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THE PEOPLE LIVING WITH HIV STIGMA INDEX

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The PLHIV Stigma Index is an initiative of four founding partners





Acronyms

ARV	Antiretroviral
CCM	Country Coordinating Mechanism (for delivery of Global Fund interventions)
CSO	Civil Society Organisation
GIPA	Greater Involvement of People Living with HIV
GNP+	Global Network of People Living with HIV
IEC	Information, education and communication
ICW	International Community of Women Living with HIV/AIDS
LGBT	Lesbian, gay, bisexual and transgender
MSM	Men who have sex with men
NGO	Non-Governmental Organisation
PLHIV	People living with HIV
PMTCT	Prevention of Mother-To-Child Transmission [preferred terminology is the prevention of vertical transmission]
SIEĆ PLUS	The Polish Network of People Living with HIV/AIDS
SRHR	Sexual and Reproductive Health and Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS



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Executive Summary

The decision to implement the People Living with HIV Stigma Index in Poland was approved by SIEĆ PLUS, the Polish Network of People Living with HIV/AIDS. The People Living with HIV Stigma Index project comprises a survey as well as a standard implementation process designed for reliability of results, while ensuring ownership of the process and data by the national networks of people living with HIV¹. This programme was developed by an international partnership consisting of the Global Network of People Living with HIV (GNP+), the International Planned Parenthood Federation (IPPF), the International Community of Women Living with HIV/AIDS (ICW) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). The SIEĆ PLUS Polish Network of People Living with HIV/AIDS collaborated with leading Polish non-governmental organisations, which work with people living with HIV. The implementation process in Poland was supported financially by the International People Living with HIV Stigma Index Partnership and HIV in Europe. Support for the project was also extended by the Family Development Society and the Global Drug Policy Program, Open Society Institute. The project was endorsed by the National AIDS Centre and the Polish Society for Science on AIDS.

The survey

Data for the People Living with HIV Stigma Index was gathered through interviews with people living with HIV, using a predefined questionnaire. This was the first such initiative of its type in Poland. The survey was conducted with a group of 502 people in seven cities. In addition to the survey data, twenty case studies were collected from this group of respondents.

Key findings

Seventy-five percent of people living with HIV in the sample reported an average income below the national average of 3033 PLN per month (US\$ 1 064 per month). Nearly half of the respondents (46%, N=233) were unemployed. Ten percent of respondents (N=52) reported that they had insufficient quantities of food on at least one day in the last month.

Twenty percent of respondents (N=98) reported that they had been excluded from a social gathering at least once in the last 12 months; 30% of these respondents indicated the exclusion was solely because of their HIV status. The experience of being verbally insulted, harassed, or threatened in the last 12 months was reported by 153 respondents (31%); 21%

¹ More information available at www.stigmaindex.org



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indicated that this was solely because of their HIV status. Eighty-four respondents (17%) told interviewers that they had been physically assaulted in the last 12 months, with 11% of these indicating that they were assaulted because of their HIV status. In addition to these numbers, 14% (N=71) reported that their wife/ husband/ or partner, or any members of their household experienced discrimination as a result of the respondent's HIV-positive status in the last 12 months. When asked, respondents expressed the opinion that a lack of knowledge about HIV was the main reason for discrimination related to HIV status.

Thirty percent of respondents (N=152) stated that they faced discrimination in the last year not only because of HIV status, but also because of their current or former membership in a key population. Twenty-six percent of these respondents (N=39) reported that they were the targets of stigma or discrimination, either wholly or partly because of their sexual orientation. Twenty-four percent of these respondents (N=36) indicated that they faced stigma or discrimination because they were, or had been formerly, people who use drugs.

Despite the fact that HIV was first reported in Poland in the mid-1980s, interviewees reported mixed behaviours toward them on the part of health care workers. Thirty percent of respondents (N=150) reported that health care workers reacted supportively or very supportively upon disclosure of the respondents' HIV status; however, one out of five respondents (20%, N=100) experienced discriminatory or very discriminatory reactions to the disclosure of their HIV status on the part of health care workers. Eighteen percent of respondents (N=89) reported that they had not disclosed their status to a health care worker.

Outcomes

SIEĆ PLUS is developing an advocacy plan based on the results. The plan will focus on advocacy with the representatives of government agencies and NGOs. Dissemination of the research results has begun through the presentation of preliminary results at the Polish National AIDS Conference in Warsaw, in December 2010, and at the HIV in the European Region Conference in Tallinn, Estonia, in May 2011. We hope that the results will initiate changes in the approach towards people living with HIV, and that stigma and discrimination experienced by people living with HIV will reduce.



1. Introduction

The People Living with HIV (PLHIV) Stigma Index is the joint initiative of four partner organisations (the International Partnership), which worked together from 2005 to 2010 to develop this survey and process. The founding partnership members were:

- The Global Network of People Living with HIV (GNP+);
- The International Community of Women Living with HIV/AIDS (ICW);
- The International Planned Parenthood Federation (IPPF); and
- The Joint United Nations Programme on HIV/AIDS (UNAIDS).

Internationally, the PLHIV Stigma Index is a programme developed and implemented by and for people living with HIV. The purpose of the index is two-fold:

1. to collect information directly from people living with HIV about their experiences of stigma, discrimination, and rights violations
2. to enhance the capacity of networks of people living with HIV to conduct rigorous scientific research, to manage and maintain ownership of the resulting data, and to use the results for evidence-based advocacy.

SIEĆ Plus, the Polish Network of People Living with HIV/AIDS, led the implementation of the People Living with HIV Stigma Index in Poland. SIEĆ Plus is the largest organisation representing the interests of HIV-positive people in Poland. The network has an office in Warsaw, providing services to more than 300 clients.

SIEĆ PLUS was one of five country networks of people living with HIV in Europe and Central Asia that implemented the PLHIV Stigma Index in 2010. In these five countries—Estonia, Moldova, Poland, Turkey, and Ukraine—the networks included additional questions to the standard questionnaire in order to examine more closely the barriers that limit access to testing, treatment, and care services for people living with HIV. A report entitled *HIV-Related Stigma: Late Testing, Late Treatment*² provides cross-country results from the additional questions in these countries.

The main aim of collecting this information and communicating the results is to broaden understanding of the extent and forms of stigma and discrimination faced by people living with HIV in different countries. The participating organisations intend to make the PLHIV Stigma Index widely available so that it can be used as a local, national and global advocacy tool to advocate for better life conditions for PLHIV in Poland.

² The *HIV-Related Stigma: Late Testing, Late Treatment* report is available in English and Russian at <http://www.gnpplus.net/en/resources/human-rights-and-stigma/item/101-hiv-related-stigma-late-testing-late-treatment>.



2. Background

HIV-related stigma and discrimination

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’³. (UNAIDS, 2005). Discrimination can occur at multiple levels and in various arenas of life: individual, family, social, and institutional (such as within employment, educational, religious, or healthcare settings, legal, or national).

With regards to documenting the situation of people living with HIV in Poland, there have only been a few studies which have been undertaken, for example, quality of life studies. The first large scale study was undertaken by Magdalena Ankiersztejn-Bartczak in 2008. The study found that a large percentage of people living with HIV faced discrimination⁴.

‘The survey will allow the elimination or reduction of discrimination toward HIV-positive people in doctor’s offices and other health care facilities so that HIV starts to be treated as a disease and not as a prison sentence’.

Interviewer, Pilot workshop

In Poland, people living with HIV continue to experience a range of social issues. For example, people are afraid to tell their family of their HIV status; often people lose their jobs after their HIV status becomes known; and they may be excluded from entry to medical facilities. Some HIV-positive children are still refused entry to schools. People who acquired HIV after 2002 are mostly aged between 20 and 29 years of age, and are often afraid of taking antiretroviral therapy because of concerns that someone could find about their condition. HIV continues to be associated with sex work, homosexuality, and drug use in Poland. ‘Normal’ people think that HIV is not their problem, and have little knowledge about HIV, so they can often be afraid when they learn of someone’s HIV-positive status.

For people living with HIV, the stigma associated with HIV and the resulting discrimination can be as devastating as HIV itself. Acts of discrimination can include abandonment by a

³ UNAIDS: Meeting on development of index on human rights, stigma and discrimination by and for people living with HIV; Report of the Meeting. 22-23 August 2005. Geneva, Switzerland.

⁴ Ankiersztejn-Bartczak M.: Jakość życia osób żyjących z HIV/AIDS – cz. II. W: Remedium nr 4 (182), kwiecień 2008, s. 26-27.

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spouse and/or family, social ostracism, job and property loss, exclusion from school, denial of medical services, lack of care and support, and violence. These consequences or fear of them mean that people are less likely to undergo HIV testing, disclose their HIV status to others, adopt HIV preventive behaviour(s), and access treatment, care and support.

In Poland the majority of the budget for HIV (95%) goes for treatment and medical care for people living with HIV. The government neither provides enough funding for prevention and prophylaxis or psycho-social and other support for people living with HIV to cope with the realities of living with HIV; nor does it undertake campaigns to challenge the myths and widely held misconceptions held by the general public about HIV.

Hearing the voices of people living with HIV allows the development of stigma reduction programmes that address their specific concerns. This research project supports the principle of the greater involvement of people living with HIV (GIPA) by supporting people living with HIV to plan and conduct a study with other people living with HIV to document their experiences regarding stigma and discrimination. The results from the study will provide a powerful advocacy tool regarding stigma and discrimination experienced by people living with HIV.

In 2010, the respondent was on the ward of the Medical University Hospital, Warsaw. The doctor was aware of the respondent's HIV status from a referral from the infectious diseases hospital. On the respondent's door, a sign was affixed that the room was an isolation area. Nurses were afraid to draw his blood for testing. On a number of occasions, the patient performed this procedure himself. Despite medical indications for a kidney transplant, the doctors did not undertake the procedure. Officially nobody is willing to state the reason for this; however, the respondent was told that no such transplants would be performed on HIV-positive people.

The story of a 50+ year old man in Poland who has been living with HIV for longer than 15

Epidemiology and Treatment Access

Due to a lack of reliable epidemiological data it has been difficult to accurately define the modes of HIV transmission in Poland, however since Poland's accession into the European Union (1st May 2004) this situation has improved slowly with more rigorous systems being in place.

The first reported case of HIV infection in Poland was in 1985, with the first AIDS diagnosis occurring in 1986. In the first years of the epidemic, the main modes of HIV transmission were injecting drug use and sexual contacts between men. From 1985 until the end of January 2011, 14 234 new HIV infections were recorded. However, the estimated number of



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HIV infections (2010) is 20 000 to 35 000. Accumulated data show that 40% of all infections were related to injecting drug use (5 713). In addition, it is known 768 have acquired HIV through heterosexual contact, and 932 through male to-male sex, though as previously stated precise figures are not yet readily available. Up to 2010, there have been 2 446 reported AIDS cases, with 1 056 HIV-related deaths recorded⁵.

The better surveillance data that has been available since 2010 and increased rates of testing show a significant change in the routes of transmission. While the number of HIV infections due to injecting drug use has declined since 2000, there has been an increase in sexual transmission. Another apparent change in the epidemic is that many people are becoming infected through unprotected sex, often accompanied by drug use. Data collected by HIV diagnostic services show that there has been a considerable increase in the number of HIV infections among men having sex with men. Reports say that the use of condoms among this population has decreased⁶.

Until 2005, the majority of HIV tests (over 80%) were undertaken among blood donors; though the majority of HIV-positive test results (over 70%) were obtained from persons testing in HIV diagnostic services.

In 2010 twenty percent of all HIV infections were detected in centres offering anonymous free of charge testing and pre- and post test counselling. According to data obtained from the Military Service Headquarters of the Ministry of Justice, some 20% of HIV infections are detected in penitentiaries⁷.

A pregnant woman had trouble making an appointment with a gynaecologist, who kept trying to postpone the appointment.

During a visit the gynaecologist told her that “I have no duty to treat an HIV infected person”. She received only 3 visits during her entire pregnancy. For the woman it has been a traumatic experience. She sees her pregnancy as a time when she had to fight for regular visits at her gynaecologist’s office.

30-39 year old woman living with HIV for 1-4 years

As of 15 July, 2011, some 5,287 people were receiving antiretroviral therapy, including 134 children. Antiretroviral therapy has been available free of charge in all regions since 2001, within the framework of the “Antiretroviral treatment of people living with HIV in Poland” programme of the Ministry of Health⁸.

⁵ http://www.aids.gov.pl/files/inter_docs/eng_version_KP.pdf

⁶ www.pzh.gov.pl

⁷ Ministry of Health National AIDS Centre, Schedule for Implementation of the National Programme for

⁸ combating AIDS and Preventing HIV Infections for the years 2007-2011, www.aids.gov.pl

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The principle of human and civil rights inviolability results from the natural and inalienable dignity of the individual. The protection of these rights falls under the auspices of public authorities. Article 32, Clause 2 of the Fundamental Law (Poland) states: “No one shall be discriminated against in political, social or economic life for any reason whatsoever.”⁹ Some Polish legislation and policy have been established that are oriented towards solutions preventing discrimination against people living with HIV.

The present law prohibits HIV testing without a person’s consent except for blood donations and organ transplants, as well as for criminal proceedings and court warrants. In addition, HIV-related data protection laws require doctors and other hospital staff to maintain confidentiality¹⁰.

The People Living with HIV Stigma Index implementation in Poland

The PLHIV Stigma Index project was approved by the SIEĆ PLUS Polish Network of People Living with HIV/AIDS for implementation in Poland. Mr Wojciech J. Tomczyński, President of the Network, attended the training course in Istanbul, Turkey, at which an initial project proposal was developed. In 2009, a Round Table meeting of non-governmental organisations (NGOs) working on behalf of HIV-positive people in Poland, the attending organisations agreed to take part in this project. In 2010, the project was approved for financing and implementation in Poland by HIV in Europe. The PLHIV Stigma Index User Guide and Questionnaire were translated into Polish, and subsequently adapted to local conditions by people with experience of working on HIV-related issues in Poland including people living with HIV. This process allowed for the adaptation of international standards to the situation prevailing in the country.

Furthermore, the National AIDS Centre of the Ministry of Health and the Polish AIDS Research Society provided patronage to this project. Support was also extended by the Family Development Society and the Global Drug Policy Program, Open Society Institute.

