and hepatitis.

- The awareness of polled PLHA concerning their need for treatment of opportunistic infections and hepatitis is also rather low. The reason for the low level of information among those surveyed may be both the inaccessibility of diagnostics for such diseases in their locations and a low general culture of health among respondents.

- More than a third of surveyed PLHA do not know whether they need ARV therapy. Another 10.8% of respondents have no knowledge at all of antiretroviral therapy. At the same time the percentage of respondents who know they need antiretroviral therapy according to medical indicators is increasing; the number of those who believe they don't need such treatment is decreasing the longer they live with HIV (are aware of their positive HIV status). However, among polled PLHA who have lived with HIV for over five years, 32.3% do not know whether they need ARV therapy; 7.7% of them know nothing about ARV treatment.

- The group of questioned PLHA who are receiving ARV therapy is quite large. They make up almost a quarter of those who need ARV therapy according to medical indicators and are aware of it.

- The survey also revealed a gradual increase in numbers of those who passed HIV testing voluntarily. The majority of respondents who were tested for HIV over six years ago were tested without their consent, while among those who were tested for HIV within the last 12 months, over half were tested voluntarily.

- The survey also discovered that pre- and post-test counseling is provided with procedural violations, and is sometimes not provided at all. Post-test counseling was provided to 32.8% of surveyed PLHA, and pre-test counseling to 22.1%. Half of respondents noted that pre- and post-test counseling did not achieve its main goals.

- Social and psychological assistance (according to the survey results) is not universally accessible to all respondents. For example, members of PLHA organizations demonstrate a much higher awareness of the accessibility of social and psychological services, and an even larger percentage of this group indicate that such services are free. The difference in evaluating accessibility of social and psychological services may be explained by the fact that membership in PLHA organizations or involvement in AIDS service allows HIV-positive people greater access to services and to information about them.

- According to all respondents, the most accessible services for HIV-positive people are information services, self-help groups, peer education and psychological counseling. Comparatively less accessible are telephone hotlines, home-based care, legal counseling and acquaintance clubs.

- The survey shows that the level of knowledge of the Law on Prevention of Acquired Immunodeficiency Syndrome (AIDS) and Social Protection of the Population among respondents with HIV is quite low. Survey data demonstrate that only 7.3% of respondents are well aware of all or almost all provisions of this law. Some of its provisions are familiar to 28.9% of respondents. 37.3% of those polled have heard about such a law but do not know its content. 20.1% know nothing about this legal document. Members of PLHA organizations show a much greater awareness of the law and its content than the remaining respondents.

- Benefits envisaged by the law are used by a very insignificant number of respondents. At the same time the number of people using benefits for free medical drugs, personal prophylaxis means and psychological and social assistance is increasing.

- The majority of PLHA are unaware of the mechanism for receiving invalid status and pensions, conditions and access to free legal, medical, social and psychological services, as well as various government payments.

- The survey data proves that violation of HIV-positive people's rights is widespread in Ukrainian society. 41.5% of respondents living with HIV

reported violations of their rights as a result of their HIV status. Given the low level of respondent awareness about their rights, such indexes may even be underestimated. Poor knowledge of PLHA rights also leads to the absence of enforcement of legal mechanisms to protect rights. It is significant that 28.6% of polled PLHA reported violations of their right to confidential diagnosis. At the same time compensation for damages connected with limitation of rights as a result of disclosure of HIV were received by only four people out of all surveyed PLHA.

- Intolerance towards people with HIV in Ukrainian society means that disclosure of HIV status generates substantial problems for people living with HIV. Hiding positive HIV status makes it impossible for PLHA to use their legitimate rights and benefits and leads to a passive response in cases of rights violations. Only 6.7% of surveyed PLHA have documented evidence of violations of their rights, and only half of these (3.4%) expressed readiness to protect their violated rights in court.

- Ukrainian social attitudes towards HIV-positive people were described by the majority of respondents as negative. Discriminatory relations

from different social circles and in different situations were most often mentioned among problems faced by respondents as a result of their positive HIV status.

- The survey results show that none of a HIV-positive person's social circles, regardless of closeness of relations, are absolutely tolerant. In particular medical personnel are the best informed about respondents' HIV status and yet make up the least tolerant social circle.

- Active IDUs report negative attitudes from other social circles because of their positive HIV status more often than other respondents. Thus, drug dependent persons are inclined to link changed or negative treatment with their positive HIV status, while negative attitudes in this case are caused by intolerance towards IDUs in society.

- Staff members of AIDS-service organizations and members of PLHA organizations questioned within the framework of the survey generally demonstrated a higher level of knowledge concerning rights and benefits of PLHA, accessibility of diagnostics and treatment of opportunistic infections and hepatitis and social and psychological services than the other respondents.



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