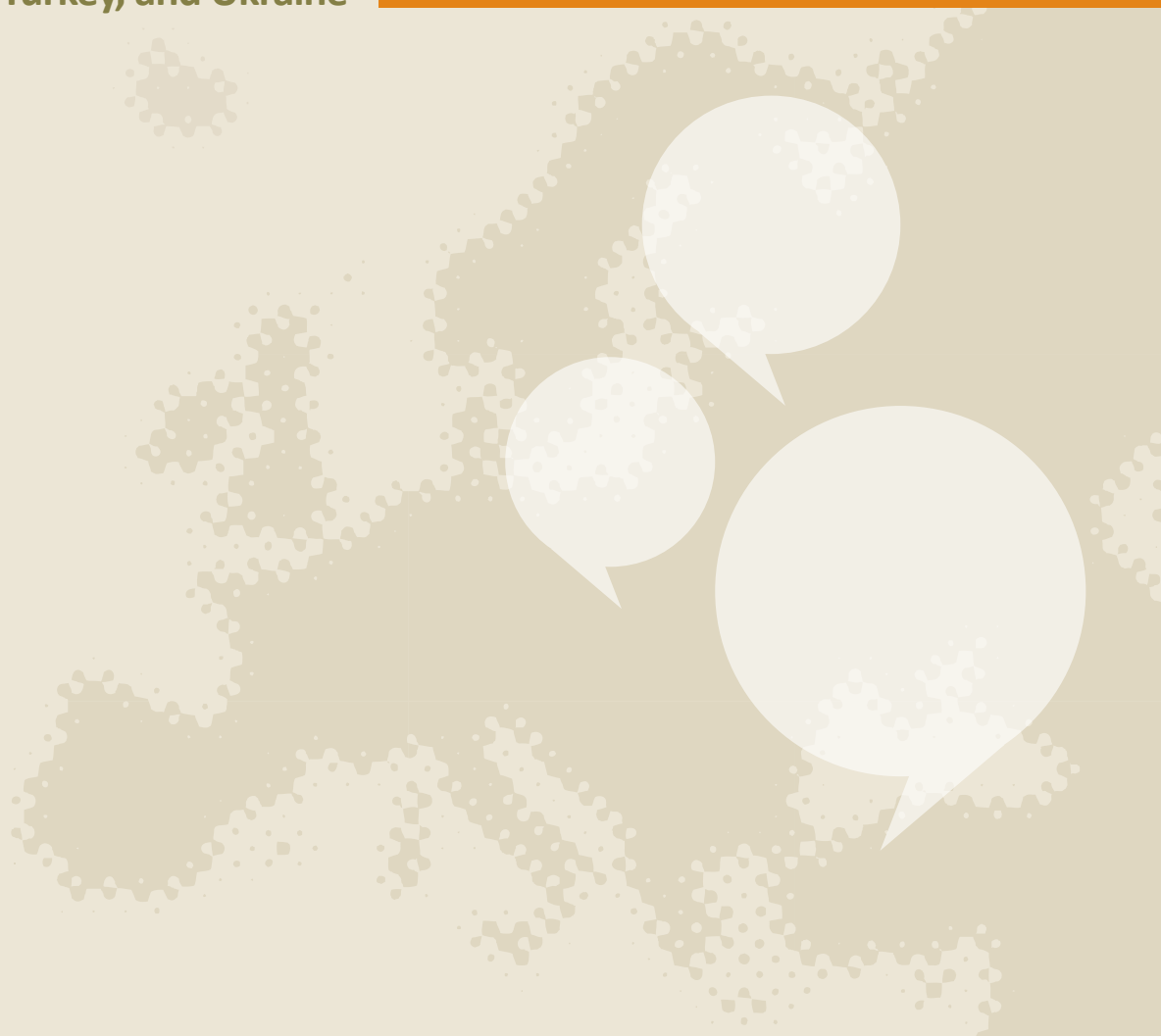


HIV-related Stigma:

A cross analysis of findings
from the People Living
with HIV Stigma Index in
Estonia, Moldova, Poland,
Turkey, and Ukraine

Late Testing,
Late Treatment





League of People Living with HIV
Republic of Moldova
www.ligaids.md



www.pozitifyasam.org



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Project Management

An advisory group oversaw this project. In keeping with the principle of GIPA (the greater involvement of people living with HIV) this was a group of three PLHIV plus a member of the steering group of HIV in Europe who convened to oversee, guide, and make recommendations to HIV in Europe on how the project would be implemented and carried out.

Review and input

The authors would like to thank the steering group of HIV in Europe and the international partners of the PLHIV Stigma Index who made comments and suggestions on the text of the report. The international partners of the PLHIV Stigma Index are: 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).

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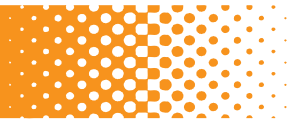
Abbreviations and Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral medication
CSW	Commercial Sex Worker
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
IDP	Internally Displaced Persons
IDU	Injecting drug users
MSM	Men who have Sex with Men
PLHIV	People Living with HIV
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV/AIDS



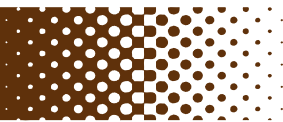
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Executive Summary



HIV in Europe, an initiative of European HIV/AIDS clinicians, research, policy and civil society organisations, was formed in 2007 to combine efforts in order to better understand, communicate, and address the barriers that Europeans face in accessing testing, treatment, and care services. A particular focus was placed on the role that stigma and discrimination might play in impeding attempts to scale up to universal access to HIV testing, treatment, and care services. To inform these efforts, evidence that was locally-specific and that spoke to current conditions was needed.

In 2009 networks of people living with HIV in Estonia, Moldova, Poland, Turkey, and Ukraine identified a need to address HIV-related stigma and discrimination in their countries and began discussions, with the support of the International Partnership of the People Living with HIV Stigma Index, about the possibilities of implementing the People Living with HIV (PLHIV) Stigma Index in each of their countries.

These efforts were joined and the PLHIV Stigma Index was chosen as the medium that could help identify whether people living with HIV in these countries were hesitating to access HIV testing, treatment, and care services and, if so, why, as part of the process of national implementation of the PLHIV Stigma Index.

A core principle of the PLHIV Stigma Index is that it is an initiative by and for people living with HIV. A resulting strength of this report is that the results portray barriers to accessing HIV testing, treatment, and care in the countries studied as experienced by people, who themselves, have tested HIV-positive, in a research process led by national level PLHIV organisations.

We hope that the information obtained by this study will complement the work of the European Late Presenter Consensus Working Group¹ in understanding some of the reasons that PLHIV may wait between realising that they should test and accessing testing services, and are sometimes reluctant in accessing treatment services.

To better understand the issues surrounding late diagnosis and delayed treatment, five new questions were made part of the roll-out of the PLHIV Stigma Index² in these countries. These questions were devised in partnership with the implementation teams in the countries involved, as well as an advisory from HIV in Europe. These questions focused directly on delays in accessing HIV testing and care and the reasons for these delays. People living with HIV in Estonia (N=87), Moldova (N=403), Poland (N=504), Turkey (N=100), and Ukraine (N=1500) were interviewed, with their responses recorded in questionnaires. All of the research was carried out in later 2010 and early 2011. A participative research process was used, people living with HIV in each country were trained as interviewers and conducted all of the interviews. The larger project (the PLHIV Stigma Index) in which these questions were embedded provided demographic information about respondents as well as answers to a variety of questions about respondents experiences, allowing cross analysis by gender, membership of a key population, rural or urban location, education level, and income.

¹The working group has suggested a consensus definition of late presentation at <http://www.hiveurope.eu/consensus>.

²The People Living with HIV Stigma Index is a joint initiative of: 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).

Answers provided by respondents revealed that the time period that they waited before seeking HIV testing and before accessing medical care post diagnosis varied widely. While many respondents reported getting tested within six months of realising their need to test, it is likely that they had been living with HIV for some time before realising that they might be HIV-positive. At the same time, a significant minority in some countries waited more than two years, sometimes more than five years, before testing. In contrast to the time waited before testing, the amount of time that elapsed between diagnosis and first seeing a healthcare worker for one's HIV infection was quite long on average.

Respondents expressed many fears about accessing both testing and care services. Large percentages of respondents from every country indicated a hesitation to test because of fears of social stigma. Other primary reasons for delayed testing were relational fears (loss of spouse or partner, ability to marry, or friends or family), fears that one's children would be stigmatised, concerns about being associated with stereotyped groups, and concerns about losing one's employment or schooling. Primary reasons for delaying uptake of care after diagnosis included emotional and psychological needs – specifically not feeling ready to deal with one's HIV infection, fears of mistreatment by healthcare workers, fears about violations of confidentiality, not knowing where to go for care, and a fear of being seen accessing care. Responses were strikingly similar for women and for men.

Young people and members of key populations expressed some fears in higher numbers than respondents over the age of 30, or those who were not members of key populations. Young people were more likely to report that they delayed testing because of fears about how others would respond. Depending on the country, higher percentages of young people said that they were concerned about intimate partner violence, about being forced to terminate a pregnancy, or that they would not be able to marry because of a positive HIV test. Members of key populations expressed even higher concerns than the general population about mistreatment by healthcare workers. They also expressed fears about criminalisation³ should they test positive and about being targeted for partner, family, and community violence – these fears were generally much less common or even absent among other respondents.

Finally, information about the current health of the respondents and the circumstances under which they tested for HIV was employed to illuminate the following research questions:

- Did respondents who waited longer to test or to access care report overall worse health than those who tested or accessed care earlier?
- Did respondents who tested voluntarily report earlier uptake of medical care?
- Did respondents who received pre and post test counselling report earlier uptake of medical care?

The answer to each of these questions, with a few qualifications, was yes. In every country, those who tested earlier and those who accessed care earlier reported better health at the time of the survey. In addition, a strong and positive relationship was found between timely uptake of care and both the voluntariness of testing and pre and post test counselling.

Recommendations for interventions follow clearly from these results: critical efforts are needed to address both the social stigma surrounding HIV and the resultant fear in people who need to access

³ Criminalisation fears include concerns by respondents about facing criminal charges, loss of civil freedoms, or being subject to increased monitoring by civil authorities due to their diagnosis confirming them as having certain behaviours or being part of a specific group – such as sex workers, homosexuals, drug users. Criminalisation fears also included concerns about the potential of facing criminal charges for potentially having transmitted HIV to others.

testing services. Employment and education non-discrimination protections must be in place and communicated widely. Upon receiving a positive diagnosis, individuals should have immediate access to psychological and emotional support. Systems and norms need to be established in which mistreatment by healthcare workers is not tolerated. At the same time, healthcare workers should be trained and supported in maintaining confidentiality and providing patient care in a non-judgmental and professional manner. Access to equitable health care for people who are living in HIV must be assured within prison and other institutional settings. Finally, the importance of voluntary counselling and testing programmes for HIV in protecting human rights, maintaining trust, and linking people to medical care post diagnosis cannot be overstated.


This report is an analysis of PLHIV Stigma Index data from the research carried out in the five countries (including the five additional questions), bringing a specific lens to bear on the issues regarding barriers to accessing testing and care. To access full reports of the PLHIV Stigma Index findings in each of the countries as they become available please visit <http://www.gnpplus.net/en/programmes/human-rights/plhiv-stigma-index>



Introduction

HIV in Europe, an initiative of European HIV/AIDS clinicians, research, policy and civil society organisations, was formed in 2007 to combine efforts in order to better understand, communicate, and address the barriers that Europeans face in accessing testing, treatment, and care services. A particular focus was placed on the role that stigma and discrimination might play in impeding attempts to scale up to universal access to HIV testing, treatment, and care services. To inform these efforts, evidence that was locally specific and that spoke to current conditions was needed.

