

**ROO “Community of PLWHIV”
UNFPA, Russia Country Office
Yuri Levada Analytical Center**

Research Report

**“People Living
with HIV Stigma Index”**

*Research period:
March - April 2010*

Sample: 660 people in 11 major towns in Russia

Data was analyzed and report was developed by Ms Alexandra Pisareva

Moscow 2010

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Section 1

Research Methodology

1.1 Introduction

This report is devoted to the results of the research, the main aim of which was to gather information about the problems of people living with HIV (PLHIV) in Russia, connected with stigma, discrimination and the violation of their rights. Stigma and discrimination connected to HIV infection are universally recognised barriers to access to preventative measures, treatment and support. In order to counteract such stigma and discrimination, it is necessary to have complete data about their actual level, how they manifest themselves in reality and what kind of influence they have on the lives of people living with HIV.

The research in Russia is part of an international project coordinated by the International Planned Parenthood Federation (IPPF) in partnership with the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV/AIDS (ICW) and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

The methodology suggested by the organisations above was adapted to circumstances in Russia by the Joint UN Team on HIV/AIDS in Russia and the regional community organisation 'Сообщество ЖЖБ' (PLHIV Community). The Levada-Center, a sociological non-governmental organisation was involved in order to provide professional services in consulting survey participants and processing data received. The Levada-Center carried out the training of interviewers, further adaptations of the existing questionnaire to Russian circumstances, professional systemisation, and introduction, monitoring and analysis of data and produced the report on the research. Non-profit organisations that provide help and support to PLHIV in the towns where the research was conducted were involved in the capacity of regional coordinators of the research, to collect information and organise the process of the survey (poll) of respondents.

The results of the research should become an instrument for protecting the interests of people living with HIV, using PLHIV organisations, activists and other interested parties in the area of counteracting stigma and discrimination connected to HIV in Russia.

Research Methodology

Research Sample

The investigated population consists of people living with HIV (PLHIV) aged 18 and over in 11 major towns in Russia (60 people in each town): Orenburg, Kazan, Krasnoyarsk, Saint Petersburg, Rostov-on-Don, Orsk, Tyumen, Kursk, Naberezhnye Chelny, Chelyabinsk, and Ufa.

The regional coordinators (non-profit organisations which provide help and support to people living with HIV), were responsible for selecting respondents from a number of clients of their organisations and in places where they provide services for PLHIV. The regional coordinators were given the task of evaluating the structure of PLHIV in their region and trying as far as possible to select respondents for interviewing in a proportional structure to that which exists in reality.

The sample size was 660 people living with HIV.

Structure of the survey (by % of those asked):

Sex	
Man	50
Woman	50
Age	
18 - 19 years	2
20 - 24 years	11
25 - 29 years	36
30 - 39 years	40
40 - 49 years	9
50 years and over	2
Time living with HIV	
0 - 1 year	8
1 - 4 years	30
5 - 9 years	36
10 - 14 years	25
More than 15 years	1
Open/undisclosed HIV status	
HIV status known to fairly many	31
HIV status known only to those closest	59
HIV status not known to anyone	10
Family situation	
I am in an official marriage, live in a civil marriage or with a long-term partner, and my husband/wife/partner currently lives with me.	39
I am in an official marriage, live in a civil marriage or with a long-term partner, but my husband/wife/partner does not	5

currently live with me.	
I have a long-term partner but do not live with them.	15
I have never been married and I do not have a long-term partner.	22
I am divorced and I do not have a long-term partner.	14
I am a widow/widower and I do not have a long-term partner.	5
Belonging to a vulnerable group of the population	
Man who has sex with men (MSM)	2
Gay/lesbian	4
Transgender (transsexual)	0
Sex worker	7
Injecting drug user	59
Refugee or asylum seeker (from another country)	1
Internally displaced person (forced to move from another region of Russia)	4
Migrant who has moved to this town/to Russia for work	1
Prisoner	24
I do not belong and have not in the past belonged to any of these groups	29
Level of Education	
Did not complete basic secondary education (did not finish years 8-9)	5
Basic secondary education (completed years 8-9 at school or at professional technical school/college based on years 8-9)	20
Full secondary education (completed years 10-11 at school or at professional technical school/college based on years 10-11)	21
Secondary vocational education (completed technical secondary school/college/specialist school with secondary vocational education)	23
Incomplete higher education (completed 2 - 4 years at an institute of higher education)	13
Higher education (hold a diploma from an institute of higher education)	18
Nature of Employment	
Full-time employment as a waged worker	39
Part-time employment as a waged worker	15
Full-time employment in own business or earn income through own activity	9
Casual worker, not in full-time employment in own business or earning income through own activity	9
Unemployed (seeking work)	15
Not working (studying, home maker, pensioner) and not seeking employment	16

Methods for conducting the survey and controls for the work of interviewers

The research was conducted by personal interview 'face to face' using a questionnaire. People living with HIV spoke to the interviewers.

Quality controls were carried out on the work of the interviewers by the regional coordinators of the research.

Logic control on the data files was also carried out using a specialist computer programme.

Methods for gathering and processing data

The research data was encoded, imported into an electronic database, and cleaned from accidental errors and blank data.

The data was weighted by age and belonging to vulnerable groups of the population on the basis of expert evaluation of the general structure of PLHIV, given by the regional coordinators of each town in order to minimise the consequences of possible bias of the sample.

Section 2

Analysis of the Results of the Research

Analysis of the data was conducted on the total survey population and also between different groups of respondents, divided by the following key characteristics: sex, age, time since diagnosis, belonging to a vulnerable group of the population, disclosure of status to those around them, presence of a long-term partner, presence of sexual relations, partner's status.

The report presents a description of the results of the research in the entire data set and a comparison within groups in cases when the differences between them are significant, however due to the fact that the representation of several groups in the sample is considerably low, the statistical significance of the data used for comparison between groups was not high enough in several cases.

2.1 Discrimination and Stigmatisation by Individuals

The research data shows that in the last 12 months more than a third of survey participants (35%) encountered some form of discrimination or stigmatisation from those around them for reasons including their HIV status.

It is necessary to mention that among those whose status is known to many, the portion who encountered some form of discrimination or stigmatisation from people around them for reasons including their HIV status was significantly higher (48 %) than among those whose status is known only to those closest to them (33 %) or whose status is known to nobody (21%). Also this portion is considerably lower among people who do not belong/have not in the past belonged to any of the vulnerable groups of the population (25%), than among people who belong to one of these groups; among prisoners this portion is 43% and among injecting drug users it is 42%.

According to the results of the research, the most common form of stigmatisation that people living with HIV are subjected to is gossip: around two thirds (72%) of all those asked had encountered it at some point, including just under half of those asked (40%) mentioned that they have encountered gossip about them in the last 12 months (see Figure 1). Sex workers encountered gossip about them most often in the last year: more than half (57%) of those asked in this group encountered gossip. People who do not belong and have not in the past belonged to any vulnerable group encountered gossip least often of all: around a third (33%) of this group experienced it. The portion of those who

encountered gossip in connection with HIV or in connection with HIV as well as for other reasons, in the last 12 months is 18% of the total number of those asked (see Figure 2).

Around half (49%) of survey participants mentioned that they had encountered insults, victimisation or verbal threats at some point, of which 21% of those asked had encountered this in the last 12 months. As regards such situations arising for reasons including the HIV status of the respondent, in the last year these were noted by 9% of those asked. Physical victimisation and threats of action were a little less common: 41% of those asked had encountered these at some point in the past, while 15% of participants had encountered these in the past 12 months. Such incidents happened to 4 % of those asked for reasons including their HIV status in the last 12 months.

Just under half (46%) of those asked had been subjected to physical violence at some time, including 14% who had encountered it in the last 12 months. Of those people who were subjected to physical violence in the last 12 months just under half (47%) of them experienced it from people who they did not know, just under a third (30%) from acquaintances/relatives who do not live with them, around a fifth (19%) from their husband/wife/partner, and 5% from another person who lives with them. For reasons including the respondent's HIV status, 2% of those asked had suffered violence in the last 12 months.

More than a quarter (26%) of those PLHIV asked had met with sexual rejection at least once due to their HIV-positive status, while 9% of those asked had encountered such rejection in the last 12 months. Among those survey participants who tried to enter into sexual contact, these portions were 29% and 11% respectively. As regards the reason for rejection, more than half (58%) of people who had encountered such a rejection in the last 12 months mentioned that it was related to the lack of a condom/safe method of protection and 38% said that it was due to the very fact that HIV was present, fear of infecting the partner or insufficient information about HIV infection. During this time the portion of those who encountered such a rejection was significantly higher among sex workers than among other groups of the population at 25%.

A fifth (20%) of survey participants were subjected to psychological pressure or manipulation from their husband/wife/long-term partner at some time, during which their HIV status was used against them, including 9% who had encountered such pressure in the last 12 months. Among those survey participants who have a husband/wife/partner, these portions were 26 % and 12 % respectively.

More than a fifth (22%) of those PLHIV asked were subjected to discrimination/restriction at some time by other people living with HIV, including 7% who had been subjected to such discrimination in the last 12 months^{*}. 14% of survey participants mentioned that somebody living with them had been

^{*} The data relating to discrimination/restriction by other PLHIV should be treated with caution because this question contained discrepancies in the printed version of the questionnaire which was given to respondents to fill in.

subjected at least once to discrimination/restriction because of the respondent's HIV status since the time of diagnosis and this had happened to 7% of those asked in the last 12 months.

The least common forms of discrimination are refusals of participation in family affairs, family or social events and also religious events.

15% of survey participants mentioned that there had been an occasion when they were not allowed to take part in family or social events or to attend some kind of gathering or public place, including 5% who had encountered such a refusal in the last 12 months. The portion of those who had encountered such a situation in the last 12 months for reasons including their HIV status was 2%.

Of all those PLHIV asked, 14% mentioned that they had not been allowed at some time to take part in family affairs (for example, preparing food, joint meals, staying overnight with somebody in the same room), including 6% who had encountered such a situation in the last 12 months. The portion of those who had not been allowed to participate in such activities in the last 12 months for reasons including the respondent's HIV status is 3%.

The portion of those who were not allowed to participate in religious events or to attend places of worship is less than 1% of those asked.

Data concerning the frequency at which those PLHIV asked encountered some form of stigmatisation and discrimination by those around them during the last 12 months is presented in Figure 1A.

Figure 1: Experience of stigmatisation and discrimination from those around you: in the last 12 months and earlier (according to data from questions 2A.1a, 2A.1b, 2A.2a, 2A.2b, 2A.3a, 2A.3b, 2A.4a, 2A.5a, 2A.6a, 2A.7a, 2A.9, 2A.10, 2A.11, 2A.12, by % of number asked)

**Was the subject of gossips
Encountered insults, victimisation
verbal threats**

**Was subjected to physical violence
Encountered physical victimisation
and/or threats of action**

Encountered sexual rejection

Was subjected to discrimination
*in connection with their HIV status/the respondent's HIV status

Figure 1A: Experience of stigmatisation and discrimination from those around you: frequency of occurrence (according to questions 2A.1a, 2A.2a, 2A.3a, 2A.4a, 2A.5a, 2A.6a, 2A.7a, 2A.9, 2A.10, 2A.11, 2A.12, by % of those asked)

Was the subject of gossip

**Encountered insults, victimisation
verbal threats**

**Encountered physical victimisation
and/or threats of action**

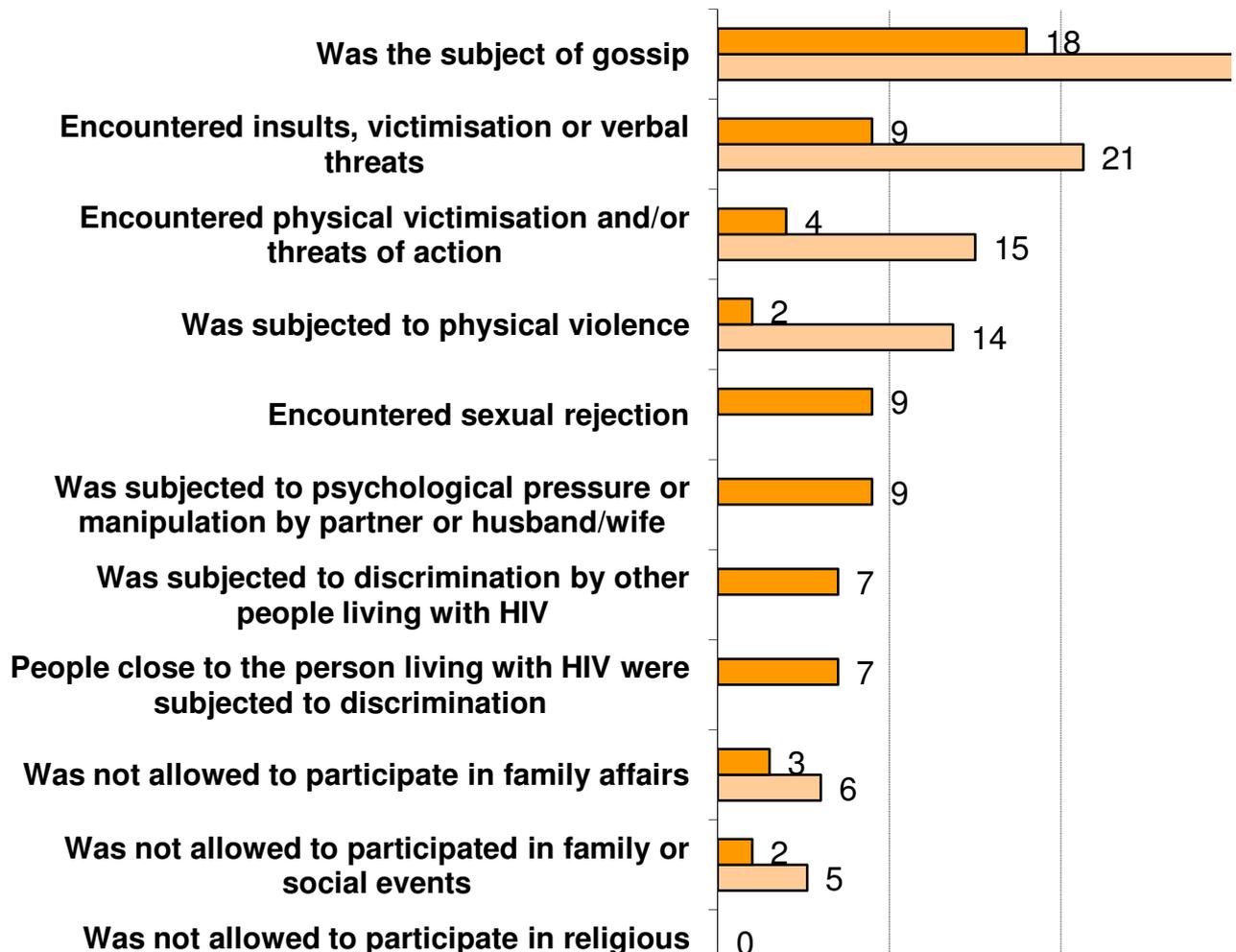
Was subjected to physical violence

Encountered sexual rejection

Was subjected to discrimination

**in connection with their HIV status/the respondent's HIV status*

Figure 2: Experience of stigmatisation and discrimination from those around you: in total and for reasons, including HIV status (according to data from questions 2A.1a, 2A.1b, 2A.1B, 2A.2a, 2A.2b, 2A.2B, 2A.3a, 2A.3b, 2A.3B, 2A.4a, 2A.4b, 2A.5a, 2A.5b, 2A.6A, 2A.6b, 2A.7a, 2A.7b, 2A.9, 2A.10, 2A.11, 2A.12, by % of number asked)