The project was jointly implemented by NGOs working on behalf of people living with HIV, including:

- Bądź z nami Association, Warszawa
- CRS Monar, Warszawa
- DADU Association, Szczecin
- Jump 93 Association, Warszawa
- Mały Książę Association, Warszawa
- MSP Słyszę serce Association, Łódź

⁹ <http://www.sejm.gov.pl/prawo/konst/angielski/kon1.htm>
¹⁰ www.aids.gov.pl

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- Plus/minus Association, Wrocław
- Pozytywni w Tęczy Association, Warszawa
- Razem Association, Toruń
- Res Humanae Foundation, Warszawa
- SIEĆ PLUS Association, Warszawa
- Society Education Foundation, Warszawa
- Solidarni Plus Eko School of Living, Wandzin

The objectives of the PLHIV Stigma Index implementation process in Poland were to:

- document the various experiences of PLHIV within their communities regarding HIV-related stigma and discrimination;
- measure changes over a period of time in relation to changing attitudes; and
- provide an evidence base on HIV-related stigma for policy change and programmatic interventions.



3. Methodology

The PLHIV Stigma Index is designed to increase understanding of how people living with HIV experience stigma and discrimination. This understanding can in turn be used by the national implementing partners to shape future programmatic interventions and advocacy for policy change.

This study aimed to analyse the problem of stigma and discrimination among members of associations of people living with HIV. The study used the Stigma Index Survey Questionnaire to conduct interviews, following the standard methodology and guidance for implementation as laid out in the PLHIV Stigma Index User guide (www.stigmaindex.org) adapted for local circumstances in consultation with GNP+ and the local implementing partnership. The important principle that underpinned the implementation of the project in Poland was that 'People living with HIV are at the centre of the process participating as interviewers and interviewees, as well as being the driving force on how information is collected, analysed and used'.

Data were collected by 25 interviewers in seven of the 11 cities in which clinics for people living with HIV are located (Bydgoszcz/Toruń, Chorzów, Gdańsk, Łódź, Szczecin Warsaw and Wrocław) between August and October 2010. From 800 questionnaires distributed, 504 questionnaires were returned. After cleaning of the data two of the questionnaires were regarded as not having satisfied the quality standards we put in place. Consequently this analysis and report is based on 502 interviews from 502 respondents. The preliminary results were presented during the XVII National HIV/AIDS Conference on "People Living with HIV in the Family and Society" in Warsaw, 1 December 2010.

Key Steps In the Implementation of the PLHIV Stigma Index in Poland

1. Introduction of the People Living with HIV Stigma Index research study to key stakeholders and partners (the people living with HIV networks and organizations) at the local, regional and national level.
2. Deciding on the sampling frame and sample size.
3. Submit the study design for ethical review.
4. Involving a researcher and research institution that had undertaken similar research.
5. Recruiting a team leader, interviewers who are people living with HIV, and data capturers and analysts.
6. Defining the roles and responsibilities of the team members in the research process.

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7. Developing systems to manage the financial and administrative aspects of the research process.
8. Identify national laws, policies and/or guidelines or regulations which protect the rights of people living with HIV.
9. Developing a list of local organizations that interviewees would be referred to should they require further support.
10. Translating the PLHIV Stigma Index User Guide and Questionnaire into Polish, and adapting it to the local context.
11. Training a group of interviewers (people living with HIV) to conduct the interviews.
12. Conducting the interviews.
13. Setting up and conducting case study interviews with those chosen interviewees.
14. Entering the data from the questionnaires into Epi-Info.
15. Analysing the responses. During this stage researchers identified recurring themes across the study sample and tried to understand, interpret and analyse the data.
16. Developing a report that documented the key results and findings.
17. Analysing the results and writing up case studies.
18. Presenting the results to the research team, members of the local networks of people living with HIV and advisory groups members for their comment and feedback during the XVII National HIV/AIDS Conference on "People Living with HIV in the Family and Society" in Warsaw, 1 December 2010.
19. Presentation of key results at AIDS2011 (Tallinn, May 2011) and first results and presentation of research.
20. Refinement of report incorporating feedback in preparation for publication and dissemination.

Study population

The target population for the study included all people in Poland known to be living with HIV. The sample size (N=502) represents approximately 3.5% of the study population (N=14,234). Since random sampling of people living with HIV in Poland was not possible, SIEĆ PLUS joined efforts with multiple non-governmental organisations in Poland to identify as representative a sample as possible. The research team made efforts to ensure that those interviewed reflected the demographics of those living with HIV in the country with respect to gender, age and what is known about route of transmission; special efforts were made to ensure that people who use drugs, sex workers and people from minority ethnic groups were adequately represented in the sample.

Approximately 70 percent of respondents (N=338) came from one of the key populations affected by HIV, primarily people who use, or have used, drugs; men who have sex with men or gays or lesbian; or prisoners or former prisoners.

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Sampling

The sample size was also determined by the maximum number of HIV-positive people that interviewers could reach at the time the study was conducted given the available resources. Interviewers contacted peer support groups, HIV testing sites, hospitals and AIDS service organizations in order to access the experiences of as many HIV-positive people as possible.

The implementation team appreciated that the study is skewed toward those who are on ART - proportionately double the number who are known to be on ART in Poland.

In total, 800 questionnaires were distributed with 504 questionnaires returned and analysed. Interviewees came from all regions of Poland. Two of the 504 questionnaires included many questions left unanswered and were, therefore, removed from the analysis for this report. The results reported here are based on 502 responses.

It is acknowledged that any sample, especially one in which interviewees self-select, has its limitations. In particular, there is no way to know whether those people living with HIV in Poland who were accessible to the research team because of their involvement with support groups, non-governmental organisations, or medical centres might have experienced more or less stigma and discrimination than those without such involvement. We have not, in this report, analysed the responses of those on ART as opposed to those who are not. However, we do suspect that as the recruitment methods we used to gather interviewees were through clinic and support groups (and consequently possible more 'engaged' with treatment and community responses) that there may be significant differences in the way that these groups experience and feel able to counter stigma.

As such, it is not claimed that the sample is representative of all Polish people living with HIV. However, the broad range of people interviewed means that this sample does provide results that are indicative of the diversity of experiences of those people known to be living with HIV.

Data Collection Instruments

The study used the PLHIV Stigma Index which was developed by GNP+, ICW, IPPF and UNAIDS. The PLHIV Stigma Index is designed so that case studies can be identified for follow up using qualitative methods. As such, the PLHIV Stigma Index employs both quantitative and qualitative research methods. The questionnaire is divided into the following three sections with the possibility for additional country-specific questions, if required:

1. General information about the respondent and her/his household
2. Reported experiences of HIV-related stigma and discrimination by PLHIV over the previous year, namely:

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- a). discrimination and stigmatising behaviour that was directed toward respondents;
 - b). internal stigma (felt or internalised stigma which can lead to low self-esteem and depression);
 - c). the protection of the rights of PLHIV through law, policy and/or practice;
 - d). effecting change at household and community level in responding to stigma and discrimination; and
3. Indicators focusing on stigma and discrimination over the last year related to HIV testing, disclosure and the provision of health care.

Administration of Data Collection Instruments

The fieldwork was conducted between August and October 2010 by a team of 25 data collectors and two supervisors/team leaders. Representatives of SIEĆ PLUS were responsible for data collection from their respective catchment areas, supervised by senior researchers from the Foundation of Social Education. Representatives were chosen because of their experience in dealing with community-based HIV issues in order to cover the entire country. Questionnaires were completed by interviewees with the interviewer in attendance.

Training

A three-day training course attended by 28 participants took place near Warsaw on the Zegrzyńskie Lake, 30 July-1 August 2010. The course sought to introduce participants to the PLHIV Stigma Index and its international reputation, as well as to prepare them for its local implementation. Each participating organisation selected at least two people to be trained as researchers. Each attendee received a set of educational materials to assist interviewees in completing questionnaires, and to provide additional knowledge for interviewers and interviewees¹¹.



¹¹ A carrier bag with the PLHIV Stigma Index User Guide and 30 copies of the Questionnaires, attachments, a briefcase containing a notebook, ballpoint pen and training program, the Lisbon Declaration, the Schedule for Implementation of the National Program for Combating AIDS and Preventing HIV Infections for the years 2007-2011, the International HIV/AIDS and Human Rights Guidelines for access to prevention, treatment, care and support and a flyer with contact data of leading organizations for HIV-positive people. Each of the participants also received 30 ballpoint pens for interviewees and T-shirts for interviewers.

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The training course provided an opportunity for participants to become acquainted with the PLHIV Stigma Index and its processes. The interviewers, all people living with HIV, were also trained in interviewing, facilitating participatory group discussions and recording case studies. The workshop was conducted by a psychologist who provided the space for participants to discuss challenging situations that might arise during interviews such as people refusing to participate in the survey, aggressive interviewees, and people with problems requiring help. Participants also had an opportunity to conduct interviews among themselves and clarify any questions as they arose. Methods of how to encourage people to take part in the survey were practiced.

During the training course a schedule of activities for implementing the project was developed and adopted. In post-training evaluation forms, the participants indicated that they considered the training to be very useful.

Translation

The PLHIV Stigma Index Questionnaire was translated into Polish. The data collection team reviewed the questionnaire during the training to ensure that the translation was accurate.

Data Analysis Plan

Supervisors undertook post-questionnaire quality checks while in the field and the questionnaires were sent to a central data management centre at SIEĆ PLUS's offices. A dedicated data processing team consisting of two people entered and processed data using Epi Info™.

The analysis helped to:

- extract experiences from the entire data set;
- make comparisons across groups with regards to issues addressed by the three sections of the PLHIV Stigma Index Questionnaire;
- identify individual characteristics in relation to the reported experience of people living with HIV of HIV-related stigma and discrimination over the past year; and
- identify people's use of HIV testing, ART and other health services.

Limitations

There are a number of study limitations arising from the design, administration and analysis of the study.

The study design means that a number of groups of people living with HIV were unable to be interviewed, these include:

- people living with HIV who do not know their status;

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- people living with HIV, who, even if they do know their diagnosis, may not be openly living with HIV and remain inaccessible.
- people living with HIV who do not access health care and do not attend a PLHIV organisation.
- people living with HIV who did not want to take part in this research for personal or other reasons.

Further limitations of the sampling process include the following:

- Participants were invited to a central place for interviews and in most cases on a working day. As a result, this sample may be biased as respondents who are unemployed and those able to take time off from work may be overly represented.
- The use of medical facilities as one location for recruitment, leading to an overrepresentation in the sample of people accessing ART compared to all people living with HIV in Poland (78% compared to 40%)¹². The great difference between study respondents and all Polish people living with HIV in this regard may indicate other differences between the sample and the study population of which the research team is not aware.

Questionnaire

A number of issues with the questionnaire were identified, including:

- *Duration living with HIV*: the starting point for the duration for many people will be the time that they first tested HIV-positive, not when the person was first infected.
- *Household income*: many interviewees were unwilling to provide an answer to this question.
- *Modification of questions to reflect the Polish situation*. The study team modified one question of the standard survey instrument.¹³

Data Collection Issues

The original intention was that all of the interviews would be completed by interviewers sitting side-by-side with interviewees. However, following on from the training workshop, it was agreed that if respondents wanted to fill in the questionnaire themselves with the interviewer there in the room just to answer any questions that arose, this would be acceptable. On reflection the survey team did feel that if the survey was conducted again

¹² See Section 3.9.2 and www.aids.gov.pl.

¹³ One of the standard PLHIV Stigma Index questions ask respondents to identify as male, female, transgender. The term transgender as applied to the Polish situation was felt to be confusing to the research team.; The right to change ones gender has been recognised since 1964 (under Article 189 of Polish Civil Procedure Code) and in 1983 the Supreme Court ruled that in some cases, when the attributes of newly-formed sex are predominant it is possible to change one's gender even before genital reassignment surgery. Consequently the question was not asked.

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that side-by-side interviewing would be the only method used. The team realised that more time had to be spent on the quality control procedures (checking questions had been answered fully, and questions had been appropriately skipped dependent upon previous answers etc) at the end of the interview for those who had 'self-administered' the questions, so no time was saved. Additionally the end of interview conversation with those who had 'self-administered' the questionnaire was not as rich or as productive (fewer requests for follow-up or information about issues that had arisen as a result of answering the questions) as those who had been interviewed side-by-side.

Ethical Issues. Confidentiality

In order to safeguard the confidentiality of participants the names of respondents were not recorded. Instead, a code was used to identify each individual questionnaire, with the master list kept by SIEĆ PLUS. No-one except the research team was permitted to access respondents' information. The completed questionnaires contained no information that would enable anyone to identify the interviewee.

Age of participants

To protect younger people living with HIV, and to avoid the requirement for guardian consent, all interviewees were over 18 years of age.



4. Background characteristics of respondents

Gender

Five-hundred and two people completed the questionnaires. Of these, 61% (N=306) were male, and 39% were female (N=196).

Age

The largest group of respondents (44%, N=220) were aged 30-39 years old. Almost one-third (32%, N=158) were aged 40-49 years old with the third largest category being adults aged over 50 years (12%,N=60). There were only 6 respondents (1%) aged 15-19 years of age. In total 13% of respondents (N=64) were under 30 years of age (**Table 1**).

Table 1. Age of interviewees

	Number	Percent
Youth aged 18-19 years	6	1
Adult aged 20-24 years	16	3
Adult aged 25-29 years	42	8
Adult aged 30-39 years	220	44
Adult aged 40-49 years	158	32
Adult aged 50+ years	60	12
Total	502	100

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Number of years living with HIV

Twenty percent of interviewees (N=99) had been living with HIV for less than 4 years; while over 60% of respondents (N=300) had been living with HIV more than 10 years (**Table 2**).

Table 2. Length of living with HIV

	Number	Percent
0-1 year	29	6
1-4 years	70	14
5-9 years	96	19
10-14 years	154	31
15+ years	146	30
No data	7	1
Total	502	100

Relationship Status and Current Sexual Activity

Fifty-two percent of respondents (N=260) were in a relationship, and a further 13% (N=66) were divorced, separated or widowed. Thirty-four percent (N=168) of respondents were married or cohabiting and living with their partner in the household. Twenty-nine percent (N=146) were single.

Seventy-two percent of respondents (N=358) reported that they were currently sexually active. The majority of women who reported being sexually active were married or cohabitating in the same household as their husband or partner. Most men who reported being sexually active were also married or cohabitating with their wife or partner; however, a much larger percentage of sexually active men than women indicated that they were single. Of women who reported that they were not sexually active, more than a third were single; however, more than a quarter were divorced or separated and almost one-fifth were widows. Of the male respondents who were not sexually active, proportionately fewer reported being widowed or divorced. Almost 70 percent of the non-sexually active men were single (**Table 3**).

