



# **THE PEOPLE LIVING WITH HIV STIGMA INDEX 2.0**

**LITHUANIA**

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The People Living with HIV Stigma Index implementation in Lithuania was carried out by people living with HIV supported as part of a process by the Coalition „I Can Live“ and implemented according to the methodology developed by GNP + (Global Network of People Living with HIV).

This report was prepared by Ausra Sirvinskiene, PhD in sociology, who conducted the data analysis using a template and structure of stigma index research by the International Partnership of the People Living with HIV. It has been peer reviewed and edited by GNP+ on behalf of the international partnership, an independent consultant, Julian Hows, and the implementing agency Coalition "I Can Live".

The study was conducted and this report was published in cooperation with ViiV Healthcare and "GlaxoSmithKline Lietuva".



WORKING ON BEHALF OF  
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The PLHIV Stigma Index 2.0 is an initiative of:



## ABBREVIATIONS

|               |   |
|---------------|---|
| <b>ART</b>    | Antiretroviral therapy                          |
| <b>GNP+</b>   | Global Network of People Living with HIV        |
| <b>HIV</b>    | Human immunodeficiency virus                    |
| <b>LGBT</b>   | Lesbian, Gay, Bisexual and Transgender People   |
| <b>MSM</b>    | Men who have sex with men                       |
| <b>NGO</b>    | Non-Governmental Organizations                  |
| <b>NTAKD</b>  | Drugs, Tobacco and Alcohol Control Department   |
| <b>PLHIV</b>  | People living with human immunodeficiency virus |
| <b>PSD</b>    | Compulsory health insurance                     |
| <b>PSDF</b>   | Compulsory Health Insurance Fund                |
| <b>STD</b>    | Sexually transmitted diseases                   |
| <b>TM</b>     | Ministry of Justice                             |
| <b>ULAC</b>   | Center for Communicable Diseases and AIDS       |
| <b>UNAIDS</b> | The Joint United Nations Programme on HIV/AIDS  |
| <b>WHO</b>    | World Health Organization                       |

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## SUMMARY

It is well known that the stigma and discrimination experienced by people with HIV creates barriers across the HIV prevention, testing and treatment cascades and reduces the impact and effectiveness of the AIDS response<sup>1</sup>. However the precise ways that these barriers are perceived by people with HIV in Lithuania and how such stigma and discrimination restricts the ability of people living with HIV (PLHIV) to access timely and needs-based prevention, treatment and care, has never been researched.

**The purpose** of the research was to identify and analyze the forms of stigma and discrimination which PLHIV experience in Lithuania and to make recommendations on how to address the obstacles that limit PLHIV in leading full and productive lives free from stigma and discrimination. Repeating the research at periodic intervals would allow for the tracking of changes in the situation of PLHIV as a result of changes to policy and practice that may have been brought about as the result of the advocacy recommendations being implemented as well as other casual factors.

**Methodology.** The questionnaire and methodology used was that developed by "The Global Network of People Living with HIV (GNP+)", "The International Community of Women Living with HIV/AIDS (ICW)", "The Joint United Nations Programme on HIV/AIDS (UNAIDS)" was used. This is an internationally validated tool.

**The target group** of the research were people living with HIV in Lithuania. The type of the selection of respondents: probabilistic cluster (nested sampling) selection. To ensure the representativeness of the data, the study sample was selected in three stages: *Stage one*: identifying the "nests" in cities and districts with the highest number of registered HIV cases and the "nests" by mode of transmission of HIV; *Stage two*: the required number of respondents (in proportion to the number of PLHIV registered according to their geographical location and in proportion to the mode of HIV transmission) was calculated in each "nest"; *Stage three*: in each "nest," contact was made with the primary contacts (that NGOs, healthcare, and social institutions had), who then referred other respondents using a "snowball" method until the target sample size was reached.

In total, 200 respondents participated in this research. The data was collected through direct individual meetings, using a standardized questionnaire. The anonymous survey was conducted by trained interviewers who were HIV positive. Thus, the "peer-to-peer" principle was applied.

**Socio-demographic data.** The "typical" HIV+ respondent in Lithuania is a man of working age (30-49 years old), having a secondary or vocational education (70%), and having experience of being incarcerated in prison (42%, n = 84). Data by sex and age show that only one age group, 18-29 year-olds, had more women than men respondents. All other age groups were dominated by men. Most respondents were unemployed or engaged in random jobs. Every third lived in a household with children. Every second respondent (53.5%, n = 107) indicated that they were injecting or otherwise regularly using illicit drugs (such as heroin, cocaine, methamphetamine). Of all the respondents, only 2% (n = 4) stated that they belonged to the group of men who have sex with men. 1% (n = 2) identified as gay/homosexual, 4% (n = 8) as bisexual and 6% (n = 12) respondents indicated that they had had sex for money.

**External stigma.** In Lithuania, HIV positive respondents are most likely to experience verbal harassment or be gossiped about because of their HIV+ status by non-family members (40.5%). One in 5 respondents had experienced receiving stigmatising and/or discriminatory remarks from their family members.

About two-thirds of the respondents (67%, n = 134) reported that their HIV status is known to their friends, other family members (61%, n = 122) and a spouse or a partner (57.5%, n = 115). However, only one in two respondents more or less agreed that disclosing their HIV+ status to close people was a positive experience. 81% pointed out that after learning about their HIV+ status their relatives showed support. Every second respondent reported that they had received supportive responses from strangers upon disclosure of their status. Almost every other person agreed that, over time, it became easier to reveal their diagnosis. The total number of respondents who stated that their HIV status was disclosed without their consent was 5% (n = 10).

**Internalised stigma.** Internalised stigma amongst respondents manifested in fears of revealing HIV+ status (90%, n = 162), Every second respondent (57.5%, n = 115) reporting that their HIV+ status made them feel worthless and 55% (n = 110) felt ashamed. Moreover, every second respondent indicated that their HIV+ status made them feel guilty (53%, n = 107) and "dirty" (51 %, n = 102). The HIV+ status had the greatest negative impact on the ability to find love (40.5%, n = 81), on self confidence

<sup>1</sup> [http://www.unaids.org/sites/default/files/media\\_asset/confronting-discrimination\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/confronting-discrimination_en.pdf)

(40%, n = 80), on the ability to maintain close and secure relationships (33.5%, n = 67), on the ability to cope with stress (32.5%, n = 65). Every fifth respondent decided not to have sex because of their HIV+ status in the past 12 months (19.5%, n = 39). Almost every seventh respondent (14%, n = 28) decided to separate themselves from their family and every eighth respondent (12.5%, n = 25) decided not to apply for a job.

**Experiences when seeking healthcare services.** More than half of the respondents received antiretroviral HIV treatment - 68% (n = 136). Almost half of all the participants in the study (46%, n = 92) indicated that they started treatment more than two years after their diagnosis. It is also important to note that 23.5% (n = 47) of the respondents do not know what virus load or virus concentration means.

**Negative experiences in healthcare settings.** The following negative reactions were reported by participants: 15% (n = 30) indicated that the staff avoided physical contact or used unnecessary additional protection measures (for example, wearing double gloves, etc.), 8.5% (n = 17) stated that information about their HIV+ status was provided to other people without their consent. 76% (n = 152) did not know if their medical records were kept confidential.

**Human rights and effecting change.** Most tellingly the majority of the respondents were not aware of any laws protecting their rights, i.e., 82% (n = 165) did not know whether there are laws that protect PLHIV against discrimination.

Out of all the possible human rights violations listed, detention or isolation (being quarantined) related to the HIV+ status was mentioned most often (although these human rights violations in most cases had happened before the past 12 months) - 6% (n = 12).

PLHIV in Lithuania experience ongoing challenges in maintaining self-support or other groups (for example, groups that seek to reduce discrimination, etc.) that could be catalysts for effecting change. Only 29.5% (n = 59) were members of a network of PLHIV or a support group. The existing groups are short-lived or fragmented and have not found ways to sufficiently publicise activities or achieve sustainability. From the research it is evident that there is a reluctance from those from the MSM community and those not marginalised due to poverty to be part of support groups or involved in effecting change through community action.

## Conclusions and recommendations

Based on the results of this study, the following five overall conclusions were drawn:

1. Study data related to the low awareness of HIV positive people of their health outcomes allows to assume that health care institutions should give more comprehensive and clearer information about the options and importance of treatment: 23.5% (n = 47) of the respondents did not know what viral load or virus concentration means. **Recommendations:** a) based on the other countries' best practice (e.g. WHO recommended Linkage to HIV Care System), the public institutions should develop a system which ensures a prompt and sustainable service that meets the needs of PLHIV; b) these institutions should also strengthen the competences of the various specialists working PLHIV.

2. Internal stigma among PLHIV in Lithuania was manifested in their fear of revealing their HIV+ status to others; this fear is associated with a low self-esteem, a sense of shame and guilt. Almost every seventh respondent (14%, n = 28) decided to separate themselves from the family, and every eighth respondent (12.5%, n = 25) decided not to apply for a job. **Recommendations:** a) the state institutions, which provide care for PLHIV, should focus on the psychological well-being of PLHIV, which is most closely related to internal stigma; b) activate the provision of psychological and social assistance to PLHIV, both in government institutions and non-governmental organizations; c) review and evaluate national programs/plans and measures (in the social, healthcare and legal areas), directly or indirectly related to HIV (such as the HIV/STD action plan, mental health strategy, etc.), and specific measures for reducing stigma and discrimination.

3. HIV positive respondents are most likely to experience external stigma (verbal harassment or be gossiped about) because of their HIV+ status by non-family members. Every second respondent indicated that in the past 12 months, his/her possibilities (social, work, etc.) were not affected by their HIV+ status. Possibilities deteriorated for every fifth HIV+ person. This indicates that the positive HIV status generally does not have significant impact on the possibilities, but there are still cases where the possibilities deteriorate because of HIV. **Recommendation:** Non-governmental and public institutions should plan and implement awareness raising activities on HIV to dispel HIV-related myths through the media and in decision-making institutions (such as the Parliamentary committees, the Ministry of Health, etc.).

4. The participants were largely unaware of the laws protecting their rights, i.e., 82%. (n = 165) did not know whether there are laws that protect PLHIV against discrimination. PLHIV in Lithuania are not active members in self-support or other groups (for example, groups that seek to reduce discrimination, etc.). Only 29.5% (n = 59) were members of a network of PLHIV or a support group. **Recommendation:** a) non-governmental organizations that are active in the HIV area should plan and implement measures on how to motivate and empower PLHIV, so that they are better informed about their rights, have evidence-based information on HIV treatment options and opportunities, and engage in activities for PLHIV; b) promote training and activities of peer-to-peer counselors on HIV, so that they can inform PLHIV about their rights, potential sources of assistance, and provide other information they need; c) municipalities should plan and take specific measures to promote the establishment and development of support groups and NGO's representing vulnerable populations by providing continuous funding and supporting the training of peer to peer counselors.

5. The study managed to reach a high number of respondents who identified themselves as drug users (the largest key population of people living with HIV in Lithuania). However, it was less successful with reaching other key populations known to be living with HIV or particularly vulnerable to it (men who have sex with men, gay/homosexual persons, bisexual persons, etc.) as well as those who do not identify themselves with the gender assigned to them at birth (despite several isolated cases). Therefore, it is very important to plan additional research in the future to reveal the reasons why these groups remain unidentified, and to encourage such people to be more involved in addressing the problems they face or to meet their HIV related needs.

## INTRODUCTION

### THE RELEVANCE OF THE TOPIC

The spread of HIV infection in Lithuania, as in many other countries, is mainly amongst groups marginalized in other ways because of identity and drug use and vulnerability through lack of access to commodities such as safer injecting equipment or substitution therapy - especially whilst incarcerated. The stigma and discrimination associated with HIV status restricts the ability of people living with HIV (PLHIV) to access timely and needs-based prevention, treatment and care. The relative lateness of Lithuania to adopt WHO (World Health Organization) recommendations for the early initiation of ART therapy does mean that the healthcare system has challenges in achieving the UNAIDS 90-90-90 targets.

In order to explore and quantify the stigma and discrimination experienced by people with HIV in Lithuania, a questionnaire and methodology of stigma index developed by The International Partnership of the People Living with HIV were used<sup>2</sup>. More detailed information about the methodology, intent and purpose of the People Living with HIV Stigma Index can be found at: <http://www.stigmaindex.org/>

### HIV SITUATION IN LITHUANIA

Based on the data of the Center of Communicable Diseases and AIDS<sup>3</sup> and the Department of Drug, Tobacco, and Alcohol Control<sup>4</sup>. As of January 1<sup>st</sup>, 2018, the total of 3,012 cases of the human immunodeficiency virus infection (hereinafter referred to as HIV) were registered in Lithuania since the time HIV was first registered in the country. Out of this number, 2,402 cases or 79.7% were among men and 610 cases, or 20.3%, among women.

In 2017, 263 new cases of HIV were registered in Lithuania. This is by 49 cases more than in 2016, and even by 106 more than in 2015 (in 2016 there were 214 new cases, in 2015 - 157, in 2014 - 141, in 2013 - 177, in 2012 - 160, in 2011 - 166, in 2010 - 153, in 2009 - 180, in 2008 - 95, in 2007 - 106).

<sup>2</sup> This is the result of a collaboration of 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)

<sup>3</sup> [http://www.ulac.lt/uploads/downloads/Ataskaitos/2017/LPI\\_2017.pdf](http://www.ulac.lt/uploads/downloads/Ataskaitos/2017/LPI_2017.pdf)

<sup>4</sup> [https://ntakd.lrv.lt/uploads/ntakd/documents/files/34862%20NTAKD%20Metinis%20prane%C5%A1imas\(1\).pdf](https://ntakd.lrv.lt/uploads/ntakd/documents/files/34862%20NTAKD%20Metinis%20prane%C5%A1imas(1).pdf)

The incidence rate of HIV infection in 2017 increased compared to 2016 (from 7.4 to 9.3 cases per 100,000 of population). The highest incidence rates of HIV in 2017 were recorded in the Vilnius and Klaipėda counties, and the lowest in the Tauragė and Kaunas counties.

In licensed laboratories, 209,922 HIV diagnostic tests were conducted in 2017 (205,621 in 2015 and 209,675 in 2016). In 2017, the number of healthcare institutions, their departments, and other legal entities conducting HIV testing decreased compared to 2016 - 115 and 108 respectively. The number of institutions reporting HIV testing decreased in Vilnius, Šiauliai, Alytus, Marijampolė, and Utena counties, while in Kaunas, Klaipėda, Panevėžys, Tauragė, and Telšiai counties the number remained the same. In 2017, the number of HIV tests went down by 1.3% as compared to 2016. In 2017, just like in the previous year, two population groups were tested the most (provider-initiated tests): blood donors and pregnant women. Compared to 2016, the number of tests among pregnant women increased, while the number of tests among blood donors decreased in 2017. Over the past three (2015-2017) years, there has been a decrease in the number of HIV tests among drug users, but there has been an increase in the testing of men who have sex with men. The number of client-initiated tests has been stable for several years, but decreased in 2017.

The 2017 data by sex show that 83.7% (220) of new HIV infections were among men and 16.3% (43) among women. Four out of ten (42.2%) of the PLHIV were of 30-39 years of age. 48.8 % of women were of 20-34 years of age, while 62.7% of men were of 30-44 years of age.

The data by education shows that 42.6% (112) of the PLHIV had secondary school education, 29.7% (78) – partial secondary education, 8.4% (22) - higher education, 6.8% (18) - primary education, 1.9% (5) - vocational education and 10.7% (28) - education was not specified. In 2017, 75.7% (199) had social insurance at the time of the HIV diagnosis, 19.0% (50) did not have social insurance, 5.3% (14) - social insurance status was not specified on the registration protocols (form No. 151-9/a). Among those who tested positive for HIV in 2017, 34.6% (91) were unemployed, 21.3% (56) were blue collar workers, 6.8% (18) civil servants, 1.9% (5) homeless people, 0.8% (2) school students. 27.0 % (71) of PLHIV belonged to other social groups - mostly incarcerated in the institutions under the Ministry of Justice (prisoners or detainees). Analysis by sex shows that every second HIV positive woman (51.2%) was unemployed and one in four (25.6%) belonged to the social group of blue color workers. Every third HIV positive man was unemployed (31.4%) or belonged to other group of socially vulnerable people (30.0%). The social group of 7.6%% (20) cases was not specified.

Regarding the possible route of transmission, 51.7% (136) - half of people became infected with HIV through injecting drug use, 24.7% (65) – through heterosexual intercourse, 6.8% (18) - through homosexual intercourse, 16.3% (43) - the route of transmission is not known, and one case of prenatal transmission of HIV was registered. A higher proportion of women (60.5%) than men (17.7%) became infected through heterosexual intercourse.

The number of new cases of HIV in Lithuanian prisons has increased more than four times over several years (from 23 new cases in 2015 to 97 in 2017). According to the Center for Diseases and AIDS, the prevailing mode of HIV transmission is the use of injecting drugs. Although research has shown that pharmacotherapy with opioids (methadone) is one of the most recommended measures in reducing the spread of HIV among people who inject drugs in prisons, such treatment was not provided in places of incarceration until April 25<sup>th</sup>, 2018. Since April 25<sup>th</sup>, 2018, after the Order Nr. V-194 of the Director of the Prisons Department under the Ministry of Justice of the Republic of Lithuania "On the Approval of the Description of the Procedure for Ensuring the Continuity of the Replacement Therapy of Opioid Dependence in Prisons" came into force, persons who were receiving opioid substitution treatment prior to incarceration, are able to continue it in prisons. However, there is still no possibility to start such treatment in prisons.

According to the Center for Infectious Diseases and AIDS, in 2016, antiretroviral therapy (ART) was prescribed for 754 PLHIV. The order of the Minister of Healthcare allowing for the initiation of ARV for all PLHIVs (including those in custody<sup>5</sup>) who are covered by the Compulsory Health Insurance (PSD) as soon as HIV is diagnosed without waiting for the infection to progress came into force only in early 2018. The treatment is funded by the Compulsory Health Insurance Fund (PSDF), except for those in prisons.

In 2015-2016, the Association of Women and Their Families Affected by HIV/AIDS "Demetra", supported by the AIDS Health Fund (AHF), developed the HIV/AIDS care and treatment cascades in Lithuania<sup>6</sup>. It shows that, when assessing the situation in Lithuania according to the UNAIDS 90-90-90 goal, an average of 66% of persons knew about their positive HIV status, 32% of them received antiretroviral treatment and 82% of those in treatment had their HIV viral load was undetectable in 2016. Despite

<sup>5</sup> <https://e-seimas.lrs.lt/portal/legalAct/lt/TAD/447b4d2071ff11e7aefae747e4b63286?jfwid=-502pzva17>

<sup>6</sup> Association of women and their families affected by HIV and AIDS Demetra and the AIDS Healthcare Foundation (research leaders Dr. Loreta Stonienė and Giedrius Likatavičius) Vilnius, 2017, HIV/AIDS care and treatment cascade in Lithuania.

the shortcomings in the data quality, it can be stated the quality of treatment (non-detectable viral load) is inconsistent with the intended UNAIDS goals.

## OBJECTIVES

The purpose of this research was to identify and analyze the forms of stigma and discrimination which PLHIV experience in Lithuania and to make recommendations on how to address the current obstacles that limit PLHIV in leading full and productive lives, free from stigma and discrimination and advocate for the recommendations to be implemented.

### Objectives of the research:

1. To collect information on the factors determining stigma and discrimination of PLHIV in Lithuania.
2. To reveal the experience and the situation of different groups of PLHIV (e.g., people who use psychoactive substances, LGBT, people who have experienced imprisonment, etc.) related to stigma and discrimination in Lithuania.
3. To identify the impact of specific problems caused by stigma and discrimination on the social life of PLHIV, their linkage to care, and on their treatment.
4. To develop recommendations for further advocacy in various policy areas (healthcare, social and legal) that would pave the way to promotion of the reduction of stigma and discrimination of PLHIV, in particular to reducing the impact of stigma and discrimination on the social life of people living with the HIV, their linkage to care, and in their treatment.

### In the future, this study will allow:

1. To track changes in the situation of PLHIV and the stigma and discrimination they experience as well as evidence to show which stigma reduction interventions work at both an individual as well as a programmatic level;
2. To develop an evidence-based research database that would help to initiate and track changes in social, healthcare, and treatment programs in the country.