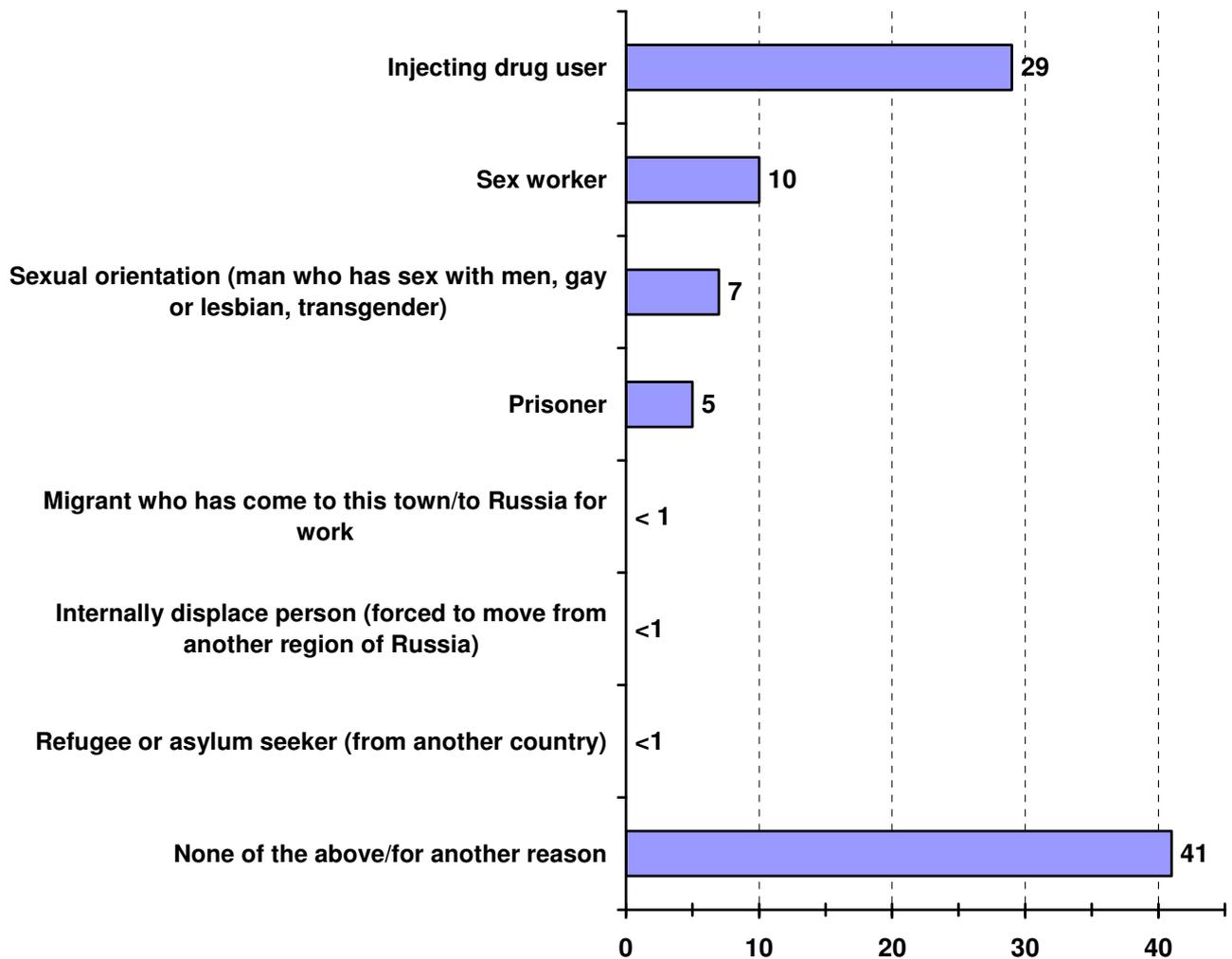


Just less than half (43%) of survey participants encountered victimisation, restriction or prejudiced relationships either unrelated to their HIV status or related to their HIV status as well as to other reasons. Just less than a third (29%) of these people named their belonging to a group of injecting drug users as the main reason for this, 10% linked these restrictions with their work in the sex industry, a further 7% with their sexual orientation and 5% with the fact that they are/were a prisoner. The portion of those who link this restriction with belonging to the injecting drug users category is 52% directly in this group and 47% in the prisoner category (at the same time only 18% of prisoners who were subjected to discrimination which was not linked to their HIV status named their belonging to the prisoner category as the main reason).

41% of those who encountered victimisation, restrictions or prejudiced relationships either unrelated to their HIV status, or related to their HIV status as well as to other reasons, said that this was linked

to reasons, other than their belonging to any of the groups listed above. Among such reasons people referred most often of all to problems in their personal relationships with other people in different areas of their lives (in the family, with friends, at work) - such reasons were mentioned by around half of those who answered that the reasons were not linked to their belonging to any of the groups mentioned above.

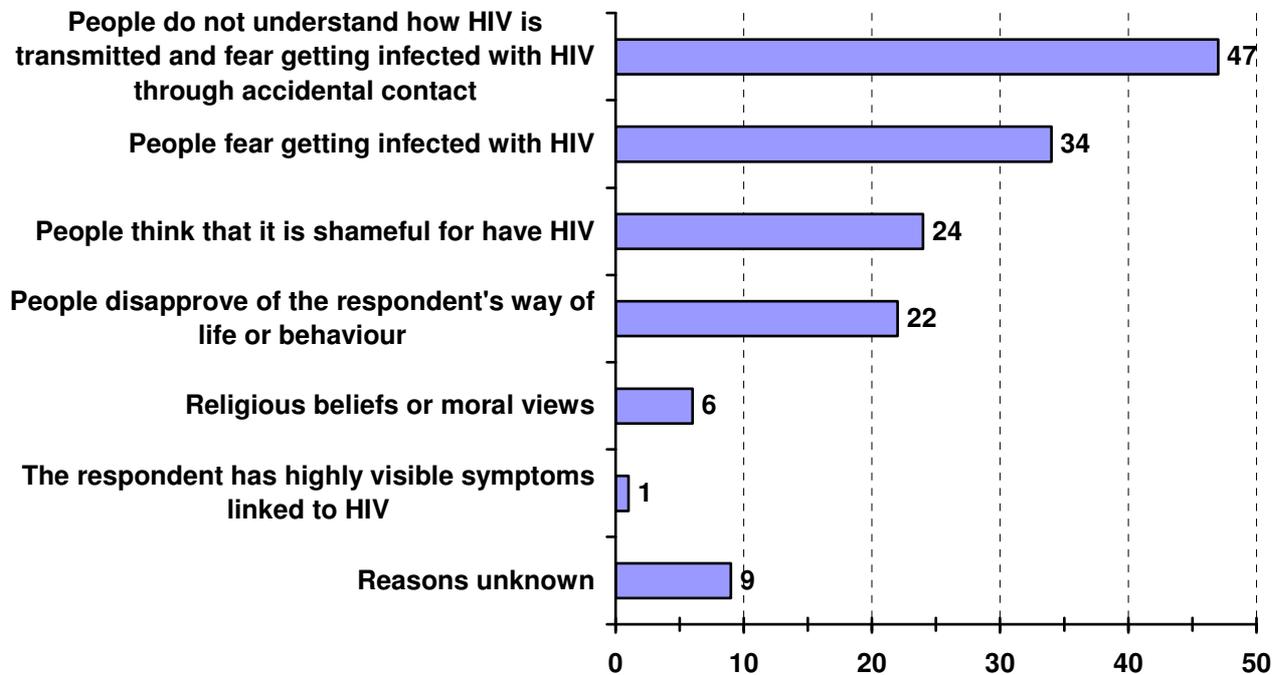
Figure 3: Main reason for victimisation, restriction, prejudiced relationships towards the respondent, not linked to HIV (according to data from question 2A.8 "What do you think the victimisation, restriction and prejudiced relationships towards you are linked to most of all, apart from your HIV status? Chose one of the groups which you belong to which in your opinion causes negative relationships towards you most of all," by % of the number of those who were subjected to discrimination or victimisation for reasons not linked to their HIV status)



As has already been mentioned earlier, in the last 12 months more than a third of survey participants (35%) had encountered some form of discrimination or stigmatisation by those around them for the reason of their HIV status or because of their HIV status and other reasons. Just under half of these people (47%) consider the reason for such discrimination or stigmatisation to be insufficient knowledge of people around them as regards transmission of the HIV infection and corresponding fear of getting infected through accidental contact.

The portion of those who consider that this victimisation/restriction/discrimination, was due to the fact that people do not approve of their way of life or behaviour, was much higher among prisoners; 40% of prisoners experienced discrimination/stigmatisation linked to their HIV status, and was lowest among people who do not belong to any vulnerable group of the population at just 4%.

Figure 4: Reason for victimisation/restriction/discrimination, linked with the respondent's HIV status (according to data from question 2A.13. "What do you think caused the victimisation/restriction/discrimination, linked to your HIV status that you encountered in the last 12 months?" by % of the number of those who were subjected to discrimination or victimisation for reasons linked to their HIV status. The total of responses exceeds 100% for this question since it was possible to give several answers.)



2.2 Discrimination by Organisations and Institutions

According to the research data, 21% of survey participants have encountered some kind of discrimination by organisations and institutions in connection with their HIV status.

The most common form of discrimination is discrimination in the area of provision of medical services: 16% of those asked had been refused some kind of service provided by medical institutions in the last 12 months, including 10% of those asked who had been refused by the health service (among those who approached these institutions and in doing so declared their HIV status, this portion reaches 17%). 5% of survey participants were refused family planning services and the same percentage encountered refusal of services for sexual and reproductive health (these portions among those who approached such services and in doing so declared their HIV status were 20% and 17% respectively) (see Figure 5).

The portion of those who were refused access by the health service is much lower for the group of people who do not belong and have not in the past belonged to any of the vulnerable groups of the population (6%), than among those who belong or have belonged to these groups (13%).

As regards displays of discrimination in the area of employment, 3% of survey participants mentioned that in the last 12 months they had been refused a job placement or opportunity to work at least once in connection with their HIV status, 2 % of those asked had lost paid work or another source of income in connection with discrimination, linked in one way or another with HIV (this portion among those who in the last 12 months had been in paid employment or had a source of income is 4%), and also 2% spoke of being refused a rise and having other duties imposed on them for this reason.

Acts of discrimination were also met with in the area of education: 3% of survey participants mentioned that in the last 12 months they had been excluded from an educational institution, dismissed from classes or hindered from attending an educational institution because of their HIV-positive status (this portion among those who tried to attend an educational institution is 5%)*, a further 1 % said that this happened to their children in connection with the respondent's HIV status (this portion among those who have children who have a necessity or intention of attending educational institutions is 2%).

One fifth (20%) of those asked had to change their place of residence or had encountered difficulties when renting accommodation in the last 12 months, including 4% who had encountered such a situation in connection with their HIV status.

* The data relating to discrimination/restriction by educational institutions should be treated with caution because this question contained discrepancies in the printed version of the questionnaire which was given to respondents to fill in.

Figure 5: Experience of stigmatisation and discrimination by organisations and institutions: In total and for reasons connected with HIV status (according to data from questions 2Б.1а, 2Б.1б, 2Б.2, 2Б.2а, 2Б.2б, 2Б.2в, 2Б.3, 2Б.4а, 2Б.4б, 2Б.5, 2Б.6, 2Б.7, 2Б.8, 2Б.9, by % of the number asked)

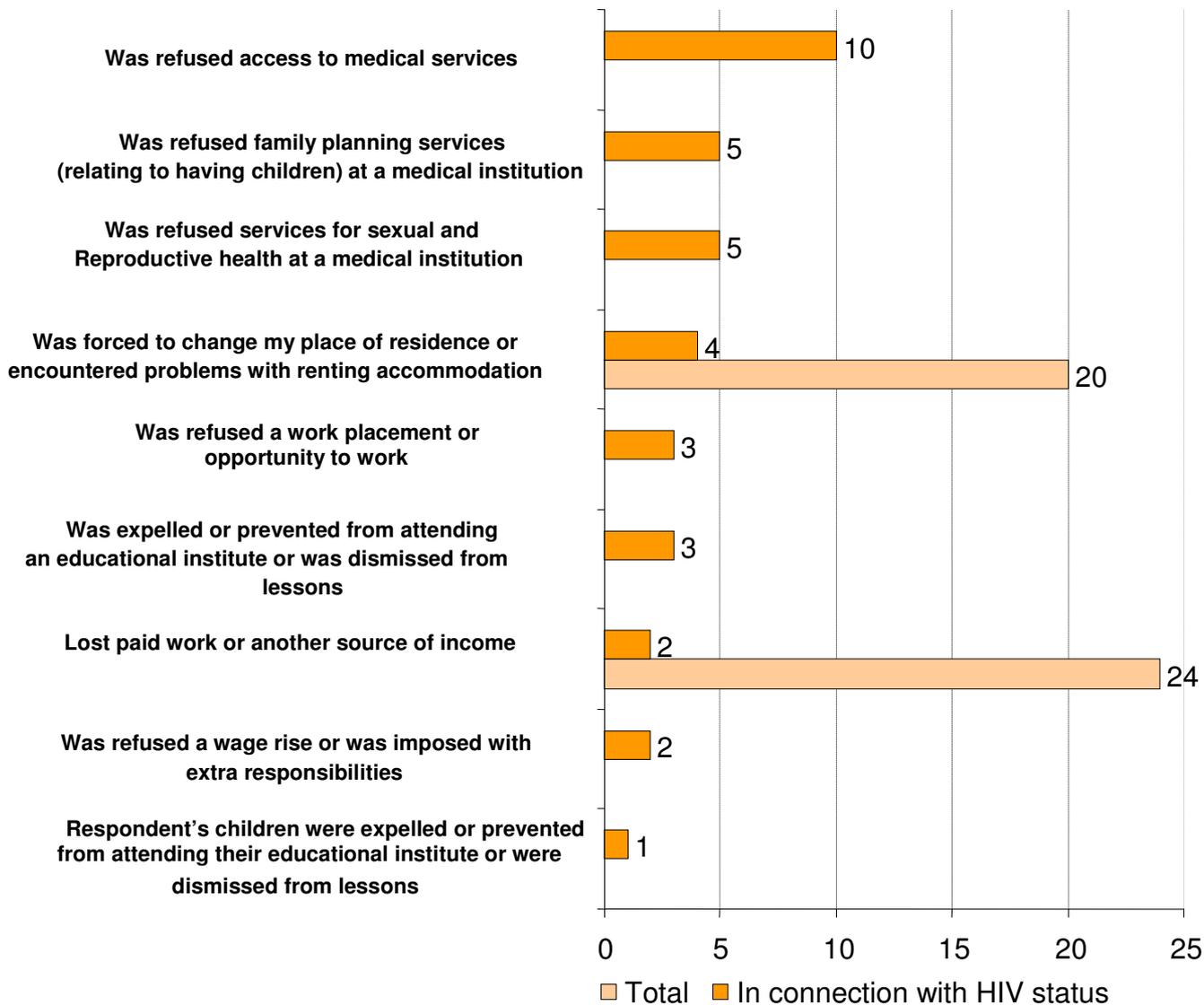
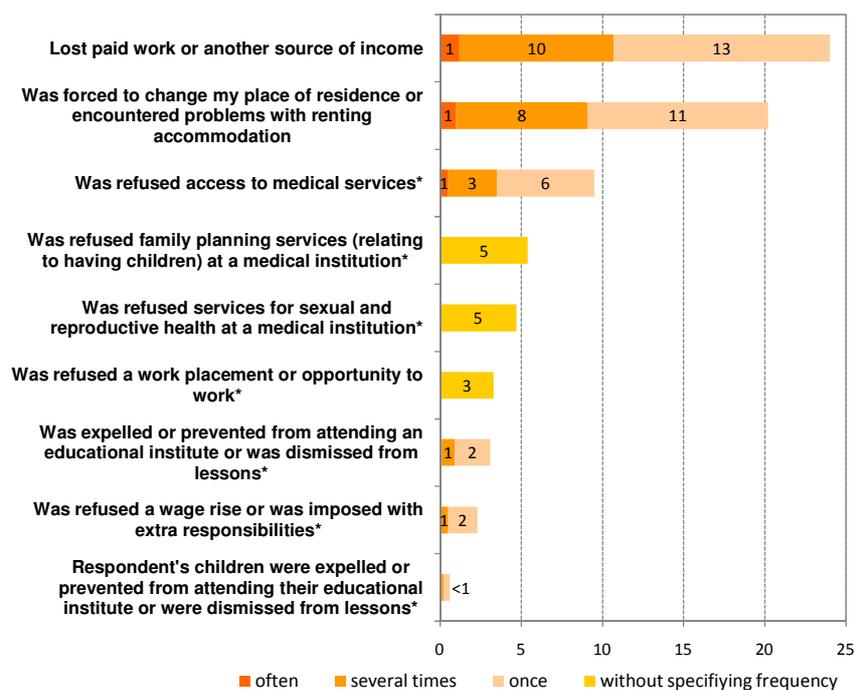


Figure 5A: Experience of stigmatisation and discrimination by organisations and institutions: frequency of occurrence (according to data from questions 2Б.1а, 2Б.1б, 2Б.2, 2Б.2а, 2Б.2б, 2Б.2в, 2Б.3, 2Б.4а, 2Б.4б, 2Б.5, 2Б.6, 2Б.7, 2Б.8, 2Б.9, by % of the number asked)



