

# Findings from the PLHIV Stigma Index in Turkey

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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**



# A. Stigma Index in Turkey

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- **Research was done among 100 PLHIV respondents from 11 different cities of Turkey, mainly from Istanbul, Izmir and Antalya.**
- **21% women, 75% men, 4% transgender.**
- **Subpopulations: Men who have sex with men, Gays, Transgendered people, Sex workers, Ethnic minorities, Prisoners.**
- **46% lives with HIV for 1-4 years.**
- **44% works fulltime.**

# **B. Barriers to HIV Testing**

## **1. Decision to HIV Testing**

- **Majority [95%] tested within 6 months since they first thought of testing.**
- **However, it should be considered that only 45% of the total sample actually made the decision themselves.**
- **The remaining 55% of the total sample were tested without their knowledge or consent.**
- **Surprisingly women were the quickest to test (3 months) most of them did so, because there was a need to know their diagnosis as they had experienced HIV symptoms, but did not feel the need to get tested.**

## 2. Reasons for HIV testing

- High percentage of those who tested did so because of symptoms related to HIV  $\implies$  they had been living for some time without realizing the need for testing.
- **WHY?**
  - Due to the lack of/inefficient education campaigns
  - Other main HIV testing reasons:
    - a) Pre-surgical tests
    - b) Tests during blood donation
    - c) Pre-marriage tests

This shows **lack of culture on individual testing** and **few facilities for voluntary testing**

### 3. Anticipation of Stigma

- **29% hesitated to test because of anticipated stigma.**
  - **anticipated stigma before testing can be interpreted in relation with high level of testing without knowledge and/or consent.**
- **As 55% did not make the decision to be tested by themselves, those people did not have the chance to think about the consequences of being tested.**
- **Respondents who identified as gay, MSM or transgender has higher levels of hesitation.**

***Speakers Notes: Anticipation of Stigma:*** 29% of respondents said that they hesitated to test because of anticipated stigma [this is notable since the sample was comprised almost entirely of people who tested within 6 months of first thinking that they should test]. The level of anticipated stigma before testing can also be interpreted in relation with the high level of testing without knowledge and/or consent.

Since 55% of the sample did not make the decision to be tested by themselves, i.e the decisions were made by health professionals or state officers without the person's knowledge, those people did not have a chance to think about the possible consequences of being tested.

Significantly more men than women indicated that they hesitated for this reason and also those who identified as gay (as well as those identifying as MSM and transgender) reported higher levels of hesitation. In addition, those who reported this hesitation tested later than those who did not.

# 4. Fears about Testing Positive

- **The most commonly reported fear is that “they would be shunned by family or friends.”**
  - **Fear of losing their job or being removed from a school program is very high (48% women, 40% men).**
  - **Fear of being left by partner leaving is also very high (52% women, 45% men).**
- **... Last two fears are three times more likely to occur compared to other countries and this finds confirmation in the reality.**

# 5. Current Health Status by Length of Time Before Testing

- Those who reported the best current health were those who tested within 6 months.
- Among 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.

# **C. Barriers to Accessing Care**

## **1. Length of Time before Accessing Care**

- **80% accessed care within 3 months, 90% within 6 months.**
- **However, those who were, or ever been sex workers received care later than non-sex workers.**
- **TG population is less likely to access care within 6 months.**

## **2. Fears & Concerns about Accessing Care**

- **Main fear expressed by overall sample care is the fear of being seen by someone they knew (48%)**
- **Other fears;**
  - **I was afraid that the health workers would treat me badly,**
  - **I could not afford health care,**
  - **I was afraid that the health workers would disclose my status without my consent**
- **Lack of referrals or not knowing where to go to get care created delays in their access of care**

## Fears and concerns about accessing care

- **between the ages of 25 and 29 respondents were more likely to say that they could not afford care (35% compared to 10% overall).**
- **Respondents aged 50 and over were much more likely to say that they were not able to access care because they were imprisoned (25% to 1% overall).**

