BELARUSIAN PLHIV COMMUNITY

TOGETHER FOR LIFE!
www.hiv.by

THE PEOPLE LIVING WITH HIV STIGMA INDEX

BELARUS

December 2013

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

HIV in Europe
Working Together for Optimal Testing and Earlier Care

Belarus

Published by:
Republican non-governmental organization Belarusian PLHIV community
Starinovskaja St., building 15, office 3
Minsk, Belarus 220056
BELARUS

Website: www.hiv.by
Email: info@hiv.by

Acronyms

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
BCP	Belarus Community of People Living with HIV
BYR	Belarus Ruble
CCM	Country Coordinating Mechanism (for delivery of Global Fund interventions)
CEDPA	Center for Development and Population Activities
CSO	Civil Society Organisation
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
HIV	Human immunodeficiency virus
IEC	Information, education and communication
ICW	International Community of Women Living with HIV/AIDS
IDU	Injecting drug user
IPPF	International Planned Parenthood Federation
LGBT	Lesbian, gay, bisexual and transgender
M&E	Monitoring and Evaluation
MIPA	Meaningful Involvement of People Living with HIV and AIDS
MSM	Men who have sex with men
NGO	Non-Governmental Organisation
NSF	National HIV/AIDS Strategic Framework
PID	People who inject drugs
PLHIV	People living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
PVT	Prevention of Vertical Transmission
SRHR	Sexual and Reproductive Health and Rights
STI	Sexually transmitted infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS

Acknowledgements

The Belarusian Community of People Living with HIV would like to express its thanks to the wide number of partners and stakeholders that made this study possible. The study and report has been supported financially by UNAIDS Belarus, the Global Network of People Living with HIV, and HIV in Europe.

It builds upon a first report published in 2010 by Eugenia Kechina (Belarus), Doctor of Sociology and Professor of the Chair of Sociology at the Belarusian State University. It is thanks to her initial data analysis and report that this report is possible.

A multi-stakeholder partnership in-country supported the Belarusian Community of PLHIV to make this study possible. These included Eleonora Gvozdeva, UNAIDS Coordinator, Belarus, Anastasia Kamlyk, UN Cares regional advisor for Eastern Europe and Central Asia, and Natallia Korzhaeva, monitoring and evaluation consultant, and Elena Khodanovich.

Of critical importance was working in partnership with government agencies (the National Centre for Hygiene, Epidemiology and Public Health) as well as involvement of the NGO and charitable sector. Partners for the voluntary sector included:

- NGO “Positive Movement”
- NGO “Alternativa”
- NGO “Vstrecha”
- NGO “Mothers against Drugs”
- NGO “TOS-Weissrussland,” Svietlahorsk rayon, Astraučycy
- NGO “Social Assistance”
- Charity Christian Mission “Vozvraschenie” (Coming-Back)
- Rehabilitation Centre “Potters House,” Svietlahorsk rayon, Baroviki

We would also like to thank Axiometrics Laboratory NOVAK(Belarus) who provided data entry and statistical analysis, Julian Hows, GNP+(Netherlands), for technical guidance throughout the study, Andrew Doupe, HIV and Legal Consultant (Australia) for additional technical assistance, Chioke Sprague (USA), Ernests Stradzins (Latvia) for data validation and review, and Kevin Connors (Netherlands) for review of the text. .

Most importantly a special thanks to all HIV-positive interviewers and respondents who voluntarily participated in the study and were willing to share their sometimes difficult experiences of living with HIV.

The People Living with HIV Stigma Index is an initiative of an International partnership

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

ICWGlobal
International Community of Women Living With HIV/AIDS

UNAIDS

Contents

List of Tables and Figures

Figures

Tables

Executive Summary

This study by the Belarusian Community of PLHIV is the first of its kind to be undertaken by HIV-positive people in Belarus, and aimed to collect information on and to understand the degree and the forms of stigma and discrimination experienced by people living with HIV.

Methodology

This study used the People Living with HIV (PLHIV) Stigma Index developed by GNP+, ICW, IPPF and UNAIDS to undertake interviews, following the standard methodology as laid out at www.stigmaindex.org. The main fieldwork was undertaken between 10 August and 30 November 2009, and involved a sample of 370 people living with HIV drawn from 13 cities. In addition, qualitative interviews were conducted with a smaller sample of 18 respondents about barriers to accessing services and specific issues faced by people living with HIV.

Sample of respondents

The study found that HIV-related stigma was prevalent and an ongoing part of life amongst the 370people living with HIV in Belarus who took part in this study. Almost 60% of respondents were men (55.7%, n=206) and over 40% were women (44.3%, n=164). Over 80% of the respondents (81.1%, n=300) were between the ages of 25-39. The largest percentage of respondents, 37.6% (n=139), have been living with HIV for 10-14 years, while a further 28.9% (n=107) for 5-9 years and 21.9% (n=81) for 1-4 years. Further, 12.4% (n=46) of respondents report having a physical disability other than HIV-related general ill health.

Over two-fifths of respondents (44.6%, n=165) lived with a spouse or partner; 32.2% (n=119) had a spouse or partner but did not live with her/him; while 23.3% (n=86) were single (unmarried, divorced or widowed). Over 80% of respondents (82.7%, n=306) reported that they were sexually active.

On average, 1.9 people lived together with the respondent (in addition to the respondent) at the time of the survey; with 10.3% (n=38) living alone. 188 respondents (50.8%) indicated that they had children living in their household, including 39.3% (n=81) of men, 65.2% (n=107) of women and 48.5% (n=94) of respondents who identify themselves as injecting drug users. Twelve (12) respondents reported having children orphaned due to AIDS living in their household: 8 reported 1 child; 3 reported 2 children and 1 reported 3 children.

The largest group of respondents was people who inject drugs (PID) (52.4%, n=194) with over quarter (27.8%, n=103) being a prisoner (or former prisoner), and 23.5% (n=87) identifying both as people who inject drugs and as prison inmates. Furthermore, 64.1% (n=132) of male and 37.8% (n=62) of female identified as PID with 77.3% (n=150) being 30 years of age or older and 90% (n=173) having lived with HIV for 5 or more years.

The effects of poverty on the sample of people living with HIV are clearly evident. 8.9% (n=33) reported some food shortage and 7.3% (n=27) of respondents reported 'severe food shortage' (i.e. during a month there had been three or more days when respondents' household members did not have enough food to eat). Furthermore, over one quarter of respondents (26.2%, n=97) were unemployed with relatively more women than men among the unemployed as well as higher unemployment among PID respondents than non-PID respondents. In terms of income, over half of respondent households (50.3%, n=186) have a monthly income below the national average.

Most respondents had a relatively high level of education with 98.4% (n=364) reporting secondary school level education or above, and only 1.6% (n=6) reporting only primary level education.

Major findings

Major findings concerning the experiences of people living with HIV by area are outlined below with the full findings presented in the **Conclusions**.

The study found that HIV-related stigma was prevalent and an ongoing part of life for the people living with HIV in Belarus who took part in this study.

Exclusion

- Two thirds of respondents (66.5%, n=246) reported that they had been gossiped about at least once in the last year with 67.1% (n=165) of them indicating that it occurred, in whole or in part, because of their HIV-positive status.
- Significant percentages of respondents reporting having been verbally insulted/harassed/threatened (41.6%, n=154), physically assaulted or threatened (15.9%, n=59), and/or physically assaulted (13.8%, n=51) at least once in the last year. Of these, 51.3% (n=79) indicated being insulted/harassed/threatened, 35.6% (n=21) physically harassed or threatened, and 19.6% (n=10) physically assaulted, in whole or in part, due to their HIV-positive status.
- 33.2% (n=123) felt that HIV-related stigma and/or discrimination is due to people not understanding how HIV is transmitted or are afraid of infection through casual contact.

Access to work and health and education services

- Significantly higher levels of discrimination were reported by respondents in access to work (approximately 25%) than in residency/accommodation and health (less than 20%) with lower levels (approximately 5%) reported for access to sexual and reproductive health, and education services.

Internalised stigma and fears

- Internalized stigma was prevalent: 71% (n=223/314) reported feeling guilt, 65.6% (n=206/314) blamed themselves, 54.5% (n=171/314) feeling ashamed, and over 36%% (113/314) reporting low self-esteem.
- 6.7% of respondents (n=21/314) reported feeling suicidal with female and younger respondents both reporting higher levels.
- The most frequent decisions made by respondents during the last 12 months because of HIV status were not to have more children (62.3%, n=170/273), not to marry (27.1%, n=74/273) and to isolate themselves from friends and relatives (14.3%, n=39/273).

Rights, laws and policies

- The Public Health Law was known to 53.8% (n=200), though it was a smaller number who had any deeper knowledge of it, or who had discussed it.
- During the previous 12 months, 27.8% (n=103) of respondents reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions.
- 94 respondents reported that that they experienced a rights violation within the previous 12 months, of whom 9 had sought legal redress; and of the 85 respondents who did not, the most common reason cited (61.2%) was belief that the outcome would be unsuccessful.

Effecting change

- Nearly 20% of respondents (18.1%, n=57) had been involved, either as a volunteer or as an employee, in a programme or project providing assistance to people living with HIV in the previous 12 months.
- Nearly three quarters of respondents (73.2%, n=230) felt unable to influence policies, laws and programmes at either national or local levels.
- In terms of the most important thing organizations should do to address stigma and discrimination, more than 40% cited advocating for the rights of all people living with HIV.

Belarus

Testing and diagnosis

- Over 12% (12.4%, n=40) of respondents were referred for HIV testing when already symptomatic.
- Human rights violations associated with involuntary HIV testing[1] and being tested without consent[2] or any counselling[3] remains a challenge.

Disclosure and confidentiality

- High levels of disclosure by respondents included to: health care workers (56.4%), other HIV-positive people (86.7%), spouses or partners (91%), and other adult family members (67.3%), injecting drug partners (76%), and social workers and other counsellors (44.1%).
- 4.8% of respondents have not disclosed to their spouse or partner, and 20% have not disclosed to injecting drug partners.
- Approximately half of respondents (51.9%) described disclosing their HIV status as an empowering experience.

Treatment

- 44.1% of respondents were taking ART with 87% indicating that they could access ART if needed.
- 51.1% of respondents had discussed HIV treatment options and 33.8% had discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months.

Having children

- 38.1% of respondents indicated that they had never received counselling on their reproductive options since their HIV diagnosis.
- Of the female respondents who have been pregnant in last 12 months, 25% reported coercion to undergo an abortion; 15.4% reported coercion in relation to birthing method; and 6.4% in relation to Infant feeding practices.

---

[1] Nearly one quarter (24%) reporting being forced to take a HIV test.

[2] 12.2% of respondents were tested while in prison (n=45), and 5.7% (n=21) while in police custody. Male respondents were twice as likely to have undergone testing while in detention compared to female respondents. Female respondents were more likely to have undergone testing during registration with drug monitoring and rehabilitation clinics and during drug treatment (20.5%, n=8/39 females compared to 15.2%, n=14/92 males); in hospital, during in-patient treatment (25.6%, n=10/39 females compared to 17.4%, n=16/92 males); and during blood screening (hepatitis/herpes/donation of blood) (10.3%, n=4/39 females compared to 2.2%, n=2/92 males).

[3] Over 40% (40.8%, (n=151) received no counselling at all, while nearly half (48.4%, n=179) received only post-test counselling, and 2.4% (n=9) received only pre-test counselling.

- In relation to prevention of vertical transmission (PVT), 2% indicated that they did not have access to ART and 11.8% did not know that such treatment existed.

Major Recommendations

Among the sample there was low socio-economic status, including significant percentages of respondents reporting low levels of employment, as well as internalized stigma, high rates of being fearful about the ways they were perceived and treated in the community (with reported examples of stigmatising and discriminatory treatment), and 21 (6.7%) of respondents reported feeling suicidal with younger and female respondents reporting higher rates. As such, psychosocial and socioeconomic support must clearly be a priority for the Belarusian Community of PLHIV, civil society, the National AIDS Programme and the Government. Concerted efforts by all the above stakeholders are required to promote positive living and provide psychosocial and socioeconomic support, including training opportunities for people living with HIV to become peer educators, capacity and network building, counselling, training, and income generation. Furthermore, there is a clear need to provide gender and age specific services, as well as for people who inject drugs (PID).

Other major recommendations directed to the Belarus Network of PLHIV, civil society, the National AIDS Programme and the Government are outlined below with the full recommendations presented in **Recommendations**.

Belarus Community of PLHIV

- Encourage and build the capacity of people living with HIV to advocate for their rights; be actively involved (either as a volunteer or as an employee) in developing and implementing stigma and discrimination reduction projects and programmes; and to provide support and assistance to people living with HIV individually, and through support groups and other local organisations.
- Advocate for the inclusion of more people living with HIV in policy-making fora and in the development and drafting of relevant legislation.
- Build the capacity of support groups and other local organisations to challenge stigma and discrimination, and to provide adequate counselling and other support to people living with HIV, including key populations, and in particular people who inject drugs and those in detention settings.

Civil Society

- Advocate for the rights of all people living with HIV, including in particular people who inject drugs and those in detention settings.

- Promote voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission to people living with HIV and the general public.

National AIDS Programme

- review and update, if needed, protocols to ensure they are rights-based and include pre-service training for health care workers as well as in-service training refresher courses for health providers, managers and other health facility staff, as well as strengthen supervision to foster non-judgmental and non-discriminatory practices towards people living with HIV, including specifically for people who inject drugs and those in detention settings;
- Scale-up the provision of correct information and appropriate options for ART and the sexual and reproductive health for people living with HIV, including PVT, and specifically for people who inject drugs and those in detention settings.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.

Government

- Take the lead in creating a policy and legal environment that will safeguard the rights of people living with HIV, specifically addresses HIV-related stigma and discrimination, requires informed consent for HIV testing protects confidentiality and provides redress for breaches.
- Support broad-based social and community awareness raising and mobilization as part of efforts to eradicate stigma and discrimination against people living with HIV and key populations, including through a human rights-based approach, addressing HIV-related myths.
- Prioritize HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in national strategic planning, funding and programmes, including support for scaled up implementation of promising programmes.
- Include HIV-related stigma and discrimination indicators as part of the national AIDS response M&E systems to monitor and evaluate progress over time.

Introduction

Background on HIV-related stigma and discrimination

Stigma is ‘an attribute that is deeply discrediting’ and results in the reduction of a person or group ‘from a whole and usual person to a tainted, discounted one’[4]. Thus, the ultimate effect of stigma is the reduction of the life chances of the stigmatised through discriminatory actions[5].

Discrimination involves treating someone in a different and unjust, unfair or prejudicial way, often on the basis of their actual or perceived belonging to a particular group. It consists of actions or omissions that are a result of stigma and directed towards those individuals who are stigmatised. In other words, discrimination is ‘enacted stigma’[6]. However, a person may feel stigma towards another but s/he may decide not to act in a way that is unfair or discriminatory. Discrimination can occur at different levels: individual, family, community or national[7].

HIV-related stigma often builds upon and reinforces other existing prejudices such as those related to gender, sexuality and race. For example, the stigma associated with HIV is often based upon the association of HIV and AIDS with already marginalised and stigmatised behaviours such as sex work, drug use and same-sex and transgender sexual practices[8]. HIV-related stigma affects those living with HIV and, often, those with whom they are associated, such as their partners or spouses, their children or other members of their households.

Internalised stigma, also referred to as ‘felt’ stigma or ‘self-stigmatisation’, is a term used to describe the way a person living with HIV feels about him/herself, particularly if he/she feels a sense of shame about being HIV-positive. Internal stigma can lead to low self-esteem, a sense of worthlessness and/or depression. Internal stigma can also result in a person living with HIV withdrawing from social and intimate contact.

---

[4] Goffman, E. (1963). Stigma: Notes on the Management of Spoiled Identity. New York: Simon & Schuster Inc.

[5] Ibid.

[6] IPPF (2008) HIV/AIDS Update Issue 13
UNAIDS (2005) HIV-related stigma, discrimination and human rights violations: case studies of successful programmes. UNAIDS best practice collection. Geneva.

[7] UNAIDS (2005) HIV-related stigma, discrimination and human rights violations: case studies of successful programmes. UNAIDS best practice collection. Geneva

[8] Ibid.

Belarus

Country Context

As of August 1 2012, 13,726 HIV cases were registered in Belarus. Within 7 months of 2012, 771 new cases were registered. From 1987 to June 1st 2011, 2126 children were born to HIV-positive mothers, including 126 in 2012 (8 months).

The cumulative number of AIDS as for August 1 2012 is 3384.

The HIV prevalence in Belarus remains 0.2 - 0.4% with 700 - 1000 new registered HIV cases annually[9]. The estimated number of people living with HIV (PLHIV) exceeds 25,000.

Fifty-three percent of PLHIV live in the Gomel region. The HIV epidemic is concentrated in injecting drug users (IDUs) (10.7%, Sentinel Surveillance Study 2009), though it is growing among men who have sex with men (2.1%) and among female sex workers (2.9%). The transmission via injecting drugs makes 53.3% of the cumulative HIV cases registered by 2009.

Since 2005, the ratio of people infected through heterosexual sexual activity has risen and reached almost 80% of new cases in 2009. Men make the majority of the registered PLHIV (63%). Sixty-six percent of all HIV cases are among young people between 15-29 years of age.

National Response

Belarus follows the *Three Ones*[10] principles in the state policy on HIV and AIDS. The National Multisectoral Council on HIV and STIs Prevention (NAC) was established in 1997 and it is chaired by the Deputy Prime Minister. The NAC was a prototype of the Country Coordination Mechanism for cooperation with the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) since 2002, however with one but crucial exception – no civil society representation on the NAC.