## METHODOLOGY

### The Areas of the Survey

The data of the survey were collected using a standardized questionnaire consisting of both open and closed ("yes" or "no") questions. The data on the following aspects were collected:

- Demographic information about the respondents;
- Experience of stigma and discrimination related to other people;
- Experience of stigma and discrimination in the labor market, healthcare, social, and education settings;
- Internal stigma and fears;
- Awareness of rights, legal acts, and other regulations of the protection of PLHIV;
- Effecting changes in relation to stigma and discrimination;
- Experience related to HIV testing and diagnosis;
- Experience related to confidentiality;
- Access to HIV treatment;
- Reproductive behavior (childbirth).

In order to ensure the validity of the obtained data, after the initial processing of the data, the main findings were discussed in focus groups of HIV positive persons participating in the study and interviewers.

### Sample and Selection

The target group of the research were people living with HIV in Lithuania. The type of the selection of respondents: probabilistic cluster (nested sampling) selection<sup>7</sup>.

To ensure the representativeness of the data, the study sample was selected in three stages:

<sup>7</sup> The essence of the cluster (nested) selection is to select not individual members or elements of the target population, but their groups (nests). Such a selection is possible when members of the target population can be naturally divided or grouped into groups. In the case of this study, cities or regions with the highest number of registered HIV-positive individuals are identified. Having identified the cities or districts, when deciding on the sampling, the different ways of contracting HIV infection is taken into account (injection drug users, persons infected through non-traditional sexual relations, persons infected during a sexual intercourse, etc.). The nested selection is done by selecting the groups (nests) are selected randomly from the existing contacts. Then all the members whose contact is known and who agree to participate in the survey are then interviewed.

*Stage one:* identifying the “nests” in cities and districts with the highest number of registered HIV cases and the “nests” by mode of transmission of HIV.

*Stage two:* the required number of respondents (in proportion to the number of PLHIV registered according to their geographical location and in proportion to the mode of HIV transmission) was calculated in each “nest”.

*Stage three:* in each “nest,” contact was made with the primary contacts (that NGOs, healthcare, and social institutions had), who then referred other respondents using a “snowball” method until the target sample was reached.

In total, 200 respondents participated in this research.

### **Data Collection**

The data was collected through direct individual meetings, using a standardized questionnaire. The survey was conducted by trained interviewers who were HIV positive. Thus, the “peer-to-peer” principle was applied.

### **Research Ethics**

The respondents, who have agreed to participate in the study, were introduced to the principles of confidentiality and anonymity. Interviews were conducted anonymously and without presence of any third parties. No identification, including name, address, or other contact information, was requested. For each respondent, a code was generated that could not be deciphered by third parties. The informed consent form was signed by the interviewees and the questionnaire questions were answered only after the written consent was given.

### **Data Analysis**

The coded data was entered into an electronic database using MS Excel, which was then converted to SPSS and analyzed. The statistical significance of the data was calculated based on the chi-square ( $\chi^2$ ), the p-value of the test criterion using Pearson Chi-Square,  $\alpha=0.05$ . Systematized data are provided in Appendix Nr. 1, which is available online at [www.galiugyventi.lt](http://www.galiugyventi.lt)

## **LIMITATIONS OF THE STUDY**

There are two major limitations that should be noted:

1. Although the study managed to reach a high number of respondents who identified themselves as drug users (the largest key population of people living with HIV in Lithuania), it was less successful in reaching other key populations known to be living with HIV or particularly vulnerable to it (especially men who have sex with men) as well as those who do not identify themselves with the gender attributed to them at birth (transgender persons) who face legislative challenges in recognition of their elected identity under Lithuanian law. As such, the conclusions reached by this study are most robust in relation to the main key population of people living with HIV in Lithuania - current or former injecting drug users - and should be taken as indicative and needing further exploration for other key populations.
2. The general level of awareness of rights and protections afforded under Lithuanian law to people living with HIV was very low amongst respondents, with 83% (166 of 200 respondents) being unaware that they had rights and protections. Therefore, their responses may not reflect the real situation of rights violations.

## SOCIO-DEMOGRAPHIC DATA OF PLHIV

### GENDER AND BIOLOGICAL SEX IDENTITY

The respondents of the study by sex<sup>8</sup> are as follows: 70% (n = 140) men; 30 % (n = 60) women. There were more men than women in all age groups, except for the age group of 18-29.

According to the gender<sup>9</sup>, the data was distributed as follows: 68.5% (n = 137) men; 29.5% (n = 59) women; 1% (n = 2) transgender; 0.5% (n = 1) did not consider themselves either a man or a woman or a transgender; 0.5% (n = 1) did not want to indicate their gender.

Most of the respondents were of working age (about 98%): the age of 0.5% was 15-17, 12% - 18-29; 33% - 30-39; 35.5% - 40-49; 18% - 50-59, and 1% - older than 60.

The youngest participant in the study was a 17-year old, the oldest – a 63-year old. The average age is 41 years (standard deviation - 8.5).

This data distribution corresponds to the distribution of the general population of PLHIV in Lithuania. For example, according to the press release of ULAC<sup>10</sup>, out of all the new HIV cases in 2017, 83.7% (220) were men, 16.3% (43) were women. Furthermore, 42.6% (112) had secondary school education, 29.7% (78) had partial secondary school education, 8.4% (22) higher education, 6.8% (18) primary education, 1.9% (5) vocational training and 10.7% (28) did not indicate their education level. By the mode of transmission, half of the respondents – 51.7%. (136) became infected through injecting drug use, 24.7% (65) through heterosexual contact, 6.8% (18) through homosexual contact, 16.3% (43) did not indicate their mode of transmission. One case of prenatal transmission was registered.

Distribution of respondents by age and sex (absolute number)

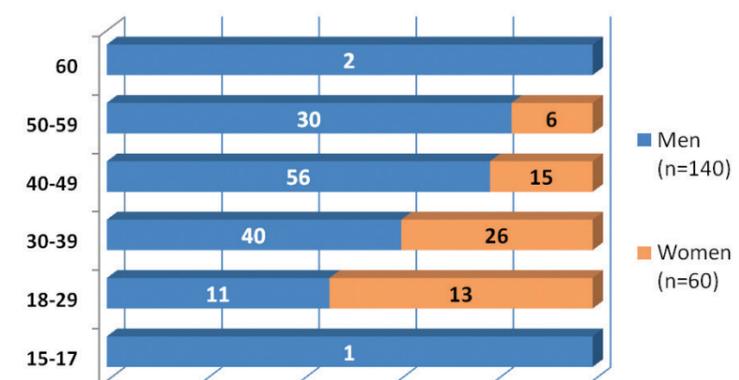


Chart 1. Distribution of respondents by age and sex (absolute nr n=200)

More detailed demographic data are presented in Table 1.

### PERIOD OF TIME OF BEING AWARE OF THE HIV STATUS

Every third respondent in the study had known about their positive HIV status for 5-9 years (38%, n=72), every fourth - for 1-4 years (25.4%, n=48).

Out of the respondents of the study, the longest period of a person living with HIV was 22 years. The average duration of living with HIV among all other respondents is 8 years (standard deviation - 5.3). Details are given in Table 1 below.

### RELATIONSHIP STATUS

Almost half of the participants of the study were sexually active - 49.5% (n = 99), 27% (n = 27) of them lived with an HIV positive partner, and 12% (n = 12) were not aware of the partner's HIV status.

### CHILDREN

29 % (n = 58) of the respondents indicated that they lived in a household with children and took care of them.

<sup>8</sup> Biological sex is the sex recorded in the respondent's birth certificate.

<sup>9</sup> Gender is the gender with which the respondent identifies himself or herself.

<sup>10</sup> [http://www.ulac.lt/uploads/downloads/Ataskaitos/2017/LPI\\_2017.pdf](http://www.ulac.lt/uploads/downloads/Ataskaitos/2017/LPI_2017.pdf)

## EDUCATION

2% (n = 4) of the respondents indicated that they were studying at the time of the research. Most of the respondents in the study had secondary education - 37% (n = 74) and vocational education - 35% (n = 70). 3 % (n = 6) reported that they did not have any formal education certificate. 7 % (n = 14) had higher education.

Analyzing the data by sex, more men than women had higher education (8% men (n = 11) and 5% women (n = 3)). More men than women had secondary education as well (18% men (n = 53) and 17% women (n = 19)). More women than men had vocational education (42% women (n = 25) and 33% men (n = 45))<sup>11</sup>. For more information about differences in education between men and women see Chart 2.

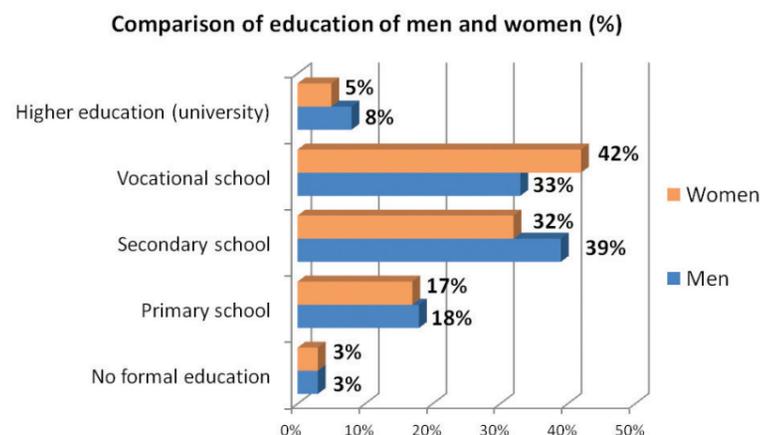


Chart 2. Comparison of education of men and women (% , n = 200).

## WORK SITUATION (EMPLOYMENT STATUS)

Most of the respondents of the study were unemployed - 49.5% (n = 99). 20% (n = 40) were doing random jobs or worked part-time (were self-employed or working for others for remuneration). Those working full-time constituted of 16% (n = 32) and part-time (hired employees) of 10.5% (n = 21). 4 % (n = 8) worked on a full-time basis, but not as a hired employee.

When analyzing employment data by sex, we see that every second man and every second woman were unemployed. There were more women working full-time (hired employee) - 25% (n = 15). Men were more often doing random jobs or worked part-time - 24%. (n = 34)<sup>12</sup>. For more details see Chart 3.

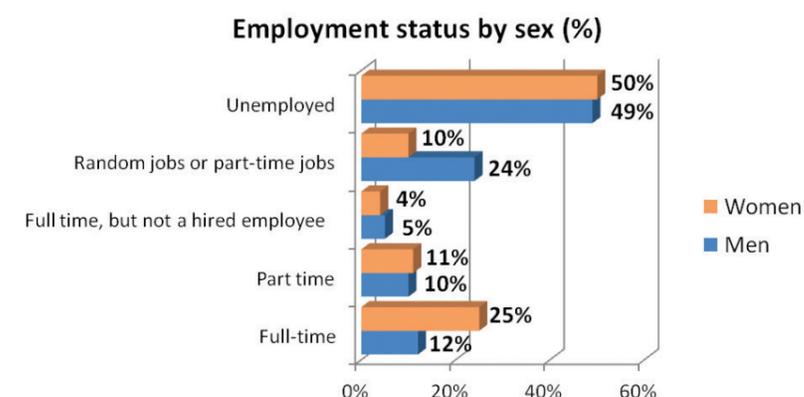


Chart 3. Respondents' employment status by sex (% , n = 200)

## MEETING BASIC NEEDS

41.5% (n = 83) of the respondents were unable to meet their basic needs (food, clothing, shelter, etc.) some of the time over the last 12 months, 9.5% (n = 19) were unable to meet basic needs most of the time. 98% (n=49) never had problems to meet their basic needs.

The analysis of the data by sex shows that, in the past 12 months, more women (65% (n = 39) than men 42% (n = 59) had no problems in meeting their basic needs<sup>13</sup>.

## BELONGING TO A SPECIFIC GROUP

Nearly every other respondent (42%, n = 84) indicated that they belong to the group of formerly incarcerated persons. 15 % (n = 30) indicated that they belong to the group of people with disabilities (had eyesight, hearing, mobility, mental health/intellectual or other disability (other than HIV)). 3.5 % (n = 7) identified themselves as members of a racial, ethnic, or religious minority.

<sup>11</sup> The differences in education between men and women are statistically significant - p <0.001. The statistical significance of the data here and further on has been calculated on the basis of the chi-square (χ<sup>2</sup>), the value of the test criterion in accordance with Pearson Chi-Square. If the p value of the test criterion exceeds the significance level of 0.05, then the data are not statistically significant.

<sup>12</sup> The differences in the employment situation (employment) between men and women are statistically significant - p <0.000, calculated on the basis of the Chi-square (χ<sup>2</sup>), the p-value of the test criterion according to Pearson Chi-Square.

<sup>13</sup> Differences between men and women in meeting their basic needs are statistically significant - p <0.001. The statistical significance of the data was calculated on the basis of the the chi-square (χ<sup>2</sup>), the p-value of the test criterion according to Pearson Chi-Square.

29.5% (n = 59) were members of a PLHIV network or support group. The proportion of women in PLHIV network or support group was 33% (n = 20) and men - 28%. (n = 39).<sup>14</sup> During the review meetings with interviewers, it was observed that the weak involvement in support groups was due to the fact that very few such groups exist in Lithuania, and the activities of those that existed were fragmented and not well-established. Observations from interviewers gathered during this study suggest that these groups did not exist because PLHIV did not have sufficient skills to set up and maintain such groups, and those who had such knowledge and skills, avoided identifying themselves with this group.

More detailed socio-demographic data of the respondents is provided in Table 1.

Table 1. Socio-demographic data of PLHIV in Lithuania (n=200).

| Sex                           | %    | n   |
|-------------------------------|------|-----|
| Men                           | 69   | 138 |
| Women                         | 30   | 60  |
| Transgender                   | 1    | 2   |
| Age                           | %    | n   |
| 15-17                         | 0,5  | 1   |
| 18-29                         | 12   | 24  |
| 30-39                         | 33   | 66  |
| 40-49                         | 35,5 | 71  |
| 50-59                         | 18   | 36  |
| 60 and older                  | 1    | 2   |
| Education                     | %    | n   |
| No formal education           | 3    | 6   |
| Primary school                | 18   | 36  |
| Secondary school              | 37   | 74  |
| Vocational school             | 35   | 70  |
| Higher (university) education | 7    | 14  |

| Employment   | %    | n   |
|--|------|-----|
| Full-time employment (hired employee)  | 16   | 32  |
| Part-time employment (hired employee)  | 10,5 | 21  |
| Full-time employment, but not a hired employee (self employed or business owner)   | 4    | 8   |
| Random jobs or part-time work (self-employed or working for others for remuneration)   | 20   | 40  |
| Unemployed   | 49,5 | 99  |
| Has an intimate / sexual partner   | %    | n   |
| Yes  | 50,5 | 101 |
| No   | 49,5 | 99  |
| Knows his or her HIV+ status (years)   | %    | n   |
| Less than 1 year   | 0,5  | 1   |
| From 1 to 4 years  | 25,4 | 51  |
| 5-9 years  | 38,1 | 76  |
| 10-14 years  | 18   | 36  |
| Longer than 15 years   | 18   | 36  |
| Belonging to social groups<br>(Respondents could choose several options)   | %    | n   |
| Member of a racial, ethnic, or religious minority  | 3,5  | 7   |
| Member of a local ethnic group (e.g., indigenous / aboriginal)   | 2    | 4   |
| Person with a disability (of eyesight, hearing, movement, mental health / intellectual, or any other disability (other than HIV) | 15   | 30  |
| Refugee or asylum seeker   | 1,5  | 3   |
| Labor migrant  | 1    | 2   |
| Internally displaced person  | 3    | 6   |
| Formerly imprisoned  | 42   | 84  |

## DISCLOSURE OF HIV+ STATUS

More than half of respondents 67% (n = 134) indicated that their HIV+ status was known to friends, 61% (n = 122) - to other family members, and 57.5% (n = 115) - to husband / wife / partner. See Chart 4.

<sup>14</sup> Differences between men and women are statistically significant - p <0.001. as calculated on the basis of the chi-square (χ<sup>2</sup>), the p-value of the test criterion according to Pearson Chi-Square.

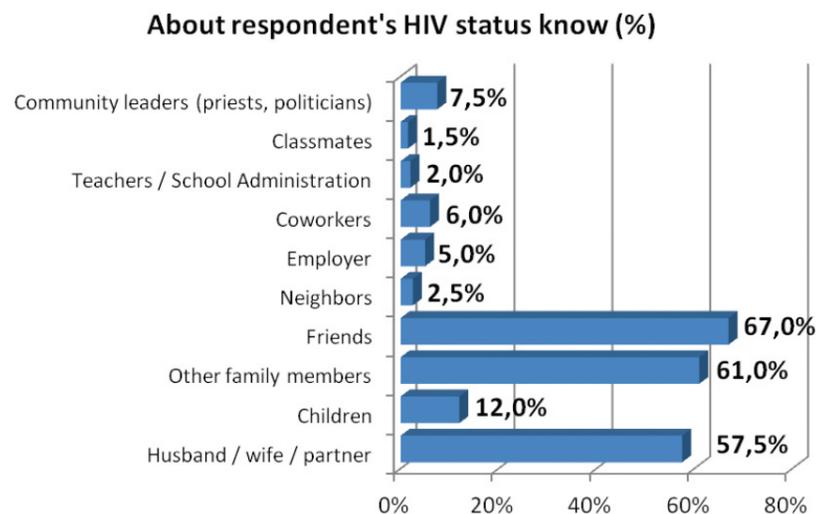


Chart 4. Persons who know about the respondents' HIV+ status (%), n = 200). Several options could have been chosen.

## EXPERIENCE IN DISCLOSING HIV+ STATUS

5% (n = 10) indicated that their HIV+ status was disclosed without their consent. Without the respondent's consent the information was most often disclosed to friends - 3% (n = 6); 2% (n = 4) of respondents indicated that it was disclosed to each of the following: colleagues, teachers / school administrators, classmates. See Chart 5.

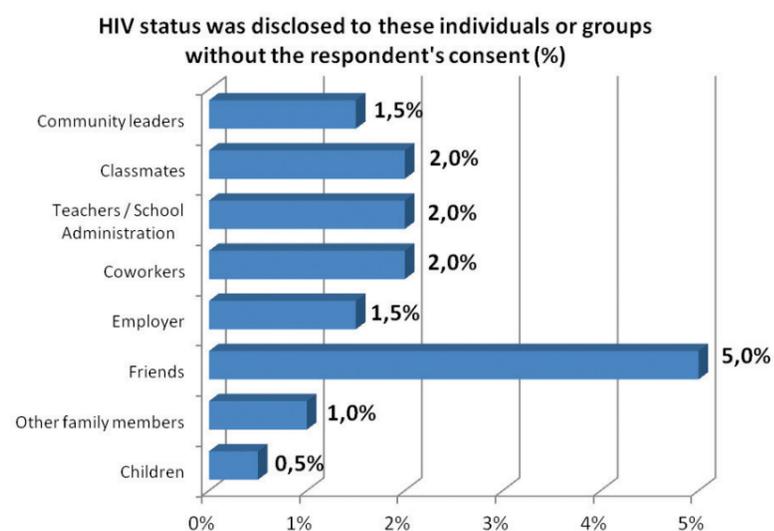


Chart 5. Disclosing HIV+ status without the respondents' consent to individuals and / or groups (%), n = 200).

Every second respondent agreed or partially agreed that the disclosure of the status to their loved ones was a positive experience. 81% agreed or partially agreed that when they had learnt about their HIV+ status, their loved ones supported them. The distribution of those who agreed or somewhat agreed and those who disagreed that revealing their HIV+ status to strangers was a positive experience was close to 50/50. Nearly every other person agreed or somewhat agreed that the strangers were supportive after learning about the person's HIV+ status. Almost every second person also agreed that, over time, it became easier to reveal their HIV+ status. See Chart 6.