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Table 3. Sexual activity by gender and relationship status

	Sexually Active		Not Sexually Active		Total
	Men	Women	Men	Women	
Married or cohabiting and husband/wife/partner is currently living in household	40.2% (N=90)	53.8% (N=71)	1.3% (N=1)	9.8% (N=6)	24% (N=117)
Married or cohabiting but husband/wife/partner is temporarily living/working away from household	3.6% (N=8)	7.6% (N=10)	1.3% (N=1)	3.3% (N=2)	4% (N=21)
In a relationship not living together	16.5% (N=37)	19.7% (N=26)	6.5% (N=5)	4.9% (N=3)	14% (N=71)
Single	26.8% (N=60)	8.3% (N=11)	68.8% (N=53)	36.1% (N=22)	29% (N=146)
Divorced/separated	12.1% (N=27)	6.1% (N=10)	16.9% (N=13)	26.2% (N=16)	13% (N=66)
Widow/Widower	0.8% (N=2)	4.5% (N=6)	5.2% (N=4)	19.7% (N=12)	5% (N=24)
Total	100% (N=224)	100% (N=134)	100% (N=77)	100% (N=61)	100% (N=496)

Key Populations

Forty percent of respondents (N=214) stated that they were currently or previously a person who used drugs, 18% (N=100) were gay or lesbian, and 2% (N=11) were sex workers. Thirty percent of respondents (N=164) did not identify as belonging to any key population at higher risk (Table 4). In addition, eighteen percent of respondents (N=85) reported a physical disability other than HIV.

Table 4. Percentage and number of respondents disaggregated by key population

Category	Number	Percent
Gay or lesbian	N = 100	18 %
Injecting drug user	N = 214	40 %
Internally displaced person	N = 8	2 %
Migrant worker	N = 2	0 %
Prisoner	N = 39	7 %
Refugee or asylum seeker	N = 1	0 %
Sex worker	N = 11	2 %
Transgender	N = 0	0 %
I don't belong to, and have not in the past belonged to, any of these groups	N = 164	30 %

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Education

More than half of respondents (52%, N=263) had completed formal education through secondary school and 19% had completed technical college/university. However, 26% (N=129) had only a primary school education and two percent had no formal education .

Table 5. Respondents' highest level of formal education completed

No formal education	N = 6	1 %
Primary school	N = 129	26 %
Secondary school	N = 263	52 %
Technical college/university	N = 96	19 %
No data	N = 8	2 %

Employment Status

Thirty percent of respondents (N=149) were in full-time employment whether as an employee (25%, N=124) or self-employed (5%, N=25). Almost half (46%, N=233) were unemployed and did not work at all; while 8% (N=43) were in part-time employment.

As most interviews were conducted during regular working hours, people living with HIV in full-time employment may be underrepresented in this sample.

Table 6. Employment status

Doing casual or part-time work (self-employed)	N = 80	16 %
In full-time employment (as an employee)	N = 124	25 %
In part-time employment (as an employee)	N = 43	8 %
Unemployed and not working at all	N = 233	46 %
Working full-time but not as an employee (self-employed)	N = 35	5 %

Household Composition

Thirty-two percent (159) respondents indicated that they had at least one child or youth living in their household. Eighty respondents (16%) reported that they had one child aged 0-14, in their household, 27 (5%) had two children, and nine (2%) had more than two children of this age. Fifty-three people (11%) had one young person aged 15-19 years, eight (2%) had

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two children, and one respondent (0.2%) had eight youths aged 15-19 years. Of these children and youth, some are orphans. Eleven respondents (2% of the sample; 7% of respondents with children or youth) reported having one or two orphans in their households. No respondents indicated that they had more than two orphans.

Table 7. Households with children and youth

		Youth aged 15-19 years				Total
		0	1	2	8	
Children aged 0-14 years	0		36 (7%)	7 (1%)		43 (9%)
	1	63 (13%)	15 (3%)	1 (0.2%)	1 (0.2%)	80 (16%)
	2	25 (5%)	2 (0.4%)			27 (5%)
	3	7 (1%)				7 (1%)
	4	1 (0.2%)				1 (0.2%)
	5	1 (0.2%)				1 (0.2%)
Total		97 (19%)	53 (11%)	8 (2%)	1 (0.2%)	159 (32%)

Geographical Location

Seventy percent (N=351) of interviewees were from large towns, 9% (N=44) from rural areas and 18% (N=92) from a small town or village. Three percent (N= 16) did not provide a response.

Table 8. Respondents' household location

A large town or city	N = 351	70 %
A rural area	N = 44	9 %
A small town or village	N = 92	18 %
No data	N = 15	3 %

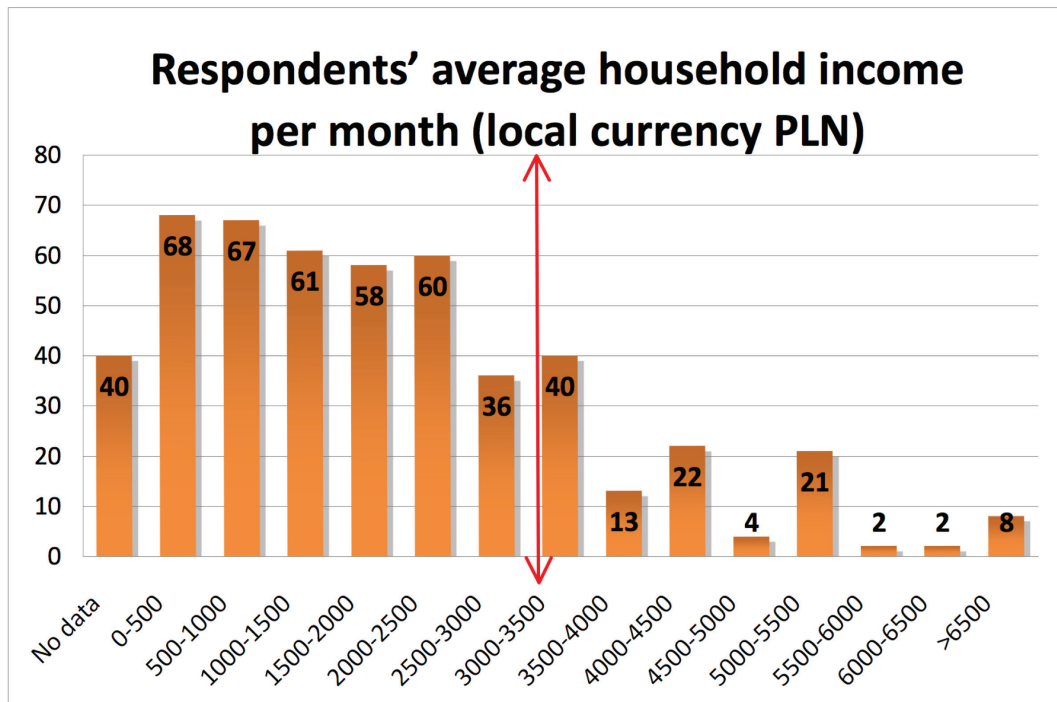
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Income

Seventy percent of respondents (N=350) had a lower than average monthly household income than the national average of 3 033 PLN (red line).

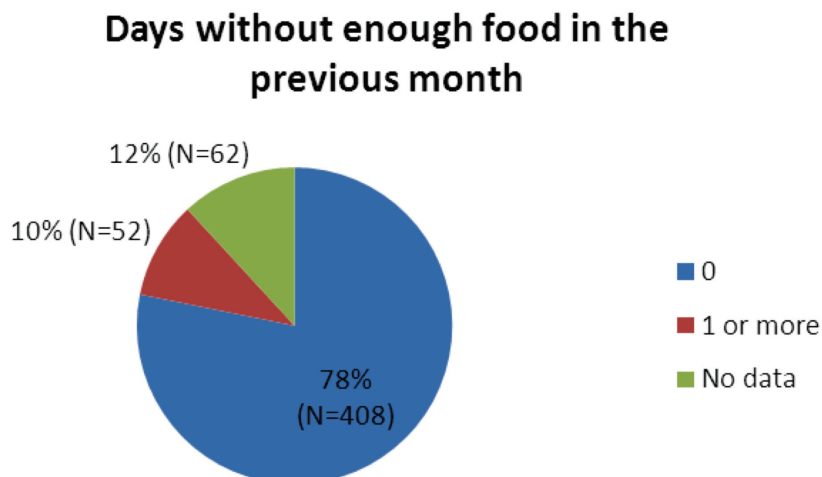
Chart 1. Respondents' average income of household per month



Access to Nutrition

Ten percent (N=52) of respondents reported that, over the previous month, there was one or more days when they did not have enough to eat (Chart 2).

Chart 2. Food insufficiency over the previous month





5. Findings

5.1 Experiences of social stigma and discrimination

Figure 12 outlines respondents' experience of HIV-related stigma and discrimination over the last 12 months. For each question, respondents were asked the extent to which they had experienced each form of stigma or discrimination in the last 12 months and whether the discrimination resulted solely because of their HIV status, because of a combination of their HIV status and some other reason, or for some reason other than HIV status. Respondents also had the option to indicate that they did not know the reason. After each question in **Table 9**, the percent of respondents who had experienced that form of discrimination and who said that the discrimination occurred *solely* because of their HIV status is given. Other reasons for stigma and discrimination are described in section 3.2.2.

Exclusion from social gatherings was reported by 20% of respondents (N=98), of which 30% indicated that they were excluded solely because of their HIV status. Twenty-five respondents (5%) reported exclusion from religious activities, of which 8% indicated the exclusion resulted from their HIV status. Fifty-one people (10%) said that they had been excluded from family activities in the last twelve months; more than half of whom (55%) were excluded solely due to HIV. More than 50% of respondents (N=260) were aware of being gossiped about in the last 12 months; 20% of whom reported that it was due to HIV.

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Table 9. Experiences of discrimination

	Never	Once	A few Times	Often	No data	Total
1. In the last 12 months, how often have you been excluded from social gathering or activities?	80% (N=401)	5% (N=26)	11% (N=54)	4% (N=18)	1% (N=3)	100% (N=502)
Because of HIV (%)	30% (N=29)					
2. In the last 12 months, how often have you been excluded from religious activities or places of worship?	94% (N=471)	3% (N=15)	1% (N=6)	1% (N=4)	1% (N=6)	100% (N=502)
Because of HIV (%)	8% (N=2)					
3. In the last 12 months, how often have you been excluded from family activities?	89% (N=445)	1% (N=6)	6% (N=30)	3% (N=15)	1% (N=6)	100% (N=502)
Because of HIV (%)	55% (N=27)					
4. In the last 12 months, how often have you been aware of being gossiped about?	47% (N=237)	4% (N=21)	29% (N=144)	19% (N=95)	1% (N=5)	100% (N=502)
Because of HIV (%)	20% (N=51)					
5. In the last 12 months, how often have you been verbally insulted, harassed and/or threatened?	69% (N=347)	9% (N=45)	19% (N=95)	3% (N=13)	0% (N=2)	100% (N=502)
Because of HIV (%)	21% (N=32)					
6. In the last 12 months, how often have you been physically harassed and/or threatened?	70% (N=351)	7% (N=37)	16% (N=82)	5% (N=24)	2% (N=8)	100% (N=502)
Because of HIV (%)	13% (N=18)					
7. In the last 12 months, how often have you been physically assaulted?	82% (N=413)	9% (N=45)	7% (N=36)	1% (N=3)	1% (N=5)	100% (N=502)
Because of HIV (%)	11% (N=9)					

Verbal insults, harassment, and threats were reported by 153 respondents (31%) and physical harassment and threats were reported by 143 respondents (28%). The verbal abuse and physical harassment were attributed solely to the respondent's HIV status by 21% and 13% of respondents, respectively. Eighty-four respondents (17%) reported that they had been physically assaulted at least once in the last twelve months, with 11% attributing the assault(s) to their HIV status.

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5.2 Stigma or discrimination because of membership of a key population

Respondents who indicated that they had been discriminated against for a reason other than HIV within the last 12 months were asked whether this discrimination was because of membership in a number of key population groups. Thirty percent of all respondents (N=152) stated that they were discriminated against because of their current or former membership in a key population. Of these, 26% (N=39) attributed the stigma or discrimination they experienced to their sexual orientation and 24% attributed stigma or discrimination to their status as a former or current injecting drug user. Smaller numbers of respondents indicated that they had experienced stigma and discrimination because of their current or former experience as a prisoner, sex worker, internally displaced person, or migrant worker. Forty-five percent of those who indicated that the stigma or discrimination they experienced was not because of HIV status, reported that it was for a reason other than belonging to a key population at higher risk (Table 10).

Table 10. Stigma and/or discrimination related to belonging to a key population at higher risk (N=152)

	Percent of those indicating that they had experienced stigma/discrimination for a reason other than HIV status
Sexual orientation	26% (N=39)
Sex worker	1% (N=2)
Injecting drug user	24% (N=36)
Internally displaced person	1% (N=1)
Migrant worker	1% (N=1)
Prisoner	3% (N=5)
None of the above – it was because of another reason	45% (N=68)

Numbers may equal greater than 100% because of rounding

5.3 Other experiences of HIV-related stigma and discrimination

Table 11 shows that 14% of respondents (N=71) reported that they were subjected to psychological pressure or manipulation by their wife, husband, or partner in which their HIV-positive status was used against them in the last 12 months. Seventy-six respondents (15%) reported sexual rejection as a result of their HIV-positive status in the last 12 months. Sixty-one respondents (12%) indicated that they had been discriminated against by other people

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living with HIV. When asked whether their spouse or partner, or a member of the household had experienced discrimination because of the respondent's HIV status, 71 respondents (14%) indicated that this had happened at least once in the last twelve months.

