# THE PEOPLE LIVING WITH HIV
# STIGMA INDEX 2.0

Russian Federation
2022

# ACKNOWLEDGEMENTS

*We thank the many people who contributed to the report, and to those who provided scientific and technical guidance during the implementation of the research. We would like to thank the people living with HIV who conducted the interviews and who participated in the study. We hope that the findings and results of our study will help to improve the quality of life of these and other people.*

### Authors

Coordinator of the research – Maria Godlevskaya
Sociologist – Anastasia Meylakhs

### Co-authors

**Tolyatty city**
Ivan Anoshkin
Ruslan Rotar'
Ludmila Karpova
Nikita Yelovskiy
Tatyana Kochetkova
Svyatoslava Il'ina
Konstantin Krotov
Talina Isaenya

**Yekaterinburg city**
Maria Greisman
Egor Savvateev
Artyom Safronov
Aleksey Letov

**Perm' city:**
Nikolay Baranov
Vyacheslav Bolkisev
Inna Lubimova
Anatoliy Freeman

**Novosibirsk city**
Vladimir Grechishkin
Alina Odinitsa
Dmitriy Narodnev
Ekaterina Gorbatova

GNP+ – Omar Syarif, Pim Looze and Alexandra Volgina
Johns Hopkins University – Daria Ocheret
HIV Legal Network – Mikhail Golichenko, Senior Policy Analyst

### Graphic Design and Layout

Maria Yakovleva

# TABLE OF CONTENT

## List of abbreviations and acronyms

**GNP+** – Global Network of People Living with HIV
**ICW** – The International Community of Women Living with HIV/AIDS
**In-care** – People who report visiting HIV care facilities and getting HIV treatment
**KP** – Key Population
**LB** – Women who have sex with women
**Out-of-care** – People who haven't visited HIV care facilities for a certain time
**PLHIV** – People Living with HIV
**PWUD** – People Who Use Drugs
**MSM** – Men who have Sex with Men
**SW** – Sex Workers and/or people who report exchanging sex for money or material reward
**TG** – People who self-identify as Transgender people
**UNAIDS** – The Joint United Nations Programme on HIV/AIDS
**NGO** – Non government organisation
**WSW** – Women who could have sex with women
**ARV or ARVT** – Antiretroviral treatment

## List of figures and tables

# EXECUTIVE SUMMARY

This report presents the findings and policy recommendations of the Stigma Index 2.0 study of PLHIV in four Russian cities. In 2020, the Russian Federation had the highest incidence of HIV infection among all countries of the WHO European Region (40.8 per 100,000 population), and new infections in Russia accounted for 57% of all infections in the European Region, according to the European CDC and WHO (HIV/AIDS surveillance in Europe, 2021). Among the main reasons for such plight in HIV treatment are PLHIV stigma and discrimination in Russia. Stigma and discrimination discourage people from seeking HIV care and treatment, and also reduce the likelihood of key populations seeking HIV testing.

There is almost nothing known about stigma and discrimination in the cities with fewer research projects, and moreover, nothing is known about the intersectional stigma among PLHIV who can simultaneously be women living with HIV or representatives of the LGBT community, sex workers, and/or use illegal substances. Therefore, the Stigma Index 2.0 was conducted in four Russian cities with the high levels of HIV prevalence – Perm, Novosibirsk, Togliatti, and Yekaterinburg – in order to better understand experiences of stigma towards PLHIV in smaller cities. With more than 1% of the population being HIV-positive, all four cities qualify as territories with a generalized epidemic (Pisani et al. 2003).

# STUDY FINDINGS

The results of the study show an updated landscape of PLHIV across the different key populations groups. The study sample was composed of participants who mostly belonged to KPs – only, about 20% did not belong to any of key population groups. The largest represented in the study subgroups were PWUD, sexual workers and MSM. Near one-third of participants identified themselves as two or even more of the key populations (28,2%, n=134). Intersectional identity in the sample was mostly frequent in subgroups of MSM-PWUD (n=19) and sex workers-PWUD (n=62).

**THE TOTAL NUMBER OF STUDY PARTICIPANTS WAS 482.**

The internalized stigma was more relevant for study participants in comparison with the "external" stigmatization and discrimination. That phenomenon draws attention to the quality of consultations before and after HIV-testing, as well as to availability and openness of PLHIV networks, peer support groups and local PLHIV communities.

Stigma Index 2.0 indicated that HIV+ status had the greatest negative impact on the ability of respondents to find love (33,8%), on self-confidence (36,1%), on the ability to maintain close and secure relationships (35,5%), on desire to have children (32,2%), on self-respect (28,2%), and on the ability to cope with stress (28%).

Restriction or impossibility for PLHIV to meet their own basic needs (such as sex, medical help, having work, communication with family and other people) were caused by hiding HIV status from others (81,3%), difficulties in telling people about HIV status (69,9%), feeling ashamed or guilty because of HIV+ status (53,7% and 51,5%). Among less significant reasons were "feeling worthless" and "dirty" (41,7% and 34,9%).

42% of participants of the Stigma Index 2.0 Study felt that their decision to get tested for HIV was involuntary. 27% were tested without their knowledge and found out only after the test had been performed. The latter tendency draws attention to HIV testing facilities quality. Russian officials put a lot of efforts into large-scale testing on HIV. The unintended consequence of these efforts were the HIV-positive results for those who didn't want to be tested for HIV.

In the last 12 months 16 participants (3,3%) were recommended not to have children. In seven cases (1,5%) medical staff suggested to use a specific method of contraception in order to get HIV treatment instead of offering the alternative type of contraception, and in two cases they pressured female participants to undergo sterilization (0,4%). As for the discriminatory and stigmatizing advice concerning pregnancy, delivery and breast feeding PLHIV indicated the violation of their reproductive rights in the near past (5 cases) and, accumulatively, more cases of violation much earlier (203 cases). That kind of situation needs to be resolved at the level of obstetric and gynecological services.

## LAW AWARENESS AND LAWS FOR PLHIV

Participants' level of knowledge about laws that protect PLHIV from discrimination in Russia was insufficient. Only 35% of PLHIV in the study answered that they were aware of laws that protect PLHIV from discrimination. Also, PLHIV were not reporting cases of violation when 9% of the participants reported having suffered human rights violations. These findings correlate with the low level of law awareness among Russian population and distrust of rights protection institutions.

### STIGMA, DISCRIMINATION AND HIV DISCLOSURE AMONG KEY POPULATION

PLHIV belonging to key populations experienced intersectional stigma and discrimination. Being verbally or/and physically harassed, as well as being in stigmatizing relationships with family was outnumbered in all subgroups. As for belonging to the peer support groups MSM had the highest levels of that indicator (37,3%); sex workers, WSW and bisexual people had the lowest rates of group membership. The high levels of social embeddedness of MSM correlated with a great inclusion of the latter in medical services.

### LOW LEVEL OF HIV RELATED TREATMENT AND LOW ACCESS TO HIV-CARE SERVICES

Additional questionnaire for Stigma Index 2.0 in Russian Federation revealed problematic trends regarding ART in the studied populations. 51% (n=246) did not take ART treatment at the time of the study. Among those 236 (49%), who had been taking treatment at the time of study, a majority of these people (n=214) have started taking new ART pills within the last year. Only 7,5% (n=16) of them have been assigned tests for ART drugs resistance.

In 57,7% of ART prescriptions there were changes during the year of the study for non-medical reasons.

About a quarter of participants faced situations when their visit to an HIV-care facility or for viral load and CD4 testing did not take place at the time of COVID19 lockdown (in the beginning of year 2020).

## RECOMMENDATIONS

### FOR IMPROVING THE PLHIV SURVEILLANCE SYSTEM IN RUSSIA

- It is crucial to upgrade the existing system of "epidemiological investigations" of newly detected HIV-cases to update surveillance data and to provide reliable epidemiological data in order to reflect the real numbers of PLHIV in key population groups. The upgraded system should eliminate the stigmatization and discrimination of key populations because of their identities.

### TO REDUCE STIGMA AND DISCRIMINATION EXPERIENCED BY RUSSIAN PLHIV, INCLUDING INTERNAL STIGMA:

- Integrate into medical departments syllabuses topics on human rights, patients' rights, gender equity, and stigma and discrimination towards the KPs.
- Strengthen the active participation of peer-to-peer counselors on HIV in multidisciplinary teams to improve access to health services and improve patients' mental health. To set up rooms for psychosocial counseling in each of AIDS Centers with the state-level financial aid.

- Promote a training programme for PLHIV and KPs on stigma and discrimination issues in health centers, places of work and at educational institutions.

### TO TACKLE INVOLUNTARY HIV TESTING AND HIV STATUS DISCLOSURE IN HEALTHCARE SERVICES:

- Train health services providers on (a) pre- and post- HIV-test counselling, (b) keeping confidentiality of HIV-positive and HIV-negative results, (c) achieving informed consent from patients.
- Changes should also be made in the Code of Administrative Offences; these modifications aim to enforce the investigation of confidentiality breach and prosecute the perpetrators among medical services providers, law enforcement officers and local authorities.

### TO ENSURE QUALITY HIV-CARE SERVICES:

- Unify official recommendations for medical specialists and include these protocols into the "roadmaps" for PLHIV services:

o Get ART treatment with no obligatory residence cards ("registration at the place of residence");

❶ Give out more tests for ARV-drugs resistance;

❷ During the COVID–19 pandemic, identify PLHIV as a specific category of socially disadvantaged citizens to provide them with targeted social assistance, and to ensure that ARV treatment is handed out for months (in advance) as in accordance with WHO recommendations;

❸ Start ART treatment immediately after diagnosis with HIV infection.

### TO IMPROVE LAW AWARENESS AMONG PLHIV:

- There is a need for a referral system that connects PLHIV and paralegals/ People's Lawyers. This system will ensure that legal advice services are available in cases of discrimination or HIV transmission criminalization.

- Include NGOs in the design of toolkits tailored for the social work with key populations, such as MSM, youth, women, PWUD, and SWs. (Support the active participation of PLHIV NGOs in the elaboration and implementation of "roadmaps" for delivery of sexual and reproductive health services and improving quality of life of female LHIV).

- Ensure participation of people living with HIV in HIV-related governmental working groups, committees and commissions.

# RECOMMENDATIONS

## TO IMPROVE REPRODUCTIVE HEALTH AND RIGHTS PREVENTION:

- Provide advice on family planning, sexual and reproductive rights to all KPs (WSW, MSM, TG people);
- Integrate into the Population Policy Statement for 2021 – 2025 a strong emphasis on a greater access of women living with HIV to services related to prevention, sexual and reproductive health, family planning and contraception.
- Combine efforts of Infectious Diseases and Obstetric and Gynecological services to create a comfortable environment for pregnancy and childbirth.
- For Obstetric and Gynecological services to initiate regular training to enhance the knowledge and capacities of health service providers on sexual and reproductive health of female LHIV.
- For AIDS Centers, medical clinics, law enforcement agencies and NGOs to initiate and maintain regular trainings on reducing stigma and discrimination of women who live with HIV and women from other key population groups.

# Section 1.

# Introduction: Context and Justification

## 1.1 HIV SITUATION IN RUSSIAN FEDERATION

Beginning in 1990s, Russia experienced HIV incidence increases that are among the sharpest in the world. In recent years, in Russia, according to the data of the federal state statistical observation, there has been a decrease in the number of new cases of HIV infection from 100,000 in 2015 to 60,396 in 2020 (Rosstat, 2021). However, the situation remains unfavorable. In 2020, the Russian Federation had the highest incidence of HIV infection among all countries of the WHO European Region (40.8 per 100,000 population), and new infections in Russia accounted for 57% of all infections in the European Region, according to the European CDC and WHO (HIV/AIDS surveillance in Europe, 2021). The same source states that due to the change in the surveillance system in Russia, data for 2009 – 2015 cannot be directly compared with data for 2016 – 2020, and the decline in the incidence of HIV infection in 2020 is mainly due to a decrease in the actual volume of testing on HIV and a decrease in the use of medical care. Since the Ministry of Health of Russia in recent years has not published available analytical materials on HIV infection in Russia, the publication of the European Center for Disease Prevention and Control/WHO contains the most up-to-date and complete data.

**IT INDICATES THAT IN RUSSIA ONLY FOR 2009 – 2020 THERE WERE A TOTAL OF 940,856 PEOPLE LIVING WITH HIV (HIV/AIDS SURVEILLANCE IN EUROPE, 2021).**

The recorded number of people living with HIV in 2019 was over 1,4 million (Nikolaieva, et al., 2020) and the estimated true number is believed to be much higher. HIV-care medical services and antiretroviral therapy are available in Russia but a large proportion of PLHIV stay out of care or discontinue their treatment. As of November 1, 2021, according to the Federal Register of Persons Infected with Human Immunodeficiency Virus, in the Russian Federation, 747,571 patients had open dispensary observation cards, of which 627,984 patients were receiving ARV therapy (Ministry of Health of Russia, 2021). As for antiretroviral treatment adherence, not all Russian PLHIV adhere to their regimens at levels needed for viral suppression. In 2020, 75,1% of those receiving ARV treatment had viral suppression (Rospotrebnadzor, 2021).

According to official statistics the incidence rate of HIV infection in the country in 2020 was 41,2 per 100 thousand population. It was higher than the national average in 31 regions of the Russian Federation, including regions of this study – Sverdlovsk region (84,4), Perm region (117,2), Novosibirsk region (68,7), and Samara region (76,3) (Rosstat, 2021a). The same regions are among the most affected by HIV infection.

In Russia HIV is widespread among the population of the working age. In 2020, 71,4% of all newly diagnosed HIV cases were attributed to patients aged 30–50. Male PLHIV was the dominant group among all registered HIV-positive people in the Russian Federation in 2020 (62,6%), while female LHIV accounted for 39,2% of newly registered cases of the disease (Rospotrebnadzor, 2021).

In recent years HIV infections have gone beyond the key populations groups and are actively spreading in the general population. 64,9% of patients newly diagnosed in 2020 acquired HIV through heterosexual contacts (Rospotrebnadzor, 2021). However, the prevalence of HIV among KPs significantly exceeds the general population. In 2017, the Open Institute of Public Health Foundation, with the support of Rospotrebnadzor, conducted a study in key vulnerable groups in 7 large cities of the Russian Federation (n=3744). According to the results of the study, a high prevalence of HIV was revealed among PWUD (from 48,1% to 75,2%), among MSM (from 7,1% to 22,8%), and among sex workers (from 2,3% to 15%) (Plavinsky et al., 2018).

Among the main reasons for such plight in HIV treatment are PLHIV stigma and discrimination in Russia. Stigma and discrimination discourage people from seeking HIV care and treatment, and also reduce the likelihood of key populations seeking HIV testing (Ho & Halloway, 2016; Peitzmeier et al., 2015).

## 1.2 PLHIV STIGMA AND DISCRIMINATION IN RUSSIA

According to recent studies, Russian PLHIV indicated high levels of internalized and anticipated HIV stigma, as well as stigma related to HIV and illicit substance use (Lunze et al., 2017; Calabrese, 2016; Burke et al., 2015). Earlier studies in Russia distinguished stigma directed toward people living with HIV (Lioznov et al., 2011; McCrae et al., 2007; Balabanova, et al., 2006) and people who inject drugs (Bobrova et al., 2006; Rhodes et al., 2006), as well as the effect of HIV and stigma related to drug use on service utilization when stigma was a major barrier to care engagement (Kelly et al., 2014; King et al., 2013). "Internalized stigma" or self-stigma and worry that one's HIV status would become known prevent people from HIV medical care visits and treatment. An in-depth interview-based study documented that one-third of out-of-care PLHIV described past negative experiences when interacting with HIV medical staff: PLHIV felt stigmatized based on some negative attitudes by care providers and observed excessive safety precautions taken by medical workers (Kuznetcova et al., 2016).

## 1.3 PLHIV STIGMA INDEX STUDIES IN RUSSIA

PLHIV often face stigma and discrimination; many of them do not know what their rights are and how they can act to change things for the better. This study aims to collect information on stigma and discrimination that people living with HIV experience, that will help their advocacy efforts in stopping these stigmatizing practices. The People Living with HIV Stigma Index 2.0 study is an updated version of the original People Living with HIV Stigma Index that was started in 2008 by the initiative of international organizations working in the field of PLHIV rights advocacy – IPPF, GNP+, ICW, and UNAIDS (www.stigmaindex.org). The PLHIV Stigma Index methodology allows witnessing the extent and various forms of stigma and discrimination faced by people living with HIV in different countries. Thereby the methodology has been used as a local, national and global tool in advocacy for improving rights for PLHIV. The PLHIV Stigma Index was created to support and reflect the Greater Involvement of People Living with HIV (GIPA) principles.

**THE PLHIV STIGMA INDEX IS A STUDY THAT HAS BEEN DEVELOPED AND IMPLEMENTED BY AND FOR PEOPLE LIVING WITH HIV. IT AIMS TO COLLECT INFORMATION ABOUT THE EXPERIENCES OF PEOPLE LIVING WITH HIV RELATED TO STIGMA, DISCRIMINATION AND THEIR RIGHTS.**

# INTRODUCTION: CONTEXT AND JUSTIFICATION

In all countries, the process of implementing and using data from the index is led and owned by people living with HIV. These are the local PLHIV networks themselves that decide to conduct a PLHIV Stigma Index in their community or country. The PLHIV Stigma Index 2.0, introduced in 2018, reflects the up-to-date conditions of PLHIV; it puts a greater focus on the inclusion of PLHIV in all their diversity, and documents intersectional stigma.

In 2010 the first research on the stigma index was conducted in Russia with participation of the community of PLHIV. 660 individuals from 6 regions of Russia took part in this research. Study sample consisted of male and female equal proportion. The study methodology used a snow-ball technique, therefore population groups coverage in the study sample was not adequate. The study sample consisted mainly of 59% PWUD and 24% incarcerated persons (Levada, 2010). Remain sample consisted of MSM (2%), “gay/ lesbian” (4%), sex workers (7%), migrants (6%) and “others” – i.e., those, “who do not belong and didn’t belong to any of these groups” (29%). Over a third of the study respondents (35%) had faced some form of discrimination or stigmatization from those around them at some point for reasons including their HIV status. Over 20% of the respondents faced some kind of discrimination from an organization or institution due to their HIV status. The majority of study participants experienced internalized stigma in relation to HIV (78%). In this study, the voices of other key affected populations of PLHIV who experience intersectional stigma based on various identities, their experience, and practices remained unrepresented. Key populations here is an umbrella term and the current PLHIV Stigma Index 2.0 is referring to the four main groups – people who use drugs; sex workers; transgender people, gay men and other MSM.

The data from the research in Russia that is currently available illustrates that much remains unstudied in the field of stigma and discrimination of PLHIV in the Russian Federation. Well documented research on stigma and discrimination has been conducted in the largest and capital cities – Moscow and Saint Petersburg. There is almost nothing known about stigma and discrimination in the cities with fewer research projects, and moreover, nothing is known about the intersectional stigma among PLHIV who can simultaneously be women living with HIV or representatives of the LGBT community, sex workers, and/or use illegal substances. Therefore, the Stigma Index 2.0 was conducted in four Russian cities: Perm, Novosibirsk, Togliatti, and Yekaterinburg in order to better understand experiences of stigma towards PLHIV in smaller cities.