In 2009 networks of people living with HIV in Estonia, Moldova, Poland, Turkey, and Ukraine identified a need to address HIV-related stigma and discrimination in their countries and began discussions, with the support of the International Partnership of the People Living with HIV Stigma Index, about the possibilities of implementing the People Living with HIV (PLHIV) Stigma Index in each of their countries. Based on their own experiences and those of people they knew, these networks identified key factors that they felt created barriers to HIV services. They recorded these issues in concept notes and reports, created as preliminary steps toward national implementation of the People Living with HIV Stigma Index. These factors included: discrimination in employment, education, and the justice system; family and social stigma; further stigma directed toward groups that were already marginalised; negative social judgments toward people living with HIV; stereotypes; and mistreatment by health workers. Among other issues, the concept note from Estonian indicates that “people are afraid to visit infectious disease hospital in their own town and forced to go to hospitals in other cities” while a report from Poland notes that people are afraid to take their medication for fear of being identified as HIV-positive. The concerns can be summed up with this statement from the Ukrainian concept note:



“According to a study conducted by the All-Ukrainian Network of PLWH in 2009, people living with HIV do not seek help until 2-3 years after they are diagnosed with HIV. From experience we know that much of the reluctance to come forward and seek the necessary help and support is due to the stigma that people living with HIV/AIDS feel and experience.”

With the needs identified and the appropriate partnerships in place, the PLHIV Stigma Index was identified as the means for engaging with networks of people living with HIV and documenting their experiences with testing, treatment, and care services.

To answer the specific questions posed by HIV in Europe, five additional questions were added in the rollout of the PLHIV Stigma Index in the countries involved in the study. These questions focused directly on delays in accessing HIV testing and care and the reasons for these delays. Respondents were queried about a wide range of possible reasons for delay, including pragmatic concerns (such as cost, transportation, or not knowing where to go) as well as concerns about stigma and discrimination. Questions on stigma and discrimination related to various arenas in which stigma and discrimination might manifest (such as legal, health care, community, and family settings) and the impact of anticipated and internalised stigma. The larger project, in which these additional questions were

embedded, provided demographic information about respondents as well as answers to a variety of questions about their experiences, allowing the responses to be analysed by gender, membership in a key population, length of time since diagnosis, rural or urban location, education level, and income as well as by the initial reason for testing, whether testing was voluntary and counselling provided, and the current health of the respondent.

Definitions

This research seeks to increase understanding of the extent to which people, in the five countries included in the study, delayed to be tested for HIV or to access medical care post diagnosis, as well as the reasons for these delays. To this end, throughout this analysis, the following definitions of late testing and late uptake of care are used:

Late Testing: Being tested for HIV more than six months after first realising that one needs an HIV test.

Delays of more than six months, more than a year, and more than two years are reported in this analysis. These delays have implications for the health and well-being of the HIV-positive person who has not been diagnosed and for the possibilities of onward transmission of HIV.

Late Uptake of Care: Waiting more than six months after diagnosis to see a medical professional for one's HIV infection, whether or not one started taking anti-HIV medications at that time.

Delays of more than six months, more than a year, and more than two years are reported, as are the percentages of respondents who are not receiving care. These delays impact the ability to evaluate when antiretroviral treatment is indicated, to prevent opportunistic infections and to address co-morbidities such as hepatitis or tuberculosis, with resulting negative implications for the health and well-being of the person living with HIV, as well increasing the burden on public health resources.

These definitions are designed to complement the consensus definition of the European Late Presenter Consensus Working Group. The Working Group focuses on late presentation for care, defining this as occurring when an HIV-positive person has an AIDS defining illness or a T-cell count under 350 cells/mL when first presenting for care. The late testing and late treatment uptake analyses in this report explore the delays in obtaining a diagnosis and in accessing medical care that precede and create the outcome that the Working Group seeks to address: presentation for care by HIV-positive individuals late in the course of their infection.

Methods

Five questions about barriers to uptake of HIV testing and treatment were added to the People Living with HIV Stigma Index, an existing survey instrument⁴.

The five specific questions added to the existing PLHIV Stigma Index were⁵:

- How long did you wait between the time you first thought you should get an HIV test and the time you took the HIV test? (*time scale*)
- Did fears about how other people (for example, your friends, family, employer, or community) would respond if you tested positive make you hesitate to get tested? Yes/No
- Were you afraid that any of the following would occur if you tested positive? (*Multiple choice, multiple responses possible*).
- How long did you wait between the time you tested positive and the time that you started seeing a health professional for your HIV infection-whether or not you started medications at that time? (*time scale*)
- 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. (*Multiple choice, multiple responses possible*).

The responses to these additional questions were cross analysed against data from existing questions (both qualitative and quantitative) in the PLHIV Stigma Index to provide the full analysis of this report. The full additional questions and the PLHIV Stigma Index data cross analysed against appear in the relevant sections.

Issues explored by the research

- How long did respondents wait to test once they first realised that they needed an HIV test?
- What reasons do respondents give for waiting to test?
- How long did respondents wait after diagnosis before accessing health care for their HIV infection?
- What reasons do respondents give for delays in accessing care?
- Did respondents who waited longer to test or to access care report overall worse health than those who tested or accessed care earlier?
- Did respondents who tested voluntarily report earlier uptake of medical care?
- Did respondents who received pre and post test counselling report earlier uptake of medical care?

Sample size

A total of 2,540 people living with HIV in Estonia, Moldova, Poland, Turkey, and Ukraine were interviewed, with their responses recorded in questionnaires. All of the respondents were people living with HIV who have accessed HIV testing services and received a diagnosis. A participative research process was used in which people living with HIV in each country were trained as interviewers and conducted all of the interviews. Descriptive and bivariate analysis of results was performed by country, gender, age, length of time living with HIV, and membership in key affected population groups.

⁴ A fuller description of the methodology and research process for the PLHIV Stigma Index can be accessed at <http://www.stigmaindex.org/userguide>

⁵ The full questions appear in the relevant sections.

Limitations

Samples were recruited in each country in line with the epidemiological profile of the epidemic in each country. Within the resources available, every effort was made for the respondent sample to be broadly representative of the various and divergent groups and regions most affected by HIV in each country.

With these caveats in mind, the following limitations apply:

Because samples of respondents were collected differently in order to gain the participation of the most affected populations in each country, direct comparisons across countries cannot be reliably made. Additionally resource constraints on the total sample size that it was possible to interview does mean that for some countries no representative data was obtained for some key populations. Particularly for countries with smaller sample sizes (Estonia, Moldova, and Turkey), results given for subpopulations should be read as general trends rather than concrete results. Thus, responses from sex workers, for example, should be understood as accurately reflecting the responses of those sex workers included in the sample. However, it is not possible from this data to state with confidence that the situation of sex workers, for example, is better in one country than another.

Some respondents were receiving medical care for their HIV infection; others were not in care. In addition, they were accessible through some mechanism to the interviewers (whether through membership in a PLHIV network, word of mouth, health clinic attendance, or other way). People who are HIV-positive but are not receiving any services, are not linked into any network, or who have not yet received their diagnosis may differ in significant ways from these respondents. In particular, whatever barriers to accessing testing and treatment were identified by these respondents may be even more acute for the PLHIV who are not included in these samples. At the same time, respondents not included here might have identified quite different barriers had we been able to identify and interview them.

Information about the Country Surveys

About the Country Samples

Table 1: Country sample sizes and characteristics

Country	Number	% Female	Ages	% Urban	% Key Population*
Estonia	87**	44%	15 to 50+	83%	87% 79% IDU, 59% Prisoner, 12% Sex worker, 6% MSM/G/L
Moldova	403	51%	15 to 50+	59%	56% 37% IDU, 24% Prisoner, 17% Migrant worker
Poland	504	39%	15 to 50+	72%	66% 43% IDU, 20% MSM/G/L, 8% Prisoner
Turkey	100	21%	21-50	89%	64% 36% MSM/G/L, 7% Sex worker, 6% Prisoner, 6% Indigenous, 5% Transgender
Ukraine	1500	45%	15 to 50+	68%	76% 65% IDU, 25% Prisoner, 6% MSM/G/L, 5% Sex worker

* Respondents could identify with multiple key populations so the percentages for each group add up to more than 100%. In addition to the main groups listed here, each country sample also included smaller numbers of other key populations.

** Though the sample size for the purposes of this study was 87 – the full PLHIV Stigma Index study for Estonia has a sample size of over 300.

Key Populations

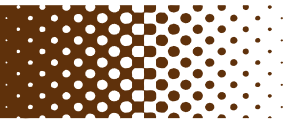
Research teams attempted to gain representative samples that reflected each national epidemic. Because of this, and because of constraints set by the resources and capacity to outreach to engage some sub-populations, each country has a different configuration of respondents from key populations.

If there were fewer than 5 respondents from a population for a country, then that population was not included in the analysis that follows.

The following list shows the key populations that are included in each country analysis. Note that respondents were asked to mark a population if they currently, or had ever, been part of that group/category.

Table 2: Key populations in each country analysis

Key Population	Country				
	Estonia	Moldova	Poland	Turkey	Ukraine
Gay/Lesbian	✓	–	✓	✓	✓
Member of an indigenous group (Indigenous person)	–	–	–	✓	✓
IDU (Injecting drug user)	✓	✓	✓	–	✓
Internally displaced person	–	–	✓	–	✓
Migrant worker	–	✓	–	–	✓
MSM	–	–	–	✓	✓
Prisoner	✓	✓	✓	✓	✓
Refugees and asylum seeker	–	–	–	–	–
Sex Worker	✓	–	✓	✓	✓
Transgender	–	–	–	✓	✓



Barriers to HIV Testing

Length of Time before Testing

Question 1:

How long did you wait between the time you first thought you should get an HIV test and the time you took the HIV test?

To understand the barriers to HIV testing, it is first important to know whether people are testing late and, if so, whether there are certain characteristics that can help identify which people are testing later than others. The first question asked people living with HIV in all five countries whether there was a delay between the time they first thought they should get an HIV test and the time they actually took the test.

Question asked: How long did you wait between the time you first thought you should get an HIV test and the time you took the HIV test?

- 0-3 months
- 4-6 months
- 7-12 months
- 1-2 years
- 2-5 years
- More than 5 years

If people reported that they felt the need to test, yet delayed doing so, then we can investigate how stigma or other factors might have acted to slow the time to test. If, on the other hand, people reported little to no wait time before testing, then we know that either people are getting tested promptly, despite any hesitations or barriers, or they needed to test earlier but were unaware of that fact.

Most respondents reported that they tested within six months of the time they first thought they should get a test. However, the percentage had a wide range, from only 58% of respondents in Estonia to 95% in Turkey. As Estonia and Turkey had the smallest sample sizes, it is possible that larger numbers of respondents might provide a modified picture of the average time before testing in these countries. Responses differed, sometimes substantially, based on the gender of the respondent, with more women than men reporting that they tested within six months in every country except Poland.

Late testing, although reported with less frequency, was also reported by respondents. From 5% to 42% of respondents waited more than six months to test. Moreover, in Estonia, Poland, and Ukraine, 10% or more of respondents indicated that they waited two or more years to test.

Table 3: Elapsed time in accessing testing

Country	Tested within 6 months	Tested between 7 months and 2 years	Tested after more than 2 years	Total
Estonia	58%	32%	10%	100%
Moldova	92%	5%	4%	100%
Poland	67%	20%	13%	100%
Turkey	95%	3%	2%	100%
Ukraine	72%	15%	13%	100%

Numbers may not equal 100% because of rounding

Table 4: Elapsed time in accessing testing by gender

Country	Men tested within 6 months	Sample (n)	Women tested within 6 months	Sample (n)
Estonia	47% (n=23)	100% (n=49)	71% (n=27)	100% (n=38)
Moldova	87% (n=171)	100% (n=196)	96% (n=199)	100% (n=207)
Poland	66% (n=175)	100% (n=266)	68% (n=144)	100% (n=167)
Turkey	93% (n=67)	100% (n=72)	100% ⁶ (n=20)	100% (n=20)
Ukraine	68% (n=542)	100% (n=793)	76% (n=495)	100% (n=648)

Numbers may not equal 100% because of rounding

Groups most and least likely to test within 6 months

The demographic information in the questionnaire allowed the identification of characteristics associated with earlier and later testing. In general, being younger (under age 25) and not belonging to any of the key population groups was associated with earlier testing. Later testing was frequently associated with having lower income and with belonging to any key population, particularly injecting drug users or prisoners, but also gay men, sex workers, and internally displaced persons.

Interestingly, Turkey had the most exceptions to these general findings. Because the variation in responses from Turkey is the smallest of any country (as almost every respondent tested within six months), these differences should be viewed with some caution.