Although it had become increasingly easier to reveal information on the HIV+ status over time, the respondents indicated that they remained fearful and anxious about the possible repercussions that disclosure of their status might have upon family members, especially children. This can be illustrated by quotes from open questions in the questionnaire:

*”It was very difficult to find out about the diagnosis; my partner left me. I became withdrawn, afraid of the reactions of people around me, it seemed that everyone knew about it. I started searching for information wherever possible. After having read it, I realized that life goes on. I am trying to help others to accept this.”*  
(29-year-old man)

*”Maybe it means a lot that I live in a small town; I constantly fear for my family. Especially since the talk about my sexual orientation has subsided just recently.”*  
(38-year-old woman)

*”I'm afraid that my children will not have friends. It is because of them that I am hiding from everyone that I am positive. My husband is also hiding this.”*  
(28-year-old woman)

*”I fear for my children, that they will be rejected because of my illness.”*  
(42-year-old man)

**Do you agree with the following statements about your experience of revealing your HIV status? (%)**

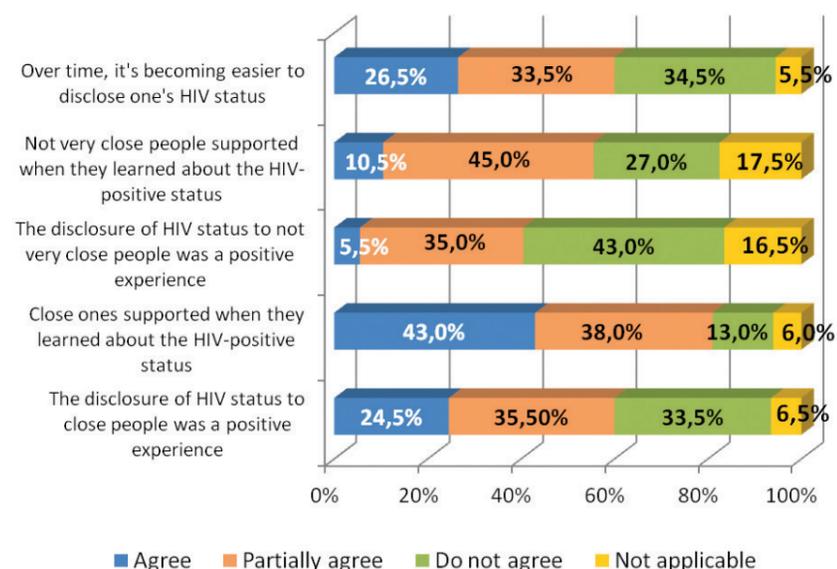


Chart 6. Patients revealing their HIV+ status (% , n = 200).

## EXTERNAL STIGMA

External stigma and discrimination in the past 12 months was most commonly experienced in the following ways:

- Being aware of non-family members making discriminatory remarks or gossiping behind the respondent's back - 13% (n = 12);
- Being harassed verbally because of the HIV status - 8% (n = 16);
- Being aware of family members making discriminatory remarks about the HIV status - 5.5% (n = 11).

Earlier than in the past 12 months, most commonly occurring external stigma was:

- Being aware of non-family members making discriminatory remarks or gossiping behind the respondent's back - 27.5% (n = 55);
- Being aware of family members making discriminatory remarks about the HIV status - 16.5% (n = 33).
- The wife/husband or partner experienced discrimination from others because of the respondent's HIV status - 12% (n = 24);

**Experience of stigma and discrimination (%)**

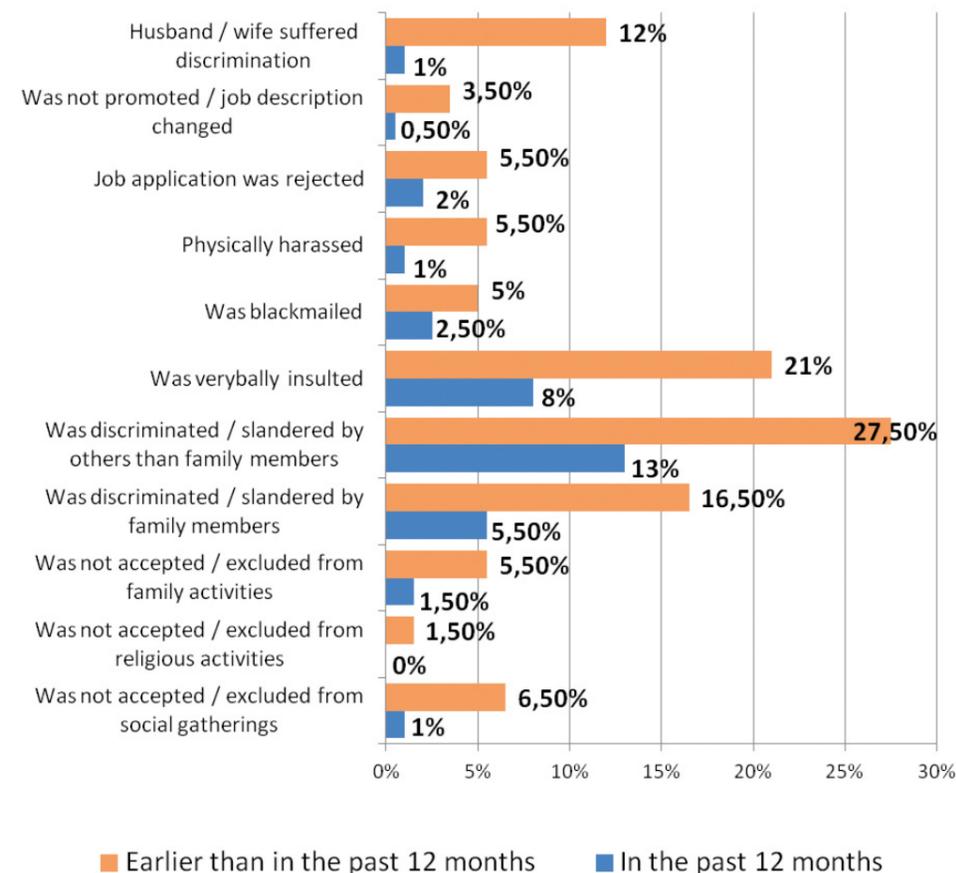


Chart 7. Stigma and discrimination experienced in the past 12 months and earlier than in the past 12 months due to the HIV+ status (% , n = 200)

## INTERNAL STIGMA

The respondents thought that the HIV+ status had the greatest negative impact on the ability to find love - 40.5% (n = 81), on self-confidence - 40% (n = 80), on the ability to maintain close and secure relationships - 33.5%. (n = 67), and on the ability to cope with stress - 32.5 (n = 65). See Chart 8.

**Impact of HIV status on the possibility of satisfying one's needs during the past 12 months (%)**

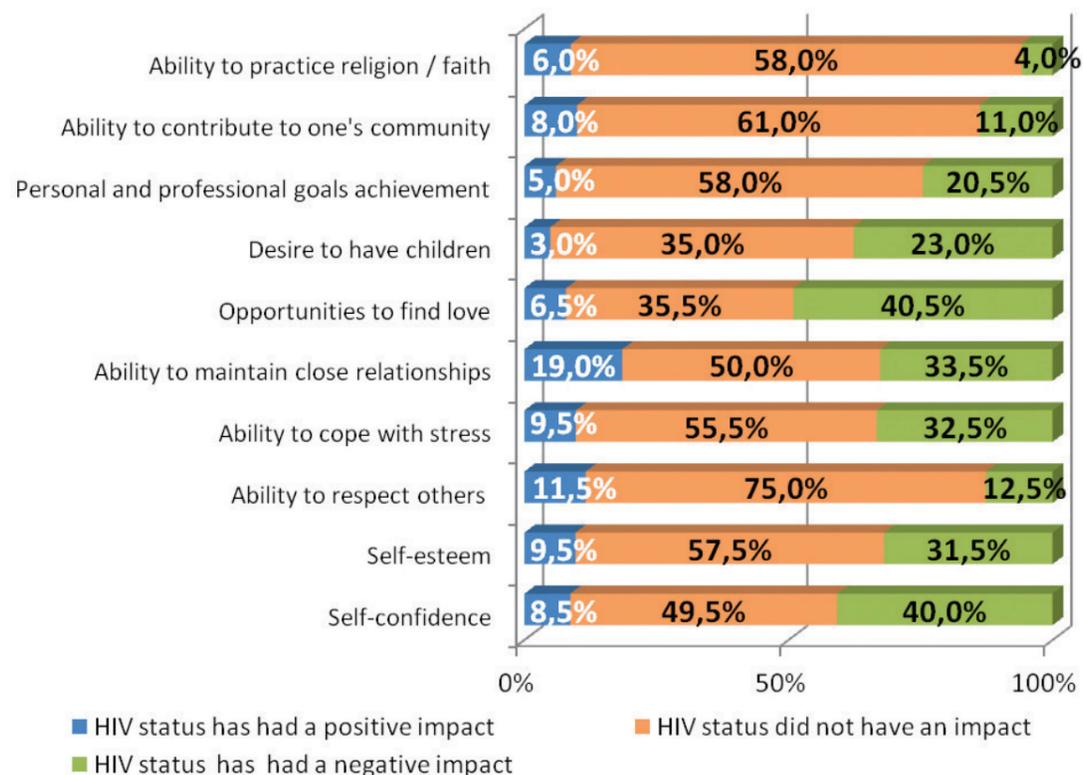


Chart 8. The impact of the HIV+ status in the last 12 months on the ability to satisfy one's needs (%; n = 200).

Every second respondent indicated that, in the past 12 months, HIV status did not have an impact on their possibilities (52%, n = 104). The same number of respondents indicated that it had a positive impact (21%, n = 42) and had a negative impact (21%, n = 42).

In the past 12 months, every fifth respondent (19.5%, n = 39) decided not to have sex due to their HIV status. Almost one in seven respondents (14%, n = 28) decided to separate themselves from the family and every eighth (12.5%, n = 25) decided not to apply for employment. See Chart 9.

**Rejection of action and/or opportunities because of the HIV-positive status in the past 12 months**

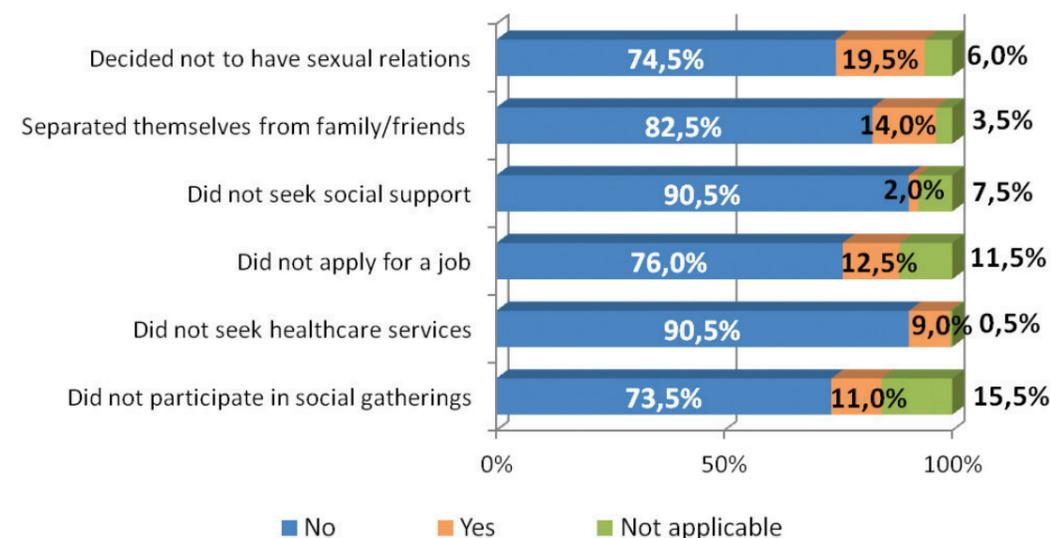


Chart 9. Restriction of one's activities over the past 12 months due to the HIV+ status (%; n = 200)

When answering an open question, one respondent described his experience with internal stigma and the desire to find close ties and love:

*”I already had information about this disease because my uncle had it. However, it was still difficult to get used to it. There was fear to start a new relationship because I felt that I could be rejected. I found a female friend (who was also positive) and it is easier to live together.”*

(40-year-old man)

Respondents experienced the following because of the HIV+ status:

- As many as 90% (n = 162) of respondents indicated that it is very difficult for them to tell others about their HIV infection;
- 77.5% (n = 154) stated that they are hiding their HIV+ status from others;
- 57.5% (n = 115) noted that they felt worthless because of their HIV+ status;
- 55% (n = 110) felt ashamed because of their HIV+ status;
- Every second respondent indicated that they felt guilty because of their HIV+ status (53%, n = 107);
- Every second respondent felt "dirty" because of their HIV+ status (51%, n = 102).

See Chart 10.

**Because of the HIV-positive status experience the following states (%)**

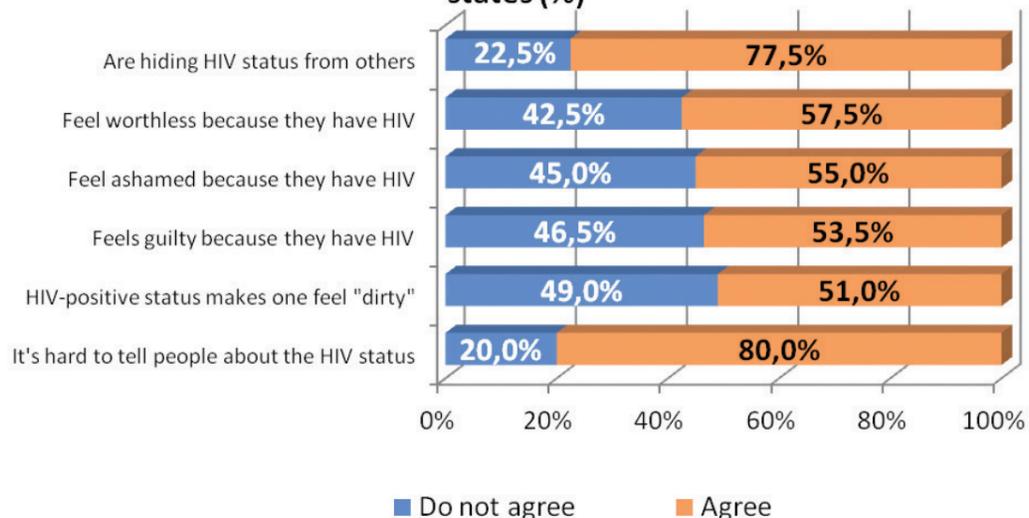


Chart 10. States experienced because of the HIV+ status (% n = 200)

In an open question, one respondent said that because of his HIV status he finds it hard to fit not only into society, but also into the groups of HIV positive people. The main reason for this is the lack of specialized groups, for example, groups for homosexuals. There are very few groups even for the largest segment of PLHIV – persons who got infected through injecting drug use.

” I have had negative experience both because of my sexuality and because of the HIV+ status. It was especially unpleasant to experience that from the community (both communities) and doctors (not the ones treating HIV). I tried to join the community of HIV+ people, but I felt isolated there because of my sexuality. I do not fit anywhere, I do not feel that I belong. I felt especially bad at the office of the National Health Insurance Fund -- every year (since I am not officially employed), I have to submit a form about my HIV status. Who needs it if there is NO CURE for this disease? To humiliate and laugh at us?! “

(37-year-old man)

## EXPERIENCE IN SEEKING HEALTHCARE SERVICES

### REASONS FOR TAKING AN HIV TEST

47% (n = 94) indicated that the decision to get tested for HIV was voluntary. 38.5 % (n = 77) were tested without their knowledge of it and found out only after the test had been done.

Every fourth respondent made a decision to get tested 6 months or more since the moment they first thought that they should do it (see Chart 11).

**Time that has passed since thinking about getting tested for HIV and getting tested for the first time (%)**

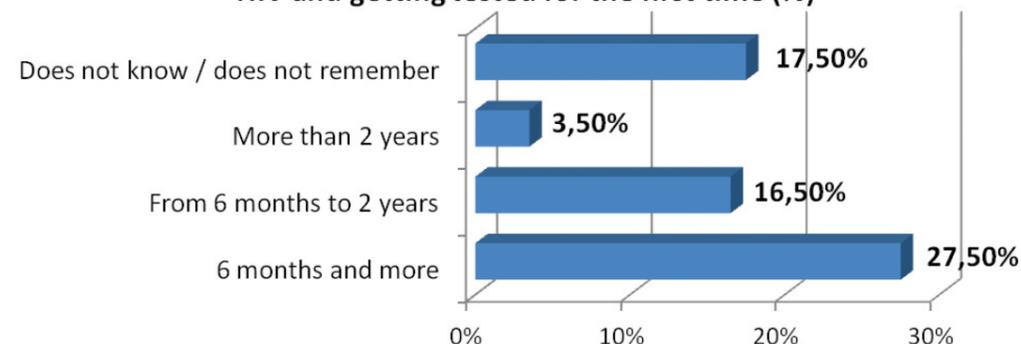


Chart 11. The time that has passed since the thought about getting tested for HIV and the moment it was done (% n = 200)

### REASONS FOR GETTING TESTED

26% (n = 52) stated that they got tested for HIV because they believed that they had been at risk of HIV, 10.5% (n = 21) simply wanted to know and 12% (n = 24) noted that there was another reason (came across a free rapid HIV testing street campaign, suspected that the partner has HIV, etc.).

25.5% (n = 51) indicated anxiety about the reactions of other people, which made them doubt whether to get tested for HIV.

Every second respondent indicated that he or she was not ready to deal with his or her HIV problems and was afraid that a partner, family, or friends would learn about their HIV+ status.

38.5% (n = 77) felt afraid that healthcare personnel would behave improperly or reveal their HIV+ status without their consent.

**Reasons for postponing HIV test (%)**

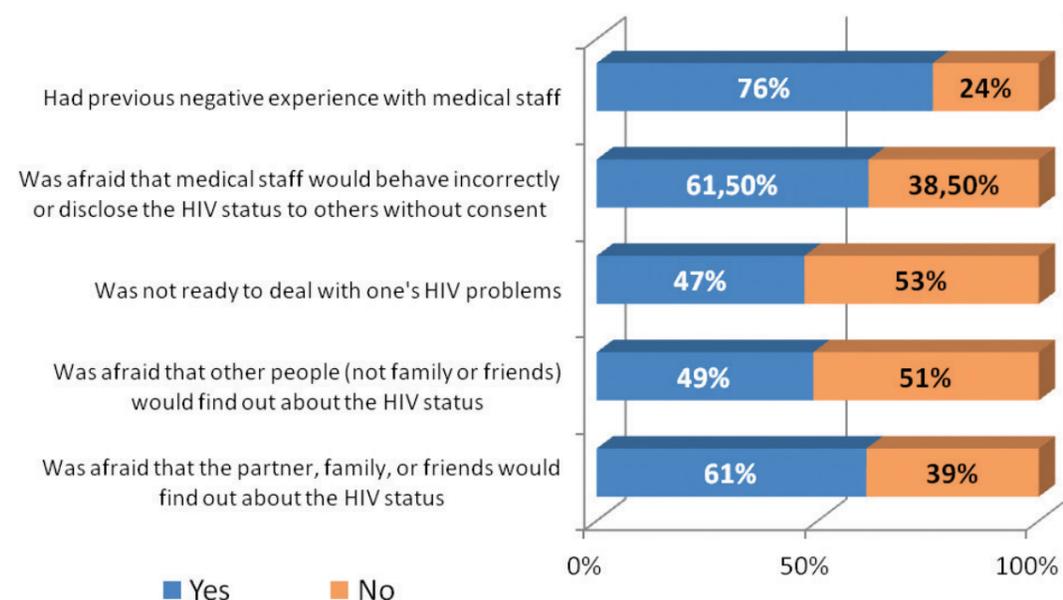


Chart 12. Reasons for postponing HIV testing (n = 200)

## PERIOD OF TIME AFTER WHICH ART WAS STARTED

Nearly half of all participants in the study (46%, n = 92) indicated that they started HIV treatment more than two years after the date of the diagnosis (see Chart 13).

Every second respondent (50.5%, n = 101) indicated that they decided to undergo antiretroviral therapy as soon as the doctor indicated the benefits of the treatment and as soon as the treatment was offered. 7.5% (n = 15) decided to postpone the treatment after they had been offered it and started treatment later. 2% (n = 4) indicated that they started treatment because of the pressure from the healthcare staff. 12% (n = 24) indicated another reason that was not specified.