**Speakers notes:** The fears and concerns about accessing care in Turkey show important facts that explain the perceived insufficiency of access to care in Turkey. According to WHO Report on Universal Access in Developing Countries, Turkey is one of the 21 countries in which up to 80% of PLHIV can receive ART. Also, ART is accessible to all those in need, (pause) according to health officials in Turkey. However, the results in this report show that because of some social and structural problems, such as the lack of knowledge about where to go and the fears about the stigmatising behaviours of health professionals, PLHIV are reluctant to seek care. It is also important to note that PLHIV have concerns about “affording” the care. This indicates that while health care is free to all who have social security, many people cannot benefit from this service either because of disclosure risks or because they cannot meet the strict poverty-level requirements necessary for them to be approved for free medical services.

# Accessing Care

- **insufficiency of access to care in Turkey**
- **However Turkey is among 21 countries that up to 80% can receive ART according to health officials (WHO Report)**
- **Problems:**
  - **the lack of knowledge about where to go**
  - **the fears about the stigmatising behaviours of health professionals**
  - **concerns about “affording” the care**
  - **social security?**

### **3. Effects of voluntary testing on uptakes of care**

- **Individuals who were tested without their knowledge and those who were forced to test accessed care later than those who tested voluntarily.**

## 4. Effects of HIV test counselling on uptake of care

- The percentage of people who did not receive pre or post counselling is 77%.
- The problems in testing reveal that the most important problem for PLHIV about testing is **the lack of counselling** (both pre and post is missing).

## **D. Experiences of discrimination and stigmatization in post diagnosis**

- **70% is aware of being negatively gossiped about. It is a general experience regardless of factors such as sex, sexual identity, income, etc.**
- **24% reported verbal assaults, harassment and threats while 13% reported physical harassment and threats, rising to 15% who did experience physical violence.**

# Experience of Stigma: Key Populations

- **Intersecting stigma (or “layered stigma”) is operative**
- **Key populations 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.**
- **Facing violence resulting from one’s HIV diagnosis was expressed in significantly higher numbers by members of key populations.**

# Experience of Stigma: Key Populations

- **Sex workers, men who have sex with men and gays reported significantly more fears about violence directed at them by intimate partners, other family members, and community members if they tested positive.**
- **Men who have sex with men reported greater fears that they would be forced to leave their home or community if diagnosed with HIV.**

# E. Access to Work, and Education Services



**Everyone has the right to work.**

- The fear of losing job/income also finds justification in data gathered.
- 23% of respondents lost their income.
- As a reason 39% indicated discrimination by the employer or colleagues, 36% deteriorating health condition and 18% indicated both health and discrimination.

## **F. Disclosure and Confidentiality**

- **44% of respondents reported that their HIV status was shared with other people without their knowledge.**
- **20% of respondents declared that their health personnel were informed about their status without their knowledge or permission.**
- **For 14% this was true for family members, for 17% for friends and neighbors. Colleagues of 11% and employers of 9% respondents were informed about respondents' HIV status without their knowledge.**
- **30% of the respondents expressed that they are not sure whether their HIV status is being kept confidential.**



## Reb Ribbon in Taksim Square, Istanbul

1st December 2010

**Turkey  
needs more  
positive  
attention!**



## **G. CHALLENGES of the PROCESS**

- **Confidentiality is a main problem in dealing with PLHIV. Despite the fact that PLA asked its support and services recipients to take part in the research, great hesitation was observed. However PLA managed to reach vulnerable groups during the field work.**
- **The official number of HIV positive people since 1984 is 4525 in Turkey and PLA managed to reach more than 3% of the whole population for sure.**



## Positive Marching

1st December 2010, Istanbul

# H. NEXT STEPS

- Findings of the research will be multiplied.
- Reports will be published.
- New advocacy measures will be planned and implemented.
- Operational priorities at PLA will be refined.
- Awareness raising activities to deal with the fear and stigma will be planned.

# THANK YOU!

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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](http://www.stigmaindex.org)





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# Thank you

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