

Late Testing, Late Treatment: Findings from the PLHIV Stigma Index in Estonia, Moldova, Poland, Turkey and Ukraine

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Overcoming obstacles for late presentation for HIV in Europe



HIV IN EUROPEAN REGION-
UNITY AND DIVERSITY
MAY 25-27

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



Всеукраїнська Мережа ЛЖВ
All-Ukrainian Network of PLWH



Лига ЛЖВ Република Молдова
League of People living with HIV
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EHPV
Eesti HIV-positiivsete võrgustik
Estonian Network of PLWH



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Much appreciation is due to the country teams in Estonia, Moldova, Poland, Turkey, and Ukraine who conducted the research. Most importantly, thanks are due to the more than 2,500 people living with HIV in these five countries who shared their personal feelings, fears, and experiences.

Thanks



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for the in country implementation of this research

This research is a cross country analysis based on the People Living with HIV Stigma Index with additional questions



This is an initiative of four founding partners
More information can be accessed at: www.stigmaindex.org



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. All of the research was carried out in later 2010 and early 2011. A participative research process was used, people living with with HIV in each country were trained as interviewers and conducted all of the interviews.

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

- 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 results described in this report portray barriers to accessing HIV testing, treatment, and care in five countries. The findings are based on the experiences of 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

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%	20 to 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.

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%

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.

The demographic information characteristics associated with earlier and later testing

- **earlier testing**
 - being younger (under age 25)
 - not belonging to any of the key population groups
- **later testing**
 - lower income
 - belonging to any key population, particularly injecting drug users or prisoners, but also gay men, sex workers, and internally displaced persons.

Notes : 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

Why people decided to get tested for HIV

Within 6 months	More than 2 years
Pregnancy	Symptoms related to HIV
Positive test of a family member	Just wanted to know
Symptoms related to HIV	Other

Notes: This ranged from 78% of those testing because of pregnancy in Poland to 99% in Moldova.

The results indicated that high percentages of respondents tested because they had **symptoms related to HIV**. Many of these tested within six months. This indicates that these individuals were likely living with HIV for quite some time without realizing that they needed to be tested. As such, this short wait time more likely reflects a lack of awareness of the risks of infection rather than true early testing.

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

Notes: 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.

Reasons for delays in accessing testing - Fears about Testing Positive

- I would be shunned by family or friends
- My husband/wife/partner would leave
- I would not be able to get married
- People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user

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

Reasons for delays medical care after their HIV diagnosis

- **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 had a bad experience with a health worker previously
- I was afraid that someone I knew would see me there

Notes:

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.

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 being in prison or the inability to afford health care.

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 also reported longer delays before accessing care.

Quote from the open-ended responses: Poland

The doctor that was handing the test result was unable to tell me whether I had the virus or not. She stated „I do not know – here are some plus signs (+)“ and went to look for help from other doctors. I was thrown out to sit in the corridor where the doctor discussed quite loudly the procedure of notifying respective institutions about the infection. I did not feel comfortable at that time. Since then I have also witnessed fear from doctors who found out that they have in their room a seropositive patient – as if I could infect them just by looking at them.

What is remarkable about the last slide ?

This was not from a long time ago.

The interviewee was:

A gay man (30-39)

living with HIV 0-1 year

And interviewed within the last year

Summary

- 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.

Notes: 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 realizing their need to test, it is likely that they had been living with HIV for some time before realizing 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.

Thank you
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The full report can be accessed at
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HIV in Europe

Working Together for Optimal
Testing and Earlier Care