The respondents who had not yet started treatment (n = 63) indicated the following reasons:

- Treatment was not offered because the number of CD4 cells was too high - (n = 28);
- They were not ready to deal with their HIV infection - (n = 8);
- They did not feel that treatment was needed - (n = 5);
- They worried that somebody would find out about their HIV+ status - (n = 3);
- They did not tolerate side effects of the medication or were worried about taking the pills - (n = 1);
- Medication was not available at the clinic / care institution - (n = 1);
- Another reason - (n = 17).

**Period after which the HIV treatment (ART) was started(%)**

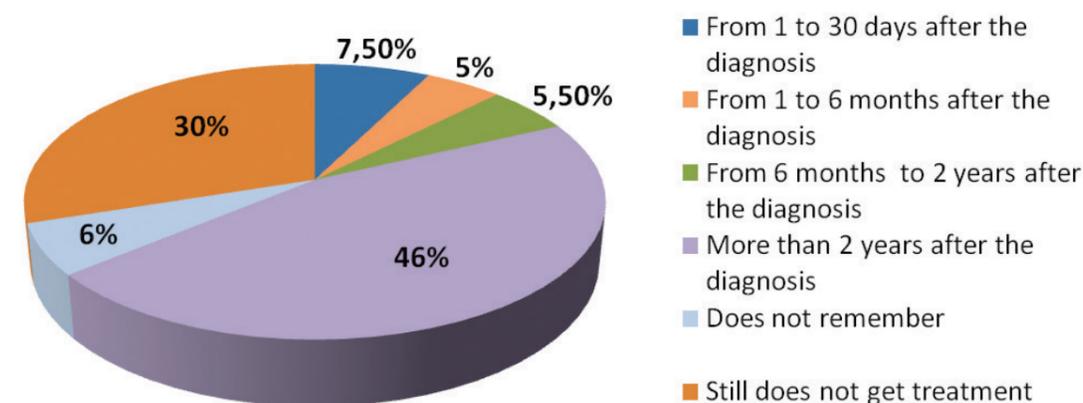


Chart 13. After what period of time since HIV was diagnosed did you start HIV (antiretroviral therapy) treatment? (n = 200).

In the past 12 months the virus was undetectable or the viral load was very low for 48.5% of respondents (n = 97). Other respondents indicated that they:

- Did not have a viral load test in the last 12 months - 5.5% (n = 11);
- Had a viral load test and still waiting for the results - 5.5% (n = 11);
- Virus was detectable / not virally suppressed - 14% (n = 28);
- Do not know what the viral load or viral suppression is - 23.5%. (n = 47).

## HEALTH STATUS AND ISSUES

Respondents were asked how they would describe their current state of health – as poor, fair, or good:

- 49% of respondents (n=98) evaluated his or her health at the time of the study as fair.
- 40.5% (n=81) evaluated their current health as good.
- 10% (n=20) evaluated their current health as poor (more men (11%, n = 15) than women (8%, n = 5)<sup>15</sup>.

In the past 12 months, 13.5% (n = 27) of respondents were diagnosed with hepatitis. 6% of all respondents (n = 12) were diagnosed with tuberculosis. 13.5% (n = 27) of the respondents received treatment for these two conditions. For more details see Chart 14.

**In the past 12 months was diagnosed with (%)**

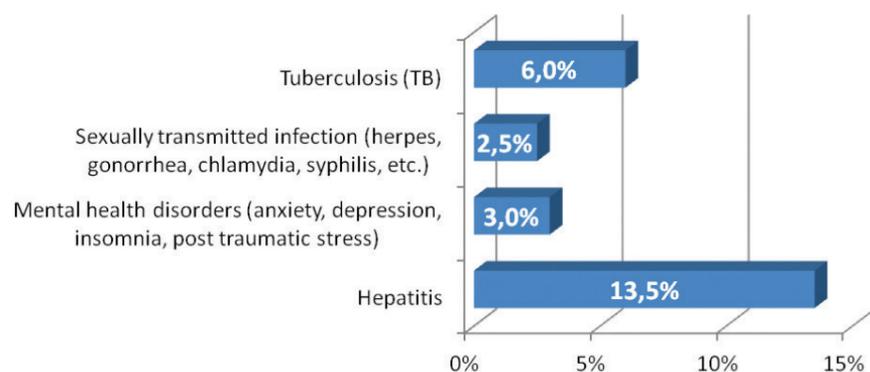


Chart 14. In the past 12 months diagnosed diseases / disorders (%), n = 200.

## PROBLEMS RELATED TO MENTAL HEALTH

Respondents were also asked about how they had felt in the last two weeks in relation to anxiety, nervousness, tension, a lack of interest or pleasure in doing things, or whether they felt 'down', depressed, or hopeless.

Frequency is presented in Chart 15 below. Only 12% (n = 24) of respondents received help for these problems.

**Problems that were bothering in the past 2 weeks (%)**

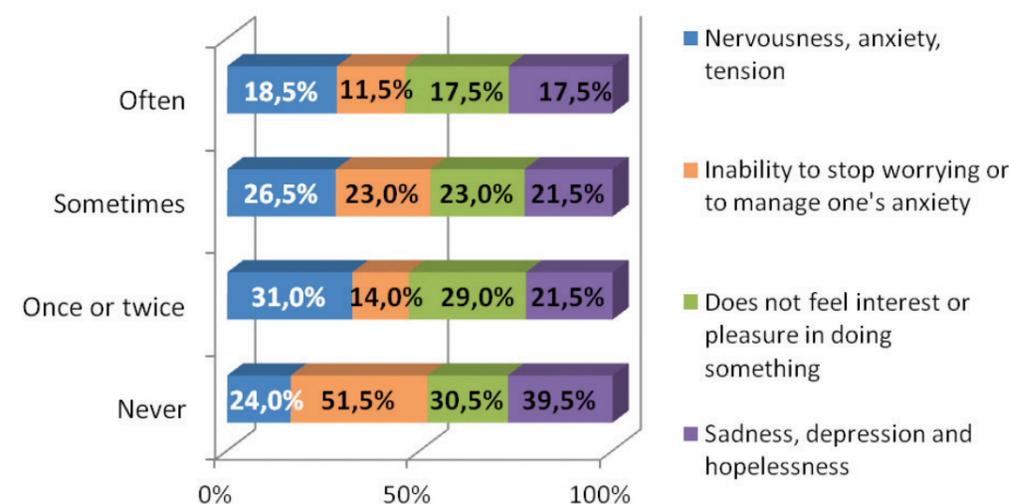


Chart 15. Problems that have been disturbing the respondents during the past two weeks, and their frequency (%), n = 200.

## EXPERIENCE IN HEALTHCARE FACILITIES

80% (n = 160) indicated that HIV-related care and treatment was generally received in state or public healthcare facilities. 5% (n = 10) of the respondents received help in community-based institutions or organizations (such as low-threshold centers), in the non-governmental clinic or organization - 1.5% (n = 3), in several places - 1.5% (n = 3). 11.5% (n = 23) did not ask for help anywhere.

In the past 12 months, the healthcare personnel providing HIV treatment and care most often behaved improperly in the following way:

- Avoided physical contact or took extra precautions (such as wearing double gloves, etc.) 15% (n = 30);
- Told other people about the HIV+ status without the respondent's consent - 8.5% (n = 17);
- Advised not to have sex because of the HIV+ status - 6% (n = 12);
- Talked badly about or gossiped about the respondent because of his or her HIV+ status - 5.5% (n = 11);
- Refused to provide healthcare services because of the HIV+ status - 4% (n = 8);
- Abused verbally (yelled, scolded, name called, etc.) because of the respondent's HIV+ status - 2% (n = 4).

<sup>15</sup> Differences between men and women are statistically significant - p < 0.001. The statistical significance of the data was calculated on the basis of the chi-square ( $\chi^2$ ), the p-value of the test criterion according to Pearson Chi-Square.

76% (n = 152) did not know whether their medical records in the establishments where they are provided with HIV-related treatment and care were kept confidentially.

In the past 12 months, 46.5% (n = 93) sought healthcare services not related to HIV, such as flu, dental care, vaccines, etc. Healthcare workers who were contacted for non-HIV related health services treated the respondents in the following way:

- Avoided physical contact or used extra precautions (such as wearing double-gloves, etc.) - 18% (n = 36);
- Told other people about the respondent's HIV+ status without consent - 10% (n = 20);
- Talked badly about or gossiped about the respondent because of his or her HIV+ status - 7.5% (n = 15);
- Refused to provide dental care because of the HIV+ status - 6% (n = 12);
- Advised not to have sex because of the HIV+ status - 5.5% (n = 11);
- Abused verbally (yelled, scolded, etc.) because of their HIV+ status - 4% (n = 8).
- Refused to provide health services because of the respondent's HIV+ status - 3.5% (n = 7);

The respondents who had negative experiences in the HIV treatment facilities or in other (non-HIV treatment) facilities, remembered these experiences as very unpleasant and stigmatizing. Respondents' quotes from answers to the open questions of the questionnaire illustrate this:

**NOTE. When answering open questions, respondents did not indicate the period during which the experiences that they mention took place. It is therefore not clear whether this experience has been in the past 12 months or earlier.**

*”I experienced great stress in the maternity hospital, because its staff was constantly scaring me that the child would be crippled, abnormal, ill.”*

(29-year-old woman)

*”I have met a doctor who was afraid to touch me when I needed first aid, and I was suffering in pain. I did not get help from him. Another doctor had written on my medical card my HIV status [...], then all the reception staff was staring at me.”*

(37-year-old woman)

*”When I brought a referral from an infectologist to my district clinic to receive state compensated medicines for AIDS, the family physician refused to prescribe them -- she ordered me to go to Kaunas. One month later, when I came to the reception desk because I felt sick, the employee asked me loudly whether I wanted to go to a doctor because of AIDS. And I also saw that, on my health card, it was written in big fat red letters “AIDS.” I felt like I was a leper and that I could hurt others just by coming to the clinic. I am glad that doctors, nurses, and receptionists in Kaunas do not do this.”*

(38-year-old man)

*”I have a disability (not caused by HIV), I cannot move or walk after a trauma. When I have to be admitted in a hospital (due to various problems), doctors do not regard me as a human being. For example, they send various people to help me without my consent. Like you, as a representative of a non-government organization. I find it humiliating. I am a human being and I want to decide for myself what I want or do not want.”*

(38-year-old man)

30.5% (n = 61) of the respondents reported their HIV+ status when they went to a non-HIV treatment facility for general (non-HIV) treatment services.

76% (n = 152) did not know if their medical records were kept confidentially in the healthcare facilities not related to the treatment of HIV. 5% (n = 10) were confident that their medical records were kept confidentially. 19% (n = 38) believed that their medical records were not kept confidentially.

## SEXUAL AND REPRODUCTIVE HEALTH

On the issues of sexual and reproductive health, respondents experienced the following from healthcare professionals:

- Advice not to have children - 10.5% (n = 21);
- Suggestion to use a specific method of contraception in order to get HIV treatment (antiretroviral therapy) - 2.5% (n = 5).

Women most often experienced the following from healthcare specialists:

- Were pressured to take antiretroviral treatment during pregnancy to reduce the chance of HIV transmission to the baby rather than counseling on this as an option - 11.6% (n = 7);
- Were pressured to use a specific type of contraceptive method rather than counseling on a range of available options - 10% (n = 5);
- Were pressured to use a particular method of giving birth - 8% (n = 5);
- Were pressured to use a particular infant feeding practice - 6.6% (n = 4);
- Were advised to terminate pregnancy - 5% (n = 3).

## HUMAN RIGHTS AND EFFECTING CHANGE

### VIOLATIONS OF HUMAN RIGHTS

The most common violations, involving forced HIV testing or the disclosure of the HIV+ status without consent were reported by those respondents who had an experience of detention or isolation prior the past 12 months - 6% (n = 12). For more details see Chart 16.

**Were forced to take an HIV test or the HIV status was disclosed for the following reasons (%)**

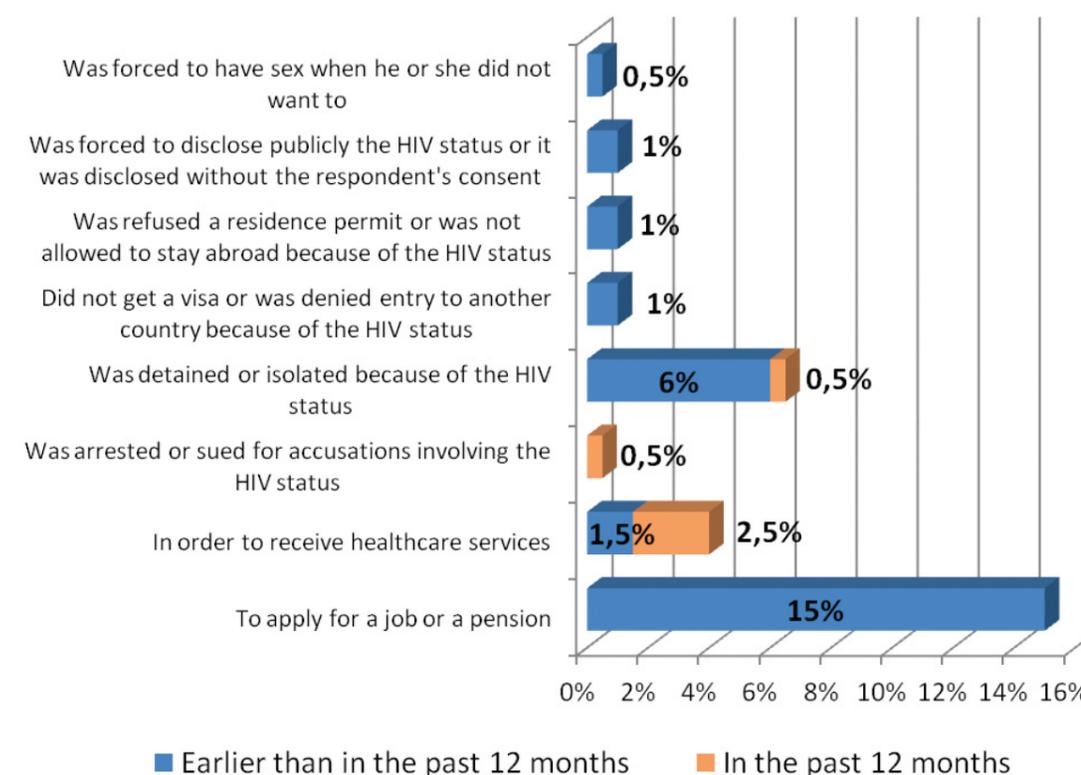


Chart 16. Causes associated with the pressure to reveal one's HIV+ status or to take an HIV test (n = 200).

## ACTIONS RELATED TO HUMAN RIGHTS VIOLATIONS

It must be noted that as many as 83% (n = 165) of the respondents were not aware of actionable laws or regulations that protect PLHIV from discrimination. See Chart 17.

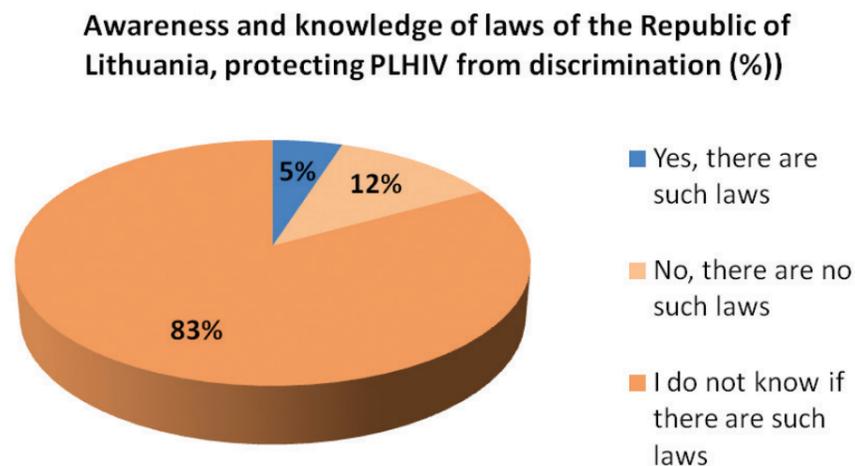


Chart 17. Awareness and knowledge of Lithuanian laws that protect the rights of PLHIV and protect against discrimination (%; n = 200).

Of the remaining 12 people (n = 6%) who reported that their rights related to HIV testing and/or disclosure of their HIV+ status had been violated, one person tried to take action (write a complaint, talk to a lawyer, etc.).

Those whose rights were violated and they did not seek help (n = 12) pointed out the following reasons as to why they did not seek help or did not take specific actions:

- Felt intimidated or scared to take action - 67%<sup>16</sup> (n = 8);
- Did not know where to go/how to take action - 58% (n = 7);
- No/ little confidence that the outcome would be successful - 58% (n = 7);
- Were worried taking action might lead people to learn about their HIV status - 58% (n = 7);
- Lack of evidence for the abuse - 50% (n = 6);
- Advised against taking action by someone else - 33% (n = 4);
- Insufficient financial resources to take action - 25% (n = 3);
- Process of addressing the problem appeared too complicated - 8% (n = 1).

<sup>16</sup> The percentage is calculated for the respondents who have answered that their rights had been violated (n = 12).

In the open questions, the respondents indicated the lack of information and a belief that nothing would change even if they asked for help or informed about the violations of their rights as one of the main reasons for not seeking help when they believed their rights had been violated:

” I simply did not know that there are such laws that protect PLHIV from discrimination, and there had been periods in prison when the medical treatment there was worse than it had been in Alytus. [...] It’s scary that nobody tells you what laws there are ...”

(45-year-old man)

” I was a victim of bullying by prison guards, but I did not report it because I would not have achieved anything.”

(29-year-old man)

Despite of the low awareness of rights, respondents indicated that in the past 12 months they:

- Encouraged a community leader to take action about issues of stigma and discrimination against PLHIV - 28%. (n = 56);
- Participated in an organization or educational campaign working to address stigma and discrimination against PLHIV - 27% (n = 53);
- Challenged or educated someone who was engaging in stigma or discrimination against other people living with HIV - 13% (n = 26);
- Provided emotional, financial or other support to help someone living with HIV deal with stigma and/or discrimination - 13% (n = 26).

The respondents indicated that they had taken the following actions earlier than in the past 12 months:

- Challenged or educated someone who was engaging in stigma or discrimination against other people living with HIV - 37% (n = 74);
- Provided emotional, financial or other support to help someone living with HIV deal with stigma and/or discrimination - 30% (n = 59);
- Challenged or educated someone who was engaging stigma or discrimination against himself - 27% (n = 54).

For more detailed information see Chart 18.

**Actions taken. Did you: (number of cases)**

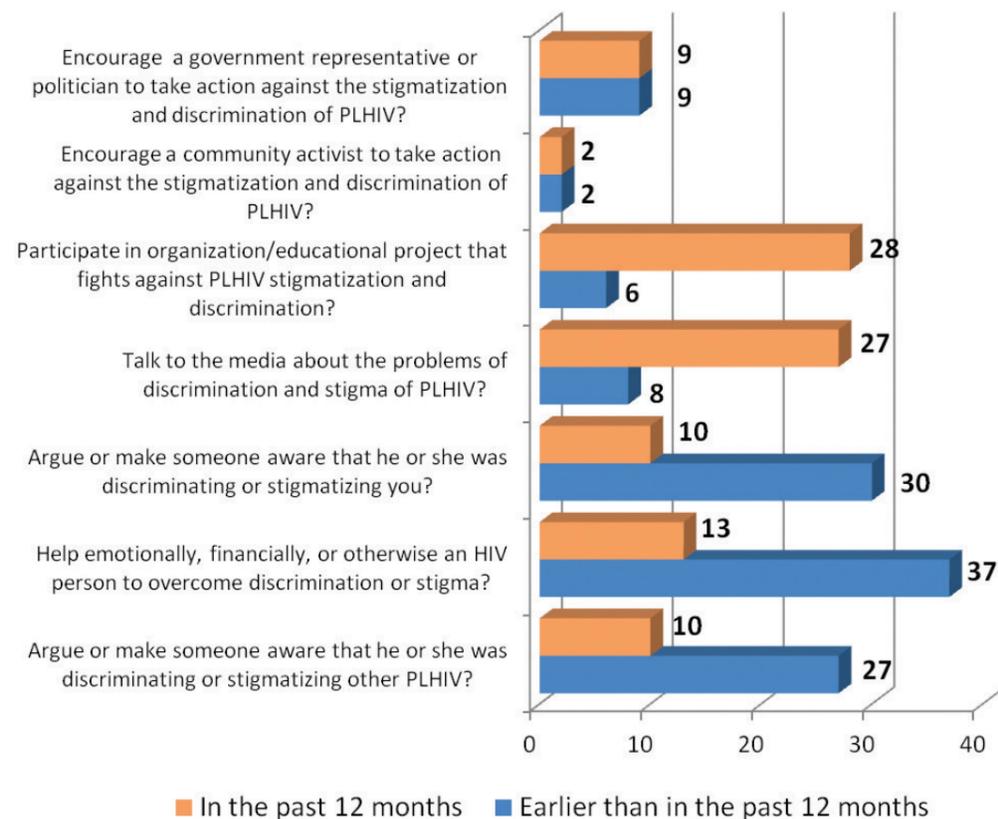


Chart 18. Actions taken to protect their rights or the rights of individuals having an HIV+ status (n = 200).