Table 11. Other experiences of stigma and discrimination

	Never	Once	A few times	Often	No data	Total
1. How often have you been subjected to psychological pressure or manipulation by your husband/wife or partner where you felt your HIV-positive status was used against you?	83% (N=419)	2% (N=11)	6% (N=29)	1% (N=6)	7% (N=37)	100% (N=502)
2. In the last 12 months, how often have you experienced sexual rejection as a result of your HIV positive status?	82% (N=410)	6% (N=28)	7% (N=36)	2% (N=12)	3% (N=16)	100% (N=502)
3. In the last 12 months, how often have you been discriminated against by other people living with HIV?	85% (N=429)	5% (N=26)	6% (N=28)	1% (N=7)	2% (N=12)	100% (N=502)
4. In the last 12 months, how often has your wife/husband/or partner, or any members of your household experienced discrimination as a result of your HIV-positive status?	76% (N=384)	5% (N=27)	8% (N=41)	1% (N=3)	9% (N=47)	100% (N=502)

5.4 Reasons for HIV-related stigma or discrimination

When asked their opinion about why people stigmatise and discriminate against people with HIV, the responses were fairly evenly divided. Twenty percent of respondents (N= 103) felt that the reason stigma and discrimination against people living with HIV was that people were afraid of getting infected and 25% (129) expressed the belief that people do not understand how HIV is transmitted and are afraid people with HIV will infect them through casual contact. Another 84 people (17%) responded that people feel HIV is shameful and that they shouldn't associate with someone living with HIV and 72 people (14%) indicated

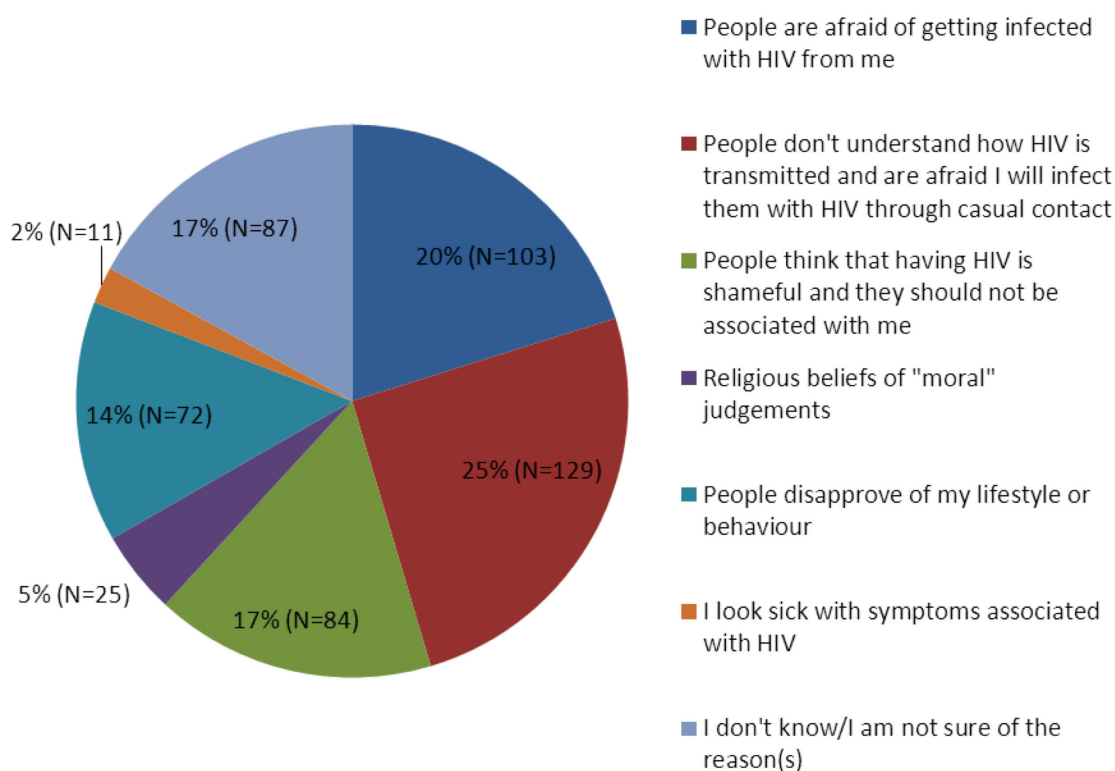
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that stigma and discrimination resulted from disapproval of their lifestyle or behaviour. Eighty-seven people (17%) responded that they did not know why people discriminated against HIV-positive people (Chart 3).

Chart 3. Reasons for experiencing HIV-related stigma and/or discrimination during the previous 12 months

Reasons for HIV-related stigma and/or discrimination





5.5 Housing, Employment and Health Care

Access to Housing

Of the respondents, 67 (13%) reported that they had been forced to move their residence or been unable to rent accommodations in the last twelve months. Of these, fourteen percent indicated that their housing difficulties were the results of their HIV status.

Table 12. Access to housing

	Never	Once	A few Times	Often	No data	Total
In the last 12 months, how often have you been forced to change your place or residence or been unable to rent accommodation?	85% (N=424)	9% (N=47)	2% (N=12)	2% (N=8)	2% (N=11)	100% (N=502)
Because of HIV (in whole or in part) (%)		14% (N=9)				

Employment, Education and Health Care

Sixty-five respondents (13%) stated that they had lost their job or a source of income in the last twelve months, with 11% of these indicating that this was because of their HIV-positive status. Thirty-eight respondents (8%) indicated that the nature of their work had changed or they had been refused a promotion because of their HIV status (**Table 13**). These results indicate that employment discrimination against people with HIV can have significant negative effects on their livelihood. This discrimination could play a role in exacerbating the high unemployment (46%) and low income reported by respondents. (**Table 13**)

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Table 13. Employment, Education and Health Care

	Never	Once	A few times	Often	N/A	No data	Total
In 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)?	85% (N=424)	10% (N=50)	3% (N=13)	0% (N=2)		3% (N=13)	100% (N=502)
Because of HIV (%)		11% (N=7)					
In the last 12 months, how often has your description or the nature of your work changed, or have you been refused promotion, as a result of your HIV status?	66% (N=331)	5% (N=25)	3% (N=13)	0% (N=0)	0% (N=0)	26% (N=133)	100% (N=502)

In addition to the reports of job and income loss in the last twelve months, eleven percent of respondents (N=49) reported that they had been refused employment or a work opportunity because of their HIV status in the last 12 months (**Table 14**).

In the previous 12 months, have you been refused employment or a work opportunity because of your HIV status?

Table 14. Refused employment or a work opportunity because of HIV-positive status

	Frequency	Percent
No	389	89
Yes	49	11
Total	438	100

Thirteen respondents (3%) indicated that they had suffered discrimination by educational institutions and seven (1%) said that their child or children had faced discrimination from an educational institution because of the respondent's HIV status.

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Table 15. Discrimination in education services

	Never	Once	A few times	Often	Not applicable	No data	Total
In last 12 months, how often have you been dismissed, suspended or prevented from attending an educational institution because of your HIV status?	70% (N=349)	1% (N=5)	1% (N=6)	0% (N=2)	19% (N=97)	1% (N=3)	100% (N=502)
In last 12 months, how often has your child/ children been dismissed, suspended or prevented from attending an educational institution because of your HIV status?	54% (N=271)	1% (N=4)	0% (N=2)	0% (N=1)	34% (N=171)	11% (N=53)	100% (N=502)

Almost 20% (N=98) of respondents reported that they had been denied health services, including dental care, because of their HIV status at least once in the last 12 months.

Table 16. Discrimination in health services

	Never	Once	A few times	Often	Not applicable	No data	Total
In the last 12 months, how often have you been denied health services, including dental care, because of your HIV status?	70% (N=353)	11% (N=56)	8% (N=38)	1% (N=4)	9% (N=44)	1% (N=7)	100% (N=502)

Officially, the Polish health system does not provide family planning services except in very restricted areas¹⁴. As a result the expectation of being able to access such services, and what they might involve, is already very low; 3% (N=13) stated that they had been denied family planning services because of their HIV-positive status, and 3% (N=17) reported being denied access to sexual and reproductive health services (**Table 17**).

The female respondent was a patient of the infectious diseases hospital and was referred to a surgical hospital. At the time, the respondent was in the corridor with a nurse when a young doctor started to shout why the infectious diseases hospital is

¹⁴ <http://www.amnestyusa.org/research/reports/annual-report-poland-2010>

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sending them such trash, that they always refer HIV-positive people and that he will not see her. The respondent started to cry and said that homeless people are brought into hospital, drunks from the street. The doctor said that he does not care. The respondent said that this was a discrimination. The doctor said that this is all because of administrative regulations and the infectious diseases hospital keeps sending them HIV patients and he will not see her.

30-39 years woman, living with HIV 1-4 year

In 2010 this woman tried on 4 occasions to arrange a visit with a gynaecologist. Every time doctor informed her that he does not have appropriate equipment (disposable plastic microscope) and due to that he refused to perform any examination of the patient.

30-39 years women, living with HIV 5-9 years

Table 17. Denied family planning and sexual and reproductive health services because of your HIV status

	Yes	No	Not applicable	No data	Total
In the last 12 months, were you denied family planning services because of your HIV status?	3% (N=13)	36% (N=179)	57% (N=288)	4% (N=22)	100% (N=502)
In the last 12 months, were you denied sexual and reproductive health services because of your HIV status?	3% (N=17)	87% (N=438)	--	9% (N=47)	100% (N=502)

5.6 Internal stigma and fears

Internalised stigma

When respondents were asked about the feelings that they have had because of their HIV status, more than 50% of respondents (N=267) had blamed themselves because of their HIV status in the last 12 months. The response given by the second highest number of respondents (42%, N=209) was that they felt ashamed, of respondents also indicated they experienced low self-esteem (38%, N=191), guilt (38%, N=188), and blaming others (20%, N=102). Ninety respondents (18%) indicated that they had felt suicidal because of their HIV status and 48 (10%) indicated that they had felt they should be punished (**Table 18**).



Table 18. Experienced feelings of internalised stigma because of HIV status

	Yes	No	No data	Total
I feel ashamed	42% N=209	51% N=254	7% N=39	100% (N=502)
I feel guilty	37% N=188	52% N=261	11% N=53	100% (N=502)
I blame myself	53% N=267	38% N=193	8% N=42	100% (N=502)
I blame others	20% N=102	67% N=338	13% N=62	100% (N=502)
I have low self-esteem	38% N=191	52% N=265	10% N=46	100% (N=502)
I feel I should be punished	10% N=48	78% N=394	12% N=60	100% (N=502)
I feel suicidal	18% N=90	73% N=365	9% N=47	100% (N=502)

Activities avoided because of HIV-positive status

As an additional measure of internal stigma and the fear of stigma and discrimination experienced by people living with HIV, respondents were asked whether they avoided any of a series of life activities in the last 12 months because of their HIV status. **Table 19** provides the results. Approximately one in four respondents reported that they chose not to attend social gatherings (25%, N=123) and isolated themselves from family or friends (25%, N=127). Six percent of respondents indicated that they stopped working (N=30) and 11% and 12%, respectively, indicated that they decided not to apply for a job or promotion (N= 62) or withdrew from education or training (N=57). Almost one in five respondents decided not to get married because of their HIV status (18%, N=90) and 15% decided not to have sex (N=75). Forty-three percent of respondents (N=217) decided not to have (more) children because of their HIV status, despite the fact that in Poland there is access to treatment and a specific protocol to prevent mother-to-child transmission.

Furthermore, 23% of respondents (N=116) indicated that they avoided going to a local clinic and 16% (N=79) avoided going to hospital when they needed to, in the last 12 months, because of their HIV status.

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Table 19. Actions avoided because of HIV-positive status in the previous 12 months

	Yes	No	No data	Total
I have chosen not to attend social gathering(s)	24% N=123	67% N=338	9% N=41	100% (N=502)
I have isolated myself from my family and/or friends	25% N=126	66% N=332	9% N=44	100% (N=502)
I took the decision to stop working	6% N=30	80% N=405	14% N=67	100% (N=502)
I decided not to apply for a job/work or for a promotion	12% N=62	76% N=380	12% N=60	100% (N=502)
I withdrew from education/training or did not take up an opportunity for education/training	11% N=57	76% N=381	13% N=64	100% (N=502)
I decided not to get married	18% N=90	70% N=355	12% N=57	100% (N=502)
I decided not to have sex	15% N=75	74% N=371	11% N=56	100% (N=502)
I decided not to have (more) children	43% N=217	47% N=237	10% N=48	100% (N=502)
I avoided going to a local clinic when I needed to	23% N=116	67% N=338	10% N=48	100% (N=502)
I avoided going to a hospital when I needed to	16% N=79	74% N=372	10% N=51	100% (N=502)

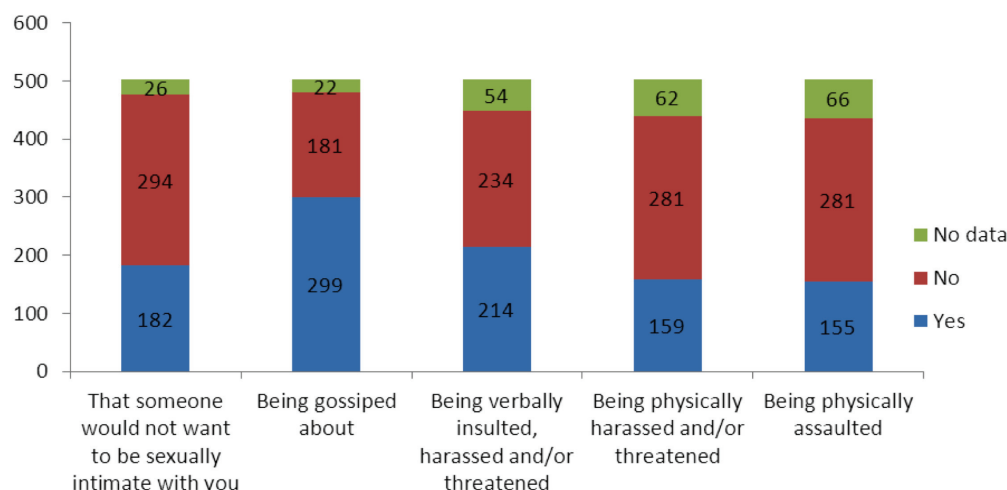
Fears of rejection and discrimination because of HIV-positive status

Respondents were asked about their fears about how others would treat them because of their HIV status, whether or not this mistreatment had happened (**Chart 4**). Sixty percent (N=299) of respondents indicated that they fear being gossiped about. Respondents indicated that they feared verbal harassment (43%, N= 214), physical harassment (32%, N=159), and physical assault (31%, N=155). Thirty-six percent (N=182) of respondents were afraid that someone would not want to be sexually intimate with them because of their HIV status.

Poland



Chart 4. 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?



5.7 Laws, Policies and Rights, Effecting change

Human Rights Violations Experienced

Table 20 shows that 15% of respondents (N=74) stated that they had encountered one or more discriminatory situations in the last 12 months. For each individual human rights violation, the number of respondents who indicated that they had experienced this violation was low. However, 5% of respondents (N=25) reported being forced to submit to a medical or health procedure (including HIV testing) and 3% (N=18) reported that they had been denied health or life insurance because of their HIV status.