The Belarus Government addressed the challenge of the HIV epidemic from 2006 – 2010 through formulating and implementing the multisectoral state HIV Prevention Programme. This was co-funded by the GFATM grant Round 3, the United Nations Development Programme (UNDP) the principal recipient. Thirty-eight percent of its funds were implemented by civil society organizations. The 4th State HIV Prevention Programme for 2011-2015 was developed with co-funding of the GFATM Round 8 (EURO 23.8 million) and Rolling Continuation Channel (RCC) (USD 13.5 million) grants. The GFATM remains the largest HIV donor for Belarus.

---

[9] http://www.unaids.org/ctrysa/EURBLR_en.pdf and http://data.unaids.org/una-docs/three-ones_keyprinciples_en.pdf (Russian: http://data.unaids.org/una-docs/three-ones_keyprinciples_ru.pdf).

[10] http://www.unaids.org.ua/un_support/strategies/ThreeOnes

During 2004 - 2009 Belarus achieved considerable progress in providing Universal Access to prevention programmes for IDUs (58.7%), men having sex with men (24.2%), commercial sex workers (44.7%), prisoners (82.5%) with the support of the GFATM (GFATM project indicators, 2009)

The Methadone treatment programme was scaled up in 2009 to 138 clients. Eighty-nine percent of HIV+ pregnant women and new born received HIV prophylaxis. Prevention of mother-to-child transmission (PMTCT) is a part of the National Demographical Security Strategy. Combined antiretroviral therapy for people living with HIV (PLHIV) was scaled up to 83.1% of registered patients in need (1,565 patients, 2009). Treatment and prevention among most at risk population remain unsustainable by state funding (National AIDS Spending Assessment.

National funding

At present (2013), except for the GFATM Belarus does not enjoy major external sources of funding for health related activities from bilateral or multilateral donors. Belarus is not a recipient of a World Bank loan or grant or any other substantive financial assistance from the EU. The only operational grants for HIV and TB are coming from the Global Fund to Fight HIV/AIDS, TB and Malaria. The Government of Belarus funds up to 68% of the majority of activities within the State HIV Prevention program (NASA report, 2008), though ARV drugs and HIV prevention activities among most at risk groups are funded by GFATM (almost 100%). GFATM provided 95% of all donor assistance to HIV and TB in Belarus. Limited assistance has been provided by UN agencies through the activities of the UN Joint team within the Joint UN HIV Program of Support (WHO, UNICEF, UNAIDS Secretariat, UNFPA) and did not exceed 200,000 USD per year. However NGOs are not funded by the government. Some NGOs receive funding from Global Fund via UNDP for social support and medical services and education, or from European Union grant programs.

Additionally, and more recently, the re-classification of Belarus by the World Bank as a country with higher middle-income has impacted upon the ongoing eligibility of Belarus to secure GFATM funding. The end of Global Fund sources of support is expected to be complete by 2016, and the ‘phased’ withdrawal already is (anecdotally) reported as having an impact upon services and ARV provision in the country (ARVT). In 2014 the first allocation from the governmental budget was made to start to make up and replace the decreasing GFATM support, however it remains to be seen whether this be a smooth and untroublesome transition.

Burning issue/ major challenge

The added value that civil society (NGO) responses bring to countering HIV and respect for human rights is generally well respected internationally. Though the necessity for the provision of medical services in relation to HIV/AIDS is accepted, NGO's and other agencies operating in Belarus who adopt a human rights approach face a very difficult operating[11]. Human rights and public health share the common goal of promoting and protecting the well-being of all individuals, when in Belarus human rights activities are strictly controlled and in most cases forbidden.

About the Belarusian Community of People Living with HIV

BPC[12] was created to meet the needs of those affected by HIV in Belarus. Its mission: to raise quality of life of PLHIV in Belarus through consolidation efforts of PLHIV all over the country. There was and still is an urgent need to reach out to people who are HIV positive as well as their family and close ones in order to get access to life-saving services and treatment promised by the government and/or to make it to give relevant promises. Currently the Belarusian PLHIV Community is the only NGO uniting HIV-positive people of Belarus at national level. In 2010 BPC initiated a platform for communication and interaction of other NGOs providing services to PLHIV in the country: Belarusian PLHIV Community Advisory Board (Belarus-CAB). Belarus-CAB administered and coordinated by BPC unites all NGOs in the country providing services to PLHIV: National NGO "Positive Movement", National NGO "BPC", National NGO "Mothers against Drugs", National NGO "Vstrecha", Local NGO "Alternative" (Svetlogorsk).

BPC is a democratically organised member organisation. The organization has initiative groups (consisted of 3-60 members) in the following cities: Vitebsk, Orsha, Mogiliov, Gomel, Rechitsa, Mozyr, Zhlobin, Svetlogorsk, Minsk, Bobruisk, and Kalinkovichy.

BPC has established links with partner organizations involved in HIV services at national level, non-governmental as well as governmental bodies (local authorities, AIDS prevention department in the Republican Centre of Hygiene, Epidemiology and Public Health, Ministry of Internal Affairs, international networks of PLHIV and HIV-service ones, local, national and international NGOs involve in HIV-service, others). Besides national efforts BPC has also established close links with partner organisations in neighbouring countries and internationally.

Advocacy is the main priority of BPC work, including human rights education and community mobilization. Second priorities are creating supportive surroundings to people living with

---

[11] As noted by the **International Center for Not-for-Profit Law (ICNL**) not for profit (NGO.) face a very difficult operating environment in Belarus , more info available at http://www.icnl.org/research/monitor/belarus.html#intro

[12] www.hiv.by

HIV/AIDS and activate civic position of PLHIV through grassroots initiatives to fight stigma, discrimination, bureaucracy and corruption.

Study Objectives

The purpose of this study was to collect information on and to understand the degree and the forms of stigma and discrimination experienced by people living with HIV (PLHIV) in Belarus.

The specific objectives were to:

- identify the experience and cases of stigma and discrimination by people against PLHIV;
- determine the reasons for stigma and discrimination as subjectively perceived by PLHIV;
- study the opinions of PLHIV on discrimination and stigma they experience in the area of accommodation, employment, health and education;
- describe the main manifestations of internal stigma experienced by PLHIV;
- identify changes in self-esteem and behaviour of PLHIV occurring after learning about their HIV-positive status;
- study the awareness of PLHIV about their rights and the exercising of such rights in practice;
- study the opinions of PLHIV on the situation concerning maintaining confidentiality in relation to their status;
- study the opinions of PLHIV on the quality of medical services they receive (diagnosis, antiretroviral therapy, and reproductive health services); and
- describe the main challenges as perceived by PLHIV in relation to the most important aspects of living with HIV.

Methodology

The study was conducted between 10 August and 30 November 2009, and involved a sample of 370 people living with HIV drawn from 13 cities.

Sampling: In order to ensure a comprehensive situation analysis, surveys were conducted in 13 cities: Minsk, 6 oblasts (regions) and 6 raions (districts) (**Table 1**). For each oblast, the epidemiological situation in the cities from which the sample population was drawn reflects the general epidemiological trend in the whole oblast.

Table 1: Total sampled population of PLHIV

Total sampled population, people		Number of reported HIV-cases
City	Number of respondents	
Brest	16	138
Pinsk	8	373
Viciebsk	20	188
Hrodna	4	71
Homieĺ	38	666
Žlobin	19	706
Svietlahorsk	144	2478
Rečyca	20	268
Mazyr	13	214
Kalinkovičy	7	151
Mahilioŭ	3	120
Salihorsk	18	767
Minsk	60	1545
Total	370	7685

Snowball sampling was used (e.g. where respondents were reached through referrals and referrals of referrals through members of mutual-help groups, infectious disease rooms of health facilities, regional departments of HIV/AIDS prevention, rehabilitation centres for drug users, and NGOs).

Data collection instruments

The study used the People Living with HIV (PLHIV) Stigma Index[13] (The Index) developed by and for people living with HIV. This is an initiative of four founding partners working together since 2005 - GNP+, ICW, IPPF and UNAIDS. The Index facilitates collection of information from people living with HIV to:

- enable people living with HIV to document their experiences;
- compare experiences across countries;
- measure changes over time; and
- provide sound evidence for policy and programme interventions.

---

[13] For more information go to www.stigmaindex.org

The study tool (questionnaire) were completed during face-to-face interviews. Informed consent forms were completed before the interview. The questionnaire was applied in Russian.

Interviewers: Of the eighteen (18) interviewers, 14 were members of the Belarusian Community of PLHIV and 4 were not.

Interviews: Special emphasis was placed on interview technique which aimed at ensuring a comfortable environment and confidentiality. Interviewing was by face-to-face and side-by-side[14] interview. Interviewees were also provided referral addresses to services, as necessary, depending on the problems identified. Before starting the interview each respondent was informed about the objective and tasks of the study (an information sheet was used) and signed the informed consent form (e.g. voluntary consent to participate in the study).

Most respondents showed positive attitude towards interviews, their motivation to participate was high as participation provided an opportunity to speak out, to receive additional and necessary information about living with HIV and other issues. For many participants, it was very important to feel their personal involvement in advocating for the rights of PLHIV.

Data analysis: The results of the survey were processed using SPSS.

Data Validation: The reconciliation of the study results with PLHIV was done through discussions with PLHIV, and members of various organizations. These discussions were organized and coordinated by the Belarusian Community of PLHIV. The results of the study were considered at the meeting of the National Advisory Council on HIV/AIDS M&E on 29 April 2010. Upon the Council's recommendation, the study report underwent further development over the course of four months.

Ethical considerations:

Challenges: During the study, a number of challenges were faced, including:

- Despite the fact the National Department of HIV/AIDS Prevention sent out letters of support, not all of infectious disease doctors could provide proper assistance in reaching potential interviewees.
- Though interviewers signed the nondisclosure statement, during interviews they had to repeatedly emphasize the confidential nature of the interview to ensure

---

[14] i.e. the interviewer was close to, and filled in the questionnaire together with, the respondent

interviewees answered questions more openly. Interviewees were very reluctant to provide their contact information.

- The wording of some questions in the questionnaire was sometimes difficult for respondents to understand, and interviewers had to repeat the question and explain its meaning. This was probably due to inadequate translation of the questionnaire from English.

Process

Following the presentation of this methodology by GNP+ at the international level at the UNAIDS meeting (Tunisia, June 2009) and at the regional orientation meeting of people living with HIV (Turkey, March 2009) attended by representatives of Belarusian PLHIV, UNAIDS advocated in Belarus for implementing the Stigma Index as an innovative way of studying issues related to causes and consequences of stigma against PLHIV in society.

The national conference to introduce the Stigma Index methodology and develop partnership for the study was held on 26 June 2009 with the support of UNAIDS. Representatives included from ministries, public and non-governmental organizations, UNAIDS co-sponsors, people living with HIV, members of the Advisory Council on HIV/AIDS Monitoring and Evaluation, representatives of the HIV Prevention Department of the National Center for Hygiene, Epidemiology and Public Health, representatives of the Country Coordinating Mechanism (CCM), specialists from the Global Fund Grant Management Group, representatives of regional and district-level HIV service organizations, and sociological research companies.

The following topics were discussed at the conference: the study protocol; sampling; the process and criteria for interviewer and interviewee selection; using Epi-info/SPSS databases; report preparation; the role of non-governmental and public HIV service organizations; the role of sociological research companies.

Following the conference, the deputy chair of the National Inter-Agency Council on HIV/AIDS and STD Prevention approved the Stigma Index study as a component of the national situation analysis for the development of the 4th State Programme on HIV Prevention, 2011-2015. The Joint UN Group on HIV/AIDS together with national partners developed a project for financing the study using UNAIDS Programme Acceleration Funds.

An evaluation committee, comprising representatives of HIV service NGOs, the UNAIDS Coordinator, a representative of the National Center for Hygiene, Epidemiology and Public Health, and a member of the Advisory Council on M&E, was created; and developed an interviewer selection plan, including selection criteria, and developed participant protocol sheets. With the support of the NGO “Belarusian Community of People Living with HIV”, partnership agreements to participate in the study were reached with non-governmental and public organizations. PLHIV interviewers were sought through a call for proposals disseminated by e-mail and mail, through the website of the Belarusian Community of PLHIV and outreach and by the study coordinator publicising the initiative at meetings, appropriate fora, and through word of mouth. This was all undertaken by the study coordinator.

Interviewers were selected by a committee consisting of 12 members, including independent experts working with PLHIV (6), representing a range of organizations such as the Belarusian Community of PLHIV, Alternativa, Positive Movement, Mothers against Drugs, the Belarusian Red Cross Society as well as the Ministry of Health of the Republic of Belarus (the AIDS prevention department of the National Center for Hygiene, Epidemiology and Public Health).

From the 22 applicants, 18 people were selected[15], of whom 14 were members of the Belarusian Community of PLHIV and 4 are not. A one-week training session facilitated by Natallia Korzhaeva and Anastasia Kamlyk for interviewers was held in July 2009.

What is in this report?

This report follows the content of the questionnaire and is divided into three sections:

Section 1: Background characteristics and household composition.
Section 2: Experience of stigma and discrimination.
Section 3: Experience of testing, disclosure, treatment and having children.

Conclusions and recommendations are then presented. Note that Annex 1: Identified problems and challenges provides further qualitative data and recommendations by respondents on problems and challenges faced by respondents in relation to:

- HIV testing, diagnosis and treatment
- Confidentiality
- ART Access
- Having children

---

[15] 20 were chosen as interviewers; however two people were unable to participate due to health-related issues.

Belarus

Section 1: Background characteristics and household composition

This section presents general background information about people living with HIV involved in the study.

Gender and Age

Among the respondents 55.7% were males (n=206) and 44.3% were females (n=164). The majority of respondents were aged 25-39 (81.1%, n=300), i.e. the majority of respondents are in their most active reproductive and working years. The percentages of respondents under 25 and over 39 of age are almost equal: 9.2% (n=34) and 9.7% (n=36) respectively. Respondents aged 15–19 represent the smallest group in the sampled population –5 respondents (1.4%).

Relationship status

Table 2 shows that over two-fifths of respondents (44.6%, n=165) lived with a spouse or partner; 32.2% (n=119) had a spouse or partner or in a relationship but did not live with her/him; while 23.3% (n=86) were single (unmarried, divorced or widowed).

Table 2: Current relationship status

Marital status	(%)	(N)	Men		Women	
Registered or common-law marriage, and the husband/wife/partner live together	44.6%	165	40.8%	84	49.4%	81
Registered or common-law marriage but the husband/wife/partner temporarily lives separately	6.5%	24	4.9%	10	8.5%	14
I am in a relationship but do not live together with my partner	25.7%	95	29.1%	60	21.3%	35
Single	14.1%	52	17.0%	35	10.4%	17
Divorced	6.2%	23	5.8%	12	6.7%	11
Widow/widower	3.0%	11	2.4%	5	3.7%	6

The percent of respondents who are married is higher among women than among men, 57.9% (n=95) compared to 45.7% (n=94). Among single never married respondents, the percentage is higher among male respondents (17%, n=35) than female respondents (10.4%, n=17).

The majority (61.6%, n=175) have been in a relationship with their partner for up to 4 years with over one third (34.5%, n=98) from 5 to 14 years.

Among female respondents, almost one quarter (23.1%, n=30 of 130) were in a relationship for one year or less.

Sexual activity

82.7% (n=306) of respondents report that they were currently sexually active, including 87.4% (n=180) of male and 76.8% (n=126) of female respondents.

Length of time living with HIV

This chart outlines the length of time respondents had been living with HIV

Figure 1: Length of time living with HIV

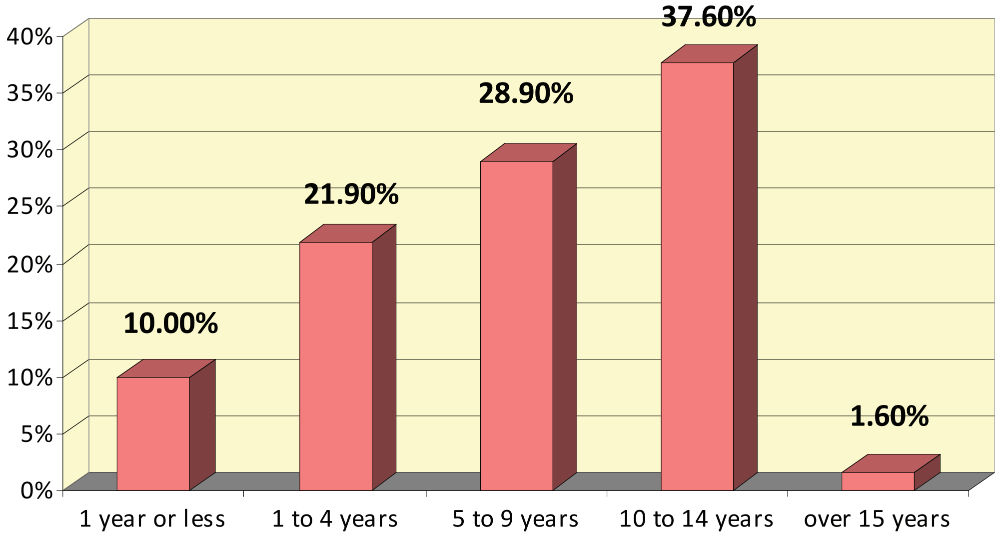


Figure 2: Length of time living with HIV, disaggregated by gender

	Male			Female		
	Frequency	Percent		Frequency	Percent	
		of subgroup	of all men		of subgroup	of all women
0-1 year	21	56.8%	10.2%	16	43.2%	9.8%
1-4 years	38	46.9%	18.5%	43	53.1%	26.2%
5-9 years	55	51.4%	26.7%	52	48.6%	31.7%
10-14 years	90	64.7%	43.7%	49	35.3%	29.9%
15+ years	2	33.3%	1.0%	4	66.7%	2.4%
TOTAL	206	55.7%	100.0%	164	44.3%	100.0%

Table 3: Correlation between the respondents' age and time living with HIV

How long have you lived with HIV?	Age				
	15–19	20–24	25–29	30–39	40–49
0–1 year	60.0%	34.5%	11.0%	6.0%	2.8%
1–4 years	40.0%	48.3%	40.0%	10.0%	13.9%
5–9 years	-	17.2%	35.0%	28.0%	30.6%
10–14 years	-	-	14.0%	53.5%	50.0%
over 15 years	-	-	-	2.5%	2.8%

Key populations

The People Living with HIV Stigma identifies a list of categories (as described below) that respondents could identify as belonging to. Dependent on country context it is people from, or identifying with one of the categories, who In general may be referred to as being part of a 'key population'[16]. In terms of key populations, the largest group of respondents was people who inject drugs (52.4%, n=194) with over one quarter (27.8%, n=103) being a prisoner (or ex-prisoner), and over one third (34.1%, n=126) not identifying themselves with any of these groups. The percentages of respondents identifying as belonging to other key populations are small, ranging from 0.3% to 5.4% (**Table 4**).