## EXPERIENCE OF STIGMA AND DISCRIMINATION THAT IS NOT RELATED TO HIV

### MEN WHO HAVE SEX WITH MEN

4.5 % (n = 9) of respondents indicated that they had had sex with men. They indicated that during the past 12 months:

- They felt afraid to seek health services because they worried that someone may learn they are an MSM/have sex with men (n = 1).
- Were verbally harassed for being MSM/having sex with men (n = 1).
- Experienced physical harassment or were hurt because they had sex with men (n = 1).

Earlier than in the past 12 months male respondents (n = 9) who have had sex with partners of the same sex indicated that they:

- Felt family members have made discriminatory remarks or gossiped about them (n = 4).
- Were verbally harassed because they are MSM/had sex with men (n = 4).
- Felt afraid to seek health services because they were worried that someone may learn they are MSM/had sex with men (n = 2).
- Felt excluded from family activities because they are MSM/had sex with men (n = 2).
- Were blackmailed because they are MSM/had sex with men (n = 1).
- Were physically harassed or hurt because they are MSM/had sex with men (n = 1).

### GAYS/HOMOSEXUALS

2 respondents indicated their identity as gay/homosexual. In the opinion of these respondents (n = 2), they were afraid to seek healthcare services in the past 12 months because they were concerned that others would learn that they were homosexual (n = 1).

Earlier than in the past 12 months these respondents (n = 2) indicated that they:

- Felt excluded from family activities because they are gay/homosexual (n = 2).
- Felt family members have made discriminatory remarks or gossiped about them because they are gay/homosexual (n = 2).
- Were verbally harassed because they are gay/homosexual (n = 2).
- Felt afraid to seek health services because they were worried that someone may learn they are gay/homosexual (n = 1).

## WOMEN WHO HAVE SEX WITH WOMEN

There were 4 respondents who indicated that they had had sex with other women. In the past 12 months, none of them had any incidents because they had sex with women. Earlier than in the past 12 months, the respondents who had sex with women indicated that:

- Family members have made discriminatory remarks or gossiped about them because they had sex with women (n = 2).
- Felt excluded from family activities because they had sex with women (n = 1).

## BISEXUAL PEOPLE

3% (n = 6) indicated that they were bisexual. Bisexual persons (n = 6) indicated that over the past 12 months they were:

- Verbally harassed, because they are bisexual (n = 2).
- Physically harassed or hurt because they are bisexual (n = 1).

Bisexual persons (n = 6) stated that earlier than in the past 12 months they:

- Were verbally harassed because they are bisexual (n = 6).
- Family members have made discriminatory remarks or gossiped about them because they are bisexual (n = 2).
- Were afraid to seek health services because they worried that someone may learn they are bisexual (n = 2).
- Avoided seeking health services because they were worried that someone may learn that they are bisexual (n = 2).
- Were blackmailed because they are bisexual (n = 1).
- Were physically harassed or hurt because they are bisexual (n = 1).

## SEX WORK OR SELLING SEX

6% (n = 12) said they had provided sex services or sold sex. Out of these, 1 respondent identified him/herself as a sex worker. Respondents who were sex workers or sold sex (n = 12) indicated that over the past 12 months they were:

- Verbally harassed because they were sex workers or sell (sold) sex (n = 1).
- Physically harassed or hurt because they were sex workers or sell (sold) sex (n = 1).

People who were selling or sold sex (n = 12) indicated that earlier than in the past 12 months they:

- Were verbally harassed because they were sex workers or sell (sold) sex (n = 3).
- Felt family members have made discriminatory remarks or gossiped about them because they were sex workers or sell (sold) sex (n = 2).
- Felt afraid to seek health services because they worried someone may learn that they were sex workers or sell (sold) sex (n = 2);
- Avoided seeking health services because they were worried that someone may learn that they were sex workers or sell (sold) sex (n = 2);
- Were blackmailed because they were sex workers or sell (sold) sex (n = 2);
- Were physically harassed or hurt because they were sex workers or sell (sold) sex (n = 1).

## USE OF ILLEGAL PSYCHOACTIVE SUBSTANCES

Every second respondent in the study (53.5% (n = 107)) indicated that they regularly used drugs (such as heroin, cocaine, or methamphetamine) by injecting or in other ways, 47.5% (n = 95) identified themselves as drug users or former drug users. Respondents who injected or otherwise used illicit psychoactive substances (n = 107) indicated that over the past 12 months they:

- Felt excluded from family activities because they use(d) drugs - 11% (n = 12);
- Felt that family members have made discriminatory remarks or gossiped about them because they use(d) drugs - 11% (n = 12);
- Avoided seeking health services because they were worried that someone may learn that they use(d) drugs - 11% (n = 12);
- Were verbally harassed because they are/were using drugs - 9% (n = 10);
- Were afraid to seek health services because they were worried that someone may learn that they use(d) drugs - 8% (n = 9);
- Were blackmailed because they use(d) drugs - 4% (n = 4);
- Were physically harassed because they use(d) drugs - 4% (n = 4).

Earlier than in the past 12 months drug users (n = 107) indicated that they:

- Felt excluded from family activities because they use(d) drugs - 61% (n = 65);

- Felt that family members have made discriminatory remarks or gossiped about them because they use(d) drugs - 54% (n = 58);
- Were verbally harassed because they use(d) drugs - 37% (n = 40);
- Were afraid to seek health services because they were worried that someone may learn that they use(d) drugs - 24% (n = 26);
- Avoided seeking health services because they were worried that someone may learn that they use(d) drugs - 19% (n = 20);
- Were physically harassed because they use(d) drugs - 11% (n = 12).
- Were blackmailed because they use(d) drugs - 6% (n = 3);

It is important to note that when comparing the negative experience of the respondents who indicated that they are/were using narcotic substances during the past 12 months and earlier than in the past 12 months, a statistically significant<sup>17</sup> decline in negative experience has been observed recently.

## CONCLUSIONS

**1.** The results of the research show that internal stigma among PLHIV in Lithuania was manifested in their fear of revealing to others their HIV+ status (90%, n = 162). Nearly every second respondent (57.5%, n = 115) noted that their HIV+ status made them feel worthless and 55% (n = 110) felt ashamed. Moreover, every second respondent indicated that their HIV+ status made them: feel guilty - 53% (n = 107) and feel "dirty" - 51% (n = 102). The HIV+ status had the greatest negative impact on the ability to find love - 40.5% (n = 81), on self confidence - 40% (n = 80), on the ability to maintain close and secure relationships - 33.5% (n = 67) and on the ability to cope with stress - 32.5% (n = 65). Every fifth respondent decided not to have sex because of their HIV+ status in the past 12 months (19.5%, n = 39). Almost every seventh respondent (14% n = 28) decided to separate themselves from the family, and every eighth respondent (12.5%, n = 25) decided not to apply for a job.

**2.** PLHIV in Lithuania are not active members in self-support or other groups (for example, groups that seek to reduce discrimination, etc.). Only 29.5% (n = 59) were members of a network of PLHIV or a support group. One of the main reasons for such a low participation in the activity of these groups was the small number of such groups in Lithuania. The existing groups are short-lived or fragmented and they have not found ways to sufficiently publicize activities. It can be assumed that the groups are scarce because people living with HIV have not found ways to develop necessary skills to set up such groups and achieve sustainability, and those who do have such skills and knowledge tend to avoid identifying themselves with a certain group of people.

**3.** The answers to the open questions have shown that some cases of healthcare professionals avoiding to give full information to PLHIV or using unnecessary excessive protection measures against HIV still exist (or have recently existed). This finding suggests a need for refresher training and guidance for healthcare providers on HIV issues.

**4.** The respondents of the survey were largely unaware of the existing laws protecting their rights, i.e., 82% (n = 165) did not know whether there are laws that protect PLHIV against discrimination.

**5.** More than half of the respondents received antiretroviral HIV treatment - 68% (n = 136). Almost half of all the participants in the study (46%, n = 92) indicated that they started the treatment more than two years after the diagnosis. 80% (n = 160)

<sup>17</sup> The difference between the past 12 months and the period earlier than 12 months is statistically significant -  $p < 0.001$ . The statistical significance of the data was calculated on the basis of the chi-square ( $\chi^2$ ), the p-value of the test criterion according to Pearson Chi-Square.

indicated that HIV-related care and treatment was most often received in state or public healthcare facilities. It is also important to note that 23.5% (n = 47) of the respondents do not know what virus load or virus concentration means.

**6.** The portrait of the "typical" HIV+ respondent in Lithuania is a man of working age (30-49 years old) having a secondary or vocational education (70%), and having prison experience (42%, n = 84). Data by sex and age show that only one age group, 18-29 year-olds, had more women than men. All other age groups were dominated by men. Most respondents were unemployed or engaged in random jobs. Every third lived in a household with children. Every second respondent (53.5%, n = 107) indicated that they were injecting or otherwise regularly using illicit drugs (heroin, cocaine, methamphetamine, etc.). Of all the respondents only 2% (n = 4) stated that they belonged to the group of men who have sex with men. 1% (n = 2) identified as gay/homosexual, 4% (n = 8) as bisexual and 12 respondents indicated that they had had sex for money (6%).

**7.** In Lithuania, HIV positive respondents are most likely to experience verbal harassment or be gossiped about because of their HIV+ status by non-family members (40.5%). Every fifth experiences discriminatory remarks from their family members.

**8.** Every second respondent indicated that in the past 12 months, his/her possibilities (social, work, etc.) remained the same because of their HIV+ status (52%, n = 104), i.e. they neither deteriorated nor improved. Possibilities deteriorated and improved for every fifth HIV+ person, which indicates that the positive HIV status does not have significant impact on the possibilities, but there are still cases when the possibilities deteriorate because for HIV.

**9.** About two-thirds of the respondents (67%, n = 134) reported that their HIV status is known to their friends, other family members (61%, n = 122) and a spouse or a partner (57.5%, n = 115). However, only one in two more or less agreed that disclosing their HIV+ status to close people was a positive experience. 81% pointed out that after learning about their HIV+ status, their relatives showed support. Every second respondent indicated that they were supported by strangers. Almost every other person agreed that, over time, it becomes easier to reveal the HIV status. Without the respondent's consent, information about their HIV status was most often disclosed to their friends - 3% (n = 6). The total number of respondents who stated that their HIV status was disclosed without their consent was n = 10.

**10.** In the opinion of every seventh participant, they most often received the following negative reactions from healthcare staff: 15% (n = 30) indicated that the staff avoided physical contact or used unnecessary additional protection measures (for example, wearing double gloves, etc.), 8.5% (n = 17) stated that information about their HIV+ status was provided to other people without their consent. 76% (n = 152) did not know if their medical records were kept confidential.

**11.** Every ninth female respondent indicated that she was forced to be treated with antiretroviral therapy during pregnancy - 3.5% (n = 7). Every tenth was pressured to use a specific method of contraception - 3% (n = 6).

**12.** Out of all the possible human rights violations listed, detention or isolation (being quarantined) related to HIV+ status was mentioned most often (but prior to the past 12 months) - 6% (n = 12).

**13.** In the group of men who have sex with men (n = 9), one respondent indicated that he had experienced harassment, blackmail, and was physically hurt in the past 12 months because he was an MSM. Earlier than in the past 12 months, respondents who had sex with men more often than other groups suffered harassment from other individuals and from family members.

**14.** Gay/homosexual persons (n = 2) were afraid to seek help from a healthcare facility in the past 12 months because their homosexuality could be disclosed. Earlier than in the past 12 months there were more negative experiences and fears in this group (experienced verbal harassment from others, discriminatory remarks, or were gossiped about by family members, felt excluded from family affairs).

**15.** Women who have sex with women (n = 4) indicated that they did not experience negative attitudes in the past 12 months. Earlier than in the past 12 months, they felt excluded from family affairs and experienced discriminating remarks from family members.

**16.** Bisexual persons (n = 6) most often experienced verbal and physical harassment from others in the past 12 months. Earlier than in the past 12 months, there were more negative experiences due to their bisexuality, i.e., the respondents were afraid and did not seek help from healthcare institutions, felt excluded and insulted by family members, felt blackmailed and suffered physical harassment.

**17.** Sex workers or persons selling sex (n = 12) experienced harassment and were physically hurt by other people over the last 12 months. Earlier than in the past 12

months, there were more negative experiences: they were discriminated against by family members, feared and avoided seeking help in healthcare facilities, were blackmailed and physically hurt.

**18.** Respondents who indicated that they had used drugs mostly experienced exclusion and discriminatory remarks by family members, avoided seeking help in healthcare facilities, and suffered from verbal harassment during the past 12 months. There is a statistically significant decline in the occurrence of negative experiences by drug using respondents during the past 12 months as compared to earlier than in the past 12 months.

**19.** The respondents who have encountered negative experiences in HIV treatment facilities, remember this as very unpleasant. The occurrence of negative experiences in healthcare facilities (where respondents feel that they are not understood or do not feel that they are given the services they should receive because they are infected with HIV) might be related to the fact that healthcare professionals lack information about the peculiarities and basic principles of communication with vulnerable groups.

## RECOMMENDATIONS

The following recommendations on the reduction of HIV stigma and discrimination in Lithuania are based on the results of this study:

### 1. For Public Institutions, National HIV/AIDS Program or Action Plan:

- Based on the other countries' best practice (e.g. WHO recommended Linkage to HIV Care System<sup>18</sup>), develop a system which ensures a prompt and sustainable services that meet the needs of PLHIV. The system should include both early diagnosis of HIV, provision of treatment and care, and addressing other related problems.
- People living with HIV and those most vulnerable to HIV often experience and take actions because of internalized stigma. Often this internalized stigma is a result of negative public attitudes toward a sub group that they belong to (such as being MSM) as well as actual experiences (or perceptions) of the way they will be treated in accessing services. Therefore, it is very important that the 'resilience' of individuals to feel good about themselves is strengthened. State institutions, in providing care for PLHIV, should focus on the psychological well-being of PLHIV through the development of a variety of specialized and accessible psychological support programs and/or methods (the necessity of such measures was stated in 2012 by the study by K. Levickaitė and A. Losakevicius<sup>19</sup>).
- To activate the provision of psychological and social assistance to PLHIV, both in government institutions and non-governmental organizations. Such assistance should be included in national programs/plans and in the measures related to the response to HIV and AIDS.
- To review and evaluate national programs/plans and measures (in the social, healthcare and legal areas) directly or indirectly related to HIV (such as the HIV/STD action plan, mental health strategy, etc.), and specific measures for reducing stigma and discrimination taking into the account the findings and recommendations of this report.
- To ensure cooperation between state and non-governmental institutions in addressing the problems people living with HIV encounter.

<sup>18</sup> <http://www.who.int/hiv/pub/guidelines/arv2013/treatment/en/>

<sup>19</sup> One of the recommendations of the study was to promote cooperation between public healthcare providers, providing various health and social services, non-governmental, and patient organizations, and to promote the development of complex services for HIV-infected patients and the case management model implementation. The study is available at: <http://www.perspektyvos.org/images/failai/GIP-AIDS-TYRIMAS.pdf>

- To strengthen the competences of the various specialists working PLHIV.
- To raise awareness among PLHIV about their rights and ways and possibilities of assistance.
- To include a course/program on the specificities of working with PLHIV and other vulnerable groups, including on their rights, in the programs of educational institutions (e.g., universities, colleges) that train specialists (doctors, social workers, psychologists, etc.) who will work with PLHIV.
- Municipalities should plan specific measures to promote the establishment and development of support groups and NGOs representing vulnerable populations by providing continuous funding and supporting the training of peer to peer counselors.

## **2. For Activists and Groups (Non-Governmental Organizations) Active or Working in the Area of HIV:**

- To plan and implement measures on how to motivate and empower PLHIV, so that they are better informed about their rights, have evidence-based information on HIV treatment options and opportunities, and engage in activities for PLHIV.
- To plan and implement awareness raising activities on HIV and to dispel HIV-related myths through the media and in decision-making institutions (such as the Parliamentary committees, the Ministry of Health, etc.).
- Promote training and activities of peer-to-peer counselors on HIV, so that they can inform PLHIV about their rights, potential sources of assistance, and provide other information they need.
- Seek methodological and organizational support from successful non-governmental organizations and international PLHIV activists.
- Actively publicize the issues experienced by the groups that are currently not inclined to make themselves public in relation to HIV (men having sex with men, women having sex with women, homosexuals, bisexuals, etc.) and inform of the ways of addressing these issues.
- The study reached mostly the respondents who indicated that they are or have been using illicit drugs. The study did not manage to reach other groups (men who have sex with men, homosexuals, transgender persons, or persons who do not identify themselves with their biological sex), except for a few isolated cases. Therefore, it is very important to conduct additional research in order to find out the reasons why these groups tend to remain unidentified and to promote their more active participation in addressing the issues they face or in meeting their HIV-related needs.



### **Disclaimer:**

The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination.

In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower People living with HIV on human rights related to HIV.

Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research participants interviewees have a right to anonymity and to confidentiality regarding their responses.

In addition to the empowerment function, appropriate uses of the data are for advocacy and in order to inform stigma/discrimination reduction programming and policy responses in the national response to HIV.