# 1.4 GOAL AND OBJECTIVES

The main goal of that study is to describe the patterns of stigma and discrimination faced by people living with HIV in Russia. The intersectional stigma is a new reality that requires a broad and correct understanding of PLHIV stigma and discrimination. To grasp the adequate and unbiased representation of the intersectional stigma among Russian population, the study is led and implemented by PLHIV. This study data helps to elaborate recommendations for social policies through:

❶ Documenting the various experiences of people living with HIV within a particular community or country regarding HIV-related stigma and discrimination and intersectional stigma due to high-risk behavior;
❷ Comparing experiences across key populations in four cities of Russian Federation;
❸ Providing an evidence base for policy change and programmatic interventions;
❹ Informing the development and implementation of national policies that protect the rights of people living with HIV;
❺ Shaping the design of programmatic interventions so that they consider the issue of HIV-related stigma and discrimination within their content.

Specific country aim was to document the challenges in getting HIV medical care and services. To achieve this aim, we included additional questions in the questionnaire provided by GNP+. Barriers to effective medical treatment and support for PLHIV contribute to development of HIV related discrimination and stigma, and also entail violation of human rights. The expected results from the PLHIV Stigma Index 2.0 are production of a new knowledge and collection of evidences on how stigma influences PLHIV quality of life and well-being.

This study was done with the scientific and technical guidance of GNP+, John Hopkins University, ICW, and with the assistance of UNAIDS and Russian HIV-positive people.

# Section 2.
# Methodology

## 2.1 GEOGRAPHICAL SCOPE

The following criteria were taken into consideration when choosing the cities in which the research was meant to be conducted: population, HIV prevalence, and access to the behavioral subgroups – PWUD, SW and LGBT communities' members. The cities of Perm (1,055,397 residents), Novosibirsk (1,625,631), Togliatti (699,367), and Yekaterinburg (1,493,749) were chosen. According to official data, all the chosen cities fall into the category of high HIV prevalence among the population and the available data from these cities shows the presence of key affected populations to which the research team has access. With more than 1% of the population being HIV-positive, all four cities qualify as territories with a generalized epidemic (Pisani et al. 2003). As it is crucial for this study to shape HIV interventions and to provide the evidence base for policy change it is quite important to study intersectional stigma appearance in various regional social and political contexts.

**ALL CITIES ARE DIFFERENT WHEN IT COMES TO NON-GOVERNMENTAL HIV PREVENTION LANDSCAPE AND COLLABORATION BETWEEN STATE, NGOS AND HIV-POSITIVE PEOPLE.**

These cities are especially interesting as intersectional stigma and discrimination of PLHIV in these cities is little studied in comparison to Moscow and Saint Petersburg, and have completely different characteristics than the capital cities which have more-or-less transparent statistics and visible LGBT and drug scenes.

## 2.2 STUDY POPULATION

### 2.2.1 ELIGIBILITY AND EXCLUSION CRITERIA

The eligibility criteria for potential participants were the following:

- aged 18 years and above;
- self-reported that they are living with HIV and have been aware of their status for at least 12 months;
- were willing to participate in the study;
- were mentally sound and capable of providing consent to participate;
- spoke the Russian language;
- have provided informed consent.

**GENDER INCLUSION:** The study sample included both men and women in approximately the same proportions as the gender distribution of PLHIV in Russia. Of the 482 study participants, approximately 54% were men and 45% were women. Three persons (0,6%) preferred not to answer questions about their gender identity. Another two respondents identified themselves as transgender people (0,4%).

**RURAL AND SMALL-TOWN POPULATION:** As it was crucial for this study to include areas where stigma could be more prevalent, we anticipated including “rural” population in HIV care facilities located in big cities. Most of the rural areas in Russia do not have HIV care facilities where CD4-cells/Viral load tests and HAART are performed. Besides that, most of PLHIV from rural areas prefer to visit big cities facilities where the confidentiality regarding HIV status is more likely to be respected. Rural people were recruited by limited chain referral method.

**INCLUSION OF YOUNG PEOPLE:** This study enrolled participants who are aged 18 and over. It was crucial for the study to involve more young people in order to represent a diversity of different ages. Approximately 16% of the sample were under the age of 29 and 84% were older.

### 2.2.2 SAMPLE SIZE

Taking into consideration the huge budget limitations and the total lack of official data on HIV prevalence from the epidemiological surveillance agency, the research team decided to calculate the sample size using estimates of the regional key informants and their suggestions. Thus, the total number of study participants is 482.

# 2.3 RECRUITMENT AND PROCEDURES WITH STUDY PARTICIPANTS

## 2.3.1 SAMPLING APPROACH

The sampling approach combined two strategies – venue-based sampling (or “time location sampling”) and limited chain referral. The first one was the main enrollment strategy and the second one was used as an additional method to the first strategy. If challenges have arisen in choosing participants from a certain subgroup for the research the limited chain referral method was used. Potential participants have been approached and enrolled to the study by the interviewers, who represented local PLHIV communities – NGO and charitable foundations' beneficiaries and/or volunteers. Study participants were recruited from community venues, local NGOs, in medical service settings, and through participants' recommendations.

## 2.3.2 DATA COLLECTION TEAM

Study data were collected by 16 interviewers (four persons in each of the four cities, 7 males and 9 females) – local outreach workers and NGO volunteers with the disclosed HIV-positive status – they have screened, enrolled, and interviewed participants. Data collection team members represented all study key population groups (MSM/SW/PWUD, etc.) and were selected based on their experience of living with HIV and background regarding conducting study and field work with a target population. Data collectors form a diverse group and represent different ages and genders.

Data collectors have been trained to be familiar with the questionnaire, and with the study procedures and research ethics. The training workshop for the interviewers was held in mid-April 2021 with the participation of GNP+, Kazakhstan Stigma Index coordinator and Russia Stigma Index coordinator. All the workshop materials and documents were provided and translated into Russian by GNP+ staff. Recruited interviewers were trained at a three-day workshop via ZOOM (the link to the workshop is available on request). During that training the interviewers learned about study ethics and code of ethical behavior during the fieldwork, research methodology and potential of advocacy, study partners and their collaborative networks. They were also guided on how to cope with participant's vulnerability, possible emotional distress and unexpected situations. They also have been advised how to refer study participants to further sources of information and help in their local setting. The list of such sources providing psychological, medical and legal help – "Local resource list of organizations and services" – was developed during the training by the interviewers as one of their homework

.

### 2.3.3 DATA COLLECTION STRATEGY

Potential participants have been approached and screened for eligibility criteria by the interviewers, who represented local PLHIV communities – NGO and charitable foundations' beneficiaries and volunteers. At the time when they have been initially screened for eligibility criteria, participants were asked to provide informed consent. Study procedures lasted one to two hours and took place in safe and confidential places (at community and NGO's offices). Answers received from respondents were collected and managed using REDCap electronic data capture tool hosted at John Hopkins University (Harris et al., 2009; Harris et al., 2019). REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources.

At the end of the interview, if needed, participants were referred to medical, legal or psychological services. According to study field reports 43,4% were referred to services, self-support groups, and for legal advice.

## 2.4 STUDY INSTRUMENTS AND ETHICAL CONSIDERATIONS

### STUDY INSTRUMENTS.

Data collection instrument, in the form of a PLHIV Stigma Index 2.0 questionnaire, was given by GNP+ office and included following sections: social and demographic characteristics, HIV-status disclosure, stigmatization and discrimination experience, external and internal stigma, HIV-testing and care, experience with the medical institutions, human rights, health status, etc. Russian study office also elaborated a set of additional questions on access to medical services and HIV-care quality at the time of COVID–19. Data collection took place with the aid of a questionnaire with open and closed questions.

### ETHICAL CONSIDERATIONS.

The Russian study protocol was approved by the local Ethics Committee at St. Petersburg (http://sociologists.spb.ru). Signing an informed consent form and confidentiality measures were the main steps to protect study participants.

Participants in the study provided a written informed consent. To avoid the bias and feeling of coercion by recruiting study participants in medical settings, potential participants have been consented only by research team and never by the staff of venues where they may receive services. With respect to data confidentiality, the study interviews were coded with a unique numerical identifier. This identifier contained two letters for country code (RF), two digits for interviewer code, two digits for interviewee code, six digits for the date of the interview (dd/mm/yy): e.g., RF0101030521. Each participant was supplied with a code, and only the code number appeared on study materials, datasets, and other information records. All the data, exported from the REDCap cloud storage, were kept as password protected Excel files; only the study coordinator and study partner had access to these files.

All study team members have signed confidentiality agreements. Also, all interviews have been conducted individually in confidential places and have been administered using REDCap application. That procedure made it unlikely for anyone to access participants' personal responses during and after the interview.

## 2.5 DATA ANALYSIS

Standard descriptive analyses were performed using IBM SPSS Statistics (version 27) and Microsoft Excel (version 16.43). Variables have been summarized using means, medians, and percentages, as appropriate. Some variables were recoded, and in some cases, data were disaggregated for the different subgroups in order to provide insights into the specific issues faced by each group – women and key population groups. Because of a great scope in intersectional identities (see Table 1, Table 2) data was disaggregated for eight big groups: male/female, LGBT/non-LGBT people, PWUD/non-PWUD, and SW/non-SW.

# Section 3. Study Results

## 3.1 DEMOGRAPHIC AND OTHER BACKGROUND CHARACTERISTICS OF PLHIV IN THE STUDY

### GENDER AND BIOLOGICAL SEX IDENTITY

The total number of PLHIV Stigma Index 2.0 participants was 482, of these 218 (45%) identified themselves as female and 259 (54%) – as male. Three persons (0,6%) preferred not to answer questions about their gender identity. Another two respondents identified themselves as transgender people (0,4%).

### AGE

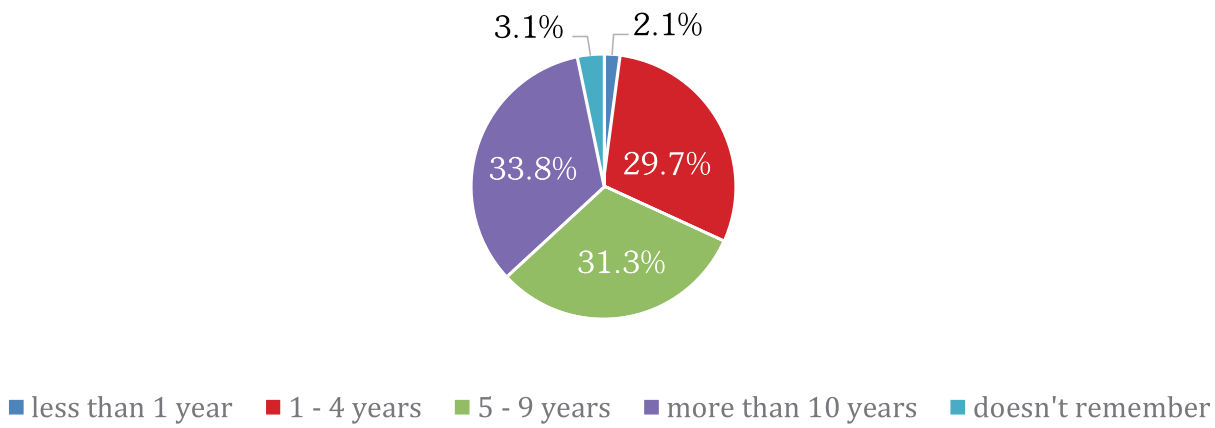
The sample reflected a range of ages. Nearly 5% of the sample was under the age of 25 years, 11% were 25–29, 50% were 30 – 39, 31% were 40–49, and 3% were aged 50 or older. The youngest participant was a 19-year-old man, and the oldest was a 58-year-old woman. The mean age for the all sample was 36,7 ± 6,95 years.

# STUDY RESULTS

## THE DURATION OF LIFE WITH HIV

The respondents include people with different duration of life with HIV. Nearly one-third was diagnosed with HIV 1–4 years ago (n=143), one-third – 5–9 years ago (n=151), and one-third – more than 10 years ago (n=163).

**Figure 1. The duration of life with HIV (n=482, %)**



## SEXUAL PARTNERS AND THEIR HIV-STATUS

75% (n=362) of the participants are currently in an intimate / sexual relationship, and almost half of them have HIV–positive partners (42%, n=200). 24% (n=117) have HIV–negative sexual partners, and 9% (n=45) are not aware of the partner's HIV–status.

## CHILDREN

Out of 482 participants 60% (n=287) indicated they do not live in a household with children; 28% (n=137) – live in a household with one child, and 12% (n=58) with two or more children.

## EMPLOYMENT STATUS AND EDUCATION

23 persons (5%) indicated that they were studying at the time of the study. 97 participants had higher education (20%), 205 (42%) had vocational education, 142 (29%) secondary education, and 38 (8%) completed primary schools. One person had no education at all.

Half of the participants (50%) worked on a full-time basis and were hired employees; 18% were unemployed and 1,7% were retired (see Table 1 below).

## Table 1. Highest level of education and current work status (n=482, %)

| **Characteristics** | Female (n=218) | Male (n=259) | Transgender (n=5*) | N=482 |
|---|---|---|---|---|
| **Highest level of formal education** | | | | |
| No formal education | 0,5% | 0% | 0 | 0,2% |
| Primary/elementary/local equivalent | 7,8% | 8,1% | 0 | 7,9% |
| Secondary/high school/local equivalent | 30,7% | 28,2% | 2 | 29,5% |
| Trade/vocational school | 41,3% | 43,2% | 2 | 42,3% |
| University/tertiary education | 19,7% | 20,5% | 1 | 20,1% |
| **Current work status** | | | | |
| In full-time work (as an employee) | 4,1% | 6,6% | 0 | 5,4% |
| In part-time work (as an employee) | 16,5% | 13,5% | 3 | 15,4% |
| Working full-time, but not as an employee (self-employed or business owner) | 48,6% | 52,1% | 0 | 50% |
| Doing casual or informal part-time work (self-employed or paid work for others) | 9,2% | 9,7% | 1 | 9,5% |
| Retired/on pension | 1,4% | 1,5% | 1 | 1,7% |
| Unemployed | 20,2% | 16,6% | 0 | 18% |
| * Observations for transgender people are shown as numbers, not as percentage | | | | |

## MEETING BASIC NEEDS

51% (n=245) of the respondents were able to meet their basic needs, such as food, clothing, paying rent and utilities over the last 12 months. 36% (n=175) said that they were unable to meet their basic needs from time to time, and 13% (n=61) most of the time.

## BELONGING TO SOCIALLY VULNERABLE POPULATIONS

One-third of the study participants were incarcerated formerly (n=143). 15% identified themselves as members of a racial, ethnic, or religious minority (n=72), and 10% indicated that they belong to the group of people with disabilities (had eyesight, hearing, mobility, mental health/intellectual or other disability) (n=46).

## Table 2. Belonging to socially vulnerable populations

| (Respondents could choose several options) | n | % |
|---|---|---|
| Member of a racial, ethnic, or religious minority | 18 | 4 |
| Member of a local ethnic group | 72 | 15 |
| Person with a disability | 46 | 10 |
| Refugee or asylum seeker | 3 | 0,6 |
| Labor migrant | 1 | 0,2 |
| Internally displaced person | 4 | 0,8 |
| Formerly imprisoned | 143 | 30 |

### BEING A MEMBER OF A NETWORK OR SUPPORT GROUP OF PLHIV

20% (n=97) of participants were members of a support group or a network of people living with HIV.

## 3.2 HIV-STATUS DISCLOSURE

PLHIV often disclosed their status to their friends – 359 (74,5%), relatives – 349 (72,4%), and partners/spouses 340 (70,5%). Less often respondents disclosed their HIV status to neighbors (7,9%), local authorities (3,9%), and to classmates (3,3%).

**Table 3. People who knew about the respondents' HIV–status (%, n=482)**

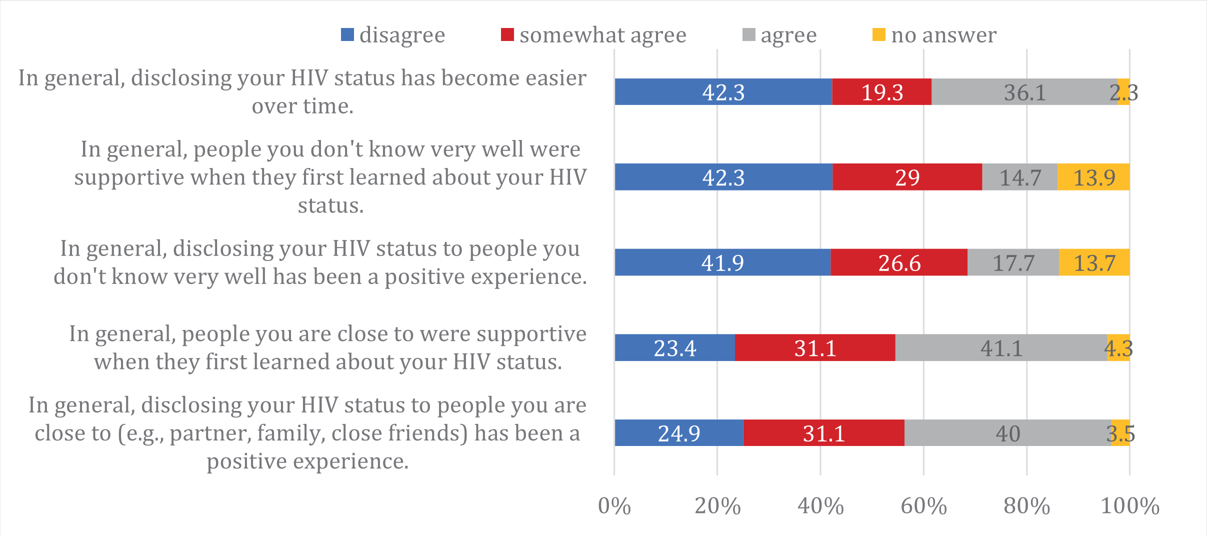
| People who knew about the respondents' HIV-status | Yes | Yes, without my consent | No | Not relevant for me |
|---|---|---|---|---|
| Husband/Wife/Partner(s) | 70,5% | 1,5% | 16,8% | 14,7% |
| Children | 13,3% | 0,8% | 47,3% | 41,3% |
| Other family members | 72,4% | 10,2% | 24,7% | 1,7% |
| Friends | 74,5% | 5,8% | 23,9% | 0,8% |
| Neighbors | 7,9% | 4,1% | 88,6% | 2,3% |
| Employers | 10,6% | 0,8% | 68,0% | 22,0% |
| Co-workers | 15,1% | 2,1% | 65,1% | 19,7% |
| Teachers/School administration | 0,4% | 0% | 37,6% | 64,1% |
| Classmates | 3,3% | 1,5% | 58,1% | 38,8% |
| Local leaders | 3,9% | 0,4% | 66,8% | 29,7% |
| Authority figures | 24,3% | 8,1% | 54,1% | 21,4% |

One out of every four participants indicated that authority figures (police, investigators, and judges) have known their status and very often without their consent or will.

Without the respondent's consent the information was most often disclosed to non-close relatives (10,2%); 8,1% respondents indicated that it was disclosed to enforcement officials, and 4,1% among the neighbors. Although such cases were rare, the proportion of unauthorized disclosures of HIV-status was significant in absolute terms (e.g. 20 cases out of 38 belonged to unauthorized disclosure among neighbors).

Most respondents agreed or partially agreed that the disclosure of the status to their loved ones was a positive experience, and that their loved ones supported them, when they had learnt about their HIV+ status (40% and 41,1%). Revealing their HIV+ status to strangers was not a positive experience at all, as well as coming-out among strangers hadn't become a ground for getting support and care from them (41,9% and 42,3%). It hadn't become increasingly easier to reveal information on the HIV+ status over time (42,3%).