---

[16] http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2236_guidance_partnership_civilsociety_en.pdf

Table 4: Respondents belonging to key populations

Population groups	Percentage	Number (people)
People who inject drugs[17]	52.4	194
I do not and did not belong to any of these groups	34.1	126
Prison inmate	27.8	103
Internally displaced person[18]	5.4	20
Gay or lesbian[19]	3.2	12
Men who have sex with men[20]	2.7	10
Sex worker	2.4	9
Member of the community of indigenous people[21]	1.9	7
Migrant worker	1.9	7
Refugee or asylum seeker[22]	0.3	1

People who inject drugs (PID)

In terms of the people who inject drugs:

- 64.1% of male (n=132/206) and 37.9% of female respondents (n=62/164) reported being people who inject drugs.
- 84.7% (n=87) of respondents in the prison inmate group (n=103) also reported being people who inject drugs.

---

[17] People who inject drugs/ injecting drug user (IDU): A preferable term that places the emphasis on people first is 'people who inject drugs'. The term 'injecting drug users' is preferable to 'drug addicts' or 'drug abusers', which are derogatory terms that are not conducive to fostering the trust and respect required when engaging with people who use drugs. Note that the term 'intravenous drug users' is incorrect because subcutaneous and intramuscular routes may be involved.
UNAIDS (October 2011) Terminology Guidelines: Revised Version.
http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf

[18] Internally displaced people are individuals or a group of individuals who were forced to leave or abandon their homes or places of ordinary residence, in particular, as a result of or to avoid the aftermath of an armed conflict, prevailing manifestations of violence, violation of human rights, natural or human-caused disasters and who did not cross the internationally recognized state borders.

[19] Gays or lesbians are men and women who have sexual intercourse only with individuals of the same sex.

[20] Men who have sex with men are men who have sexual intercourse both with men and women.

[21] Members of the community of indigenous people are people who have a long historical bond with a specific region or part of the region; members of a separate community related by special bonds of kinship, language and culture.

[22] Refugees and asylum seekers are people forced to cross the international borders because of a conflict or political instability which causes them to fear persecution on grounds of race, religious affiliation, ethnic background, belonging to a particular social group, adherence to certain political views.

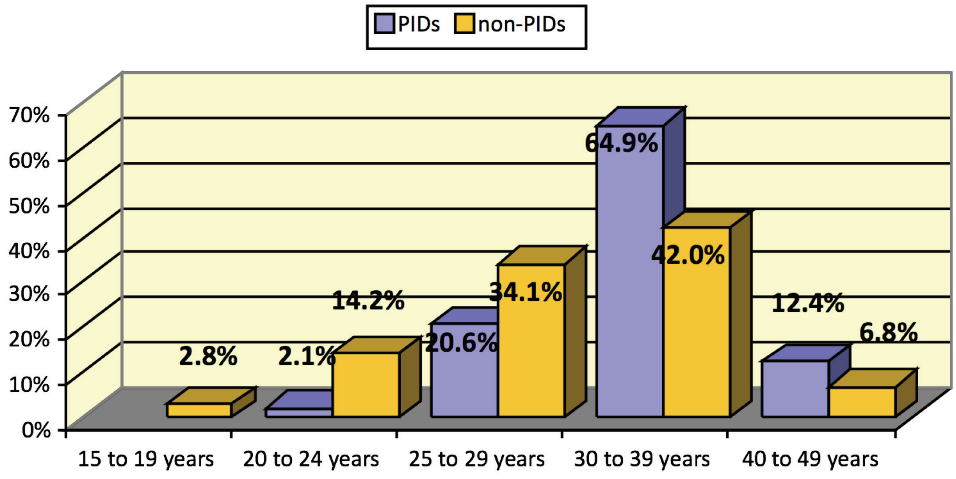
For the purpose of analysis, differentiating respondents by population group, the following categories (based on most numerous and non-intersecting populations) are used:

- Respondents being people who inject drugs (52.4% (n=192) of the study population);
- Respondents who did not identify themselves as people who inject drugs (47.6% (n=176) of the study population).

The gender composition of these groups varies:

- 68% of PID are male (n=132) and 32% female(n=62)
- The age composition of these groups also differs (**Figure 3**):
- 77.3% (n=150) of PID are 30 or older with only 21.7% (n=44) younger than 30; and
- over half of non-PID (51.1%, n=90) are younger than 30 with 48.9% (n=86) being 30 or older.

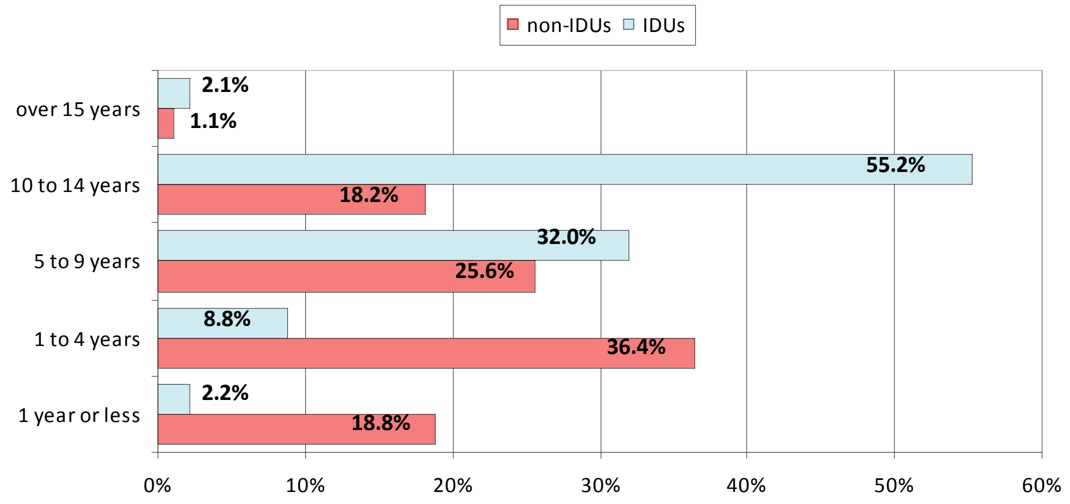
Figure 3: PID and non-PID respondents disaggregated by age



There are also differences between these groups in terms of the length of time living with HIV (**Figure 4**):

- among PID respondents, nearly 90% have lived with HIV for 5 or more years (89.2%, n=173); and
- among non-PID respondents, over half (55.1%, n=97) have lived with HIV for less than 5 years

Figure 4: PID and non-PID respondents, disaggregated by length of time living with HIV



Physical disability

12.4% of respondents (n=46) reported a physical disability of any kind (not including general ill health related to HIV) of which 30 were men (14.6% of 206) and 16 women (9.8% of 164). Of these 46 people (15%) were under 30 years old and only 7 (15%) were living with HIV less than 5 years.

Education

The respondents' education level varied with more than 57.9% (n=214) of respondents reporting technical college or university level, 40.5% (n=150) reporting secondary school, and only 1.6% (n=6) reporting primary level education only[23].

Employment status

Over one quarter of respondents reported being unemployed (26.2%, n=97), 62.2% (n=230) are employed either part- or full-time with an additional 5.7% (n=21) describing themselves as self-employed, and the remaining 7.8% (n=29) undertaking casual work[24]. Furthermore, **Table 5** shows that amongst the respondents there were relatively more unemployed women than men (31.7%, n=52 compared to 21.8%, n=45), and more men among full time and part time employees (51.5% (n=106) and 13.1% (n=27) than women (49.4% (n=81) and 9.8% (n=16).

---

[23] However it must be noted that 5 respondents who reported secondary level education only were under 20 so may not have yet completed secondary education; respondents were not asked to disclose a specific age only which 'age band ' they fitted into.

[24] This was a multiple choice question – with respondents able to report various types of work status that were not mutually exclusive – for example both being in full time employment but also having a secondary part time (or casual) occupation or source of income. No distinction was made for the purposes of this question between whether the income generating activity was part of the formal or informal economy.

Table 5: Current employment status of respondents, disaggregated by gender (%)

Current employment of respondents by gender	Men (n,%)		Women (n,%))		TOTAL (n,%)	
Full-time employment (as an hired employee)	106	51.5	81	49.4	187	50.5
Part-time employment (as an hired employee)	27	13.1	16	9.8	43	11.6
Full-time employment, but not as a hired employee (self-employment)	16	7.8	5	3.0	21	5.7
Performance of odd jobs or part-time employment (self-employment)	18	8.7	11	6.7	29	7.8
Unemployed or do not work at all	45	21.8	52	31.7	97	26.2
RESPONSES	212		165		377	
TOTAL in group	206	100.0	164	100.0	370	100.0
Subtotal: any type of employment:	161	78.2	112	68.3	273	73.8

When disaggregating the data by PID and non-PID respondents:

- The percent of non-PID respondents in full-time employment is higher than among PID (56.3%, n=99 compared to 45.4%, n=88).

Table 6 shows that the current employment status of respondents is independent of the length of time living with HIV. The lowest levels of unemployment (23.5% and 23.7%) are among respondents who have lived with HIV for 1 to 4 years, and 10 to 14 years.

Table 6: Current employment status of respondents disaggregated by lengths of time living with HIV

Form of employment	Span of life with HIV				
	0–1 year	1–4 years	5–9 years	10–14 years	over 15 years
Full-time employment (as an hired employee)	48.6	55.6	42.1	55.4	33.3
Part-time employment (as an hired employee)	10.8	9.9	14.0	11.5	-
Full-time employment, but not as a hired employee (self-employment)	-	3.7	7.5	6.5	16.7
Performance of odd jobs or part-time employment (self-employment)	5.4	7.4	9.3	6.5	33.3
Unemployed or do not work at all	35.1	23.5	28.0	23.7	33.3

Number of persons who live in respondents' households

3.2% of respondents (n=12) reported having children orphaned due to AIDS living in their household. Of those 12 people: 8 reported 1 child; 3 reported 2 children and 1 reported 3 children.

On average, 1.9 people (in addition to the respondent) lived with the respondent at the time of the survey[25]; with 10.3% (n=38) indicating living alone. The majority of respondents (72.2%, n=267) live in 1 to 3-person households.

Economic status

The average monthly income of respondents' households in the last 12 months varied from 500,000 BYR and less (21.4%, n=79) to 2m BYR and more (13.8%, n=51).[26] Nearly half of respondent households (47.6%, n=176) have an average monthly income which exceeds 1m BYR. According to Belarus official statistical data for 2009[27], the average household income

---

[25] Median=2

[26] 1.00 USD = 9,709.67 BYR; 1.00 BYR = 0.0001 USD http://www.xe.com/currencyconverter/convert/?Amount=1&From=USD&To=BYR (16 Feb 2014)

[27] As published at http://belstat.gov.by/homep/en/households/main2.php

was 1,057,000 BYR per month; over half of respondent households (50.3%, n=186) have a monthly income below the national average[28].

Food security and insecurity

8.9% of respondents (n=33) reported members of their families experiencing shortage of food in the last month (1.6% (n=6) during 1-2 days; 4.3% (n=16) during 3 to 5 days; 3.0% (n=11) during 6 to 20 days). With twice as much PIDs reporting severe shortage 9.8% (n=19/194) than non-PIDs 4.5% (n=8/176).

---

[28] The %'s do not add up to 100 as some respondents elected not to answer this question

Section 2: Experience of stigma and discrimination

This section comprises five sub-sections: experiences of HIV-related stigma and discrimination; access to work and health and education services; internalised stigma; the protection of the rights of people living with HIV through the law, policy or practice; and effecting change.

2.1 Experience of HIV-related stigma and discrimination

Respondents were asked about their experiences of stigma and discrimination in the previous 12 months (**Table 7**). Of the respondents (66.5%, n=246) reported being gossiped about with little gender difference (68% (n=140/206) of men and 64.6% (n=106/164) of women) of whom 91.1% or 60.5% of all respondents (n=224) reporting repeated instances. 19.5% (n=48) indicated that it occurred, in whole or in part, because of their HIV-positive status and a further 47.6% (n=117) believe it happened both because of their HIV status and other reasons; while 21.5% (n=53) indicated that it happened because of other reasons, and 10.6% (n=26) do not know the reasons.

Table 7: Respondents' experience of and attributed reasons for stigma and discrimination in the previous 12 months

Manifestation of stigma and discrimination	Percentage *(of the number of respondents)*	Reasons for stigma and discrimination *(% of the number of all respondents and of the number of those who reported such cases; in the table these values are divided by a slash)*			
		Because of the HIV status	For other reasons	Because of the HIV status and other reasons	Reason unknown
Were not allowed to participate in meetings and events	**10.5%**	3.8% / 35.9%	2.4% / 23.1%	3.8% / 35.8%	0.5% / 5.1%
Were not allowed to participate in religious events	**1.5%**	-	0.8% / 60%	0.3% / 20%	0.3% / 20%
Were not allowed to participate in family affairs	**7%**	4.3% / 61.5%	2.2% / 30.8%	0.5% / 7.7%	-
Found out about the existence of gossips concerning them personally	**66.5%**	13% / 19.5%	14.3% / 21.5%	31.6% / 47.6%	7.9% / 10.6%
Were insulted, persecuted and/or threatened verbally	**41.6%**	7% / 16.9%	18.1% / 43.5%	14.3% / 34.4%	1.2% / 5.1%
Were physically persecuted and/or threatened with action	**15.9%**	1.4% / 8.5%	8.9% / 55.9%	4.3% / 27.1%	1.4% / 8.5%
Were subjected to physical abuse	**13.8%**	0.3% /2%	10% / 72.5%	2.4% / 17.6%	1.1% / 7.8%

Significant percentages of respondents reported having been verbally insulted/harassed/threatened (41.6%, n=154), of whom 16.9% (n=26) believe their HIV status to be reason and a further 34.4% (n=53) believing that both HIV status and other reasons were the cause. In addition, lower percentages of respondents reported exclusion from social gatherings (e.g. meetings and events) 10.5%, n=39); family activities (7%, n=26), and religious activities (1.5%, n=5).

Physical harassment and threats of violence

Furthermore, in the last 12 months 15.9% of respondents (n=59) reported being physically harassed and/or threatened with action (**Table 8**); with 8.1% (n=30) reporting more than one instance. Of the 59 respondents reporting being physically harassed and/or threatened with action, 8.5% (n=5) believe their HIV status to be reason and a further 27.1% (n=16) believe that both their HIV status and other reasons to be the cause. More men reported being subjected to persecuted and/or threatened with action than women: 19.4% (n=40) compared to 11.6% (n=19).

Table 8: Respondents physically harassed and/or threatened, disaggregated by gender

Gender	How often have you been physically persecuted and/or threatened with action in the last 12 months?									
	Never		At least once		Once		On several occasions		Often	
Men	166	80.6%	40	19.4%	22	10.7%	17	8.3%	1	0.5%
Women	145	88.4%	19	11.6%	7	4.3%	11	6.7%	1	0.6%
Total	311	84.1%	59	15.9%	29	7.8%	28	7.6%	2	0.5%

Physical abuse

In the last 12 months 13.8% of respondents (n=51) were subjected to physical abuse, including 15% of male (n=31) and 12.2% of female respondents (n=20) and 5.7% (n=21), reporting more than one instance. **Table 9** shows that women were more likely to report repeated physical abuse than men (8.5% (n=14) compared to 3.4% (n=7)). Of the 51 respondents reporting physical abuse, only 2% believe their HIV status to be reason, most 72.5% (n=37) believe abuse were for other reasons and a further 17.6% (n=9) believe that both their HIV status and other reasons to be the cause. Of possible note is that no respondent under the age of 20 reported being subjected to physical abuse.

Table 9: Physical abuse towards respondents, disaggregated by gender

Gender	How often have you been physically abused in the last 12 months?									
	Never		At least once		Once		On several occasions		Often	
Men	175	85.0%	31	15.0%	24	11.7%	6	2.9%	1	0.5%
Women	144	87.8%	20	12.2%	6	3.7%	10	6.1%	4	2.4%
Total	319	86.2%	51	13.8%	30	8.1%	16	4.3%	5	1.4%

Perpetrators of physical abuse included both family members and people outside of the family (e.g. acquaintances and strangers). Of the 51 respondents reporting physical abuse, nearly 30% (29.4%, n=15) cited family members as the perpetrator, including a spouse or partner in nearly a quarter of the total cases (23.5%, n=12). However, the majority of respondents (70.6%, n=36) cited other people, including acquaintances (35.3%, n=18) and strangers (35.3%, n=18).

Women were much more likely to report being physically abused by their spouses and partners than men (45% (n=9) compared to 9.7% (n=3)); by other family members (10% (n=2) compared to 3.2% (n=1)); and by acquaintances (45% (n=9) compared to 29% (n=9)); while only men reported being physically abused by strangers (58.1%, n=18).

Other perceived causes for experiencing stigma or discrimination: belonging to key population

Table 10 shows other perceived causes for experiencing stigma or discrimination other than HIV status were reported by 137 respondents and included being a person who injects uses drugs (24.8%, n=34), a man who has sex with men (2.9%, n=4) and/or prisoner (4.4%, n=6).

