

# Findings from the PLHIV Stigma Index in Estonia Jekaterina Voinova

PARALLEL SESSION XII May 27th, 2011. 09.00 - 10.30. Nokia Concert Hall, Blue room



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

#### **Acknowledgements**

- 300 People living with HIV who shared their personal feelings, fears, and experiences.
- NGO Convictus Eesti for cooperation and support (interviewing in prisons)
- Infectious disease department in West-Tallinn Central Hospital
- Ministry of Justice
- Igor Sobolev, Chair of the Board of Estonian Network of PLWH (final report)

### **Thanks**



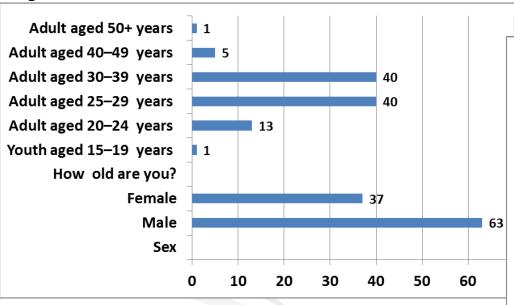
HIV in Europe supported the research undertaken



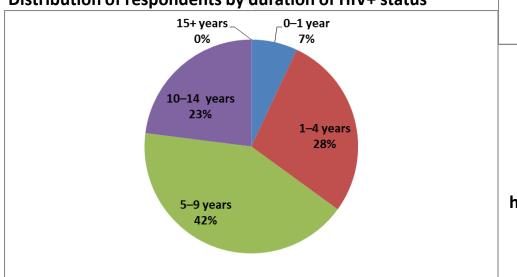
Technical support provided by GNP+ for the in country implementation of this research

# **Background characteristics Sampling total = 300**

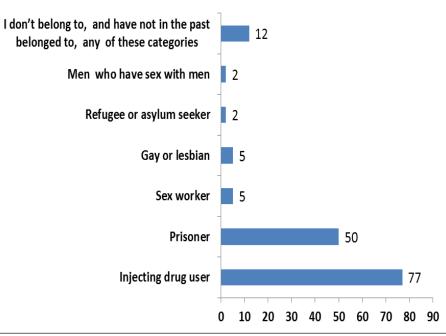
Age and Sex distribution







#### Belonging to the following categories



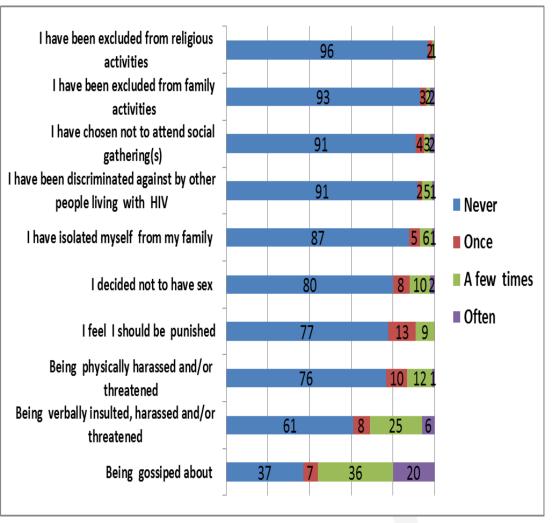
74% of respondents are sexually active, 26% are not

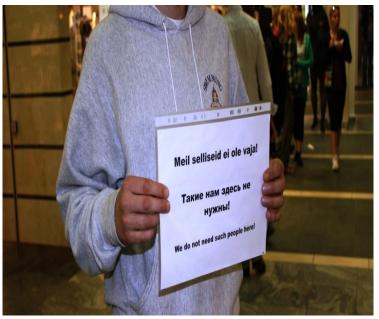
Physically disabled - 10% of the respondents.

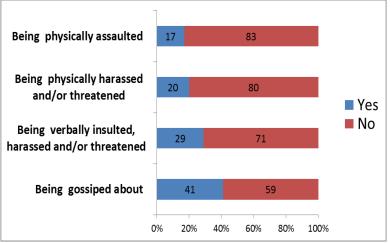
Children aged 0-14 years, living 37% of respondents in households, including with 56% of women respondents.