**Figure 2. Do you agree with the following statements about your experience of revealing your HIV status (%)**

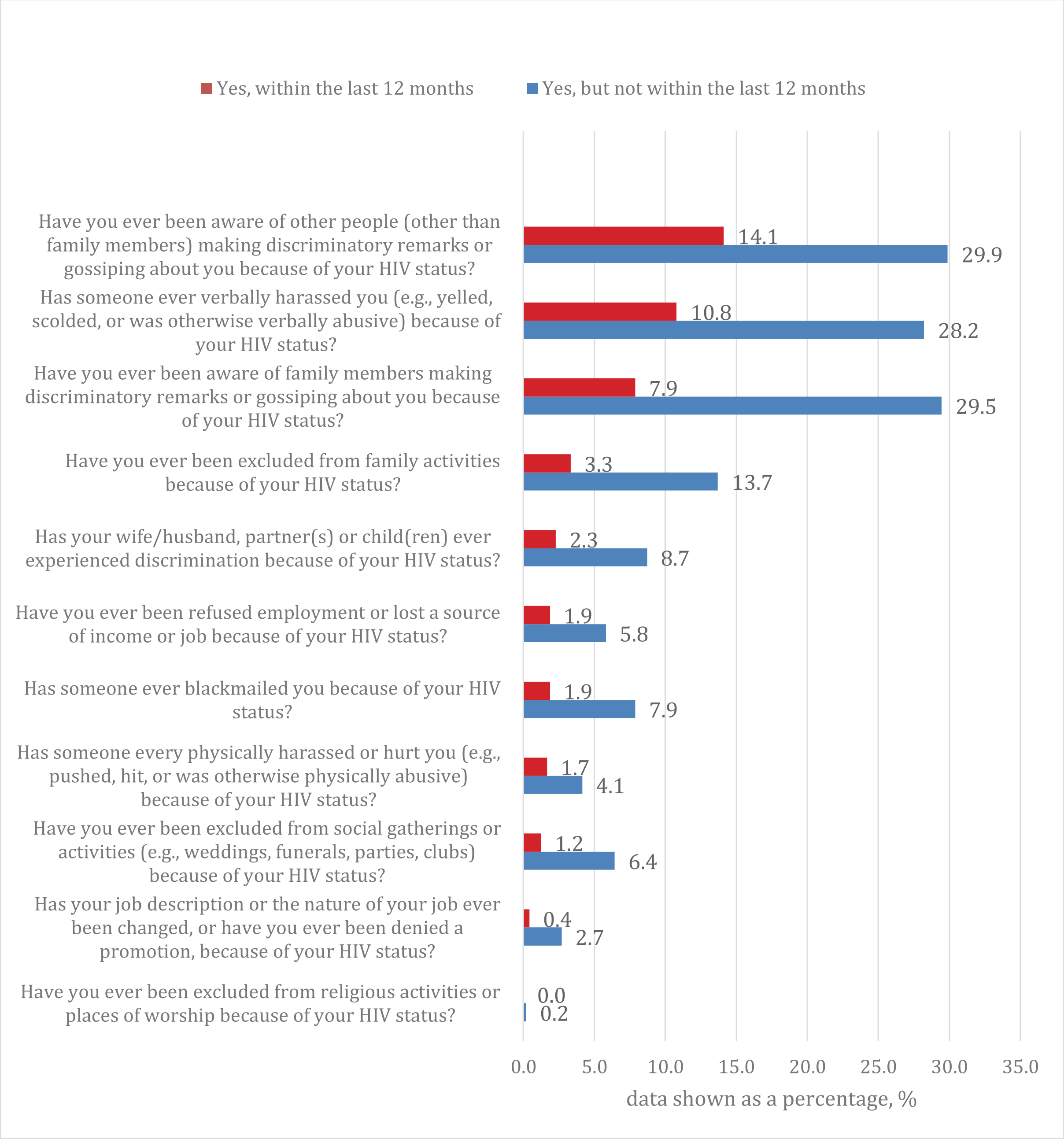


## 3.3 EXTERNAL STIGMA

External stigma or negative attitudes, beliefs, practices that were directed to participants from others and discrimination towards respondents over the last 12 months were most commonly experienced in the following ways: being aware of non-family members making discriminatory remarks or gossiping behind the respondent's back (14,1%); being harassed verbally because of the HIV status (10,8%); being aware of family members making discriminatory remarks about the HIV (7,9%); being excluded from family gatherings and meetings (3,3%); the wife/husband or partner experienced discrimination from others because of the respondent's HIV status (2,3%) (see Figure 3 below).

Not within the last 12 months, most commonly occurring forms of external stigma were the same, but its frequency was much higher, up to 2 – 2,5 times.

**Figure 3. Stigma and discrimination experienced in the past 12 months and earlier (n=482, %)**



In comparison with the female participants of the study male participants experienced different forms of abuse in higher proportions. These forms included discriminatory remarks by other people and family members and verbal abuse among others (see Table 4).

## Table 4. Stigma and discrimination experienced in the past 12 months and earlier by gender

| | Yes, within the last 12 months | | | Yes, but not within the last 12 months | | |
|---|---|---|---|---|---|---|
| | Male, (n=259) | Female, (n=218) | Trangender people* (n=5) | Male, (n=259) | Female, (n=218) | Trangender people* (n=5) |
| Have you ever been aware of other people (other than family members) making discriminatory remarks or gossiping about you because of your HIV status? | 17,8% (46) | 9,6% (21) | 1 | 30,5% (79) | 28,9% (63) | 2 |
| Has someone ever verbally harassed you (e.g., yelled, scolded, or was otherwise verbally abusive) because of your HIV status? | 13,9% (36) | 7,3% (16) | 0 | 25,9% (67) | 30,7% (67) | 2 |
| Have you ever been aware of family members making discriminatory remarks or gossiping about you because of your HIV status? | 9,7% (25) | 5,5% (12) | 1 | 25,1% (61) | 34,9% (76) | 1 |
| Have you ever been excluded from family activities because of your HIV status? | 3,5% (9) | 3,2% (7) | 0 | 12,7% (33) | 15,1% (33) | 0 |
| Has your wife/husband, partner(s) or child(ren) ever experienced discrimination because of your HIV status? | 3,9% (10) | 0,5% (1) | 0 | 10% (26) | 6,9% (15) | 1 |
| Has someone ever blackmailed you because of your HIV status? | 2,7% (7) | 0,9% (2) | 0 | 4,6% (12) | 11,5% (25) | 1 |
| Have you ever been refused employment or lost a source of income or job because of your HIV status? | 2,3% (6) | 1,4% (3) | 0 | 6,2% (16) | 5,5% (12) | 0 |
| Has someone every physically harassed or hurt you (e.g., pushed, hit, or was otherwise physically abusive) because of your HIV status? | 2,3% (6) | 0,9% (2) | 0 | 4,2% (11) | 4,1% (9) | 0 |
| Have you ever been excluded from social gatherings or activities (e.g., weddings, funerals, parties, clubs) because of your HIV status? | 1,5% (4) | 1,4% (3) | 0 | 4,6% (12) | 8,3% (18) | 1 |
| Has your job description or the nature of your job ever been changed, or have you ever been denied a promotion, because of your HIV status? | 0,4% (1) | 0,5% (1) | 0 | 2,3% (6) | 3,2% (7) | 0 |
| Have you ever been excluded from religious activities or places of worship because of your HIV status? | 0,4 (1) | 0 | 0 | 0 | 0,5% (1) | 0 |

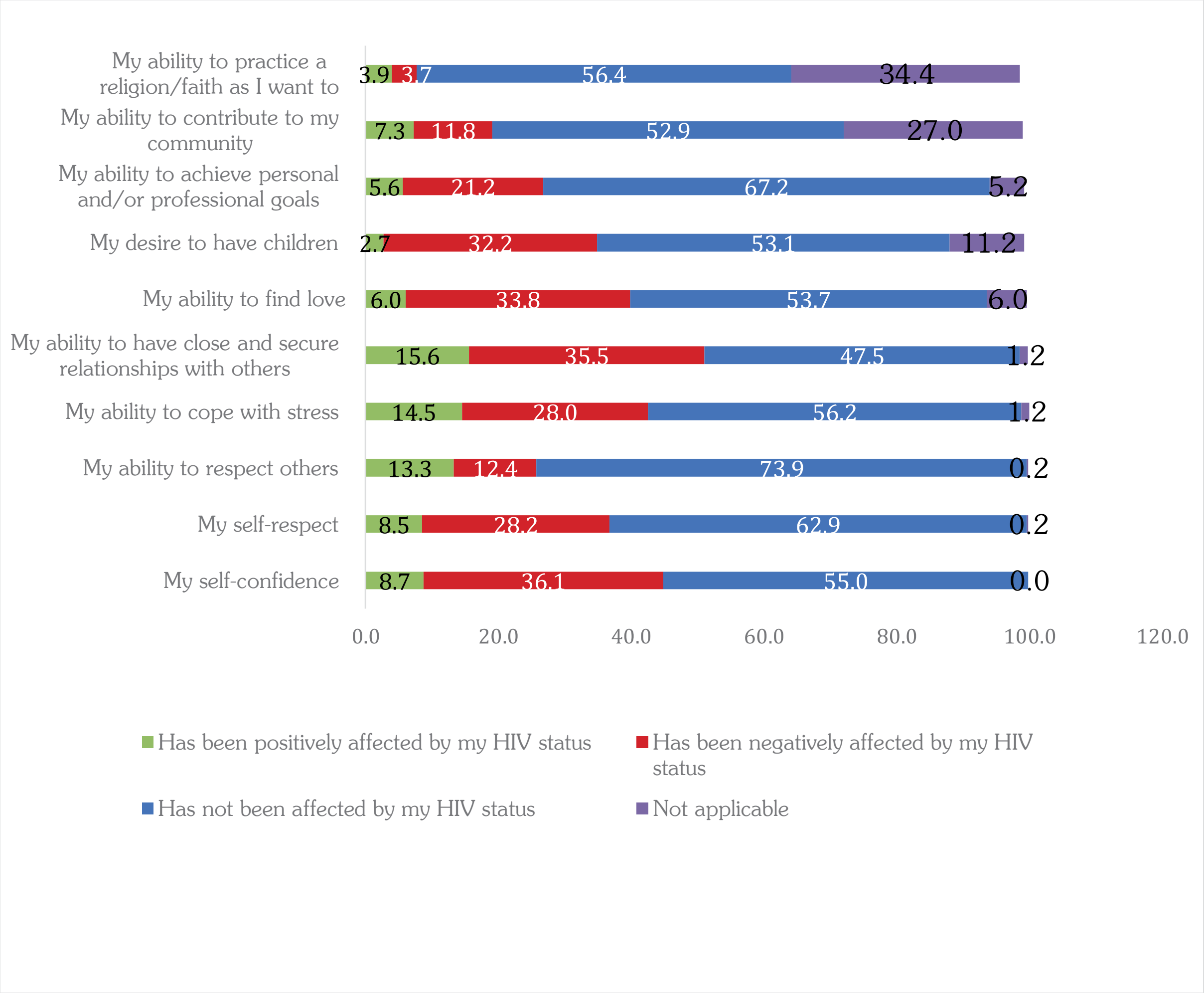
* Observations for transgender people are shown as numbers, not percentage

# 3.4 INTERNALIZED STIGMA

Study participants experienced internalized stigma when they were aware of negative attitudes and beliefs towards PLHIV, agreed with it and applied it to themselves (Corrigan et al., 2009). The respondents indicated that HIV+ status had the greatest negative impact on their ability to find love (33,8%), on self-confidence (36,1%), on the ability to maintain close and secure relationships (35,5%), on desire to have children (32,2%), on self-respect (28,2%), and on the ability to cope with stress (28%) (See Figure 4 below).

Almost one out of every two participants thought that HIV+ status had no influence on their ability to practice faith or religion, ability to participate in community life, achieving personal and professional goals, on desire to have children, and ability to find love.

**Figure 4. The impact of HIV status on various aspects of respondents' lives, %**



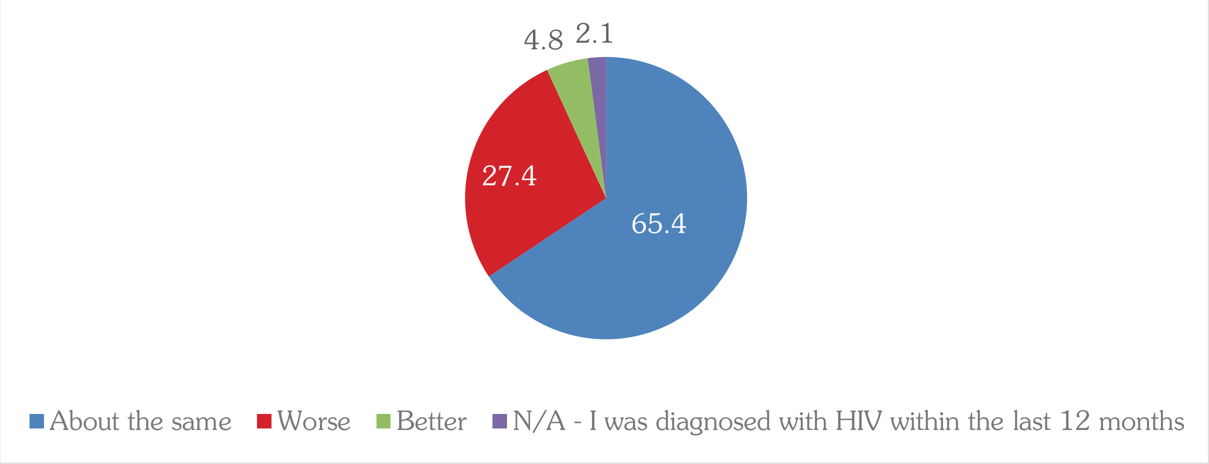
The comparison of the negative experience of female, male and transgender people showed that transgender people were much more likely to feel negative impact of HIV status on their ability to have close relationships and ability to cope with stress. For male participants subgroup the most negatively affected abilities – comparing to female subgroup – were ability to have close relationships, ability to find love, and ability to achieve personal or professional goals. In comparison with male, for female LHIV the abilities to respect others and to cope with stress were more affected negatively by their HIV status (see Table 5).

**Table 5. The negative impact of HIV status on various aspects of respondents' lives in subgroups by gender (%, n=482)**

|  | Male, (n=259) | Female (n=218) | Trangender people* (n=5) |
|---|---|---|---|
| My self-confidence | 35,5% (92) | 36,7% (80) | 2 |
| My self-respect | 27,4% (71) | 29,4% (64) | 1 |
| My ability to respect others | 10,4% (27) | 15,1% (33) | 1 |
| My ability to cope with stress | 22,8% (59) | 33,5% (73) | 3 |
| My ability to have close and secure relationships with others | 39% (101) | 30,3% (66) | 4 |
| My ability to find love | 37,5% (97) | 29,4% (64) | 2 |
| My desire to have children | 31,3% (81) | 33,5% (73) | 1 |
| My ability to achieve personal and/or professional goals | 24,3% (63) | 17% (37) | 2 |
| My ability to contribute to my community | 11,2% (29) | 12,4% (27) | 1 |
| My ability to practice religion/faith as I want to | 4,6% (12) | 2,3% (5) | 1 |
| * Observations for transgender people are shown as numbers, not percentage |  |  |  |

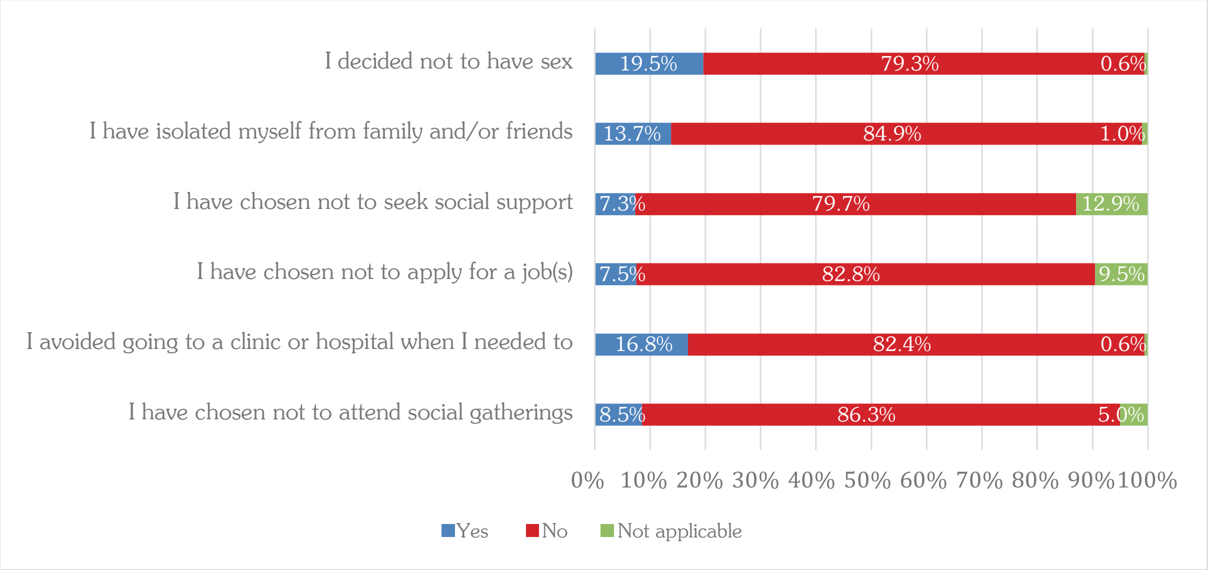
The impact of HIV status on various aspects of lives has remained the same since last year: that was confirmed by 65,4% of participants (n=315).

### Figure 5. How did your HIV status affect relevant aspects of your life earlier than 12 months ago? (n=482, %)



In the past 12 months, every fifth respondent (19.5%, n = 94) decided not to have sex due to their HIV status. Almost one in six respondents (16,8%, n= 81) decided not to use medical services, and one in seven separated themselves from family and friends (13,7%, n=66).

### Figure 6. Rejection of action and/or opportunities because of the HIV+ status in the past 12 months (n=480, %)



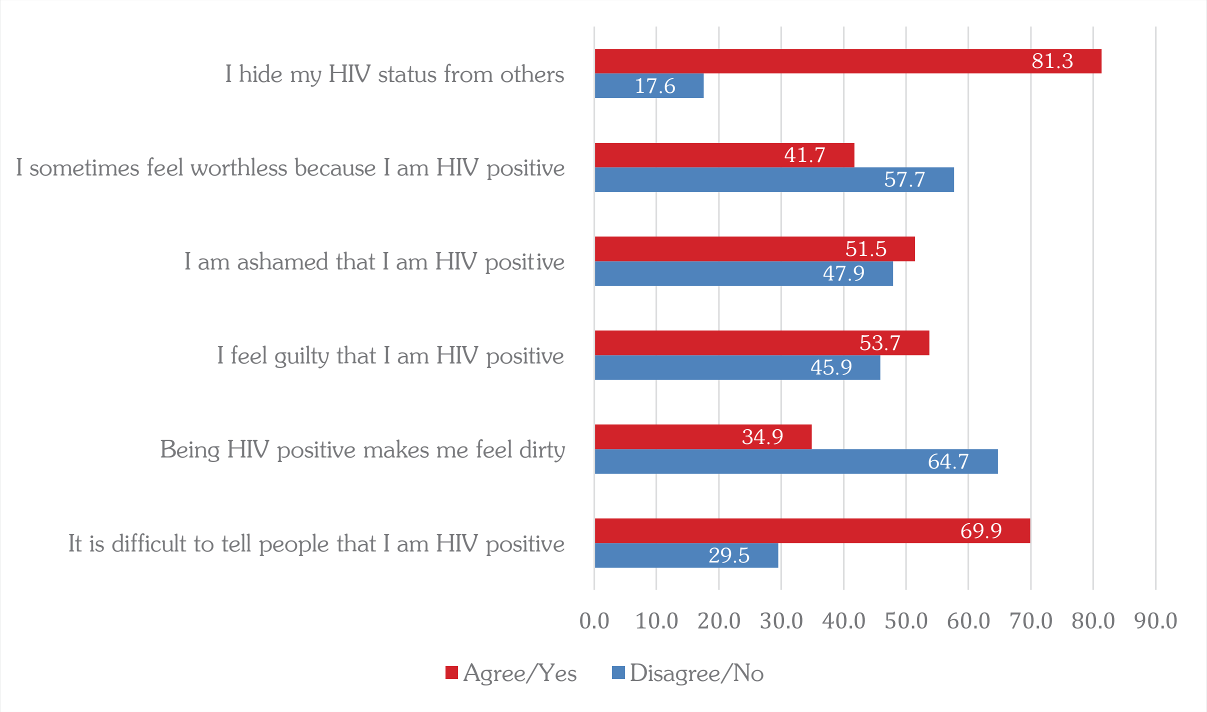
Percentages of male respondents referring to some of avoided activities (e.g. avoiding sexual contacts, self-isolation, and refuse to apply for a job) because of their HIV-positive status were higher compared to the ones of the other female subgroup (see Table 6).