*in connection with the respondent's HIV status

2.3 Internal Stigma

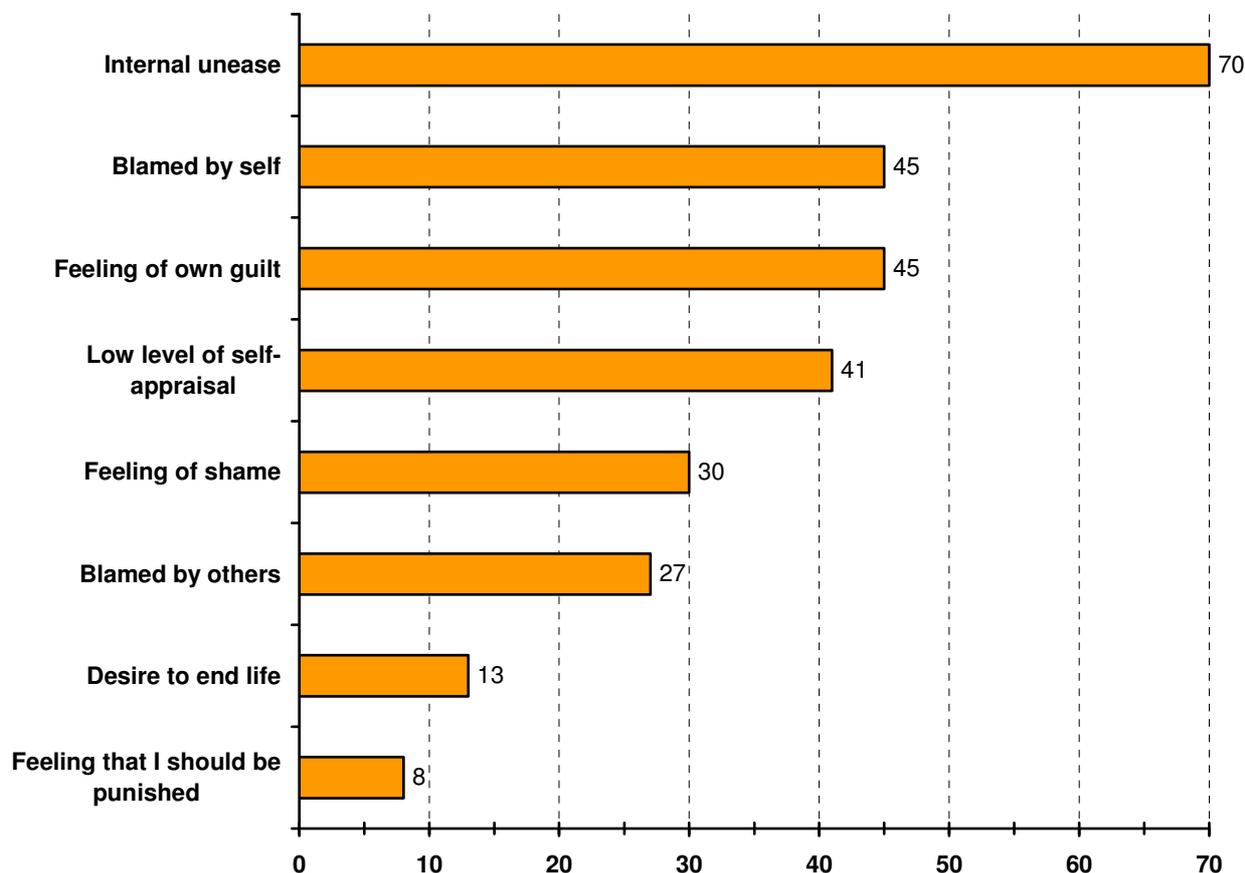
More than three quarters (78%) of those asked experienced negative feelings of one kind or another towards themselves in connection with their HIV status in the last 12 months. The most common feeling among PLHIV was internal unease, which was experienced in the last 12 months by more than two thirds of survey participants (70%) and feelings of self blame and condemnation which was mentioned by just less than half of those asked (45%).

The portion of those experiencing negative feelings towards themselves does not vary greatly between different groups of the population, however it may be said that it is much lower among prisoners and much higher among migrants* in the case of the majority of the emotions listed above

*Included in the 'migrant' group were people, belonging or who had in the past belonged to the following groups: refugees or asylum seekers (from another country), internally displaced persons (forced to move from another region of Russia), migrants who have more to this town/to Russia for work, because of there being too little representation of each of these groups in the survey sample separately.

in comparison with the data on the whole. For example, 41% of those asked had experienced a low level of feeling of self-worth in the last 12 months, while this portion was just 35% among prisoners.

Figure 6: Feelings experiences towards yourself in the last 12 months in connection with your HIV status (according to the data from question 2B.1. "Have you experienced any of the following feelings personally towards yourself in the last 12 months in connection with your HIV status?" by % of the number asked)

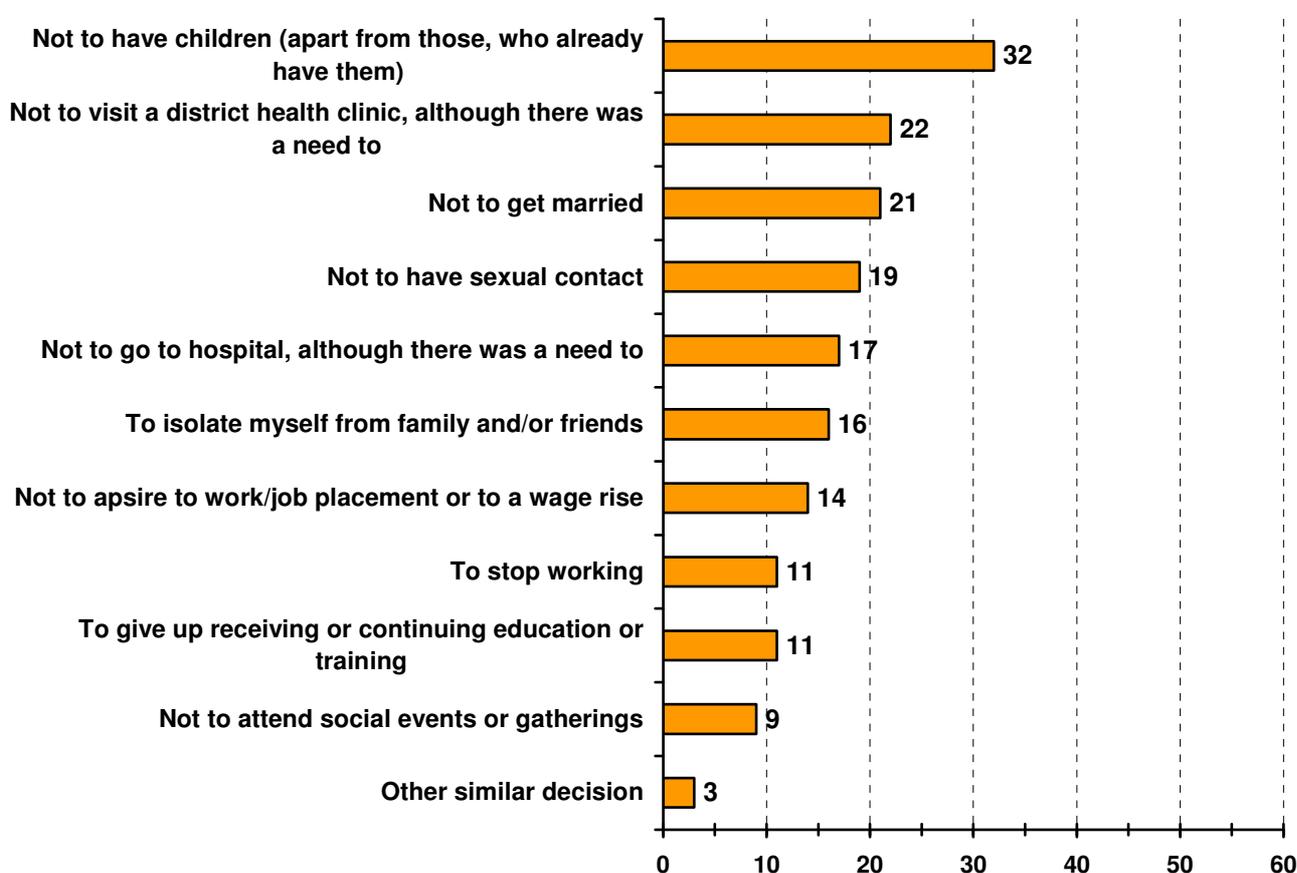


Survey participants were asked to say whether in the last 12 months they had avoided some kind of social event, life opportunity or visit to a medical institution. More than half (56%) of those PLHIV asked had taken some kind of auto-discriminatory decision in the last 12 months, including around a third of those asked (32%) who had made the decision not to have children, around a fifth of those asked who had decided not to get married and not to have sexual contact (21% and 19% respectively), 16% who had decided to isolate themselves from their family/friends. As regards approaching medical institutions, 22% of those asked had taken the decision not to visit a health centre and 17% had decided not to visit a hospital when it was necessary to do so. As regards making decisions in the areas of work and study, 14% had decided not to aspire to work or promotions, 11% had stopped working and 11% had decided to give up on receiving or continuing education. 9% of survey participants had decided not to attend social events.

As regards making decisions not to have sexual contact, the portion of people making this decision is significantly higher among people who do not belong and have not in the past belonged to any of the vulnerable groups at 28%, while it is just 12 % among prisoners and injecting drug users.

The peak of auto-discrimination occurs in the first year following diagnosis and over time the number of PLHIV taking such decisions falls. An exception to this is the decision to give up on receiving or continuing education, which is most often made by PLHIV who have received diagnosis between 1 and 4 years ago (15%).

Figure 7: Decisions made by the respondent in the last 12 months in connection with their HIV status (according to data from question 2B.2. "Have you made any of the following decisions in the last 12 months in connection with your HIV status?" by % of the number asked)

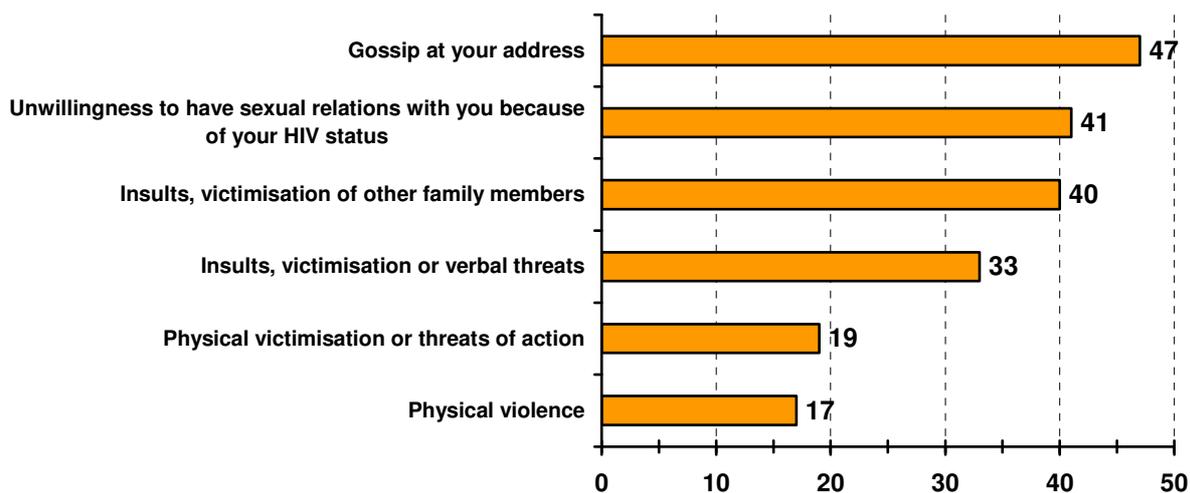


The most common fear among PLHIV is the fear of encountering gossip at their address, which was mentioned by just less than half of those asked (47%). More than a third of PLHIV (41%) are afraid that somebody will refuse to have sexual relations with them due to their HIV status, 40% fear that other members of their family may be subjected to insults or victimisation, while 33% of those asked fear encountering insults or verbal victimisation themselves. Physical victimisation/threats of action

and physical violence were mentioned by significantly fewer respondents - 19% and 17% respectively.

As regards fear or receiving refusal of entering sexual relations, more than a third (36%) of those asked experienced fear that somebody (husband/wife/long-term partner or somebody else), knowing about their positive status, would refuse to have sexual relations with them (38% mentioned that all their possible partners know about their positive HIV status, whilst among those who have at least one possible sexual partner who does not know about their HIV-positive status, this fear is experienced by 59%). 14% fear that somebody who has known about their HIV-positive status for a long time will not want to continue sexual relations in connection with this (this percentage is 23% for those who have a husband/wife/long-term partner who knows about their HIV status).

Figure 8: Presence of fears (according to data from question 2B.3. "Have you feared in the last 12 months that you may encounter victimisation in the following forms (regardless of whether something similar has happened to you or not)?" and 2B.4A, 2B.46, by % of number of those asked)



It is important to mention that the portion of those asked who fear being subjected to some kind of discrimination or stigmatisation is significantly higher in all cases than the portion of those who were subject to it in reality in the last 12 months but is lower than the portion of those who had been subjected to it at some point in the past (see Figure 1 and Figure 2). Exceptions are the cases of refusal of sexual relations and insults or victimisation of other family members; in these cases the portions of those experiencing fear relating to this are significantly higher (especially in cases concerning discrimination of other family members/people close to them) than the portion of those who had encountered it at some point.

2.4. Knowing and Protecting Rights

A substantial problem with the spread and manifestation of discrimination is the fact that a considerable portion of people living with HIV do not know their rights and do not know how to protect them, while the data resulting from the research conducted clearly demonstrates the fact that these rights are quite often violated.

As regards knowledge of laws and regulatory documents, only 13% of those asked had at some point read or discussed the contents of the Declaration of Commitment on HIV/AIDS, which protects the rights of people living with HIV (see Figure 9). This figure in the case of the Federal Law "On preventing the spread of disease in the Russian Federation caused by the human immunodeficiency virus (HIV infection)" which protects the rights of people living with HIV in Russia is higher than in the case of the Declaration at 37% (see Figure 10).

The portion of those who had never heard of these legal documents was considerably higher in the group whose status is not known to anyone (75 % had never heard of the Declaration, 51 % had never heard of the Federal Law) and the group whose status is known only to those closest to them (68 % in the case of the Declaration, 36 % in the case of the Federal Law), than among those whose status is known to many people (51 % in the case of the Declaration, 22% in the case of the Federal Law).

Figure 9: Knowledge of the existence of the Declaration of Commitment of HIV/AIDS and knowledge of its contents (according to data from questions 2Г.1а., 2Г.1б., by % of total asked)

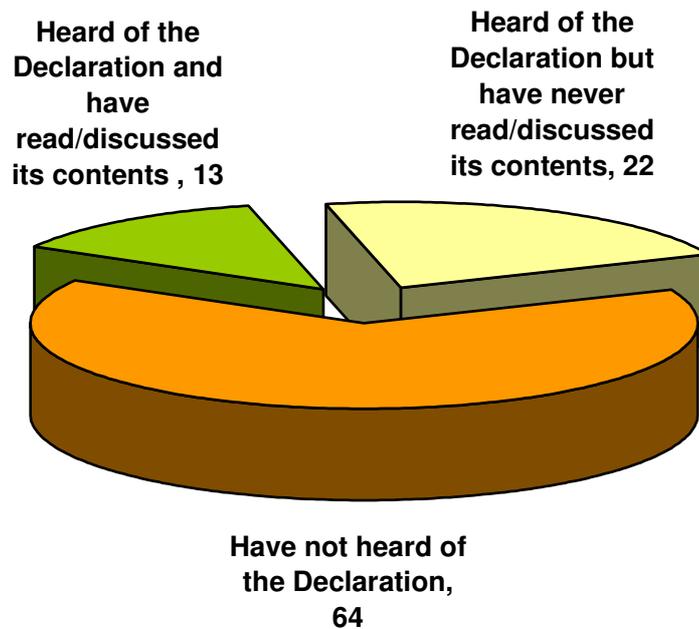
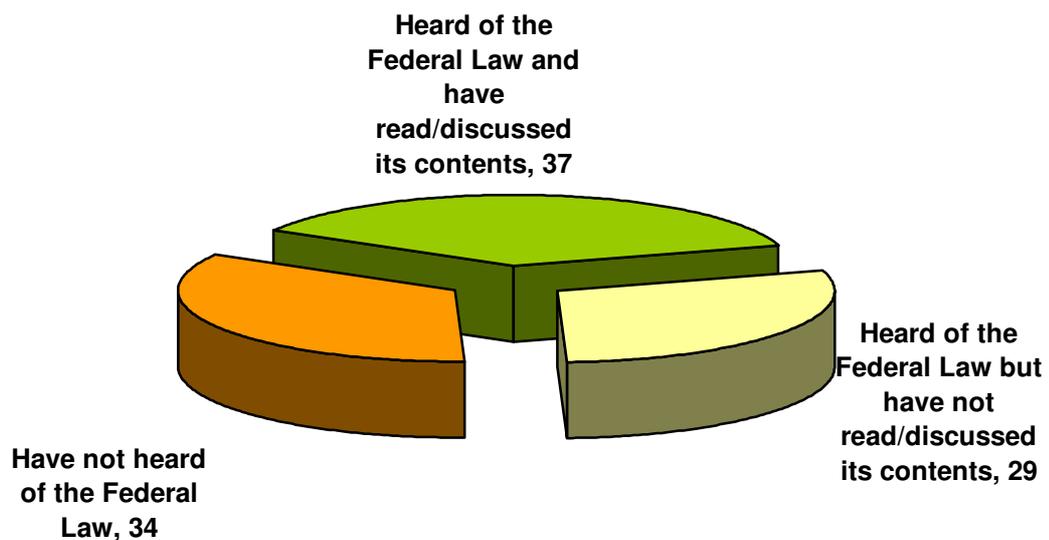