Table 20. Human Rights violation

I was forced to submit to a medical or health procedure (including HIV testing)	N = 25	5 %
I was denied health insurance or life insurance because of my HIV status	N = 18	3 %
I was arrested or taken to court on a charge related to my HIV status	N = 4	1 %
I had to disclose my HIV status in order to enter another country	N= 8	2 %
I had to disclose my HIV status to imply for residence or nationality	N = 1	0 %
I was detained, quarantined, isolated or segregated	N = 1	0 %
Non of these things happend to me	N = 428	85 %
No date	N = 10	2 %

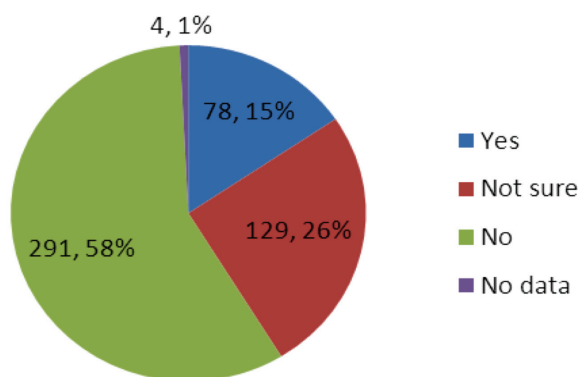
Chart 5 shows 58% of respondents (N=291) reported that none of their rights as a person living with HIV were abused in the last 12 months; however, 26% (N=129) of respondents were unsure and 16% (N=78) stated that their rights had been abused.



Stigma Index

Chart 5. In the last 12 months, have any of your rights as a person living with HIV been abused?

In the last 12 months, have any of your rights as a person living with HIV been abused ?

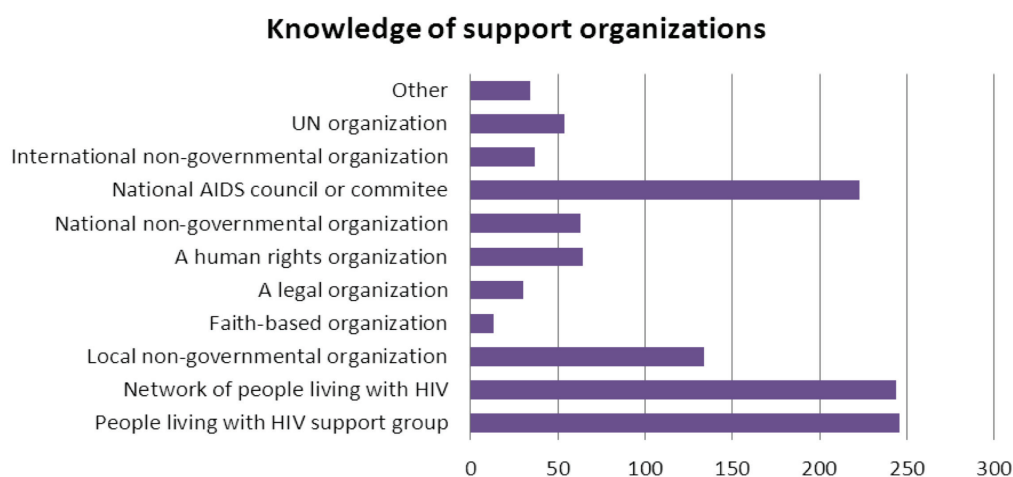


5.8 Effecting change

Seeking and Offering Support

Sixty-nine percent of respondents (N=336) knew of organisations or groups that they could go to for help if they experienced stigma or discrimination. **Chart 6** shows the types of organizations that respondents identified as places they could seek support. The most popular type of organization was a support group for people living with HIV (N=246) followed by a network of people living with HIV (N=244). It should be noted that often the support group and the network is one and the same organization. Large numbers of people also knew of the National AIDS Centre Agenda of the Ministry of Health (N=223) and many people (N=134) knew of local non-governmental organizations (NGOs) providing support services.

Chart 6. Knowledge of support organizations



Poland



Even though respondents knew of support organizations, only 17% (N=84) of respondents had sought help from one for issues relating to stigma and discrimination.

5.9 Responding to Stigma and Discrimination

Twenty-nine percent of respondents (N=142) reported that they had confronted, challenged or educated someone who stigmatised and/or discriminated against them in the previous 12 months.

Sixty-three percent of respondents (N=315) reported that they supported other people living with HIV. Of all the respondents in the sample, 58% (N=291) indicated that they had provided emotional support for other people with HIV in the last 12 months; 19% (N=93) gave physical support such as providing money or food or running errands; and 21% (N=104) provided a referral to other services (**Table 21**).

Table 21. Responding to Stigma and Discrimination

	Yes	No	No data	Total
In the last 12 months, have you confronted, challenged or educated someone who was stigmatizing and/or discriminating against you?	28% (N=142)	69% (N=345)	3% (N=15)	100% (N=502)
In the last 12 months, have you supported someone else living with HIV?	63% (N=315)	35% (N=173)	3% (N=14)	100% (N=502)
If yes, did you provide emotional support?	92% (N=291)	8% (N=24)		100% (N=315)
If yes, did you provide physical support?	30% (N=93)	71% (N=222)		100% (N=315)
If yes, did you provide a referral to other services?	33% (N=104)	67% (N=211)		100% (N=315)

Totals may equal more than 100% because of rounding.

Respondents were asked about their involvement in organisations and activities related to HIV. Twenty-seven percent (N=138) of respondents said that they were currently a member of a support group for people living with HIV. Eighteen percent of respondents reported that they had been involved, in the last 12 months, either as a volunteer or employee, in a government or NGO that provides assistance to PLHIV. Eight percent (N= 42) had been involved in efforts to develop legislation, policies or guidelines related to HIV over the previous 12 months (**Table 22**).

Stigma Index



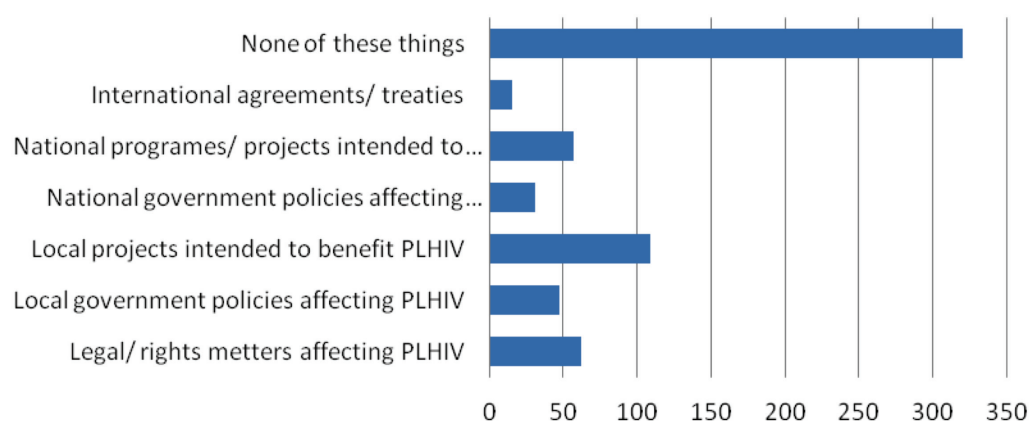
Table 22. Involvement in HIV organizations and policy activity

	Yes	No	No data	Total
1. Are you currently a member of a people living with HIV support group and/or network?	27% N=138	71% N=354	2% N=10	502
2. In the last 12 months have you been involved, either as a volunteer or as employee, in any programme or project (either government or non-governmental) that provides assistance to people living with HIV?	18% N=90	79% N=396	3% N=16	502
3. In the last 12 months have you been involved in any efforts to develop legislation, policies or guidelines related to HIV?	8% N=42	90% N=448	2% n=12	502

The majority of respondents (64%, N=320) felt that they were unable to influence decisions that affect people living with HIV at local, national, or international levels. Approximately one in five respondents (22%, N=109) felt that they had the power to influence decisions in local projects intended to benefit PLHIV. Even fewer respondents (from 3% (N=15) to 12% (N=62)) felt they had the ability to influence international agreements, national policies, national programmes, local government policies, or legal and rights matters affecting people living with HIV (**Chart 7**).

Chart 7. Respondents' feeling of power to influence decisions at the international, national and/or local levels.

Respondents' feeling of power to influence decisions at the international, national and/or local levels.





5.10 Priorities for Addressing Stigma and Discrimination

Respondents selected, from a list of options, the choice that they felt best represented the most important thing that should be done by organisations to address stigma and discrimination for people living with HIV. The results, ranked in descending order by the number of respondents who selected them, were as follows:

- Raise awareness and knowledge of the public about HIV (33%, N=167);
- Provide emotional, physical and referral support to people living with HIV (26%, N=129);
- More advocacy for the rights of all people living with HIV (21%, N=107)
- Advocating for the rights and/or providing support to particularly marginalized groups (men who have sex with men, injecting drug users, sex workers) (10%, N=50)
- Educating people living with HIV about living with HIV (including treatment literacy) (6%, N=28)

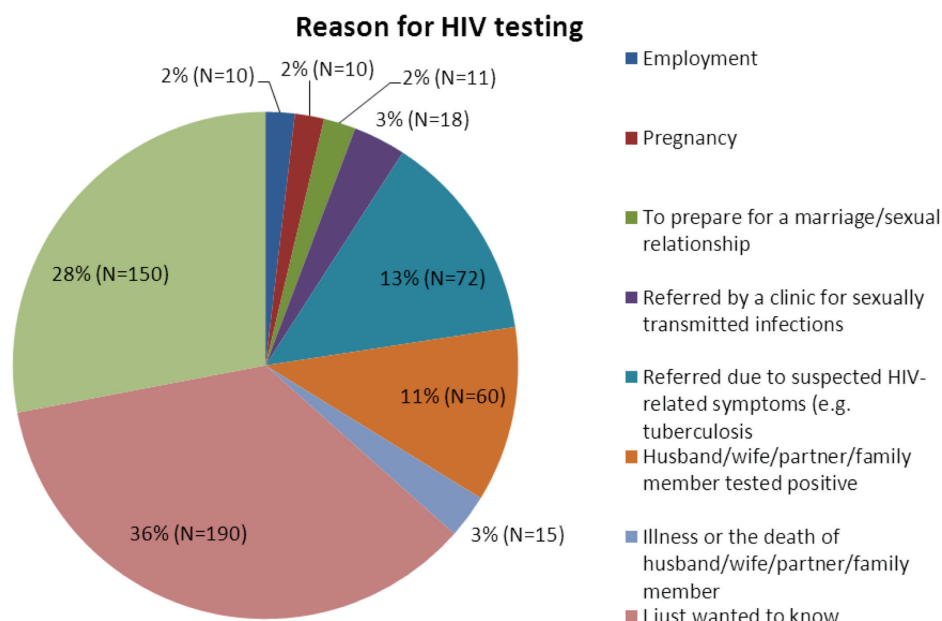
5.11 HIV testing

The principal reported reason why respondents undertook an HIV test was a feeling that they just wanted to know (36%, N=190). Twenty seven percent reported HIV-related reasons, of these, 13% tested because they exhibited suspected HIV-related symptoms, such as tuberculosis (N=72), 11% indicated that a partner or family member tested HIV-positive (N=60) and 3% said they tested because of the illness or death of a partner or family member due to HIV (N=15). Smaller percentages reported testing because of pregnancy, for employment purposes, to prepare for marriage or a sexual relationship, or because they were referred by a clinic for sexually transmitted infections. A total of 28% of participants (N=150) noted other reasons than those listed as possible responses (**Chart 8**).

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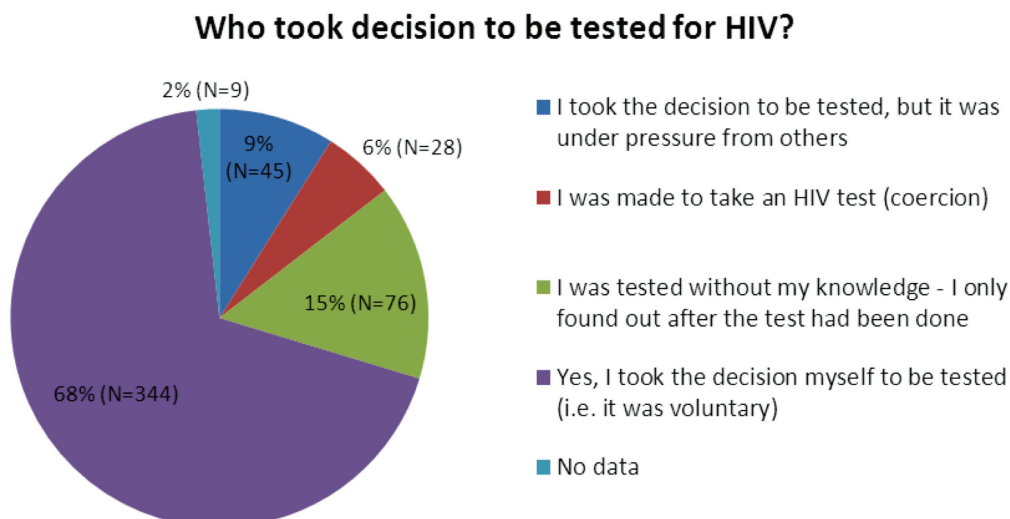
Chart 8. Reason for HIV testing (N=502)



Decision to Test

Sixty-eight percent of respondents (N=344) reported that they took the decision to be tested themselves; while 30% of respondents (N=149) did not test for HIV voluntarily. Involuntary testing was reported by 15% of respondents (N=76) who indicated that they were tested without their knowledge, 6% of respondents (N=28) who said that they were forced to test, and 9% of respondents (N=45) who indicated that they tested under pressure from others (Chart 9).