## Table 6. Actions avoided because of HIV-positive status in the previous 12 months in subgroups by gender (%, n=482)

| | Male, (n=259) | Female (n=218) | Trangender people* (n=5) |
|---|---|---|---|
| I have chosen not to attend social gatherings | 8,9% | 7,8% | 1 |
| I avoided going to a clinic or hospital when I needed to | 16,2% | 17,4% | 1 |
| I have chosen not to apply for a job(s) | 9,7% | 4,6% | 1 |
| I have chosen not to seek social support | 6,9% | 7,3% | 1 |
| I have isolated myself from family and/or friends | 15,4% | 11,5% | 1 |
| I decided not to have sex | 24,7% | 13,8% | 0 |
| * Observations for transgender people are shown as numbers, not percentage | | | |

Restriction or impossibility for PLHIV to meet their basic needs (such as sex, medical help, having work, communication with family and other people) were caused by PLHIV hiding their HIV status from others (81,3%), by having difficulties in telling people about HIV status (69,9%), and by feeling ashamed or guilty because of HIV+ status (53,7% and 51,5%). Among less significant reasons were "feeling worthless" and "dirty" (41,7% and 34,9%).

## Figure 7. States experienced because of HIV+ status (n=480, %)



According to the data analysis among subgroups by gender, female participants and transgender people had the highest levels of self-stigmatization in some areas (see Table 7 below). Transgender participants in big proportions (n=4) found it hard to tell people about their HIV+ status, many (n=4) feel guilty about being HIV+

and many (n=5) hide their status from others. Likewise, high proportions of females (87.6%) hide their HIV status from others and find it difficult to tell others about their HIV+ status (80.7%).

**Table 7. Internalized stigma in subgroups by gender (%, n=482)**

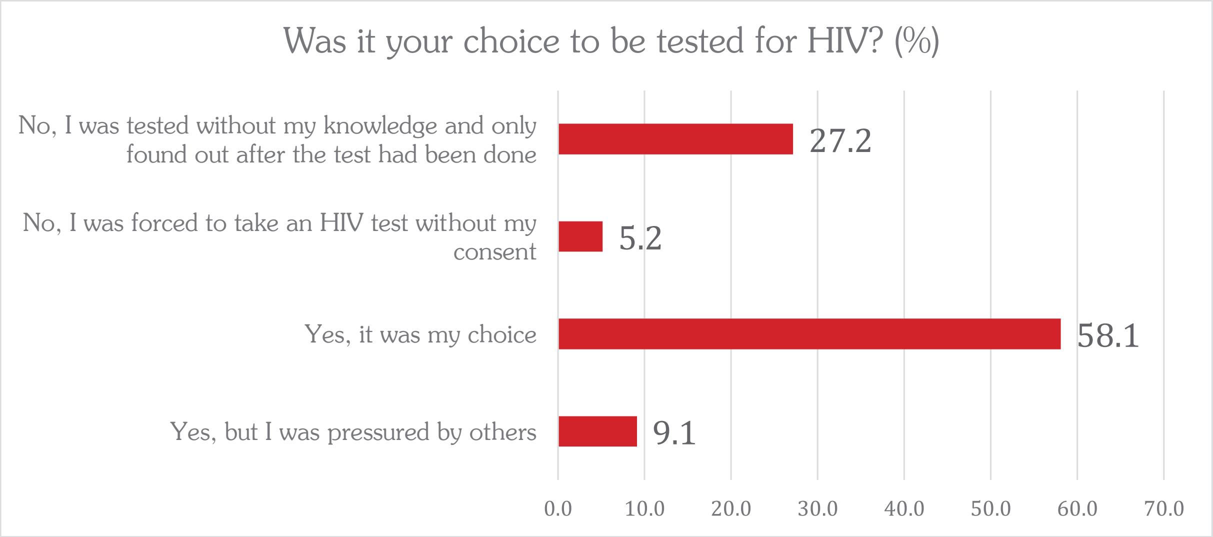
| Please tell me if, in general, you agree or disagree with the following statements | Male , n=259 | Female, n=218 | Trangender people* (n=5) |
|---|---|---|---|
| It is difficult to tell people that I am HIV positive | | | |
| Disagree/No | 38,6% | 18,8% | 1 |
| Agree/Yes | 61,0% | 80,7% | 4 |
| Being HIV positive makes me feel dirty | | | |
| Disagree/No | 71,0% | 57,3% | 4 |
| Agree/Yes | 28,6% | 42,7% | 1 |
| I feel guilty that I am HIV positive | | | |
| Disagree/No | 47,9% | 44,5% | 1 |
| Agree/Yes | 51,7% | 55,5% | 4 |
| I am ashamed that I am HIV positive | | | |
| Disagree/No | 57,1% | 37,2% | 3 |
| Agree/Yes | 42,5% | 62,4% | 2 |
| I sometimes feel worthless because I am HIV positive | | | |
| Disagree/No | 65,3% | 48,6% | 3 |
| Agree/Yes | 34,4% | 50,5% | 2 |
| I hide my HIV status from others | | | |
| Disagree/No | 23,6% | 11,0% | 0 |
| Agree/Yes | 75,7% | 87,6% | 5 |
| * Observations for transgender people are shown as numbers, not percentage | | | |

## 3.5 EXPERIENCE OF SEEKING HEALTHCARE SERVICES

### TAKING AN HIV-TEST: REASONS AND MOTIVES

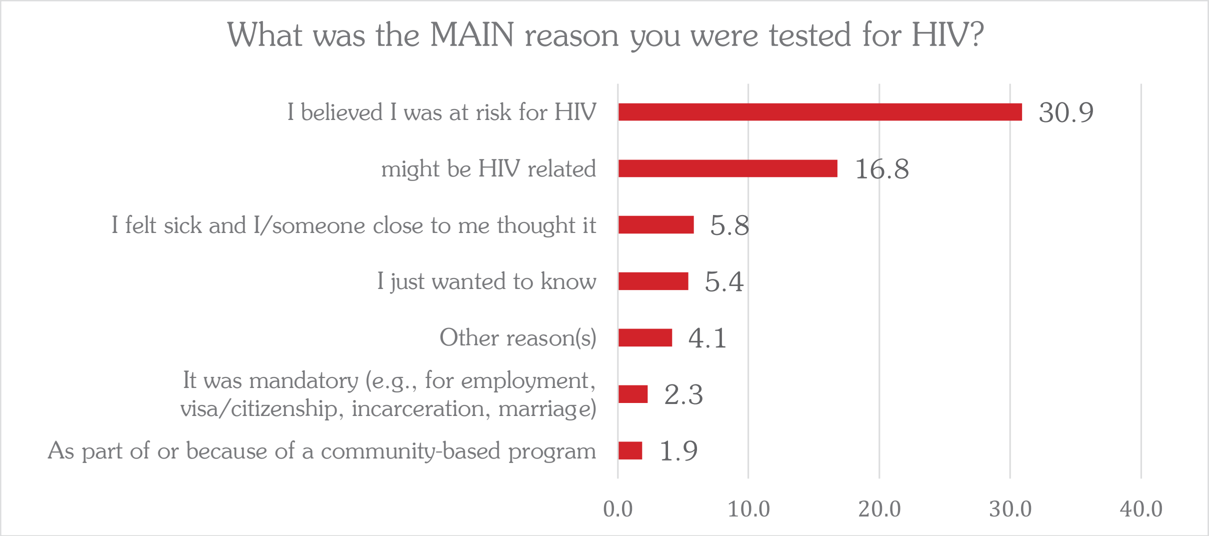
Almost 42% felt that their HIV test was involuntary: 27% (n=131) were tested without their knowledge and found out only after the test had been performed, 9% (n= 44) reported having been pressured by others, 5% (n=25) reported having been tested without their consent. 58% (n=280) of participants indicated that the decision to get tested for HIV was voluntary. There were no participants in the study who reported being born with HIV.

## Figure 8. The voluntary decision to take HIV test (n=480, %)



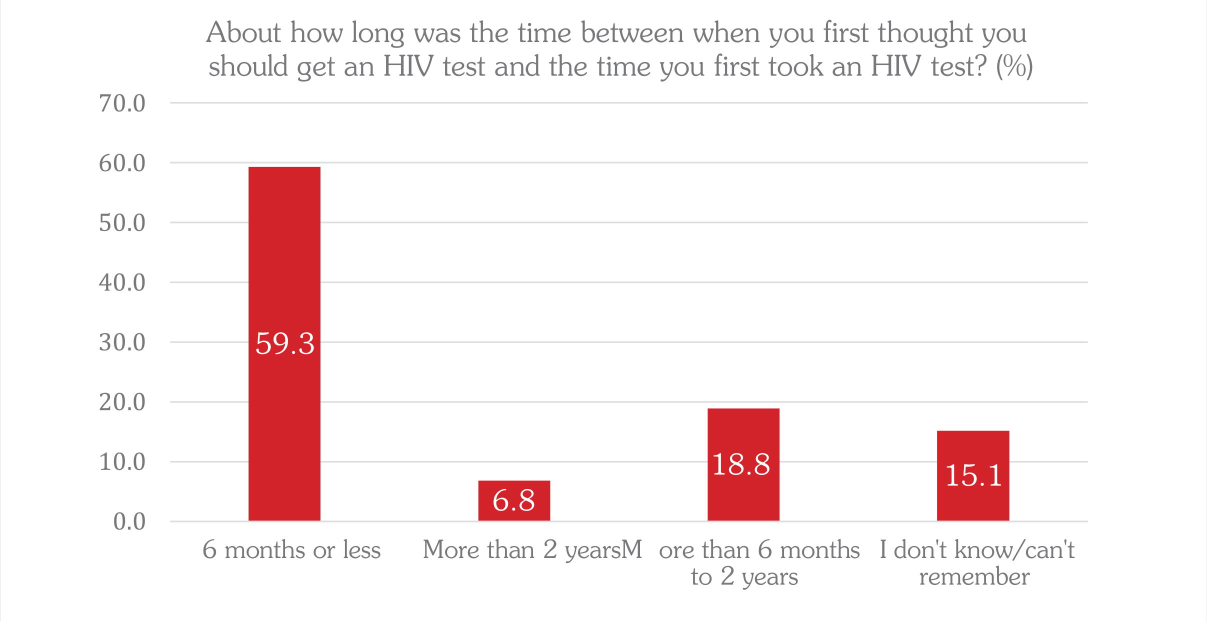
The respondents (those who decided to take the test themselves and who have been pressured by others) mentioned that the main reason for taking HIV test was that the respondent suspected the risk of HIV infection; this reason was relevant for 30,9% or 149 respondents. In addition, 8% had symptoms that, according to respondents, could indicate HIV. 16,8% (n=81) of respondents were tested following the advice of healthcare workers or as part of a specific medical procedure.

## Figure 9. Main reasons to take HIV test (n=324, %)



Most participants – more than half (59,3%, n=192) indicated, that they took the test within six months after the thought of wanting to be tested occurred. The majority of respondents (59,3%) got tested for HIV within 6 months of hinking about testing. Fewer participants waited 6 – 24 months (18,8%), 6,8% waited more than 24 months, 15,1 % could not remember (see Figure 10 below).

**Figure 10. The time that has passed between the thought about getting tested for HIV and the moment it was done (n=324, %)**

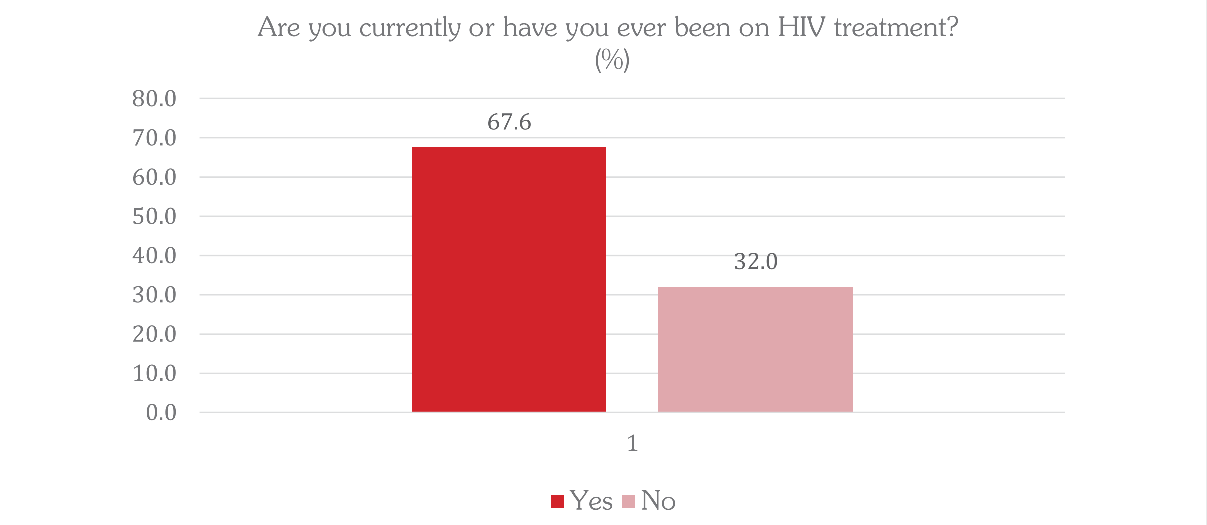


Participants were asked if they delayed the testing because of fear of how other people would react if they knew a person got positive test results. 59,9% (n = 194) indicated anxiety about the reactions of other people, so the fear was a factor in making participants hesitate to get tested.

## EXPERIENCE OF HIV CARE AND TREATMENT

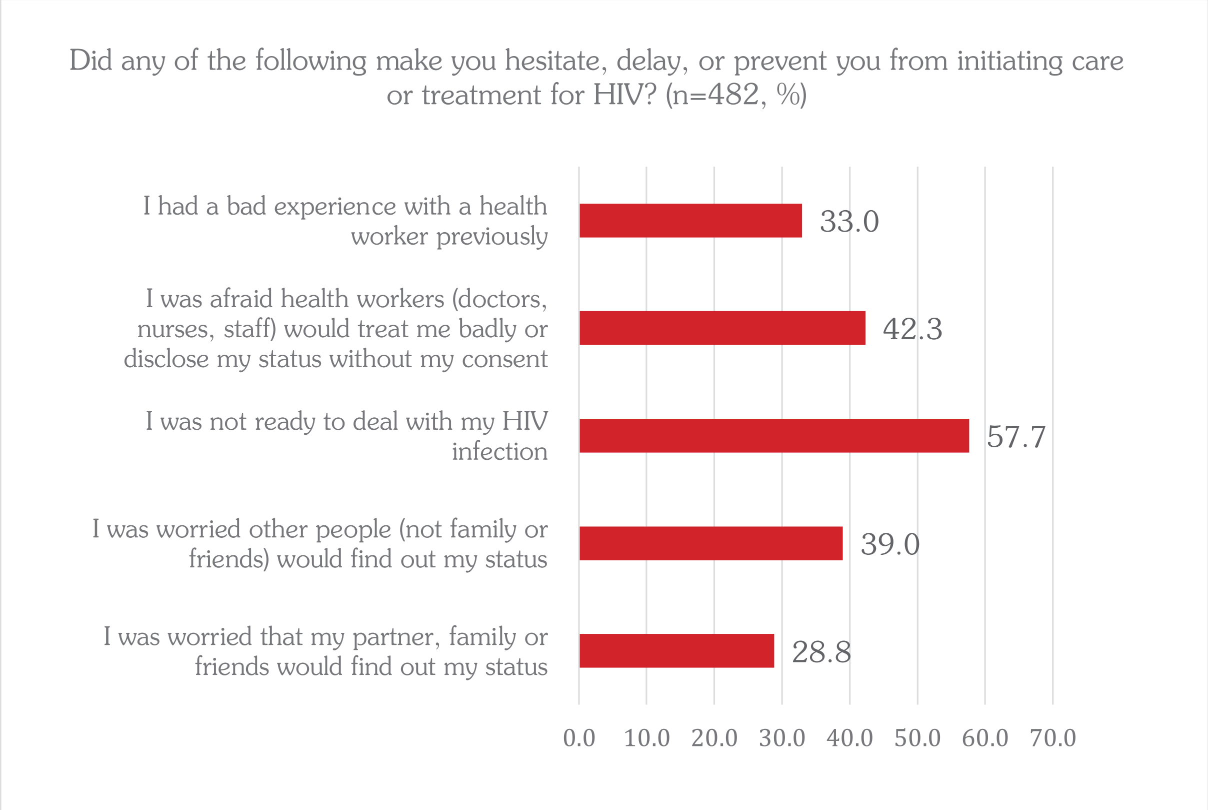
Most of participants are currently or have ever been on HIV treatment (67,6%, n=326).

**Figure 11. Experience of HIV treatment (n=482, %)**



Before the start of HIV treatment, participants hesitated, postponed or prevented the HIV treatment because they were not ready to deal with HIV (57,7%, n=278), they were afraid that health workers would treat them badly or disclose their status without their consent (42.3%) or because they were afraid that other people (family members) would find out about their status (39%).

**Figure 12. Reasons for hesitating, postponing or preventing the HIV treatment (n=482, %, respondents were allowed to choose more than one option)**



38% of participants have started to take ART after two years of living with HIV+ status; 19% have started treatment within one month and 14% started their treatment on the same day when diagnosis was made.

Almost every second participant who is or ever been on HIV treatment have decided to do that consciously and voluntarily (52,5%, n=171), and every third made decision to wait and start treatment later (33,1%, n=108). While taking the treatment, 33,1% (n=108) of participants missed a dose of their treatment due to a fear that someone would discover their HIV status.A vast majority of those who have been on ART during the last 12 months said they had an undetectable viral load (78.2%), which was a sign of success in medical treatment. For more detailed results, please see the table 8 below.