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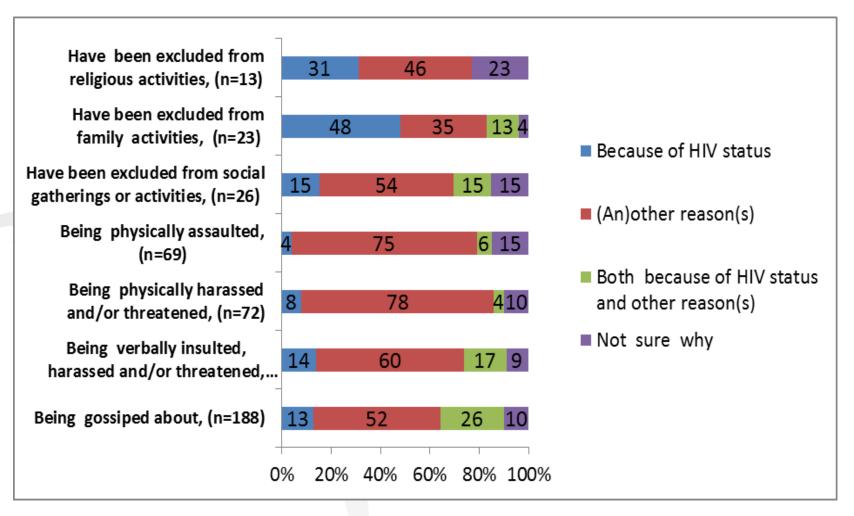
**Experience of stigma and discrimination Fears** 



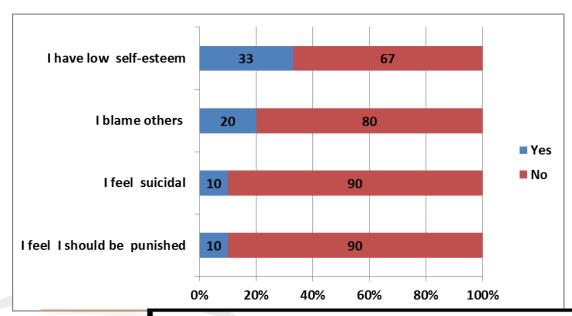




## **Experience of stigma and discrimination**



# Internalised stigma

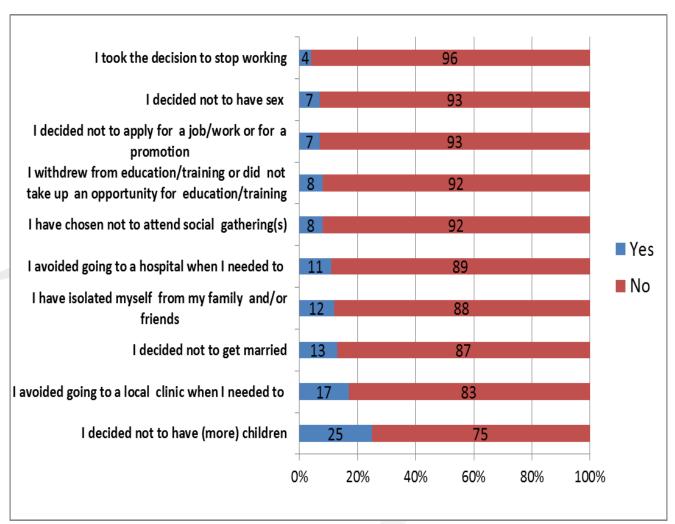




	SEX		LANGUAGE		SITUATION		ALL
Feelings	Male	Female	Russian	Estonian	Injecting drug user	Prisoner	TOTAL
I feel ashamed	39%	47%	40%	62%	40%	34%	42%
I feel guilty	62%	57%	58%	79%	58%	58%	60%
I blame myself	59%	53%	56%	61%	58%	58%	57%
I blame others	18%	23%	20%	18%	17%	15%	20%
I have low self-esteem	18%	23%	31%	48 %	29%	27%	33%
I feel I should be punished	9%	12%	10%	7%	10%	8%	10%
I feel suicidal	7%	15%	10%	7%	12%	11%	10%