Table 5: Those most likely to test within six months of diagnosis

	Most likely to test within 6 months, by country				
	Estonia	Moldova	Poland	Turkey	Ukraine
Age	20-24	<25	20-24		<25
Income level	Higher income			Lower income	
Key population		Belong to no key population		Belong to no key population	Belong to no key population
Education level			Technical college or university education	Only a primary-level education	
Location				Live in a small town	

⁶ In the sample from Turkey, all women reported testing within 3 months of the time they first thought they needed an HIV test. Few women in this sample tested for pregnancy. Many of these women tested because they had suspected HIV symptoms (almost 30%). While the percentage of those testing within 3 months appears unusually high, it is important to recognise the likelihood that many of these women had been living with HIV for quite some time, as demonstrated by the number whose HIV infection was advanced at the time of testing. This situation indicates that these women needed to know their diagnosis much earlier but were unaware that they needed to be tested.

Groups least likely to test within 6 months:

Table 6: Those least likely to test within 6 months of diagnosis

	Least likely to test within 6 months, by country				
	Estonia	Moldova	Poland	Turkey	Ukraine
Age	>40	40-49	>30, especially >50	40-49	30-39
Income	Lower income		Lower income		Lower income
Key population	Belong to no key population	Injecting drug users Prisoners	Injecting drug users Prisoners Internally-displaced people	Gay men	Sex workers Prisoners Injecting drug users
Education level					
Location				Live in an urban area	

Reasons for HIV Testing

To better understand the factors associated with late testing, the length of time that respondents waited to test was examined against the reasons that respondents gave for testing.

This process allows us to identify whether certain reasons for testing were associated with earlier versus later testing. This is important because it shows where and how interventions might be targeted to increase testing.

Question from the PLHIV Stigma Index: Why were you tested for HIV? (Tick one or more boxes as appropriate).

- Employment
- Pregnancy
- To prepare for a marriage/sexual relationship
- Referred by a clinic for sexually transmitted infections
- Referred due to suspected HIV-related symptoms (e.g. tuberculosis)
- Husband, wife, partner, or family member tested positive
- Illness or the death of husband, wife, partner, or family member
- I just wanted to know
- Other

Some reasons are intuitively associated with earlier testing. When people test because of employment or pregnancy, for example, they generally have little time to delay the test. However, these people may have thought previously that they should test and just not done it yet, so respondents who reported testing because of employment or pregnancy might still report that they waited before testing. The results from Poland demonstrate this scenario: 22% of those testing because of pregnancy

and 40% of those testing because of employment reported that they had thought that they should get tested more than a year earlier.

The charts in this section show the top testing reasons associated with testing within six months and the top reasons associated with testing after more than two years for each country. The percentage given is for how many of the people who tested for each reason tested within 6 months or after two years respectively.

Reasons given for testing within 6 months

Pregnancy, referral because of other sexually transmitted infections, the positive test result of a spouse, partner or family member, to prepare for marriage or a sexual relationship, and symptoms of HIV infection, were the top reasons associated with testing within 6 months.

In every country, those testing because of pregnancy had the highest percentages for testing within six months. This ranged from 78% of those testing because of **pregnancy** in Poland to 99% in Moldova. Respondents were likely to point to the **positive test of a family member** as the reason for testing. In every country, those who tested for this reason were likely to test within six months. This indicates that these respondents were not aware that they and their family members might be at risk before the first positive test was received.

The results from Estonia indicating that high percentages (75%) of those who tested because they had **symptoms related to HIV** tested within six months, and similar results seen in the Turkish sample, require some comment. This indicates that these individuals were likely living with HIV for quite some time without realising that they needed to be tested. As such, this short wait time more likely reflects a lack of education campaigns to raise awareness of the risks of infection rather than true early testing.

In the tables below, the percentages given equal the percentage of respondents who tested for each reason who tested within six months of first thinking that they needed to test. For example, in Estonia, of those who tested because of pregnancy, 86% tested within six months.

Table 7: Reasons given for HIV testing given by those who tested within 6 months of diagnosis

Reasons for HIV testing given by those who tested within 6 months					
	Estonia	Moldova	Poland	Turkey	Ukraine
Pregnancy	86%	99%	78%	100%	89%
Referred due to suspected HIV symptoms	75%	86%	69%	86%	73%
Referred to a clinic because of an STI	17%	84%	75%	100%	71%
Partner or family member tested HIV positive	67%	98%	75%	100%	81%
Preparing for sexual relationship or marriage	100%	94%	73%	100%	84%

Reasons given for testing after more than 2 years of thinking one ought to have an HIV test

The top reasons associated with seeking testing late (defined as more than two years after one first thought that one ought to have an HIV test) were referral due to suspected HIV symptoms, referral because of other sexually transmitted infections, employment, death of a spouse, partner, or family member, the respondent wanted to know, and other reasons. What is clear from these results is how many people who needed to have an HIV test considered it for a substantial period of time before they actually sought testing.

That so many of the respondents from Moldova and Ukraine who tested because of **symptoms related to HIV** indicated that they had waited more than two years to test (and that so many waited at least one year in the case of Turkey) is particularly troubling. Anytime a person tests because she or he is experiencing HIV-related symptoms, it is a personal and community tragedy. In these cases, it is possible that the symptoms, and the related stress on their immune systems was avoidable had these individuals felt ready, supported, and safe to learn their serostatus. In addition, it is notable that, in Estonia, Poland, and Turkey, many of those who delayed testing were people who chose to test because they **just wanted to know**. In both cases, this indicates that messages about testing are reaching at least some of the people who need them; however something(s) are interfering with testing as early as people need.

Preliminary analysis of responses given to explain an answer of **“Other”** shows that this response in the countries surveyed seems to frequently be because of jail or prison, but may also be from blood donation, joining the military, or routine medical exam. This will become clearer once all the surveys have been translated and a qualitative analysis has been performed of the open-ended questions.

Both lists demonstrate that some programs, such as referrals from STI clinics and programs that encourage testing for pregnant women and partners/spouses of those who test positive, appear to be performing their desired function and are responsible for providing many of the respondents with their diagnoses.

Table 8: Reasons for HIV given by those who waited more than 2 years to test

Reasons for HIV testing given by those who waited more than 2 years to test*					
	Estonia*	Moldova	Poland	Turkey*	Ukraine
Referred due to suspected HIV symptoms	25%	6%	8%	14%	16%
Referred to a clinic because of an STI	83%	7%	6%	0%	12%
Death of partner or family member	0%	0%	14%	0%	17%
Preparing for sexual relationship or marriage	0%	6%	0%	0%	11%
Employment	0%	6%	20%	0%	14%
Other	32%	2%	19%	0%	19%
I just wanted to know	28%	6%	15%	20%	14%

* Because of small sample sizes, percentages presented for Estonia and Turkey are for those who waited more than 1 year to test, rather than 2 years as for the other countries

Anticipation of Stigma

To better understand whether respondents had hesitated to test for HIV because of fears about how other people would respond (anticipated stigma), the following question was asked:

Question 2: Did fears about how other people (for example, your friends, family, employer, or community) would respond if you tested positive make you hesitate to get tested?

- Yes
- No

Significant percentages from every country indicated that they did hesitate for this reason. Reports of hesitation because of anticipated stigma were most pronounced in Estonia and Ukraine, where majorities of respondents (60% and 58% respectively) answered affirmatively.

The lowest percentage of responses came from Turkey and Moldova, where just under one third of respondents said that they hesitated to test because of anticipated stigma. This is notable given that the samples from these countries were comprised almost entirely of people who tested within 6 months of first thinking that they should test.

In Moldova and Turkey, significantly more men than women indicated that they hesitated for this reason. In Estonia and Poland, more men than women reported this hesitation but the difference was not significant. By contrast, in Ukraine, this anticipation of social stigma was reported by more women than men.

Reasons given about fears regarding testing and how other people would respond if tested positive

In all countries, those who reported this hesitation tested later than those who did not. The biggest effect of this hesitation on the time to test was seen in Estonia where, of those who reported that they hesitated because of this fear, only 38% tested within 6 months while 17% waited more than 2 years to test. By contrast, none of those who answered “no” to this question waited 2 years to test.

Table 9: Fears about testing - anticipated stigma (all respondents)

Percentage who answered “Yes” to the question Did fears about how other people would respond if you tested positive make you hesitate to get tested?					
	Estonia	Moldova**	Poland**	Turkey	Ukraine***
% of Men	61	37	41	34	55
% of Women	58	25	38	0	61
% Cumulative	60	31	40	29	58

** Differences are statistically significant at the $p < .01$ level

***Differences are statistically significant at the $p < .05$ level

Examining only the responses of those who tested within 6 months, the impact of this hesitation is marked. For example, in Estonia, of those who said that fears of others’ reactions made them hesitate to test, only 38% were tested within 6 months. This compares with 86% of those who answered this question “No.” The difference in testing behaviour within 6 months between those who hesitated because of anticipated stigma and those who did not ranges from 8% to 47%. While fear of social stigma cannot explain all late testing, these results point to a key role for this kind of anticipated stigma in delaying HIV testing.

Table 10: Fears about testing - anticipated stigma (respondents testing within 6 months of diagnosis)

Those who reported getting tested within 6 months and how they answered the question Did fears about how other people would respond if you tested positive make you hesitate to get tested?					
	Estonia	Moldova	Poland	Turkey	Ukraine
Yes	38%	81%	60%	79%	68%
No	86%	97%	71%	100%	77%
Difference	-47%	-16%	-11%	-21%	-8%

Key : (yes minus no)

(impact of fear on getting tested within 6 months)

>0% (fear for what others will react causes early testing)

<0% (people decide to test early irrelevant of their fears of others’ reactions)

Differences are statistically significant at the $p < .003$ level for every country

The responses above imply that fear based testing approaches do NOT work and additionally people's motivations to test early are for other reasons than reactions of peers/colleagues/community.

Significant differences between subpopulations

Some populations were more likely than others to report hesitation based on anticipated stigma. In Estonia, Poland, Turkey, and Ukraine, **those under 30** reported more hesitation, while those over 30 in Moldova were more likely to report that they hesitated because of anticipated stigma. In Estonia and Turkey, those who identified as gay or lesbian (as well as those identifying as MSM and transgender in Turkey) reported higher levels of hesitation. In Moldova, injecting drug users reported more hesitation; as did sex workers in Poland and Ukraine.

In Estonia and Ukraine, significantly higher hesitation was reported among those who were diagnosed more recently (in the last 10 years in Estonia and the last 5 years in Ukraine). This provides some indication that stigma, or at least the fear of stigma, may be growing in these areas. However, the opposite effect was seen in Moldova, where higher percentages of those diagnosed more than 5 years ago reported this hesitation than those diagnosed more recently.

Reasons for delays in accessing testing - Fears about Testing Positive

To further identify factors that could inhibit people who think they should get tested to actually seek testing, interviewers asked respondents whether they were afraid that any, of a list of potential concerns, might happen if they tested positive for HIV.

Question 3 : Were you afraid that any of the following would occur if you tested positive? (Tick one or more boxes.)

- I would lose my job or be removed from my school program
- I would be shunned by family or friends
- My husband/wife/partner would be physically violent with me
- Other family members would be physically violent with me
- Members of my community would be physically violent with me
- My husband/wife/partner would leave me
- My children would be taken from me
- I would be forced to terminate a pregnancy
- My children would be treated badly by our family, our community, or their school
- I would not be able to get married
- I would be forced to leave my home or community
- The police or legal authorities might attempt to bring criminal charges against me
- People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user
- People might find out that I am, or have been, sexual outside of marriage, a man who has sex with men, a sex worker, or an IV drug user
- Other fears

The top fears were largely consistent across women and men and across countries, although these fears were ranked differently. The top three concerns for women and for men, by country, can be

found in the tables below. A complete list of the percentage of respondents who selected each factor, by country and by gender, is in Appendix A.

Overall, relational concerns (about marriage, partners, children, and families) were high for all respondents. The most commonly reported fear among women and men in every country was that they would be **shunned by family or friends** – a situation that can be emotionally, psychologically, and financially devastating. In addition, respondents expressed strong fears about being **left by their spouse or partner** or about **not being able to marry** if they tested positive. Fears that one’s children would be treated badly by their family, community, or school also ranked very high, particularly for women in Poland and Ukraine and for both men and women in Moldova.