Figure 10: Knowledge of the existence of the Federal Law "On preventing the spread of disease in the Russian Federation caused by the human immunodeficiency virus (HIV infection)" which protects the rights of people living with HIV in Russia and knowledge of its contents (according to data from questions 2Г.2a. 2Г.2б., by % of total asked)

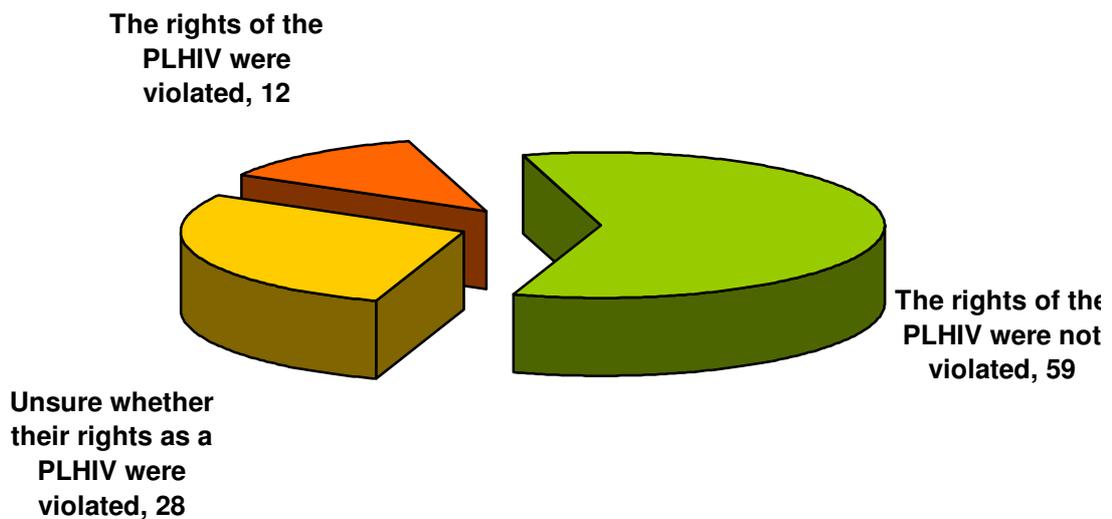


12 % of survey participants said with certainty that in the last 12 months some of their rights as people living with HIV had been violated (see Figure 11). A further 28% could not say with certainty whether their rights had been violated or not, and only just over half of respondents (59%) said with confidence that none of their rights had been violated in the last 12 months.

The number of those who mentioned that a violation of their rights had taken place was highest among prisoners (18%) and lowest among people who do not belong and have not in the past belonged to any of the vulnerable groups (8%).

The portion of those who were not certain whether their rights had been violated or not is significantly higher among men under 30 (45%), in comparison with other sex and age groups. Furthermore this portion was higher among those who had been living with their diagnosis for less than a year; in this group it is 46%, while among those who were diagnosed between one and four years ago it is lower at 34%, and among those who were diagnosed more than four years ago it is only around 20%

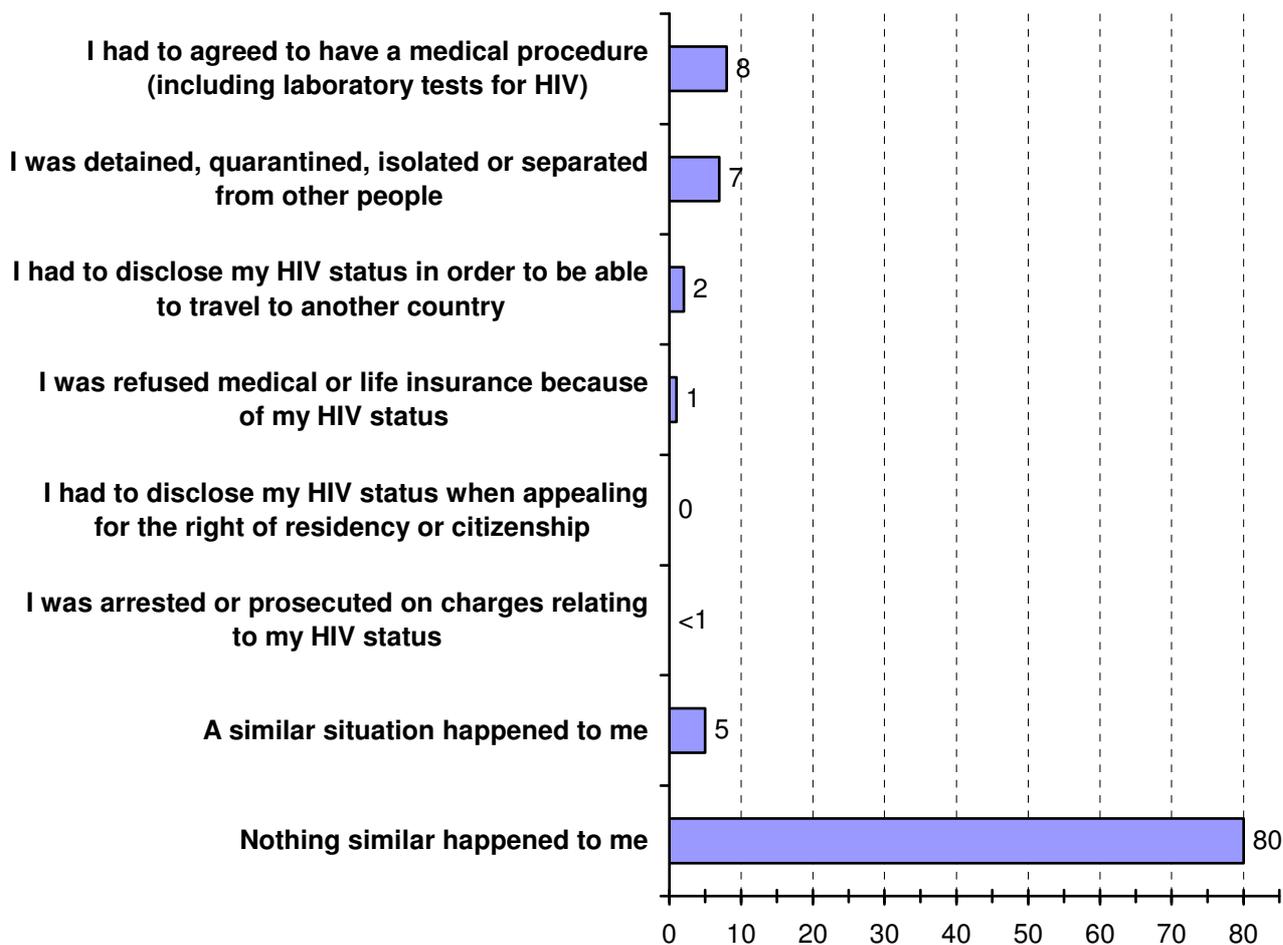
Figure 11: Violation of the rights of the person living with HIV (according to data from questions 2Г.4a, by % of total asked)



When participants were given a list of different events relating to some kind of violation of the rights of a person living with HIV (see Figure 12) and they were asked to mention whether any of the events listed or anything similar had happened to them in the last 12 months, 20% of those asked (higher than the 12% of those asked who answered the question about whether their rights had been violated with certainty) mentioned that a violation from the list or something similar had taken place. The portion of those to whom at least one of the listed events had happened is significantly lower among people who do not belong and have not in the past belonged to any vulnerable group of the population at just 6%.

The violation of rights most often met by those PLHIV asked is compulsion to agree to medical procedures (including laboratory examinations for HIV); 8% of survey participants encountered this, including 5% of those who had to agree to having a medical procedure, as stipulated by law in connection with arranging some kind of work, and 3% of those who had to agree to a medical procedure, not stipulated by law.

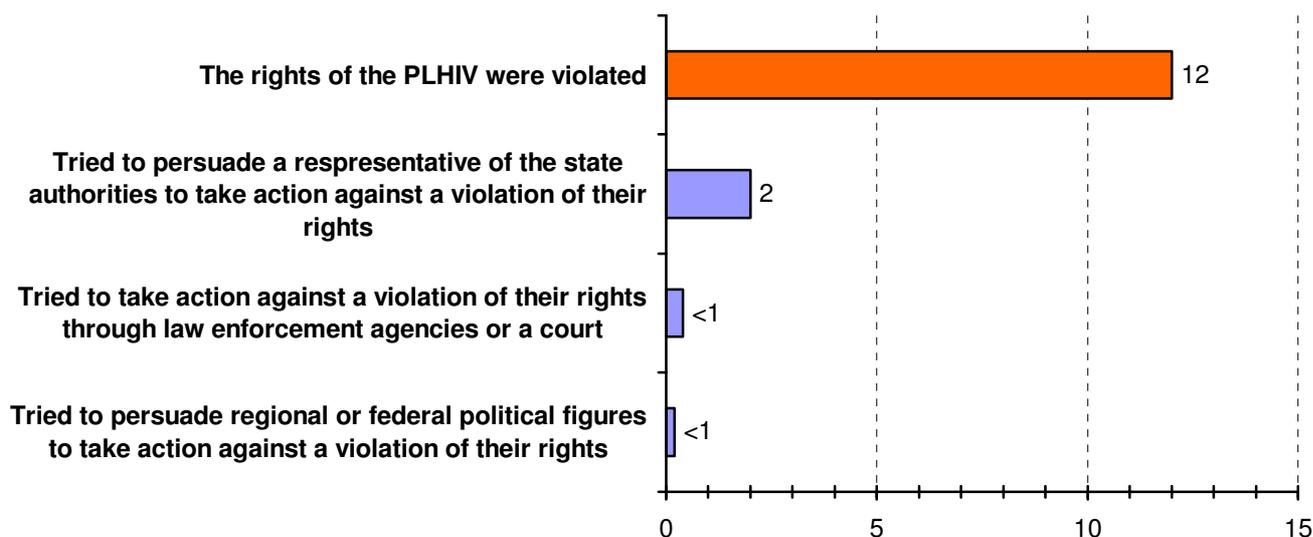
Figure 12: Violation of the rights of the person in connection with their HIV status (according to data from question 2Γ.3, by % of total asked)



Only 18% of those whose rights had been violated (2% of all those people living with HIV asked) decided to take action to protect their rights as a person living with HIV (NB: this percentage was even lower for the period of the last 12 months), including 15% who tried to persuade a representative of the state authorities to take action (2% of those PLHIV asked), 11% who tried to take action through law enforcement agencies or a court (1% of those PLHIV asked) and 8% who tried to persuade regional or federal political figures to take action (1% of those PLHIV asked). This data clearly demonstrates the lack of any action among the overwhelming portion of PLHIV to protect and assert their rights.

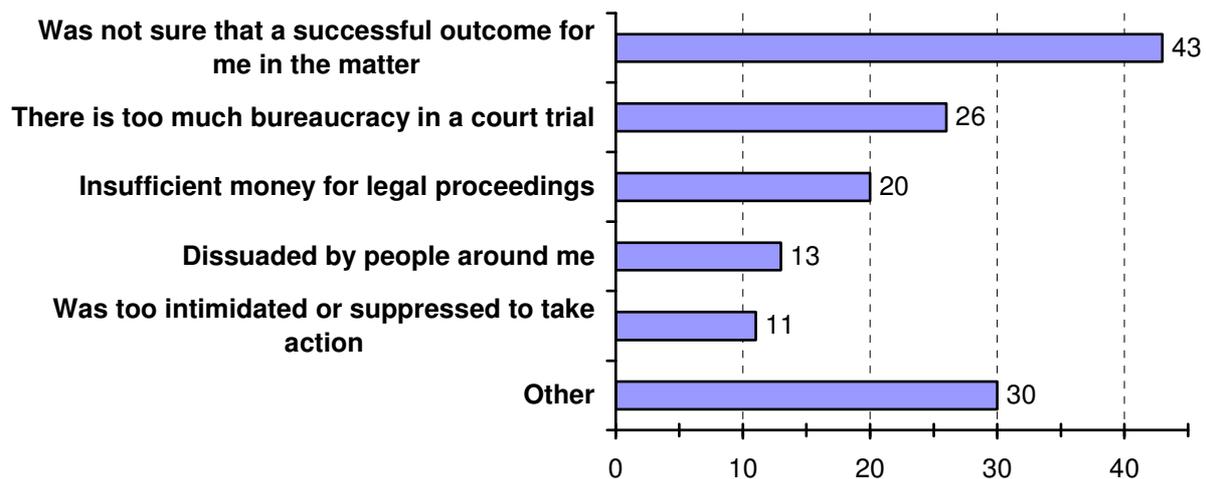
Those people who turned to some kind of level of authority to protect their rights nevertheless, were asked the question about the results of this request, however due to the number of requests being too small (less than 2% of those PLHIV asked) it was not considered possible with the existing data to draw a conclusion concerning the effectiveness of the work of different levels of authorities in the area of protecting the rights of PLHIV.

Figure 13: Violation of the rights of the person living with HIV in the last 12 months and taking measures (according to data from questions 2Г.4a, 2Г.4б, 2Г.5a, 2Г.6a, by % of those asked)



People living with HIV whose rights had been violated but who had not turned to a court/law enforcement agencies to protect them (89 % of those whose rights had been violated), gave the following reasons for this (see Figure 14): just under half (43%) of respondents were not sure of a successful outcome to the matter for them, 26% considered that there is too much bureaucracy in a court trial, 20% did not have sufficient money for legal proceedings on the matter, 13% were dissuaded from doing so by people around them, and 11% were too intimidated or suppressed to take any measures.

Figure 14: Reasons why the respondent did not turn to a court/law enforcement agencies when their rights as a person living with HIV were violated (according to data from question 2Г.4д. "For what reasons did you not turn to law enforcement agencies/a court in connection with this?" by % of the number of people whose rights as a person living with HIV were violated in the last 12 months, but who did not turn to a court/law enforcement agencies in connection with this violation. The total number of answers exceeds 100 %, since it was possible to give several answers to this question)



Thus the research data clearly demonstrates that frequent violations of the rights of people living with HIV take place and also that many PLHIV do not have a sufficient understanding of their rights and do not make use of possible instruments to protect them.

2.5 Opposing Stigma and Discrimination

60% of those asked knew of organisations or groups which they can turn to for help in case of defamation and discrimination, but only 12% had approached any of these organisations (see Figure 15).

The percentages of appeals for help to such organisations are lower among migrants (6%) and people who do not belong and have not in the past belonged to a vulnerable group (6%), than they are among sex workers (23 %) and injecting drug users (16 %). The following tendency was also found: the longer the time since diagnosis, the more people knew about such organisations (40% of people who were diagnosed in the last year and 80% of people who were diagnosed more than 10 years ago) and the more they turned to them for help (7% of those diagnosed less than a year ago and 19% of those diagnosed more than 10 years ago).