Chart 9. Who took the decision to be tested for HIV? (N=502)



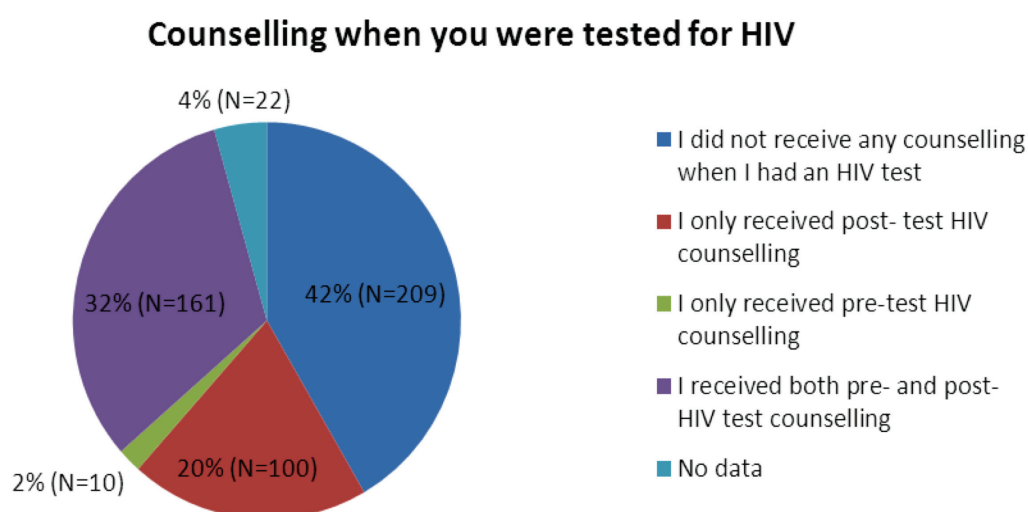
Poland



HIV Test Counselling

Forty-two percent of respondents (N=209) reported that they did not receive any counselling at all when they were tested for HIV. An additional 2% (N=10) reported that they only received pre-test counselling and a further 20% (N=100) indicated that they only receiving post-test counselling. In total, only 32% of respondents (N=161) reported receiving both pre- and post-test counselling (**Chart 10**).

Chart 10. Counselling when you were tested for HIV (N=502)



Stigma Index



Barriers to Uptake of HIV Testing

Time waited before accessing an HIV test

Forty-four percent of respondents (N=222) indicated that they undertook a HIV test within 6 months of the time that they first thought that they needed to test, and 66% (N=331) within the first year. However, eight percent (N=40) reported that they waited from one to two years, five percent (N=25) between two and five years and seven percent (N=35) waited longer than five years. There is no data about a further fourteen percent of respondents (N=70) (Table 23).

Table 23. Waiting time before testing for HIV

Waiting time before testing for HIV	0-3 months	4-6 months	7-12 months	1-2 years	2-5 years	More than 5 years	No data	Total
Percentage and number	44% N=222	13% N=67	9% N=46	8% N=40	4% N=22	7% N=36	14% N=69	502
Cumulative percentage	44%	57%	66%	74%	79%	86%	100%	502

Fear of stigma and discrimination resulting from an HIV diagnosis

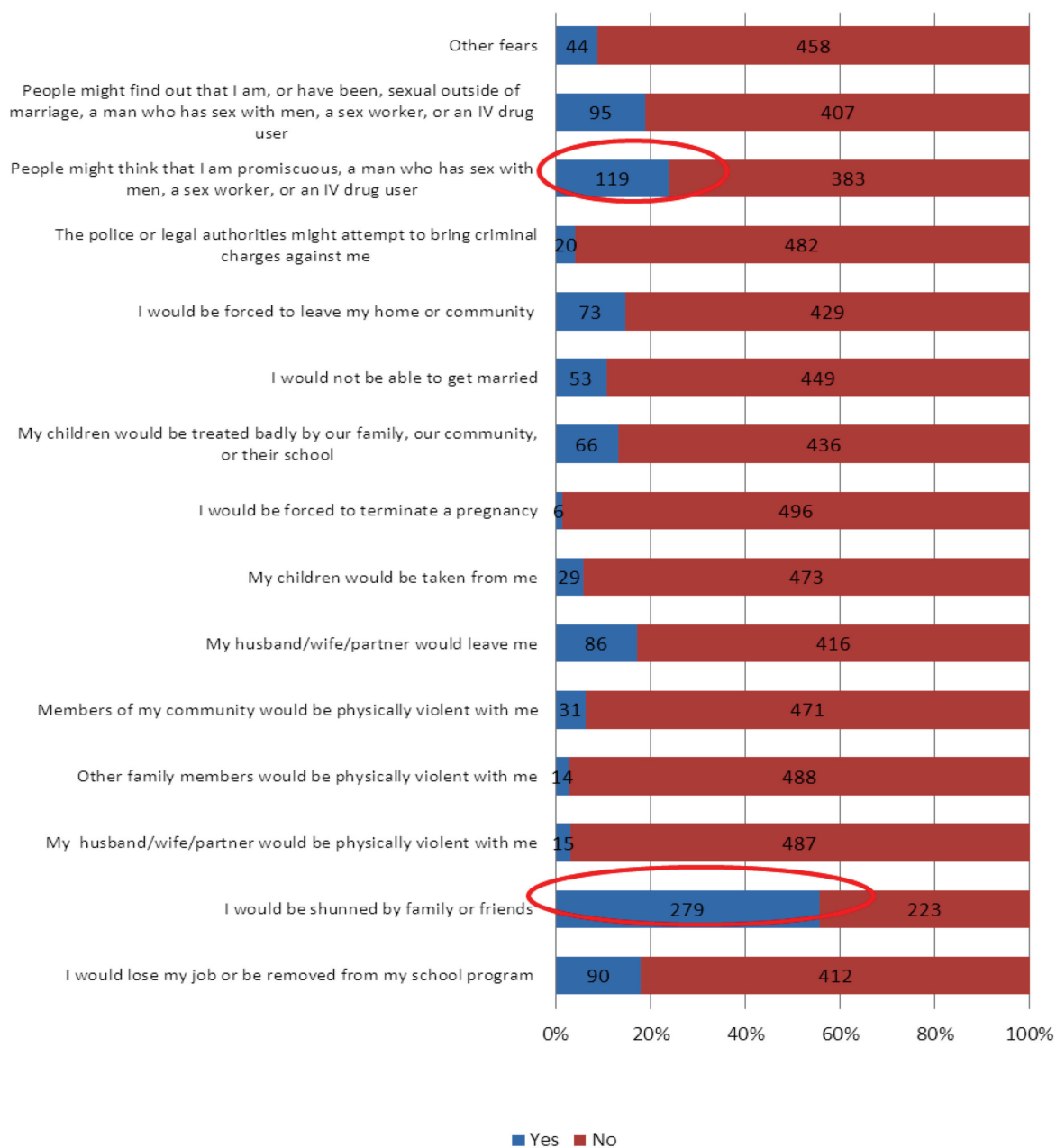
One hundred and eighty-four people (37%) reported that they hesitated to access an HIV test because they were afraid of how other people, such as, friends, family, employer or the community would respond to their HIV-positive test result.

In a separate question, more than 50% (N=279) of respondents reported that, before they tested, they were afraid that they would be shunned by family or friends if their test was positive. Twenty-four percent (N=119) were afraid that people might think that they were promiscuous, a man who has sex with men, a sex worker or an injecting drug user. See **Chart 11** for a list of the possible response options provided to survey respondents and the percentage of respondents who indicated that they held each fear.

Poland



Chart11. Figure 35: Were you afraid that any of the following would occur if you tested positive? (N=502)



Further information about about barriers to accessing HIV testing, treatment, and care is available in the report, *HIV-Related Stigma: Late Testing, Late Treatment*¹⁵.

¹⁵ Available at <http://www.gnpplus.net/en/resources/human-rights-and-stigma/item/101-hiv-related-stigma-late-testing-late-treatment>.

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5.12 Disclosure and Confidentiality

Respondents were asked if they had disclosed their HIV status to specific people or groups of people and how their status was first disclosed. (Table 24)

Table 24. Disclosure

How were each of the following people or groups of people first told about your HIV status?						
	I told them	Someone else told them, with my consent	Someone else told them, without my consent	They don't know my HIV status	Not applicable	Total number of responses
Husband/wife/partner	66% N=333	3% N=14	2% N=10	3% N=15	18% N=90	462
Other adult family members	55% N=277	6% N=29	11% N=56	25% N=124	5% N=25	511
Children in my family	18% N=90	2% N=11	3% N=15	30% N=149	36% N=182	447
Friends & neighbours	20% N=100	2% N=11	11% N=54	51% N=257	11% N=57	479
Co-workers	12% N=59	1% N=3	3% N=13	40% N=202	36% N=179	456
Employer(s)	10% N=51	0% N=1	2% N=10	38% N=190	38% N=192	444
Clients	3% N=15	0% N=2	1% N=4	34% N=170	50% N=249	440
Injecting drug partners	31% N=153	0% N=2	1% N=6	7% N=36	51% N=257	454
Religious leaders	7% N=35	1% N=5	1% N=5	29% N=146	50% N=250	441
Community leaders	8% N=39	1% N=3	2% N=35	35% N=173	44% N=220	444
Health care workers	66% N=330	4% N=21	8% N=42	18% N=89	8% N=39	521
Social workers or counsellors	39% N=193	1% N=5	2% N=12	20% N=99	29% N=143	454
Teachers	2% N=9	0% N=2	0% N=1	20% N=101	63% N=318	431
Government officials	3% N=14	0% N=1	0% N=2	23% N=113	61% N=306	436
The media	3% N=16	0% N=2	0% N=2	23% N=115	61% N=308	443

Poland



Total number of responses varies for two reasons: 1) some people did not select any of the responses for a given group and 2) multiple responses were possible if the answer was different for different people within the group. Note that the percentages in each column represent the percent of respondents out of the whole sample (N=502) who answered “yes” to each response for each group of people.

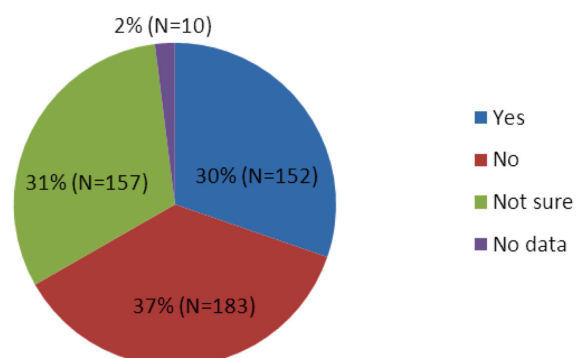
The largest numbers of respondents had disclosed their status to their spouse or partner (66%, N=333), healthcare workers (66%, N=330), and other adult family members (55%, N=277). However, it is notable that no more than two-thirds of respondents had disclosed to even these people. Eleven percent of respondents reported that their HIV status had been disclosed to adult family members and to friends and neighbours without their consent (N=56 and N=54, respectively) and eight percent indicated that their HIV status had been disclosed to healthcare workers without their consent (N=42). Many people reported that they maintained the confidentiality of their status in many situations: 25% said that adult family members beyond their spouse or partner did not know their HIV status (N=124); 30% said that their children did not know (N=149); more than half did not tell their friends or neighbours (51%, N=257), 38% reported that their employer(s) did not know their status (N=190); 29% said that their religious leaders did not know their status (N=146); and 18% indicated that their healthcare worker(s) did not know their HIV status (N=89) (**Table 24**).

Confidentiality

Thirty percent of respondents (N=152) reported that a health care professional had revealed their HIV status to another person without their consent with a further 31% (N=157) unsure of whether this had occurred or not. Only 37% (N=183) stated that their confidentiality had been protected by health care professionals.

Chart 12. Has a health care professional ever told other people about your HIV status without your consent?

Has a health care professional ever told other people about your HIV status without your consent ?

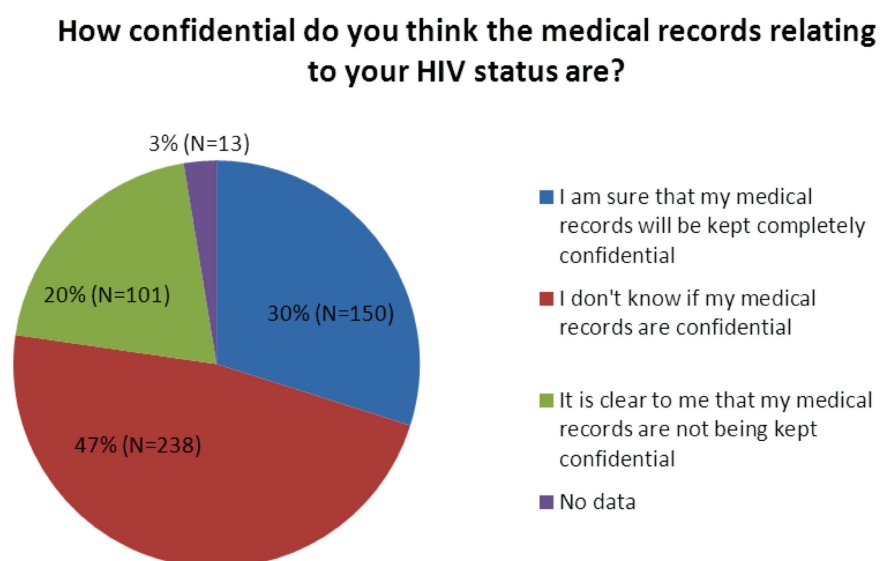


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One in five (20%, N=101) of respondents were convinced that their medical records were not being kept confidential, 47% (N=238) reported that they did not know if their records were kept confidential, and only 30% (N=150) indicated that they were sure that their medical records were kept completely confidential (**Chart 13**).

Chart 13. How confidential do you think the medical records relating to your HIV status are?



Other People's Reactions to Respondent's HIV Status

When asked how other people reacted to their HIV status, respondents' results varied widely depending on the person or group. **Table 25** shows the percent of respondents who indicated that people from various groups reacted with discrimination versus support upon learning of the respondent's HIV status. Large percentages of respondents selected "not applicable" for some categories of relationships; this may mean that the respondent had not disclosed her or his status to this group or people or it may mean that she or he did not have anyone in their life for a given category.

The people that respondents reported most often as being supportive or very supportive were their spouse or partner (52%, N=253), other adult family members (48%, N=237), other people living with HIV (46%, N=227), and health care workers (30%, N=150).

The groups that were most and least supportive overlapped. The people that were selected as having discriminatory and very discriminatory reactions were health care workers (20%, N=100), other adult family members (15%, N=71), and friends and neighbours (12%, N=57).

Poland



Disclosure is a complicated matter. When possible, people living with HIV can choose to only disclose to people whom they expect to respond supportively. However, some groups of people are likely to find out one's HIV status whether or not one wishes them to know. Health care workers, family members, and neighbours and friends fall into this category. In Section 3.8.1, Table showed that these three groups were the most likely to have been told the respondent's HIV status without the respondent's consent (with 8% (N=42) of respondents indicating their HIV status had been disclosed without their consent to health care workers, and 11% indicating that adult family members and friends and neighbours had been told their HIV status without their consent (N=56 and 54, respectively).