# Annex No. 1

|  | All (n=200) |      | Subgroups by gender |      |       |      |             |     | Subgroups by narcotic drug use |      |                       |      |
|--|-------------|------|---------------------|------|-------|------|-------------|-----|--------------------------------|------|-----------------------|------|
|  |             |      | Men                 |      | Women |      | Transgender |     | Drug users (n=107)             |      | Non-drug users (n=93) |      |
|  | Total       | %    | Total               | %    | Total | %    | Total       | %   | Total                          | %    | Total                 | %    |
| <b>SOCIAL DEMOGRAPHIC DATA</b>   |             |      |                     |      |       |      |             |     |                                |      |                       |      |
| <b>Gender (n=200)</b>  |             |      |                     |      |       |      |             |     | <b>(n=107)</b>                 |      | <b>(n=93)</b>         |      |
| Men  | 138         | 69   | 138                 | 69   | -     | -    | -           | -   | 74                             | 69   | 64                    | 69   |
| Women  | 60          | 30   | -                   | -    | 60    | 30   | -           | -   | 32                             | 30   | 28                    | 30   |
| Transgender  | 2           | 1    | -                   | -    | -     | -    | 2           | 1   | 1                              | 1    | 1                     | 1    |
| <b>Age (n=200)</b>   |             |      |                     |      |       |      |             |     | <b>(n=107)</b>                 |      | <b>(n=93)</b>         |      |
| 15-17 years  | 1           | 0,5  | 1                   | 0,5  | 0     | 0    | 0           | 0   | 1                              | 0,5  | 0                     | 0    |
| 18-29 years  | 24          | 12   | 16                  | 8    | 8     | 4    | 0           | 0   | 11                             | 5,5  | 13                    | 6,5  |
| 30-39 years  | 66          | 33   | 46                  | 23   | 19    | 9,5  | 1           | 0,5 | 29                             | 14,5 | 36                    | 18   |
| 40-49 years  | 71          | 35,5 | 46                  | 23   | 23    | 11,5 | 1           | 0,5 | 47                             | 23,5 | 25                    | 12,5 |
| 50-59 years  | 36          | 18   | 27                  | 13,5 | 10    | 5    | 0           | 0   | 19                             | 9,5  | 17                    | 8,5  |
| > 60 years   | 2           | 1    | 2                   | 1    | 0     | 0    | 0           | 0   | 0                              | 0    | 2                     | 1    |
| <b>Are you currently in an intimate/sexual relationship? (n=200)</b>           |             |      |                     |      |       |      |             |     | <b>(n=107)</b>                 |      | <b>(n=93)</b>         |      |
| No   | 101         | 50,5 | 79                  | 39,5 | 29    | 14,5 | 1           | 0,5 | 50                             | 47   | 50                    | 54   |
| Yes  | 99          | 49,5 | 68                  | 34   | 31    | 15,5 | 1           | 0,5 | 57                             | 53   | 43                    | 46   |
| <b>Is your partner also living with HIV? (n=101)</b>                           |             |      |                     |      |       |      |             |     | <b>(n=52)</b>                  |      | <b>(n=49)</b>         |      |
| Yes  | 27          | 27   | 22                  | 22   | 5     | 5    | 0           | 0   | 17                             | 33   | 10                    | 20   |
| No   | 61          | 60   | 40                  | 40   | 19    | 19   | 1           | 1   | 26                             | 50   | 35                    | 71   |
| Unsure   | 12          | 12   | 8                   | 8    | 4     | 4    | 0           | 0   | 9                              | 17   | 4                     | 9    |
| <b>How many children live in your household that you take care of? (n=200)</b> |             |      |                     |      |       |      |             |     | <b>(n=107)</b>                 |      | <b>(n=93)</b>         |      |
| None   | 142         | 71   | 101                 | 51   | 41    | 21   | 1           | 0,5 | 81                             | 76   | 63                    | 68   |
| 1 child  | 36          | 18   | 25                  | 12,5 | 11    | 5,5  | 1           | 0,5 | 17                             | 16   | 17                    | 18   |
| 2 children   | 16          | 8    | 9                   | 4,5  | 6     | 3    | 0           | 0   | 4                              | 4    | 12                    | 13   |
| 3 children   | 4           | 2    | 2                   | 1    | 2     | 1    | 0           | 0   | 3                              | 3    | 1                     | 1    |
| 5 children   | 1           | 0,5  | 1                   | 0,5  | 0     | 0    | 0           | 0   | 1                              | 0,5  | 0                     | 0    |
| 7 children   | 1           | 0,5  | 1                   | 0,5  | 0     | 0    | 0           | 0   | 1                              | 0,5  | 0                     | 0    |
| <b>Are you currently in school? (n=200)</b>                                    |             |      |                     |      |       |      |             |     | <b>(n=107)</b>                 |      | <b>(n=93)</b>         |      |
| No   | 196         | 98   | 130                 | 65   | 60    | 30   | 2           | 1   | 104                            | 97   | 92                    | 99   |
| Yes  | 4           | 2    | 4                   | 2    | 0     | 0    | 0           | 0   | 3                              | 3    | 1                     | 1    |
| <b>Highest level of formal education (n=200)</b>                               |             |      |                     |      |       |      |             |     | <b>(n=107)</b>                 |      | <b>(n=93)</b>         |      |
| No formal education  | 6           | 3    | 4                   | 2    | 2     | 1    | 0           | 0   | 6                              | 6    | 0                     | 0    |
| Primary school   | 36          | 18   | 24                  | 12   | 10    | 5    | 1           | 0,5 | 28                             | 26   | 8                     | 7    |
| Secondary/high school  | 74          | 37   | 53                  | 26,5 | 19    | 9,5  | 1           | 0,5 | 33                             | 31   | 41                    | 45   |
| Vocational school  | 70          | 35   | 46                  | 23   | 26    | 13   | 0           | 0   | 37                             | 35   | 33                    | 36   |
| University   | 14          | 7    | 11                  | 5,5  | 3     | 1,2  | 0           | 0   | 3                              | 2    | 11                    | 12   |
| <b>Current work status (n=200)</b>   |             |      |                     |      |       |      |             |     | <b>(n=107)</b>                 |      | <b>(n=93)</b>         |      |

|   |     |      |    |      |    |      |   |     |                |      |               |      |
|---|-----|------|----|------|----|------|---|-----|----------------|------|---------------|------|
| Full-time work (as an employee)   | 32  | 16   | 21 | 10,5 | 11 | 5,5  | 0 | 0   | 9              | 8    | 23            | 25   |
| Part-time work (as an employee)   | 21  | 10,5 | 13 | 6,5  | 7  | 3,5  | 1 | 0,5 | 11             | 10   | 10            | 11   |
| Full-time, but not as an employee (self-employed or business owner)               | 8   | 4    | 6  | 3    | 2  | 1    | 0 | 0   | 1              | 1    | 7             | 8    |
| Casual or part-time work (self-employed or paid work for others)                  | 40  | 20   | 24 | 12   | 16 | 8    | 0 | 0,5 | 26             | 25   | 14            | 15   |
| Unemployed  | 99  | 49,5 | 74 | 37   | 24 | 12   | 1 | 0,5 | 60             | 56   | 39            | 41   |
| <b>Inability to meet basic needs in the last 12 months (n=200)</b>                |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Never   | 98  | 49   | 66 | 33   | 30 | 15   | 2 | 1   | 42             | 39   | 56            | 60   |
| Some of the time  | 83  | 41,5 | 59 | 30   | 24 | 12   | 0 | 0   | 50             | 47   | 33            | 35   |
| Most of the time  | 19  | 9,5  | 13 | 7    | 6  | 3    | 0 | 0   | 15             | 14   | 4             | 5    |
| <b>Belong (current of previous) to the following groups (n=200)</b>               |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Member of a racial, ethnic, or religious minority                                 | 7   | 3,5  | 4  | 2    | 3  | 1,5  | 0 | 0   | 3              | 2,8  | 4             | 4,3  |
| Member of an Indigenous/Aboriginal group  | 4   | 2    | 3  | 1,5  | 1  | 0,5  | 0 | 0   | 2              | 1,8  | 2             | 2    |
| Living with a disability  | 30  | 15   | 18 | 9    | 11 | 5,5  | 1 |     | 16             | 14,9 | 14            | 15   |
| Refugee or asylum seeker  | 3   | 1,5  | 2  | 1    | 1  | 0,5  | 0 | 0   | 2              | 1,8  | 1             | 1    |
| Migrant worker  | 2   | 1    | 1  | 0,5  | 1  | 0,5  | 0 | 0   | 1              | 0,9  | 1             | 1    |
| Internally displaced person   | 6   | 3    | 4  | 2    | 2  | 1    | 0 | 0   | 3              | 2,8  | 3             | 3,2  |
| Incarcerated/in prison  | 84  | 42   | 52 | 26   | 31 | 15,5 | 1 | 0,5 | 58             | 54   | 26            | 27,9 |
| <b>Membership of a network or support group of people living with HIV (n=200)</b> |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Yes   | 59  | 29,5 | 40 | 20   | 18 | 9    | 1 | 0,5 | 34             | 31,7 | 25            | 26,8 |
| No  | 141 | 70,5 | 98 | 49   | 41 | 20,5 | 1 | 0,5 | 73             | 68   | 68            | 73   |
| <b>DISCLOSURE</b>   |     |      |    |      |    |      |   |     |                |      |               |      |
| <b>HIV status known by the following groups of people (n=200)</b>                 |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Husband/wife/partner  | 115 | 58   | 78 | 39   | 36 | 18   | 0 | 0   | 61             | 57   | 54            | 58   |
| Children  | 24  | 12   | 16 | 8    | 8  | 4    | 0 | 0   | 10             | 9,3  | 14            | 15   |
| Other family members  | 122 | 61   | 84 | 42   | 37 | 18,5 | 1 | 0,5 | 64             | 59,8 | 58            | 62   |
| Friends   | 134 | 67   | 93 | 46,5 | 40 | 20   | 1 | 0,5 | 77             | 71,9 | 57            | 61   |
| Neighbours  | 0   | 0    | 0  | 0    | 0  | 0    | 0 | 0   | 0              | 0    | 0             | 0    |
| Employer  | 0   | 0    | 0  | 0    | 0  | 0    | 0 | 0   | 0              | 0    | 0             | 0    |
| Co-workers  | 0   | 0    | 0  | 0    | 0  | 0    | 0 | 0   | 0              | 0    | 0             | 0    |

|   |    |      |    |      |    |      |   |     |    |      |    |      |
|---|----|------|----|------|----|------|---|-----|----|------|----|------|
| Teachers/school administration  | 0  | 0    | 0  | 0    | 0  | 0    | 0 | 0   | 0  | 0    | 0  | 0    |
| Classmates  | 0  | 0    | 0  | 0    | 0  | 0    | 0 | 0   | 0  | 0    | 0  | 0    |
| Community leaders   | 0  | 0    | 0  | 0    | 0  | 0    | 0 | 0   | 0  | 0    | 0  | 0    |
| <b>HIV status disclosed without consent to the following groups of people (n=10)</b>            |    |      |    |      |    |      |   |     |    |      |    |      |
| Children  | 0  | 0    | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| Other family members  | 1  | 0,5  | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| Friends   | 2  | 1    | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| Neighbours  | 6  | 5    | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| Employer  | 0  | 0    | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| Co-workers  | 3  | 1,5  | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| Teachers/school administration  | 4  | 2    | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| Classmates  | 4  | 2    | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| Community leaders   | 4  | 2    | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| Children  | 3  | 1,5  | -  | -    | -  | -    | - | -   | -  | -    | -  | -    |
| <b>Disclosing HIV status to people you are close to has been a positive experience (n=200)</b>  |    |      |    |      |    |      |   |     |    |      |    |      |
| Agree   | 49 | 24,5 | 37 | 18,5 | 12 | 6    | 0 | 0   | 27 | 25   | 22 | 23,6 |
| Somewhat agree  | 70 | 35,5 | 47 | 11,5 | 23 | 11,5 | 0 | 0   | 41 | 38   | 27 | 29   |
| Disagree  | 67 | 33,5 | 44 | 22   | 22 | 11   | 1 | 1,5 | 30 | 28   | 35 | 37,6 |
| <b>People you are close to were supportive after finding out your HIV status (n=200)</b>        |    |      |    |      |    |      |   |     |    |      |    |      |
| Agree   | 86 | 43   | 59 | 29,5 | 27 | 13,5 | 0 | 0   | 48 | 44   | 35 | 37,6 |
| Somewhat agree  | 76 | 38   | 53 | 26,5 | 22 | 11   | 1 | 1,5 | 41 | 38   | 33 | 35   |
| Disagree  | 26 | 13   | 16 | 8    | 10 | 5    | 0 | 0   | 10 | 9,3  | 16 | 17   |
| <b>Disclosing HIV status to people you are not close has been a positive experience (n=200)</b> |    |      |    |      |    |      |   |     |    |      |    |      |
| Agree   | 11 | 5,5  | 5  | 2,5  | 6  | 3    | 0 | 0   | 4  | 3,7  | 7  | 7,5  |
| Somewhat agree  | 70 | 35   | 48 | 24   | 22 | 11   | 0 | 0   | 41 | 38   | 28 | 30   |
| Disagree  | 86 | 43   | 59 | 29,5 | 25 | 12,5 | 1 | 0,5 | 41 | 38   | 43 | 46   |
| <b>People you are not close were supportive after finding out your HIV status (n=200)</b>       |    |      |    |      |    |      |   |     |    |      |    |      |
| Agree   | 21 | 10,5 | 12 | 6    | 9  | 4,5  | 0 | 0   | 7  | 6,5  | 14 | 15   |
| Somewhat agree  | 90 | 45   | 63 | 31,5 | 26 | 13   | 1 | 1,5 | 56 | 52   | 32 | 34   |
| Disagree  | 54 | 27   | 35 | 17,5 | 17 | 8,5  | 0 | 0   | 26 | 24   | 26 | 27,9 |
| <b>Disclosing HIV status has become easier over time (n=200)</b>                                |    |      |    |      |    |      |   |     |    |      |    |      |
| Agree   | 53 | 26,5 | 33 | 16,5 | 20 | 10   | 0 | 0   | 35 | 32,7 | 18 | 19,3 |
| Somewhat agree  | 67 | 33,5 | 50 | 25   | 50 | 25   | 0 | 0   | 33 | 30,8 | 34 | 36,5 |
| Disagree  | 69 | 34,5 | 45 | 22,5 | 45 | 22,5 | 0 | 0   | 34 | 31,7 | 30 | 32   |
| <b>EXPERIENCE WITH STIGMA AND DISCRIMINATION</b>  |    |      |    |      |    |      |   |     |    |      |    |      |
| <b>Excluded from social gatherings or activities because of HIV status (n=200)</b>              |    |      |    |      |    |      |   |     |    |      |    |      |
| Yes, within the last 12 months  | 2  | 1    | 1  | 0,5  | 1  | 0,5  | 0 | 0   | 0  | 0    | 2  | 2,1  |
| Yes, but not in the last 12 months  | 13 | 6,5  | 6  | 3    | 5  | 0,5  | 1 | 0   | 7  | 6,5  | 6  | 6,4  |
| <b>Excluded from religious activities or places of worship because of HIV status (n=200)</b>    |    |      |    |      |    |      |   |     |    |      |    |      |

|  |    |      |    |      |    |     |   |     |    |      |    |      |
|--|----|------|----|------|----|-----|---|-----|----|------|----|------|
| Yes, within the last 12 months   | 0  | 0    | 0  | 0    | 0  | 0   | 0 | 0   | 0  | 0    | 0  | 0    |
| Yes, but not in the last 12 months   | 3  | 1,5  | 2  | 1    | 1  | 0,5 | 0 | 0   | 2  | 1,8  | 1  | 1    |
| <b>Excluded from family activities because of HIV status (n=200)</b>   |    |      |    |      |    |     |   |     |    |      |    |      |
| Yes, within the last 12 months   | 3  | 1,5  | 1  | 0,5  | 2  | 1   | 0 | 0   | 1  | 0,9  | 2  | 2,1  |
| Yes, but not in the last 12 months   | 11 | 5,5  | 7  | 3,5  | 4  | 2   | 0 | 0   | 4  | 3,7  | 7  | 7,5  |
| <b>Being aware of family members making discriminatory remarks or gossiping because of HIV status (n=200)</b>                    |    |      |    |      |    |     |   |     |    |      |    |      |
| Yes, within the last 12 months   | 11 | 5,5  | 6  | 3    | 5  | 2,5 | 0 | 0   | 3  | 2,8  | 8  | 8,6  |
| Yes, but not in the last 12 months   | 33 | 16,5 | 24 | 12   | 9  | 4,5 | 0 | 0   | 9  | 8,4  | 24 | 25,8 |
| <b>Being aware of other people (not family members) making discriminatory remarks or gossiping because of HIV status (n=200)</b> |    |      |    |      |    |     |   |     |    |      |    |      |
| Yes, within the last 12 months   | 26 | 13   | 12 | 6    | 12 | 6   | 1 | 0,5 | 15 | 14   | 11 | 11,8 |
| Yes, but not in the last 12 months   | 55 | 27,5 | 36 | 18   | 17 | 8,5 | 1 | 0,5 | 28 | 26   | 27 | 29   |
| <b>Being verbally harassed because of HIV status (n=200)</b>   |    |      |    |      |    |     |   |     |    |      |    |      |
| Yes, within the last 12 months   | 16 | 8    | 6  | 3    | 9  | 4,5 | 1 | 0,5 | 8  | 7,4  | 8  | 8,6  |
| Yes, but not in the last 12 months   | 42 | 21   | 27 | 13,5 | 13 | 6,5 | 1 | 0,5 | 20 | 18,6 | 22 | 23,6 |
| <b>Being blackmailed because of HIV status (n=200)</b>   |    |      |    |      |    |     |   |     |    |      |    |      |
| Yes, within the last 12 months   | 5  | 2,5  | 1  | 0,5  | 4  | 2   | 0 | 0   | 2  | 1,8  | 3  | 3,2  |
| Yes, but not in the last 12 months   | 10 | 5    | 6  | 0    | 3  | 1,5 | 0 | 0   | 5  | 2,5  | 5  | 5,3  |
| <b>Being physically harassed or hurt because of HIV status (n=200)</b>   |    |      |    |      |    |     |   |     |    |      |    |      |
| Yes, within the last 12 months   | 2  | 1    | 0  | 0    | 2  | 1   | 0 | 0   | 1  | 0,9  | 1  | 1    |
| Yes, but not in the last 12 months   | 11 | 5,5  | 6  | 3    | 4  | 2   | 0 | 0   | 5  | 2,5  | 6  | 6,4  |
| <b>Being refused of employment or lost a source of income or job because of HIV status (n=200)</b>                               |    |      |    |      |    |     |   |     |    |      |    |      |
| Yes, within the last 12 months   | 4  | 2    | 2  | 1    | 2  | 1   | 0 | 0   | 2  | 1,8  | 2  | 2,1  |
| Yes, but not in the last 12 months   | 11 | 5,5  | 9  | 4,5  | 1  | 0,5 | 0 | 0   | 8  | 7,4  | 3  | 3,2  |
| <b>Changing the job description or the nature of the job or a promotion denial because of HIV status (n=200)</b>                 |    |      |    |      |    |     |   |     |    |      |    |      |
| Yes, within the last 12 months   | 1  | 0,5  | 1  | 0,5  | 0  | 0   | 0 | 0   | 0  | 0    | 1  | 1    |
| Yes, but not in the last 12 months   | 7  | 3,5  | 4  | 2    | 3  | 1,5 | 0 | 0   | 3  | 2,8  | 4  | 4,3  |
| <b>Wife/husband or partner ever experienced discrimination because of HIV status (n=200)</b>                                     |    |      |    |      |    |     |   |     |    |      |    |      |