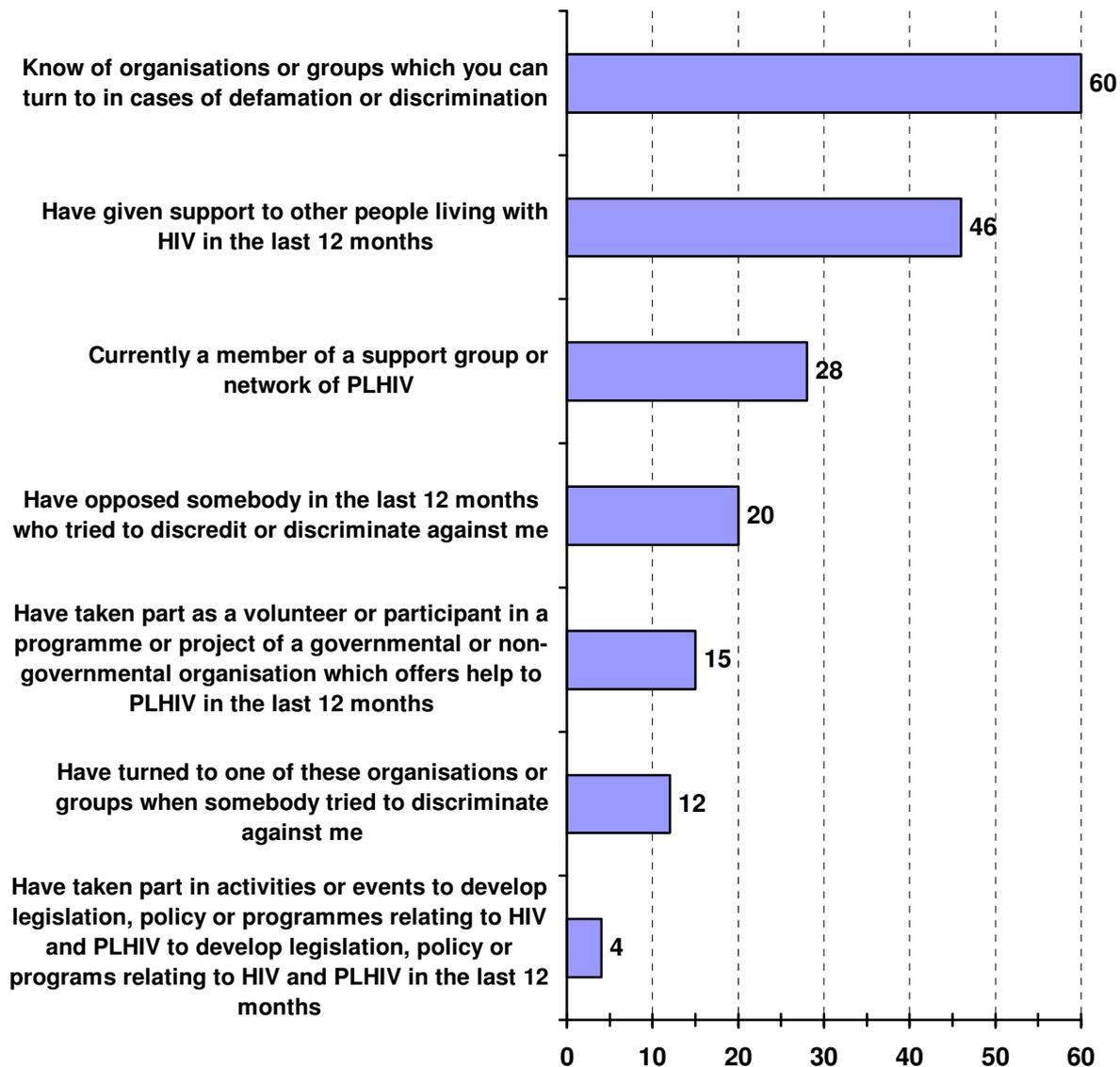
Only 20% of those asked had resisted somebody who had tried to discredit them or discriminate against them in the last 12 months, while during that time around half of survey participants had encountered some form of discrimination or stigmatisation.

28% of survey participants are currently members of a help group or a network of people living with HIV. At the same time the portion is lower among people who do not belong and have not in the past belonged to a vulnerable group (22%). This portion is much higher among those people whose status is known to many people; in this group 44% are members of a help group or network of PLHIV.

Just less than half of survey participants (46%) have given some kind of support to other people living with HIV in the last 12 months. The portion of people giving support to other PLHIV increases

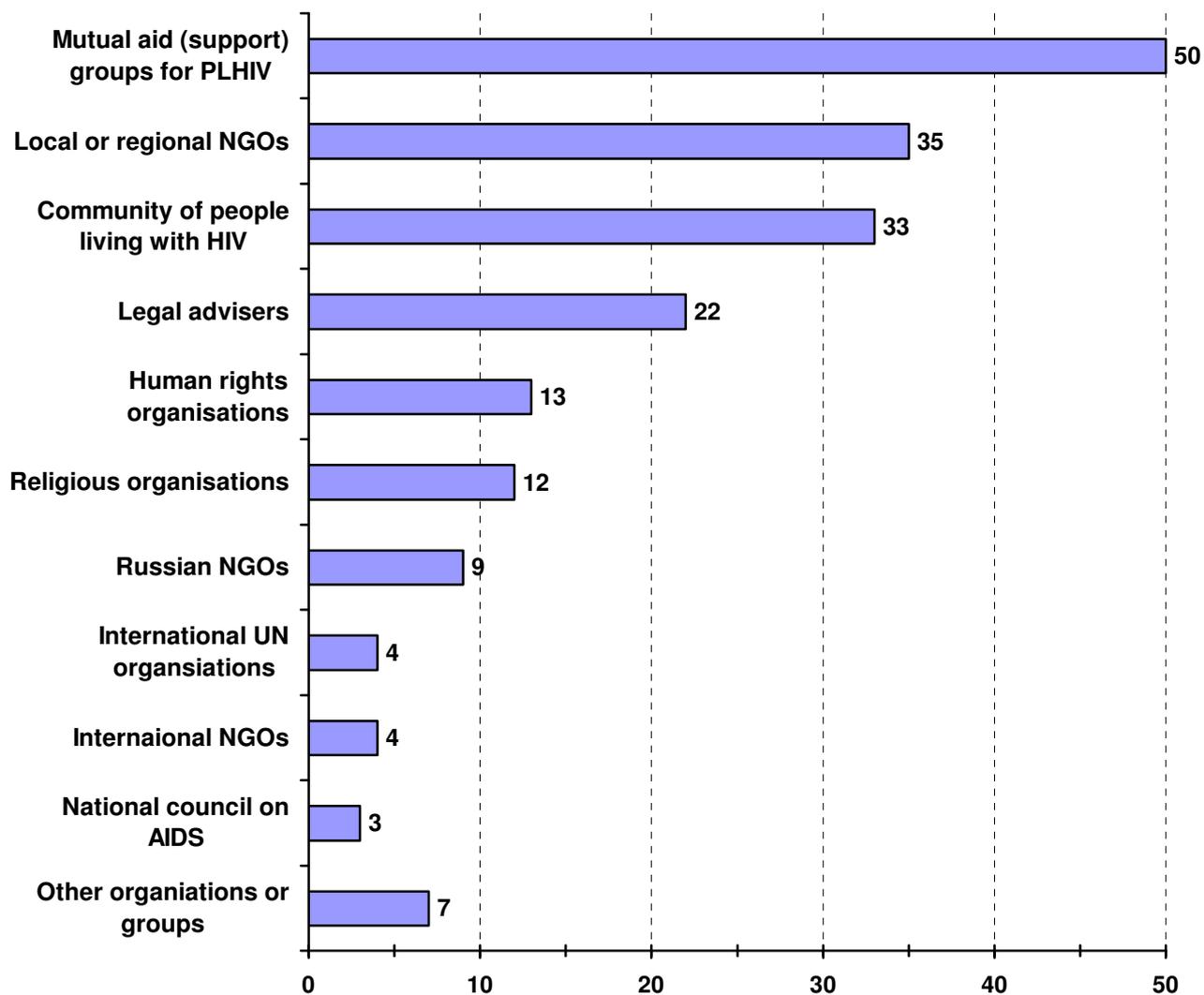
significantly with time since diagnosis: this portion is 24% among people whose diagnosis was confirmed less than a year ago and reaches 71% among those who have been living with HIV for more than 10 years. Among those whose status is known to many, this percentage is 73%, while among those whose status is known only to those closest to them, it is just 41%, and among those whose status is known to nobody, it is 22%. Also the amount of help given to other PLHIV varies greatly between different vulnerable groups: the highest portions of people giving support to other PLHIV are found among injecting drug users (55%) and also prisoners (54%) while in other groups the portions are considerably lower: 36% among migrants, 35% among sex workers, 38% among people who do not belong and have not in the past belonged to any vulnerable group.

Figure 15: Form of opposition to stigma and discrimination (according to data from questions 2Д.1, 2Д.2a, 2Д.3, 2Д.5a, 2Д.6, 2Д.7, 2Д.8, by % of those asked)



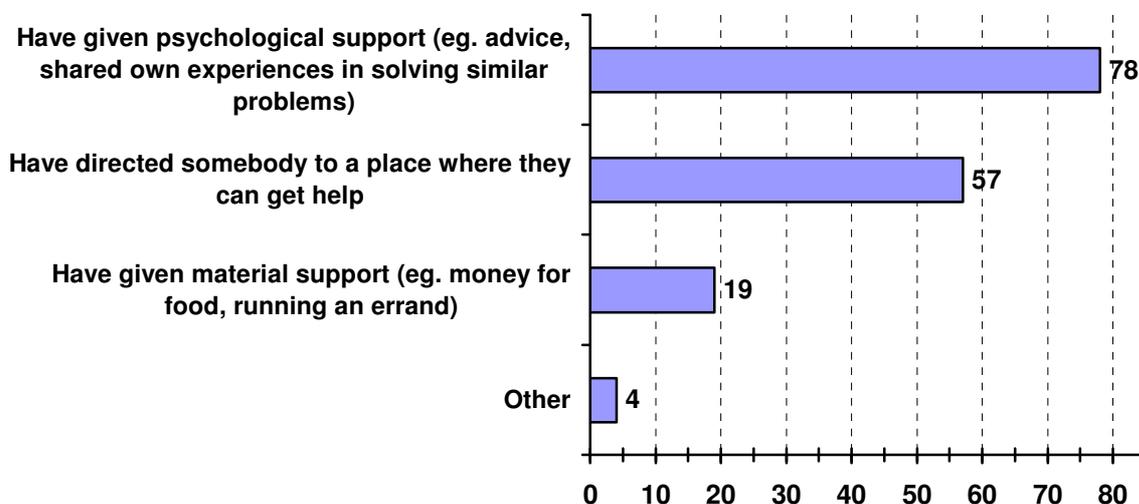
As has already been mentioned, 60% of survey participants know of some organisations or groups which they can turn to for help in cases of defamation and discrimination. The most well known organisations among those asked were mutual aid (support) groups for people living with HIV; half (50%) of survey participants know of them (see Figure 16). The second best known types of organisations are local and regional non-governmental organisations; just over a third (35%) of those PLHIV asked knew of these. In third place are communities of people living with HIV; a third (33%) of survey participants knew of these. The other organisations were known to less than a quarter of those people living with HIV asked.

Figure 16: Organisations or groups known by the respondent (according to data from question 2Д.26. "What kind of organisations or groups do you know of that you can turn to for help in cases when somebody tries to discredit or discriminate against you?", by % of those asked)



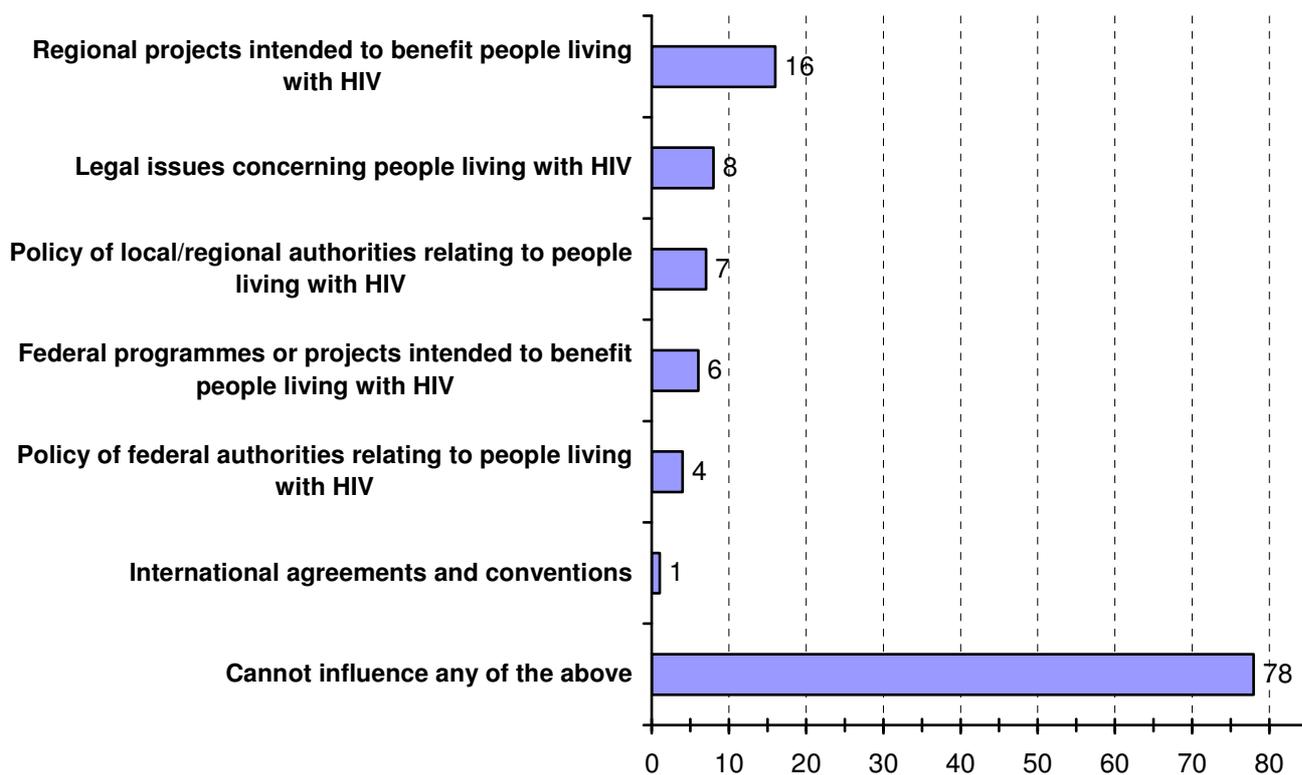
As has already been mentioned, just less than half of survey participants (46%) have given some kind of support to other people living with HIV in the last 12 months. The most frequent type of support for other PLHIV is psychological support; 78% of those who had given support mentioned this, followed by these support types: directing somebody to a place where PLHIV can receive support, and material help. These were mentioned by 57% and 19% respectively of those who had supported PLHIV in the last 12 months.

Figure 17: Type of support given to other people living with HIV (according to data from question 2Д.5б. "What kind of support have you given in the last 12 months to other people living with HIV?", by % of those who gave support to other people living with HIV in the last 12 months)



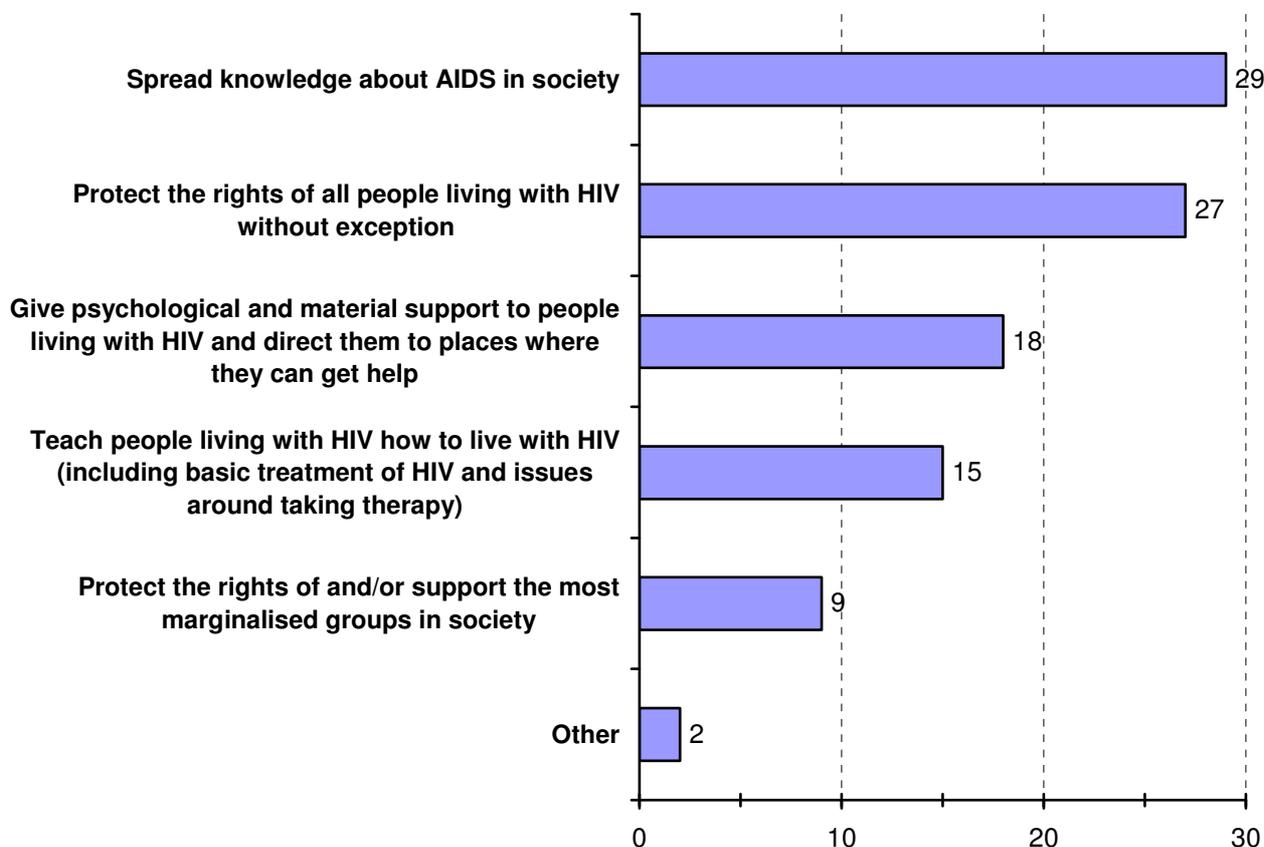
The overwhelming majority of survey participants (78%) considered themselves to be able to influence the shaping of policy relating to PLHIV and help for them (see Figure 18). At the same time this percentage is the highest among people who do not belong and have not in the past belonged to a vulnerable group (86%) while the lowest percentages are to be found among prisoners (76%) and injecting drug users (71%). This portion also falls with time since diagnosis: among people whose diagnosis was confirmed in the last year, 90% considered themselves able to have an influence on policy, while among people living with HIV for more than 10 years this portion is considerably lower at 70%.