A urologist made a note on the patient's medical information card which was displayed by the bed of the pregnant HIV-positive woman. He told her that he had notified all hospital staff, including the cleaners, of her HIV status and she was given a separate room.

The patient's status was discussed loudly in the doctor's office and other patients in the corridor could hear what was said. The doctor was annoyed that he had not been not informed about her status earlier, asking what would have happened if had not been a separate room available, as it would not be possible to put her in the same room with other patients. He kept repeating that his duty was to protect doctors not me, that he does not have to protect her confidentiality, and that two sets of gloves have to be used by staff.

When she asked him how he knew who has HIV in an emergency ward, he said that this is obvious (i.e. HIV-positive people are injecting drug users). She replied that she is not a drug addict and the doctor admitted it is not obvious that she is HIV-positive. The patient succeeded in getting the doctor to remove the HIV-related information from her patient card. On the day of her discharge, the doctor apologised.

30-39 year old woman, living with HIV 1-4 years

The high numbers for health care workers and adult family members in both groups is a likely consequence of the fact that these groups are more likely to know a respondent's HIV status than some other people in the list (for example, community leaders or religious leaders) and that respondents do not always have the luxury of only disclosing to those members of the group whom they feel will respond in supportive ways. In fact, regarding health care workers, the case studies and comments by interviewees suggested that the most common setting for discrimination by health care workers was in local outpatient clinics or units that were not specialised in HIV treatment and care.



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Table 25. How would you describe the reaction of these people (in general) when they first knew about your HIV status?

How would you describe the reaction of these people (in general) when they first knew about your HIV status?								
	Very Discriminatory	Discriminatory	No different	Supportive	Very Supportive	Not Applicable	No Answer	Total
Husband/wife/partner	3% N=17	3% N=17	13% N=65	23% N=115	28% N=138	24% N=121	6% N=29	502
Other adult family members	5% N=23	10% N=48	14% N=70	30% N=149	18% N=88	19% N=97	5% N=27	502
Children in my family	0% N=2	1% N=5	8% N=40	9% N=44	5% N=25	67% N=336	10% N=50	502
Friends & neighbours	5% N=24	7% N=33	15% N=76	9% N=47	4% N=18	53% N=266	8% N=38	502
Other people living with HIV	1% N=3	1% N=6	30% N=152	35% N=174	11% N=53	16% N=78	7% N=36	502
Co-workers	1% N=7	2% N=11	7% N=36	5% N=26	2% N=8	72% N=360	11% N=54	502
Employer(s)	1% N=7	3% N=13	6% N=32	5% N=23	1% N=6	72% N=360	12% N=61	502
Clients	1% N=6	1% N=5	4% N=21	1% N=5	0% N=0	82% N=411	11% N=54	502
Injecting drug partners	0% N=2	1% N=5	22% N=109	5% N=26	2% N=9	60% N=300	10% N=51	502
Religious leaders	1% N=3	1% N=7	4% N=20	4% N=19	1% N=7	78% N=391	11% N=55	502
Community leaders	1% N=6	1% N=6	4% N=22	2% N=9	1% N=6	75% N=377	15% N=76	502
Health care workers	7% N=36	13% N=64	23% N=115	23% N=115	7% N=35	19% N=95	8% N=42	502
Social workers or counsellors	1% N=7	6% N=30	16% N=81	17% N=86	2% N=10	48% N=242	9% N=46	502
Teachers	0% N=1	2% N=8	2% N=12	1% N=6	0% N=0	84% N=421	11% N=54	502
Government officials	1% N=3	1% N=3	4% N=18	1% N=6	0% N=1	81% N=408	13% N=63	502
The media	2% N=11	1% N=4	4% N=20	1% N=5	0% N=0	83% N=414	10% N=48	502

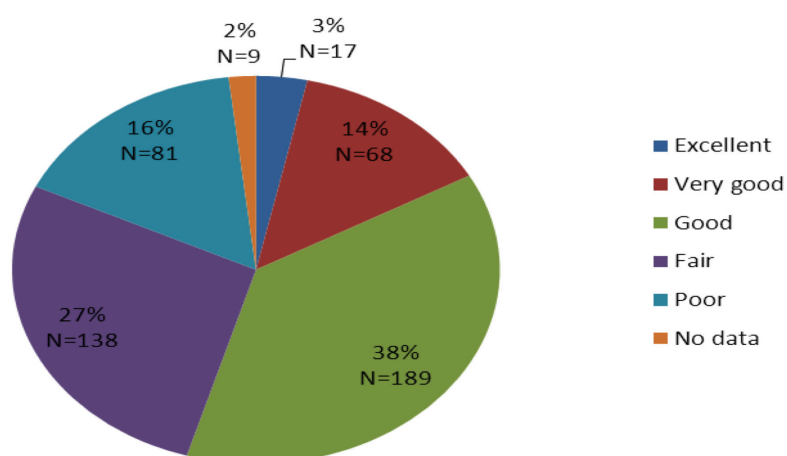


5.13 Health Status

Seventeen percent (N=85) described their current health as either excellent or very good. Thirty-eight percent (N=189) selected the middle option of “good.” On the lower end of the scale, 27% rated their health as fair and a further 16% as poor (Chart 14). The relatively low state of health reported by respondents creates cause for even broader concerns when one takes into account the numbers in the next section which indicate that respondents were almost twice as likely to be taking antiretroviral treatment as other people with HIV in Poland.

Chart 14. Description of current health

In general, how would you describe your health at the moment?



Access to Medicine

Seventy-eight percent (N=397) of respondents reported that they were on antiretroviral therapy. In addition, 90% (N=455) of respondents reported that they had access to antiretroviral therapy, even if they were not currently taking antiretroviral (Table 26). The percent of respondents currently on antiretroviral therapy is double the percent of people with HIV overall in Poland who are receiving this therapy. As of the end of January 2011, there were 14 234 reported cases with 1 056 HIV-related deaths. At the beginning of May 2011, some 5 162 people were receiving free antiretroviral therapy, including 135 children. So, just over 39% of all people known to be living with HIV are on treatment in Poland. Fifty percent of respondents (N=249) indicated that they were taking medication to prevent or to treat opportunistic infections. Eighty-three percent (N=421) reported that they had access to such medications, even if they were not currently taking them (Table 26).

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Table 26. Access to medications and discussions with health care providers

	Yes	No	Don't know	No data	Total
Are you currently taking antiretroviral treatment?	78% N=394	19% N=96	---	3% N=13	502
Do you have access* to antiretroviral treatment, even if you are not currently taking it?	91% N=455	3% N=13	3% N=14	4% N=20	502
Are you currently taking any medication to prevent or to treat opportunistic infection?	50% N=249	47% N=237	---	3% N=16	502
Do you have access* to medication for opportunistic infections, even if you are not currently taking it	84% N=421	4% N=19	8% N=38	5% N=24	502
In the last 12 months, have you had a constructive discussion with a health care professional(s) on the subject of your HIV-related treatment options?	82% N=414	16% N=78	---	2% N=10	502
In the last 12 months, have you had a constructive discussion with health care professional(s) on other subjects such as your sexual and reproductive health, sexual relationship(s), emotional well-being, drug use, etc?	58% N=291	38% N=193	---	4% N=18	502

Totals may not equal 100% due to rounding

* In this context access means that antiretroviral treatment is available and free or you can afford it.

Constructive Discussions with Health Care Providers

When asked if they had had a constructive discussion on HIV-related treatment options in the previous 12 months, 82 percent of respondents (N=414) stated that they had and 16% (N=78) had not. A smaller percentage, 58% (N=291), reported that they had had a constructive discussion with a health care professional on subjects such as their sexual and reproductive health, sexual relationships, emotional well-being, and drug use in the previous 12 months (**Table 26**).

The doctor who was handing the respondent's HIV test result was unable to tell him his HIV status. According to the respondent, although the doctor was holding the report with the results, she stated that she did not know, describing the results as "here are some plus signs". She had to leave the room to seek help from other doctors to read the test results.

The respondent was thrown out of the consultation room and made to sit in the corridor while the doctors loudly discussed the procedure for notification of authorities. The respondent did not feel comfortable. He has also witnessed some

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doctors' fear of having a HIV-positive person in the room – as if he could infect them just by looking.

30-39 years gay man

Entry into Care

The majority of respondents saw a medical professional to receive care for their HIV infection within one year of receiving their diagnosis. Forty-nine percent of respondents (N=246) entered into care within 3 months of diagnosis with the percentage rising to 62% within the first year. However, 33% of respondents (N=166) indicated that they did not receive medical care for more than a year after diagnosis or that they had not yet received care (with an additional 5% of respondents not providing an answer this question). Fourteen percent of respondents (N=68) waited more than five years before accessing care for their HIV infection (**Table 27**).

Table 27. Wait time after diagnosis before seeing a medical professional for care for one's HIV infection (N=502)

Wait time before initiating care after HIV diagnosis	0-3 month	4-6 months	7-12 months	1-2 years	2-5 years	More than 5 years	Not yet in care	No data
Percentage and number	49% N=246	6% N=31	7% N=33	7% N=37	8% N=42	14% N=68	4% N=19	5% N=26
Cumulative percentage	49%	55%	62%	69%	77%	91%	95%	100%

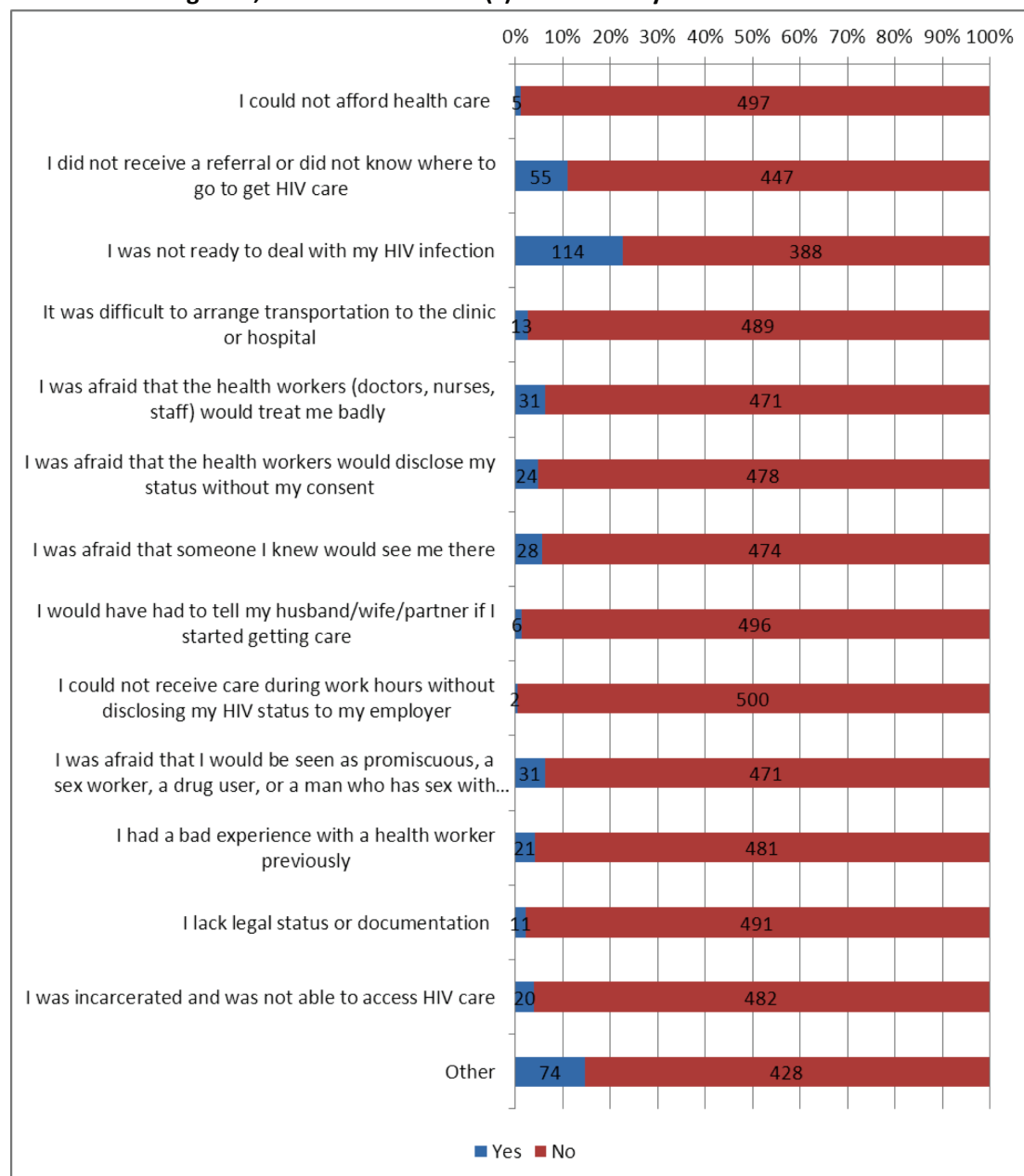
Barriers to Accessing Care

Respondents were asked about barriers to accessing care after they received their HIV-positive diagnosis. The most common response was related to respondents' mental and emotional health, with 114 respondents (23%) saying "I was not ready to deal with my HIV infection." Concerns about health care workers were selected as reasons for delays in accessing care, with 6% (N=31) expressing fear that health care workers would treat them badly, 5% (N=28) saying they were afraid that health care workers would disclose their status without their consent, and 4% (N=21) indicating a previous bad experience. Other main concerns were that respondents did not have a referral or know where to get care (11%, N=55), fear of being seen as part of a population that is associated with stereotypes about HIV (as promiscuous, a sex worker, a drug user, or a man who has sex with men) (6%, N=31), and fear that someone they knew would see them (5%, N=28). In addition, 20 respondents (4%) indicated that their delay was because they were incarcerated and were not able to access care.

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Chart 15. If there was a gap in time between your HIV positive test and the time you started receiving care, indicate the reason(s) for the delay.



Further information about the Polish responses to the questions about barriers to accessing HIV treatment and care as described, as well as responses from Estonia, Moldova, Turkey, and Ukraine, is available in the report, *HIV-Related Stigma: Late Testing, Late Treatment*¹⁶.

¹⁶ Available at <http://www.gnppplus.net/en/resources/human-rights-and-stigma/item/101-hiv-related-stigma-late-testing-late-treatment>.