Table 10: Reasons for stigma and discrimination towards disaggregated by key population

Populations	Existence of reasons for stigma and discrimination related to belonging to a particular population (%)	
Sexual orientation (men who have sex with men)	4	2.9
Sex worker	1	0.7
Injecting drug user	34	24.8
Internally displaced person	2	1.5
Member of the community of indigenous people	1	0.7
Migrant workers	1	0.7
Prison inmate	6	4.4
None of the above populations – it happened because of something else	78	56.9
No answer	10	7.3
	137	100

Note that 56.9% cited that stigma or discrimination happened because of something else. The following reasons (grouped) were cited:

- Alcohol intoxication (e.g. “got into a drunken fight with brother,” “was beaten by drunken guys,” “alcohol intoxication of offenders”);
- Family conflicts (e.g. “the cohabitant is jealous, lacks manners,” “my wife blamed me for infecting her,” “birth of a child”);
- Relations with the opposite sex (e.g., “because of the woman,” “could not come to terms concerning a women,” “personal relations with an ex-spouse”);
- Personal dislike from another individual (e.g. “envy at being lucky,” “negative attitude towards creative people”);
- Situations at home and at work (e.g. “had to pass my turn to the gynaecologist,” “because of the absence of “the labour book”, “because of lack of education,” “work-related issues”).

Psychological pressure or manipulation

In the last 12 months, 15.1% (n=56) of respondents reported being subjected to psychological pressure or manipulation from the husband/wife/partner when the HIV-positive status was used against the respondent (13.1% (n=27/206) of men and 17.7% (n=29/164) of women); with 11.6% (n=43) of respondents reporting that this had happened more than once.

Refusal sexual intercourse

In the last 12 months, 22.7% of respondents (n=84) reported refusal to have sexual intercourse because of their HIV-status; with 17.8% of respondents (n=66) stating that this occurred more than once. Men were twice as likely to report having been refused sexual intercourse than women: 28.6% (n=59) compared to 15.2% (n=25).

Stigmatized and/or discriminated against by other people living with HIV

Some 5.9% of respondents (n=22; 7.3%, n=15, of men and 4.3%, n=7, of women) reported being stigmatized and/or discriminated against by other people living with HIV during the last 12 months; with 3.0% of respondents (n=11) stating that this occurred more than once.

Relatives/members of the household have been stigmatized and discriminated

Furthermore, 20.8% of respondents (n=77; 21.4%, n=44, of men and 20.1%, n=33, of women) stated that their relatives/members of the household have been stigmatized and discriminated in last 12 months because of the respondents' HIV status; with 13.0% of respondents (n=48) stating that this occurred more than once.

Perceived reasons as to why HIV-positive respondents experienced stigma and discrimination

Approximately one third of respondents:

- Felt that HIV-related stigma and/or discrimination they have faced is due to people not understanding how HIV is transmitted/ afraid of getting infected by casual contact (33.2%, n=123);
- 29.7% (n=110) cited other people's fears of infection by contact, and
- 32.4% cited people thinking HIV is shameful and they should not be associated with the respondent (n=120)[29].

---

[29] Note that multiple responses to this question were permissible. Therefore percentages do not add up to 100%.

Table 11: Perceived reasons of experienced stigma and discrimination

Perceived reasons	Male		Female		TOTAL	
	n	%	n	%	n	%
People are afraid of getting infected with HIV from me	58	28.2%	52	31.7%	110	29.7%
People don't understand how HIV is transmitted/ are afraid that I will infect them through casual contact	54	26.2%	69	42.1%	123	33.2%
People think having HIV is shameful and they should not be associated with me	52	25.2%	68	41.5%	120	32.4%
Religious beliefs or "moral" judgements	4	1.9%	5	3.0%	9	2.4%
People disapprove of my lifestyle or behaviour	36	17.5%	20	12.2%	56	15.1%
I look sick with symptoms associated with HIV	5	2.4%	4	2.4%	9	2.4%
I don't know/I am not sure of the reason(s)	28	13.6%	24	14.6%	52	14.1%
No answer / Not applicable	59	28.6%	26	15.9%	85	23.0%
Total sample	206		164		370	

Note that multiple responses to this question were permissible.

2.2 Access to work and health and education services

This sub-section focuses on the extent to which access to accommodation, work, health and education services were influenced by respondents' HIV positive-status.

Accommodation

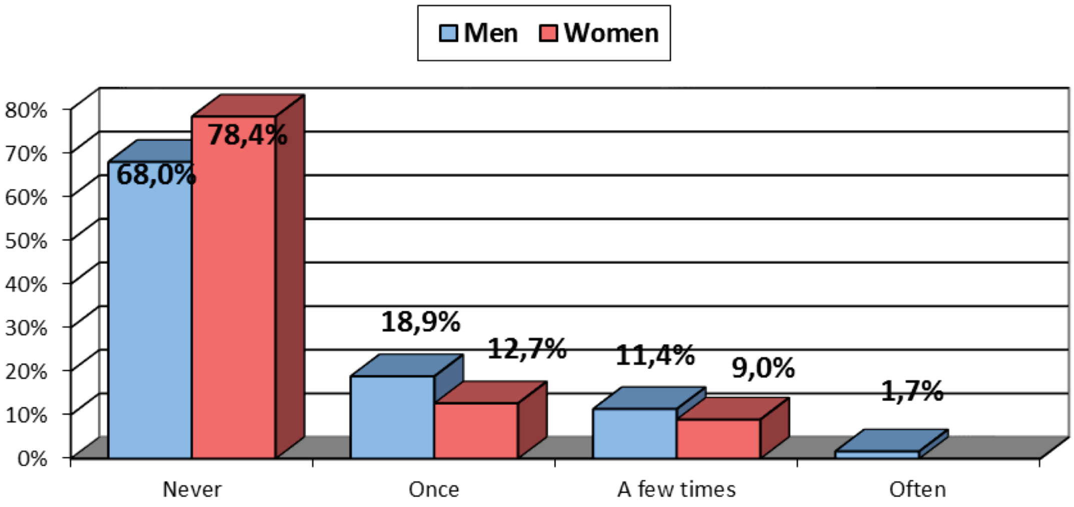
While 80.8% (n=299) of respondents had not been forced to change residence or being unable to secure rental accommodation in the previous 12 months, 19.2% (n=71) had with little gender difference (18.9%, n=39, of men and 19.5%, n=32, of women) and with 5.9% of respondents (n=22) stating that this occurred more than once. Of the 71 respondents reporting having been forced to change residence or being unable to secure rental accommodation, 73.2% (n=52) believe their HIV status to be the reason and a further 12.7% (n=9) believe that both their HIV status and other reasons to be the cause.

Work

Of those who were employed[30] (n=309, 83.5%) in the last 12 months, 72.5% (n=224) did not lose their job or income source, though over one quarter (27.5%, n=85) did. Of those who had been employed in the last 12 months and changed/lost their job (n=85), 11.8% (n=10) believe their HIV status to be the reason with a further 14.1% (n=12) believing it happened both because of their HIV and other reasons.

Figure 5 shows that when disaggregated by gender, nearly one third of men (32%, n=56) compared to one fifth of women (21.6%, n=29) had lost their job or other source of income.

Figure 5: Loss of job or other source of income, disaggregated by gender



When disaggregated by PID and non-PID, nearly one third of PID respondents (32.1%, n=52) had lost their job or other source of income in the last 12 months compared to 22.4% of non-PID respondents n=33).

Of the 86 respondents who reported losing their job or income source, 25.6% (n=22) thought it was just because of HIV with or without other reasons; 65.1% (n=56) thought was due to other reasons and 8.1% (n=7) were not sure.

---

[30] Had a job as hired employees or other source of income (self-employment, unofficial earnings).

Table 12: Link between disclosure and loss of income

Have you disclosed your status to Your employer(s)/boss(es)	In the last 12 months, how often have you lost a job (if employed) or another source of income (if self-employed or an informal/casual worker?						
	Never	Once	A few times	Often	No Answer	Total	Subtotal Lost
I told them	23	3	2	1	1	29	6
Someone else told them, with my consent	2	1				3	1
Someone else told them, without my consent	6	8	4		4	18	12
They don't know my HIV status	152	30	20	1	19	203	51
Not applicable	42	9	6	1	37	58	16
Total	225	51	32	3	61	311	86
Subtotal - Status is known	31	12	6	1	5	50	19

Furthermore in the last year, 5.9% (18 of 303 respondents answering the question) reported being refused employment due to their HIV-positive status.

Additionally 16.7% of respondents (n=62) reported changes in their job responsibilities or being refused a career promotion due to their HIV-positive status with 9% (n=34) stating that this had occurred more than once. Of these, discrimination was implicated in nearly a third of instances (32.4%, n=12) and poor health in nearly two thirds (64.9%, n=27) (**Table 13**).

Table 13: Reasons for changing duties or job description

If it happened, what were the specific reasons for that? (percentage of respondents who reported having their duties or job description changed because of their HIV status)	
Because of discrimination from the employer or colleagues	24.3% (n=9)
Because of the necessary to quite working as a result of poor health	56.8% (n=24)
Both because of discrimination and poor health	8.1% (n=3)
For other reasons	10.8% (n=4)

Health Services

Of those answering this question nearly one in five respondents (17.9%, n=33), reported being denied health services, including dental care, at least once in the last 12 months. Furthermore, nearly one in five (18.9%, n=21) respondents reported having been refused family planning services in the last 12 months.

While the percent of respondents reporting being refused sexual and reproductive health services in the last 12 months was relatively low (4.6%, n=17).

Education

From a sample of 94 respondents who reported experiencing rights violations, 5 (5.9%) had experienced that their children have been dismissed, suspended or prevented from attending an educational institution because of the respondent's HIV status during the last 12 months with 3 (3.6%) reporting that this had occurred more than once.

2.3 Internal stigma and fears

This sub-section focuses on identifying forms of internalised stigma among respondents.

Feelings

The results presented in **Table 14** highlight that internal stigma was prevalent among respondents in the last 12 months. Over 71% (n=263) feel guilt, 65.6% (n=243) blame themselves, 54.5% (n=202) feel shame, and 36% (n = 133) have low self-esteem. Furthermore, 6.7% of respondents (n=21) reported feeling suicidal.

Table 14: Feelings experienced during last 12 months

Have you ever experienced any of the following feelings related to your HIV status? (%)	
I feel guilty	71.0
I blame myself	65.6
I feel shame	54.5
I have low self-esteem	36.0
I blame others	18.5
I feel the desire to commit suicide	6.7
I feel I need to be punished	6.4

Note that multiple responses to this question were permissible. Therefore percentages do not add up to 100%.

Figure 6 shows that when reported feelings experienced during last 12 months are disaggregated by gender:

- fewer female than male respondents reported feeling guilty (64.8% compared to 76.3%) and blamed themselves (62.1% compared to 68.6%);
- more female than male respondents reported low self-esteem (38.6% compared to 33.7%), feeling shame (51.5% compared to 68.6%) or suicidal (8.3% compared to 5.3%).

Figure 6: Feelings experienced, disaggregated by gender

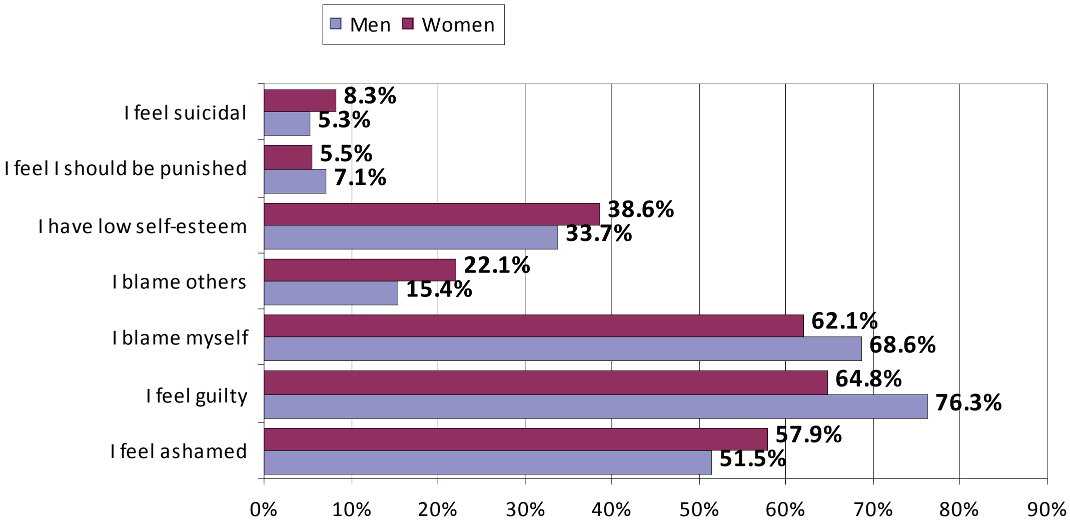


Table 15 shows that when reported feelings experienced during last 12 months are disaggregated by age, in general, younger respondents experience higher incidence of these negative feelings, including suicidal ones (13.8% respondents aged 15–24 compared to a range 5.3%-7% for older age groups).

Table 15: Feelings experienced during last 12 months, disaggregated by age

Have you ever experienced any of the following feelings related to your HIV status? (% of those who answered "yes" in each age group)	Age			
	15–24	25–29	30–39	40–49
I feel ashamed	65.5	67.4	47.1	48.3
I feel guilty	89.7	69.8	67.6	75.9
I blame myself	65.5	66.3	64.7	69.0
I blame others	24.1	19.8	16.5	20.7
I have low self-esteem	48.3	29.1	36.5	41.4
I feel I should be punished	6.9	5.8	5.9	10.3
I feel suicidal	13.8	7.0	5.3	6.9

Decisions, resignations, avoidance

Table 16 shows respondents' decisions not to engage in some activities because of their HIV positive status. The most frequently cited reaction, by 60.3% of respondents (n=168) was the decision not to have (more) children. Furthermore, 26.2% (n=97) opted not to marry; and 13.8% (n=51) isolated themselves from friends and relatives.

Internalised stigma also affected the respondents in many other ways. In relation to health care 45.4% (n=168) avoided going to a local clinic when they needed care, and 34.8% (n=129) avoided going to hospital. In relation to study and employment: 23.4% (n=87) withdrew from education or training, 20.9% (n=77) decided not to apply for a job or a promotion because of their HIV status and 7.4% (n=27) gave up their job.

Table 16: Decisions, resignations and avoidances

In the last 12 months, have you done any of the following things because of your HIV status? (% of those who said “yes”)	
I decided not to have (more) children	60.3
I avoided going to a local clinic when I needed to	45.4
I avoided going to a hospital when I needed to	34.8
I decided not to get married	26.2
I withdrew from education/training or did not take up the opportunity for education/training	23.4
I decided not apply for a job/employment or for a promotion	20.9
I have isolated myself from my family and/or friends	13.8
I decided not to have sex	12.8
I have chosen not to attend social gathering(s)	11.7
I took the decision to stop working	7.4

Table 17 shows that when decisions not to engage in some activities because of their HIV-positive status are disaggregated by gender:

- more female than male respondents reported avoiding going to a local clinic (52.6% compared to 38.9%) and avoided going to hospital (38.9%compared to 26.8%) when needed;
- more male than female respondents reported deciding not to get married (52.6% compared to 38.9%); and
- more female than male respondents reported deciding not to have sexual intercourse (16.5% compared to 9.4%);

Table 17: Decisions, resignations and avoidances, disaggregated by gender

Did you perform in the last 12 months the following actions related to your HIV status? (% of those who said "yes" by gender)	Men	Women	Difference in men's and women's shares
I have chosen not to attend social gathering(s)	10.7	12.8	2
I have isolated myself from my family and/or friends	12.8	15.0	3.8
I took the decision to stop working	9.4	5.3	4
I decided not apply for a job/employment or for a promotion	22.1	19.5	3
I withdrew from education/training or did not take up the opportunity for education/training	23.5	23.3	
I decided not to get married	30.2	21.8	10
I decided not to have sex	9.4	16.5	8
I decided not to have (more) children	59.1	61.7	2.6
I avoided going to a local clinic when I needed to	38.9	52.6	16
I avoided going to a hospital when I needed to	26.8	43.6	17

Table 18 shows that when decisions not to engage in some activities because of their HIV-positive status are disaggregated by age, young people aged 15–24 reported a higher incidence of secluding themselves, for example: from social gatherings (20% compared to a range 9.3%-13.3% for older age groups) and family and friends (28% compared to a range 6.5%-16% for older age groups).

Table 18: Decisions, resignations and avoidances, disaggregated by age

Did you perform in the last 12 months the following actions related to your HIV status? (% of those who said "yes" in each age group)	Age			
	15–24	25–29	30–39	40–49
I have chosen not to attend social gathering(s)	20.0	13.3	9.3	12.9
I have isolated myself from my family and/or friends	28.0	16.0	11.9	6.5
I took the decision to stop working	4.0	8.0	6.6	12.9
I decided not apply for a job/employment or for a promotion	16.0	13.3	23.8	29.0
I withdrew from education/training or did not take up the opportunity for education/training	16.0	18.7	23.8	38.7
I decided not to get married	28.0	20.0	27.2	35.5
I decided not to have sex	8.0	12.0	14.6	9.7
I decided not to have (more) children	64.0	50.7	61.6	74.2
I avoided going to a local clinic when I needed to	56.0	54.7	41.7	32.3
I avoided going to a hospital when I needed to	40.0	40.0	34.4	19.4

Fears

Respondents' level of fear of being gossiped about, verbally insulted, harassed and/or threatened, and physically harassed/or threatened or bring physically assaulted is shown in **Table 19**. Overall, three quarters of respondents feared being gossiped about (78.2%, n= 289); significantly higher levels of fear than from verbal insult (61.5%, n=228), physical harassment and/or threat (32.2%, n=119), and physical assault (30.3%, n=112). Furthermore, nearly two thirds of respondents reported fear that someone would not want to be sexually intimate with them because of their HIV-positive status (65.6%, n=243).