Second to relational concerns, were fears that one might be perceived as **sexually active outside of marriage, a man who has sex with men, a sex worker, or an injecting drug user**. Fears about being associated with these stereotypes about HIV-positive people, and the related negative judgements toward those who are part of any of these groups, were strongest in Moldova and Poland, but were present in high numbers among male and female respondents from every country.

Respondents from Turkey indicated a fear of **losing their job or being removed from a school program** if they tested positive in much higher percentages than in any other country. In Turkey, 41% selected this fear compared to less than 20% in every other country.

In addition to the reasons for delay listed in the tables, respondents indicated that there were other reasons that they delayed testing. The percentage of respondents who noted “Other” fears varied greatly; from 9% in Poland to 55% in Estonia (percentages for each country can be found in Appendix A). The PLHIV Stigma Index contains an open-ended question on barriers to testing; translation and analysis of the responses to this question may provide insights into these other fears.

Table 11: Women’s Top 3 testing fears by Country

Women’s Top 3 testing fears by Country					
	Estonia	Moldova	Poland	Turkey	Ukraine
1	I would be shunned by family or friends	I would be shunned by family or friends	I would be shunned by family or friends	I would be shunned by family or friends	I would be shunned by family or friends
2	My husband/wife/partner would leave me and I would not be able to get married (equally indicated)	People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user	My children would be treated badly by our family, our community, or their school	My husband/wife/partner would leave me	I would not be able to get married
3	My husband/wife/partner would leave me and I would not be able to get married (equally indicated)	My children would be treated badly by our family, our community, or their school	People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user	I would lose my job or be removed from my school program	My children would be treated badly by our family, our community, or their school

Table 12: Men's Top 3 testing fears by Country

Men's Top 3 testing fears by Country					
	Estonia	Moldova	Poland	Turkey	Ukraine
1	I would be shunned by family or friends	I would be shunned by family or friends	I would be shunned by family or friends	I would be shunned by family or friends	I would be shunned by family or friends
2	People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user	My children would be treated badly by our family, our community, or their school	People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user	My husband/wife/partner would leave me	I would not be able to get married
3	I would lose my job or be removed from my school program	People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user	My husband/wife/partner would leave me	People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user	My husband/wife/partner would leave me

Significant differences between subpopulations

When analysed by subpopulations, key differences emerged in the responses selected to this question. Below are the conclusions and differences by country.

Estonia:

In Estonia, significant differences emerged based on:

- Membership in a key population
- Length of time one had been living with HIV
- Income level

Of note, not one respondent in the Estonian sample indicated a fear of violence by intimate partners, family members, or community members and no one expressed concern about being forced to terminate a pregnancy.

Concerns about one's children being mistreated by the community may be an emerging issue in Estonia. These fears were expressed only by those **infected within the last ten years**, even though this group was not any more likely to have children. Respondents from the **lowest income category**, all women, expressed the most fear about their children being mistreated as a result of their positive diagnosis. This was also the case with all **lesbians** in the sample and those **respondents who did not identify with any of the key populations** (20% of lesbians and 18% of non-key populations, compared with 8% of all women in the sample and 3% of the entire sample).

Further fears about the possible effects on one's children of a positive test result were expressed by **sex workers** (all female in this sample), with 10% of sex workers worried that their children might be taken from them compared with 5% of all women in the sample.

On the other hand, fears of being associated with a stigmatised group or being identified as a member of a stigmatised group have steadily decreased, with **those diagnosed in the last 5 years** being the least likely to express these fears. The exception to this is among **prisoners and former prisoners**, who expressed significantly higher fears about being stereotyped (as promiscuous, a man who has sex with men, a sex worker, or a person who uses drugs) no matter when they were diagnosed, with 31% compared to 11% of non-prisoners. This overall decline can be explained, in part, by the increased numbers of people in the sample who have not been incarcerated. However, this cannot explain the decrease from 7% of members of key populations fearing being 'outed' more than 10 years ago to 0% of these members reporting this fear in the last 5 years. In addition, the change in the composition of groups cannot explain why those respondents who are not from key populations demonstrated so much less fear of the negative stereotypes that have generally been associated with HIV.

Moldova:

Significant differences in responses from Moldova were based on:

- Age
- Membership in a key population
- Urban or rural location
- Length of time living with HIV
- Income

Unlike Estonia, fear of being associated with stereotypes about HIV-positive people appears to be on the increase in Moldova, with respondents in the sample who were **diagnosed in the last year** indicating much higher concerns about these stereotypes than those who have been diagnosed longer than this (whose fears about stereotypes are also high). For those diagnosed in the last year, the percentage that fear association with these stereotypes is equal to the fear they express of being shunned by family and friends (47% compared with 33% overall). Those respondents most afraid of being seen as promiscuous or as belonging to one of the key, stigmatised, populations associated with HIV were **young people under the age of 25, migrant workers, and people in rural areas**.

Related to the fear of stereotypes about people with HIV, fear that testing positive would reveal that one belonged to one of the groups stereotypical associated with HIV was expressed in higher percentages by those who were ever **prisoners** or **injecting drug users**.

In Moldova, **young people under the age of 25** were more concerned about intimate partner violence and about being forced to terminate a pregnancy.

Migrant workers were much more afraid than the rest of the sample of being shunned by family and friends, left by one's spouse or partner, and being forced to leave one's home or community.

Respondents from **rural areas** expressed significantly more concerns on almost every category: being shunned by family and friends (shared by those in small towns), intimate partner violence, being left by one's spouse or partner, losing one's children, being forced to terminate a pregnancy, mistreatment of one's children, not being able to marry, and being forced from one's community.

Respondents from **urban areas** expressed more concern about losing a job or being removed from a school program, and facing criminal charges because of their HIV status.

Those with the **lowest income** expressed significantly more concerns about being shunned by family and friends and about experiencing violence by family members (other than one's spouse or partner).

Poland:

In Poland, significant differences in responses to this question were based on:

- Age
- Membership in a key population
- Urban or rural location
- Level of education

The young people in the sample had significantly higher concerns than those over the age of 30. Those **between the ages of 20 and 30** were much more concerned about losing their job or being removed from their school program. Those **under the age of 30** were significantly more concerned about being left by their spouse or partner and those **between the ages of 25 and 29** expressed significantly more concern that people would find out about private behaviours or identities (membership in a stigmatised group).

Respondents who belonged to **any key population** were significantly more concerned that people might find out that they were, or had been, sexual active outside of marriage, a man who has sex with men, a sex worker, or an injecting drug user. Current or former **sex workers** and **injecting drug users** expressed the greatest concerns about this.

Gays and lesbians in the Polish sample were much more afraid of losing their job or their school program, of losing their spouse/partner, and of being associated with stereotypes about people who are living with HIV.

Internally displaced people and **sex workers** were highly concerned about family member violence. **Sex workers** were also significantly more concerned about violence directed toward them by intimate partners and by community members. Large and statistically significant percentages of **sex workers** expressed fears that their children would be taken away from them. In addition, **sex workers, injecting drug users** and **prisoners** expressed higher concerns about their children being treated badly if they tested positive.

Those in **small towns** reported significantly higher fears of being left by a spouse or partner, having their children mistreated, being forced to leave their home or community, facing criminal charges, and being perceived as promiscuous, as a man who has sex with men, as a sex worker or an injecting drug user, than those in either rural or **urban** areas. Note that large numbers of respondents from all locations reported all of these fears, with the exception of criminalisation, however respondents from small towns reported levels of fear that ranged from 1.3 to 3.75 times higher.

Those with **higher levels of education** were significantly more concerned about losing their job or being removed from their school program. Those with no more than a **primary level of education** were most concerned about not being able to marry.

Turkey:

In the sample from Turkey, significant differences emerged based on:

- Membership in a key population
- Urban or rural location
- Level of education

Those who identified as **men who have sex with men** or as **sex workers**, were significantly more concerned about violence by partners or spouses, by other family members, and by community members. **Men who have sex with men** also expressed substantially higher concerns that they would be forced to leave their home or community.

Men who have sex with men and **gay men** both expressed significantly higher levels of concern that people would find out that they belonged to a group that received negative social judgements (that they were a man who has sex with men, a sex worker, an injecting drug user, or sexually active outside of marriage).

Respondents who identified with **any of the key populations** were significantly more likely to fear that criminal charges would be brought against them.

Those from **small towns** were significantly more concerned that they would be forced to terminate a pregnancy and that they would not be able to marry. No respondents in the sample from Turkey came from rural areas.

In the Turkish sample, those with the **least education** were the most concerned that they would be targets of violence by family or community members. Those with the **highest education** expressed the most fears about being associated with negative stereotypes.

Ukraine:

In Ukraine, significant differences in responses were based on:

- Age
- Membership in a key population
- Rural location

Young people (under the age of 30) had many more concerns than those over the age of 30. Those under the age of 30 were more concerned about being shunned and that they would not be able to get married. Those between the ages of 20 and 29 expressed higher fears of being forced to terminate a pregnancy and those under the age of 25 were substantially more concerned about intimate partner violence and family violence.

In Ukraine, those who belong to **any of the key populations** are significantly more afraid of criminalisation if they test positive. In addition, **men who have sex with men, gays and lesbians**, and **sex workers** expressed substantially higher fears of violence directed at them by intimate partners, family members, and community members.

People from **rural areas** reported significantly more fear of being forced to leave their homes or communities, of violence directed at them by community members, of being shunned by family and friends, and of mistreatment of their children by their families, communities, or schools.

Effects on current health status of Length of Time before Testing

To explore whether people who wait to get an HIV test have later negative health effects we used an existing question in the PLHIV Stigma Index which asks respondents to describe their health at the

time of the survey and cross analysed this in relation to the time that respondents had waited before getting an HIV test.

Question from the PLHIV Stigma Index: In general, how would you describe your health at the moment?

- Excellent
- Very good
- Good
- Fair
- Poor

As demonstrated in the chart below, excellent or very good health at the time of the survey is strongly associated with testing within 6 months; from this analysis it appears to be the case that amongst the respondents to this survey people are suffering negative health outcomes because of delaying testing for HIV.

Table 13: Cross Analysis - Respondents perception of their current health in relation to amount of time before accessing care

Cross Analysis: Respondents perception of their current health in relation to amount of time before accessing care					
		0-6 months	7-12 months	1-2 years	2 years or more
Estonia***	Excellent or very good	71%	14%	14%	0%
	Good	74%	0%	22%	4%
	Fair or poor	49%	16%	21%	14%
Moldova***	Excellent or very good	100%	0%	0%	0%
	Good	94%	1%	1%	4%
	Fair or poor	89%	3%	4%	4%
Poland***	Excellent or very good	78%	8%	4%	10%
	Good	70%	11%	7%	12%
	Fair or poor	60%	11%	13%	16%
Turkey**	Excellent or very good	96%	0%	2%	2%
	Good	100%	0%	0%	0%
	Fair or poor	79%	0%	14%	7%
Ukraine**	Excellent or very good	83%	3%	4%	10%
	Good	78%	7%	6%	10%
	Fair or poor	68%	6%	11%	14%

***Differences between groups statistically significant at the p<.005 level using a one tailed T-test

**Differences between groups statistically significant at the p<.10 level using a one tailed T-test

In every country, those who reported the best current health were those who tested within 6 months while those with the poorest current health were disproportionately represented by those who waited more than a year to test.

Overall, respondents reported very high levels of poor health. In Estonia, Moldova, Poland and Ukraine, very few respondents reported excellent or very good health. In Estonia, Moldova, and Po-

land, more respondents characterised their health as poor than excellent or very good combined.

By contrast, in Turkey, most respondents reported their health as good or very good. The proportion of those with good versus ill health was very different from the other countries, but the direction in which the numbers moved was the same.

In Estonia, for example, only 8% of respondents reported excellent or very good health. However, 71% of those who reported the best health indicated that they tested within 6 months. In Moldova, 100% of those reporting excellent or very good health tested within 6 months. In Ukraine, 83% tested within 6 months.