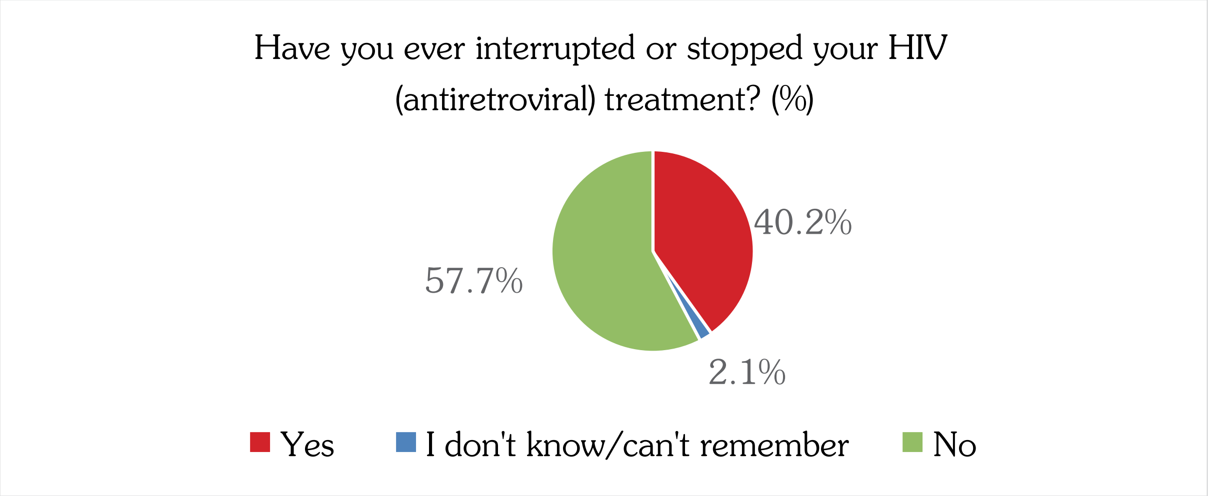
## Table 8. HIV care and treatment experience (n=326)

| After being diagnosed with HIV, how long was it before you began taking HIV (antiretroviral) treatment? | % | n |
|---|---|---|
| >1 day to 1 month (30 days) after being diagnosed | 19 | 62 |
| >1 month to 6 months after being diagnosed | 15,3 | 50 |
| >2 years after being diagnosed | 38 | 124 |
| >6 months to 2 years after being diagnosed | 14,4 | 47 |
| Immediately -or the same day I was diagnosed | 14 | 4,3 |
| I can't remember | 8,9 | 29 |
| **Was it your choice to start taking HIV (antiretroviral) treatment or were you pressured or forced by anyone to start HIV treatment?** | **%** | **n** |
| I was told the benefits and chose to start as soon as it was offered to me | 52,5 | 171 |
| When treatment was offered to me, I took the decision to wait and started at a later time | 33,1 | 108 |
| I felt pressured or forced to start by health care staff | 5,8 | 19 |
| Other reason(s) | 28 | 8,6 |
| **In the past 12 months, did fears about someone learning your HIV status lead you to miss a dose of your HIV (antiretroviral) treatment** | **%** | **n** |
| Yes | 33,1 | 108 |
| No | 66,9 | 218 |
| **Did your most recent viral load test in the last 12 months show you have an undetectable viral load?** | **%** | **n** |
| Yes | 78,2 | 156 |
| No, the virus was detectable/I am not virally suppressed | 9,2 | 30 |
| No, I have not had a viral load test in the last 12 months | 8 | 26 |
| No, I had a viral load test and am waiting for the results | 2,8 | 9 |
| I don't know what viral load or viral suppression are | 1,8 | 6 |

## INTERRUPTIONS IN ART

ART interruptions were common among study participants. 40,2% (n=131) have ever interrupted their treatment. The vast majority (57,7%, n=188) have never interrupted their treatment.

### Figure 13. Interruptions in ART-taking (n=326, %)



The respondents who had problems with taking ART often mentioned stigma-related factors as reasons for discontinuation of ART. In particular, participants mentioned a fear that health workers would treat the respondent badly or disclose their HIV status (n=3); a fear to be denied HIV treatment because they were using drugs at that time (n=2); a fear of HIV status disclosure (n=6). 10 persons were not ready to deal with HIV. Among other reasons participants reported "issues related to use of alcohol or illicit substances", "being tired of taking ARV", "denying a diagnosis".

### Table 9. Reasons for ART interruptions related to stigma (%, n=131)

| If you have ever stopped taking HIV (antiretroviral) treatment for any period of time in the last 12 months, was that for any of the following stigma-related reasons? | % | n |
|---|---|---|
| I am worried that someone would find out my HIV status | 4,6 | 6 |
| I am not ready to deal with my HIV infection | 7,6 | 10 |
| I am worried the healthcare workers would treat me badly or disclose my HIV status without my consent | 2,3 | 3 |
| I was denied HIV treatment due to currently using drugs | 1,5 | 2 |
| N/A – I have not been taking HIV (antiretroviral) treatment in the last 12 months or I have not stopped taking HIV (antiretroviral) treatment in the last 12 months | 26,7 | 35 |
| Other reason(s) | 58,8 | 77 |

Reasons for ART interruptions that are not related to stigma were more frequent and showed that among those respondents who have ever started ART, 36,1% (n=103) did not think that treatment was necessary; 14,7% (n=42) couldn't tolerate side effects of pills, and 6,3% (n=18) had no opportunity to pick up ART at clinics. Among other reasons were "emotional distress", "treatment fatigue", "AIDS denialism", "no registration by place of residence".

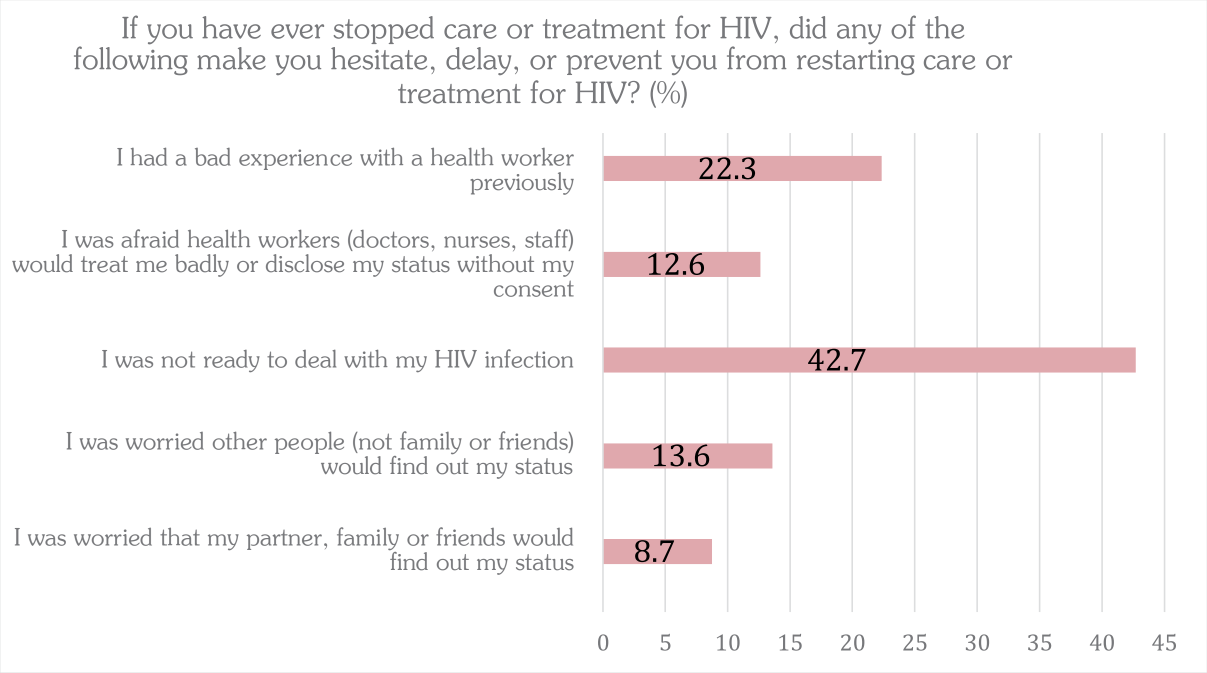
### Table 10. Reasons for ART non-taking or interruptions not related to stigma (%, n=285)

| What is the main non-stigma related reason you are not currently taking HIV (antiretroviral) treatment or ever stopped it? | % | n |
|---|---|---|
| Medication is not available at the clinic (based on policy or stock outs) | 1,4 | 4 |
| Medication is not affordable to me | 1 | 3 |
| I am unable to collect medications at the clinic or pharmacy | 6,3 | 18 |
| I cannot tolerate medication side effects | 14,7 | 42 |
| I do not feel treatment is needed | 36,1 | 103 |
| I do not qualify for treatment because of my CD4s or viral load count | 1,4 | 4 |
| I was in prison or detention and treatment was not available | 3,1 | 9 |
| I have stopped treatment, but not in the last 12 months | 13,7 | 39 |
| Other reason(s) | 22,5 | 64 |

The reasons for delaying the restart of ART are the following: unwillingness to deal with HIV status (42,7%, n=44), negative experience with the medical staff

(22,3%, n=23), a fear that health workers would disclose person's HIV status (12,6%, n=13).

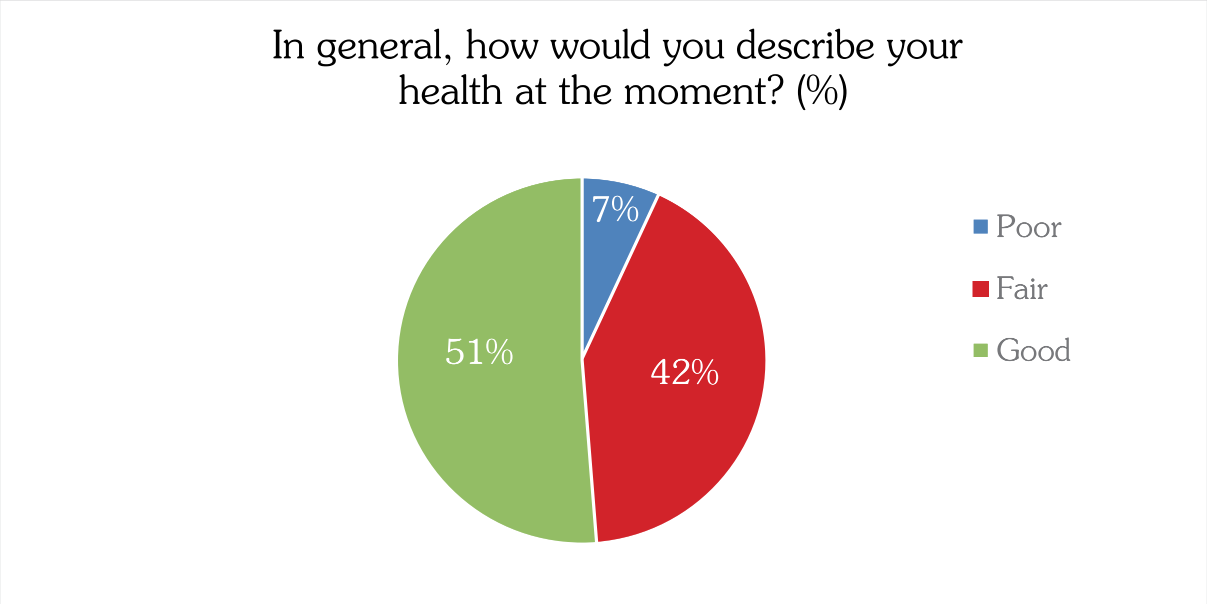
**Figure 14. Reasons for delaying the ART taking after interruptions, % (n=103)**



## HEALTH STATUS

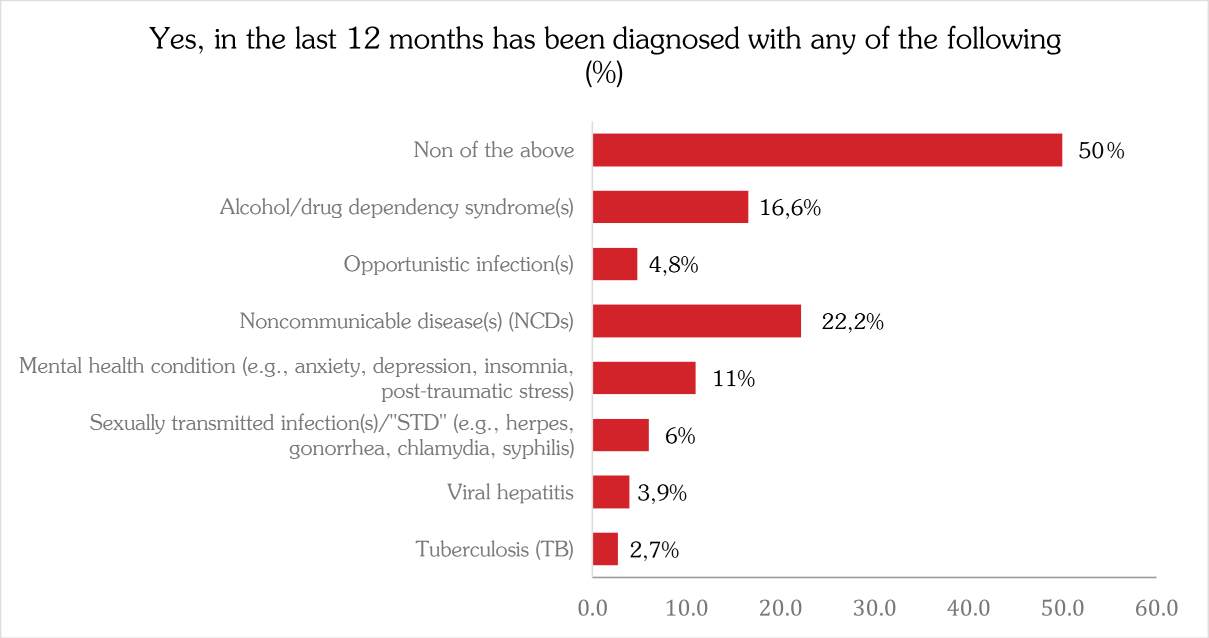
Nearly 51% of PLHIV in the study assessed their health as 'good', 42% as 'fair' and only 7% evaluated their health at the time of the study as 'poor'.

**Figure 15. Self-report on health status (n=482)**



In the past 12 months, 22,2% of respondents were diagnosed with non-communicable diseases (n=107). 16,6% of all respondents (n=80) had alcohol and/or drug withdrawal syndrome, and 11% (n=53) were diagnosed with mental health conditions.

**Figure 16. Diagnoses made in the last 12 months (n=482, %)**



Most participants who had aforementioned conditions had received appropriate treatment in the past 12 months (64,6%).

The proportion of respondents who reported having been diagnosed with the conditions mentioned within last 12 months, is not significantly different among female, male and transgender people. The exceptions to this generalization were the high percentage of noncommunicable diseases in the group of male and transgender people, and high percentage of tuberculosis in the group of male LHIV.

**Table 11. Diagnoses made in the last 12 months by gender (n=480).**

| In the last 12 months, have you been diagnosed with any of the following: | | | |
|---|---|---|---|
| | Male, (n=259) | Female, (n=218) | Trangender people* (n=5) |
| Tuberculosis (TB) | 3,5% (9) | 1,4% (3) | 1 |
| Viral hepatitis | 4,6% (12) | 2,8% (6) | 1 |
| Sexually transmitted infection(s) | 5,4% (14) | 6,4% (14) | 1 |
| Mental health condition | 11,6% (30) | 10,1% (22) | 1 |
| Noncommunicable disease(s) (NCDs) | 23,6% (61) | 19,7% (43) | 3 |
| Opportunistic infection(s) | 4,6% (12) | 4,6% (10) | 1 |
| Alcohol/drug dependency syndrome(s) | 17,4% (45) | 16,1% (35) | 0 |

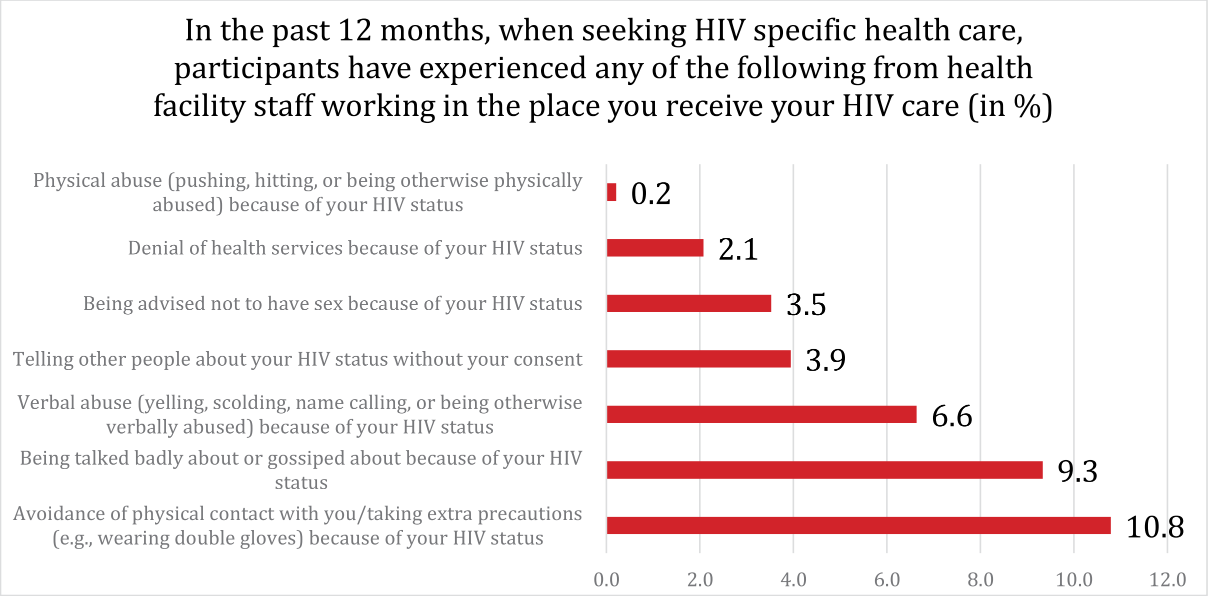
* Observations for transgender people are shown as numbers, not percentage

## EXPERIENCE IN HIV CARE FACILITIES

67% (n=321) of participants indicated that HIV-related care and treatment was generally received in state healthcare facilities. 2% (n=10) received help in several places; two persons in community-based institutions and two persons in the non-governmental clinic. One-third of PLHIV in the study is currently not receiving HIV-care and treatment (n=145).

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.) – 11% (n=52); talked badly about or gossiped about the respondent – 7% (n=32), and practiced verbal abuse – 9% (n=45). 3,5% (n=17) have given advices to PLHIV not to have sex because of the HIV+ status. 4% (n=19) of PLHIV in the study had their status disclosed without their consent, and 2,1% (n=10) received no healthcare services because of HIV+ status.

## Figure 17. Manifestations of stigma and discrimination by the staff of healthcare facilities that provide HIV treatment, in the last 12 months (n=335, %)



Male participants more often than female reported being advised not to have sex and being verbally abused by health facility staff because of HIV positive status (7,1% vs 2%, 12% vs 6,8%). Female participants reported more often than male that medical staff avoided physical contact with them because of HIV (23% vs 9,3%). For more details see Table 12 below.