Table 19: Fear of gossip, insults, harassment, and assault in the last 12 months

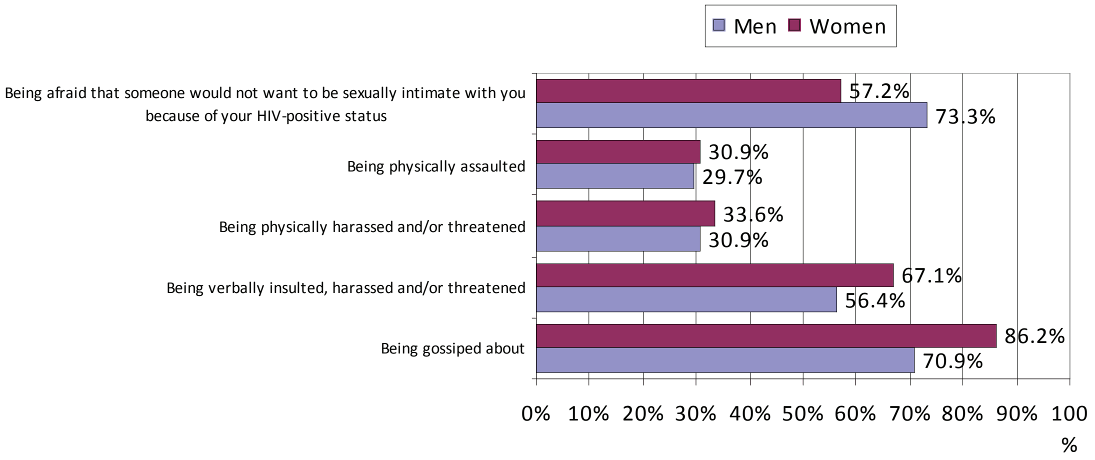
In the last 12 months, have you been fearful of any of the following things happening to you – whether or not they actually have happened to you? (% of those who answered "yes")	
Being gossiped about	78.2
Being afraid that someone would not want to be sexually intimate with you because of your HIV-positive status	65.6
Being verbally insulted, harassed and/or threatened	61.5
Being physically harassed and/or threatened	32.2
Being physically assaulted	30.3

Figure 7 shows that when fears of gossip, insults, harassment, and assault are disaggregated by gender:

- women reported higher levels of fear than men: being gossiped about (86.2% (n=141/164) compared to 70.9% (n=146/206)), verbal insults (67.1% (n=110/164) compared to 56.4% (n=116/206)), and threats of physical violence (33.6% (n=33/164) compared to 30.9% (n=64/206).
- more male than female respondents reported fear that someone would not want to be sexually intimate because of HIV-positive status (73.3% compared to 57.2%).

There was little gender difference for physical assault (female=30.9% compared to male=29.7%).

Figure 7: Fear of gossip, insults, harassment, and assault, disaggregated by gender



Finally, the results show that young respondents aged 15–24 are more afraid than older age groups of physical abuse (50% compared to 30.3% for all respondents).

2.4 Rights, laws and policies

This sub-section focuses on awareness of the 2001 Declaration of Commitment on HIV[31] and knowledge of national laws and policies, as well as violations of rights experienced in various settings.

Knowledge of the Declaration of Commitment and national laws

45.7% of respondents (n=169) had heard of The Declaration of Commitment on HIV/AIDS (including 41.7% of men (n=86/206) and 50.6% of women (n=83/164)); of whom, 37.3% (n=138) had read or discussed the Declaration. When disaggregated by age, there was no significant difference in having heard about the Declaration.

53.8% of respondents (including 50.5% of men (n=104/206) and 57.9% of women (n=95/164) had heard about the Public Health Law[32], which protects the rights of people living with HIV; of whom, 45.7% (91/200) had read or discussed it.

Discriminatory treatment by governmental, legal, and/or medical institutions

During the previous 12 months, 27.8% (n=103) of respondents reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions. The most frequent violation reported by 29.5% of respondents (n=109) was having been forced to submit to a medical procedure (including HIV testing). Smaller numbers of respondents indicated that they had been detained, quarantined, isolated, or segregated (7.6%, n=28); denied health or life insurance (0.8%, n=3); or arrested or taken to court on an HIV-related charge (0.5%, n=2). In terms of travel-related discrimination, 10 respondents (2.7%) indicated that they had to disclose their HIV status in order to enter another country; while 8 respondents (2.2%) had to disclose to apply for residence or nationality.

Any violation of the rights

25.4% of respondents (n=94) reported that their rights had been violated in the last 12 months, 42.2% (n=156) reported that they had not, and 32.4% (n=120) were unsure. **Table 20** shows that women reported higher percent of violations than men: 32.9% (n=54/164) compared to 19.4% (n=40/206).

---

[31] http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf

[32] http://www.hsph.harvard.edu/population/aids/BELARUS.htm

Table 20: Violation of rights of people living with HIV, disaggregated by gender

In the last 12 months, have any of your rights as a person living with HIV been abused?	Gender	
	Men	Women
Yes	19.4%	32.9%
No	44.7%	39.0%
Not sure	35.9%	28.0%

Legal Redress

Nine (9) of 94 respondents who indicated that they experienced a rights violation (9.6%; 10% of men (n=4/40) and 9.3% of women (n=5/54)) had tried to get legal redress for abuse of rights as a person living with HIV within the previous 12 months. Six (6) respondents (1.6%) reported the case having been considered in the last 12 months; while 2 respondents indicated that the matter was still in process, and 1 person did not have the case considered.

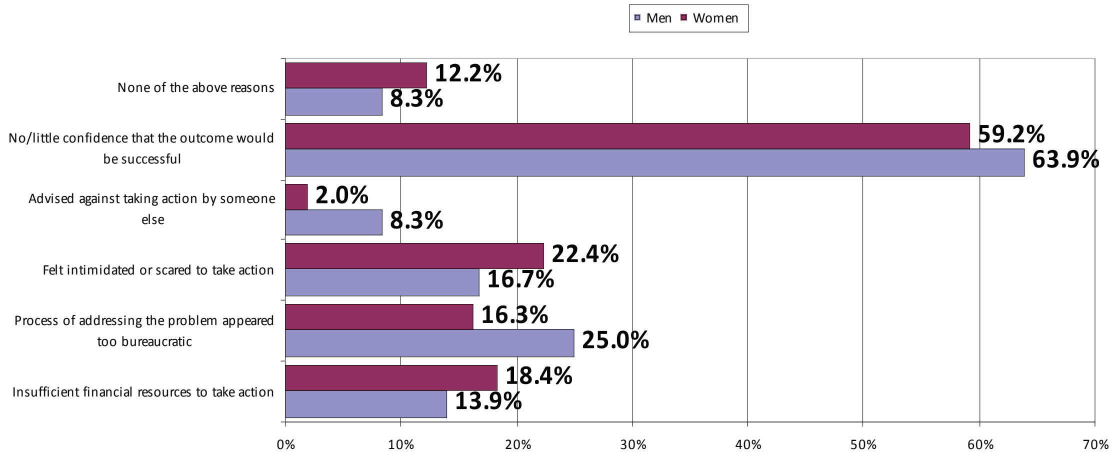
Table 21 shows that of the 85 respondents who indicated that they experienced a rights violation and did not seek legal redress, the most common reason was no/little confidence that the outcome would be successful (61.2%, n=52/85) with the next equal most common reasons being the process of addressing the problem appeared too bureaucratic, and felt intimidated or scared to take action (20%, n=17/85).

Table 21: Reasons for not seeking legal redress for rights violations

What was the reason for your not trying to get legal redress? (%)	
No/little confidence that the outcome would be successful	61.2
Process of addressing the problem appeared too bureaucratic	20.0
Felt intimidated or scared to take action	20.0
Insufficient financial resources to take action	16.5
None of the above reasons	10.6
Advised against taking action by someone else	4.7

When disaggregated by gender, male respondents were slightly more likely than female respondents to report no/little confidence that the outcome would be successful: 63.9% (n=23/36) males compared to 59.2% (n=29/49) females (**Figure 8**).

Figure 8: Reasons for not seeking legal redress, disaggregated by gender



Furthermore, only 13 respondents (3.5%) who had experienced an abuse of their rights reported trying to get a government employee to take action; of these, 12 (3.2%) had tried within the previous 12 months. Two (2) cases have been considered; one is under consideration and no action has been taken in 10 cases, namely: the cases have not been considered and are not proposed for consideration.

Further, 5 respondents (1.4%), who had experienced an abuse of their rights, had tried to get regional policy-makers to take action; 4 (1.1%) had tried within the previous 12 months. Two (2) cases have been considered and in 3 cases no action has been taken, namely: the cases have not been considered and are not proposed for consideration.

2.5 Effecting change

This sub-section explores respondents' reactions to incidents of stigma and discrimination; awareness of potential sources of assistance when confronted with stigma and discrimination; and participation in policy reform on HIV-related stigma and discrimination.

44.6% (n=165) of respondents reported having confronted, challenged or educated someone who was stigmatizing and/or discriminating against him or her in the last 12 months, including 50% of female respondents (n=82) and 40.3% of male respondents (n=83).

Overall, 70.5% of respondents (n=260) knew of an organization or group providing support to those experiencing stigma or discrimination, including 76.2% of women (n=125/164) and 66% of men (n=136/206). **Table 22** shows that when disaggregated by age, young people aged 15-24 are less aware of such an organization or group than respondents in older age group: 55.9% compared to a range of 66.7%-74.5% for older age groups.

Table 22: The percentage of respondents identifying any organization or group that offers help in cases of stigma and discrimination, disaggregated by age

Do you have information about any organization or group you can resort to in case of stigma and discrimination?	Age			
	15–24	25–29	30–39	40–49
Yes	55.9%	69.0%	74.5%	66.7%
No	44.1%	31.0%	25.5%	33.3%

Table 23 shows respondents' knowledge of different types of organisations or groups providing support to those experiencing stigma or discrimination. Support group for people living with HIV (mutual-help groups[33]) were the most frequently cited entity to approach (79.7%, n=295); followed by the Belarusian Community of People Living with HIV (52.9%, n=196). Other groups and organizations which were identified by significant percentages of respondents, include FBOs (28.7%), regional NGO (20.3%) and national NGO (20.3%) and UN organization (17.2%). Each of the remaining types of organisations was mentioned by less than 10% of respondents.

Table 23: The percentage of respondents identifying each kind of organization that offers help in cases of stigma and discrimination

Groups and organizations one can resort to in case of discrimination and stigma (% of the number of respondents who know about such groups)	
Support group for people living with HIV	79.7
Belarusian Community of People Living with HIV	52.9
Faith-based organization	28.7
Regional non-governmental organization	20.3
National non-governmental organization	20.3
UN-based organization	17.2
Legal practice	8.8
Human rights organization	7.3
National Council or Committee on AIDS	5.4
International non-governmental organization	4.2
Other[34]	3.8

---

[33] Mutual-help groups work on the basis of various non-governmental organizations and consist of PLHIV. Often members of these groups do not associate their participation in the group as membership in the NGO on the basis of which the group works, since the main principle of the group's work is openness for PLHIV and full acceptance of each person as an equal member of the group.

[34] includes the following answers of the respondents:

- infectious disease doctor;
- methadone replacement therapy group;
- friends and acquaintances;
- health institutions/narcologist;
- regional/district executive committee;
- organization for MSM.

Table 24 shows that when disaggregated by gender:

- Male respondents are more aware about, *inter alia*, regional NGO (25.7% compared to 14.4%) and FBOs (33.8% compared to 23.2%).
- Female respondents are more aware about, *inter alia*, national NGOs (22.4% compared to 18.4%), support groups for PLHIV (84.8% compared to 75%)
- No significant gender disparity in relation to knowledge of the Belarusian Community of People Living with HIV.

Table 24: The percentage of respondents identifying each kind of organization that offers help in cases of stigma and discrimination, disaggregated by gender

Groups and organizations one can resort to in case of discrimination and stigma (% of the number of respondents who know about such groups)	Men	Women
Support group for people living with HIV	75.0	84.8
Belarusian Community of People Living with HIV	52.2	53.6
Regional non-governmental organization	25.7	14.4
Faith-based organization	33.8	23.2
Legal practice	12.5	4.8
Human rights organization	11.0	3.2
National non-governmental organization	18.4	22.4
National Council or Committee on AIDS	6.6	4.0
International non-governmental organization	7.4	0.8
UN-based organization	23.5	10.4
Other	4.4	3.2

21.6% of respondents (n=80) indicated that they had sought help from these organizations or groups for stigma or discrimination-related issues, including 14.6% of men (n=31/206) and 30.5% of women (n=50/164). **Table 25** describes the areas of stigma and discrimination experienced by respondents.

Table 25: Areas of stigma and discrimination experienced by respondents

Categories	Examples of respondents' replies
Medical services	
Attitude of medical workers towards PLHIV	"I was verbally abused by a medical worker;" "I was isolated in a separate ward;" "the nurse informed me about my status in an negative way;" "in health institutions they treated me as a leper;" "doctors do not give referrals for consultations;" "negative attitude from medics;" "contemptuous attitude in the maternity clinic;" "the doctor prohibited my going to a health resort;" etc.
Access to medical assistance	"they refused to prescribe the required drugs;" "I was refused an surgery;" "I was refused medical services in a policlinic;" "I was refused treatment in a private clinic;" "I was refused the doctor's/gynaecologist's visit;" "they did not want to provide therapy because I inject drugs;" "I was refused dental care;" etc.
Medical workers' maintaining of confidentiality about the HIV status of the patient	"medics disclosed my status;" "disclosure of confidential information;" "disclosure of my status among medical personnel;" "the doctor disclosed information about my status;" "the doctor disclosed my status to a third party;" etc.
Reproductive health	"the doctor tried to coerce me into having an abortion;" "the doctor tried to persuade me into terminating the pregnancy;" "doctors referred me for abortion;" "they pressed me to use a contraceptive coil;" "the doctor pressed me to have an abortion because of HIV;" "they persistently recommended abortion without providing any reasons;" "they suggested I have an abortion and undergo sterilization;", etc.
Relations with spouse/partner, family and friends	
Relations with spouses (partners)	"my wife blames me for infecting her;" "my wife filed for divorce because of my HIV status;" "my wife seeks divorce;"

Categories	Examples of respondents' replies
	"my wife sued me as a source of infection;" "my husband filed for divorce;" "my husband said I could not create a new family;" "nobody helped me; my husband left me because of HIV;" "talks, explanations, apologies to the wife;" "not everybody agrees to have sexual intercourse;" "my girlfriend and I had a talk about the HIV status;" "my girlfriend blamed me and tried to manipulate me;" "my boyfriend insulted me and left me;" etc.
Relations with other relatives and friends	"my daughter-in-law's grandmother made a row and insulted;" "discrimination in the family;" "constant criticism from relatives;" "my relatives, except grandmother, turned back on me;" "constant threat to disclose my status;" "prejudiced attitude towards HIV from friends;" "parents do no allow their son to live with me;" "a family friend disclosed my status;" "relatives' gossiping about my HIV status;" "the son did not allow to see the grand-daughter, separate dishware;" "a person stopped talking to me;" etc.
Social life and work	
Neighbours and acquaintances	"my family were forced to change their place of residence;" "neighbours are wary of us and our child;" "neighbours made a complaint about my being a negligent mother;" "people are afraid of becoming infected through household activities;" "surrounding people won't accept me;" "lots of talks and gossip;" "inadequate attitude towards me upon learning about my status;" "increasing gossips;" "contemptuous stigmatizing attitude;" etc.
Children of HIV-infected parents	"they refused to admit my child at the hospital;" "they tried to prevent me from placing my child in the kindergarten;" "the paediatrician refused to treat my children;"

Categories	Examples of respondents’ replies
	“during examination the doctor told my child about HIV;” “they wouldn’t take my child in the kindergarten; neighbours insulted us;” “parents at the kindergarten are against my child;” etc.
Employers and colleagues	“at work there are gossips about my disease;” “at work they learnt about my HIV status and did not prolong the contract;” “they refused to rent me premises; threatened;” “gossips among colleagues who suspect of AIDS;” “I was dismissed from work because of HIV;” et.
Other categories	“isolation of HIV-positive people from HIV-negative people in penitentiaries;” “I was denied entry to a foreign country;”
Internal stigma	
	“I am afraid to disclose my status;” “I was afraid of my status being disclosed;” “internal psychological problems;” “everybody is afraid of me;” “feeling of inferiority;” “forced seclusion;” “psychological problems;” “I had to lie about my HIV status;” “one-on-one talks;” etc.

Helping other HIV-positive people

In last 12 months, over three quarters of respondents (75.4%, n=279) reported offering support to other PLHIV, including 73.3% of men (n=151/206) and 78% of women (n=128/164). **Table 26** outlines the types of support respondents reported providing to other people living with HIV in the previous 12 months. Emotional support (in the form of counselling, sharing personal stories and experiences) was the most common type of assistance rendered (99.3%, n=277/279), with 19.7% (n=55/279) indicating that they had provided a referral to other services, while 19.4% (n=54/279) provided material support.

Table 26: Types of support provided to other PLHIV

What specific support did you provide? (% of the number of respondents who provided support to other people)	
Emotional support (e.g. counselling, the story about one's own life; exchange of experience)	99.3
Material support (e.g. financial assistance, provision of food, rending help with particular problems)	19.4
Referrals to other services	19.7

Table 27 shows that when disaggregated by age, respondents aged 15-24 reported providing support to other PLHIV less often than older respondents: 55.9% compared to a range of 76% - 78%).