Looking at those with fair or poor current health, the pattern is reversed. In Estonia, 14% of those with fair or poor health waited 2 years or more to test, compared with none of those with the best current health. In Poland and Ukraine, 16% and 14% of those with fair or poor health waited 2 or more years to test, compared with only 10% of those reporting their health as excellent or very good. In Turkey, of those with fair or poor health currently, fewer than 80% tested within 6 months and 21% waited more than a year to test (with 7% of those waiting more than 2 years to test). In a sample in which only 5% of respondents waited more than 6 months to test, it is particularly notable that these respondents comprise more than 20% of those with the worst health outcomes currently.

When interpreting these numbers, it is important to remember that a portion of the people who tested within 6 months was already exhibiting symptoms related to HIV infection. Those individuals might be expected to have worse health outcomes. Interestingly, despite this possibility, the relationship between testing within 6 months of first realising that one needs a test and one's health at the time of the interview is strong.

Barriers to Accessing HIV Care

Length of Time before Accessing Care after diagnosis

To explore the transition between diagnosis and accessing care we asked respondents to report the length of time that had elapsed between receiving their diagnosis and accessing care services. In posing this question we made the distinction that accessing care services for HIV was not only accessing ART.

Question 4: How long did you wait between the time you tested positive and the time that you started seeing a health professional for your HIV infection (whether or not you started medications at that time)?

- 0-3 months
- 4-6 months
- 7-12 months
- 1-2 years
- 2-5 years
- More than 5 years
- I have not yet started receiving treatment

Respondents reported the following lengths of time from diagnosis to accessing care services:

Table 14: Lengths of time from diagnosis to accessing care services

	Estonia	Moldova	Poland	Turkey	Ukraine
care within 6 months	51%	31%	58%	90%	44%
care between 7 months and 2 years	34%	9%	15%	4%	16%
care after more than 2 years	14%	24%	23%	4%	25%
Not yet in care	1%	36%	4%	2%	15%

Numbers may not equal 100% because of rounding

Additionally a breakdown was made between men and women for those accessing care within 6 months of diagnosis:

Table 15: Lengths of time from diagnosis to accessing care services breakdown by gender of those accessing care within 6 months

	Estonia	Moldova	Poland	Turkey	Ukraine
care within 6 months (Men)	49%	26%	60%	91%	40%
care within 6 months (Women)	54%	36%	15%	56%	95%

Numbers may not equal 100% because of rounding

With the exception of the sample from Turkey (with 90% reporting that they accessed care within 6 months), the percentage of respondents who accessed care within six months after diagnosis ranged from 31% in Moldova to 58% in Poland. High percentages of both men and women in Moldova, Poland, and Ukraine reported accessing care very late (more than 2 years after diagnosis). In addition, high percentages in Moldova and Ukraine reported that they are not receiving any care at all.

In every country but Poland, women were more likely than men to access care within 6 months.

From the responses received it appears the time before accessing care may be growing shorter in Moldova, Poland, and Ukraine. In Moldova, 40% of those diagnosed accessed care within six months, compared with 25% of those diagnosed more than five years ago. For Poland, the percentage jumped to 84% from 52%. In Ukraine, the percentage went to 58% from 32%. This deserves further examination to identify the factors that might have influenced this development.

Respondents from key populations accessed care later than their counterparts. Overall, in Moldova, Poland, and Ukraine, respondents who belonged to at least one key population group were significantly less likely to access care within six months than respondents who belonged to no key population group. Nineteen percent of members of key populations' accessed care in six months in Moldova compared to 49% of respondents who were not members of key a population. In Poland and Ukraine, the percentages were 45% to 60% and 36% to 63% respectively. In Turkey and Estonia, with the smallest sample sizes in the study, overall numbers were similar between those who were members of key populations and those who were not. Looking at groups, some key population groups were notably later to access medical care. **Prisoners** and former prisoners in Estonia, Moldova, Poland, and Ukraine were significantly less likely to be in care within six months. Those who were, or ever had been, **sex workers** reporting receiving care later than non-sex workers in Turkey and Poland. **Injecting drug users** in Moldova, Poland and Ukraine also reported significantly later access of medical care. Finally, **transgender** respondents in

Turkey and **internally displaced people** in Ukraine were also significantly less likely to report access of medical care within six months.

In addition to the later uptake of care among members of traditional key populations, rural people in Ukraine were more likely to wait more than two years, and even more than five years, for care, while people with the lowest incomes in the Polish sample were significantly more likely to wait more than two years before accessing medical care.

Fears and Concerns about Accessing Care

To better understand the issues in each country that discourage or prevent people from accessing care after their HIV diagnosis, respondents were presented with a list of possible reasons that they might have had for delaying to seek care.

Question 5: 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. (Tick one or more boxes)

- I could not afford health care
- I did not receive a referral or did not know where to go to get HIV care
- I was not ready to deal with my HIV infection
- It was difficult to arrange transportation to the clinic or hospital
- I was afraid that the health workers (doctors, nurses, staff) would treat me badly
- I was afraid that someone I knew would see me there
- I would have had to tell my husband/wife/partner if I started getting care
- I could not receive care during work hours without disclosing my HIV status to my employer
- I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with men
- I had a bad experience with a health worker previously
- I lack legal status or documentation
- I was incarcerated and was not able to access HIV care
- Other reasons

Across the region, the most commonly reported reason for delaying medical care was that the respondent was **not ready to deal with her or his HIV infection**, with particularly high numbers seen in Estonia, Poland, and Ukraine. Although these numbers declined for those diagnosed within the last five years in Moldova, Turkey, and Ukraine (although the Ukrainian numbers remain very high), the proportion of people in the Polish and Estonian samples who delayed seeking care because they felt they were not ready to deal with their diagnosis remained uniformly high, whether one was diagnosed one or fifteen years ago. The breadth of this response highlights a real need for psycho-social support for people after diagnosis so that they are able to make informed choices about accessing care.

The role played by healthcare workers in creating safe environments for people to seek care emerged as a key issue. High percentages of respondents from all countries, with smaller numbers in Moldova, expressed concerns about **mistreatment and lack of confidentiality by health care workers**. In addition, women and men in Estonia and Ukraine indicated that they hesitated to access care because of a previous **bad experience with a health care worker**.

In Estonia, Turkey, and Ukraine, many respondents indicated an additional fear about confidentiality, saying that the **fear that someone they knew would see them there** created a delay (with smaller numbers in Moldova and Poland selecting this fear as well). In addition, Estonian women in the sample reported concerns about having to **disclose to their spouse or partner**.

Fear of being associated with **stereotypes** about HIV-positive people appeared again as a frequent concern, particularly among respondents in Estonia and Turkey.

Pragmatic issues also materialised as concerns: Respondents in Poland, Turkey, and Ukraine indicated that the **lack of referrals or not knowing where to go to get care** created delays in their access of care. In addition, men from Turkey noted that the **cost of care** was a barrier; women from Turkey indicated that the need for **transportation** created a barrier; and men from Ukraine indicated that they were not able to access care while **incarcerated**.

The top three concerns for women and for men, by country, can be found in the tables below. Overall, almost all of the top reasons for delaying the uptake of care for women were related to anticipated stigma. This is also the case for men, however, they also report more physical barriers to access, such as incarceration or the inability to afford health care. A complete list of the percentage of respondents who selected each factor, by country and by gender, is in Appendix B.

Table 16: Men's Top three reasons for delaying care by country

Men's Top three reasons for delaying care by country					
	Estonia	Moldova	Poland	Turkey	Ukraine
1	I was not ready to deal with my HIV infection	I was not ready to deal with my HIV infection	I was not ready to deal with my HIV infection	I could not afford health care	I was not ready to deal with my HIV infection
2	I was afraid that someone I knew would see me there	I was afraid that the health care workers would disclose my status without my consent	I did not receive a referral or did not know where to go to get HIV care	I was not ready to deal with my HIV infection	I was incarcerated and not able to access HIV care
3	I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with men	I did not receive a referral or did not know where to go to get HIV care	I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with men and I was incarcerated and not able to access HIV care were equally recorded as reasons	I was afraid that the health care workers would disclose my status without my consent and I was afraid that someone I knew would see me there and I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with men were equally recorded as reasons	I was afraid that someone I knew would see me there

Table 17: Women’s top three reasons for delaying care by country

Women’s Top three reasons for delaying care by country					
	Estonia	Moldova	Poland	Turkey	Ukraine
1	I was not ready to deal with my HIV infection	I was afraid that someone I knew would see me there	I was not ready to deal with my HIV infection	I was afraid that the health workers (doctors, nurses, staff) would treat me badly	I was not ready to deal with my HIV infection
2	I was afraid that someone I knew would see me there	I was not ready to deal with my HIV infection and I did not receive a referral or did not know where to go to get HIV care were equally recorded as reasons	I did not receive a referral or did not know where to go to get HIV care	I was afraid that the health care workers would disclose my status without my consent	I was afraid that someone I knew would see me there
3	I was afraid that the health care workers would disclose my status without my consent		I was afraid that the health care workers would disclose my status without my consent	I was afraid that someone I knew would see me there	I was afraid that the health care workers would disclose my status without my consent

In addition to the reasons for delay listed in the tables, many respondents indicated that there were “Other” reasons that they delayed receiving care. The percentage of respondents who noted other reasons varied greatly; from 2% in Turkey to 22% in Ukraine (percentages for each country can be found in Appendix B). The PLHIV Stigma Index contains open-ended questions on challenges in relation to diagnosis, confidentiality, and antiretroviral treatment; translation and analysis of the responses to these questions may provide insights into these other reasons for delaying care.

Significant differences between subpopulations

When analysed by subpopulations, key differences emerged in the responses selected to this question.

Estonia

In Estonia, significant differences in responses emerged based on:

- Membership in a key population
- Length of time living with HIV
- Level of education

Those who identified as having even been **lesbians** (60%), **injecting drug users** (10%), or **prisoners** (14%) were significantly more likely to point to previous bad experiences with health workers as a reason for delaying care after their positive HIV test. By contrast, 5% of non-lesbians and none of the non-drug users and non-prisoners selected this as a reason for delaying care.

A lack of trust in healthcare workers to protect confidentiality is prominent among the **newly diagnosed**, with 67% of those diagnosed in the last year expressing a fear that healthcare workers would disclose their status without their consent. This compares with 19% of the overall sample. By contrast, concern about being associated with stereotypes about HIV-positive people has declined, with the newly diagnosed being the least likely to express these concerns as a reason for delaying care.

Those with the **highest levels of education**, technical or university degree, were the most likely to say that they delayed getting care because they were afraid that someone they knew would see them (64% compared to 30% overall).

Moldova

In Moldova, significant differences were seen based on:

- Membership in a key population
- Length of time living with HIV
- Level of education

Those who identified as having ever been **people who used drugs**, were significantly more likely to say that they delayed care because they were not ready to deal with their infection (11% to 3%). They were also more likely to report concerns about health care workers, specifically: fears of mistreatment (5% compared to 2%), concerns about lack of confidentiality (6% compared to 3%), and having experienced a previous bad experience with a healthcare worker (3% compared to 1%).

Respondents who identified with **any of the key populations** were much more likely to say that they delayed care because they were not ready to deal with their infection (8% compared to 3%).

In Moldova, concerns about the cost of care and knowing where to go to get care, and not being ready to deal with one's HIV infection have diminished over time and are less prominent among those **diagnosed within the last 5 years**.

Similar to Estonia, those with the **highest education** were most concerned that they might be seen accessing care.

Poland

In Poland, significant differences in responses were based on:

- Membership in a key population
- Length of time living with HIV
- Urban or rural location

Those **diagnosed within the last year** were much more likely to say that they could not afford care (7% compared to 1% overall).

The most striking differences in the Polish sample were between those who were gay/lesbian, sex workers, drug users, internally displaced, or prisoners and those who did not belong to these groups. Respondents who belonged to **any of the key populations** were ten times more likely to report having had a bad experience with a health worker previously (6% to 0.6%). In addition:

Sex workers were much more likely to hesitate to get care because of a bad experience with a health care worker previously (18% compared to 4% of non-sex workers). Sex workers were also much less likely to have received a referral for care or to know where to go to get care (27% versus 11% of non-sex workers).

