

Multi –Country Findings from the PLHIV Stigma Index
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Workshop on People Living with HIV Stigma Index
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Nokia Concert Hall, Yellow room



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

Country and Sample Size

Africa

Cameroon (1200)
Ethiopia (2300)
Kenya (1086)
Malawi
Nigeria (720)
Rwanda (1530)
Swaziland
Zambia (854)

Asia Pacific

Bangladesh (238)
Cambodia
China (2096)
Malaysia (600)
Myanmar (324)
Pakistan
Philippines (80)
Sri Lanka (120)
Thailand
Fiji (100)

Europe

Belarus (370)
Estonia (300)
Moldova (403)
Poland (504)
Russia (600)
Turkey (100)
Ukraine (1500)
UK (867)

Latin America

Argentina
Colombia
Dominican
Republic (1000)
Ecuador (497)
El Salvador
Mexico
Paraguay (256)

Selection of Participants

- **Purposive sampling**
- **Focus**
 - **3% of the number of people living with HIV in a country or sub-country region**
 - **Inclusion of key populations**
- **Goal**
 - **Data that is broadly indicative of the range of experiences of PLHIV in an area**

Presenters notes:

Collecting random samples of PLHIV is not possible, therefore the PLHIV stigma index uses purposive sampling. That is, each country team decides where to focus their recruitment of participants in order to gain a sample that is broadly inclusive of the key affected populations in their country. This process can include recruitment from a mix of urban and rural locations, support groups, clinics, and other networks of key population groups.

The research teams attempt to include approximately 3% of the number of people known to be living with HIV in a country or sub-national region, such as a province or state. Within this sample, efforts are made to recruit members of key populations.

Interpreting Results across Countries

- **Differences in results can be related to differences in the:**
 - **Collection of samples**
 - **Key population portion of the sample**
 - **Disclosure of one's HIV status**

Presenters notes:

In the next slides we share a number of results from around the world to demonstrate some simple cross-national analyses. In the presentations that follow, you will hear more in depth results from Turkey, Ukraine, Moldova, Poland, and Estonia.

When examining the differences between countries, a few key points should be kept in mind:

First, the process for collecting samples varied between countries. This allows the country teams to get a mix of respondents that matched as closely as possible the demographics in each country.

Second, Different country samples have different percentages of key population groups in their sample. Many of the completed studies indicate that members of key populations often experience stigma and discrimination more frequently and more severely than other people living with HIV. This means that countries with larger numbers of people who belong to key population groups may show higher levels of stigma in their results.

Third, whether or not people experience discrimination from others can depend on whether they disclose their status. Low levels of enacted stigma or discrimination can result from situations in which people feel so afraid of being mistreated that they hide their HIV status completely. On the other hand, low levels of enacted stigma might mean that stigma is truly lower in those areas.

Overall, this does NOT mean that results can't be compared across countries. What it DOES call for is caution. At this point, the data can not be used to say with any confidence that the situation in one country is clearly better or worse than the situation in another country. What we can say is simply, "In this country, X% of respondents told us that they were excluded by family members or felt suicidal or were refused medical care because of their HIV status."

Social Stigma related to HIV



Country	Gossiped about in the last 12 months	Gossip was related to HIV status
Estonia	63%	39%
Moldova	38%	50%
Poland	52%	20%
Turkey	70%	66%
Ukraine	59%	68%
Zambia	75%	90%
UK	63%	77%

Presenters notes:

Around the world, PLHIV report gossip as a main vehicle for stigma. This table shows the percentage of people who reported being gossiped about in the last year. For example, 38% of those in the Moldova sample reported being gossiped about. One-half of these indicated that the gossip was related to their HIV status. In Turkey, 70% experienced gossip in the last year. For 68% of these, they were gossiped about because of their HIV status. We have included numbers from Zambia and the UK, which are similarly high.

Employment Discrimination

Were refused employment or work opportunities in the last 12 months because of HIV status

Estonia	7%
Moldova	5%
Poland	11%
Turkey	12%
Ukraine	8%

Discrimination by Health Care Workers



Denied health services because of HIV status in the last 12 months

Estonia and Philippines	8%
China	12%
Paraguay and UK	17%
Moldova	14%
Poland, Turkey, and Ukraine	20%

Internalized Stigma



I avoided going to a local clinic or a hospital when I needed to (in the last 12 months)

Rwanda and Turkey	8-10%
Bangladesh and Moldova	17-21%
Paraguay	38-40%
Estonia	11-17%
Poland and Ukraine	18-26%

Presenters notes:

The effects of social stigma at the individual level.

Paraguay - (various personal statements indicated that this was because didn't want to disclose)

Reasons for HIV Testing



Employment	Symptoms of HIV infection	I just wanted to know	Other
Bangladesh (27%)	China (18%)	Kenya (30%)	Moldova (34%)*
Philippines (45%)	Dominican Republic (29%)	Myanmar (69%)*	Turkey (43%)*
	Paraguay (40%)	Ukraine (33%)*	
		Estonia (43%)	
		Poland (38%)*	

***Testing because of symptoms of HIV was the 2nd or 3rd most common reason for testing**

Issues with HIV Testing

Tested under Coercion or without Consent

Estonia	34%
Moldova	52 %
Paraguay	24%
Philippines	44%
Poland	29%
Turkey	66%
Ukraine	31%

Issues with HIV Counseling



Received no pre- or post-test counseling

Myanmar	15 to 20%
China, Estonia, Moldova, Philippines, Ukraine, UK	31 to 40%
Dominican Republic	21 to 30%
Poland	41 to 50%
Turkey	More than 75%

Effecting Change



Country	Confronted someone who stigmatized you in the last 12 months
Estonia and Poland	29%
Moldova and Ukraine	37%
Turkey	47%
Kenya	62%

The PLHIV Stigma Index does not look only at what is done TO people living with HIV. It looks also at how people living with HIV respond to stigma and discrimination and work to change their environment for the better.

The research for the stigma index is done for a greater purpose beyond the simple gathering of data and resulting increase in knowledge. The results offer powerful evidence from the lives of PLHIV that can inform advocacy on our own behalf.

In the final 2 slides, we give give examples from Poland and from Turkey about how they are using the stigma index for advocacy in their countries.

Using the Stigma Index for Advocacy



- **Poland**

- Results presented at multiple conferences throughout Poland, including conference of leading scientists from the Polish AIDS Society and during the national meeting of PLHIV
- Results published on website and in the National AIDS Center electronic journal
- Sections written and sent to relevant government agencies and NGOs
- Reports to be available in both Polish and English
- Sharing experience outside the country

Using the Stigma Index for Advocacy



- **Turkey**
 - Focus on issues of social security, violence, sexuality education, legal code, raising awareness about stigma
 - Lobbying, educating, and petitioning MPs
 - Meetings and dialogue with members of national government, state organizations, and civil society to share results of this and other research
 - Inviting CSOs from other issue areas to work collaboratively to address gov't and identify approaches for further advocacy



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Thanks



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



Thank you

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