## Table 12. Negative experiences of participants in HIV treatment services by gender (%, n=335)

| In the past 12 months, when seeking HIV specific health care, you have experienced any of the following from health facility staff working in the place you receive your HIV care: | | | |
|---|---|---|---|
| | Male, (n=183) | Female, (n=147) | Trangender people* (n=5) |
| Denial of health services because of HIV status | 23,8% (7) | 2% (3) | 0 |
| Being advised not to have sex because of HIV status | 7,1% (13) | 2% (3) | 1 |
| Being talked badly about or gossiped about because of HIV status | 14,8% (27) | 12,2% (18) | 0 |
| Verbal abuse (yelling, scolding, name calling, or being otherwise verbally abused) because of HIV status | 12% (22) | 6,8% (10) | 0 |
| Physical abuse (pushing, hitting, or being otherwise physically abused) because of HIV status | 0 | 0,7% (1) | 0 |
| Avoidance of physical contact /taking extra precautions (e.g., wearing double gloves) because of HIV status | 9,3% (17) | 23% (34) | 1 |
| Telling other people about HIV status without consent | 4,9% (9) | 6,8% (10) | 0 |

* Observations for transgender people are shown as numbers, not percentage

Among PLHIV who received health care or HIV treatment services, near half of respondents (45%, n=152) were aware of the work of community-led clinics (NGOs) and were aware of where they could get HIV care services. 55% of respondents were not aware at all. Those who knew about community-based clinics demonstrated a high level of awareness of specific services they might get there:

**Table 13. Awareness of available services in community-led clinics (%, n=152)**

| | % | n |
|---|---|---|
| Information about HIV | 96,7% | 147 |
| Peer-to-peer support (self-help groups) | 94,7% | 144 |
| Counseling related to adherence | 85,5% | 130 |
| Services and means of prevention | 70,4% | 107 |
| HIV treatment ART | 49,3% 7 | 5 |
| Social support | 67,1% | 102 |
| HIV-related care, HIV testing | 70,4% | 107 |

## EXPERIENCE IN OTHER MEDICAL CARE FACILITIES

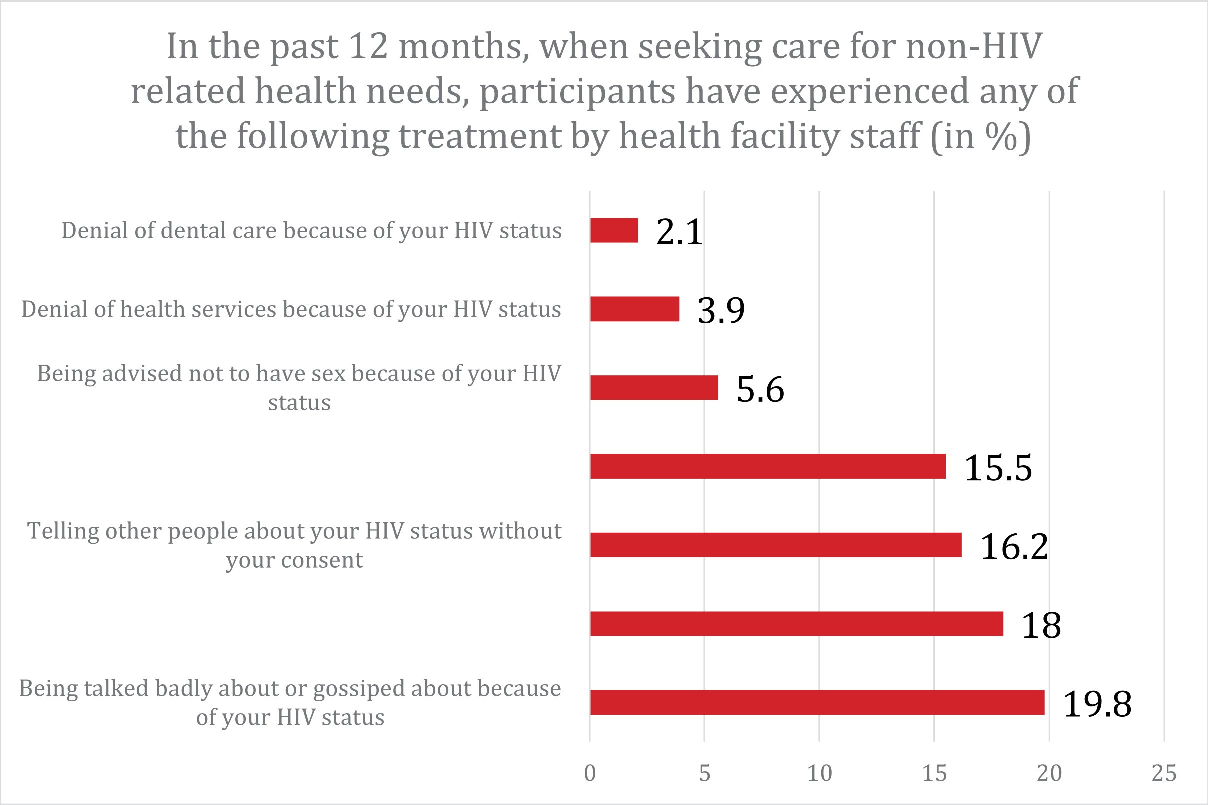
### HIV DISCLOSURE IN HEALTHCARE SERVICES FOR REASONS NOT RELATED TO HIV

Almost half of the PLHIV in the study 44% (n=210) said that they disclosed their HIV+ status in the health care services that were not related to HIV.

### STIGMATIZATION AND DISCRIMINATION IN HEALTHCARE FACILITIES NOT RELATED TO HIV.

In the past 12 months, 283 persons (58,7%) sought healthcare services not related to HIV, such as vaccination, dental care, and so on. Healthcare staff in those facilities stigmatized and discriminated participants in the following way: talked badly or gossiped about the respondent because of their HIV status (n=56, 19,8%); avoided physical contact or used extra precautions (n=51, 18%); told other people about the respondent's HIV status without their consent (n=46, 16,2%); abused the respondent verbally (n=44, 15,5%); recommended not to have sex because of their HIV status (n=16, 5,6%); refused to provide medical services (n=11, 3,9%), and refused to provide dental care (n=6, 2,1%). No participants reported being physically abused.

## Figure 18. Stigmatization and discrimination in healthcare facilities not related to HIV (n=283, %)



The comparison of frequencies of negative experience in non-HIV treatment facilities between genders showed no great differences. The exception from this generalization was attributed to a subgroup of transgender people, who did not report any negative experience in medical care setting at all. Also, female participants, more often than male, reported being talked badly or gossiped about because of their HIV status.

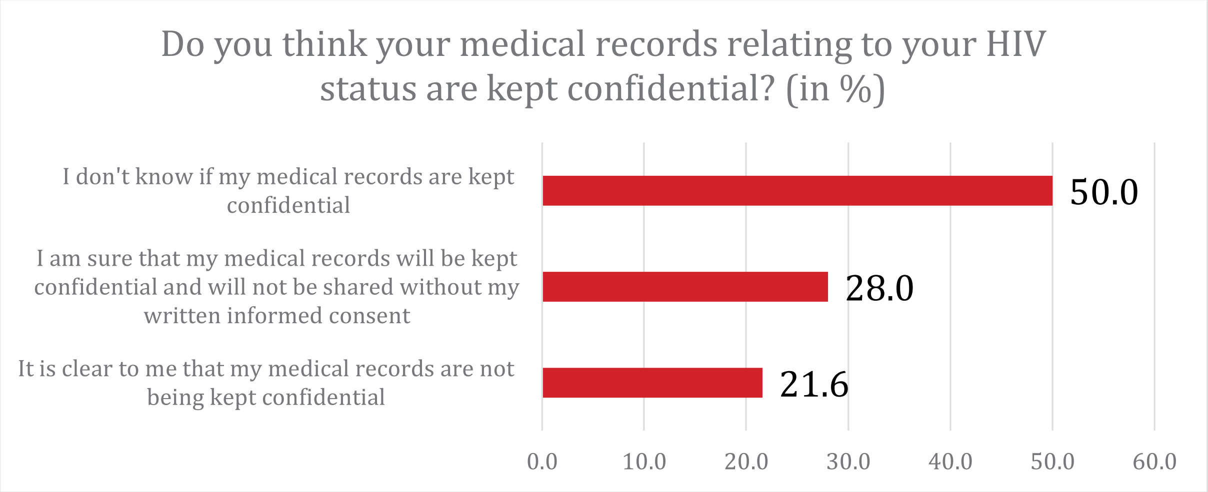
## Table 14. Negative experiences of participants in non-HIV treatment services by gender (%, n=284)

| In the past 12 months, when seeking care for non-HIV related health needs, you have experienced any of the following treatment by health facility staff: | | | |
|---|---|---|---|
| | Male, (n=143) | Female , (n=138) | Trangender people* (n=3) |
| Denial of health services because of HIV status | 2,7 % (4 ) | 5,1 % (7) | 0 |
| Denial of dental care because of your HIV status | 1,4 % (2) | 2,9 % (4) | 0 |
| Being advised not to have sex because of HIV status | 6,3 % (9 ) | 4,3 % (6) | 1 |
| Being talked badly about or gossiped about because of HIV status | 14,7 % (21) | 25,4 % (35) | 0 |
| Verbal abuse (yelling, scolding, name calling, or being otherwise verbally abused) because of HIV status | 17,5 % (25) | 13,8 % (19) | 0 |
| Physical abuse (pushing, hitting, or being otherwise physically abused) because of HIV status | 0 | 0 | 0 |
| Avoidance of physical contact /taking extra precautions (e.g., wearing double gloves) because of HIV status | 18,2 % (26) | 18,2 % (25) | 0 |
| Telling other people about HIV status without consent | 18,9 % (27) | 13,8 % (19) | 0 |

* Observations for transgender people are shown as numbers, not percentage

Medical records confidentiality. 50% (n=241) did not know if their medical records were kept confidential in the healthcare facilities not related to the treatment of HIV. 28% (n=135) were confident that their medical records were kept confidential. 22% (n=104) believed that their medical records were not kept confidential.

**Figure 19. Assessment of the confidentiality level of medical records (n=482, %)**



## REPRODUCTIVE HEALTH AND REPRODUCTIVE RIGHTS

In the last 12 months seven female and nine male respondents (3,3%) were recommended not to have children. Four female and three male participants (1,5%) were advised by medical staff to use a specific method of contraception in order to get HIV treatment instead of offering the alternative type of contraception. Two female participants were pressured to undergo sterilization (0,4%).

**Table 15. Discrimination related to reproductive health (n=482)**

| | Yes | No | No answer / Did not want to answer |
|---|---|---|---|
| Advised not to have children | 3,3% (n=16) | 84,6% (n=408) | 12% (n=58) |
| Advised by medical staff to use a specific method of contraception in order to get HIV treatment instead of offering the alternative type of contraception | 1,5% (n=7) | 87,5% (n=422) | 11% (n=53) |
| Pressured to undergo sterilization | 0,4% (n=2) | 81,5% (n=393) | 18% (n=87) |

As for the discriminative and stigmatizing advice concerning pregnancy, delivery and breastfeeding PLHIV indicated the violation of their reproductive rights in the near past (in the last 12 months) and more cases of violation much earlier than in the past 12 months (see Table 16).

**Table 16. Reproductive rights violation and stigmatization (n=217)**

| | Yes, in the last 12 months | Yes, but not within the last 12 months |
|---|---|---|
| Advised to terminate pregnancy | 0,5% (n=1) | 17,5% (n=38) |
| Pressured to use a specific type of contraceptive method rather than counseling on a range of available options | - | 12,9% (n=28) |
| Pressured to use a particular delivery method | 0,5% (n=1) | 16,6% (n=36) |
| Pressured to use a particular infant feeding practice | 1% (n=2) | 20,3% (n=44) |
| 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 | 0,5% (n=1) | 21,7% (n=47) |

## 3.6 HUMAN RIGHTS AND EFFECTING CHANGE

The most common violation was the forced HIV testing to receive healthcare service (3,3%, n=16). The most common violations earlier (not within the last 12 months) were the following situations: the forced HIV testing (15,1%, n=73) and disclosure of HIV+ status without consent (8,1% n=39).

## Table 17. Human rights violations

| Human rights violations (n=482) | Yes, in the past 12 months | Yes, not within the last 12 months |
|---|---|---|
| Compulsory HIV test or HIV disclosure for obtaining a visa, submitting documents for a residence permit/ citizenship in the country | 0,4% (n=2) | 1 % (n=5) |
| Compulsory HIV test or HIV disclosure for employment or receiving a pension | 0,2% (n=1) | 2,3% (n=11) |
| Compulsory HIV test or HIV disclosure for receiving healthcare services | 3,3% (n=16) | 15,1% (n=73) |
| Compulsory HIV test or HIV disclosure for obtaining health insurance | 0,2% (n=1) | 0,2% (n=1) |
| The respondent was arrested or convicted for a reason related to HIV status | 0 | 0,2% (n=1) |
| The respondent was detained or placed in a pre-trial detention center due to HIV status | 0,2% (n=1) | 1 % (n=5) |
| The respondent was refused to obtain a visa or entry into the country due to HIV status | 0 | 0,2% (n=1) |
| The respondent was refused to stay in the country or obtain a residence permit due to HIV status | 0 | 0,2% (n=1) |
| The respondent was forced to disclose his/her HIV status publicly or the status was disclosed without his/her consent | 2,9% (n=14) | 8,1% (n=39) |
| The respondent was forced to get tested for HIV or disclose my status in order to attend an educational institution or get a scholarship | 0 | 0 |
| The respondent was forced to have sex against the will | 1,2% (n=6) | 9,8% (n=47) |
| The respondent was refused to stay in a shelter* | 0 | 0,9% (n=2)* |
| The respondent's partner did not allow the person to get healthcare services* | 0,9% (n=2)* | 5,5% (n=12)* |

* only women were addressed in these questions (n=217)

From all the 43 cases of violation in the last 12 months, only four persons tried to take following actions: «writing a complaint» (n=3), «talking to a lawyer» (n=2), «referring to NGO or PLHIV community» (n=1). Three cases have been resolved successfully.

Regarding the reasons why PLHIV did not act against the violation of their rights, participants reported the following: being unaware how to take action, no or little confidence that the outcome would be successful, feeling intimidated or scared, being worried that taking action might lead people to learn about their HIV status, among other reasons.

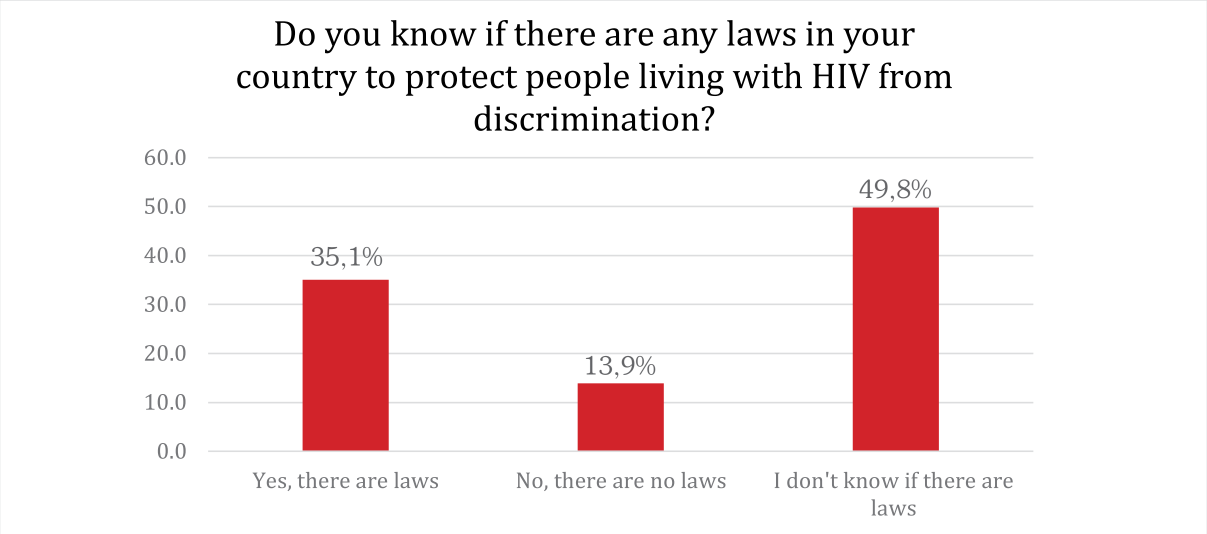
### Table 18. The main reason for not trying to do something about the violation

| | (n) |
|---|---|
| I did not know where to go/how to take action | 32 |
| I had insufficient financial resources to take action | 2 |
| The process of addressing the problem appeared too complicated | 5 |
| I felt intimidated or scared to take action | 8 |
| I was worried taking action might lead people to learn about my HIV status | 9 |
| I was worried taking action might lead people to learn that I am a man having sex with men/transgender person/person who sells sex/person who uses drugs | 6 |
| I was advised against taking action by someone else | 6 |
| I had no/little confidence that the outcome would be successful | 13 |
| There was a lack of evidence of the abuse | 3 |
| Other | 20 |

## KNOWLEDGE OF LAWS, PROTECTING PLHIV FROM DISCRIMINATION

According to the data every two out of three people were unaware of antidiscrimination laws in Russia. Only 35% of PLHIV in the study answered that they were aware of laws that protect PLHIV from discrimination.

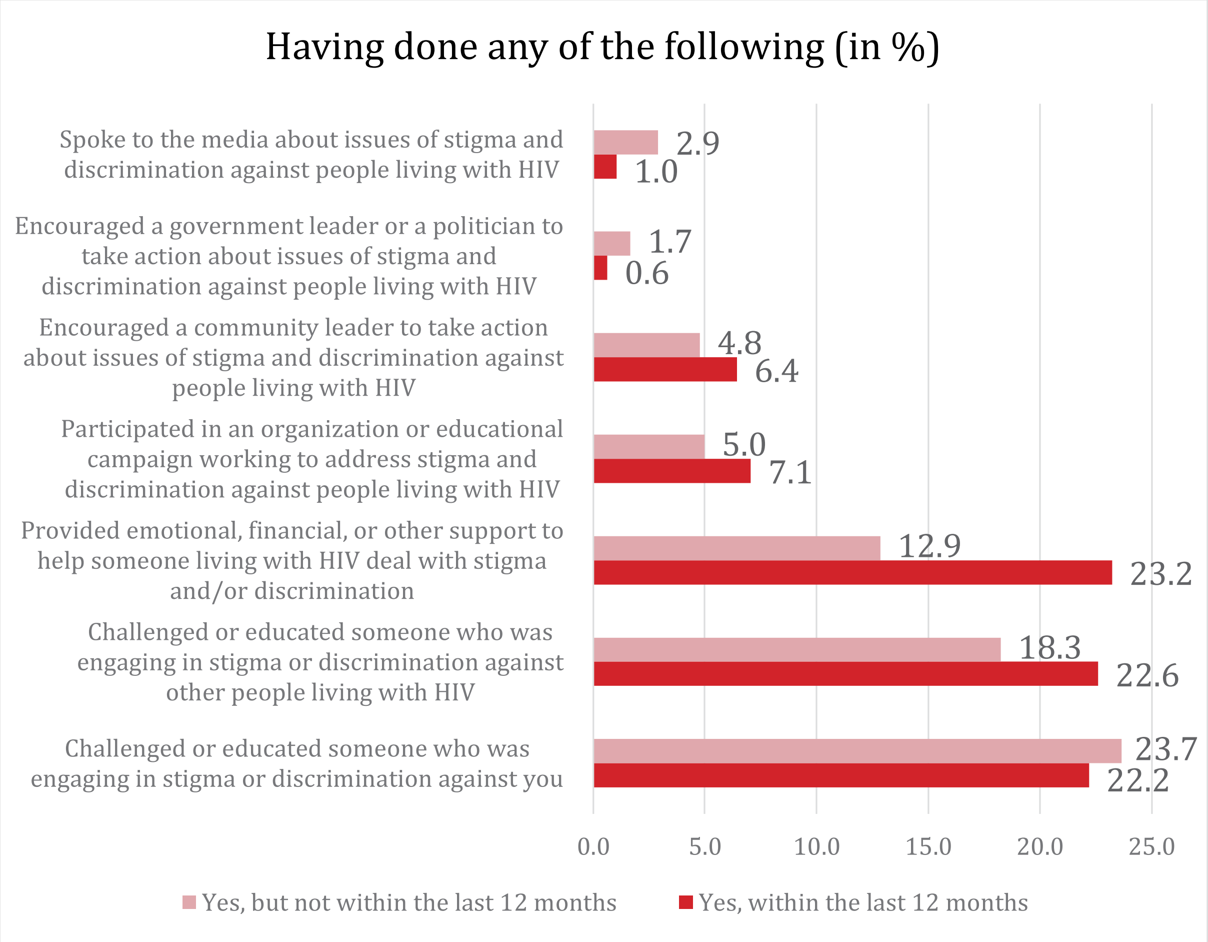
Figure 20. Awareness of laws that protect PLHIV against discrimination (n=476, %)



## ACTIONS RELATED TO HUMAN RIGHTS VIOLATIONS

Despite the low awareness of their rights, participants indicated that in the past 12 months they did the following: 23,2% (n=112) participants "provided emotional, financial or other support to help someone living with HIV deal with stigma and/or discrimination»; 22,6% (n=109) participants "challenged or educated someone who was engaging in stigma or discrimination against other people living with HIV"; 22,2% (n=107) participants "challenged or educated someone who was engaging in stigma or discrimination against them"; 7,1% (n=34) participants "participated in an organization or educational campaign working to address stigma and discrimination against PLHIV"; 6,4% (n=31) participants "encouraged a community leader to take action about issues of stigma and discrimination against PLHIV". Regarding the time period not within the last 12 months, participants took those actions less often (see Figure 21 below).