Injecting drug users reported higher numbers for almost every reason for delay. Significantly more people who were or had been intravenous drug users indicating that they could not afford care (2% to 0%), were fearful that they would be mistreated by health workers (8% to 5%), were afraid that health workers would disclose their status without their consent (7% to 4%), had a previous bad experience with a health worker (8% to 1%), were afraid they would be associated with negative stereotypes (9% to 4%), lacked legal status or documentation (4% to 1%), were unable to access care because they were incarcerated (7% to 2%), and had other reasons for delay as well (19% to 12%).

Although the numbers of **internally displaced people** were small, they reported issues with transportation to care in significantly higher numbers compared to non-IDPs (13% to 2%). They also were significantly more likely to report that they were unable to access care because of incarceration (25% to 4%).

Those who were or had been **prisoners** reported higher numbers than non-prisoners for multiple reasons for delay. These included not receiving a referral or knowing where to go to get care (21% to 10%), having had a previous bad experience with a health worker (13% to 3%), being afraid they would be associated with negative stereotypes (13% to 6%), lacking legal documentation (13% to 1%), and being unable to access care because they were incarcerated (23% to 2%).

Compared to those in rural and urban areas, **respondents from small towns** were significantly more concerned that someone they knew would see them if they accessed care for their HIV infection (10% compared to 6% overall) and that they would be associated with negative stereotypes (12% compared to 6% overall).

Turkey

In Turkey, significant differences were identified based on:

- Age
- Membership in a key population group
- Income

In the sample from Turkey, those between the **ages of 25 and 29** were more likely to say that they could not afford care (35% compared to 10% overall). Those aged 50 and over were much more likely to say that they were not able to access care because they were incarcerated (25% to 1% overall).

Transgender respondents were much more concerned about being seen accessing care (40% compared to 12% of non-transgendered respondents) and having to disclose their status to their spouse or partner (40% versus 3%).

Prisoners and former prisoners, unsurprisingly, were more likely to indicate that they were unable to access care because they were incarcerated (17% to 0%).

Somewhat intriguingly, those with the **highest income** were significantly more likely to report that they could not afford health care (21% versus 10% overall).

Ukraine

In Ukraine, the significant differences that emerged were based on:

- Age
- Membership in a key population group
- Rural location

In Ukraine, **young people** had significantly more “other” reasons (more than 30% of those between 15 and 24 indicated other reasons). In addition, young people under 30 expressed the highest levels of fear that someone they knew would see them there.

For **members of key populations**, not being ready to deal with the infection was a much bigger issue than it was for those with no such group identification (31% to 21%). This shows a particular need for support services for members of marginalised and vulnerable populations in Ukraine. Those groups most affected were **injecting drug users** and **sex workers**. In addition, **sex workers** expressed much more fear of mistreatment by health workers.

For those in **rural areas** and those with **no formal education**, transportation was a big concern with 24% and 31% of these respondents, respectively, indicating that transportation was a barrier, compared with 8% overall. Finally, confidentiality concerns were stronger in **rural areas and small towns**, with 15% of these respondents concerned about health worker violations of confidentiality and 20% afraid that someone they knew would see them.

Impact that the lack of autonomy has on accessing care

A crucial question for this analysis was this: Did the degree of choice (or autonomy) which respondents had over testing affect the time that individuals waited to seek care after their diagnosis?

This question is important both because of the need to clearly understand the factors that support people with a new HIV diagnosis to access health care and because, unlike social stigma which is broadly dispersed and requires deep level changes, the testing (and counselling) process can provide a quick, clear, and accessible point of entry for interventions.

As part of the larger PLHIV Stigma Index project, respondents were asked standard questions about their testing experience - the extent to which it was voluntary and whether or not individuals received counselling and, if yes, when. Analysing these questions against the time that respondents reported waiting before accessing care, one of the supplementary questions specific to this study, allowed us to identify this relationship.

Question from the PLHIV Stigma Index: Was the decision to be tested for HIV up to you?

- Yes, I took the decision myself to be tested (i.e. it was voluntary)
- I took the decision myself to be tested, but it was under pressure from others
- I was made to take an HIV test (coercion)
- I was tested without my knowledge – I only found out after the test had been done

Table 18: Cross Analysis: Time elapsed between diagnosis and accessing care in relation to the degree of autonomy experienced by the respondent in taking the test

Cross Analysis: Time elapsed between diagnosis and accessing care in relation to the degree of autonomy experienced by the respondent in taking the test.

		0-6 months	7-12 months	1-2 years	2 years or more	Not in care
Estonia	I took the decision myself to be tested (i.e. it was voluntary)	57%	15%	17%	9%	2%
	I took the decision myself to be tested, but it was under pressure from others	42%	25%	17%	17%	0%
	I was made to take an HIV test (coercion)	30%	0%	30%	40%	0%
	I was tested without my knowledge – I only found out after the test had been done	55%	27%	9%	9%	0%
Moldova**	I took the decision myself to be tested (i.e. it was voluntary)	37%	6%	5%	19%	32%
	I took the decision myself to be tested, but it was under pressure from others	33%	2%	10%	24%	31%
	I was made to take an HIV test (coercion)	33%	0%	2%	37%	29%
	I was tested without my knowledge – I only found out after the test had been done	18%	1%	6%	28%	47%
Poland***	I took the decision myself to be tested (i.e. it was voluntary)	63%	7%	7%	18%	5%
	I took the decision myself to be tested, but it was under pressure from others	52%	11%	9%	25%	2%
	I was made to take an HIV test (coercion)	43%	4%	11%	43%	0%
	I was tested without my knowledge – I only found out after the test had been done	45%	7%	6%	36%	3%
Turkey**	I took the decision myself to be tested (i.e. it was voluntary)	94%	0%	0%	3%	3%
	I took the decision myself to be tested, but it was under pressure from others	82%	0%	0%	9%	9%
	I was made to take an HIV test (coercion)	67%	0%	33%	0%	0%
	I was tested without my knowledge – I only found out after the test had been done	90%	6%	0%	4%	0%
Ukraine**	I took the decision myself to be tested (i.e. it was voluntary)	48%	7%	9%	20%	15%
	I took the decision myself to be tested, but it was under pressure from others	40%	7%	10%	28%	15%
	I was made to take an HIV test (coercion)	35%	2%	7%	42%	14%
	I was tested without my knowledge – I only found out after the test had been done	32%	4%	14%	37%	13%

** Differences between groups are statistically significant at the p<003level

***Differences between groups are statistically significant at the p<.03level

As can be seen from the data above the relationship between voluntary testing and timely uptake of medical care was robust – as was the opposite relationship between involuntary testing and delayed uptake of care. Using Poland as an illustration, of those who reported that they tested voluntarily, 63% were accessing care within 6 six months. By contrast, only 43% of those who were forced to test and 45% of those tested without their knowledge were in care within the same time period. At the other end of the scale, 18% of those who tested voluntarily waited more than two years to access care, while 43% of those forced to test and 36% of those tested without their knowledge also waited more than two years for care. The trend is repeated in every country and is statistically significant in all but Estonia. The numbers for each country are available in the chart below.

In Estonia, Poland, and Turkey, those who were tested without their knowledge (and who were, therefore, tested without their consent) seemed, overall, to be accessing care earlier than those who knew they were being forced to test. However examining the reasons for testing given by those who were tested without their knowledge shows two primary reasons: a) most indicated that they were tested for reasons “other” than those in the list provided, and b) others reported they were tested because that had symptoms of diseases indicative of HIV, such as tuberculosis. In the latter case, immediate care would be required as these individuals had already fallen ill by the time of their diagnosis. For the former case, preliminary analysis of the open-ended explanations of why people were tested shows that many of these reasons were related to institutions – joining the military, going to jail, donating blood, or going for routine medical care. In both cases, individuals who were tested without their knowledge and those who were forced to test accessed care later than those who tested voluntarily.

Impact that the provision of counselling around diagnosis has on the uptake of care

To explore whether the presence or absence of counselling impacted upon the uptake of care we cross analysed data from an existing question that is part of the larger PLHIV Stigma Index project, against the supplementary question specific to this study, ‘how long did you wait after diagnosis before accessing care’.

Question from the PLHIV Stigma Index: Did you receive counselling when you were tested for HIV?

- I received both pre and post HIV test counselling
- I only received pre test HIV counselling
- I only received post test HIV counselling
- I did not receive any counselling when I had an HIV test

Table 19: Cross Analysis - Time elapsed between pre and post test HIV Counselling and accessing care

Cross Analysis: Time elapsed between pre and post test HIV Counselling and accessing care.						
		0-6 months	7-12 months	1-2 years	2 years or more	Not in care
Estonia	Both pre and post test counselling	65%	10%	20%	5%	0%
	Only pre test counselling	100%	0%	0%	0%	0%
	Only post test counselling	45.2%	12.9%	16.1%	22.6%	3.25%
	No Counselling	45.5%	24.2%	18.2%	12.1%	0%
Moldova**	Both pre and post test counselling	33.8%	8.8%	5%	17.5%	35%
	Only pre test counselling	15.83%	5.3%	5.3%	31.6%	42.1%
	Only post test counselling	44.7%	2.7%	5.3%	18%	29.3%
	No Counselling	18.1%	1.3%	6%	33.6%	40.9%
Poland**	Both pre and post test counselling	74.4%	5.8%	6.4%	9.6%	3.8%
	Only pre test counselling	62.5%	0%	25.0%	12.5%	0%
	Only post test counselling	60.8%	10.3%	4.1%	23.7%	1%
	No Counselling	44.3%	6.5%	10.4%	32.8%	6%
Turkey**	Both pre and post test counselling	100%	0%	0%	0%	0%
	Only pre test counselling	0%	0%	0%	0%	0%
	Only post test counselling	90.56%	4.8%	4.8%	0%	0%
	No Counselling	89.6%	2.6%	0%	5.2%	2.6%
Ukraine**	Both pre and post test counselling	50.7%	10%	8.4%	14.7%	16.26%
	Only pre test counselling	40.5%	7.1%	7.1%	23.8%	21.4%
	Only post test counselling	45.0%	4.3%	11.2%	28%	11.5%
	No Counselling	35.3%	3.6%	10.3%	35.7%	15.1%

*The number of respondents reporting that that had received pre test counselling only is very small (n=2) in Estonia and Poland(n=8). No respondents selected this answer in Turkey.

** Differences between groups are statistically significant at the p=.000 level

The relationship between HIV test counselling and timely access to medical care post diagnosis matches the relationship for voluntary testing and uptake of care. It held true across the region that, when individuals received both pre and post test counselling, they were much more likely to access care within 6 months. The slight exception to this rule was seen in Moldova where those who received post test counselling only were the most likely to be in care.

As seen in the table, in Estonia, of those receiving both pre and post test counselling, 65% reported accessing care within 6 months, compared with 45-46% of those who received only post test counselling or no counselling at all.

In Ukraine, only a small percentage of the whole sample (44%) had accessed care within six months, however, 51% of those who received both pre and post test counselling were in care. Those who received no counselling were least likely to be in care within 6 months (only 35%) and most likely to take more than 2 years to do so.

In Turkey, almost the entire sample received care within six months. The lack of response variation on this question means that the differences based on whether or not one received counselling were small. A further complication for the Turkish results is that only two respondents (2% of the sample) received both pre and post test counselling. Even so, the relationship between counselling and access-

ing care is clear and matches the results from Estonia, Poland, and Ukraine. While 90% of the sample was in care within 6 months, 100% of those who received pre and post test counselling were in care. Of those who received no counselling at all, 5% did not access care for more than 2 years (compared to 4% overall) and 3% were not yet receiving care at the time of the survey (compared to 2% overall).

Current Health Status by Length of Time before Accessing Care

Similar to the examination of the relationship between late testing and on-going health effects, we examined the relationship between respondents' perception of their current health and the time delay they reported between their diagnosis and their uptake of care. Are those who waited longest experiencing worse health outcomes?

We would not necessarily predict this to be so, as those with fewer symptoms might have felt less urgency in seeking care and those who were more ill might have accessed care even if they preferred to avoid it. To explore this question we used data obtained from the PLHIV Stigma Index and cross analysed it against the length of time between diagnosis and accessing care.

Question from the PLHIV Stigma Index: In general, how would you describe your health at the moment?