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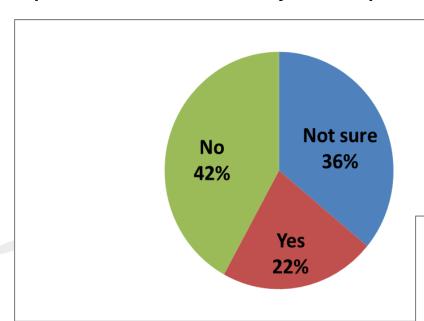
### How stigma stopped PLHIV leading full lives





# Disclosure and confidentiality

HIV-positive status disclosure by medical personnel without the consent of the respondent









# **Problems and challenges**

#### Answers to the open questions

1. The doctor is not accessible, because there are long queues (six ways), or must pay for the visit:

Three months of waiting for a doctor's appointment number!

If you miss you must wait another half a year

2. Once people get to know the diagnosis, then left without support and information how to act further:

I was not given any information (after positive test)

Doctors gave little information, visit fee

Diagnosis and analysis were made without consent and after didn't receive any information how to live with this...

Took blood, gave diagnosis and nothing explained

Not given enough information! I would like psychological help.

3. Bad or even discriminatory attitude of medical staff towards PLWH.

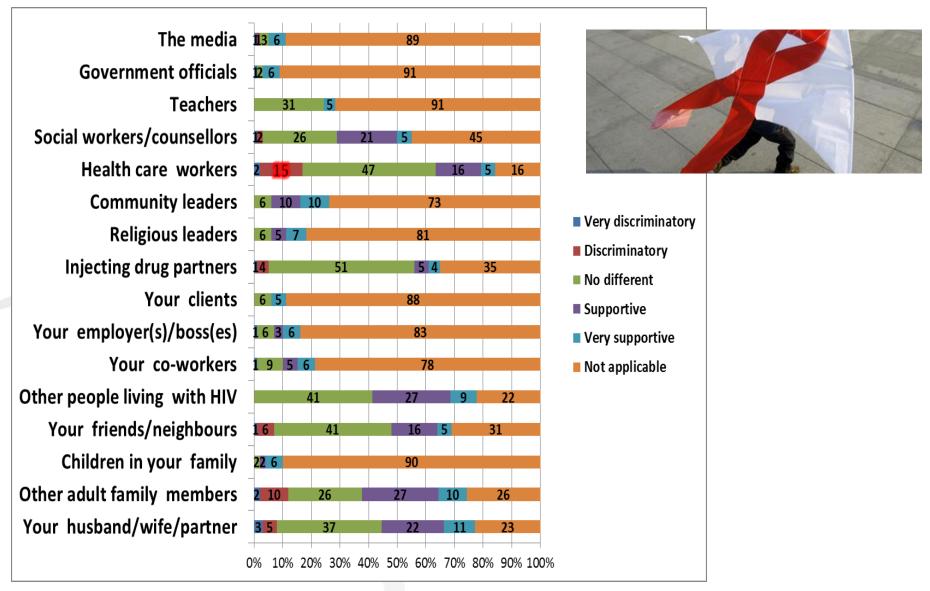
Sometimes doctors attitude towards me was very bad

Can not see a doctor, long waiting list, providing little support after I got to know my status