**Figure 21. Actions related to human rights violations, % (n=482)**



To prevent stigma and discrimination, male participants were more likely than female to provide emotional, financial and other support. Beyond the last 12 months male participants were much more likely than female participants to challenge or educate people who were engaging in stigmatizing behaviours.

**Table 19. Action related to human right violations in subgroups by gender (%, n=482)**

| | Yes, within the last 12 months | | | Yes, but not within the last 12 months | | |
|---|---|---|---|---|---|---|
| | Male, (n=259) | Female (n=218) | Trangender people* (n=5) | Male, (n=259) | Female (n=218) | Trangender people* (n=5) |
| Challenged or educated someone who was engaging in stigma or discrimination against you | 21,2 | 22,9 | 2 | 25,5 | 21,6 | 1 |
| Challenged or educated someone who was engaging in stigma or discrimination against other people living with HIV | 22 | 22,5 | 3 | 17,4 | 19,3 | 1 |
| Provided emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination | 25,1 | 20,6 | 2 | 12,7 | 12,4 | 2 |
| Participated in an organization or educational campaign working to address stigma and discrimination against people living with HIV | 6,9 | 7,3 | 0 | 4,2 | 5,5 | 1 |
| Encouraged a community leader to take action about issues of stigma and discrimination against people living with HIV | 7,7 | 4,6 | 1 | 3,5 | 6,4 | 1 |
| Encouraged a government leader or a politician to take action about issues of stigma and discrimination against people living with HIV | 0,4 | 0,9 | 0 | 1,5 | 1,8 | 0 |
| Spoke to the media about issues of stigma and discrimination against people living with HIV | 1,2 | 0,9 | 0 | 2,7 | 3,2 | 0 |

* Observations for transgender people are shown as numbers, not percentage

As for engagement with communities almost every fifth participant was a member of local PLHIV communities and networks (19,9%, n=96). Despite that fact, only 6,4% of participants encouraged a community leader to take action against stigma against PLHIV (within the last 12 months) and only 7,1% participated in community-level events or educational campaigns working to address stigma and discrimination (see Figure 21).

# 3.7 STIGMA, DISCRIMINATION AND HIV DISCLOSURE AMONG KEY POPULATION

## SELF-IDENTIFICATION, PRACTICES AND BELONGING TO KEY AND PRIORITY POPULATIONS

Belonging to the priority populations most affected by HIV in Russia was identified by two parameters. Firstly, participants were asked to report whether they identify themselves as belonging to transgender people, MSM/gay, bisexual, lesbian/WSW, sex workers and PWUD groups. Secondly, participants were asked to report the practices, that might identify them as a priority population (e.g. same-sex intercourse, material rewards for sex and so on). The largest groups were PWUD, sex workers and MSM. Some participants refused to answer these questions. These participants might represent the 'hidden' part of key populations and they might witness high levels of self-stigma and of stigma towards certain groups. An example of that was a group of 31 female LHIV who refused to answer a question on having ever had sex with other women.

**Table 20. Self-identification, practices and belonging to key populations**

| | n | Refuse to answer (n) |
|---|---|---|
| Identified themselves as MSM/gay | 64 | - |
| Identified themselves as bisexual men | 6 | - |
| Having sex with men among those who didn't identify themselves as MSM/gay/bisexual men | 3 | 4 |
| Identified themselves as lesbian/WSW | 8 | - |
| Identified themselves as bisexual women | 10 | - |
| Having sex with women among those who didn't identify themselves as lesbian/WSW | 14 | 31 |
| Having sex in exchange for money or other rewards: | 137 | 19 |
| Identified themselves as SW | 65 | 4 |
| Identified themselves as TG | 2 | 3* |
| Having experience of injectable or regular use of cocaine, heroin, methamphetamine: | 285 | 27 |
| Identified themselves as PWUD | 212 | 7 |

* three participants refused to answer a question on gender, but they answered all the questions from the section D about the transgender people related stigma.

## INTERSECTIONAL IDENTITY

The comparison of data showed three categories of participants. 51,9% (n=250) of participants identified themselves as one of the key population; near one-third identified themselves as two or more key populations (28,2%, n=134), and approximately 19,9% did not belong to any of the key populations (n=96). The most frequent combinations in the sample were MSM–SW–PWUD (n=19) and SW–PWUD (n=62).

**Table 21. Key populations groups intersections (n=482)**

| Combinations of identities | N of observations (%) |
|---|---|
| MSM- SW-PWUD | 19 (3,9%) |
| WSW- CP-PWUD | 13 (2,7%) |
| SW-PWUD | 62 (12,9%) |
| MSM- PWUD | 18 (3,7%) |
| MSM- SW | 11 (2,3%) |
| WSW- PWUD | 5 (1%) |
| WSW- SW | 2 (0,4%) |
| TG-PWUD | 1 (0,2%) |
| TG-SW | 1 (0,2%) |

One of the main focuses of this study – besides the stigma and discrimination related to HIV+ status – was stigma not related to HIV. Belonging to the groups of transgender people, MSM, PWUD and sex workers raised the issues that were concerned with stigma and discriminative practices, directed towards respondents in the study. Representatives of these populations answered seven questions on their experiences of stigmatization and discrimination related to their identity or practices; three questions on people who knew about their identity or practices, and one question on belonging to the certain communities or networks of people.

## STIGMA AND DISCRIMINATION EXPERIENCED FOR BEING TRANSGENDER

Five participants reported experiencing different forms of stigma and discrimination because of being transgender over the last 12 months and prior to that time. The most frequent cases of stigma and discrimination were physical harassment (4 people), exclusion from family activities (3 people), discriminatory remarks from family members, feeling afraid and avoiding seeking health care, verbal abuse, and blackmail (2 people). As for the last 12 months transgender people reported fewer cases of stigmatization and discrimination because of their gender identity.

In terms of who knew their gender identity (as a transgender) 3 people responded that family and friends know about their transgender identity, and 2 transgender people responded that other transgender people from community know about their trans identity. Three transgender participants reported belonging to a network or support group of people with the same (transgender) identity (see Table 22).

### STIGMA AND DISCRIMINATION EXPERIENCED BY GAY MEN AND OTHER MSM

For those 67 men who identified as gay, MSM or had had sex with other men previously, the most frequent recent cases of stigmatization and/or discrimination were related to discriminatory remarks from their families and verbal harassment (16,4% and 13,4%). During the period prior to the last 12 months study participants reported cases of stigmatization and/or discrimination much more often. 35 participants (52,3%) were verbally harassed, 17 participants (25,4%) confronted gossips and discriminatory remarks from their families, 15 men (22,4%) were physically abused, and 12 people (17,9%) were blackmailed.

In terms of who knew their identity as gay men and other MSM, participants responded “other peers” (92,5%, n=62), “friends and family” (79,1%, n=53) and “other people in the community” (47,8% n=32). 42 gay / MSM participants (62,7%) indicated that they did not belong to any support group of people with the same (gay, MSM) identity (see Table 22).

### STIGMA AND DISCRIMINATION EXPERIENCED BY LESBIANS AND WSW

For the 22 participants who identified as a lesbian or other WSW, the most common experiences of stigma and discrimination were attributed to the period prior to the last 12 months. Four participants indicated that they received discriminatory remarks from their family members and were verbally harassed. Only 3 participants reported belonging to peer support groups for lesbians and WSW. In terms of who knew their sexual identity 9 lesbian/WSW respondents said that people with the same identity know about their lesbian / WSW identity, 8 respondents replied that family and friends know about their lesbian/ WSW identity, and 4 respondents replied that other people in the community know about their lesbian / WSW identity (see Table 22).

## STIGMA AND DISCRIMINATION EXPERIENCED BY BISEXUAL PEOPLE

Of 16 participants identified as bisexual, only one reported being blackmailed within the last 12 months. Other participants experienced stigma or discrimination prior to the last 12 months. The most common experiences, as shown in Table 22, were discriminatory remarks from family members (n=5), and verbal harassment (n=8). Only 2 out 16 participants reported belonging to the network or support group for people who are bisexual. In terms of who knew their identity as a bisexual person, or someone who has sex with men and women, participants reported "other peers" (n=10), "friends and family" (n=9), and "other people in the community" (n=4).

## STIGMA AND DISCRIMINATION EXPERIENCED BY SEX WORKERS

Within the last 12 months, a total of 13 participants (sex workers) (out of the total 137) reported being physically harassed (9,6%). 11 respondents were verbally assaulted (8,1%) and 5 received discriminatory remarks from their families (3,7%). People from that subgroup experienced many more cases of stigmatization and discrimination earlier – in the period not within the last 12 months. 128 sex workers PLHIV (94,1%) indicated that they did not belong to a network or support group for people who were sex workers or sold sex. In terms of who knew their identity as a sex worker / or a person selling sex, participants responded "other peers" (50%, n=68), "friends and family" (24,5%, n=36) and "other people in the community" (16,2% n=22).

## STIGMA AND DISCRIMINATION EXPERIENCED BY PEOPLE WHO USE DRUGS

For 285 participants from the subgroup of PWUD the most common cases of stigmatization and/or discrimination were related to discriminatory remarks from their families and verbal harassment (23,8% and 23,1%); exclusion from family gatherings (16,5%), and feeling afraid to seek medical help and avoiding seeking medical help (11,6% and 11,2%). During the period prior to the last 12 months study participants reported cases of stigmatization and/or discrimination much more often (details see in Table 22).

Despite the stigmatizing experience, in terms of who knew their identity as a drug user, 269 (94,4%) participants responded that "other peers" knew about their identity as PWUD, 244 (85,6%) responded that "friends and family" knew about their PWUD identity, and 203 (71,2%) responded that "other people in the community" knew about their PWUD identity. 208 PWUD participants (73%) indicated that they did not belong to any support group of people who use drugs (see Table 22).

### Table 22. Stigma and discrimination that is not related to HIV (% depends on number of respondents in a certain subgroup).

| Stigma and discrimination related to identity and practices | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | TG (n=5) | | MSM (n=67) | | WSW (n=22) | | Bisexual (n=16) | | SW (n=13 7) | | PWUD (n=285) | |
| | 12 mnth. | > 12 mnth. | 12 mnth. | > 12 mnth. | 12 mnth. | > 12 mnth. | 12 mnth. | > 12 mnth. | 12 mnth. | > 12 mnth. | 12 mnth. | > 12 mnth. |
| Being excluded from family gatherings | - | 3 | 3 (4,5%) | 8 (12%) | 1 | 3 | - | 3 | 1 (0,7%) | 6 (4,4%) | 47 (16,5%) | 139 (48,8%) |
| Had a feeling that family members have made discriminatory remarks or gossiped about them | 1 | 2 | 11 (16,4%) | 17 (25,4%) | 1 | 4 | - | 5 | 5 (3,7%) | 22 (16,2%) | 68 (23,8%) | 150 (50,3%) |
| Felt afraid to seek health services because they were worried that someone may learn their identity/practices | - | 2 | 4 (6%) | 9 (13,4%) | 1 | - | - | 2 | - | 12 (8,8%) | 33 (11,6%) | 113 (39,6%) |
| Avoided to seek health services because they worried that someone may learn their identity/practices | - | 2 | 2 (3%) | 4 (6%) | - | - | - | 2 | - | 10 (7,3%) | 32 (11,2%) | 109 (38,2%) |
| Were verbally harassed | - | 2 | 9 (13,4%) | 35 (52,3%) | 1 | 4 | - | 8 | 11 (8,1%) | 39 (28,7%) | 66 (23,1%) | 146 (51,2%) |
| Were blackmailed | 1 | 2 | 2 (3%) | 12 (17,9%) | - | - | 1 | 2 | - | 27 (19,8%) | 12 (4,2%) | 58 (20,3%) |
| Were physically harassed or hurt | 1 | 4 | 2 (3%) | 15 (22,4%) | - | - | - | 3 | 13 (9,6%) | 38 (27,9%) | 27 (9,5%) | 112 (39,3%) |
| People who know about their identity/practices | | | | | | | | | | | | |
| Other people with the same identity/practices (peers) | 4 | | 62 (92,5%) | | 9 | | 10 | | 68 (50%) | | 269 (94,4%) | |
| Family and friends | 3 | | 53 (79,1%) | | 8 | | 9 | | 36 (24,5%) | | 244 (85,6%) | |
| Other people in the community | 2 | | 32 (47,8%) | | 4 | | 4 | | 22 (16,2%) | | 203 (71,2%) | |
| Belonging to the support group with the same identity/experience | | | | | | | | | | | | |
| Yes | 3 | | 25 (37,3%) | | 3 | | 2 | | 8 (5,9%) | | 77 (27%) | |
| No | 2 | | 42 (62,7%) | | 18 | | 14 | | 128 (94,1%) | | 208 (73%) | |

The gender distribution of stigma and discrimination experienced by key populations was done for two biggest groups – sex workers and PWUD. Table 23 shows that female sex workers were verbally and physically harassed more often than male and transgender sex workers. Female PWUD experienced stigma and discrimination less often than male PWUD (e.g. "being excluded from family gatherings", "having a feeling that family members have made discriminatory remarks or gossiped about them", "feeling afraid to seek health services because they were worried that someone may learn their identity/practices" and so on). Transgender PWUD didn't report any stigma or discrimination against them because of their PWUD identity.

**Table 23. Gender distribution of stigma and discrimination experienced by sex workers and PWUD in the last 12 months (number of participants)**

| | SW female (n=93) | SW male (n=43) | SW transgender (n=1) | PWUD female (n=112) | PWUD male (n=171) | PWUD transgender (n=2) |
|---|---|---|---|---|---|---|
| Being excluded from family gatherings | 1 | 0 | 0 | 11 | 36 | 0 |
| Had a feeling that family members have made discriminatory remarks or gossiped about them | 3 | 2 | 0 | 16 | 52 | 0 |
| Felt afraid to seek health services because they were worried that someone may learn their identity/practices | 0 | 0 | 0 | 7 | 26 | 0 |
| Avoided to seek health services because they worried that someone may learn their identity/practices | 0 | 0 | 0 | 7 | 25 | 0 |
| Were verbally harassed | 8 | 2 | 1 | 15 | 51 | 0 |
| Were blackmailed | 0 | 0 | 0 | 3 | 9 | 0 |
| Were physically harassed or hurt | 12 | 1 | 0 | 5 | 22 | 0 |

## 3.8 ADDITIONAL QUESTIONS ON ACCESS TO MEDICAL SERVICES AND HIV-CARE QUALITY AT THE TIME OF COVID-19

The interrupted access to the updated HIV care services and the quality ART pills have been an enduring problem in Russia for a long time. Russian PLHIV networks and NGOs have been monitoring the access to quality HIV care and services for years. PLHIV patients' communities and experts from the third sector have paid attention to quality of prescribed ART schemes and to availability of necessary tests and analysis for all PLHIV engaged into medical care. Stigma Index 2.0 has given an opportunity to take a new step in this direction. 17 questions were added to the original Stigma Index 2.0 questionnaire.

According to the additional section tailored for Stigma Index 2.0 in Russian Federation 236 (49%) participants were taking ART treatment and 246 (51%) participants did not take ART at the time of the study. Among those 236, who had been taking treatment at the time of study, 40 respondents encountered situations when their visit to an HIV-care facility did not take place because of lockdown in the beginning of year 2020 (17%). 60 respondents (25,4%) encountered situations where their viral load and CD4 testing had to be postponed due to COVID-related safety measures and due to supply issues and test-systems shortages.

214 respondents of the study have started ART again or for the first time at the time of study. A majority of these people have been assigned tests for viral load and CD4-cells (see Table 24 below). 7,5% (n=16) have been assigned tests for ART drugs resistance.

**Table 24. Assigned tests at the beginning of the new ART schemes.**

| 1. At the beginning of therapy, have you been assigned tests for viral load? (n=214) | |
|---|---|
| Yes | 134 (62,6%) |
| No | 53 (24,8%) |
| Don't know/have difficulties to answer | 27 (12,6%) |
| 2. At the beginning of therapy, have you been assigned tests for CD4? (n=214) | |
| Yes | 140 (65,4%) |
| No | 51 (23,8%) |
| Don't know/have difficulties to answer | 23 (10,7%) |
| 3. At the beginning of therapy, have you been assigned tests for ART drugs resistance? (n=214) | |
| Yes | **16 (7,5%)** |
| No | 122 (57%) |
| Don't know/have difficulties to answer | 76 (35,5%) |

215 respondents have experienced changes in their ART schemes during the year of the study. For 24,7% of them their treatment schemes have been changed for medical reasons. 30% of these respondents have been scheduled for VL and CD4-

cells testing before the changes were applied to their prescribed schemes. 3,3% have been tested on ART drugs resistance (see Table 25).

### Table 25. Changes in ART schemes and assigned tests due to it

| Has the treatment regimen been changed for medical reasons? (n=215) | |
|---|---|
| Yes | 53 (24,7%) |
| No | 124 (57,7%) |
| Don't know/have difficulties to answer | 38 (17,7%) |
| When you changed your treatment regimen, were you scheduled for CD4 tests? (n=215) | |
| Yes | 70 (32,6%) |
| No | 106 (49,3%) |
| Don't know/have difficulties to answer | 39 (18,1%) |
| When you changed your treatment regimen, were you scheduled for VL tests? (n=215) | |
| Yes | 69 (32%) |
| No | 107 (49,8%) |
| Don't know/have difficulties to answer | 39 (18,1%) |
| When you changed your treatment regimen, were you scheduled for resistance tests? (n=215) | |
| Yes | 7 (3,3%) |
| No | 138 (64,2%) |
| Don't know/have difficulties to answer | 70 (32,6%) |

During the last 12 months study participants received ART pills supply for less than two months and received generics (61,9% and 36,4%).

### Table 26. Problems related to acquiring ARVT pills

| Have you encountered any of the following problems in acquiring ARVs in the past 12 months (n=236) | |
|---|---|
| Change of drugs by INN (generics, international non-proprietary names) | 86 (36,4%) |
| Incomplete scheme | 3 (1,3%) |
| Receiving ART pills for less than 2 months | 146 (61,9%) |

33 participants reported experiencing side effects from taking ART (14%). One of them filled out the pharmacovigilance form by himself; 30 out of 33 told their doctors about the side effects of ARV. In half of situations HIV care specialists did nothing to resolve a problem (see Table 27).