Table 27: Provision of support to other PHLIV, disaggregated by age

In the last 12 months, have you supported other people living with HIV?		
Age	Yes	No
15–24	55.9%	44.1%
30–39	76.0%	24.0%
40–49	78.0%	22.0%
50 and older	77.8%	22.2%

Among the respondents, 29.7% (n=110) reported being a member of a support group and/or network of people living with HIV with more female respondent members than male: 39% (n=64/164) females compared to 22.3% (n=46/206) as shown in **Table 28**).

Table 28: Membership in support groups and/or the network of people living with HIV, disaggregated by gender

Are you currently a member of a support group and/or the network of people living with HIV?	Gender	
	Men	Women
Yes	22.3%	39%
No	77.7%	61%

Respondents were also asked to indicate whether in the previous 12 months, they had been involved (as a volunteer or employee) in a programme or project providing assistance to people living with HIV: 18.1% (n=67) reported being involved with little gender-based difference.

Development of legislation, policies or guidelines

Most respondents (96.5%) indicated that in the previous 12 months, they had not been involved in efforts to develop legislation, policies or guidelines relating to HIV with only 3.5% (n=13) reporting such involvement.

Table 29 focuses on respondents' feelings of being able to influence policies, laws and programmes. Nearly three quarters (73.2%, n=271) of respondents felt unable to influence any of the areas, including 75.2% of men (n=155/206 and 70.7% of women (n=116/164). The most common areas in which respondents felt they had the power to influence decisions were in local projects (16.2%, n=60) and national programmes/projects intended to benefit people living with HIV (10.3%, n=38). Less than 10% of respondents reported being able to influence any of the other areas of policies, laws and programmes.

Table 29: Feelings of being able to influence policies, laws and programmes

Do you feel that you have the power of influence decisions in any of the following aspects? (% of the respondents who said "yes")	
None of the mentioned in the list	73.2
Local projects intended to benefit people living with HIV	16.2
National programs/project intended to benefit people living with HIV	10.3
Legal/rights matters affecting of people living with HIV	9.2
Local government policies affecting people living with HIV	5.1
National government policies affecting people living with HIV	2.4
International agreements/treaties	1.6

Table 30 outlines respondents' recommendations regarding the most important things organizations should do to address stigma and discrimination. More than 40% (41.9%, n=155) of respondents cited advocating for the rights of all people living with HIV; while one quarter (27%, n=100) cited raising society's awareness and knowledge of HIV and 16.5% cited providing emotional and physical support to people living with HIV as the most important strategies organisations should adopt to address stigma and discrimination. Less than 5% (n=4.1%, n=15) mentioned work in support of particularly marginalized groups.

Table 30: Most relevant areas of activity of organizations working to eliminate stigma and discrimination against PLHIV

There are a number of organizations of people living with HIV working against stigma and discrimination. What do such organizations most need to do to address stigma and discrimination? (%)	
Advocating for the rights of all people living with HIV	41.9
Raising society's awareness about HIV	27.0
Providing emotional and physical support to people living with HIV	16.5
Educating people living with HIV about living with HIV (including treatment literacy) and adherence to treatment	10.5
Advocating for the rights and/or to providing support to particularly key populations (men who have sex with men, people who inject drugs, sex workers)	4.1

Section 3: Experience of testing, disclosure, treatment and having children

This section comprises four sub-sections: testing and diagnosis; disclosure and confidentiality; treatment; and experience of having children.

3.1 Testing and diagnosis

Testing

Table 31 shows that among respondents, 17.8% (n=66) reported taking a HIV test just to know their status, and 12.4% were referred for HIV testing when already symptomatic. 11.9% (n=44) underwent HIV testing due to a HIV-positive partner, 11.6% (n=43) were referred by a clinic for STI testing, and 10.5% (n=39) when pregnant.

Table 31: Reasons for undergoing HIV testing

Why were you tested for HIV? (%)	
Other	35.4
I just wanted to know	17.8
Referred due to suspected HIV-related symptoms	12.4
Husband/wife/partner/family member tested positive	11.9
Referred by a clinic for STI testing	11.6
Pregnancy	10.5
Employment	2.7
To prepare for marriage/sexual relationship	1.4
Illness or death of husband/wife/partner/family member	1.1

Table 32 shows that when disaggregated by gender:

- Male respondents were more likely to have been referred by a clinic for STI testing (15%, n=31/206 males compared to 7.3%, n=12/164 females) or due to suspected HIV-related symptoms (15.5%, n=32/206 males compared to 8.5%, n=14/164 females), and for other reasons (44.7%, n=92/206 males compared to 23.8%, n=39/164 females).

- Female respondents were more likely to have been undergone HIV testing due to a husband/partner/family member testing positive (17.1%, n=28/164 females compared to 7.8%, n=16/206 males). Nearly one quarter of women (23.8%, n=39/164) had been tested because of pregnancy.

Table 32: Reasons for undergoing HIV testing, disaggregated by gender

Why did you have an HIV test? (%)	Men	Women
Employment	1.5	4.3
Pregnancy	-	23.8
To prepare for marriage/sexual relationship	2.4	-
Referred by a clinic for STI testing	15.0	7.3
Referred due to suspected HIV-related symptoms	15.5	8.5
Husband/wife/partner/family member tested positive	7.8	17.1
Illness or death of husband/wife/partner/family member	1.0	1.2
I just wanted to know	18.0	17.7
Other	44.7	23.8

Table 33 shows that the “other” reasons for HIV testing relate to:

- When respondents were in the custody of law enforcement bodies (17.7%, n=65), including penitentiaries (12.2%, n=45) and police (5.7%, n=21).
- When respondents were undergoing medical treatment (14.5%, n=54): during registration with drug monitoring and rehabilitation clinics and during drug treatment (5.9%, n=22); in hospital, during in-patient treatment (7%, n=26); and during blood screening (hepatitis/herpes/donation of blood) (1.6%, n=6).

Table 33: Other reasons for undergoing HIV testing

Reason for having an HIV test	Percentage of the total number of respondents	Percentage of the number of respondents who chose the answer “Other”
In penitentiaries	12.2	34.4
Registration with drug monitoring and rehabilitation clinics as a PID and during treatment from drug dependency	5.9	16.8
Under the constraint of the police	5.7	16.0
In hospital, during in-patient treatment	7.0	19.8
Hepatitis/herpes/donation of blood	1.6	4.6
No answer	3.1	8.4
Did not indicate other reasons	64.6	-

Table 34 shows that when the ‘other category’ (n=131) is disaggregated by gender:

- Male respondents were twice as likely to have undergone testing in prison (40.2%, n=37/92 males compared to 20.5%, n=8/39 females)
- Female respondents were more likely to have undergone testing during registration with drug monitoring and rehabilitation clinics and during drug treatment (20.5%, n=8/39 females compared to 15.2%, n=14/92 males); in hospital, during in-patient treatment (25.6%, n=10/39 females compared to 17.4%, n=16/92 males); and during blood screening (hepatitis/herpes/donation of blood) (10.3%, n=4/39) females compared to 2.2%, n=2/92 males).

Table 34: Other reasons for undergoing HIV testing, disaggregated by gender

Reason for having an HIV test	Men (percentage of the number of respondents who chose the answer “Other”)	Women (percentage of the number of respondents who chose the answer “Other”)
In penitentiaries	40.2%	20.5%
Registration with drug monitoring and rehabilitation clinics as an IDU and during treatment from drug dependency	15.2%	20.5%
Under the constraint of the police	16.3%	15.4%
In hospital, during in-patient treatment	17.4%	25.6%
Hepatitis/herpes/donation of blood	2.2%	10.3%
No answer	8.7%	7.7%

Respondents were asked about their decision to be tested for HIV and whether their HIV test was undertaken voluntarily, under pressure or coercion, or without their knowledge (**Table 35**). Overall, slightly less than two-fifths of respondents (38.6%, n=143) indicated that their HIV test was completely voluntarily. 82 respondents (22.2%) reported that they were forced to take a HIV test, while 50 respondents (13.5%) indicated that they were tested under pressure from others. The remaining 24.6% (n=91) reported that they were tested without their knowledge.

Table 35: Experience of HIV testing and voluntary consent

Was the decision to be tested for HIV up to you? (%)	
Yes, I took the decision myself to be tested	38.6
I took the decision to be tested, but it was under pressure from others	13.5
I was made to take HIV test (coercion)	22.2
I was tested without my knowledge – I only found out after the test had been done	24.6
No answer	1.1

For further qualitative data and recommendations by respondents see **Annex 1: Identified problems and challenges.**

Counselling

Table 36: outlines respondents reported access to counselling during HIV testing. Less than 10% of respondents received both pre- and post-test counselling (8.1%, n=30); with over 40% (40.8%, (n=151) receiving no counselling at all, while nearly half (48.4%, n=179) received only post-test counselling, and 2.4% (n=9) received only pre-test counselling. There were no significant gender-based differences in the data.

Table 36: Counselling when having an HIV test

Did you receive counselling when you were tested for HIV?	
I received both pre- and post-test counselling	8.1
I only received pre-test counselling	2.4
I only received post-test counselling	48.4
I did not receive any counselling when I had an HIV test	40.8
No answer	0.3

For further qualitative data and recommendations by respondents see **Annex 1: Identified problems and challenges.**

3.2 Disclosure and confidentiality

Of those with spouses or partners, over 90% of respondents informed them themselves about their HIV status. This category of people is the most informed among all people who are in contact with respondents. There is a small share of respondents (4.8%), whose spouses and partners are unaware of their status.

Approximately two thirds of respondents informed other adult family members about their status. Family members of 27.3% of respondents do not know about their status. Children are mostly not aware of their parents' HIV status (84.1%). If children know about it, it is mainly because they were told about it by respondents themselves.

60% of respondents reported that their friends did not know about their HIV status. All respondents whose status is known to their friends (40%) told them about it themselves. Besides, the information about the respondents' HIV status comes to their friends from other people as well (29.6%).

Most respondents disclose their status to other PLHIV but sometimes this information comes to other PLHIV without the respondent's consent. Colleagues, mainly do not know about respondents' status.

Injecting drug using respondents mostly inform their IDU partners about their status. However, 20% of IDU respondents reported their IDU partner not knowing about it. Although such information does not come to their partners only from respondents themselves (24%).

Most respondents informed people they contact with in the sphere in religion about their status themselves. Health workers are, mainly, aware of respondents' status. They receive this information equally both from respondents themselves and other people often without PLHIV respondents' consent.

In half of the cases social workers and consultants do not know about respondents' status (49.3%). In cases when they know about it, most respondents informed about their status themselves. Teachers are poorly aware of respondents' HIV status; the question is applicable only to 21.6% of respondents. Most governmental officials do not know about respondents' status (75%). They are informed about it equally both by respondents themselves and other people without the persons consent. The question was applicable only to 25.9% of respondents. Information about the status of PLHV that appears in the media mainly comes from respondents themselves. Of the 81 reported occurrences of people being contact with the media there were 2 of the HIV status being given to the media without the persons consent.

Thus, there are varying degrees of awareness about respondents' HIV status in different categories of people with whom respondents are in contact. Most aware are spouses and partners of PLHIV (only 4.8% do not know about their status) and medical workers (12.2%) followed by other people living with HIV and injecting drug- partners. In the workplace of 80% of respondents people mostly do not know about respondents' status: only one fifth of respondents reporting having their colleagues and employers know about their HIV status (**Table 37**).

On the whole, most respondents inform surrounding people about their HIV status themselves. Information about the respondent's status is mostly spread without the respondent's consent only in certain groups that differ considerably in the levels of their awareness of PLHIV status:

- Among health workers (this was reported by more than half of respondents whose status is known to health workers);
- In the workplace (half of respondents respectively);
- Among governmental officials (also almost half);
- In the circle of friends (one third of respondents respectively);
- In the circle of drug-injecting partners (one fifth of respondents respectively).

Table 37: How did others first learn of respondents' HIV status?

	I told them.		Someone else told them with my consent.		Someone else told them without my consent.		They do not know of my HIV status.		Not applicable
	% of all respondents	% to whom applicable	% of all respondents	% to whom applicable	% of all respondents	% to whom applicable	% of all respondents	% to whom applicable	% of all respondents
Spouse/partner	76.5	91.0	1.2	1.3	4.6	5.5	4.1	4.8	16.2
Other adult family members	62.4	67.3	2.7	2.9	14.1	15.2	25.4	27.4	7.3
Children	6.8	13.7	0.3	0.5	1.9	3.8	41.4	84.1	50.8
Friends & neighbours	48.9	51	4.9	5.1	23.5	24.5	57.6	60.0	4.1
Other people living with HIV	79.5	86.7	5.9	6.5	14.9	16.2	15.4	16.8	8.4
Colleagues	13.2	17.3	0.8	1.1	7.0	9.2	60.0	78.4	23.5
Employers & managing staff	8.1	10.9	0.8	1.1	5.9	8.0	60.0	80.7	25.7
Clients	2.4	5.7	-	-	1.4	3.2	38.9	91.7	57.6
Injecting drug user partners	30.8	76.0	2.2	5.3	7.6	18.7	8.1	20.0	59.5
Religious leaders	24.3	59.2	1.6	3.9	2.4	5.9	15.7	38.2	58.9
Community leaders	14.6	60.0	1.1	4.4	0.8	3.3	8.4	34.3	75.7
Health workers	53.8	56.4	8.1	8.5	49.5	51.8	11.6	12.2	4.6
Social workers & consultants	18.1	44.1	1.1	2.6	3.2	7.9	20.3	49.3	58.9
Teachers	0.8	3.8	0.3	1.3	0.8	3.8	20.0	92.5	78.4
Government officials	3.2	12.5	-	-	3.5	13.5	20.0	92.5	74.1
Mass media	2.7	12.5	0.3	1.3	0.5	2.5	18.4	85.0	78.4

Most respondents reported that they had not felt pressured to disclose their HIV status by others (89.7%, n=332), though:

- 10.3% (n=38) of respondents report having felt pressure from other PLHIV to disclose their HIV status with 7.6% (n=28) reporting that this had occurred more than once; and
- 24.1% of respondents (n=89) report having felt pressure from people other than PLHIV to disclose the HIV status with 19.2% (n=71) reporting that this had occurred more than once.

Disclosure of HIV status by health care professionals is clearly an issue. Overall 40.5% of respondents (n=150) with 34% of males (n=70/206) and 48.8% of females (n=80/164) reported that a health care professional (for example, a doctor, nurse, counsellor, laboratory technician) had told other people about their HIV status without their consent. 8.6% of respondents (n=32) reported no such disclosure; while 50.8% (n=189) were unsure. **Table 38** shows that when disaggregated by age, young people aged 15-24 were less likely to report disclosure of their status than older respondents: 23.5% compared to a range of 41% - 44.4%.

Table 38: Respondents experience of disclosure of HIV status by health care professional, disaggregated by age group

Has a health care professional (e.g. doctor, nurse, consultant, laboratory technician) ever told other people about your HIV status without your consent?	Age			
	15–24	25–29	30–39	40–49
Yes	23.5%	41.0%	42.5%	44.4%
No	17.6%	10.0%	6.5%	8.3%
Not sure	58.8%	49.0%	51.0%	47.2%

Confidentiality of medical records is also clearly an issue. **Table 39** shows that just 4.1% (n=15) of respondents think that their medical records are completely confidential; 33.5% (n=124) indicated that they do not know if their records are kept confidential; while it was clear to 62.2% (n=230) of respondents that their medical records were not being kept confidential.

Table 39: Confidentiality of medical records

How confidential do you think the medical records relating to your HIV status are? (%)	
I am sure that my medical records will be kept completely confidential	4.1
I do not know if my medical records are confidential	33.5
It is clear to me that my medical records are not being kept confidential	62.2
No answer	0.3

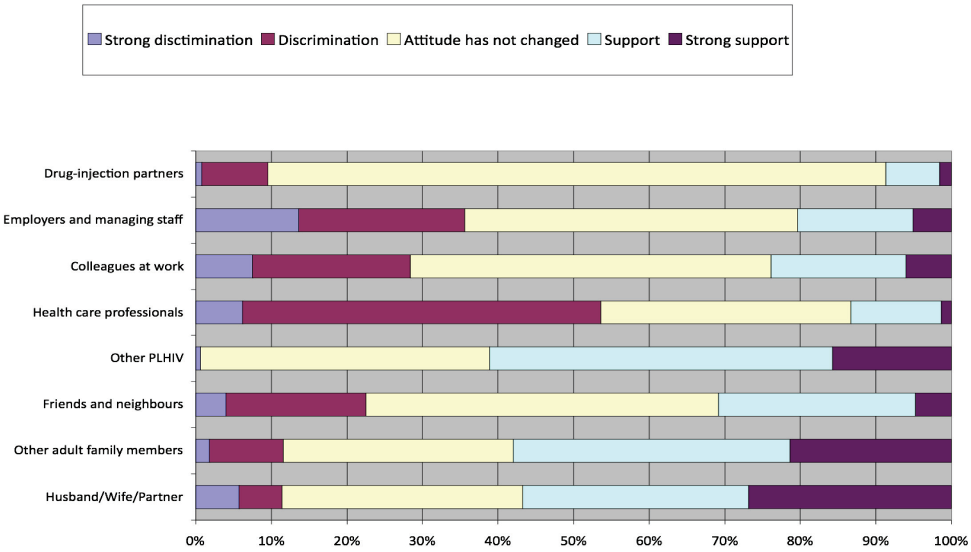
For further qualitative data from respondents see **Annex 1: Identified problems and challenges.**

Respondents were asked about the reactions of different people when they first knew about their HIV status. **Figure 9** shows perceived reactions, with categories ranging from strong discrimination to strong support. Respondents reported varying reactions from spouses and partners, with 9.2% (n=34) saying that their spouses or partners reactions were discriminatory or strong discriminatory and 45.7% (n=169) saying that their spouses or partners were supportive or strongly supportive.

Furthermore, 8.7% of respondents (n=32) reported that they faced discriminatory reactions by adult family members and with 43.2% (n=160) stated that family members had been supportive; while 22.7% (n=84) of respondents reported no change in their attitude.