|  |     |      |     |      |    |      |   |     |                |               |    |      |
|--|-----|------|-----|------|----|------|---|-----|----------------|---------------|----|------|
| Yes, within the last 12 months   | 2   | 1    | 1   | 0,5  | 1  | 0,5  | 0 | 0   | 2              | 1,8           | 0  | 0    |
| Yes, but not in the last 12 months   | 24  | 12   | 12  | 6    | 10 | 5    | 1 | 0,5 | 10             | 9,3           | 14 | 15   |
| <b>INTERNAL STIGMA</b>   |     |      |     |      |    |      |   |     |                |               |    |      |
| <b>Influence of HIV status on self-confidence (n=200)</b>  |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 17  | 8,5  | 13  | 6,5  | 4  | 2    | 0 | 0   | 9              | 8,4           | 8  | 8,6  |
| No influence   | 99  | 49,5 | 71  | 35,5 | 27 | 13,5 | 0 | 0   | 62             | 57,9          | 33 | 35   |
| Negative influence   | 80  | 40   | 50  | 25   | 27 | 13,5 | 2 | 1   | 34             | 31,7          | 46 | 49   |
| <b>Influence of HIV status on self-respect (n=200)</b>   |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 19  | 9,5  | 14  | 7    | 5  | 2,5  | 0 | 0   | 12             | 11,2          | 7  | 7,5  |
| No influence   | 115 | 57,5 | 80  | 40   | 34 | 17   | 0 | 0   | 69             | 64,4          | 42 | 45   |
| Negative influence   | 63  | 31,5 | 41  | 20,5 | 19 | 9,5  | 2 | 1   | 23             | 21,4          | 39 | 41,9 |
| <b>Influence of HIV status on ability to respect other people (n=200)</b>                            |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 23  | 11,5 | 15  | 7,5  | 8  | 4    | 0 | 0   | 9              | 8,4           | 14 | 15   |
| No influence   | 150 | 75   | 108 | 54   | 40 | 20   | 1 | 0,5 | 84             | 78,5          | 61 | 65,5 |
| Negative influence   | 25  | 12,5 | 12  | 6    | 11 | 5,5  | 1 | 0,5 | 12             | 11,2          | 13 | 13,9 |
| <b>Influence of HIV status on ability to cope with stress (n=200)</b>                                |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 19  | 9,5  | 14  | 7    | 5  | 2,5  | 0 | 0   | 10             | 9,3           | 9  | 9,6  |
| No influence   | 111 | 55,5 | 77  | 38,5 | 32 | 16   | 1 | 0,5 | 67             | 62,6          | 39 | 41,9 |
| Negative influence   | 65  | 32,5 | 41  | 20,5 | 22 | 11   | 1 | 0,5 | 27             | 25,2          | 38 | 40,8 |
| <b>Influence of HIV status on ability to have close and secure relationships with others (n=200)</b> |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 28  | 14   | 17  | 8,5  | 27 | 13,5 | 0 | 0   | 11             | 10,2          | 16 | 17,2 |
| No influence   | 100 | 50   | 72  | 36   | 11 | 5,5  | 0 | 0   | 66             | 61,6          | 30 | 32   |
| Negative influence   | 67  | 33,5 | 44  | 22   | 20 | 10   | 2 | 1   | 27             | 25,2          | 40 | 43   |
| <b>Influence of HIV status on ability to find love (n=200)</b>                                       |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 13  | 6,5  | 10  | 5    | 3  | 1,5  | 0 | 0   | 8              | 7,4           | 5  | 5,3  |
| No influence   | 71  | 35,5 | 48  | 24   | 22 | 11   | 0 | 0   | 48             | 44,8          | 23 | 24,7 |
| Negative influence   | 81  | 40,5 | 58  | 29   | 20 | 10   | 2 | 1   | 35             | 32,7          | 46 | 49   |
| <b>Influence of HIV status on desire to have children (n=200)</b>                                    |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 6   | 3    | 5   | 2,5  | 1  | 0,5  | 0 | 0   | 5              | 4,6           | 1  | 1    |
| No influence   | 70  | 35   | 47  | 23,5 | 23 | 11,5 | 0 | 0   | 46             | 42,9          | 24 | 25,8 |
| Negative influence   | 46  | 23   | 32  | 16   | 11 | 5,5  | 2 | 1   | 23             | 21,4          | 22 | 23,6 |
| <b>Influence of HIV status on achievement of personal or professional goals (n=200)</b>              |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 41  | 20,5 | 8   | 4    | 2  | 1    | 0 | 0   | 5              | 4,6           | 5  | 5,3  |
| No influence   | 116 | 58   | 81  | 40,5 | 33 | 16,5 | 1 | 0,5 | 76             | 71            | 40 | 43   |
| Negative influence   | 41  | 20,5 | 26  | 13   | 13 | 6,5  | 1 | 0,5 | 16             | 14,9          | 25 | 26,8 |
| <b>Influence of HIV status on ability to contribute to the community (n=200)</b>                     |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 16  | 8    | 9   | 4,5  | 7  | 3,5  | 0 | 0   | 9              | 8,4           | 7  | 7,5  |
| No influence   | 122 | 61   | 89  | 44,5 | 31 | 15,5 | 1 | 0,5 | 78             | 72,8          | 42 | 45   |
| Negative influence   | 22  | 11,1 | 15  | 7,5  | 5  | 2,5  | 1 | 0,5 | 7              | 6,5           | 15 | 16   |
| <b>Influence of HIV status on ability to practice a desired religion/faith (n=200)</b>               |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Positive influence   | 12  | 6    | 9   | 4,5  | 2  | 1    | 0 | 0   | 7              | 6,5           | 5  | 5,3  |

|  |     |      |     |      |    |      |   |     |                |               |    |      |
|--|-----|------|-----|------|----|------|---|-----|----------------|---------------|----|------|
| No influence   | 116 | 58   | 82  | 41   | 32 | 16   | 1 | 0,5 | 73             | 68            | 41 | 44   |
| Negative influence   | 8   | 4    | 5   | 2,5  | 2  | 1    | 1 | 0,5 | 3              | 2,8           | 5  | 5,3  |
| <b>Was the effect of HIV status on ability to meet these kinds of needs better, the same or worse? (n=200)</b> |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Better   | 42  | 21   | 27  | 13,5 | 13 | 6,5  | 1 | 0,5 | 24             | 22,4          | 18 | 19   |
| About the same   | 104 | 52   | 78  | 39   | 26 | 13   | 0 | 0   | 57             | 53,2          | 44 | 47   |
| Worse  | 42  | 21   | 27  | 13,5 | 14 | 7    | 0 | 0   | 20             | 18,6          | 20 | 21,5 |
| <b>Because of HIV status in the past 12 months decided not to: (n=200)</b>                                     |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Attend social gatherings   | 22  | 11   | 16  | 8    | 5  | 2,5  | 0 | 0   | 9              | 8,4           | 13 | 13,9 |
| Not to seek for health care  | 18  | 9    | 9   | 4,5  | 7  | 3,5  | 1 | 0,5 | 7              | 6,5           | 11 | 11,8 |
| Not to apply for job(-s)   | 25  | 12,5 | 15  | 7,5  | 8  | 4    | 0 | 0   | 13             | 12            | 11 | 11,8 |
| Not to seek for social support   | 4   | 2    | 2   | 1    | 2  | 1    | 0 | 0   | 2              | 1,8           | 2  | 2,1  |
| Isolate from family and/or friends   | 28  | 14   | 20  | 10   | 7  | 3,5  | 0 | 0   | 7              | 6,5           | 21 | 22,5 |
| Not to have sex  | 39  | 19,5 | 27  | 13,5 | 11 | 5,5  | 0 | 0   | 15             | 14            | 22 | 23,6 |
| <b>Agreed on the following statements (n=200)</b>  |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| It is difficult to tell people about my HIV  | 162 | 80,5 | 114 | 56,5 | 44 | 22   | 2 | 1   | 61             | 57            | 73 | 78   |
| Being HIV positive makes me feel dirty   | 102 | 51   | 72  | 36   | 26 | 13   | 2 | 1   | 83             | 77,5          | 48 | 51,6 |
| I feel guilty that I am HIV positive   | 107 | 53   | 73  | 36,5 | 31 | 15,5 | 1 | 0,5 | 52             | 48,5          | 48 | 51,6 |
| I am ashamed that I am HIV positive  | 110 | 53,5 | 71  | 34,5 | 37 | 18   | 2 | 1   | 52             | 48,5          | 50 | 53,7 |
| I sometimes feel worthless because I am HIV positive   | 115 | 57,5 | 76  | 38   | 35 | 17,5 | 2 | 1   | 52             | 48,5          | 49 | 52,8 |
| I hide my HIV status from others   | 154 | 77   | 102 | 51   | 48 | 24   | 2 | 1   | 78             | 72,8          | 71 | 76,3 |
| <b>INTERACTIONS WITH HEALTHCARE SERVICES</b>   |     |      |     |      |    |      |   |     |                |               |    |      |
| <b>Was it your choice to be tested for HIV? (n=200)</b>  |     |      |     |      |    |      |   |     | <b>(n=107)</b> | <b>(n=93)</b> |    |      |
| Yes, it was my choice  | 94  | 47   | 66  | 33   | 26 | 13   | 1 | 0,5 | 50             | 46,7          | 42 | 45   |
| Yes, but I was pressured by others   | 16  | 8    | 9   | 4,5  | 6  | 3    | 0 | 0   | 12             | 11,2          | 4  | 4,3  |
| No, I was tested without my knowledge  | 77  | 38,5 | 55  | 27,5 | 21 | 10,5 | 1 | 0,5 | 36             | 33,6          | 39 | 41   |
| No, I was forced to take an HIV test   | 13  | 6,5  | 7   | 3,5  | 6  | 3    | 0 | 0   | 9              | 8,4           | 3  | 3,2  |
| No, I was born with HIV or acquired HIV in infancy/childhood   | 0   | 0    | 0   | 0    | 0  | 0    | 0 | 0   | 0              | 0             | 0  | 0    |

| Your MAIN reason for testing for HIV (n=200)  |     |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
|---|-----|------|----|------|----|-----|---|-----|---------|------|--------|------|
| A provider recommended it   | 6   | 3    | 5  | 2,5  | 5  | 2,5 | 0 | 0   | 4       | 3,7  | 2      | 2,1  |
| I believed I was at risk for HIV  | 52  | 26   | 38 | 19   | 12 | 6   | 1 | 0,5 | 26      | 24   | 25     | 26,8 |
| I felt sick   | 8   | 4    | 5  | 2,5  | 3  | 1,5 | 0 | 0   | 7       | 6,5  | 1      | 1    |
| As part of a community-based program  | 8   | 4    | 7  | 3,5  | 7  | 3,5 | 0 | 0   | 4       | 3,7  | 4      | 4,3  |
| It was a requirement  | 16  | 8    | 8  | 4    | 8  | 4   | 0 | 0   | 11      | 10,2 | 5      | 5,3  |
| I just wanted to know   | 21  | 10,5 | 14 | 7    | 7  | 3,5 | 0 | 0   | 14      | 13   | 6      | 6,4  |
| Other reason  | 24  | 12   | 15 | 7,5  | 8  | 4   | 0 | 0   | 5       | 4,6  | 19     | 20   |
| About how long was it between the time you first thought you should get an HIV test and the time you first took the HIV test? (n=200) |     |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
| 6 months or less  | 55  | 27,5 | 36 | 18   | 18 | 9   | 1 | 0,5 | 28      | 26   | 27     | 29   |
| 6 months to 2 years   | 33  | 16,5 | 26 | 13   | 7  | 3,5 | 0 | 0   | 19      | 17,7 | 14     | 15   |
| More than 2 years   | 7   | 3,5  | 6  | 3    | 1  | 0,5 | 0 | 0   | 3       | 2,8  | 4      | 4,3  |
| Don't know/can't remember   | 35  | 17,5 | 21 | 10,5 | 12 | 6   | 0 | 0   | 18      | 16,8 | 15     | 16   |
| Did fears about how other people would respond make you hesitate to get tested for HIV? (n=200)                                       |     |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
| Yes   | 51  | 25,5 | 35 | 17,5 | 13 | 6,3 | 1 | 0,5 | 27      | 25   | 22     | 23,6 |
| No  | 81  | 40,5 | 55 | 27,5 | 26 | 13  | 0 | 0   | 42      | 39   | 39     | 41,9 |
| What was the reason for the delay of HIV testing? (n=200)   |     |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
| I was worried that my partner, family or friends would find out my status   | 78  | 39   | 51 | 25,5 | 24 | 12  | 1 | 0,5 | 47      | 43,9 | 26     | 27,9 |
| I was worried other people (not family or friends) would find out my status   | 102 | 51   | 66 | 33   | 32 | 16  | 2 | 1   | 56      | 52   | 41     | 44   |
| I was not ready to deal with HIV infection  | 106 | 53   | 71 | 35,5 | 32 | 16  | 1 | 0,5 | 63      | 58,8 | 38     | 40,8 |
| Was afraid health workers would treat me badly/disclose my status without consent   | 77  | 38,5 | 54 | 27   | 19 | 9,5 | 2 | 1   | 44      | 41   | 30     | 32,2 |
| I had a bad experience with a health worker previously  | 48  | 24   | 30 | 15   | 15 | 7,5 | 2 | 1   | 35      | 32,7 | 13     | 13,9 |
| Started the treatment after the diagnosis: (n=200)  |     |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
| Immediately   | 1   | 0,5  | 1  | 0,5  | 0  | 0   | 0 | 0   | 1       | 0,9  | 0      | 0    |
| >1 day to 1 month   | 15  | 7,5  | 8  | 4    | 7  | 3,5 | 0 | 0   | 3       | 2,8  | 12     | 12,9 |
| >1 month to 6 months  | 10  | 5    | 7  | 3,5  | 3  | 1,5 | 0 | 0   | 1       | 0,9  | 9      | 9,6  |

| >6 months to 2 years   | 11  | 5,5  | 8  | 4    | 3  | 1,5  | 0 | 0   | 5       | 4,6  | 6      | 6,4  |
|--|-----|------|----|------|----|------|---|-----|---------|------|--------|------|
| > 2 years  | 92  | 46   | 64 | 32   | 26 | 13   | 1 | 0,5 | 55      | 51   | 36     | 38,7 |
| Can't remember   | 71  | 35,5 | 49 | 24,5 | 20 | 10   | 1 | 0,5 | 42      | 39   | 25     | 26,8 |
| The motives to start the treatment (n=200)   |     |      |    |      |    |      |   |     | (n=107) |      | (n=93) |      |
| I was told the benefits and chose to start as soon as possible   | 101 | 50,5 | 66 | 33   | 34 | 17   | 1 | 0,5 | 45      | 42   | 55     | 59   |
| I just decided to delay the treatment  | 15  | 7,5  | 11 | 5,5  | 3  | 1,5  | 0 | 0   | 9       | 8,4  | 3      | 3,2  |
| I felt pressured or forced to start by health care staff   | 4   | 2    | 2  | 1    | 2  | 1    | 0 | 0   | 2       | 1,8  | 2      | 2,1  |
| Are you currently on HIV treatment? (n=200)  |     |      |    |      |    |      |   |     | (n=107) |      | (n=93) |      |
| Yes  | 17  | 8,5  | 13 | 6,5  | 4  | 2    | 0 | 0   | 9       | 8,4  | 8      | 8,6  |
| No   | 136 | 68   | 91 | 45,5 | 43 | 21,5 | 1 | 0,5 | 69      | 64   | 63     | 67,7 |
| Reasons for not being the HIV treatment (n=200)  |     |      |    |      |    |      |   |     | (n=107) |      | (n=93) |      |
| Medication is not available at the clinic  | 1   | 0,5  | 0  | 0    | 1  | 0,5  | 0 | 0   | 1       | 0,9  | 0      | 0    |
| Medication is not affordable for me  | 0   | 0    | 0  | 0    | 0  | 0    | 0 | 0   | 0       | 0    | 0      | 0    |
| I am unable to collect medications at the clinic or pharmacy   | 0   | 0    | 0  | 0    | 0  | 0    | 0 | 0   | 0       | 0    | 0      | 0    |
| I cannot tolerate medication side effects or am worried about taking the pills                               | 1   | 0,5  | 1  | 0,5  | 0  | 0    | 0 | 0   | 1       | 0,9  | 0      | 0    |
| I do not feel treatment is needed  | 5   | 2,5  | 4  | 2    | 1  | 0,5  | 0 | 0   | 5       | 4,6  | 0      | 0    |
| Worried my HIV status can be disclosed   | 3   | 1,5  | 2  | 1    | 1  | 0,5  | 0 | 0   | 1       | 0,9  | 2      | 2,1  |
| I am not ready to deal with my HIV   | 8   | 4    | 7  | 3,5  | 1  | 0,5  | 0 | 0   | 5       | 4,6  | 3      | 3,2  |
| I am worried the healthcare workers would treat me badly or disclose my HIV status without consent           | 0   | 0    | 0  | 0    | 0  | 0    | 0 | 0   | 0       | 0    | 0      | 0    |
| CD4 count is too high  | 28  | 14   | 20 | 10   | 8  | 4    | 0 | 0   | 15      | 14   | 12     | 12,9 |
| Did fear about someone learning your HIV status lead you to miss a treatment dose in past 12 months? (n=200) |     |      |    |      |    |      |   |     | (n=107) |      | (n=93) |      |
| Yes  | 12  | 6    | 7  | 3,5  | 5  | 2,5  | 0 | 0   | 4       | 3,7  | 8      | 8,6  |
| No   | 140 | 70   | 94 | 47   | 43 | 21,5 | 2 | 1   | 75      | 70   | 60     | 64,5 |
| In the last 12 months, have you been told you have a "good viral load"? (n=200)                              |     |      |    |      |    |      |   |     | (n=107) |      | (n=93) |      |
| Yes  | 97  | 48,5 | 65 | 32,5 | 30 | 15   | 1 | 0,5 | 47      | 43,9 | 47     | 50,5 |

|  |     |      |    |      |    |      |   |     |                |      |               |      |
|--|-----|------|----|------|----|------|---|-----|----------------|------|---------------|------|
| No, I haven't had a viral load test  | 11  | 5,5  | 7  | 3.5  | 3  | 1.5  | 1 | 0.5 | 7              | 6.5  | 3             | 3.2  |
| No, I'm still waiting for the test results   | 11  | 5,5  | 7  | 3.5  | 4  | 2    | 0 | 0   | 7              | 6.5  | 4             | 4.3  |
| No, virus was detectable   | 28  | 14   | 20 | 10   | 8  | 4    | 0 | 0   | 18             | 16.8 | 10            | 10.7 |
| I don't know what the viral load is  | 47  | 23,5 | 35 | 17.5 | 12 | 6    | 0 | 0   | 23             | 21.4 | 23            | 24.7 |
| <b>GENERAL HEALTH STATUS</b>   |     |      |    |      |    |      |   |     |                |      |               |      |
| <b>Current health status in general: (n=200)</b>   |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Good   | 81  | 40,5 | 57 | 28.5 | 23 | 11.5 | 1 | 0.5 | 29             | 27   | 51            | 54.8 |
| Fair   | 98  | 49   | 67 | 33.5 | 28 | 14   | 1 | 0.5 | 62             | 57.9 | 32            | 34   |
| Poor   | 20  | 10   | 12 | 6    | 8  | 4    | 0 | 0   | 16             | 14.9 | 4             | 4.3  |
| <b>In the last 12 months were diagnosed with: (n=200)</b>  |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Tuberculosis   | 12  | 6    | 7  | 3.5  | 5  | 2.5  | 0 | 0   | 6              | 5.6  | 6             | 6.4  |
| Hepatitis  | 27  | 13,5 | 20 | 10   | 5  | 2.5  | 1 | 0.5 | 25             | 23   | 2             | 2.1  |
| Sexually transmitted infection(s)  | 5   | 2,5  | 2  | 1    | 3  | 1.5  | 0 | 0   |                |      | 5             | 5.3  |
| Mental health disorders  | 6   | 3    | 3  | 1.5  | 3  | 1.5  | 0 | 0   | 3              | 2.8  | 3             | 3.2  |
| <b>Currently on treatment or took any treatment within last 12 months for the mentioned conditions (n=200)</b> |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Yes  | 27  | 13,5 | 15 | 7.5  | 12 | 6    | 0 | 0   | 14             | 13   | 13            | 13.9 |
| No   | 71  | 35,5 | 52 | 26   | 17 | 8.5  | 1 | 0.5 | 54             | 50   | 12            | 12.9 |
| <b>Feeling nervous, anxious or on edge within past 2 weeks (n=200)</b>   |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Never  | 48  | 24   | 34 | 17   | 13 | 6.5  | 0 | 0   | 32             | 29.9 | 56            | 60   |
| Once or twice  | 62  | 31   | 46 | 23   | 16 | 8    | 0 | 0   | 27             | 25   | 14            | 15   |
| Several times  | 53  | 26,5 | 32 | 16   | 19 | 9.5  | 2 | 1   | 26             | 24   | 23            | 24.7 |
| Most of the time   | 37  | 18,5 | 25 | 12.5 | 11 | 5.5  | 0 | 0   | 22             | 20.5 | 14            | 15   |
| <b>Not being able to stop or control worrying within past 2 weeks (n=200)</b>                                  |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Never  | 103 | 51,5 | 75 | 37.5 | 26 | 13   | 1 | 0.5 | 48             | 44.8 | 13            | 13.9 |
| Once or twice  | 28  | 14   | 17 | 8.5  | 10 | 5    | 1 | 0.5 | 12             | 11.2 | 34            | 36.5 |
| Several times  | 46  | 23   | 30 | 15   | 15 | 7.5  | 0 | 0   | 26             | 24   | 26            | 27.9 |
| Most of the time   | 23  | 11,5 | 15 | 7.5  | 8  | 4    | 0 | 0   | 21             | 19.6 | 15            | 16   |
| <b>Little interest or pleasure in doing things within past 2 weeks (n=200)</b>                                 |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Never  | 61  | 30,5 | 43 | 21.5 | 17 | 8.5  | 0 | 0   | 44             | 41   | 22            | 23.6 |
| Once or twice  | 58  | 29   | 36 | 18   | 21 | 10.5 | 1 | 0.5 | 13             | 12   | 33            | 35.4 |
| Several times  | 46  | 23   | 35 | 17.5 | 10 | 5    | 1 | 0.5 | 22             | 20.5 | 20            | 21.5 |
| Most of the time   | 35  | 17,5 | 23 | 11.5 | 11 | 5.5  | 0 | 0   | 9              | 8.4  | 13            | 13.9 |
| <b>Feeling down, depressed, or hopeless within past 2 weeks (n=200)</b>  |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Never  | 79  | 39,5 | 52 | 26   | 25 | 12.6 | 1 | 0.5 | 52             | 48,5 | 27            | 29   |
| Once or twice  | 43  | 21,5 | 30 | 15   | 12 | 6    | 1 | 0.5 | 12             | 11,2 | 31            | 33   |
| Several times  | 43  | 21,5 | 34 | 17   | 8  | 4    | 0 | 0   | 26             | 24,2 | 17            | 18   |
| Most of the time   | 35  | 17,5 | 21 | 10.5 | 14 | 7    | 0 | 0   | 22             | 20,5 | 13            | 13.9 |
| <b>Received any type of support for experienced problems (n=200)</b>   |     |      |    |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Yes  | 24  | 12   | 14 | 7    | 10 | 5    | 0 | 0   | 12             | 11.2 | 12            | 12.9 |