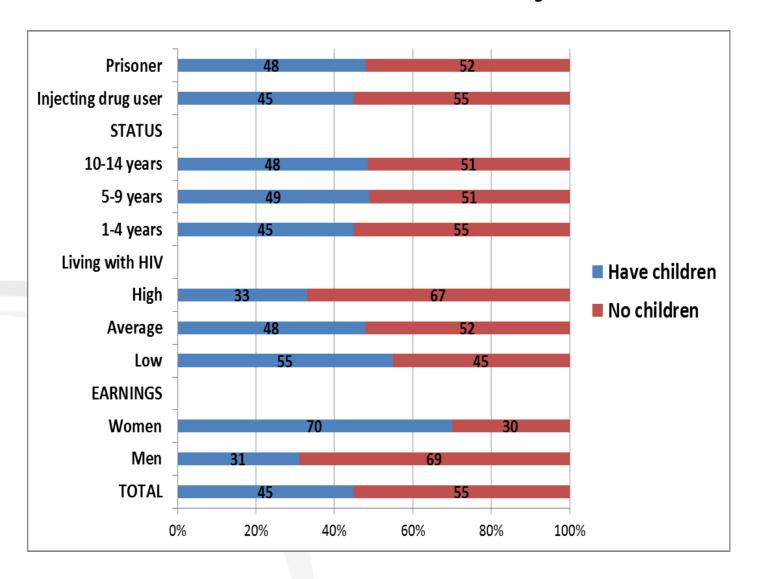
4. Henceforth, there will be even more difficult to obtain treatment, because doctors do not want to deal with patients

Would suggest to open more centers where rapid tests could be done. Health professionals need better communication skills.

## **HIV** status disclosure

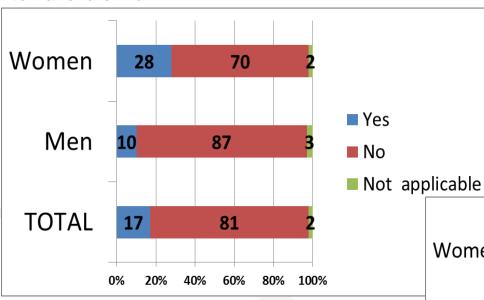


# **Children & Family**



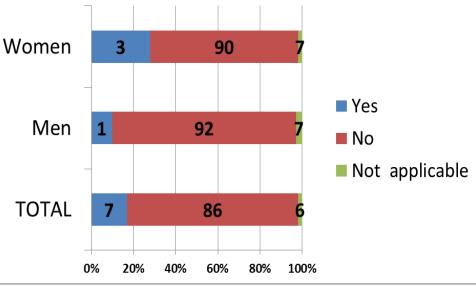
# Having children

## Health care professional advised not to have a child



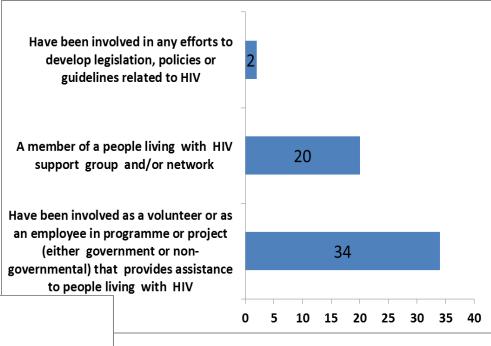


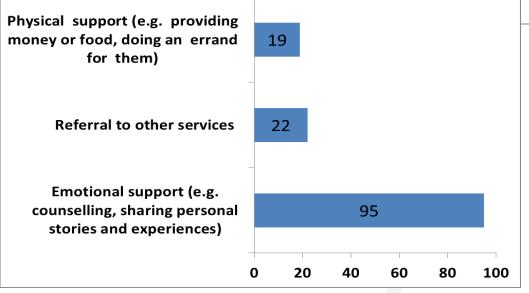
Has a health care professional ever coerced you into *being sterilized since* you were diagnosed as HIV-positive?



## Helping others







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# Conclusions what is needed?

#### what is needed - headlines?

- increased and sustained access to psycho-emotional and social support for PLHIV before, during and after testing
- Support, training, and dialogue with medical workers so that they understand the importance of confidentiality / make it part of their professional practice and be unprejudiced towards PLHIV

#### what will we do next?

- We will be producing a full report detailing all of the results this will be available on our website and the data made available for others via the international partnership to inform regional and global understanding of PLHIV-related stigma
- The results will be used for advocacy to ensure practices and policy are grounded in the real life experiences and perspectives of people living with HIV.



# Thank you for your attention

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The PLHIV Stigma Index has now been implemented nationally in 30 countries lead by PLHIV organisations in those countries - working in partnership with government and other civil society organisations and research institutions

More information can be accessed at: www.stigma index.org and www.gnpplus.net



#### This is an initiative of four founding partners