The highest rates of discriminatory reactions reported by respondents concerned health care workers (44.6%, n=165) with only 11.1% of respondents (n=41) reporting that the health care workers' attitude was supportive or strongly supportive; though 27.6% (n=102) reported no change in their attitude.

Figure 9: Perceived reactions to HIV disclosure



Furthermore, **Figure 9** shows that respondents received supportive reactions mainly from:

- Other people living with HIV (61.3%, n=227);
- Adult family members (58%, n=215);
- Spouses and partners (56.7%, n=210).

Among PID (people who inject drugs) respondents, 81.7% reported no changing of attitude towards them.

The levels of both discrimination and support in this group are 10%.

When disaggregated by gender:

- Female respondents received more supportive responses from other PLHIV than male respondents: 62% compared to 2.5%. This is probably related to the fact that more female than male PLHIV provide support to other HIV-positive people (**Table 40**).
- With regards to medical workers (**Table 41**):
  - Female respondents are more stigmatized than male respondents: 63.2% compared to 46.3%.

- Male respondents were more likely to report no change in attitude towards them: 42.9% and 20.3% respectively.
- Female respondents receive more support than male respondents: 16.5% compared to 10.8%.

Table 40: Reaction of other PLHIV to learning about the respondent's HIV positive status, disaggregated by gender

Reaction of other PLHIV	Men	Women
Strong discrimination	1.1%	-
Attitude not changed	46.3%	27.9%
Support	44.6%	46.3%
Strong support	7.9%	25.7%

Table 41: Reaction of medical workers to learning about the respondent's HIV status, disaggregated by gender

Reaction of health care professionals	Men	Women
Strong discrimination	4.6%	8.3%
Discrimination	41.7%	54.9%
Attitude not changed	42.9%	20.3%
Support	9.7%	15.0%
Strong support	1.1%	1.5%

With regards to disclosure of HIV status, 15.7% (n=58) of respondents reported not having disclosed their HIV status to anyone with 84.3% (n=312) having done so. Approximately half of respondents (51.9%, n=192) described disclosing their HIV status as an empowering experience (male= 49.2% (n=101) and female=55.6% (n=91)).

3.3 Treatment

Respondents were asked to provide information on how they perceived their current health, their access to treatment for opportunistic infections and their experiences of sexual and reproductive health information in health care facilities. **Table 42** shows that only 11.6% described their health as 'excellent' or 'very good'. Nearly 60% of respondents (57%) indicated that their current health was 'fair' or 'poor', while 31.4% described their health as 'good'. There were no significant gender-based differences in the data. When disaggregated by age, respondents in younger age groups (15–24 and 25–29) more often assessed their health as 'excellent' or 'very good'.

Table 42: Respondents' assessment of their health, disaggregated by age

In general how would you describe your health at the moment?	Age			
	15–24	25–29	30–39	40–49
Excellent	23.5%	4.0%	3.0%	5.6%
Very good	5.9%	12.0%	4.5%	-
Good	44.1%	34.0%	29.0%	25.0%
Fair	23.5%	44.0%	51.0%	47.2%
Poor	2.9%	6.0%	12.5%	22.2%

44.1% of respondents were taking ART at the time of the survey with 87% indicating that they could access ART if needed (i.e. it is free of charge or the person can afford it). **Table 43** also shows that when disaggregated by age, respondents aged 15–24 reported having less access to ART than older PLHIV: 64.7% compared to a range of 86% - 94.4% for older age groups). Furthermore, nearly every third respondent in this age group (32.4%) does not know whether he/she has access to ART.

Table 43: Access to ART, disaggregated by age depending on their age

Do you have access to antiretroviral treatment even if you are not currently taking it?	Age			
	15–24	25–29	30–39	40–49
Yes	64.7%	86.0%	90.0%	94.4%
No	2.9%	4.0%	2.0%	-
I do not know	32.4%	10.0%	8.0%	5.6%

Some 37.6% of respondents (n=139) indicated that they were taking some medication to prevent or to treat opportunistic infections, and 45.9% (n=170) reported having access to these medications even if they were not currently taking it.

Over half of respondents (51.1%) indicated that they discussed HIV treatment options with a health care professional during last 12 months, including 52.9% of male and 48.8% of female respondents.

Over one third of respondents (33.8%) reported that they have discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months, including 31.6% of male and 36.6% of female respondents.

For further qualitative data and recommendations by respondents see **Annex 1: Identified problems and challenges.**

3.4 Having children

This sub-section focuses on respondents' experiences regarding reproductive options and sexual and reproductive health services. Female respondents were asked additional questions relating to pregnancy and infant feeding practices.

50.8% of respondents (n=188) indicated that they had children, including 39.3% of men (n=81) and 65.2% of women (n=107) and 5.9% (n=22) have HIV-positive children (11.7% of those with children). Furthermore, 48.5% of respondents who identify themselves as injecting drug users (n=94/194) have children in their household.

Since learning the HIV status, less than 40% of respondents (38.1%, n=141) have ever been counselled on reproductive health and childbearing, with female respondents reporting nearly twice the rate of men: 49.4% (n=81) and 29.1% (n=60).

Furthermore, nearly half of respondents (47%, n=174) had been advised to have no more children, including 35.9% (n=74/206) of male and 61% (n=100/164) of female respondents. When disaggregated by PID and non-PID, 55.9% of PID (n=108/194) had been advised to have no more children compared to 48.4% of non-PID (n=85/176). Furthermore, **Table 44** shows that when PID and non-PID is further disaggregated by gender, female respondents in both groups are more likely than their male counterparts to have been advised to have no more children: PID: 75.9% (n=47/62) compared to 46.3% (n=61/132); non-PID: 60.2% (n=61/102) compared to 30.0% (n=22/74).

Table 44: PID and non-PID advised not to have a child since diagnosis, disaggregated by gender

Has a health care professional ever advised you not to have a child since you were diagnosed as HIV-positive?			
		Men	**Women**
non-PID	Yes	30.0%	60.2%
	No	68.3%	37.6%
	No answer	1.7%	2.2%
PID	Yes	46.3%	75.9%
	No	52.9%	24.1%
	No answer	0.8%	-

11.4% of respondents (n=42) reported being coerced into being sterilized, including 1.9% of male (n=4/206) and 23.2% of female (n=38/164) respondents, additionally 7 respondents (1.9%) stated that the use of contraceptives is a precondition for receiving ART.

Table 45 shows that of the female respondents who have been pregnant in last 12 months, 59.1% had not experienced coercion from health care staff; however: 25% reported coercion to undergo an abortion; 15.4% reported coercion in relation to birthing method; and 6.4% in relation to Infant feeding practices.

Table 45: Coercion by health care workers in relation to reproductive health services for female respondents

In the last 12 months have you been coerced by a health care professional in relation to any of the following because of your HIV status… (% of the number of female respondents)		
Termination of pregnancy (abortion)	Yes	25.0%
	No	59.1%
	No answer	15.9%
Method of giving birth	Yes	15.4%
	No	62.8%
	No answer	21.8%
Infant feeding practices	Yes	6.4%
	No	70.5%
	No answer	23,1%

Belarus

All 164 women were asked about their access to prevention of vertical transmission (PVT) services. However 62 respondents did not answer this question. Of the remaining 102, 37 had not been HIV+ when pregnant. Of the remaining 65, 78.5% (n=51) had received ART for PVT, 18.5% (12) did not know that such treatment existed, and 3.0% (n=2) reported that they did not have access to such treatment. Of those 51 women who had received ART during pregnancy 33 (64.7%) were provided information about healthy pregnancy and motherhood as part of the programme and 18 (35.3%) were not.

For further qualitative data and recommendations by respondents see **Annex 1: Identified problems and challenges.**

Annex 1: Identified problems and challenges

In the Belarusian study, additional questions were included to identify problems and challenges faced by respondents in relation to:

- HIV testing, diagnosis and treatment
- Confidentiality
- ART Access
- Having children

The qualitative data and recommendations are outlined below.

HIV testing, diagnosis, and treatment

Table 46 outlines some of the problems and challenges identified by 85.4% of respondents (n=316) in relation to HIV testing and diagnosis, and treatment (CD4, viral load, resistance).

Table 46: Problems and challenges related to HIV testing, diagnosis, and treatment

Running of tests
Tests must be taken in another city ("testing centres are too distant," "it is not convenient to go to another city for testing," "trips for testing to the oblast centre," "it is difficult to visit counselling centres located in another city," "tests are not taken at the place of residence," etc.);
Challenges in relation to having to make trips for testing ("testing is done too distant from the place of residence," "financial difficulties because of trips to another city," "it is hard and expensive to go to another city," "it is hard to obtain permission to be absent from work for testing," "to obtain permission to be absent from work and to lie," "I live in village alone with my child, I do not have time for this," etc.);
Long lines;
Inconvenient working hours of the laboratory ("testing is performed only in the morning on working days");
Testing and diagnosis being performed in different health care institutions ("testing and diagnosis done in the opposite ends of the city," etc.).
Disruptions in the supply of test systems ("no tests for viral load/resistance, CD4, ELISA");

Prolonged waiting for the results (“before you know your results, you need to run new tests,” “often there are no reagents,” etc.).
Quality of pre- and post-test counselling
Low coverage with pre- and post-test counselling;
Poor quality of pre- and post-test counselling (“atmosphere of a sentence being passed during testing,”, “one should be prepared for the diagnosis,” “no information about how to live with it,” etc.);
Testing and counselling are performed in different places
Keeping the anonymity of the test results
Doubts about the anonymity of HIV testing being kept (“conditionally anonymous testing,” etc.);
Fear of disclosure of the results and negative reaction from other people (“fear of my relatives turning back on me,” “fear of being rejected by society and family,” “fear of inflicting harm to relatives,” etc.).
Obtaining of information and psychological help by PLHIV
Lack of psychological support and counselling after the diagnosis (“one on one with the diagnosis and one’s own problems,” etc.);
Insufficient counselling on HIV/AIDS during visits to the doctor and incompetence of doctors (“the doctor in the policlinic cannot answer my questions,” “the doctors are not ready to hear about HIV,” “no psychological support from doctors,” “there is no infectious diseases doctor,” etc.);
Difficulties in obtaining information about HIV (“lack of access to full information,” “no reliable information about life with HIV,” etc.).

Respondents made the following recommendations to improve HIV testing and diagnosis:

- Run tests for HIV at the place of residence;
- Improve the quality of diagnosis (including continuous access);
- Perform quality pre- and post-test counselling (involving peer consultants); and
- Provide psychological counselling to PLHIV, including through peer counselling mechanisms.

Confidentiality

Table 47 outlines some of the problems and challenges identified by 83.5% of respondents (n=309) in relation to confidentiality in institutions.

Table 47: Problems and challenges in relation to confidentiality

Confidentiality of information about the HIV status of patients in health care institutions
Marks on the HIV positive status in the medical records (“codes in patient medical records,” “marks in the medical records, code 120,” “a red spot on the medical record,” “the status is not codified in the hospital records;” “accessibility of the list of people with HIV,” “data being indicated on the first page of the medical record,” “earmarks on mine and my child’s medical records,” “anyone can see it on the cover of the medical record,” “I am not easy with visiting the doctor with my personal record,” etc.).
Disclosure of information by health care professional (“doctors discuss it with other doctors,” “health care professional disclose information more than anyone else,” “the nurse is present during the talk,” “information is not even kept secret from other patients,” “violation of basic ethical rules by health care professionals;” “medics feel repulsion,” “medical attendants told my relatives about it,” “doctors told my employers about my status,” etc.).
Difficulties in bringing to responsibility for the disclosure of the status (“to ensure punishment you need to disclose your status,” “it is not possible to prove the disclosure ever taking place,” “the problem is there but it is difficult to prove anything,” “our laws do not always work,” “problems with observing the law on non-disclosure,” “the court is on the side of doctors,” etc.).
Confidentiality of information about the HIV status of patients in prisons
“disclosure of my status in prison,” “problems with confidentiality in prisons,” “my relative were informed by prison authorities without my consent,” etc.
Confidentiality of information about the HIV status of patients in other settings
Stigma from neighbours (“the neighbours discussed by status,” “gossiping,” “both my wife and I suffer,” etc.).
Requirements for disclosing the status at work and other institutions (“you have to informed the employer,” “the department for visas and registration demanded the certificate of diagnosis,” “you cannot apply for residence permit without having a test,” “the manicurist told me…,” etc.
PLHIV perception of the situation with non-disclosure of their status
“I do not believe in this law,” “it is clear that it is no secret to anyone,” “I repeatedly faced cases of disclosure,” “I do not trust all doctors,” “I am not confident that no one will know,” “it is impossible to keep the confidentiality,” “no confidentiality is ever possible,” “I am concerned about lack of confidentiality in the medical records,” “diagnosis should be kept secret,” “I am in no power change anything,” “there will always be disclosure,”, etc.

Respondents made the following recommendations to improve confidentiality:

- better inform PLHIV about the rights (“to study one’s own rights,” “we need to fight against it,” “it is time to lose fear of this disease,” etc.);
- inform other people about the inadmissibility of disclosure of the status of HIV-

positive people ("to raise the awareness of society about non-disclosure," "society is not ready to perceive," "not to disclose until high awareness of society is ensured," "people should understand what should not be disclosed," "people do not know that it is prohibited to disclose the diagnosis," etc.);

- remove and to bar marks on the HIV status in medical records ("I am tired of the earmark on my medical record," etc.), to narrow the circle of health care professionals who have access to information about a patient's having HIV infection;
- raise the awareness of health care professionals about the unlawfulness of disclosure of information about the HIV status ("to hold courses for doctors on non-disclosure," "to work with medical attendants," "to work with medical personnel on non-disclosure," "to inform about the criminal nature of such actions," etc.);
- increase the responsibility for disclosing HIV status ("to punish medical personnel for disclosure," "to increase doctor's responsibility for disclosure," "to increase the responsibility of medical personnel," "to hold a demonstrative trial for disclosure," "medics should sign a non-disclosure statement," "to make the law on non-disclosure more severe," "to introduce more severe responsibility," "to make the law on confidentiality more severe," etc.).
- scale up work with population aimed at preventing stigma against PLHIV;
- enhance work with medical personnel aimed at overcoming stereotypes with the participation of PLHIV trained in preventive skills.
- take measures aimed at bringing in line the current legislation and the instructions regulating the actions of officials with respect to HIV-positive people[35].

Access to ART

While most respondents indicated high accessibility of ART; 65.4% of respondents (n=242) report experiencing some difficulties (**Table 48**).

Table 48: Problems and challenges in relation to access to ART

Pharmacological support of ART
Issues related to the quality of ARVs ("a small number of registered antiretroviral," "branded drugs are better," "a large number of generics which results in side effects," "sometimes tablets were expired," "in prisons they give you expired antiretroviral," "no information about ARVs," etc.);
Disruptions in the supply of drugs ("disruption in the supply of drug at the local level," "the doctor does not always have ARVs in stock," "disruptions in the supply lasted 2 weeks," "changing of treatment regimens because of out-of-stocks," etc.).

---

[35] E.g., it is mandatory to indicate the disease to receive a number of benefits and social help, which automatically leads to disclosure of the diagnosis at the place of receiving of assistance and in some cases in the workplace.

Financial difficulties when buying supporting drugs and medication for opportunistic infections (“expensive drugs with no reduction of costs,” “supporting drugs are too expensive,” etc.).
ART
Concerns about one’s own health (“I am afraid I will feel bad after therapy,” “I am concerned about side effects,” “there are many rumours about side effects,” “I am not confident it will help,” “inconvenient administration, toxicity of drugs,” etc.).
Problems with obtaining information about treatment (“the doctors provide little information,” “need for additional information about treatment,” “I do not clearly understand what it is,” “I know little about side effects,” “little and incorrect information about ARVs,” “insufficient counselling on ARVs,” “I do not know what it is and when it is necessary,” “I do not know how efficient the treatment regimen is,” “no information about treatment,” “poor counselling on treatment,” “too little information,” “too little counselling,” etc.).
Fear of the strict drug administration schedule during ART (“life will depend on tablets,” “it is difficult to strictly follow the schedule,” “too many pills,” etc.).
Concerns about future accessibility of ART (“I am afraid I will need to pay for ART,” “I fear I will have to pay for ARVs,” “I am not confident it will also be accessible,” “I am afraid ARVs may run out of stock,” “at the moment everything is fine, but what will happened when financing is ceased,” etc.
Disruptions in testing (“no tests for resistance,” “no test systems for ART consequences,” etc.).

Respondents made the following recommendations to improve ART access:

- introduce mandatory counselling of patients on various aspects of treatment (information about drugs, treatment regimens, side effects); there is need for both medical counselling and the presence of peer counsellors, i.e. from among other PLHIV;
- ensure uninterrupted supply of ARVs;
- ensure the supply of quality ARVs;
- ensure greater involvement of PLHIV in the decision making process of committees and work groups engaged in planning, procurement and distribution of ARVs; and
- ensure transparency of planning, procurement and distribution of ARVs.

Having children

Most respondents indicated a positive attitude towards the possibility of having children, exemplified by:

- it is good such a possibility exists;

- I plan to do it future; and
- I learned about capabilities of medicine

However, 54.8% of respondents (n=203) report experiencing some difficulties (**Table 49**).