Figure 18: Opinion about the sphere of your possible influence (according to data from question 2Д. 9 "Do you think that you can have an influence on solving any of the following questions?", by % of those asked)



The survey participants consider the main tasks in the fight against stigmatisation and discrimination of people living with HIV to be spreading knowledge in society about HIV/AIDS and protecting the rights of all people living with HIV without exceptions - 29% and 27% referred to these tasks respectively (see Figure 19).

Figure 19: Main tasks in the fight against stigmatisation of and discrimination against people living with HIV (according to data from question 2Д.10. "There are organisations whose activity is directed against stigmatisation of and discrimination against people living with HIV. If one of them asked you: "What should our organisation do to eradicate stigmatisation and discrimination? What should we put the most effort into?", what would you recommend?", by % of those asked)



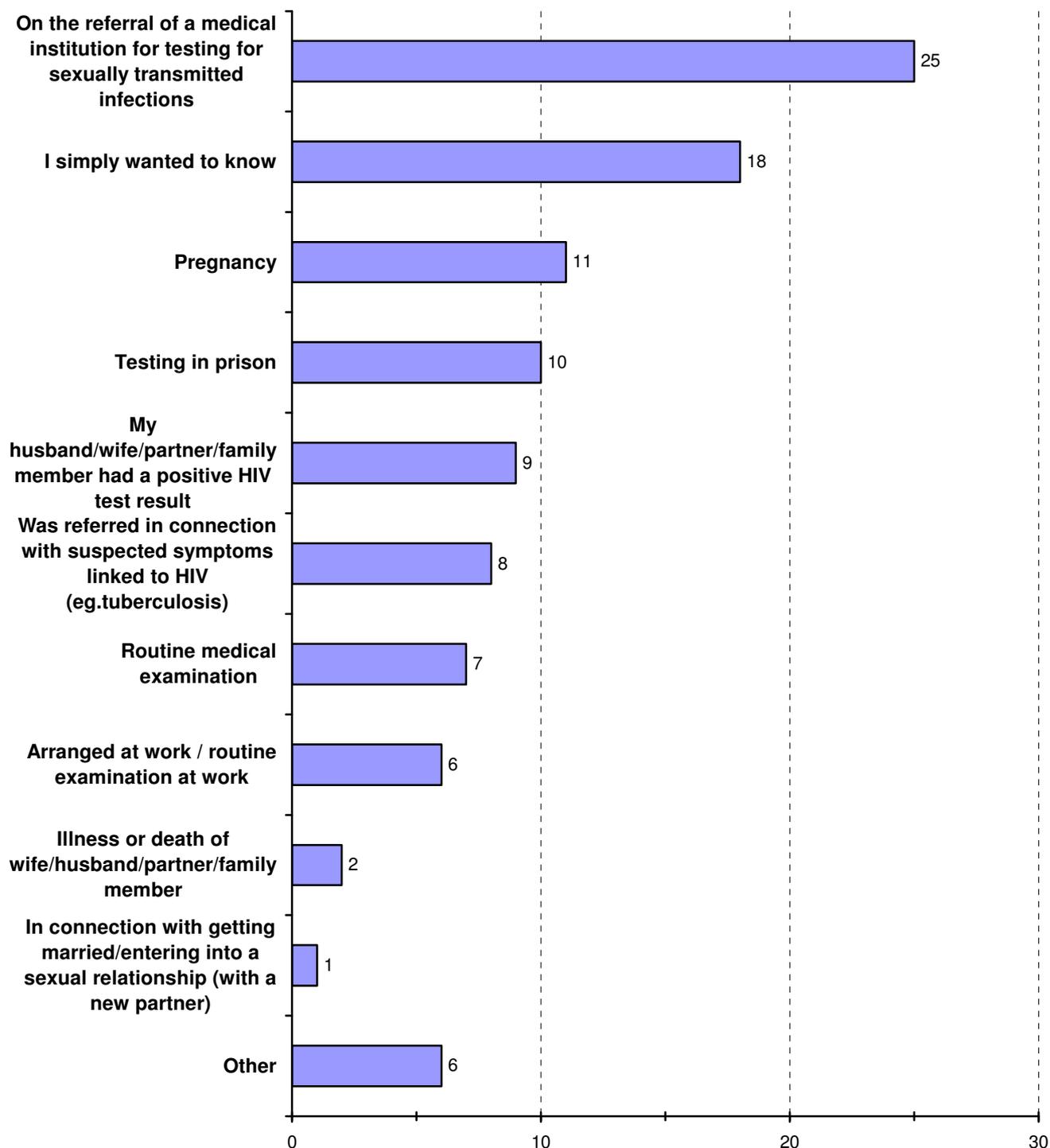
2.6 HIV Testing and Positive Results

As regards the reason for taking HIV tests, a quarter (25%) of those asked took the test on a referral from a medical institution for testing for sexually transmitted infections. The second most frequently mentioned reason is the individual wish of the person to know their status; this was mentioned by 18% of those asked. 11% of survey participants took the test in connection with pregnancy, 10% in prison and the other reasons for taking the test were mentioned by less than 10% of those asked. Among MSM and gay/lesbian people* a significantly higher portion took the test in connection with the fact that a partner/family member had received a positive result for an HIV test; in this group the portion is 20%. The highest portions of those who were tested in connection with pregnancy were

* People who belong or have in the past belong to the MSM and gay/lesbian categories were aggregated into one group because of there being too little representation of each of these groups in the survey sample separately.

among sex workers (18%) and people who do not belong to a vulnerable group of the population (15%). The highest portions of those who took the test in connection with suspected symptoms linked to HIV, were found among prisoners and migrants (14% and 15% respectively).

Figure 20: Reason for taking the HIV test (according to data from question 3A.1. "For what reason did you take the HIV test before being informed of your HIV positive status?", by % of those asked)

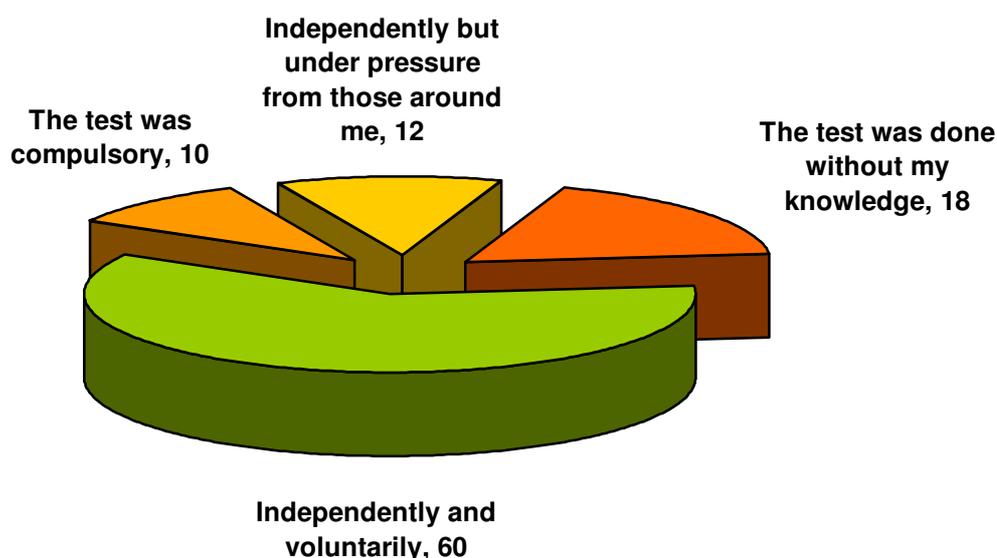


Less than two thirds of survey participants (60%) took the decision to take an HIV test independently and voluntarily, while a further 12% took this decision voluntarily but under pressure from those

around them. 10 % of respondents were forced to take an HIV test and 18% only found out about the test after it had been done (see Figure 21).

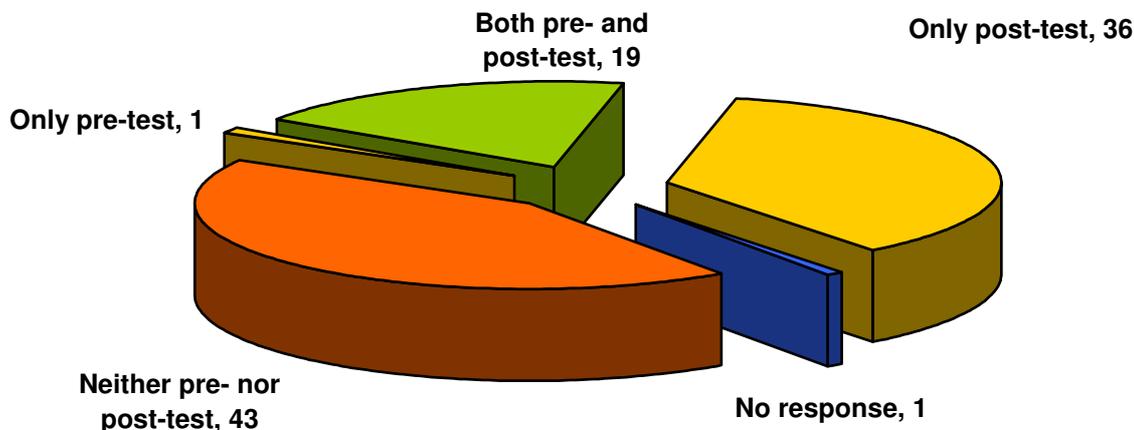
The portions of those who took the test voluntarily and independently are lowest among prisoners (45%) and among migrants, internally displaced persons and refugees (42%) and are highest among people who do not belong and have not in the past belonged to any vulnerable group of the population (72%) and among MSM and gay/lesbian people (70%). The portion of those who were forced to take the test is highest among sex workers (25%) and prisoners (18%). The portion of those who mentioned that the test was done without their knowledge is highest among prisoners (27%) and lowest among MSM, gay/lesbian people (8%) and people who do not belong and have not in the past belonged to a vulnerable group of the population (14%).

Figure 21: Voluntariness and independence of taking the decision to get tested for HIV (according to data from question 3A.2. "Did you take the decision to take this HIV test yourself?", by % of those asked)



Only just more than half of those asked (56%) received advice on HIV testing, however only 19% received advice both before and after testing, while 43% mentioned that they did not receive any kind of consultation at all when they took the HIV test (see Figure 22). The portion of those who did not receive consultation either before or after the HIV test is significantly higher among vulnerable groups of the population, including prisoners (66%), refugees, migrants and internally displaced persons (54%), injecting drug users (50%) and sex workers (53%) than among people who do not belong to a vulnerable group (30%).

Figure 22: Presence of pre- and post- test advice (according to data from question 3A.3 "Did you receive pre- and post- test advice when you took the test?", by % of those asked)



It is entirely probable that one can speak of several improvements in recent years in relation to the observance of rules for HIV testing: among those who took the test more than 10 years ago the portion who did so independently and voluntarily is 48% and the portion of those who received some kind of consultation is 43% and of those who took the test less than a year ago these portions are 65% and 63% respectively. However it does not appear to be possible to draw such a conclusion from the figures given on existing data as this may be explained, amongst other things, by varying representations of different vulnerable groups in groups divided by time since diagnosis, which is a result of the peculiarities of the sample.

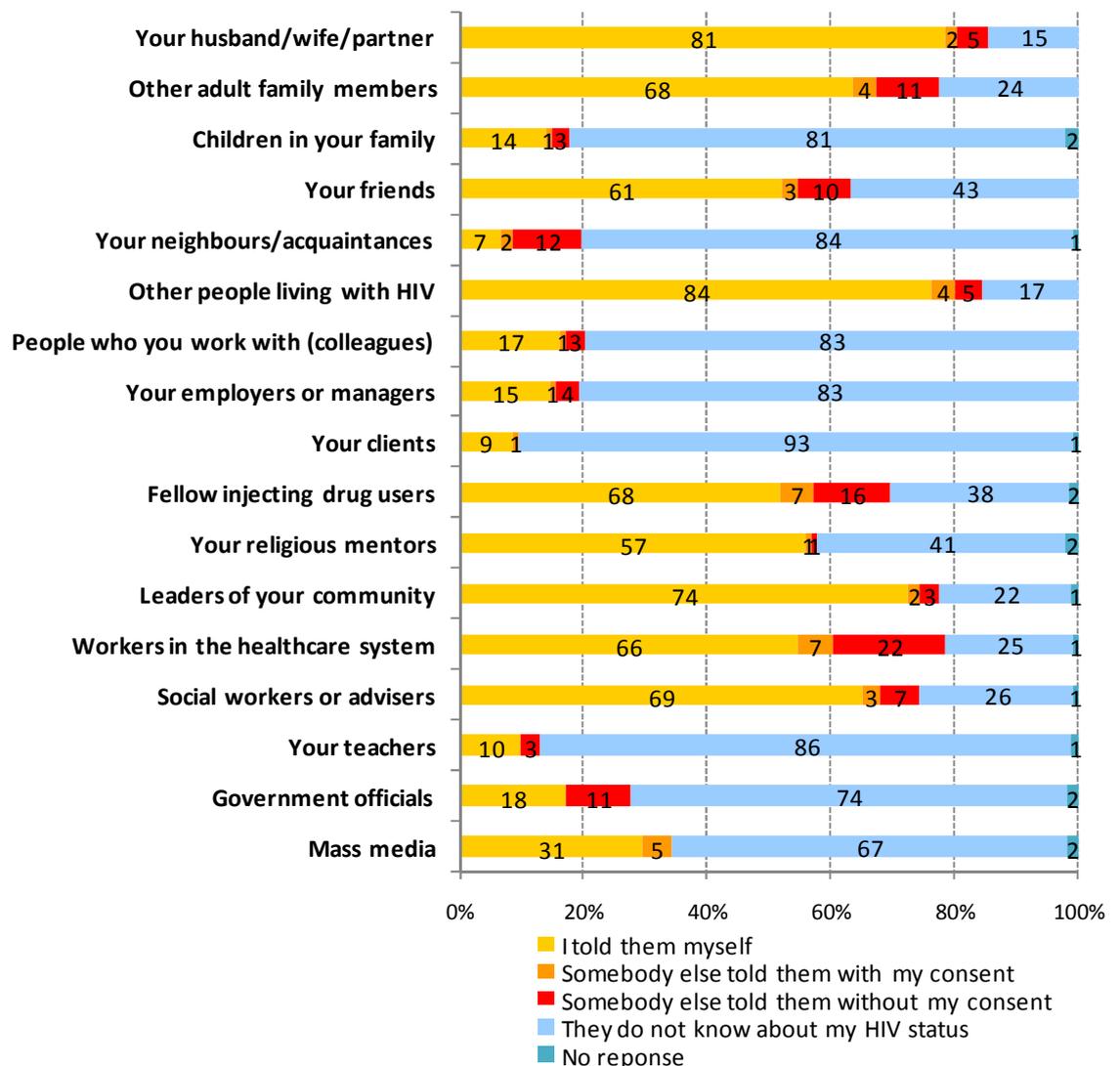
2.7 Confidentiality and Disclosure of Information

All people living with HIV have the right to confidentiality as regards their HIV status. The necessity for strict observance of the principle of confidentiality as regards HIV status is the result of an atmosphere of fear, incomprehension and prejudice, which are typical characteristics for people's attitudes to HIV infection and to people living with HIV. Disclosure of a person's HIV status may often lead to negative consequences for that person and for their family members. In the previous section of the report on the research data it has been clearly demonstrated that today in Russia a large number of PLHIV encounter stigmatisation and discrimination in connection with their HIV-positive status. Lack of faith in the confidentiality of medical documents can discourage people from approaching medical institutions for testing and for medical help of any kind.

Just less than half of survey participants (41%) have encountered an occasion when information about their positive HIV status was disclosed by somebody they know. Most often information about HIV

status is communicated without the consent of the respondent by a healthcare worker (such a situation was mentioned by 22% of those who encountered medical workers in some way), by partners of injecting drug users (16%) and also neighbours and acquaintances of the respondent (12%) (see Figure 23). Nearly three quarters of those asked (72%) mentioned that neighbours and acquaintances who know about their HIV status had found out this information from other people without the respondent's consent.