5.14 Sexual and Reproductive Health and Rights

Respondents were asked a series of questions about their access to reproductive health services and health care provider behaviours toward their reproductive health needs. Fewer than half (44%, N=222) reported that they had ever received counselling about their reproductive options since their diagnosis. Fifteen percent of respondents (N=77) had been advised by a health care professional not to have a child post-HIV diagnosis. Seven respondents (1%) reported that they had been coerced by a health professional into being sterilised after their HIV diagnosis and 23 (5%) said that they were required to use certain forms of contraception in order to have access to antiretroviral treatment (**Table 28**).

Table 28. Reproductive health experiences with health providers (N=502)

	Yes	No	Not applicable	Don't know	No data	Total
Since being diagnosed as HIV-positive, have you ever received counselling about your reproductive options?	44% N=222	23% N=116	29% N=144		4% N=20	502
Has a health care professional ever advised you not to have a child since you were diagnosed as positive?	15% N=77	57% N=286	23% N=116		5% N=23	502
Has a health care professional ever coerced you into being sterilized since you were diagnosed as positive?	1% N=7	70% N=350	25% N=125		4% N=20	502
Is your ability to obtain antiretroviral treatment conditional on the use of certain forms of contraception?	5% N=23	55% N=278	29% N=144	4% N=19	8% N=38	502



6. Conclusions

The 502 people living with HIV in Poland who were interviewed for this study reported experiences of stigma and discrimination related to their HIV-positive status across a range of life activities. Taken together, the responses demonstrate the challenges faced by Polish people living with HIV when they seek to engage in community and social life, to provide economically for themselves and their families, and to obtain the health care necessary to maintain their physical and mental well-being. Particular challenges were notable in the areas of: social discrimination, employment discrimination, discrimination by health care workers, and the internal stigma that people with HIV direct toward their own selves. Addressing each of these areas offers opportunities to increase the quality of life of people living with HIV in Poland.

Social discrimination

Experience of social exclusion, gossip, and verbal harassment were widespread among respondents, both because of their HIV status and for other reasons.

- 260 respondents (52%) reported that they were aware of being gossiped about in the last 12 months; 20% of these indicated that the gossip was solely because of their HIV status.
- 153 respondents (31%) reported the experience of being verbally insulted, harassed, or threatened in the last 12 months; 21% of these indicated that this was solely because of their HIV status.
- 98 respondents (20%) reported that they had been excluded from a social gathering one or more times in the last 12 months; 30% of these respondents indicated the exclusion was solely because of their HIV status.

In addition, actual physical assaults in the last 12 months were reported by 84 respondents (17%), with 11% of these (N=9) indicating that they were assaulted because of their HIV status.

These percentages are high, given the low percentage of respondents who had told others about their HIV diagnosis. Over half of respondents (51%, N=257) indicated that they had not disclosed their status to their friends or neighbours and one-quarter (25%, N=124) indicated that they had not told any of the adult members of their family.

Social stigma and discrimination diminish the quality of live for people living with HIV; they also affect efforts to encourage people to test for HIV. Of the respondents to the study, 37%

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(N=184) reported that they hesitated to access an HIV test because they were afraid of how other people, such as, friends, family, employer or the community would respond to their HIV-positive test result. More than 50% (N=279) of respondents reported that, before they tested, they were afraid that they would be shunned by family or friends if their test was HIV-positive. Seventeen percent (N=86) said that they were afraid that their spouse or partner would leave them if their HIV test was positive.

Employment discrimination

Almost one in five respondents (18%, N=90) told interviewers that, before they tested for HIV, they were afraid that they would lose their job or be removed from their school programme. The results about employment discrimination indicate that these fears were founded in reality.

- 65 respondents (13%) stated that they had lost their job or a source of income in the last twelve months, with 7 (11%) of these indicating that this loss occurred, in whole or in part, because of their HIV-positive status.
- 49 respondents (11%) reported that they had been refused employment or a work opportunity because of their HIV status in the last 12 months.
- 38 respondents (8%) indicated that the nature of their work had changed or they had been refused a promotion because of their HIV status.

Again, these numbers are even more remarkable when disclosure is taken into account: only 62 respondents (12%) indicated that their employers knew their HIV status (whether because the respondent shared the information or because the information was shared without the respondent's consent). Employment discrimination has direct effects on one's ability to provide for oneself and one's family. The high unemployment (46%) and low income reported by respondent's increases the urgency to address employment discrimination based on HIV status in Poland.

Health care workers

Respondents indicated that the health care workers they encountered were sources of support in some cases and sources of discrimination in others.

- 150 respondents (30%) reported that health care workers reacted supportively or very supportively upon disclosure of the respondents' HIV status;
- 100 respondents (20%) experienced discriminatory or very discriminatory reactions to the disclosure of their HIV status on the part of health care workers.
- 98 respondents (18%) reported that they had been denied health services, including dental care, because of their HIV status at least once in the last 12 months.
- 152 respondents (30%) indicated that that a health care professional had revealed their HIV status to others without their consent. A further 157 respondents (31%)

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were unsure of whether this had occurred or not.

- 101 respondents (20%) were sure that their medical records were not being kept confidential.

A number of respondents described experiences of counselling, testing, and care that violate norms of appropriate medical care.

- 149 respondents (30%) indicated that they were tested against their will, without their knowledge, or under pressure from others.
- 209 respondents (42%) reported that they did not receive any counselling at all when they were tested for HIV. Only 161 respondents (32%) reported receiving both pre- and post-test counselling (the others received either pre- or post-test counselling).
- 20 respondents (4%) reported that, after testing positive for HIV, medical care was not accessible to them because they were incarcerated.

Experiences and fears of discrimination by health care workers had an effect on the care-seeking behaviour of respondents.

- 21 respondents (4%) indicated that they delayed seeking care after their diagnosis because of previous bad experiences with health care workers.
- 31 respondents (6%) said they delayed accessing care after their diagnosis because they feared health workers would treat them badly.
- 89 respondents (18%) reported that they had not disclosed their status to their health care workers.
- 116 respondents (23%) said that they avoided going to a local clinic when they needed to in the last 12 months because of their HIV status.
- 79 respondents (16%) said that they avoided going to hospital when they needed to in the last 12 months because of their HIV status.

The information gathered in the qualitative interviews indicates that many of the discriminatory experiences occurred in general health care settings, and not in those dedicated specifically to HIV care. This data highlights the importance of ensuring that the doctors, nurses, and other workers in all areas of health care are knowledgeable about the basics of HIV transmission, universal precautions, and HIV care and about the detrimental effects of stigma and discrimination on people with HIV and those at risk of infection.

Reasons for discrimination

When respondents were asked their opinion about why stigma and discrimination existed against people with HIV, most indicated that fear and ignorance were the drivers.

- 129 respondents (25%) indicated that people do not understand how HIV is transmitted and are afraid people living with HIV will infect them through casual contact.

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- 103 respondents (20%) felt that stigma and discrimination against people living with HIV stemmed from people's fear of getting infected.

In some cases, respondents faced stigma and discrimination for reasons in addition to their HIV status.

- 153 respondents (30%) reported that they had been stigmatised or discriminated in the last year, not only because of HIV status, but also because of their current or former membership in a key population.
- 39 respondents (26% of those reporting stigma or discrimination for other reasons) reported that they were the targets of stigma or discrimination, either wholly or partly, because of their sexual orientation (gay, lesbian, or men who have sex with men).
- 36 respondents (24% of those reporting stigma or discrimination for other reasons) indicated that they faced stigma or discrimination because they were, or had been formerly, people who use drugs.

The fears of casual contact and ignorance about actual routes of HIV transmission, as described by respondents, indicate a need for broad public education efforts in addition to other efforts designed specifically to address discrimination. In addition, these results demonstrate that Polish people living with HIV often face other forms of stigma and discrimination that are intertwined with HIV stigma.

Internal stigma

Stigma does not only come from external sources. People living with HIV can internalize the negative social messages that are directed toward them and others living with HIV. Respondents indicated that they experienced a number of manifestations of internal stigma in the previous 12 months.

- 267 respondents (53%) blamed themselves because of their HIV status.
- 209 respondents (42%) felt ashamed because of their HIV status.
- 191 respondents (38%) reported low self-esteem because of their HIV status.
- 188 respondents (38%) felt guilty because of their HIV status.
- 90 respondents (18%) indicated that they had felt suicidal because of their HIV status.

In response to stigma, whether external or internal, respondents reported that they removed themselves from social situations, and the possible support that they might receive.

- 123 respondents (25%) reported that they chose not to attend social gatherings and isolated themselves from family or friends.
- 90 respondents (18%) said that they decided not to get married because of their HIV status.



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In addition, respondents described very high levels of fear about what might happen to them because of their HIV status.

- 299 respondents (60%) said that they feared being gossiped about.
- 214 respondents (43%) indicated that they feared verbal harassment.
- 159 respondents (32%) feared physical harassment.
- 155 respondents (31%) told researchers that they feared being physically assaulted.

These results call for attention to the mental health and social support needs of people living with HIV. The internal stigma experienced by people living with HIV needs to be addressed as an integral part of any efforts designed to decrease stigma and those designed to meet the health care needs of people living with HIV.

Challenging stigma and self-advocacy

The study respondents demonstrated in this research that people living with HIV are not merely passive recipients of stigma and discrimination. Instead, respondents indicated that they engage in a variety of activities to challenge stigma, to support one another, and to advocate on their own behalf.

- 315 respondents (63%) reported that they supported other people living with HIV, emotionally, physically, and by providing information about services, in the last 12 months.
- 142 respondents (29%) reported that they had confronted, challenged or educated someone who stigmatised and/or discriminated against them in the last 12 months.
- 138 respondents (27%) indicated that they were currently a member of a support group for people living with HIV.
- 90 respondents (18%) reported that they had been involved, as a volunteer or employee, in a programme that provided assistance to people living with HIV in the last 12 months.
- 42 respondents (8%) said that they had been involved in efforts to develop legislation, policies or guidelines related to HIV in the last 12 months.

These data show that people living with HIV are working already to combat HIV-related stigma and discrimination. The respondents who indicated that they support other people living with HIV, challenge discrimination, educate others, and work with programmes or policy development are engaged in stigma-reduction efforts. Supportive policies and programmes for people living with HIV can build on and systematise this existing work, and further assist people living with HIV to develop their own advocacy strategies and to build their capacity and empowerment to address both internal stigma and external stigma and discrimination.



7. Recommendations

It is clear from the findings of this research that there is a pressing need to address the challenges faced by people living with HIV in Poland resulting from the stigma and discrimination that they encounter.

It is evident from the research that despite the stigma and discrimination encountered many people living with HIV are actively supporting their peers and challenging, challenging stigmatising attitudes and behaviours. Within any response it should be a priority to further build the capacity of people living with HIV to do this work in a systematic and properly supported fashion.

Among the sample there was low socio-economic status, including significant percentages of respondents reporting food insecurity¹⁷, education¹⁸ and employment¹⁹, 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 18% of respondents reported feeling suicidal. As such, psychosocial and socioeconomic support must clearly be a priority for SIEĆ PLUS, civil society, the National AIDS Centre and the Government. Concerted efforts 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 SIEĆ PLUS, civil society, the National AIDS Centre and the Government are outlined below.

SIEĆ PLUS, the Polish Network of People Living with HIV/AIDS

- Disseminate the findings of this study to the Government, National AIDS Centre, civil society, UN agencies and donors, especially to inform and influence The national strategy on HIV (the National Programme for Preventing HIV Infections and Combating AIDS in the years 2012-2016) in Poland
- Advocate for the rights of all people living with HIV, including key populations, and advocate against/ challenge rights violations.
- Empower HIV-positive people to know and assert their rights, including by providing information and referrals to organizations and services which can assist PLHIV to

¹⁷ 10% (n=52) reported that they had insufficient quantities of food on at least one day in the last month.

¹⁸ 26% (n=129) had only a primary school education and two percent had no formal education.

¹⁹ 46%, (n=233) were unemployed.

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seek redress in case of rights violations.

- Encourage and build the capacity of people living with HIV to be actively involved (either as a volunteer or as an employee) in developing and implementing stigma and discrimination reduction projects and programmes, and in providing 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 provide adequate counselling and other support to people living with HIV, including key populations.

Civil Society

- Advocate for the rights of all people living with HIV, including key populations.
- 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.
- With 13% of respondents being symptomatic at time of diagnosis, invest more in promoting voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Support the active participation of people living with HIV in the development of laws, policies and guidelines; and in providing community-based services and support.

National AIDS Centre

- With 13% of respondents being symptomatic at time of diagnosis, invest more in promoting 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 rights to people living with HIV in health care settings²⁰:

²⁰ For example:

- 20% (n=100) reported that health care workers reacted discriminatorily or very discriminatorily upon disclosure of respondents' HIV status;
- 18% (n=98) reported that they had been denied health services, including dental care, because of their HIV status at least once in the last 12 months.
- 30% (n=152) indicated that a health care professional had revealed their HIV status to others without their consent.
- 20% (n=101) were certain that their medical records were not being kept confidential.
- 30% (n=149) indicated that they were tested against their will, without their knowledge, or under pressure from others.
- 42% (n=209) reported that they did not receive any pre- or post-test HIV counselling.



- 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; and
- 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.
- Given that there is a low level but consistent pattern of denial of SRH rights to people living with HIV²¹; scale up the provision of correct information and appropriate options for the sexual and reproductive health for people living with HIV, including on PMTCT, across all locations.
- Support SRH and HIV linkages, including the integration of SRH services for people living with HIV into HIV programmes.
- Support the active participation of people living with HIV in the development of laws, policies 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 and specifically address HIV-related stigma and discrimination in areas such as employment, health.
- Support the active participation of people living with HIV in the development of

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- 4% (n=21) indicated that they delayed seeking care after their diagnosis because of previous bad experiences with health care workers, and 6% (n=319) because of fear that health workers would treat them badly.
 - 18% (n=89) reported that they had not disclosed their status to health care workers.
 - Internal stigma also affects access to health care: 23% (n=116) avoided going to a local clinic when they needed care, and 16% (n=79) avoided going to hospital.

²¹ For example:

- 3% (n=13) stated that they had been denied family planning services because of their HIV-positive status.
- 3% (n=17) reported being denied access to sexual and reproductive health services.
- 23% (n=116) reported that they had never received counselling about their reproductive options since their diagnosis.
- 15% (n=77) had been advised by a health care professional not to have a child post-HIV diagnosis.
- 1% (n=7) reported that they had been coerced by a health professional into being sterilised after their HIV diagnosis.
- 5% (n=23) said that they were required to use certain forms of contraception in order to have access to ART.

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laws, policies 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 and misinformation.
- 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.

The data is not available as a source of allegations of individual instances of wrong-doing.

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