- Excellent
- Very good
- Good
- Fair
- Poor

Table 20: Cross Analysis - Respondents perception of their current health in relation to the length of time between diagnosis and accessing care

Cross Analysis: Respondents perception of their current health in relation to the length of time between diagnosis and accessing care.

		0-6 months	7-12 months	1-2 years	2 years or more	Not in care
Estonia	Excellent or very good	71%	0%	14%	0%	0%
	Good	39%	26%	17%	13%	4%
	Fair or poor	54%	14%	18%	14%	0%
Moldova	Excellent or very good	43%	6%	3%	15%	33%
	Good	36%	2%	5%	19%	38%
	Fair or poor	28%	4%	5%	29%	34%
Poland***	Excellent or very good	80%	5%	3%	10%	3%
	Good	61%	9%	5%	21%	4%
	Fair or poor	48%	6%	12%	30%	4%
Turkey	Excellent or very good	96%	2%	0%	2%	0%
	Good	80%	7%	3%	3%	7%
	Fair or poor	87%	0%	0%	13%	0%
Ukraine**	Excellent or very good	57%	4%	4%	14%	20%
	Good	50%	8%	10%	18%	13%
	Fair or poor	39%	6%	10%	30%	15%

** Differences between groups are statistically significant at the p=.000 level

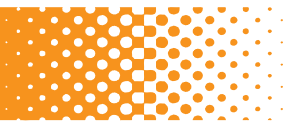
*** Differences between groups are statistically significant at the p<.02 level

As can be seen the same results emerged for treatment delays as for testing delays, albeit not so strongly: those who delayed the least, report the best health, while those who delayed the most report the worst current health.

As seen in the table, in Estonia, of those with excellent or very good health, 71% accessed care within 6 months. No one who reported excellent or very good health in Estonia had waited more than two years to access care. By contrast, only 54% of those with fair or poor health accessed care within six months and 14% of those with the worst health had waited more than two years. In Ukraine, 57% of those with excellent or very good health accessed care within six months while 14% waited more than two years. Of those with fair or poor health in the Ukrainian sample, the numbers are split more evenly with 39% accessing care within six months and 30% waiting more than two years.

To look at the question differently, in Poland, of those who received care within 6 months, 23% reported excellent or very good health currently. This is significantly more than any other group. Only about 5% of those who waited more than a year reported excellent or very good health. Of those who waited from 1-2 years or more than 2 years, 68% and 56% have fair or poor health currently.

When interpreting these results, it is important to remember that few respondents from any country except for Turkey reported excellent or very good health, which makes the relationship between the time to access care and excellent/very good health all the more notable.



The results described in this report portray barriers to accessing HIV testing, treatment, and care in five countries. The findings are based on the experiences PLHIV who have themselves faced the need to test for HIV, and to determine whether or not they will seek medical care for their HIV infection.⁷ Further, in this report, information about the current health of the respondents and the circumstances under which they tested for HIV was employed to illuminate three sets of relationships. The first relationship explored was between delays in testing and care and on-going health effects for respondents – that is, did the respondents who waited longer to test or to access care report overall worse health than those who tested or accessed care earlier? The second relationship under examination was between the voluntariness of testing and the subsequent amount of time elapsed before seeking medical care – that is, did the respondents who tested voluntarily report earlier uptake of medical care? The third relationship explored was between the counselling that respondents received when they tested for HIV and the subsequent amount of time before seeking medical care - that is, did the respondents who received pre and post test counselling report earlier uptake of medical care? Responses by participants revealed that the answer to each of these questions, with a few qualifications, was yes. In the paragraphs that follow, the barriers to the uptake of testing, treatment, and care, as reported by respondents, and the analysis of these three sets of relationships are summarised.

Testing Delays

In many countries, respondents reported timely testing, with a majority of those in every sample indicating that they tested within six months of the time they first thought they should get an HIV test. This is an encouraging indication that progress in assisting people to know their HIV status may be occurring within these countries. However, the prominence of symptoms related to HIV as a reason for testing for HIV, whether the respondent tested within six months or after two years, highlights the missed opportunities for people entering into care earlier. These opportunities are sometimes missed because the person did not realise they needed to test or, at other times, because they thought they should test but something stood in the way of actually getting the test. The high proportion of those testing only after presenting with suspected HIV symptoms is not only a tragedy in its indication of an advanced stage of HIV infection; it is a tragedy that might have been avoided for many of these people if they had been aware of their infection and felt able to access testing services in the two years, five years, or longer time period in which they were infected.

Barriers to Testing

The number one fear expressed about testing for HIV was the anticipation of social stigma. When respondents were asked directly whether they had hesitated to get an HIV test because of fears about how other people would react if they tested positive, 29% to 60% of respondents answered that they had hesitated for this reason. Similarly, when provided with a list of possible concerns related to testing, the numbers of respondents who indicated that, before they tested, they were afraid that they would be shunned by family and friends if their test came back positive, were very high everywhere and among all populations (with overall numbers for country-level results ranging from 39% to 61%).

⁷ Indeed, for some prisoners, the primary determination was whether or not they would be *allowed* to access medical care for their HIV infection, not whether they, themselves, chose to access such care.

There was a striking similarity in the dominant concerns about HIV testing that were expressed by women and men. Both expressed the fear of being shunned by friends or family in relatively equal numbers. Other relational concerns also emerged as critical for both women and men: particularly, fears of being left by a spouse or partner, not being able to marry, or having one's children mistreated. This point is critical as social and community relationships are often assumed to be women's concerns and men's needs for inclusion in family and social relationships may be invisible or ignored.

Care Delays

In contrast to the time waited before testing, the amount of time that elapsed between diagnosis and first seeing a healthcare worker for one's HIV infection was quite long on average. With the exception of those in the Turkish sample, responses revealed that less than one-third to slightly more than one-half of people in the study were seen by a healthcare professional for their HIV infection within six months. Further, in Moldova, Poland, and Ukraine, approximately one-quarter of respondents did not access care for more than two years.

The primary reason provided for waiting to access to care after diagnosis - not feeling ready to deal with one's infection - also cut across differences of national origin and gender. The next most commonly reported reasons for delayed uptake of care were fears of being seen by someone one knew and of discrimination by healthcare workers. Multiple concerns about healthcare workers were identified as barriers to accessing care including: fears of being mistreated by healthcare workers, beliefs that healthcare workers would not protect one's confidentiality, and having had a previous experience of having been treated badly by a healthcare worker. Further, respondents identified structural barriers, such as not having access to care while in prison, as causing delays in care.

Concerns of Young People

Young people, under the age of thirty, indicated some specific concerns about HIV testing in significantly higher numbers than older respondents. In every country but Moldova, young people were more likely to report that they delayed testing because of fears about how other people would respond. In Moldova and Ukraine, higher percentages of young people said that they were concerned about intimate partner violence and about being forced to terminate a pregnancy. Also in Ukraine, young people were more likely to express the fear that they would not be able to marry because of a positive HIV test. In Poland, young people indicated higher levels of a number of fears: losing a job or being removed from school; being left by a spouse or partner; and that people would find out that they were part of an additionally stigmatised group (such as sexually active, men who have sex with men, injecting drug users, or sex workers).

Concerns of Members of Key Populations

Members of key populations fared worse on many measures than respondents who indicated that they had never been a member of a key population. These results indicate that intersecting stigma (or "layered stigma") is operative in the experiences of these populations. Intersecting stigma occurs when stigma related to key population group membership interacts with, and thus is compounded by, stigma related to HIV-positive status.

Overall, key populations were more hesitant to test because of fears over how others would treat them should the result come back positive. Depending on the country sample, this was true for men who have sex with men, gays and lesbians, transgender respondents, injecting drug users, and sex workers.

Once diagnosed, being a member of a key population meant that one generally waited more time before accessing medical care. In Moldova, Poland, and Ukraine, there was a 15% to 30% difference in uptake of medical care within six months between members of key populations and respondents who were not part of a key population group. This was particularly the case, again, depending on the country sample, for sex workers, prisoners, injecting drug users, transgender respondents, and internally displaced people.

The biggest differences between members of key populations and other respondents occurred in the areas of healthcare worker discrimination, criminalisation, and violence enacted by intimate partners, other family members, and community members. In many countries, members of key populations, particularly injecting drug users, gays and lesbians, sex workers, prisoners, and internally displaced persons were significantly more likely to report that they delayed accessing medical care because of a bad previous experience with a healthcare worker. In addition, higher numbers of injecting drug users in most countries also reported that they delayed their uptake of care because of fears that healthcare workers would treat them badly, and that healthcare workers would disclose their status without their consent. Fears that one might face criminal charges if diagnosed with HIV were rare in the overall samples from every country. However, key populations in Turkey and Ukraine expressed significantly higher levels of concern about the potential for the use of the criminal law against them should their HIV test come back positive. Finally, facing violence resulting from one's HIV diagnosis was expressed in significantly higher numbers by members of key populations. In particular, sex workers in Poland, Turkey, and Ukraine, as well as men who have sex with men, and gays and lesbians in Turkey and Ukraine, reported significantly more fears about violence directed at them by intimate partners, other family members, and community members if they tested positive. In addition, in Turkey, men who have sex with men reported greater fears that they would be forced to leave their home or community if diagnosed with HIV.

Effects of Counselling and Testing Programmes

Voluntary testing, in every country, was associated with timely uptake of care after diagnosis. Those who were tested voluntarily were more likely to report that they saw a healthcare worker within six months. By contrast, those respondents who reported that they tested under pressure from others, were coerced or forced to test, or were tested without their knowledge reported longer delays before accessing care. Similarly, in every country, with the exception of Moldova, those who received no test counselling were the least likely to receive medical care within six months, while those who received both pre and post test counselling were the most likely to report accessing care within six months. In the sample from Moldova, somewhat curiously, the best results were for those respondents who received post test counselling only, with the second best outcomes seen in those who received both pre and post test counselling.

The results related to the effects of voluntary testing and counselling suggest that treating individuals with dignity and protecting their human rights to bodily integrity and to receiving the information and health education they need to take care of their health also facilitates their movement into timely medical care. It is reasonable to expect that the reason that voluntary testing and pre and post test counselling are so closely associated with uptake of care within six months is due to the transfer of information that occurs during counselling to ensure that patients understand their diagnosis, the benefits of care, and where to go to access care; voluntary testing also allows for a relationship based on trust to be developed between the person receiving the diagnosis and the medical provider. These relationships should be examined further. In addition, further exploration should be undertaken to better understand the structural effects of the settings in which people were tested on their uptake of care. For example, it might be the case that being diagnosed in prison, or other institutional setting, matters much more in timely uptake of care than what happens during a counselling session.

Effects of Late Testing and Late Treatment and Care on Current Health

Examining respondents' descriptions of their current health (as of the time of the survey) demonstrated the existence of on-going ill health effects related to late testing and late uptake of care. Overall, everywhere but Turkey, respondents reported high levels of ill health, with most describing their health as good or fair (from three to four on the five-point scale). In Turkey, by contrast, most respondents described their health as very good or good. Despite these general differences in current health, the trend was the same in all five countries. In every country, those who tested within six months, whatever their reason for testing were disproportionately more likely to be in excellent or very good health at the time of the survey than those who waited to test. Similarly, when examining the uptake of care, those who waited the longest to see a healthcare worker post diagnosis had the worst current health while those with the shortest wait time reported the best current health.

Changing Trends over Time since diagnosis

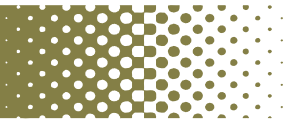
Examining responses made by those who were diagnosed within the last five years compared with those diagnosed more than ten or fifteen years ago revealed some possible changes over time in different countries. Potential positive trends among the more recently diagnosed included diminished fear of social stigma in Moldova and reduced fear in Estonia of being associated with stereotypes about HIV-positive people. In addition, in Moldova, Turkey, and Ukraine, there was a decline in the percentage of respondents who said they hesitated to seek care because they were not ready to deal with their infection. However, numbers remained very high for this response, particularly in Ukraine. Finally, in Moldova, Poland, and Ukraine, those diagnosed more recently were more likely to access care within six months.