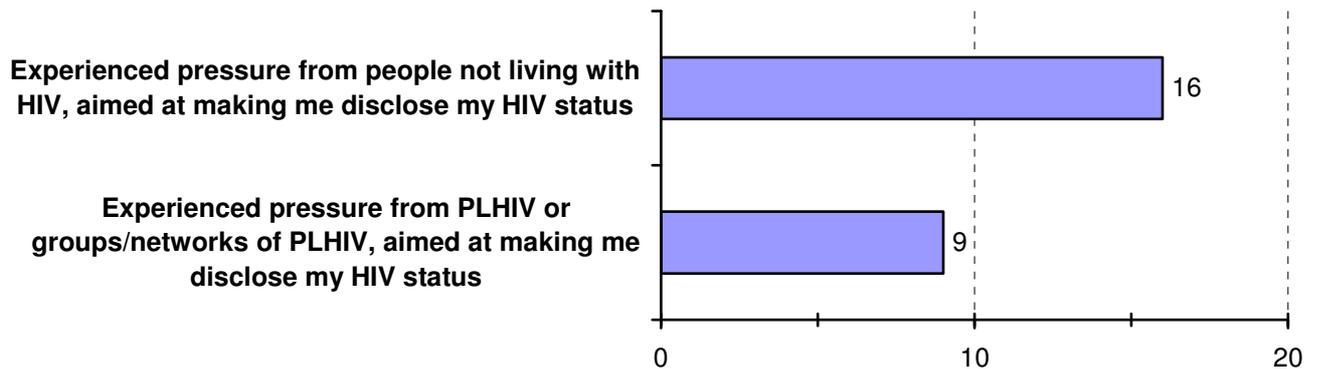
Figure 23: Knowledge of people around you of your status and way in which they were told about it (according to data from question 3B.1. "Do people around you know about your HIV status? If yes, how did they find out about it?", by % of those who have people who know around them)



People living with HIV often experience pressure from people around them aimed at making them disclose their HIV status. Such pressure from people not living with HIV was mentioned by 16% of those PLHIV asked and pressure from other people living with HIV or from a group/network of PLHIV was mentioned by 9% of those asked.

The portion of those who experienced pressure from people not living with HIV is lower among people who do not belong and have not in the past belonged to any vulnerable group of the population at just 7%, in comparison with those who belong or have in the past belonged to one of these groups.

Figure 24: Pressure from those around you aimed at making you disclose your HIV status
 (according to data from questions 3B.2a, 3B.2b, by % of those asked)

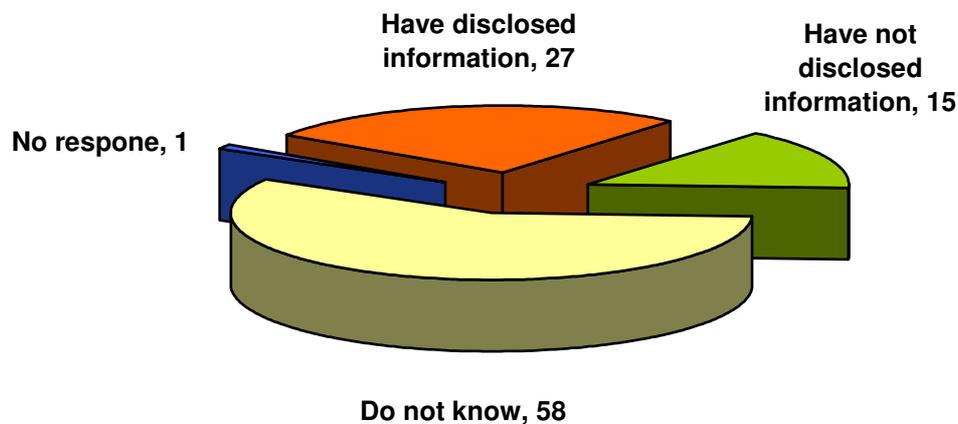


As regards the opinion of people about the extent to which medical workers maintain the confidentiality of their HIV status, only 15% of those asked considered that healthcare workers have not told other people about their HIV status without their consent, while 27% were certain of the opposite and 57% could not answer this question with certainty (see Figure 25).

At the same time the portion of those who were certain that their HIV status had been disclosed by healthcare workers to other people is higher the longer it has been since diagnosis of the HIV infection: among those whose diagnosis was confirmed less than a year ago this portion is just 20%, among people living with HIV positive status for between 5 and 9 years it is 27% and among those who were diagnosed more than 10 years ago it is 44%. This regularity may show the improvement of the level of observing confidentiality in recent years, however the existing data is insufficient to establish such links.

It is necessary to mention that the portion of people who said with certainty that medical workers had disclosed their HIV status is considerably lower among people who do not belong and have not in the past belonged to a vulnerable group of the population; for these people it is just 14%, while among people who belong/have in the past belonged to one of the vulnerable groups of the population, this portion is 33% (percentages are practically equal amongst different vulnerable groups of the population).

Figure 25: Disclosure of the respondent's HIV status by healthcare workers without their consent (according to data from question 3B. 3. "Have healthcare workers (for example a doctor, nurse, consultant, laboratory assistant) told other people about your HIV status without your consent?", by % of those asked)

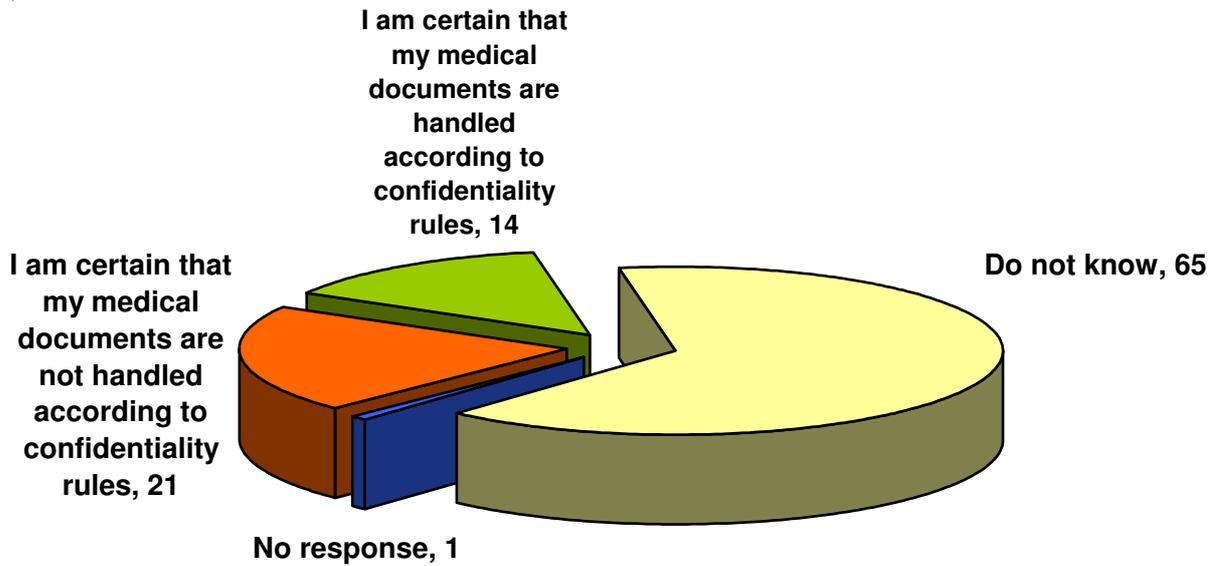


As regards the opinion of those PLHIV asked about the observance of confidentiality, only 14% of those asked were certain that their medical documents were handled according to all rules of observing confidentiality, while 21% of survey participants are certain of the opposite and a further 65% do not know whether their documents were handled as confidential information or not.

The portion of people certain of non-observance of the rules of confidentiality in relation to their medical documents is higher the longer it is since diagnosis of HIV. This portion among those who were diagnosed less than a year ago is 17% and among those who have known their HIV-positive status for more than 10 years this percentage reaches 36%. As has already been mentioned in connection with the opinion of survey participants concerning disclosure of information by healthcare workers, this difference may show an improvement in relation to observance of rules of confidentiality in recent years, however there is insufficient current data to draw such a conclusion.

The portion of people who are certain of non-observance of the rules of confidentiality is higher among people who belong to a vulnerable group of the population (26%, highest among prisoners at 30%), than among people who do not belong to any of these groups (12%).

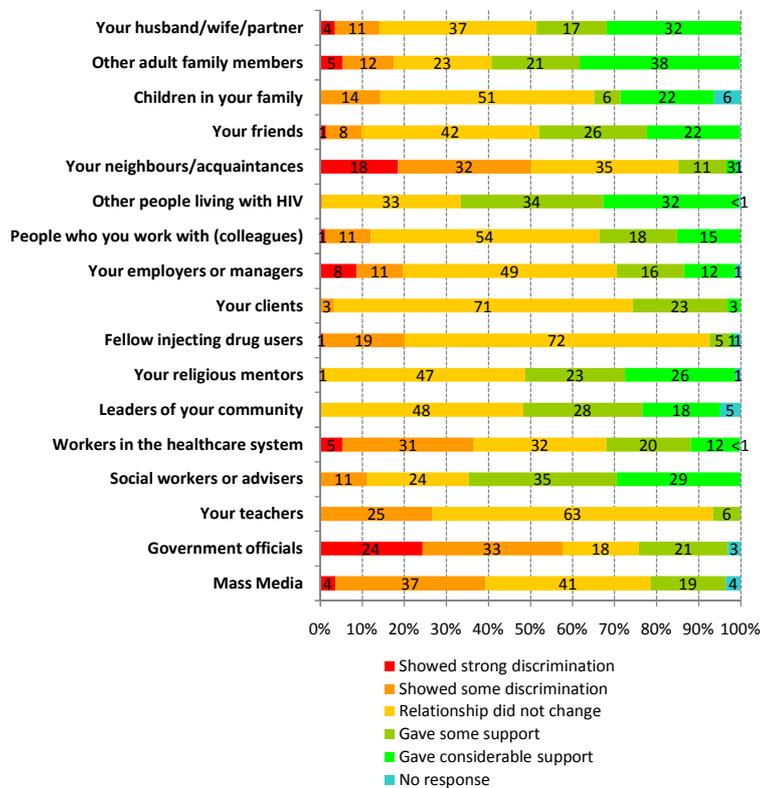
Figure 26: Guaranteeing confidentiality of medical documents concerning the respondent's HIV status (according to data from question 3Б.4. "To what extent do you think confidentiality is observed (confidential to strangers and impossible to disclose) for medical documents concerning your HIV status?", by % of those asked)



According to the results of the research, other people living with HIV proved to be the most ready to show support for the respondents concerning their HIV status (support from them was mentioned by 66%) and also social workers and advisers (support was received from them by 64%) (see Figure 26). The people closest to the respondents also came out as ready to show support: husband/wife/partner (49% mentioned that they showed support), other adult family members (59%) and friends (48%) and also religious mentors (49%) and community leaders (46%). However it is necessary to mention that in these two last cases the portion of those who have such people close to them, is extremely low and as such, the portion of those who know about their HIV status is even lower.

The most prone to discriminating behaviour were neighbours and acquaintances (40% mention that they showed discrimination), healthcare system workers (36%), employers/managers (19%) and also government officials and the mass media (41%). The fact that medical workers proved to be one of the most negatively inclined in relation to PLHIV, is very worrying, in as far as discrimination and stigmatisation coming from them is a significant barrier to preventing the spread of HIV and treating the HIV infection since they may reduce the desire and willingness of people to get tested and to receive treatment.

Figure 26: Disclosure of HIV status: discrimination and support (according to data from question 3B.5. "How did people around you start to act in relation to you on the whole when they first found out about your HIV status?", by % of those who have people close to them who know about the respondent's HIV status and where the respondent knows what their reaction was)

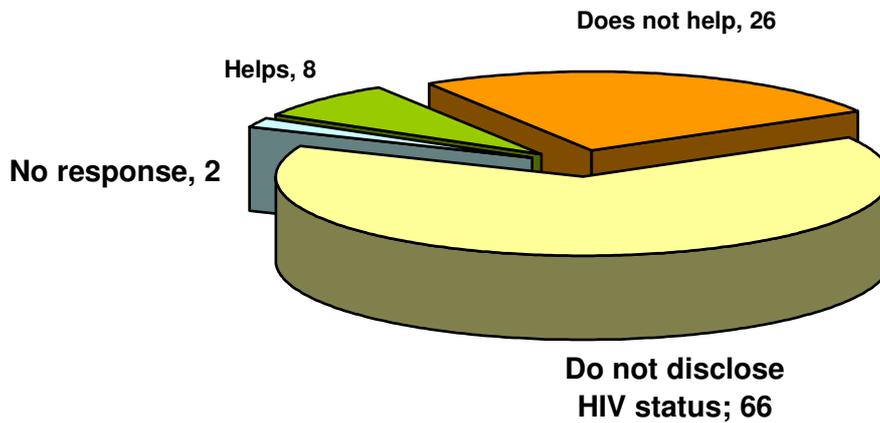


Survey participants were asked to evaluate whether disclosure of their HIV status helped them to solve their problems as a rule. 66% of those asked mentioned that they do not disclose their HIV status (see Figure 27) and among those who did disclose it only 23% said that it helped them, while 73% said the opposite.

At the same time the portion who did not disclose their status is significantly higher among people who do not belong and have not in the past belonged to any of the vulnerable groups, at 79%. The portion of those who disclosed their HIV status and consider that it helps them to solve problems is

practically the same regardless of whether they belong to one of the vulnerable groups of the population.

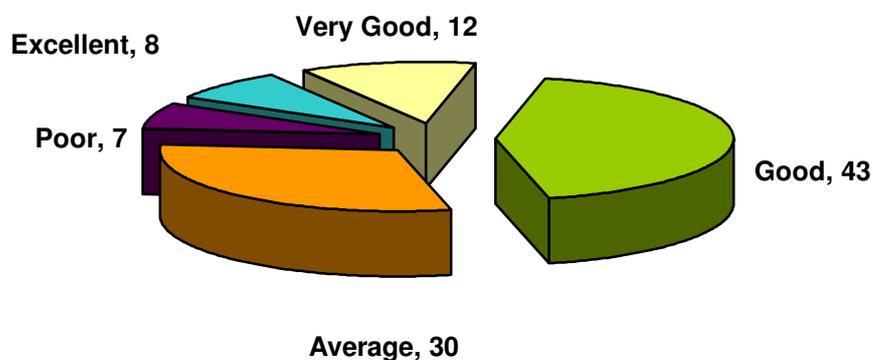
Figure 27: Subjective evaluation of the benefit of disclosing HIV status to solve problems (according to data from question 3B.6. "As a rule does disclosing your HIV status help you to solve your problems?, by % of those asked)



2.8 Treatment

Only 7% of survey participants defined the state of their health as 'poor', while just less than two third of PLHIV asked (63%) describe the state of their health as 'good', 'very good' or 'excellent' (see Figure 20). At the same time the portion of the latter is 79% among people who found out about their diagnosis less than a year ago and 43% among people living with HIV for more than 10 years.

Figure 20: State of health (according to data from question 3B.1 "How would you describe the state of your health on the whole at the moment?", by % of those asked)



35% of survey participants mentioned that they were currently taking antiretroviral therapy (ART) and 15% were taking drugs to prevent or treat opportunistic infections (see Figure 30).

Among those whose diagnosis had been confirmed less than a year ago the portion of those taking ART was 18%, among those who were diagnosed between one and four years ago it was 27%, among people living with HIV positive status for between five and nine years it was 43% and among people living with HIV for more than 10 years it is 48%. In cases where drugs are being taken against opportunistic infections the portion of people taking these drugs also rises with time since the diagnosis was confirmed: among those whose diagnosis was confirmed less than a year ago it is 4%, among those who have been living with their HIV-positive status for between one and four years it is 12%, for between five and nine years it is 16%, for more than 10 years it is 23%.

As regards differences in treatment between different vulnerable groups of the population, the portion of those receiving treatment is considerably higher among prisoners than among the sample as a whole: 49% in cases of those taking antiretroviral therapy and 29% in cases of those taking drugs against opportunistic infections. Among people who do not belong and have not in the past belonged to a vulnerable group of the population the portions are lower: 28% in the case of ART and 6% in the case of drugs against opportunistic infections. However this may be explained by the fact that in the structure of those asked there is a higher portion of those who have been living with their HIV diagnosis for 5 years and more among prisoners and injecting drug users (78% and 68% respectively), whereas among people who do not belong to a vulnerable group this portion is much lower at just 30%.