|  |     |      |     |      |    |      |   |     |                |      |               |      |
|--|-----|------|-----|------|----|------|---|-----|----------------|------|---------------|------|
| No   | 132 | 66   | 89  | 44.5 | 39 | 19.5 | 2 | 1   | 72             | 67   | 56            | 60   |
| <b>Where do you usually receive your regular HIV care and treatment? (n=200)</b>   |     |      |     |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Government or public clinic or facility  | 160 | 80   | 110 | 5.5  | 49 | 24.5 | 1 | 0.5 | 83             | 74.7 | 77            | 82.7 |
| Private clinic, hospital or doctor   | 0   | 0    | 0   | 0    | 0  | 0    | 0 | 0   | 0              | 0    | 0             | 0    |
| Non-governmental clinic or facility  | 3   | 1,5  | 1   | 0.5  | 2  | 1    | 0 | 0   | 2              | 1.8  | 1             | 1    |
| Community-based care   | 10  | 5    | 8   | 4    | 1  | 0.5  | 0 | 0   | 10             | 8.4  | 0             | 0    |
| Multiple places  | 3   | 1,5  | 3   | 1.5  | 0  | 0    | 0 | 0   | 2              | 1.8  | 1             | 1    |
| <b>In the past 12 months, when seeking HIV care, experienced the health care staff behaviour: (n=200)</b>  |     |      |     |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Denial of health services  | 8   | 4    | 4   | 2    | 3  | 1.5  | 1 | 0.5 | 5              | 4.6  | 3             | 3.2  |
| Advised not to have sex  | 12  | 6    | 9   | 4.5  | 3  | 1.5  | 0 | 0   | 8              | 7.4  | 3             | 3.2  |
| Being talked badly or gossiped about   | 11  | 5,5  | 7   | 3.5  | 3  | 1.5  | 1 | 0.5 | 4              | 3.7  | 6             | 6.4  |
| Verbal abuse   | 4   | 2    | 1   | 0.5  | 3  | 1.5  | 0 | 0   | 2              | 1.8  | 2             | 2.1  |
| Physical abuse   | 0   | 0    |     |      |    |      | 0 | 0   | 0              |      | 0             |      |
| Avoidance of physical contact  | 30  | 15   | 22  | 11   | 8  | 4    | 0 | 0   | 17             | 15.8 | 13            | 13.9 |
| Disclosing HIV status without consent  | 17  | 8,5  | 12  | 6    | 5  | 2.5  | 0 | 0   | 9              | 8.4  | 8             | 8.6  |
| <b>In the past 12 months, have you sought healthcare for non-HIV related health needs? (n=200)</b>   |     |      |     |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Yes  | 93  | 46,5 | 60  | 30   | 31 | 15.5 | 1 | 0.5 | 48             | 44.8 | 45            | 48   |
| No   | 107 | 53,5 | 77  | 38.5 | 28 | 14   | 1 | 0.5 | 59             | 55   | 43            | 46   |
| <b>When seeking care for non-HIV related health needs, have you experienced any of the following treatment by health facility staff? (n=200)</b> |     |      |     |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Denial of services   | 7   | 3,5  | 4   | 2    | 2  | 1    | 1 | 0.5 | 4              | 3.7  | 3             | 3.2  |
| Denial of dental care  | 12  | 6    | 6   | 3    | 6  | 3    | 0 | 0   | 0              | 0    | 12            | 12.9 |
| Advised not to have sex  | 11  | 5,5  | 9   | 4.5  | 2  | 1    | 0 | 0   | 5              | 4.6  | 6             | 6.4  |
| Being talked badly or gossiped about   | 15  | 7,5  | 9   | 4.5  | 5  | 2.5  | 1 | 0.5 | 5              | 4.6  | 10            | 10.7 |
| Verbal abuse   | 8   | 4    | 4   | 2    | 4  | 2    | 0 | 0   | 1              | 0.9  | 7             | 7.5  |
| Physical abuse   | 0   | 0    | 0   | 0    | 0  | 0    | 0 | 0   | 0              |      | 0             |      |
| Avoidance of physical contact  | 36  | 18   | 23  | 11.5 | 13 | 6.5  | 0 | 0   | 15             | 14   | 21            | 22.5 |
| Disclosing HIV status without consent  | 20  | 10   | 15  | 7.5  | 5  | 2.5  | 0 | 0   | 9              | 8.4  | 11            | 11.8 |
| <b>When applying for non-HIV related health care, do you disclose that you are living with HIV? (n=200)</b>                                      |     |      |     |      |    |      |   |     | <b>(n=107)</b> |      | <b>(n=93)</b> |      |
| Yes  | 61  | 30,5 | 40  | 20   | 20 | 10   | 1 | 0.5 | 28             | 26   | 33            | 35   |
| No   | 136 | 68   | 95  | 47.5 | 38 | 19   | 1 | 0.5 | 78             | 72.8 | 53            | 56   |

| Do you think your medical records relating to your HIV status are kept confidential? (n=200)             |     |      |     |      |    |     |   |     |    | (n=107) |    | (n=93) |  |
|--|-----|------|-----|------|----|-----|---|-----|----|---------|----|--------|--|
| I'm sure they are kept confidential  | 10  | 5    | 5   | 2.5  | 5  | 2.5 | 0 | 0   | 8  | 7.4     | 1  | 1      |  |
| I don't know   | 152 | 76   | 107 | 53.5 | 44 | 22  | 0 | 0   | 78 | 72.8    | 72 | 77     |  |
| It is clear to me that my medical records are not being kept confidential                                | 38  | 19   | 25  | 12.5 | 10 | 5   | 2 | 1   | 21 | 19.6    | 15 | 16     |  |
| SEXUAL AND REPRODUCTIVE HEALTH   |     |      |     |      |    |     |   |     |    |         |    |        |  |
| In the past 12 months experienced such health care staff behaviour: (n=200)                              |     |      |     |      |    |     |   |     |    | (n=107) |    | (n=93) |  |
| Advice not to have children  | 21  | 10,5 | 12  | 6    | 8  | 4   | 1 | 0,5 | 7  | 6.5     | 12 | 12.9   |  |
| Pressure to get sterilized   | 0   | 0    | 0   | 0    | 0  | 0   | 0 | 0   | 0  | 0       | 0  | 0      |  |
| Sterilized without knowledge or consent  | 0   | 0    | 0   | 0    | 0  | 0   | 0 | 0   | 0  | 0       | 0  | 0      |  |
| Denial of contraception services   | 1   | 0,5  | 1   | 0,5  | 0  | 0   | 0 | 0   | 0  | 0       | 1  | 1      |  |
| Told that in order to get the ART, the specific contraception is necessary                               | 5   | 2,5  | 4   | 2    | 1  | 0,5 | 0 | 0   | 3  | 2.8     | 1  | 1      |  |
| WOMEN ONLY: In the past 12 months experienced such health care staff behaviour: (n=60)                   |     |      |     |      |    |     |   |     |    |         |    |        |  |
| Advice to terminate pregnancy  | 3   | 5    | 1   | 1,6  | 2  | 3,3 | 0 | 0   | -  | -       | -  | -      |  |
| Pressure to use a specific type of contraceptive method  | 6   | 10   | 3   | 5    | 3  | 5   | 0 | 0   | -  | -       | -  | -      |  |
| Pressure to use a particular method of giving birth  | 5   | 8,3  | 2   | 3,3  | 3  | 5   | 0 | 0   | -  | -       | -  | -      |  |
| Pressure to use a particular infant feeding practice   | 4   | 6,6  | 1   | 1,6  | 3  | 5   | 0 | 0   | -  | -       | -  | -      |  |
| Pressure to take antiretroviral treatment during pregnancy   | 7   | 11,6 | 4   | 6,6  | 3  | 5   | 0 | 0   | -  | -       | -  | -      |  |
| HUMAN RIGHTS AND EFFECTING CHANGE  |     |      |     |      |    |     |   |     |    |         |    |        |  |
| Was forced to test for HIV or disclose HIV status in order to obtain visa or apply for residency (n=200) |     |      |     |      |    |     |   |     |    | (n=107) |    | (n=93) |  |
| Yes, within the last 12 months   | 0   | 0    | 0   | 0    | 0  | 0   | 0 | 0   | 0  | 0       | 0  | 0      |  |
| Yes, but not in the last 12 months   | 0   | 0    | 0   | 0    | 0  | 0   | 0 | 0   | 0  | 0       | 0  | 0      |  |

| Was forced to test for HIV or disclose HIV status in order to apply for a job or get a pension (n=200)                    |    |     |   |     |   |     |   |   |    | (n=107) |   | (n=93) |  |
|---|----|-----|---|-----|---|-----|---|---|----|---------|---|--------|--|
| Yes, within the last 12 months  | 2  | 1   | 1 | 0,5 | 1 | 0,5 | 0 | 0 | 1  | 0,5     | 1 | 0,5    |  |
| Yes, but not in the last 12 months  | 0  | 0   | 0 | 0   | 0 | 0   | 0 | 0 | 0  | 0       | 0 | 0      |  |
| Was forced to test for HIV or disclose HIV status in order to attend educational institution or get a scholarship (n=200) |    |     |   |     |   |     |   |   |    | (n=107) |   | (n=93) |  |
| Yes, within the last 12 months  | 0  | 0   | 0 | 0   | 0 | 0   | 0 | 0 | 0  | 0       | 0 | 0      |  |
| Yes, but not in the last 12 months  | 0  | 0   | 0 | 0   | 0 | 0   | 0 | 0 | 0  | 0       | 0 | 0      |  |
| Was forced to test for HIV or disclose HIV status in order to get health care (n=200)                                     |    |     |   |     |   |     |   |   |    | (n=107) |   | (n=93) |  |
| Yes, within the last 12 months  | 3  | 1,5 | 1 | 0,5 | 2 | 1   | 0 | 0 | 2  | 1.8     | 1 | 1      |  |
| Yes, but not in the last 12 months  | 1  | 0,5 | 1 | 0,5 | 0 | 0   | 0 | 0 | 0  | 0       | 1 | 1      |  |
| Was forced to test for HIV or disclose HIV status in order to get medical insurance (n=200)                               |    |     |   |     |   |     |   |   |    | (n=107) |   | (n=93) |  |
| Yes, within the last 12 months  | 5  | 2,5 | 3 | 1,5 | 2 | 1   | 0 | 0 | 1  | 0,9     | 4 | 4      |  |
| Yes, but not in the last 12 months  | 3  | 1,5 | 1 | 0,5 | 2 | 1   | 0 | 0 | 0  | 0       | 3 | 3,2    |  |
| Was arrested or taken to court on a charge related to HIV status (n=200)  |    |     |   |     |   |     |   |   |    | (n=107) |   | (n=93) |  |
| Yes, within the last 12 months  | 1  | 0,5 | 1 | 0,5 | 0 | 0   | 0 | 0 | 0  | 0       | 1 | 1      |  |
| Yes, but not in the last 12 months  | 0  | 0   | 0 | 0   | 0 | 0   | 0 | 0 | 0  | 0       | 0 | 0      |  |
| Was detained or quarantined because of HIV status (n=200)   |    |     |   |     |   |     |   |   |    | (n=107) |   | (n=93) |  |
| Yes, within the last 12 months  | 1  | 0,5 | 1 | 0,5 | 0 | 0   | 0 | 0 | 0  | 0       | 1 | 1      |  |
| Yes, but not in the last 12 months  | 12 | 6   | 7 | 3,5 | 5 | 2,5 | 0 | 0 | 11 | 10,2    | 1 | 1      |  |
| Was denied a visa or permission to enter another country because of HIV status (n=200)                                    |    |     |   |     |   |     |   |   |    | (n=107) |   | (n=93) |  |
| Yes, within the last 12 months  | 0  | 0   | 0 | 0   | 0 | 0   | 0 | 0 | 0  | 0       | 0 | 0      |  |
| Yes, but not in the last 12 months  | 2  | 1   | 1 | 0,5 | 1 | 0,5 | 0 | 0 | 1  | 0,9     | 1 | 1      |  |
| Was denied residency or permission to stay in another country because of HIV status (n=200)                               |    |     |   |     |   |     |   |   |    | (n=107) |   | (n=93) |  |
| Yes, within the last 12 months  | 0  | 0   | 0 | 0   | 0 | 0   | 0 | 0 | 0  | 0       | 0 | 0      |  |
| Yes, but not in the last 12 months  | 2  | 1   | 1 | 0,5 | 1 | 0,5 | 0 | 0 | 2  | 1,8     | 0 | 0      |  |
| Was forced to disclose HIV status or HIV status was publicly disclosed without consent (n=200)                            |    |     |   |     |   |     |   |   |    | (n=107) |   | (n=93) |  |
| Yes, within the last 12 months  | 0  | 0   | 0 | 0   | 0 | 0   | 0 | 0 | 0  | 0       | 0 | 0      |  |
| Yes, but not in the last 12 months  | 2  | 1   | 1 | 0,5 | 1 | 0,5 | 0 | 0 | 1  | 0,9     | 1 | 1      |  |

| Was forced to have sex against his/her will (n=200)  |     |      |     |      |    |      |   |     | (n=107) |      | (n=93) |      |
|--|-----|------|-----|------|----|------|---|-----|---------|------|--------|------|
| Yes, within the last 12 months   | 0   | 0    | 0   | 0    | 0  | 0    | 0 | 0   | 0       | 0    | 0      | 0    |
| Yes, but not in the last 12 months   | 2   | 0,5  | 1   | 0,5  | 1  | 0,5  | 0 | 0   | 1       | 0,9  | 1      | 1    |
| If any rights abuses happened in the last 12 months, did he/she tried to do anything about that? (n=200) |     |      |     |      |    |      |   |     | (n=107) |      | (n=93) |      |
| Yes  | 1   | 0,5  | 0   | 0    | 1  | 0,5  | 0 | 0   | 1       | 0,9  | 0      | 0    |
| No   | 129 | 64,5 | 90  | 45   | 35 | 17,5 | 2 | 1   | 80      | 74,7 | 44     | 47   |
| If no, what was the main reason for not trying to do something about the matter? (n=200)                 |     |      |     |      |    |      |   |     | (n=107) |      | (n=93) |      |
| Did not know where to go/what to do  | 7   | 3,5  | 5   | 2,5  | 2  | 1    | 0 | 0   | 7       | 6,5  | 0      | 0    |
| Insufficient finances to take action   | 3   | 1,5  | 1   | 0,5  | 2  | 1    | 0 | 0   | 2       | 1,8  | 1      | 1    |
| Process of addressing the problem appeared too complicated   | 1   | 0,5  | 0   |      | 1  | 0,5  | 0 | 0   | 1       | 0,9  | 0      | 0    |
| Felt intimidated or scared to take action  | 8   | 4    | 7   | 3,5  | 1  | 0,5  | 0 | 0   | 5       | 4,6  | 3      | 3,2  |
| Was worried taking action might lead people to learn about my HIV status                                 | 7   | 3,5  | 6   | 3    | 0  | 0    | 1 | 0,5 | 3       | 2,8  | 4      | 4,3  |
| Advised against taking action by someone else  | 4   | 2    | 2   | 1    | 2  | 1    | 0 | 0   | 3       | 2,8  | 1      | 1    |
| No/little confidence that the outcome would be successful  | 7   | 3,5  | 5   | 2,5  | 2  | 1    | 0 | 0   | 6       | 5,6  | 1      | 1    |
| Lack of evidence for the abuse   | 6   | 3    | 5   | 2,5  | 1  | 0,5  | 0 | 0   | 6       | 5,6  | 0      | 0    |
| Other  | 12  | 6    | 8   | 4    | 3  | 1,5  | 1 | 0,5 | 7       | 6,5  | 5      | 5,3  |
| Do you know if there are laws in your country to protect people with HIV from discrimination? (n=200)    |     |      |     |      |    |      |   |     | (n=107) |      | (n=93) |      |
| Yes, there are laws  | 11  | 5,5  | 6   | 3    | 4  | 2    | 1 | 0,5 | 6       | 5,6  | 5      | 5,3  |
| No, there are no laws  | 24  | 12   | 18  | 9    | 6  | 3    | 0 |     | 12      | 11,2 | 10     | 10,7 |
| I don't know if there are laws   | 165 | 82,5 | 113 | 56,5 | 49 | 24,5 | 1 | 0,5 | 89      | 83   | 73     | 78   |
| Challenged/educated someone who was engaging in stigma or discrimination against him/her (n=200)         |     |      |     |      |    |      |   |     | (n=107) |      | (n=93) |      |
| Yes, but not in the last 12 months   | 54  | 27   | 38  | 19   | 14 | 7    | 1 | 0,5 | 23      | 21,4 | 30     | 32   |
| Yes, within the last 12 months   | 19  | 9,5  | 11  | 5,5  | 7  | 3,5  | 1 | 0,5 | 10      | 9,3  | 9      | 9,6  |
| Challenged/educated someone who was engaging in stigma/discrimination against PLHIV (n=200)              |     |      |     |      |    |      |   |     | (n=107) |      | (n=93) |      |
| Yes, but not in the last 12 months   | 74  | 37   | 51  | 25,5 | 21 | 10,5 | 1 | 0,5 | 31      | 28,9 | 41     | 44   |

| Yes, within the last 12 months  | 26 | 13   | 16 | 8    | 9  | 4,5 | 1 | 0,5 | 19      | 17,7 | 7      | 7,5  |
|---|----|------|----|------|----|-----|---|-----|---------|------|--------|------|
| Provided emotional, financial or other support to help PLHIV deal with stigma/discrimination (n=200)                          |    |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
| Yes, but not in the last 12 months  | 56 | 28   | 42 | 21   | 17 | 8,5 | 0 | 0   | 24      | 22,4 | 32     | 34   |
| Yes, within the last 12 months  | 20 | 10   | 12 | 6    | 7  | 3,5 | 1 | 0,5 | 13      | 12   | 7      | 7,5  |
| Participated in an organization or educational campaign working to address stigma and discrimination against PLHIV (n=200)    |    |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
| Yes, but not in the last 12 months  | 16 | 8    | 11 | 5,5  | 4  | 2   | 0 | 0   | 10      | 9,3  | 6      | 6,4  |
| Yes, within the last 12 months  | 53 | 26,5 | 39 | 19,5 | 13 | 6,5 | 1 | 0,5 | 34      | 31,7 | 19     | 20   |
| Encouraged a community leader to take action about issues of stigma and/or discrimination against PLHIV (n=200)               |    |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
| Yes, but not in the last 12 months  | 12 | 6    | 7  | 3,5  | 4  | 2   | 0 | 0   | 7       | 6,5  | 5      | 5,3  |
| Yes, within the last 12 months  | 56 | 28   | 37 | 18,5 | 18 | 9   | 1 | 0,5 | 34      | 31,7 | 22     | 23,6 |
| Encouraged a government leader or a politician to take action about issues of stigma and discrimination against PLHIV (n=200) |    |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
| Yes, but not in the last 12 months  | 4  | 2    | 2  | 1    | 2  | 1   | 0 | 0   | 3       | 2,8  | 1      | 1    |
| Yes, within the last 12 months  | 4  | 2    | 3  | 1,5  | 1  | 0,5 | 0 | 0   | 2       | 1,8  | 2      | 2,1  |
| Spoke to the media about issues of stigma and discrimination against PLHIV (n=200)  |    |      |    |      |    |     |   |     | (n=107) |      | (n=93) |      |
| Yes, but not in the last 12 months  | 9  | 4,5  | 5  | 2,5  | 3  | 1,5 | 1 | 0,5 | 5       | 4,6  | 4      | 4,3  |
| Yes, within the last 12 months  | 9  | 4,5  | 6  | 3    | 3  | 1,5 | 0 | 0   | 6       | 5,6  | 3      | 3,2  |