Negative trends also emerged, particularly in Estonia, and, to a lesser extent, in Moldova, Poland, and Ukraine. Those more recently diagnosed indicated increased fear of social stigma in Estonia and Ukraine, of being associated with stereotypes in Moldova, as well as, in Estonia, increased fears that one's children would be mistreated if one tested positive and that healthcare workers would disclose one's status without consent. In Poland, those diagnosed more recently were more likely to say that they delayed medical care because they could not afford it.

Summary

The overall picture provided by these responses shows varied time spans that respondents waited before testing and before accessing medical care post diagnosis. While many respondents reported testing within six months of realising their need to test, it is likely that they had been living with HIV for some time before realising that they might be HIV-positive. Respondents expressed many fears that could delay uptake of both testing and care; predominant among these were anticipated social stigma and fear of mistreatment by healthcare workers. Those respondents who belonged to key populations expressed generally higher levels of fear overall, and, specifically, more fears of discrimination by healthcare workers, criminalisation, and family and community violence. A strong relationship was revealed between voluntary counselling and testing programmes and timely uptake of medical care; those respondents who tested voluntarily were much more likely to access care within six months and were those respondents who received pre and post test counselling (or, at least, post test counselling).

Conclusions



The results described in this report highlight the need for interventions at three critical moments in the process that individuals navigate in the HIV testing, treatment, care, and support continuum: 1) before testing; 2) during testing; 3) after diagnosis.

The conclusions that we have grouped under the three headings below are those that apply almost universally across the five countries studied. The way that these will be shaped into recommendations that are specific to the priorities and plans for advocacy activities within each of the countries are detailed in the 'Next Steps' section.

Before Testing

Some programmes, such as referrals from STI clinics and those that encourage testing for pregnant women and partners/spouses of those who test positive, appear to be responsible for providing many respondents with their diagnosis. These programmes should continue to be supported. In addition, care must be given to ensuring that the suggestions for activities that are needed during and after testing are integrated into these programmes.

The need for sustained, evidence-based, HIV education campaigns in the region is evidenced by the number of people who reported that they tested for HIV within six months of realising that they needed to test, yet already had symptoms of HIV at that time. These campaigns must ensure that people have the information they need to accurately understand their risks and identify for themselves whether they need to be tested.

Critical efforts are needed to address both the social stigma surrounding HIV and the resultant fear experienced by people who need to access testing services. The work to address social stigma needs to target the population as a whole. Everyone should be recruited to the project of ensuring that those who need to test receive social support and concern throughout processes of testing, diagnosis, treatment, and care.

Protective legislation, including education and employment, non-discrimination and health care confidentiality laws, must be in place and communicated widely. This legislation must include accessible and confidential points of entry for those who feel their rights could or have been violated. Before they are tested, people need to know what kinds of rights they have and how their rights will be protected if they receive a positive HIV test. In addition, those who have not tested positive need clarity about the laws and their responsibilities to those who are living with HIV.

During Testing

The importance of voluntary counselling and testing programmes for HIV in maintaining trust between individuals and their healthcare providers and for linking people to medical care post diagnosis cannot be overstated. More fundamentally, pressuring, coercing, or forcing individuals to be tested, or testing them without their knowledge, is a violation of the human right to bodily integrity.

Systems and norms need to be established in which mistreatment by healthcare workers is not tolerated.

Healthcare workers should be trained and supported in maintaining confidentiality and providing patient care in a non-judgmental and professional manner.

All efforts need to be taken to create, promote, and enforce confidentiality policies within health care settings - in every location where health care is provided and with every employee who might have contact with patients or patient records.

After Diagnosis

The frequency with which people indicated that they delayed accessing medical care because they did not feel ready to deal with their HIV infection highlights the need for psychological, emotional, and social support services to be in place to immediately assist people at the time of their diagnosis.

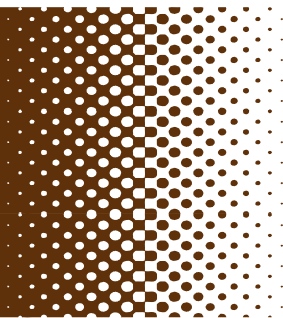
Programmes to provide transportation and assist with the costs of medical care are needed in places where transportation and cost are barriers to the uptake of medical treatment and care.

Information about how and where to receive HIV care and treatment services needs to be provided to all people diagnosed as HIV-positive and should be widely available for all community members.

Full access to medical care within jail and prison settings that matches international guidelines for appropriate HIV treatment must be implemented. HIV education and anti-stigma campaigns must reach into jail and prison settings and address both employees and inmates. Processes by which prisoners can appeal decisions about medical matters without fear of reprisal must be established and communicated to all prisoners.

The efforts described in the suggestions for ending discrimination by healthcare workers and ensuring patient confidentiality during testing are equally important after diagnosis.

Next steps, the PLHIV Stigma Index in the 5 countries



The data presented and the recommendations contained in this report are only the beginning of the journey in communicating, detailing, and working further with the PLHIV Stigma Index data and evidence, including the issues of barriers to earlier and more opportune testing and to accessing treatment.

The five country teams are committed over the coming year to:

Continue to present the findings to local groups of people living with HIV that were key partners in the research process as:

- many of the interviewees will be interested to hear about how their individual experiences compare with the bigger picture;
- it will help to define new issues for possible organisational or individual advocacy, capacity building and refinement of existing operational priorities at the local as well as the national level.

Identify and establish:

- priorities for areas of action on HIV-related stigma and plan, develop and undertake advocacy actions arising from the evidence;
- synergies of action at regional and country level in carrying out advocacy actions;
- mechanisms and frameworks for PLHIV networks to measure the impact of their advocacy activities.

Work with the International founding partnership of the PLHIV Stigma Index and others to:

- share the data and the findings in an appropriate way to contribute to a better understanding of how PLHIV-related stigma and discrimination operate as barriers to an effective global response;
- collaborate with, and share the lessons learnt through implementation so far, with other PLHIV networks and partnerships implementing the PLHIV Stigma Index.

Appendix A: Anticipated Stigma Reactions to an HIV-positive Test by Country and by Gender

Women's Testing Fears by Country:

Table 21: Women's Testing Fears by Country:

Women's Testing Fears by Country*	Estonia	Moldova	Poland	Turkey	Ukraine
I would lose my job or be removed from my school program	8%	17%	17%	48%	17%
I would be shunned by family or friends	29%	52%	58%	62%	65%
My husband/wife/partner would be physically violent with me	0%	8%	3%	10%	13%
Other family members would be physically violent with me	0%	3%	5%	5%	22%
Members of my community would be physically violent with me	0%	1%	3%	10%	4%
My husband/wife/partner would leave me	26%	23%	12%	52%	18%
My children would be taken from me	5%	13%	10%	24%	11%
I would be forced to terminate a pregnancy	0%	19%	3%	10%	17%
My children would be treated badly by our family, our community, or their school	8%	26%	24%	14%	23%
I would not be able to get married	26%	23%	12%	24%	29%
I would be forced to leave my home or community	8%	18%	17%	29%	10%
The police or legal authorities might attempt to bring criminal charges against me	0%	5%	4%	24%	4%
People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user	21%	44%	21%	38%	19%
People might find out that I am, or have been, sexual outside of marriage, a man who has sex with men, a sex worker, or an IV drug user	0%	10%	19%	24%	10%
Other Fears	53%	8%	11%	43%	28%

* Multiple responses possible

Men's Testing Fears by Country:

Table 22: Men's Testing Fears by Country

Men's Testing Fears by Country*	Estonia	Moldova	Poland	Turkey	Ukraine
I would lose my job or be removed from my school program	18%	15%	18%	40%	14%
I would be shunned by family or friends	47%	43%	54%	61%	53%
My husband/wife/partner would be physically violent with me	0%	1%	3%	13%	8%
Other family members would be physically violent with me	0%	2%	2%	9%	10%
Members of my community would be physically violent with me	0%	1%	8%	11%	3%
My husband/wife/partner would leave me	16%	10%	20%	45%	20%
My children would be taken from me	0%	7%	3%	8%	5%
I would be forced to terminate a pregnancy	NA**	NA**	NA**	NA**	NA**
My children would be treated badly by our family, our community, or their school	0%	20%	7%	17%	5%
I would not be able to get married	2%	13%	9%	24%	27%
I would be forced to leave my home or community	0%	9%	13%	28%	6%
The police or legal authorities might attempt to bring criminal charges against me	2%	6%	4%	24%	8%
People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user	25%	18%	25%	35%	15%
People might find out that I am, or have been, sexual outside of marriage, a man who has sex with men, a sex worker, or an IV drug user	4%	14%	19%	44%	11%
Other Fears	57%	9%	8%	45%	32%

*Multiple responses possible

** Not applicable

Appendix B: Reasons for Delays in Accessing Care by Country and by Gender

Women's Reasons for Care Delays by Country:

Table 23: Women's Reasons for Care Delays by Country

Women's Reasons for Care Delays by Country*	Estonia	Moldova	Poland	Turkey	Ukraine
I could not afford health care	0%	1%	1%	0%	4%
I did not receive a referral or did not know where to go to get HIV care	0%	5%	13%	10%	10%
I was not ready to deal with my HIV infection	32%	5%	28%	10%	28%
It was difficult to arrange transportation to the clinic or hospital	3%	2%	2%	10%	7%
I was afraid that the health workers (doctors, nurses, staff) would treat me badly	3%	4%	10%	14%	16%
I was afraid that the health workers would disclose my status without my consent	18%	3%	8%	14%	13%
I was afraid that someone I knew would see me there	29%	6%	8%	14%	18%
I would have had to tell my husband/wife/partner if I started getting care	13%	0%	1%	5%	1%
I could not receive care during work hours without disclosing my HIV status to my employer	0%	1%	0%	5%	1%
I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with man	8%	0%	6%	10%	6%
I had a bad experience with a health worker previously	8%	1%	4%	5%	8%
I lack legal status or documentation	0%	1%	1%	0%	1%
I was incarcerated and was not able to access HIV care	0%	0%	1%	0%	5%
Other	16%	20%	17%	5%	21%

* Multiple responses possible

Men's Reasons for Care Delays by Country:

Table 24: Men's Reasons for Care Delays by Country

Men's Reasons for Care Delays by Country*	Estonia	Moldova	Poland	Turkey	Ukraine
I could not afford health care	0%	2%	1%	12%	7%
I did not receive a referral or did not know where to go to get HIV care	0%	4%	9%	8%	10%
I was not ready to deal with my HIV infection	47%	7%	19%	11%	29%
It was difficult to arrange transportation to the clinic or hospital	2%	3%	3%	3%	8%
I was afraid that the health workers (doctors, nurses, staff) would treat me badly	0%	3%	4%	7%	10%
I was afraid that the health workers would disclose my status without my consent	20%	5%	3%	11%	9%
I was afraid that someone I knew would see me there	33%	3%	4%	11%	11%
I would have had to tell my husband/wife/partner if I started getting care	6%	1%	2%	3%	2%
I could not receive care during work hours without disclosing my HIV status to my employer	0%	2%	1%	9%	1%
I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with man	16%	2%	6%	11%	6%
I had a bad experience with a health worker previously	8%	2%	4%	0%	7%
I lack legal status or documentation	2%	2%	3%	1%	1%
I was incarcerated and was not able to access HIV care	0%	3%	6%	1%	15%
Other	8%	15%	13%	1%	23%

* Multiple responses possible

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**THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX**



**GLOBAL NETWORK OF
PEOPLE LIVING WITH HIV**



IPPF International
Planned Parenthood
Federation



HIV in Europe
Working Together for Optimal
Testing and Earlier Care

About the PLHIV Stigma Index:


The PLHIV Stigma Index is the initiative of 4 founding partners: 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).

More information about the initiative can be accessed at:
www.stigmaindex.org

About HIV in Europe:

Further information about HIV in Europe can be accessed at:
www.hiveurope.eu





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Disclaimers

This report

The stated opinions and views in this report are not to be regarded as the views of the organisations publishing this product and cannot be regarded as the views or standpoints of the Global Network of People Living with HIV (GNP+), HIV in Europe, or the international partnership of the People Living with HIV Stigma Index.

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The People Living with HIV Stigma Index

The PLHIV Stigma Index and this additional study 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 PLHIV 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 in the national response to HIV and to contribute to our regional and global understanding.