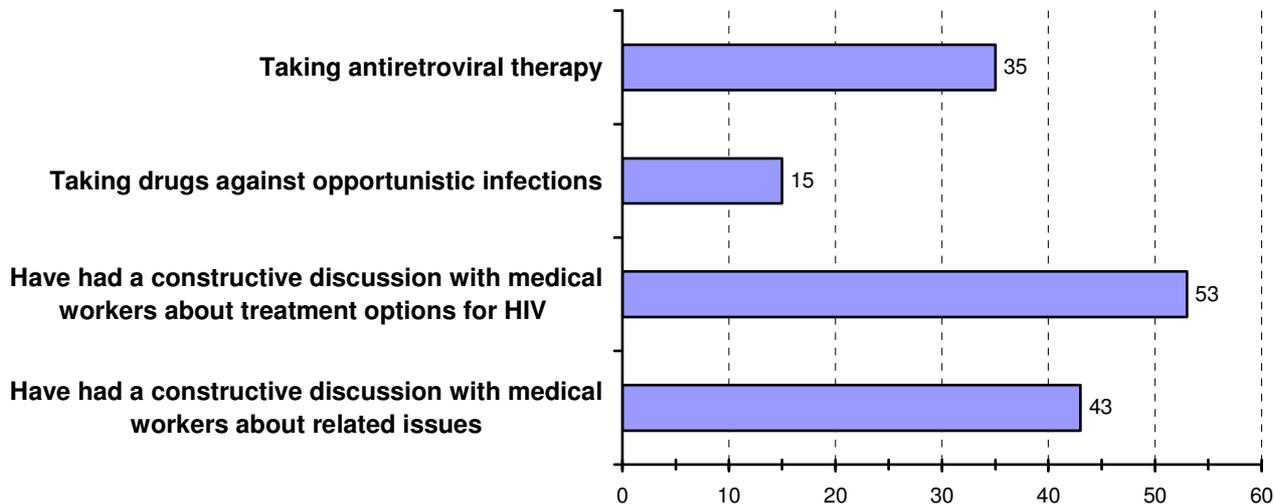
Of those people who were not taking antiretroviral therapy, 60% knew that they had the means to receive it (for free or at a price which is affordable for them), while 39% did not know if they had that option or not, and 1% of these people mentioned that they did not have this opportunity. Among those people who were not taking drugs to prevent or treat opportunistic infections, 32% mentioned that they had the option to take these drugs (for free or at a price affordable for them), 16% spoke of the possibility of receiving a complete course and a further 16% about the possibility of receiving several courses, while 61% of these people did not know if they had the opportunity to do so or not and 7% said that they did not have such an option.

53% of the respondents asked mentioned having a constructive discussion with medical workers about the treatment options for HIV in the last 12 months, and 43% of survey participants said that they had had a constructive discussion about other issues relating to, for example, sexual and reproductive health, sexual relationships, emotional well-being, or drug use.

The portion of those who had a constructive discussion about HIV treatment options and related issues is higher the more time has passed since diagnosis was confirmed: in the first year since diagnosis was confirmed these portions were 46% and 33% respectively and after 10 years since HIV

was confirmed they were 65% and 47%. This portion is much higher in the categories for prisoners (65%) and injecting drug users (60%) and much lower among people who do not belong and have not in the past belonged to any of the vulnerable groups (44%).

Figure 30: Treatment of HIV (according to data from questions 3B.2a., 3B.3a., 3B.4., 3B.5, by % of those asked)

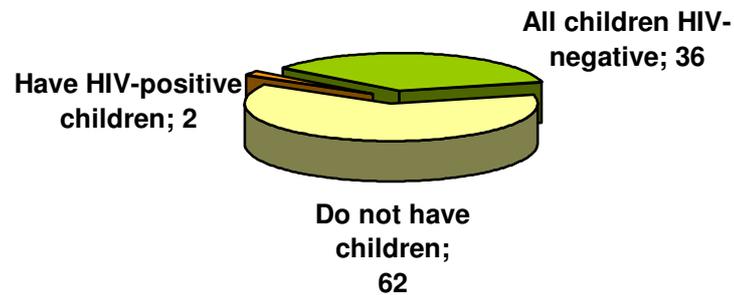


The research data thus demonstrates the existing problems in the sphere of treatment of HIV infection including the fact that just half of those PLHIV asked (53%) had a constructive discussion about the treatment options for HIV with healthcare workers in the last year. Among those who found out their diagnosis less than a year ago this portion is even lower at 46%, which indicates that more than half of respondents did not have any constructive discussion with medical workers about the treatment options in the first year following diagnosis.

2.9 Having Children

38% of the PLHIV asked have natural children, among which only 4% have had at least one child since their HIV status was confirmed (this is 2% of the total number asked) (see Figure 33).

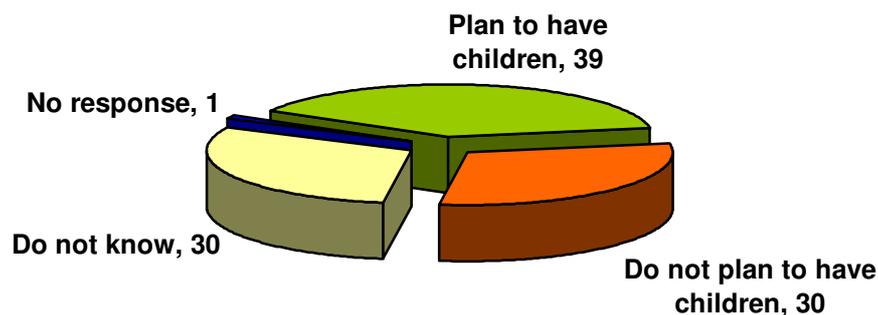
Figure 33: Presence of children and their HIV status (according to data from question 3Γ.1a. "Do you have natural children (either living with you or separately from you)?" and question 3Γ.16. "Have any of your children been confirmed as having an HIV positive status?",by % of those asked)



As regards plans to have children, 39% of those PLHIV asked intended to have children in the future, while a further 30% did not know for sure if they would have children or not, and 30% answered with certainty that they were not planning to have children in the future (see Figure 34).

The portion of those intending to have children was lower among those whose diagnosis had been confirmed less than a year ago, in comparison with those who had been diagnosed with HIV more than a year ago: 32% and 40% respectively. This percentage is also considerably lower among people living with an undisclosed status at just 17%. With regard to people who belong to different vulnerable groups of the population, there were not any particular differences in reproductive plans, however the lowest portion of those not planning to have children was found among people who do not belong to any vulnerable group (25%) and highest among MSM and gay/lesbian people (58%, but at the same time the portion of those planning to have children was much lower in this group than in other groups at 26%). As regards differences in sex and age, the portion planning to have children was the highest among women under 30: in this group it was 58%.

Figure 33: Plans to have children (according to data from questions 3Г.1В. "Are you planning to have children in the future (other than those that you already have)?", by % of those asked)



48% of those PLHIV asked had been advised at least once about their reproductive possibilities since they found out about their positive HIV status (see Figure 34).

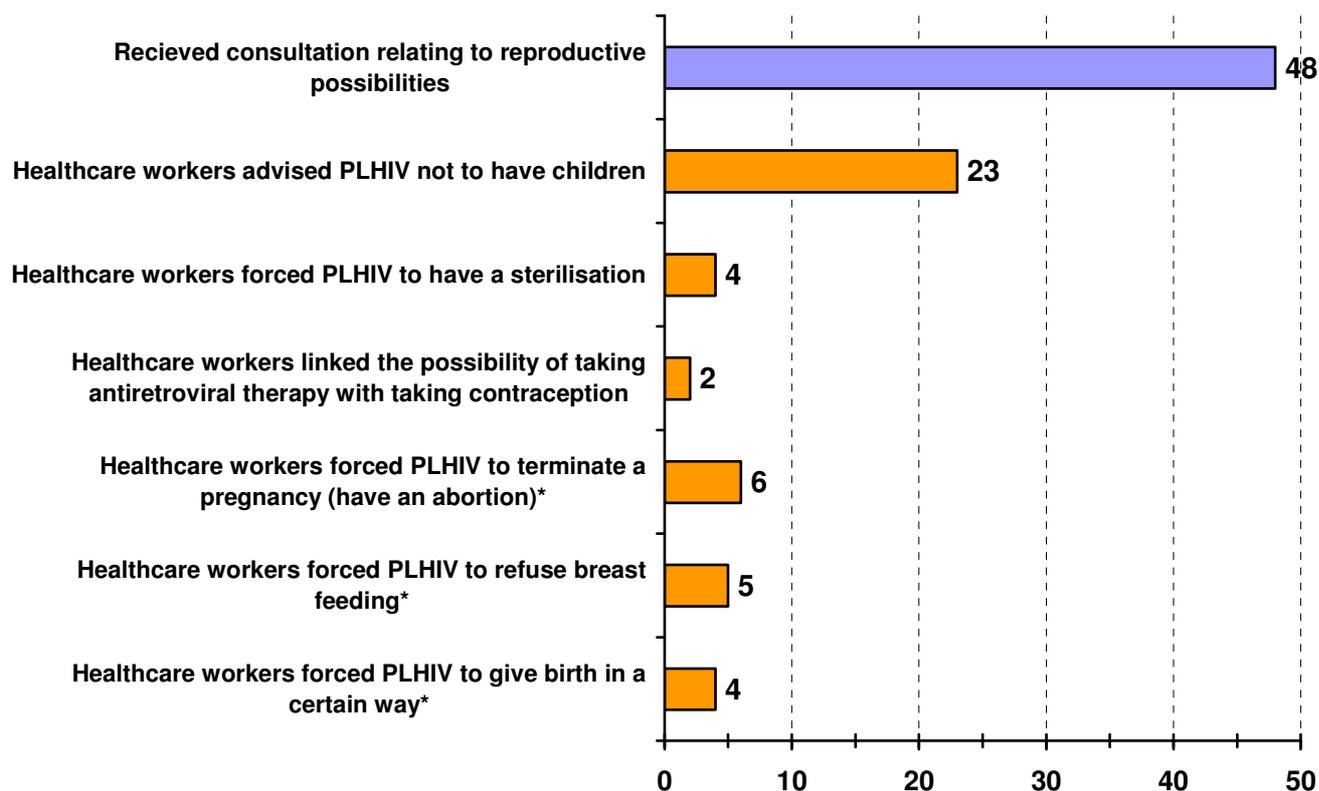
This portion is 62% among women (it is higher among women under 30, than among women over 30), while it is lower among men at 34%. This portion is also higher among people who have a long-term partner (58%) than among those who do not (36%). This portion hardly varies according to whether people belong to different vulnerable groups of the population.

23% of survey participants had received advice at least once from healthcare workers not to have children. At the same time this percentage is significantly higher among women than among men: 34% of women and just 12 % of men received such advice. This portion is much higher among injecting drug users (27%), prisoners (26%) and sex workers (32%) in comparison with the total and is lower among people who do not belong to any vulnerable group of the population (16%).

Of those asked, 4% indicated that healthcare workers had forced them to have a sterilisation; this portion is also higher among women (7%) than among men (1%). 2% of survey participants mentioned that their possibility to receive antiretroviral therapy was linked to the use of contraception or specific methods of it.

Of those women asked, 6% mentioned that in the past 12 months healthcare workers had forced them to terminate a pregnancy (this portion was 21% among those who had been in such a situation more than 12 months ago) and among sex workers this percentage is higher than in other groups of the population at 40%). 5% said that they were had been forced to refuse breast feeding (among those who had been in such a situation in the past this portion was 21%) and 4% said that they had been forced to give birth in a certain way (among those who had been in such a situation in the past this percentage was 18%).

Figure 34: Consultation and violation of rights in the area of reproductive behaviour (according to data from questions 3Г.2., 3Г.3., 3Г.4., 3Г.5., by % of those asked)



*by percentage of women asked

As regards taking antiretroviral therapy during pregnancy to prevent transmission of HIV from the mother to the child, 27% of women asked took ART, which is more than half (55%) of those women who were HIV-positive during pregnancy.

The results of the research thus show that the portion who encountered a violation of their rights in the area of reproduction is not high, however the fact that such serious violations of a person's right to make decisions independently in reproductive matters take place, is an indicator that significant discrimination by healthcare workers exists in this area.

2.10. Problems and Tasks

Survey participants were invited to answer an open question regarding what kind of problems they see in several aspects of the lives of people living with HIV and to also suggest what in their opinion could be methods of solving these problems.

As regards testing for HIV and positive results, survey participants referred most often of all to problems in this area with the lack of anonymity in testing for HIV infection, forced testing, lack of pre- and post-test advice with qualified psychologists and equivalent advisers.

As regards disclosure of information and guaranteeing confidentiality of information about HIV-positive status, the biggest problem for people was the gross violation of the rules of confidentiality faced by survey participants who proposed tighter control for observing these rules and increased penalties for disclosing information, including as far as the introduction of criminal responsibility.

Among the answers to the question about problems in the area of HIV treatment and antiretroviral therapy, the majority of participants indicated that it is necessary to make ART more accessible and also more effective. They proposed the development of new treatment regimen for HIV and the use of ART and also to increase the qualifications of doctors who prescribe HIV treatment.

As regards having children by HIV-positive parents, survey participants referred to the main problem being low levels of knowledge of PLHIV about the possibility of having children, including lack of provision of information about prenatal prevention in order to have a healthy baby.

Section 3

Conclusion

The research data demonstrates that discrimination, stigmatisation and violation of the rights of people living with HIV are widespread in Russia at present.

- **More than a third of survey participants (35 %) have at some point encountered some form of discrimination or stigmatisation from those around them for reasons, including their HIV status during the last 12 months.** Around half (47%) of those people, who had been subjected to victimisation/restrictions/discrimination in the last 12 months in connection with their HIV status, gave the reason for its occurrence as insufficient knowledge of those around them as regards transmitting the HIV infection and corresponding fear of infection by accidental contact.
- **More than a fifth of those asked (21 %) said that they had encountered some form of discrimination from organisations or institutions in the last 12 months for reasons including their HIV status.** Just less than one fifth (17%) of those people who approached medical institutions without concealing with HIV status, were refused access to medical services.
- As regards internal stigma, around **4 in 5 survey participants (78 %) experienced some kind of negative feelings towards themselves in connection with their HIV status in the last 12 months.** The wish to end their life was experienced by more than 1 in 10 of those asked (13%). **More than half (56 %) of PLHIV asked had made some kind of auto-discriminatory decision in the last 12 months.** More than 1 in 5 survey participants (22%) took the decision not to visit a regional health centre although there was a need to do so and just less than 1 in 5 of those asked (17%) did not go to hospital.
- **The portion of people experiencing fears of being subjected to some kind of discrimination was significantly higher in all cases than the portion who had encountered it in reality in the last 12 months,** however lower in the majority of cases **than the portion of those who had encountered it at any time in the past.** Exceptions are the fear of encountering refusals of sexual contact and the fear that family members/people close to them will be subjected to discrimination; the portions experiencing these are significantly higher than the portions of those who had encountered such situations at any time.

- **More than 1 in 10 of those asked (12 %) said that their rights as people living with HIV had been violated in the last 12 months and more than a quarter of survey participants (28 %) could not say with certainty whether their rights had been violated or not. Less than one fifth (18 %) of those whose rights had been violated, took some kind of action to protect them.** Less than 2 in 3 survey participants (60%) knew any kinds of organisations or groups that they could turn to for help in cases of defamation and discrimination while only just over 1 in 10 of those asked (12%) had turned to a similar organisation or group at some point when somebody had tried to discredit them or discriminate against them. Around 4 in 5 survey participants (78%) considered that they were unable influence creation of policy relating to people living with HIV. Around a third of those asked (29%) named the spreading of knowledge about HIV/AIDS as the main task in the fight against stigmatisation and discrimination.

- **Less than two third of survey participants (60 %) took the decision to be tested for HIV independently and voluntarily. Less than one fifth of those asked (19 %) received both pre- and post-test advice, while around half of survey participants (43 %) did not receive any kind of advice.**

- **More than a third of those asked (41 %) encountered a situation where information about their HIV status was disclosed to somebody they knew without their consent. Just less than 1 in 6 survey participants believed that medical workers had never told other people about their HIV status without their consent, while more than a quarter (27 %) were certain of the opposite. Less than 1 in 7 of those asked (14 %) were certain of the observance of confidentiality rules in relation to medical documents** regarding their HIV status while more than a fifth (21 %) of those asked were certain of non-observance. Public health workers proved to be more inclined to acts of discrimination in relation to the HIV status of those asked - **more than a third of survey participants (36%) say that public health workers displayed discrimination when they first found out about their HIV status.** 2 in 3 of those asked did not disclose their HIV status and around 3 in 4 (73%) of those people who disclosed their status said that it did not help them to solve their problems.

- As regards treatment, around a third of survey participants (35%) take antiretroviral therapy and less than 1 in 6 (15%) take drugs to prevent or treat opportunistic infections. Only **half of**

those asked (53 %) had had a constructive discussion about treatment options for HIV with medical workers in the last twelve months.

- As regards the area of reproduction, **more than one fifth of those asked (23%) had received advice from public health workers not to have children** at least once since their diagnosis of HIV was confirmed. **4 % of survey participants** mentioned that **healthcare workers had forced them to have a sterilisation**. Among women who had been pregnant in the last 12 months, **more than one fifth (21 %) had encountered a situation where medical workers had forced them to terminate the pregnancy.**