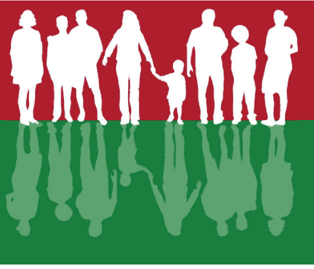
Table 49: Problems and challenges in relation to having children

Doctors' attitude towards children being born to HIV-infected parents
Doctors' attitude towards children being born to HIV-infected parents ("the doctor said I could not have children," "doctors were against my being pregnant, did not register my pregnancy," "the doctors insisted on abortion," "the doctors' pressure on my wife to have an abortion," "they called my wife and tried to talk her into having an abortion," "the gynaecologist offered making an abortion and placing a contraceptive coil," "they argued for terminating the pregnancy," etc.).
Doctors' attitude towards HIV-positive women ("insolent attitude of doctors in prenatal clinics," "the doctors in a rude manner recommend not having a baby," "they expert psychological pressure," "terrible attitude of gynaecologists," "ill treatment, they suggest undergoing sterilization," etc.).
Therapeutic issues
Lack of capabilities (equipment) for sperm washing
Informing of HIV-positive parents on reproductive issues
"radical and one-sided advice," "no techniques of working with HIV-positive people," "poor skills of doctors," "little information," "no proper counselling," etc.
Parents' concerns about the future of their children and refusal to have children
"there is no guarantee that the child will be healthy," "the doctors' attitude does not promote having children," "discrimination against children," "seclusion of children," "I am very scared," "I would not risk it myself," "I agree to being sterilized," "stigma against me will pass on to my child," "the risk of giving birth to a sick child," "it is difficult to overcome fear," "my health will worsen," "the child may be born sick and orphaned," "the risk of discrimination in the nursery and kindergarten," etc.

Respondents made the following recommendations in relation to having children:

- increase the skills of health care professionals (gynaecologists, in particular) in working with HIV-positive patients;
- change the attitude of doctors towards PLHIV having children ("not to prevent women to from having children," "HIV is not an obstacle to having children; each individual has make an independent decision," "to eliminate the pressure exerted by doctors," etc.);

- form more careful attitude towards HIV-positive women among medical personnel ("health workers should be more humane," "more attention should be paid to HIV and pregnant women," etc.);
- raise awareness of PLHIV about the legal aspects of their reproductive behaviour; and
- scale up counselling for HIV-positive people on most urgent medical aspects related to reproduction ("raise awareness on maternity," "to provide information to parents about risks," "to reduce the risk of mother-to-child transmission," "to scale up counselling for pregnant women," "to improve the quality of counselling for future parents," etc.).



Conclusion

The study found that HIV-related stigma and discrimination is ongoing and acts as a barrier for people living with HIV to access HIV prevention, treatment and care services in Belarus. The findings of the experiences of people living with HIV by area are outlined below.

Exclusion

- Over two thirds of respondents (66.8%) reported that they had been gossiped about at least once in the last year, indicating that two thirds of the gossip occurred, in whole or in part, because of their HIV-positive status.
- Significant percentages of respondents reporting having been verbally insulted/harassed/threatened (41.6%), physically harassed or threatened (15.9%), and/or physically assaulted (13.8%) at least once in the last year. Of these, 51.3% indicated being insulted/harassed/threatened, 35.6% physically harassed or threatened, and 90.1%, physically assaulted, in whole or in part, due to their HIV-positive status.
- Over one third of respondents (36.7%) feel that HIV-related stigma and/or discrimination is due to people not understanding how HIV is transmitted or are afraid of infection through casual contact.

Access to work and health and education services

- Nearly one in five respondents (19.2%, n=71) had been forced to change residency/refused accommodation in the last year with 85.9% thinking the reason was HIV-positive status-related.
- Over one quarter (27.6%) reported having lost a job or another source of income in the last 12 months.
- Of those answering the question nearly one in five respondents (17.9%, n=33) report being denied health services, including dental care, at least once in the last 12 months.
- Of those answering the question nearly one in five respondents (18.9%, n=21) had been refused family planning services during the last 12 months.
- The percent of respondents reporting being refused sexual and reproductive health services in the last 12 months was relatively low (4.6%, n=17).
- 5 respondents (5.9% of the 94 who reported rights violations) stated that their children have been dismissed, suspended or prevented from attending an educational institution because of the respondent's HIV status during the last 12 months.

Internalised stigma and fears

- Internalised stigma was prevalent: over 71% feel guilt, 65.6% blame themselves, 54.5% feel ashamed, and over 36%% report low self-esteem.
- 6.7% of respondents (n=21/314) reported feeling suicidal with women reporting more suicidal thoughts than men (8.3% compared to 5.3%); and higher levels reported by younger respondents (13.8% of respondents aged 15–24 compared to a range 5.3%-7% for older age groups).
- The most frequent decisions made by respondents during the last 12 months because of HIV status were not to have more children (60.3%), not to marry (26.2%) and to isolate themselves from friends and relatives 13.8%). (62.3%, n=170/273), not to marry (27.1%, n=74/273) and to isolate themselves from friends and relatives (14.3%, n=39/273).
- Internal stigma affects:
    - access to health care: 45.4% (n=168) avoided going to a local clinic when they needed care, and 34.8% (n=129) avoided going to hospital; and
    - study and employment: 23.4% (n=87) withdrew from education or training, 20.9% (n=77) decided not to apply for a job or a promotion because of their HIV status and 7.4% (n=27) gave up their job.
- Overall, 78.2% of respondents feared being gossiped about; significantly higher levels of fear than verbal insult (61.5%), physical harassment and/or threat (32.2%), and physical assault (30.3%).

Rights, laws and policies

- The Public Health Law[36] was known to 53.8% (n=199) of respondents, of whom 45.7% (n=91/200) had read or discussed it.
- During the previous 12 months, 27.8% (n=103) of respondents reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions.
- The most frequent violation reported by 29.5% of respondents (n=109) was being forced to submit to a medical procedure (including HIV testing).
- 94 respondents reported that that they experienced a rights violation within the previous 12 months, of whom 9 had sought legal redress; and of the 85 respondents who did not, the most common reason cited (61.2%) was belief that the outcome would be unsuccessful.

---

[36] This can be accessed at http://www.hsph.harvard.edu/population/aids/BELARUS.htm

Effecting change

- During the last 12 months, 44.6% (n=165) of the respondents reported having confronted, challenged or educated someone who was stigmatizing and/or discriminating against him or her.
- Overall, 70.5% (n=260)of the respondents knew of an organization or groups providing support to those experiencing stigma or discrimination, with PLHIV support groups the most frequently cited (79.7%, n=295); followed by the Belarusian Community of People Living with HIV (52.9%,n=196).
- 80 respondents (21.6%) indicated that they had sought help from an organization for problems related to stigmatization or discrimination.
- Over three quarters of respondents (75.4%) reported having provided some form of support to other people living with HIV in the previous 12 months with emotional support (99.3%) being the most common type of assistance rendered.
- Nearly 30% of respondents (29.7%) reported being a member of a support group and/or network of people living with HIV.
- Nearly 20% of respondents (18.1%) had been involved, either as a volunteer or as an employee, in a programme or project providing assistance to people living with HIV in the previous 12 months.
- Only 3.5% of respondents had been involved in efforts to develop HIV-related legislation, policies or guidelines.
- Nearly three quarters of respondents (73.2%) felt unable to influence policies, laws and programmes at either national or local levels.
- In terms of the most important thing organisations should do to address stigma and discrimination, more than 40% cited advocating for the rights of all people living with HIV (41.9%).

Testing and diagnosis

- 17.8% (n=66) reported taking a HIV test just to know their status.
- 12.4% (n=46) were referred for HIV testing when already symptomatic.

In terms of coerced testing or without a person's consent:

- 12.2% of respondents were tested while in prison (n=45), and 5.7% (n=21) while in police custody. Male respondents were twice as likely to have undergone testing in prison compared to female respondents.
- Female respondents were more likely to have undergone testing during medical treatment (14.5%, n=54): during registration with drug monitoring and rehabilitation clinics and during drug treatment (5.9%, n=22); in hospital during in-patient

treatment (7%, n=26); and during blood screening (hepatitis/herpes/donation of blood) (1.6%, n=6).

- Overall, slightly less than two-fifths of respondents (38.6%, n=143) indicated that their HIV test was completely voluntarily with nearly one quarter (24%) reporting being forced to take a HIV test.
- Less than 10% of respondents received both pre- and post-test counselling (8.1%, n=30); however, with over 40% (40.8%, (n=151) receiving no counselling at all, while nearly half (48.4%, n=179) received only post-test counselling, and 2.4% (n=9) received only pre-test counselling.

Disclosure and confidentiality

- High levels of disclosure by respondents included to: health care workers (56.4%), other HIV-positive people (86.7%), spouses or partners (91%), and other adult family members (67.3%), injecting drug partners (76%), and social workers and other counsellors (44.1%);
- 4.8% of respondents have not disclosed to their spouse or partner, and 20% have not disclosed to injecting drug partners.
- Many respondents had not disclosed their HIV status to their children (84%), or to their employers (80%) or co-workers (78.4%).
- Approximately 90% of respondents (89.7%) reported that they had not felt pressured to disclose their HIV status by others.
- 40.5% of respondents (n=150) with 34% of males (n=70) and 48.8% of females (n=80) reported that a health care professional (had told other people about their HIV status without their consent.
- Over one third of respondents (33.5%) indicated that they do not know if their records are kept confidential; while it was clear to over 60% of respondents (62.2%) that they were not being kept confidential.
- Health care workers reported as having the highest levels of discriminatory reactions to learning of a respondent’s HIV status (44.6%, n=165).
- Respondents reported varying reactions from spouses and partners to learning of their HIV status, with 9.2% saying that their spouses or partners reactions were discriminatory or strong discriminatory and 45.7% saying that their spouses or partners were supportive or strongly supportive.
- Approximately half of respondents (51.9%) who had disclosed their status described this as an empowering experience.

Treatment

- Only 11.6% of respondents described their health as 'excellent' or ‘very good’; while nearly 60% of respondents (57%) described it ‘fair’ or ‘poor’, and under one third

(31.4%) as ‘good’ with the longer respondent has lived with HIV the more likely he or she is to describe health status as ‘fair’ or ‘poor’.

- 44.1% of respondents were taking ART with 87% indicating that they could access ART if needed.
- 37.6% of respondents indicated that they were taking some medication to prevent or to treat opportunistic infections, and 45.9% reported having access to these medications, if needed.
- 51.1%of respondents had discussed HIV treatment options and 33.8% had discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months.

Having children

- 40% of respondents (38.1%, n= 141) respondents indicated that they had not received counselling on their reproductive options since their HIV diagnosis.
- Nearly half of respondents (47%, n=174) reported that they have been advised by a health care worker not to have a child since their diagnosis with women significantly more likely to report this irrespective of drug use.
- 42 respondents (11.4%), of whom 38 were women (23.2%) and 4 were men (1.9%), reported that they had been coerced by a health care professional into being sterilized since HIV-positive diagnosis, all of whom identified as current or former people who inject drugs.
- Seven respondents (1.9%) reported that their ability to obtain ART was conditional on using certain forms of contraception.
- Of the female respondents, who have been pregnant in last 12 months, one quarter reported coercion from the health care staff to undergo an abortion; 15.4% had been coerced in relation to birthing method; and 6.4% in relation to Infant feeding practices.
- In relation to prevention of vertical transmission, of women who had been pregnant:
- 50% indicated that they had received ART; 2% did not have access to ART; 11.8% did not know that such treatment existed; and 36.3% were not HIV-positive when pregnant.
- 64.7% reported that were also given information about healthy pregnancy and motherhood in order to prevent mother-to-child transmission.

Recommendations

The following recommendations are made in light of:

- high levels of stigma and discrimination in a number of areas, including exclusion; access to residency/accommodation, employment and health care;
- high levels of internalized stigma; and
- low levels of perceived ability to effect change reported by people living with HIV in Belarus involved in this study.

The overall recommendation derives from the facts that among the sample there was low socio-economic status, including significant percentages of respondents reporting low levels of employment, as well as internalized stigma, high rates of being fearful about the ways they were perceived and treated in the community (with reported examples of stigmatizing and discriminatory treatment), and 6.8% of respondents reported feeling suicidal. As such, psychosocial and socioeconomic support must clearly be a priority for the Belarusian Community of PLHIV, civil society, the National AIDS Programme and the Government. Concerted efforts by all the above stakeholders are required to promote positive living and provide psychosocial and socioeconomic support, including training opportunities for people living with HIV to become peer educators, capacity and network building, counselling, training, and income generation.

Other specific recommendations directed to the Belarusian Community of PLHIV, civil society, the National AIDS Programme and the Government are outlined below.

Belarusian Community of PLHIV

- Disseminate the findings of this study to the Government, National AIDS programme, civil society, UN agencies and donors.
- Advocate for the rights of all people living with HIV, including key populations, and advocate against and challenge rights violations.
- Intensify education efforts with people living with HIV on positive health, dignity and prevention.
- Provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission to the general public.
- Encourage and build the capacity of people living with HIV to advocate for their rights; be actively involved (either as a volunteer or as an employee) in developing and implementing stigma and discrimination reduction projects and programmes;

and to provide support and assistance to people living with HIV individually, and through support groups and other local organisations.
- Empower HIV-positive people to know and assert their rights.
- Advocate for the inclusion of more people living with HIV in policy-making fora and in the development and drafting of relevant legislation.
- Build the capacity of support groups and other local organisations to challenge stigma and discrimination, and to provide adequate counselling and other support to people living with HIV, including key populations, and in particular people who inject drugs and those in detention settings.
- Undertake further research into the underlying facilitators of disclosure of HIV status, including disclosure-related feelings of empowerment and stigma.

Civil Society actors involved in the response

- Build the capacity of support groups and other local organisations to challenge stigma and discrimination, and to provide adequate counselling and other support to people living with HIV, in particular to younger PLHIV as well as people who inject drugs and those in detention settings.
- Advocate for the rights of all people living with HIV, including in particular people who inject drugs and those in detention settings.
- Promote voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission to people living with HIV and the general public.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.

National AIDS Programme

- Promote voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Given that there is a low level but consistent pattern of denial of the rights of people living with HIV in health care settings[37], including SRH rights[38]:

---

[37] For example:
- Nearly one in five respondents (17.9%, n=33), reported being denied health services, including dental care, at least once in the last 12 months. Furthermore, nearly one in five (18.9%, n=21) respondents reported having been refused family planning services in the last 12 months.
- Internal stigma also affects access to health care: 45.4% (n=168) avoided going to a local clinic when they needed care, and 34.8% (n=129) avoided going to hospital.
- 29.5% of respondents (n=109) were forced to submit to a medical procedure (including HIV testing).
- In terms of coerced testing or without a person’s consent:

    - revise pre- and in-service training curricula to enhance the capacity of health providers to provide non-judgmental and non-discriminatory services to people living with HIV, including PVT, and specifically for people who inject drugs and those in detention settings;
    - review and update, if needed, protocols to ensure they are rights-based and include pre-service training for health care workers as well as in-service training refresher courses for health providers, managers and other health facility staff, as well as strengthen supervision to foster non-judgmental and non-discriminatory practices towards people living with HIV, including specifically for people who inject drugs and those in detention settings; and
    - scale up the provision of correct information and appropriate options for ART and the sexual and reproductive health for people living with HIV, including PVT, and specifically for people who inject drugs and those in detention settings.
- Support SRH and HIV linkages, including the integration of SRH services for people

---

    - Nearly one quarter (24%) reporting being forced to take a HIV test.
    - 12.2% of respondents were tested while in prison (n=45), and 5.7% while in police custody. Male respondents were twice as likely to have undergone testing while in detention compared to female respondents.
- Female respondents were more likely to have undergone testing during registration with drug monitoring and rehabilitation clinics and during drug treatment (20.5%, n=8/39 females compared to 15.2%, n=14/92 males); in hospital, during in-patient treatment (25.6%, n=10/39 females compared to 17.4%, n=16/92 males); and during blood screening (hepatitis/herpes/donation of blood) (10.3%, n=4/39 females compared to 2.2%, n=2/92 males).
- Just over 40% (40.8%, (n=151) receiving no counselling at all, while nearly half (48.4%, n=179) received only post-test counselling, and 2.4% (n=9) received only pre-test counselling.
- 40.5% of respondents (n=150) reported that a health care professional had told other people about their HIV status without their consent.
- Health care workers reported as having the highest levels of discriminatory reactions to learning of a respondent's HIV status (44.6%).

[38] For example:

- 18.9% (n=70) respondents have been refused family planning services during the last 12 months.
- 4.6% (n=17) respondents had been denied sexual and reproductive health services.
- Less than 40% of respondents (38.1%) respondents indicated that they had never received counselling on their reproductive options since their HIV diagnosis.
- Nearly half of respondents (47%, n=174) reported that they have been advised by a health care worker not to have a child since their diagnosis with women significantly more likely to report this irrespective of drug use.
- 42 respondents (11.4%) reported that they had been coerced by a health care professional into being sterilized since HIV-positive diagnosis, all of whom identified as current or former people who inject drugs.
- Seven respondents (1.9%) reported that their ability to obtain ART was conditional on using certain forms of contraception.
- Of the female respondents, who have been pregnant in last 12 months, one quarter reported coercion from the health care staff to undergo an abortion; 15.4% had been coerced in relation to birthing method; and 6.4% in relation to infant feeding practices. In relation to prevention of vertical transmission, of women who had been pregnant 2% indicated that they did not have access to ART and 11.8% did not know that such treatment existed.

living with HIV into HIV programmes.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.

Government

- Take the lead in creating a policy and legal environment that will safeguard the rights of people living with HIV, specifically addresses HIV-related stigma and discrimination, requires informed consent for HIV testing, protects confidentiality and provides redress for breaches.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Support broad-based social and community awareness raising and mobilization as part of efforts to eradicate stigma and discrimination against people living with HIV and key populations, including through a human rights-based approach, addressing HIV-related myths.
- Prioritize HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in national strategic planning, funding and programmes, including support for scaled up implementation of promising programmes.
- Include HIV-related stigma and discrimination indicators as part of the national AIDS response M&E systems to monitor and evaluate progress over time.

Notes

Disclaimer:

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

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

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

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

Published by:
Republican non-governmental organization Belarusian PLHIV community
Starinovskaja St., building 15, office 3
Minsk, Belarus 220056
BELARUS
Website: www.hiv.by
Email: info@hiv.by