## Table 27. ARVT side effects and actions taken to overcome them

| During the last year, have you had any problems (adverse events or side effects) that you think are related to taking HIV therapy? (n=236) | |
|---|---|
| Yes | 33 (14%) |
| No | 166 (70,3) |
| Don't know/have difficulties to answer | 34 (14,4%) |
| If "yes", did you fill out the pharmacovigilance form by yourself? (n=33) | |
| Yes | 1 |
| No | 32 |
| If "yes", did you tell your doctor about these problems? (n=33) | |
| Yes | 30 |
| No | 3 |
| If "yes, did tell": What was the reaction of your doctor? (n=30) | |
| The doctor ordered additional tests | 4 |
| The doctor prescribed or recommended medications (non-ARVs) and procedures to relieve symptoms | 6 |
| The doctor changed the ARV regimen | 9 |
| The doctor has completed the pharmacovigilance form | 0 |
| The doctor advised to fill out the pharmacovigilance form | 0 |
| The doctor has not done any of the above | 14 |
| I myself have contacted the manufacturer of the drugs directly | 0 |

# Section 4. Discussion, study limitations and future studies

The main goal of the study was to describe the patterns of stigma and discrimination faced by people living with HIV in Russia. This study was an attempt to grasp an unbiased and honest picture of stigma and discrimination among key PLHIV populations in Russia.

**THE INTERSECTIONAL STIGMA IS A NEW REALITY THAT REQUIRES A BROAD AND CORRECT UNDERSTANDING OF PLHIV STIGMA AND DISCRIMINATION.**

The most important and/or controversial findings of that study were related to the following issues:

### SPECIFIC AND UNEXPECTED CHARACTERISTICS OF THE STUDY SAMPLE

Russian system of epidemiological investigations of newly detected HIV-cases as well as HIV surveillance services do not provide reliable epidemiological data on real numbers of PLHIV in key population groups. Facing the scarcity of official data this study sample provided some distinctive features. Firstly, it was composed of participants who mostly belonged to KPs – only about 20% did not belong to any of key population groups. The largest represented in the study subgroups were PWUD, sexual workers and MSM. Secondly, near one-third of participants identified themselves as two or even more groups of the key populations (28,2%, n=134). Intersectional identity in the sample was mostly frequent in subgroups of MSM–PWUD (n=19) and sex workers-PWUD (n=62).

### MANIFESTATIONS OF STIGMATIZATION AND DISCRIMINATION AGAINST PLHIV IN RUSSIA

The frequency of stigmatization and discrimination against study participants by their social circle is declining compared to the previous 2010 Stigma Index study and previous experiences of respondents. Comparison showed that Stigma Index respondents in 2010 suffered from gossiping or discriminatory remarks in 18% of cases (vs 14,1% in 2021), were physically harassed in 4% of cases (vs 1,7% in 2021) and have been discriminated at work in 2% of cases (vs 0,4% in 2021). Stigma Index 2.0 study also indicated that previously – not within 12 months prior to the study – participants experienced stigma and discrimination more frequently than now.

### INTERNALIZED STIGMA

The internalized stigma was more prevalent among study participants than "external" stigmatization and discrimination. That phenomenon draws attention to the quality of consultations before and after HIV-testing, as well as to the availability and openness of PLHIV networks, peer support groups and local PLHIV communities.

Stigma Index 2.0 indicated that HIV+ status had the greatest negative impact on the ability to find love (33,8%), on self-confidence (36,1%), on the ability to maintain close and secure relationships (35,5%), on desire to have children (32,2%), on self-respect (28,2%), and on the ability to cope with stress (28%). However, there were gender differences: male LHIV more frequently than female LHIV replied that their HIV status had negatively affected their "ability to have close and secure relationships with others" (39% vs 30,3%), "ability to find love" (37,5% vs 29,4%), "ability to achieve personal and/or professional goals" (24,3% vs 17%). In comparison, female LHIV were more likely than male LHIV to report concerns about their abilities to cope with stress (33,5% vs 22,8%) and to respect others (15,1% vs 10,4%) because of their HIV status.

### REJECTION OF ACTION AND/OR OPPORTUNITIES BECAUSE OF THE HIV+ STATUS

The analysis of internalized stigma showed that the positive changes in this area were not significant. Although the data between the 2010 and 2021 Russian Stigma Indexes are not completely comparable, some of indicators on internalized stigma experienced by PLHIV were similar or at slightly lower levels than those reported in 2010. The only exception was the question that asked if the respondent has chosen not to apply for a job: participants of 2021 study answered affirmative in 7,5% of cases (vs 14% in 2010). Restriction or impossibility to meet their own basic needs in 2021 (such as sex, medical help, having work, communication with family and other people) were caused by hiding HIV status from others (81,3%), by finding it difficult to tell people about HIV status (69,9%), by feeling ashamed or guilty because of HIV+ status (53,7% and 51,5%). Among less significant reasons were "feeling worthless" and "dirty" (41,7% and 34,9%).

## Involuntary HIV testing and HIV status disclosure in healthcare services

42% of participants in 2021 Stigma Index 2.0 study indicated that the decision to get tested for HIV was involuntary. 27% were tested without their knowledge and found out only after the test had been performed (vs 18% in 2010). The latter tendency draws attention to the quality of HIV testing facilities. Russian officials put a lot of efforts into large-scale HIV testing. The unintended consequence of these efforts were the HIV-positive results for those who didn't want to be tested for HIV.

Almost half of the PLHIV in the study (44%, n=210) said that they disclosed their HIV+ status in the health care services that were not related to HIV. Such a high proportion of voluntary HIV disclosure with no particular reason brings to the attention two problems – the stigmatization and discrimination in healthcare facilities, and participant's uncertainty whether the health care setting would respect confidentiality of medical records related to HIV status. That fact again draws attention to the quality of pre- and post-testing consultations on HIV, as well as to the low level of medical staff awareness.

## Violations of PLHIV reproductive rights

For the last 12 months, 16 participants (3,3%) were recommended not to have children. In seven cases (1,5%) medical staff suggested to use a specific method of contraception in order to get HIV treatment instead of offering the alternative type of contraception; and in two cases medical staff pressured female participants to undergo sterilization (0,4%). As for the discriminative and stigmatizing advice concerning pregnancy, delivering and breastfeeding women LHIV indicated the violation of their reproductive rights in the near past (last 12 months) and more cases of violation much earlier. That kind of situation needs to be resolved at the level of obstetric and gynecological services.

## Low awareness of laws protecting PLHIV

Participants' level of knowledge about laws that protect PLHIV from discrimination in Russia was insufficient. Only 35% of PLHIV in the study answered that they were aware of laws that protect PLHIV from discrimination. People living with HIV are not reporting cases of violation in an official way; only 9% of the participants reported having suffered human rights violations. These facts correlate with the low level of law awareness among Russian population, and lack of trust towards the rights protecting institutions.

## Stigma, discrimination and HIV disclosure among key population

PLHIV belonging to key populations experienced intersectional stigma and discrimination. Being verbally or/and physically harassed, as well as being in stigmatizing relationships with family was outnumbered in all subgroups. As for belonging to the peer support groups, MSM had the highest levels of that indicator (37,3%); sex workers, WSW and bisexual people had the lowest rates of group membership. The high levels of social embeddedness of MSM correlated with the great inclusion of the latter in medical services.

## LOW LEVEL OF HIV RELATED TREATMENT AND LOW ACCESS TO HIV-CARE SERVICES

Additional questions added in the Stigma Index 2.0 in Russian Federation revealed problematic trends with the ART provision and adherence in the researched populations. 51% (n=246) did not take ART treatment at the time of the study. Among those 236 (49%), who had been taking treatment at the time of study, a majority of these people (n=214) have started taking new ART pills within the last year. Only 7,5% (n=16) of them have been assigned tests for ART drugs resistance. In 57,7% of ART prescriptions there were changes during the year of the study for non-medical reasons.

40 respondents encountered situations when their visit to an HIV-care facility did not take place because of lockdown in the beginning of year 2020 (17%). 60 respondents (25,4%) encountered situations where their viral load and CD4 testing had to be postponed due to COVID-related safety measures and due to supply issues and test-systems shortages.

**STUDY LIMITATIONS:** The small sample size of some key population groups (women who have sex with women and transgender people) made it difficult to break down the results by sex and gender identity, that is why descriptive statistics did not really include these groups. The major age group in the study was 30 years and older; that also limited data analysis for younger groups. However, the small number of these aforementioned groups in the study reflected their number in the general population of PLHIV in Russia.

**FUTURE STUDIES MAY REVEAL THE REASONS WHY SOME GROUPS, FOR EXAMPLE, TRANSGENDER PEOPLE REMAIN UNDERREPRESENTED AND ENCOURAGE SUCH PEOPLE TO BE MORE INVOLVED IN COMMUNITY-BASED RESEARCH.**

Any future research needs to have a qualitative component to record narratives of some underrepresented key populations on stigma and discrimination in greater depth.

Funding for this study was limited and the study population is small, but still, it was very important to get updated data on stigma and discrimination in different key populations groups. Findings and results presented in this report require earnest collaboration and practical cooperation of all main stakeholders – policymakers, authorities, civil society representatives – so that Russian PLHIV can improve their quality of life and wellbeing.

# Section 5. Recommendations

This report presents following recommendations aimed at reducing HIV/AIDS related stigma and discrimination in Russian Federation, such as outlined below:

### TO IMPROVE THE EPIDEMIOLOGICAL SURVEILLANCE SYSTEM IN RUSSIA:

- It is crucial to upgrade the existing system of “epidemiological investigations” of newly detected HIV-cases to update surveillance data and to provide reliable epidemiological data in order to reflect the real numbers of PLHIV in key population groups. The upgraded system should eliminate the stigmatization and discrimination of key populations because of their identities.

### TO REDUCE STIGMA AND DISCRIMINATION AGAINST RUSSIAN PLHIV, INCLUDING INTERNAL STIGMA:

- Integrate into medical departments syllabuses topics on human rights, patients' rights, gender equity, and stigma and discrimination towards the KPs.
- Strengthen the active participation of peer-to-peer counselors on HIV in multidisciplinary teams to improve access to health services and improve patients' mental health. To set up rooms for psychosocial counseling in each of AIDS Centers with the state-level financial aid.
- Promote a training programme for PLHIV and KPs on stigma and discrimination issues in health centers, places of work and at educational institutions.

### TO TACKLE INVOLUNTARY HIV TESTING AND HIV STATUS DISCLOSURE IN HEALTHCARE SERVICES:

- Train health services providers on (a) pre- and post- HIV-test counselling, (b) keeping confidentiality of HIV-positive and HIV-negative results, (c) achieving informed consent from patients.

- Changes should also be made in the Code of Administrative Offences; these modifications aim to enforce the investigation of confidentiality breach and prosecute the perpetrators among medical services providers, law enforcement officers and local authorities.

## TO ENSURE QUALITY HIV-CARE SERVICES:

- Unify official recommendations for medical specialists and include these protocols into the "roadmaps" for PLHIV services:
  - o Get ART treatment with no obligatory residence cards ("registration at the place of residence");
  - o Give out more tests for ARV-drugs resistance;
  - o During the COVID-19 pandemic, identify PLHIV as a specific category of socially disadvantaged citizens to provide them with targeted social assistance, and to ensure that ARV treatment is handed out for months (in advance) as in accordance with WHO recommendations;
  - o Start ART treatment immediately after diagnosis with HIV infection.

## TO IMPROVE LAW AWARENESS AMONG PLHIV:

- There is a need for a referral system that connects PLHIV and paralegals/People's Lawyers. This system will ensure that legal advice services are available in cases of discrimination or HIV transmission criminalization.
- Include NGOs in the design of toolkits tailored for the social work with key populations, such as MSM, youth, women, PWUD, and SWs. (Support the active participation of PLHIV NGOs in the elaboration and implementation of "roadmaps" for delivery of sexual and reproductive health services and improving quality of life of female LHIV).
- Ensure participation of people living with HIV in HIV-related governmental working groups, committees and commissions.

## TO IMPROVE REPRODUCTIVE HEALTH AND RIGHTS PREVENTION:

- Provide advice on family planning, sexual and reproductive rights to all KPs (WSW, MSM, TG people);
- Integrate into the Population Policy Statement for 2021 – 2025 a strong emphasis on a greater access of women living with HIV to services related to prevention, sexual and reproductive health, family planning and contraception.
- Combine efforts of Infectious Diseases and Obstetric and Gynecological services to create a comfortable environment for pregnancy and childbirth.
- For Obstetric and Gynecological services to initiate regular training to enhance the knowledge and capacities of health service providers on sexual and reproductive health of female LHIV.
- For AIDS Centers, medical clinics, law enforcement agencies and NGOs to initiate and maintain regular trainings on reducing stigma and discrimination for women who live with HIV and women from other key population groups.

# Section 6. References

Balabanova, Y., Coker, R., Atun, R. A., & Drobniewski, F. (2006). Stigma and HIV infection in Russia. AIDS Care, 18(7), 846–852. https://doi.org/10.1080/09540120600643641

Bobrova, N., Rhodes, T., Power, R., Alcorn, R., Neifeld, E., Krasiukov, N., Latyshevskaia, N., & Maksimova, S. (2006). Barriers to accessing drug treatment in Russia: A qualitative study among injecting drug users in two cities. Drug and Alcohol Dependence, 82 Suppl 1, S57–63. https://doi.org/10.1016/s0376-8716(06)80010-4

Burke, S. E., Calabrese, S. K., Dovidio, J. F., Levina, O. S., Uuskьla, A., Niccolai, L. M., Abel-Ollo, K., & Heimer, R. (2015). A Tale of Two Cities: Stigma and Health Outcomes Among People with HIV who Inject Drugs in St. Petersburg, Russia and Kohtla-Jдrve, Estonia. Social Science & Medicine (1982), 130, 154–161. https://doi.org/10.1016/j.socscimed.2015.02.018

Calabrese, S. K., Burke, S. E., Dovidio, J. F., Levina, O. S., Uuskьla, A., Niccolai, L. M., & Heimer, R. (2016). Internalized HIV and Drug Stigmas: Interacting Forces Threatening Health Status and Health Service Utilization Among People with HIV Who Inject Drugs in St. Petersburg, Russia. AIDS and Behavior, 20(1), 85–97. https://doi.org/10.1007/s10461-015-1100-4

Edelman, E. J., Lunze, K., Cheng, D. M., Lioznov, D. A., Quinn, E., Gnatienko, N., Bridden, C., Chaisson, C. E., Walley, A. Y., Krupitsky, E. M., Raj, A., & Samet, J. H. (2017). HIV Stigma and Substance Use among HIV-Positive Russians with Risky Drinking. AIDS and Behavior, 21(9), 2618–2627. https://doi.org/10.1007/s10461-017-1832-4

European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2021 – 2020 data. Stockholm: ECDC; 2021.

# REFERENCES

PA. Harris, R. Taylor, R. Thielke, J. Payne, N. Gonzalez, JG. Conde, Research electronic data capture (REDCap) – A metadata-driven methodology and workflow process for providing translational research informatics support, J Biomed Inform. 2009 Apr;42(2):377-81.

PA. Harris, R. Taylor, BL. Minor, V. Elliott, M. Fernandez, L. O'Neal, L. McLeod, G. Delacqua, F. Delacqua, J. Kirby, SN Duda, REDCap Consortium, The REDCap consortium: Building an international community of software partners, J Biomed Inform. 2019 May 9 [doi: 10.1016/j.jbi.2019.103208]

HIV infection (2020). Information Bulletin No. 45. Federal Scientific and Methodological Center for the Prevention and Control of AIDS. http://www.hivrussia.info/wp-content/uploads/2020/12/Byulleten-45-VICH-infektsiya-2019-g..pdf (in Russian)

Ho SS, Holloway A. The impact of HIV-related stigma on the lives of HIV-positive women: an integrated literature review. Journal of clinical nursing. 2016 Jan;25(1-2):8-19.

Kelly, J., Amirkhanian, Y., Yakovlev, A., Musatov, V., Meylakhs, A., Kuznetsova, A., & Chaika, N. (2014). Stigma reduces and social support increases engagement in medical care among persons with HIV infection in St. Petersburg, Russia. Journal of the International AIDS Society, 17(4S3), 19618. https://doi.org/10.7448/IAS.17.4.19618

King, E. J., Maman, S., Bowling, J. M., Moracco, K. E., & Dudina, V. (2013). The Influence of Stigma and Discrimination on Female Sex Workers' Access to HIV Services in St. Petersburg, Russia. AIDS and Behavior, 17(8). https://doi.org/10.1007/s10461-013-0447-7

Kuznetsova, A. V., Meylakhs, A. Y., Amirkhanian, Y. A., Kelly, J. A., Yakovlev, A. A., Musatov, V. B., & Amirkhanian, A. G. (2016). Barriers and Facilitators of HIV Care Engagement: Results of a Qualitative Study in St. Petersburg, Russia. AIDS and Behavior, 20(10), 2433–2443. https://doi.org/10.1007/s10461-015-1282-9

Levada, 2010. Study Report for Stigma Index in Russia (in Russian).

Lunze, K., Lioznov, D., Cheng, D. M., Nikitin, R. V., Coleman, S. M., Bridden, C., Blokhina, E., Krupitsky, E., & Samet, J. H. (2017). HIV Stigma and Unhealthy Alcohol Use Among People Living with HIV in Russia. AIDS and Behavior, 21(9), 2609–2617. https://doi.org/10.1007/s10461-017-1820-8

McCrae, R. R., Costa, P. T., Martin, T. A., Oryol, V. E., Senin, I. G., & O'Cleirigh, C. (2007). Personality correlates of HIV stigmatization in Russia and the United States. Journal of Research in Personality, 41(1), 190–196. https://doi.org/10.1016/j.jrp.2005.11.002

Ministry of Health of Russia, 2021. Background information on HIV infection for 2018-2021, Ministry of Health of Russia. https://стопвичспид.рф/doc/spravka-vich_2021.pdf (in Russian)

Nikolieva, N.A., Ladnaia, N.N., Pomazkin, D.V., Korotkich, A.M., Sanischvili, T.T., Beletzkii, Y.Y., Chinarkhina, G.G. (2020). Assessment of socio-economic losses of society from the HIV/AIDS epidemic in Russia. Report of Analytical Center for the Government of Russian Federation.

Peitzmeier SM, Grosso A, Bowes A, Ceesay N, Baral SD. Associations of stigma with negative health outcomes for people living with HIV in the Gambia: implications for key populations. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2015 Mar 1;68:S146-53.

Pisani E., Garnett GP., Grassly NC., Brown T., Stover J, Hankins C., Walker N., Ghys PD. Back to basics in HIV prevention: focus on exposure. BMJ. 2003 Jun 21;326(7403):1384-7. doi: 10.1136/bmj.326.7403.1384. PMID: 12816830; PMCID: PMC1126255.

Plavinsky, S. L., Ladnaya, N. N., Barinova, A. N., & Zaitseva, E. E. (2018). Prevalence of HIV infection and risk behavior among vulnerable groups of the population in 7 regions of the Russian Federation, results of a biobehavioral study, 2017

Rhodes, T., Platt, L., Sarang, A., Vlasov, A., Mikhailova, L., & Monaghan, G. (2006). Street Policing, Injecting Drug Use and Harm Reduction in a Russian City: A Qualitative Study of Police Perspectives. Journal of Urban Health : Bulletin of the New York Academy of Medicine, 83(5), 911–925. https://doi.org/10.1007/s11524-006-9085-y

Rospotrebnadzor, 2021. On the state of sanitary and epidemiological well-being of the population in the Russian Federation in 2020: State report. Moscow: Federal Service for Supervision of Consumer Rights Protection and Human Welfare, 2021, 256 p. (in Russian)

Rosstat, 2021. Number of registered patients with diagnosed HIV infection for the first time in their life. https://www.fedstat.ru/indicator/41719 (in Russian)

Rosstat, 2021a. The incidence of HIV infection diagnosed for the first time in life per 100 thousand population. https://www.fedstat.ru/indicator/41718 (in Russian)